

ZQP Analysis “Young People’s Experiences with Care Dependency in the Family”

I. Background

Currently, there are about 2.6 million people in Germany in need of long-term care, who are receiving benefits from the statutory nursing care insurance (Federal Statistical Office, 2015). Experts estimate that this number will rise to approximately 4.5 million by 2050 (Federal Statistical Office, 2010). Caregivers are usually partners and adult children. Currently, about 6 per cent of the working-age population have relatives in need of care; 27 per cent of them care for their parents and 25 per cent for their partner (Geyer, 2016, see ZQP-Report Vereinbarkeit von Beruf und Pflege – Reconciling Career and Care).

For adult primary caregivers, children and adolescent family members can provide important support. Some of them regularly take on nursing care responsibilities; some are even the responsible caregiver. Despite facing significant mental and physical demands, their situation has attracted little public attention. These children and adolescents have to cope with the repercussions of parents or grandparents being diagnosed with cancer, multiple sclerosis, or dementia. As caregiving relatives, they are heavily involved in a family member’s everyday life, are responsible for doing household chores, or have to look after siblings. They help their family members in need of care, for example, with their personal hygiene, going to the toilet, or administering medication. These demands can overburden children and adolescents and make it difficult to maintain friendships and pursue age-appropriate interests. It may also lead to poor performance in school or to health problems. In the long term, all of this can result in chronic physical and mental illness, social isolation, and poorer educational opportunities. Such an undue burden can also hinder vocational training and successfully entering gainful employment.

Currently, there are hardly any established initiatives in Germany that explicitly address the needs of children and adolescents who care for a relative. There is also little data on how often and to what extent children and adolescents are involved in care and how they cope with this situation. Previous estimates suggest that around 2 to 4 per cent of all children and adolescents in western countries are caregiving relatives (Becker, 2007). An Austrian study revealed that 4.5 per cent of 10 to 14 year olds are young carers (Nagl-Cupal et al., 2015). A 2017 study at the University of Witten/Herdecke funded by the Federal Ministry of Health is expected to provide up-to-date information on the numbers of young carers in Germany.

To get an overview of this subject, the Centre for Quality in Care (ZQP) surveyed young people in Germany. They were asked about their experiences with long-term care in their family and what kind of contact they have had with the topic of care in their everyday lives. The study captured, for example, which family member is in need of help or care, to what extent the young people are involved in assisting with tasks or care, how they are experiencing the situation, and what support services they would like to make use of.

II. Method and Procedure

The analysis is based on a survey of 12 to 17 year olds who were asked about their experiences with care-dependent relatives. The sample size was 1,005 respondents. The survey was conducted by Forsa from 14 to 27 June 2016. The data were collected by PC in an in-home survey. All surveyed participants (sampling frame) were 12 to 17 year olds from throughout Germany whose parents are represented in a panel with approximately 20,000 persons (forsa.omninet).

The adolescents were invited through their parents to take part in the survey. The parents were allowed to be present and offer support during the survey, if necessary. In order to increase the comprehensibility of the questionnaire, no strict definition of “need for assistance and care” was given. The sample was weighted by region, age, and gender according to population statistics for the surveyed age group. Thus, the sample is representative of the population of 12 to 17 year olds in Germany. It cannot be determined with certainty whether the proportion of adolescents who need to provide help or care is based on a selection bias in our sample.

The sampling error of the total sample is +/- 3 percentage points.

Considered subgroups

When analysing the results, various subgroups of all respondents (n = 1,005) were considered:

- Respondents with a relative in need of help or care living in or near the household (n = 278)
- Respondents who support a relative in need of help or care (n = 82)
- Respondents classified as so-called young carers (definition below) (n = 51)
- Respondents who know at least one child or adolescent with relatives in need of care but who have no dependents in need of help or care in the household or living nearby (n = 210); including respondents who know that the other adolescents help or care for a relative (n = 137)
- Respondents who know of children and adolescents with relatives in need of help or care but who have no relatives in need of care or affected acquaintances (n = 371).

The Centre for Quality in Care (ZQP) is a Berlin-based operative and non-profit foundation established by the Association of Private Health Insurance in November 2009. The objective of the foundation's work is a science-based quality and structural development of care and support for elderly and dependent people. The ZQP is the only institution of this sort in Germany with a multidisciplinary and cross-professional approach. Its work integrates renowned nursing and academic experts as well as consumer and patient organisations.

