

# **Children and adolescents as informal caregivers.**

An Inside look into the past and present situation of young carers in Austria.

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Children and adolescents as informal caregivers. An inside look into the past and present situation of young carers in Austria. University of Vienna

# Children and adolescents as informal caregivers. An inside look into the past and present situation of young carers in Austria.

## Summary

Children and adolescents, which regularly care for a chronically ill family member, are a global phenomenon. The situation of young carers in Austria has gotten little attention as of yet, with the exception of a considerable number of master theses at the Department of Nursing Science at the University of Vienna. In general it lacks both the inside look into the area of the so-called “Young Carers” and qualified structures of support and help. Based on a parliamentary resolution proposal, the Federal Ministry of Labour, Social-affairs and Consumerism has assigned the Department of Nursing Science, at the University of Vienna, a study, which should investigate the situation of caregiving children in Austria.

## Aim of the study

The aim of the study is to take a closer look into the situation of caregiving children<sup>1</sup>. This will be achieved by the use of figures and statistics concerning the current situation of young carers, as well as on the basis of former caregiving children and their resulting experiences in that field. Deducted from the results, in combination of international discourse, recommendations will be defined, which are suitable and adaptable for professionals in that field. Due of the aim of this study, the study consists of two separate parts:

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<sup>1</sup> In this paper the term children is referred to children and adolescents at the same time. Expect the difference needs to be expressively indicated.

## 1. Evaluation of the current situation of young carers

With a survey focus on,

- The number of young carers, in the defined random sample, between the ages of 10 to 14 respectively between the 5th-8th school grade, in the federal states of Vienna and Lower-Austria. Including a calculation of the number of caregiving children, onto the entire population of children and adolescents, between the ages of 5-18, in Austria
- Extent and the impact of the caring activities
- Children's needs wishes for themselves and their families

This part of the study is based on quantitative methods. Therefore a self-reporting questionnaire was created, which evaluated "general children's help in the family" from the children's perspective. With approval of the legal guardians 7.403 (Return rate of 71%) children, at 85 schools, respectively 474 school classes filled in the questionnaire. With the help of a theoretical and literature-based model the number of caregiving children was identified.

## 2. The situation of former young carers and young adult carers

With a qualitative study focus on

- the retrospective experienced impact of former young carers in general and impact on their private and professional/work life
- The kind of helpful support would have been of use during their childhood

Data collection was carried out through semi-structured interviews. All of the interviews were audio taped, transliterated word by word and analysed via open and axial coding, as well as the method of constant comparison with data. In total 16 former young carers, now adults were interviewed about their situation.

## Ethical considerations

The entire study was presented in the form of an ethic proposal to the Ethics Committee of the University of Vienna, during the planning stage of this study. There was no objection concerning the planned approach of this study. A positive ethic vote was given before the start of the study.

## The present situation of caregiving children and adolescents

The prevalence of caregiving by children in the age group of 10-14, respectively between the 5th and 8th school grade amounts to 4.5%. There are 335 identified young carers in the sample (n=7.403). The average age of caregiving children is 12,5 years. 69.8% of the caregiving children are female. On average caregiving children have more siblings than non caregiving children. The number of adults in the household doesn't show a statistically significant influence on the emergence of children's care. 11.3% of caregiving children live with one parent in the household in comparison to the 12.5% of the non caregiving children. Neither does migration have a significant impact on children's caregiving activities. Around 30% of the parents of young carers and non caregiving children are born in a foreign country. Concerning prosperity it is shown that the objective prosperity, which was calculated through 4 characteristics (holidays, car, pocket money, own room), has no significant influence on the emergence of childcare. However caregiving children subjectively assess themselves, in direct comparison to other children as less wealthy.

## Young carer's caring activities

Young carers provide support in various areas of life. They help in the household, their healthy siblings or directly help the chronically ill family member. 23% of caregiving children give help in all 3 mentioned areas above average. 14% of caregiving children claim, 5 or more hours, each day, of supportive and caregiving work. This represents clearly, how much responsibility these children carry in their all day life. Not only caregiving but also non caregiving children contribute partially enormous amounts of help, if somebody in the family is ill. It is important to say, that young carers very frequently, respectively always face confrontation with the chronic illness of a family member. On the contrary non caregiving children only help, when someone at home is temporary ill. This

shows, that the sum of support activities of young carers is permanently on a higher level because of a constant need of help of a family member, and considerably higher in comparison to non caregiving children.

## Household tasks

Regarding all the necessary work processes in the household it becomes clear, that young carers perform a higher level of work than non young carers. About 16% claim more than 5 hours of weekly work in the household. Especially activities that include hovering, buying groceries and preparing meals. These activities are carried out more often by care giving than non caregiving children.

## Sibling care

At average caregiving children have 1,6 siblings. For them they prepare the meals, watch out for them, help them with school work, take them to bed and accompany them to school or kindergarten. Above all caregiving children prepare meals more often than non caregiving children, whereas the difference to general/usual help by siblings becomes really visible.

## General care

General care refers to direct care to the person in need and is divided up into physical and emotional care, as well as intimate care. In all of these areas caregiving children carry out more support than non caregiving children. Considering general care it becomes apparent, that 10-15% often or very often help in all of those 3 areas. The frequency of support activities of young carers in this area implies how strongly connected these children are to direct care. Although young carers take not so much responsibility in the area of intimate care, they do it more frequently than non caregiving children. The circumstance that young carers are less involved in that area can be directly associated with the young age of these children. International literature implies that the older the caregiving children are the more responsibility they inherit in this area.