Figure 1 presents a schematic of the sub-groups and their overlapping.

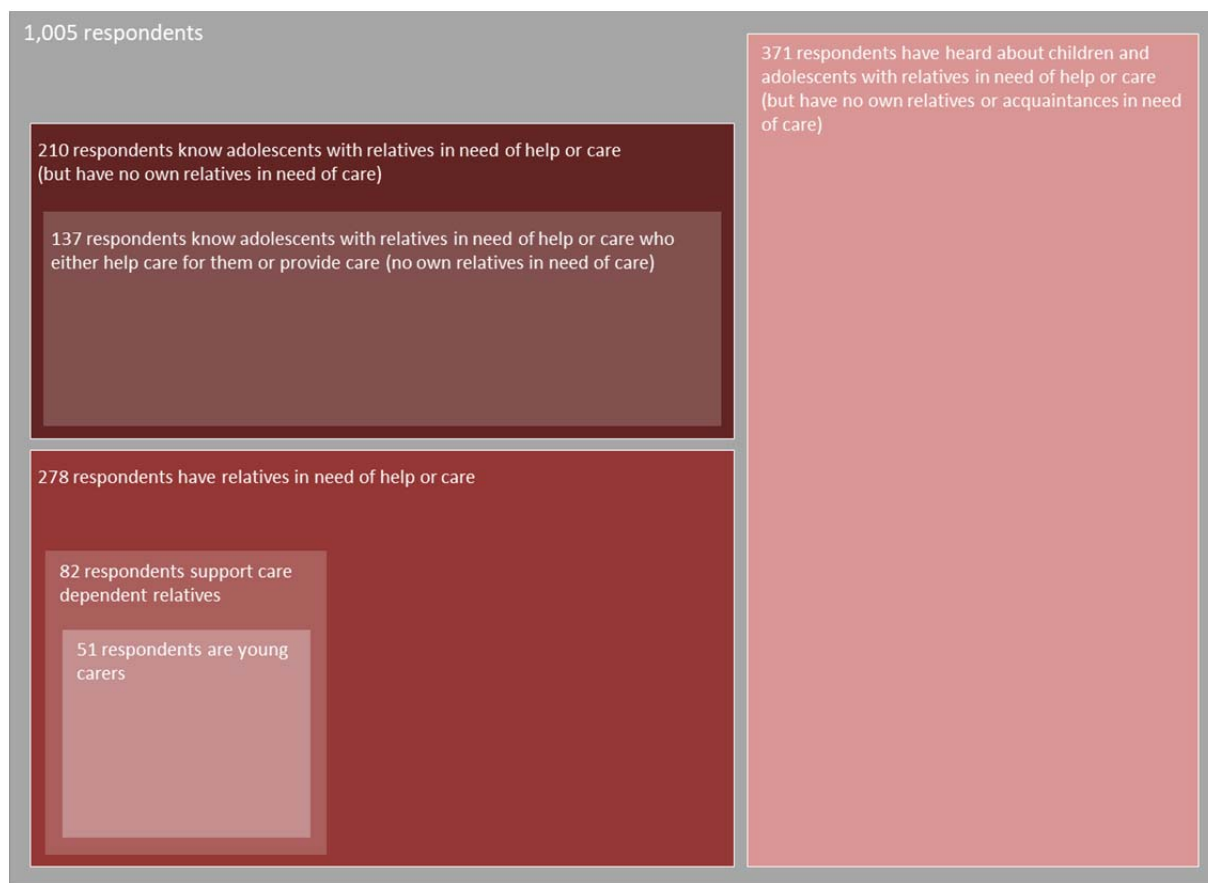


Figure 1: Schematic of sub-groups, illustration by ZQP

Defining criteria of young carers

Definitions of young carers vary in the literature. The criteria developed by the ZQP for the purpose of this study are based on this definition of young carers: “Young carers can be defined as children and young persons under 18 who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks [...]” (Becker 2000).

Following this definition, the ZQP formulated these criteria for young carers:

Young carers are minors who are at least 13 years old and support relatives in need of care. They regularly assume substantial nursing tasks or significantly contribute to stabilising a family caregiving setting.

The substantiality of nursing or family assistance was assessed based on information regarding the regularity and extent of the task. Daily help with personal hygiene or weekly help with administering medication, for example, are considered substantial, whereas helping with shopping once a month was not a criterion for inclusion in the category of young carers.

Example 1: A respondent required to help or provide care in the family who says that he/she helps administer medication at least daily and/or with shopping several times a week and/or with washing, showering, or bathing once a month would be considered a young carer in the study.

Example 2: A respondent who supports a relative in need of care who says that he/she helps a relative to stand up or walk once a month and/or looks after siblings once a week would be considered as having caregiving experience but would not be considered a young carer.

The table below presents these criteria in detail. To be considered a young carer, at least one of the criteria with a ticked box must be met.

Help	Daily	Several times a week but not daily	Approx. once a week	2 to 3 times a month	Approx. once a month
Washing, bathing, or showering	✓	✓	✓	✓	✓
Going to doctors or public authorities	✓	✓	✓	✓	
With meals, e.g. cutting and feeding/serving food	✓	✓	✓	✓	
Administering medication	✓	✓	✓		
Going shopping	✓	✓			
During leisure time, e.g. reading the newspaper, going for a walk	✓	✓			
Looking after siblings	✓	✓			
Helping with standing up and walking	✓				

Table: Defining criteria of young carers, illustration by ZQP

III. Results

Summary of survey results for young carers

About 5 per cent of the surveyed 12 to 17 year olds regularly take on substantial nursing tasks in the care of their relatives. Extrapolating this figure amounts to about 230,000 of such 12 to 17 year olds in Germany.

The vast majority of these young carers (90%) help several times a week, a third of them (33%) even daily. They take on a variety of tasks: In most cases they support those in need of care with shopping (58%) or during leisure time activities (50%). Many help their relatives prepare meals (34%) or stand up or walk (33%). They also perform nursing tasks: 27 per cent help their family member eat and drink, e.g. by cutting food or serving/feeding meals. 16 per cent help to administer medication, and 7 per cent help with personal hygiene.

The effects of caregiving tasks on young carers are manifold. 54 per cent of the young carers worry a lot about the dependent relative. A lack of free time (12%), the physical strain (10%), and having nobody to talk to (9%) were other negative factors mentioned. 7 per cent do not feel well supported in their situation. Nearly all young carers (93%) consider being able to help a positive aspect. Many also think it is good that the family sticks together (74%) and for them to take on responsibility (56%). About a third regard spending a lot of time with the dependent family member (32%) and learning a lot through the help (28%) as positive aspects.

Although almost half of the young carers (49%) do not feel burdened by their nursing activities, 46 per cent see themselves as being slightly burdened, and 5 per cent even feel much stressed.

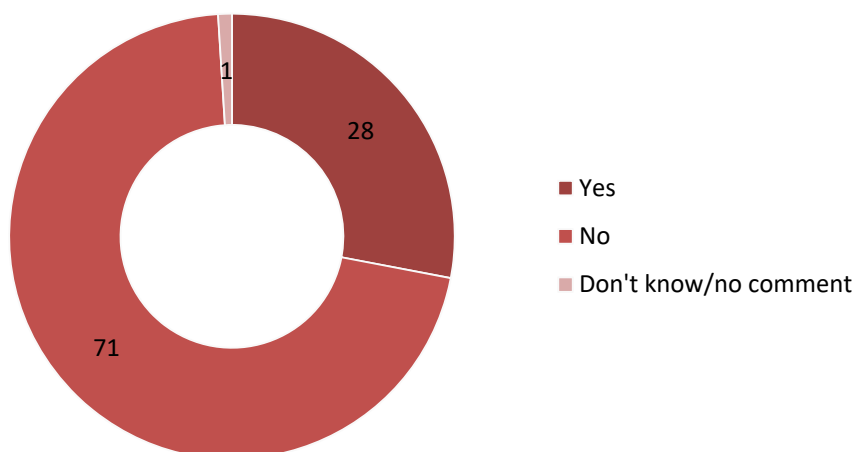
When asked about potential support, more than a third stated that they would want to use help from a nursing service (34%) or counselling service (36%). 24 per cent would like to utilise a helpline.

1. Experiences of young people with care dependency

- The need for help and care also plays a role for young people; 28 per cent of the 12 to 17 year olds surveyed have experienced it in their family.
- Some of the surveyed adolescents are involved in caregiving: about 8 per cent of the respondents support their relatives. The 5 per cent who provide substantial help are considered young carers.
- The level of support provided by young carers is considerable. The vast majority (90%) helps several times a week. They help with shopping (58%) or leisure activities (50%). 27 per cent help their family members with their meals, 16 per cent with administering medication, and 7 per cent with personal hygiene.

Many adolescents have personal experience with care dependency in their family or know it from families of friends or acquaintances. Over a quarter of respondents (28%) say that someone in the family needs help or care (Fig. 2). 21 per cent of respondents know children or adolescents with relatives in need of help or care but are not themselves affected by long-term care in the family. About 8 per cent of all respondents support their dependent relatives, and 5 per cent provide substantial and regular support to such an extent that they are considered young carers for the analysis. In addition, 72 per cent of those with neither close relatives in need of help or care nor affected acquaintances have heard of children and adolescents affected by long-term care in their families – mostly at school, in their immediate surroundings, or in the media.

Figure 2: “Some people depend on help in their daily life because they are ill or disabled or because they are in poor health. Is there such a dependent person in need of help or care in your family who lives with you or very close to you (i.e. grandparents in need of care, for example)?” Figures in per cent.

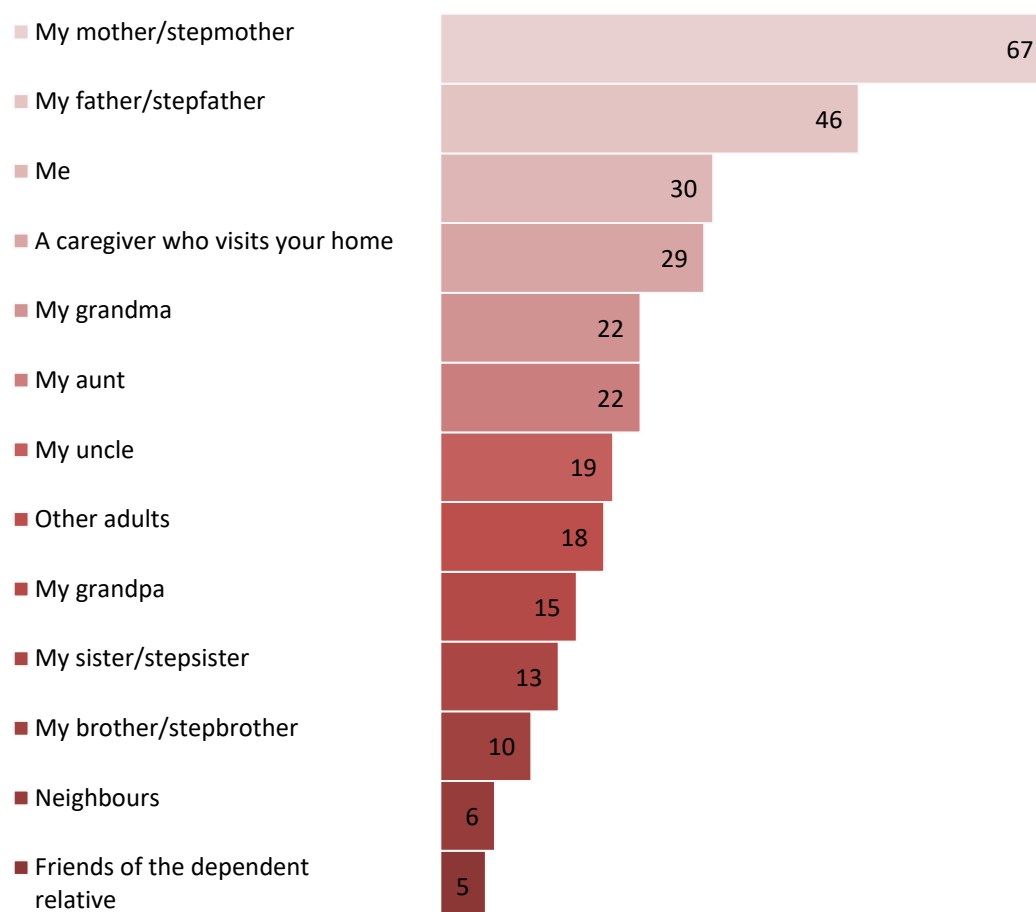


ZQP survey “Young People’s Experiences with Care Dependency in the Family”, 2016, n = 1,005

The surveyed adolescents mainly report that their grandparents – especially grandmothers (52%), followed by grandfathers (26%) – are in need of help or care in the affected families (n = 278). The respondents’ mothers or stepmothers and fathers or stepfathers rarely need help (5%). 4 per cent have siblings in need of care. Of the subgroup of young carers (n = 51) 14 per cent have a mother or stepmother in need of help or care and 9 per cent a father or stepfather.

Choosing from multiple answer options, respondents with a relative in need of care (n = 278) stated that their mothers (67%), their fathers (46%), they themselves (30%), or an outpatient nursing service (29%) are the main caregivers for a family member (Fig. 3). Some of the young people with dependent relatives see themselves as the person bearing most of the caregiving responsibilities: of the young carers (n = 51) 13 per cent are the primary caregiver.

Figure 3: “Who looks after this person, i.e. who helps or provides care for your dependent relative?” Multiple answers were possible. Figures in per cent.

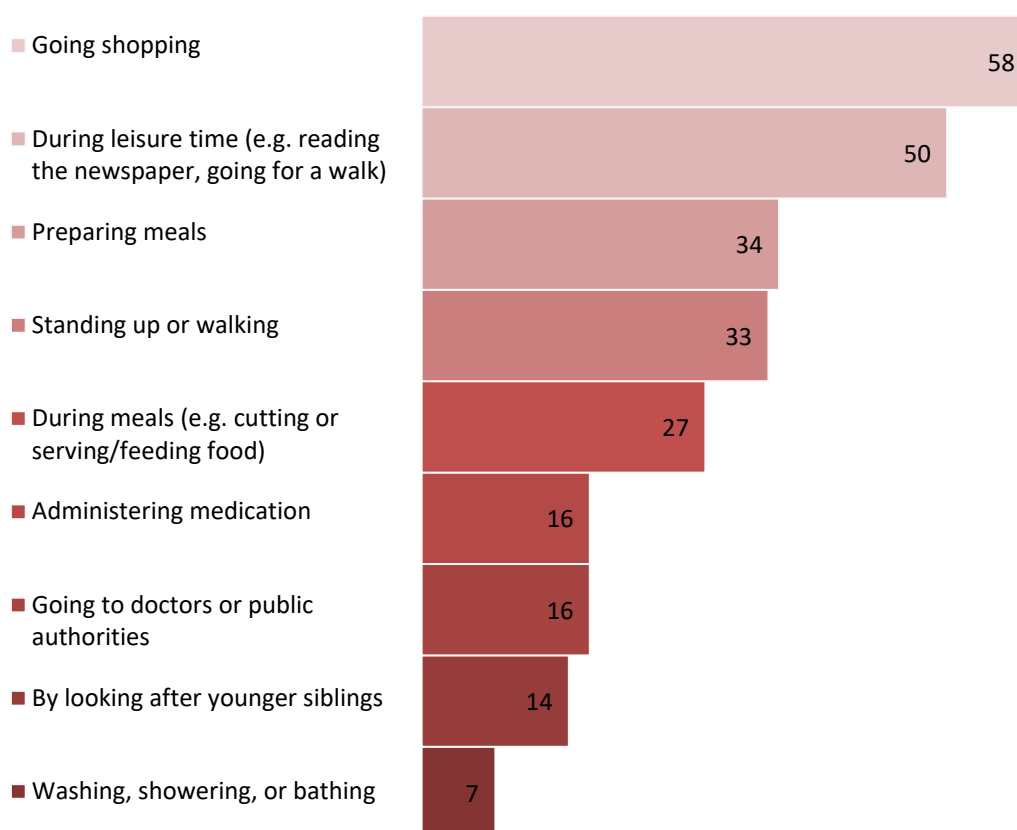


Note: Only persons who support relatives in need of help or care were asked this question.
ZQP survey “Young People’s Experiences with Care Dependency in the Family”, 2016, n = 278

The young carers (n = 51) provide substantial help and care. They take on various tasks (Fig. 4): Most help with shopping (58%) or leisure activities (50%). Many help the relative with preparing meals (34%) or standing up or walking (33%). They also perform nursing duties: 27 per cent help a family member eat his/her meals, e.g. cutting or serving/feeding food. 16 per cent of the young carers assist with administering medication and 6 per cent with personal hygiene. Over one in seven of these adolescents help their relative go to doctors or public authorities (16%) or take care of younger siblings (14%).

Figure 4: “How or in what situations do you help your relative in need of care?” Multiple answers were possible. Figures in per cent.

Young carers: I help this person ...



Note: Only persons who support relatives in need of help or care were asked this question. The diagram only evaluates the answers of the analysis group “young carers”.

ZQP survey “Young People’s Experiences with Care Dependency in the Family”, 2016, n = 51

Young carers carry out these tasks on a regular basis – e.g. 90 per cent help several times a week – and a third even every day (33%), thus providing substantial support in the family caregiving setting.

As external observers also those respondents (n = 137) who know other children and adolescents who support relatives in need of care similarly describe the tasks they think are taken on. These most

often include, for example, leisure activity support (63%) and shopping (42%). They also see their friends or acquaintances providing support by looking after siblings (22%), helping with eating (16%), or helping with personal hygiene (6%).

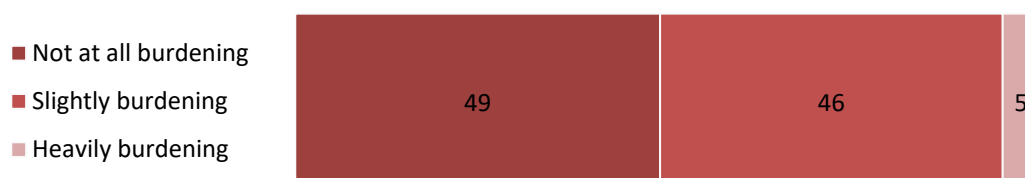
2. Assessment of support in caregiving

- About half of the young carers are “slightly” burdened (46%) and some “heavily” burdened (5%). The remaining half does not feel burdened by providing care (49%).
- The impact of caregiving tasks on young carers is manifold. Concerns about the relative are reported as the biggest burden (54%). A lack of free time (12%), the physical strain (10%), and having nobody to talk to (9%) are mentioned less often.
- Being able to help (93%), strengthening family ties (74%), and assumed responsibility (42%) are mentioned as positive aspects in relation to caregiving responsibilities.

In total, of the young carers (n = 51) 49 per cent say they do not feel at all burdened by caregiving (Fig. 5). The remaining half sees it as a burden – many of them as a slight burden (46%) and some as a heavy one (5%).

Figure 5: “How exhausting or burdening is supporting your relative in need of help or care? “. Figures in per cent.

Young carers:



Note: Only persons who support relatives in need of help or care were asked this question. The diagram only evaluates the answers of the analysis group “young carers”.

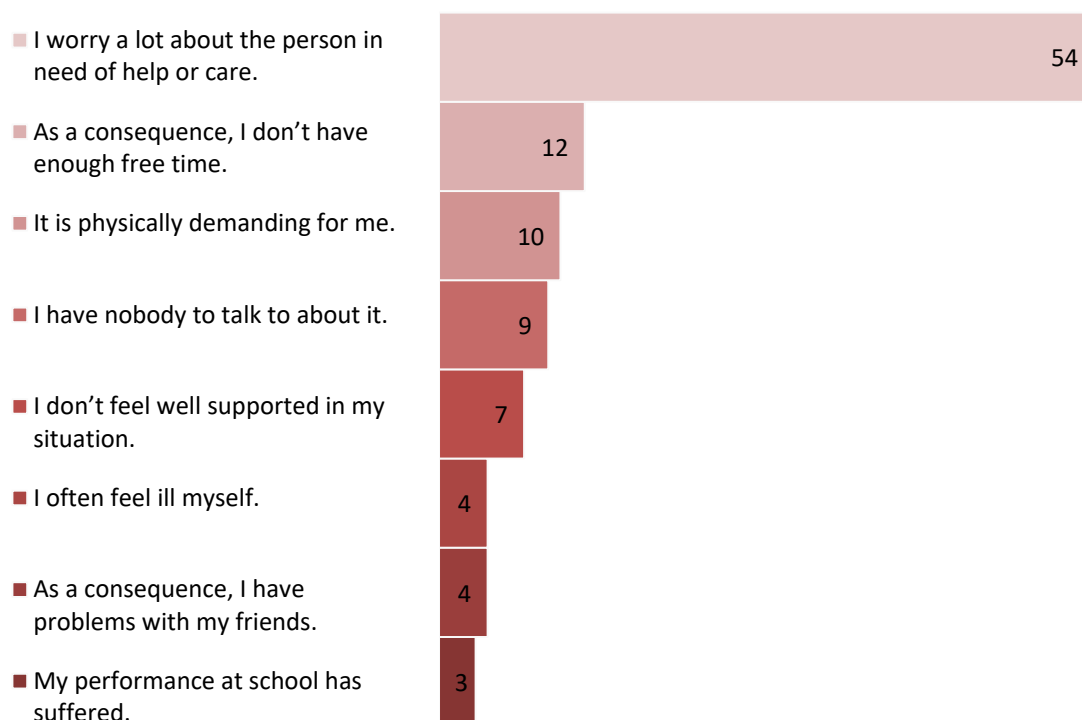
ZQP survey “Young People’s Experiences with Care Dependency in the Family”, 2016, n = 51

Asked about specific burdens (Fig. 6), the most frequent answer was concern for the relative in need of help or care (54%). In addition, a lack of free time (12%), the physical strain (10%), problems with friends (4%), or worse performance at school (3%) are reported as a negative consequence of the care situation. Some answered that they have nobody to talk to about their situation (9%), do not feel well supported (7%), or often feel sick themselves (4%).

The vast majority of young carers (93%) think it is good that they are able to help. Strengthened family bonds due to the care situation are also reported as a positive aspect (74%). Many respondents (56%) like taking on responsibility. About a third regard spending a lot of time with the dependent family member (32%) and learning a lot through the help (28%) as positive aspects.

Figure 6: “If someone supports a relative in need of help or care like you do, this may also have negative impacts. To what extent is this statement true for you?” Summary of responses: ‘completely agree’ and ‘rather agree’. Figures in per cent.

Young carers:



Note: Only persons who support relatives in need of help or care were asked this question. The diagram only evaluates the answers of the analysis group “young carers”.

ZQP survey “Young People’s Experiences with Care Dependency in the Family”, 2016, n = 51

Young people who have no relatives in need of help or care but know helping or caring adolescents (n = 137), find that these are worried (58%). Almost a quarter of them (24%) believe that these young people have too little free time because of their responsibility. Significantly fewer respondents perceive that the caregiving adolescents have problems with friends (7%), at school (4%) or seem to be sick (5%). The available free time of young carers is likely to be rated differently by other young people. The young carers (n = 51) themselves consider the reduction in free time less important (12%).

Of those young people without dependent relatives (n = 137), almost all (97%) rate the help of caring children and adolescents very positively. Most of them (71%) think that their help is “very good” (Fig. 7).

Figure 7: “What do you think of the fact that this child or adolescent helps his/her relative in need of care?” Figures in per cent.

I think it is ...



Note: Only persons without relatives in need of help or care knowing children or adolescents who provide help for relatives in need of help or care were asked this question.

ZQP survey “Young People’s Experiences with Care Dependency in the Family”, 2016, n = 137

3. Assessment of support services

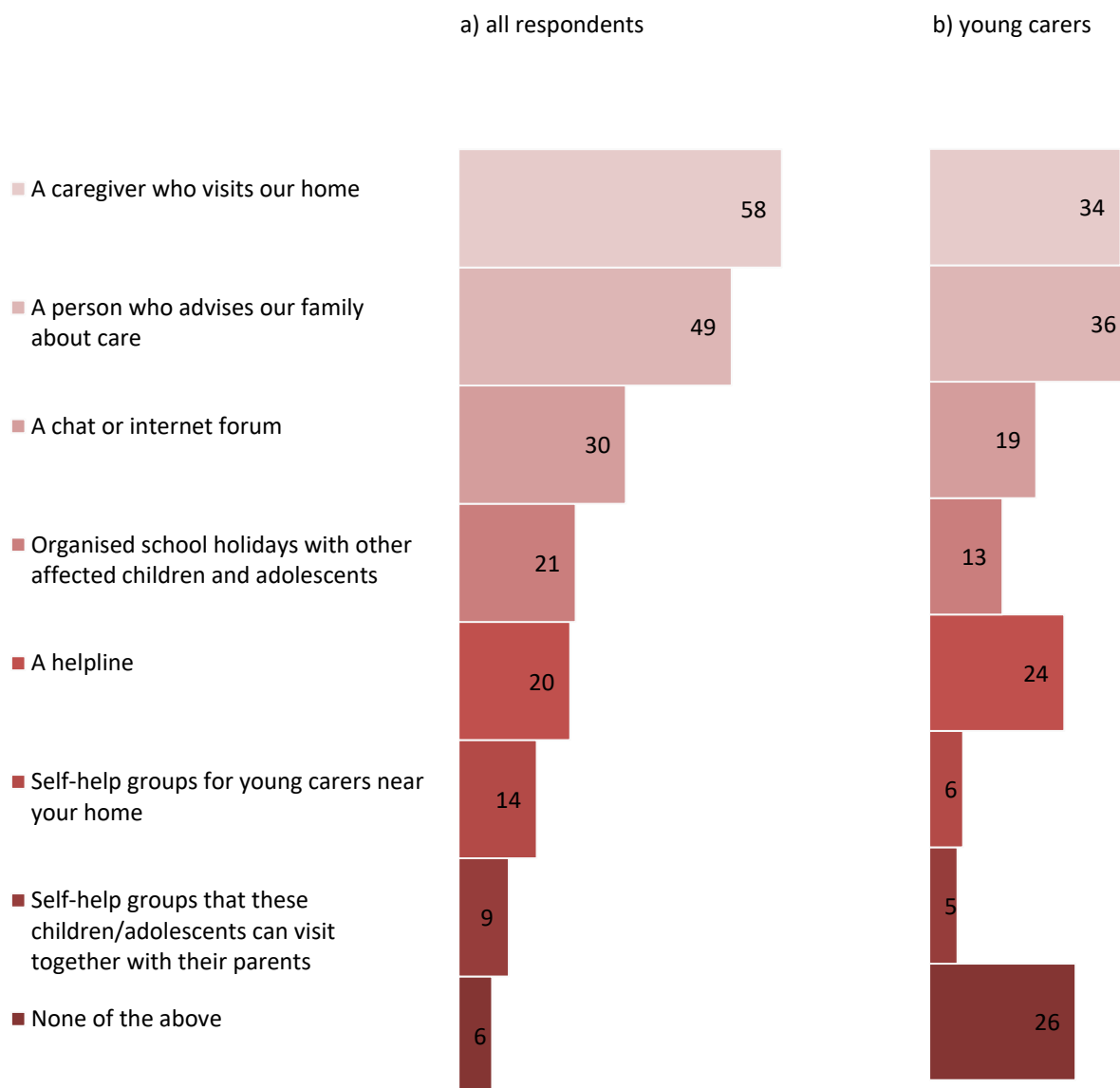
- More than half of the respondents (58%) – most of them without care experience in the family – reported that they would want to use nursing services to reduce workload if they were involved in the care of a relative. In addition, 49 per cent consider counselling for the family very important.
- Young carers are more reserved with regard to support. Over a quarter say that they do not want to use any of the suggested offers. Most important for them, however, is also to get help from a nursing service (34%) or counselling service (36%). 24 per cent would like to utilise a helpline.
- Young carers see both relatives and professional assistance such as health insurances (41%), outpatient services (28%) and physicians (20%) as potentially important helpers for children and adolescents providing care.

In order to get information about support needed when caring for a dependent relative from the perspective of young people, and young carers in particular, the respondents were asked about the help they would like to use to better manage the situation (Fig. 8).

Clearly more than half of all respondents (58%) would want to seek help from an outpatient nursing service if they had to help with caring for a relative in need of help or care. Nearly half of them (49%) consider counselling for caregivers to be helpful. 30 per cent would want to use help via a chat or an internet forum. 21 per cent of all respondents say that they would be interested in organised school holidays with other affected children or adolescents and 20 per cent would utilise a helpline. 14 per cent would like to use self-help groups for affected young people and 9 per cent groups for affected parents and their children. The subgroup of young carers (n = 51) partially shows preferences different from the overall group, which includes a large part young people without care experience. Over a quarter of the young carers say that they would not want to use any of the mentioned offers. In terms of percentage compared to the overall group, a lower proportion of respondents consider assistance of a supporting caregiver or nursing counselling to be attractive. Both types are stated, however, most frequently (36% and 34%). 24 per cent of the young carers are interested in a

helpline. This number is similarly to the interested respondents of the overall group. Chats (19%) and holiday offers (13%), however, are less frequently mentioned than by all respondents.

Figure 8: “There are different offers to support children and adolescents who provide care or help with caring for a relative. Which of the following offers would you want to use in such a case?” Multiple answers were possible. Figures in per cent.



ZQP survey “Young People’s Experiences with Care Dependency in the Family”, 2016, a) n = 1,005, b) n = 51

Asked who should provide more professional support for children and adolescents helping with care, the young carers (n = 51) named health insurances (41%) more often than outpatient nursing services (28%) and doctors (20%). On the part of the family, they want to get more support from the parents (36%) and relatives who do not live in the family (26%).

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