## Why and whom young carers help

23% of the young carers give support to their mother, 22% to the grandmother, 14% to the father and 12% to a sibling followed by others or more than one person. This differs to international data where caring for the father ranked usually second after caring for the mother. 81% of children state helping their mother often to very often. These answers are not inevitably connected to the ill family member and can be retraced to various possible causes. Two explanations are on the one hand the stronger bond between mother and child and on the other hand the assumption, that the mother is traditionally, most likely, the supporting person in the household, when someone is ill. Young carers frequently care together with their mother or father, but sometimes they care for someone alone or with their siblings. It is claimed by young carers, that they rarely receive support from friends or professional care.

The motivation behind caring for someone was also evaluated. Nearly all motivational factors in the areas of implicitness, self-esteem and necessity showed significant differences between caregiving and non caregiving children. Particularly there is a significant difference, when it comes to the point "I have always helped". This makes it obvious, that a lot of children grow up with care.

## Impact of children's care

To be a young carer shows effects in many areas. Especially in the area of physical impacts it was established, that caring children often claim to suffer from fatigue, sleeping problems, back-pains and headaches. Significant differences are also shown with the mental state of young carers. Statements such as "I often worry" and "I am often sad" were significant rated more often by young carers than non caregiving children. Caregiving children feel more adult in comparison to non caregiving children, which shows that the impact cannot exclusively be evaluated as negative.

## Wishes of caregiving children

Inquired about their wishes only 19% of caregiving children stated wishes that were exclusively for themselves. All the other wishes evolved around their family or general things. The most important topics for the children were health, respectively the healing of



an existent illness. Only a few children claimed wishes that were not directly connected to their special situation.

### Identified caregiving children as a minimum number

The percentage of identified young carers, in this study, is the lowest assumable merit. Not included are those children who claimed, that a family member is “often” or “always” ill and they “often” or “very often” help, even though they couldn’t mention a chronicle illness. These are further 0.8% of the children. Another group are these children that are able to name a chronicle illness, however they are below the calculated “cut-off-point” with the extent of support and help that they contribute. These are again 0.97% of the children. Another undocumented group are those children that were not able to deliver a signed declaration of agreement by their parents, which was a requirement to participate in this study.

### Extrapolation of the number of young carers in Austria

By means of numbers from this study and published data from the UK Household Survey of 2001, the number of children in Austria, that can be classified as young carers, was projected through the use of a regression analysis. It can be assumed, that the proportion of young carers increases linear with age. However there is a stronger increase in the age group of 10-14 year-olds, in comparison to other age groups. The projected fraction of young carers between the age of 5-18, in Austria, amounts to 3.5%. Based on the fact, that the fraction of young carers not only applies to the federal states of Vienna and Lower-Austria, but also to the rest of the country, this would approximately amount to a number of 42,700 caregiving children in Austria. Thereby the number of young carers in Austria is assumption of main experts in this field that existing quantitative data concerning young carers are probably underestimated. remarkably higher as estimated. This refers not to the specific situation in Austria, but rather to methodological and sampling considerations in this study. This highlights the assumption of main experts in this field that existing quantitative data concerning young carers are probably underestimated.

# The situation of former young carers: impact of (early) caregiving experience

## Caring experiences as a condition of context concerning the impact

The impact of early caring experience on to adulthood can't be explained without taking a look into the experienced past of the former caregiving child. It depends on the starting age, respectively the point of time, where it all started, the manner and the extent of provided care and the nature of the illness. As well as who is being cared for and the period of involvement. It is very obvious, that a negative impact on the present life appears more massively the longer the care endured during childhood. This is frequently in direct connection with the missed childhood that the former young carers often described during the interview stage of this study.

## Begin and period of care

Many children grow up along with the chronicle illness of the family member, from a very young age. With some the very first memories about the ill family member and their participation in caring go back to the age of 3. This means that they were involved with the caregiving duties for an extensive amount of time and described this state as normality. Others only knew their family member as ill and take on caregiving duties at a later point in life, when the needs of the ill family member were constantly increasing. Only a few former young carers experienced a so-called "normal" childhood, only if the illness appeared at a very late stage of their childhood. If that was the case then the illness was often quite severe and appeared abruptly. The care of an ill family member mostly didn't end at the age of 18 but rather was extended to adulthood. Very often the end of the care is marked by the death of the ill family member.

## Transition from childhood to adulthood and thereby connected decisions

During the life period between the ages of 15 to 25 major decision of life are being made and often the path for the future life is being paved. The care situation influences these decision-making processes, which means decision have to be adapted to this specific situation within the family. With increasing independence and age for most of the affected children the caregiving duties continue and three different kinds of life-adapting decision are being made:

1. Keeping the role of a caregiver and continue caregiving. These people continue to care as intensively as before. Professional and private decision making processes are put on hold. Frequently even beyond the death of the family member.
2. Keeping the role of a caregiver but sharing responsibilities. Different arrangements are decided, where the areas of professional and private life are combined with the responsibility towards the ill family member. Frequently the responsibility part is outsourced to professional services or other people, such as new life-partners. Besides these circumstances the feeling of being the responsible person for major and life-changing decisions for the ill family member remains.
3. Relinquishing the role as a caregiver – “suddenly the responsibility was gone“. No caregiving child leaves the role as caregiver, unless other prior arrangements are made. Even so there is a certain amount of responsibility left. The role as a carer is only left, when the ill family member passes away. With that not only a loved one dies but also the function as a carer extinguishes, which afterwards causes quite a vacuum in the person’s life.

## How does (early) caregiving experience influence adulthood?

The existence of puerile care experience doesn’t allow the conclusion, that all affected people experience the same impact or carry the same heavy burden like others in this situation. This is, as mentioned before, strongly connected with the different care experiences in childhood. However, there is no former caregiving child, which states no kind of impact on later adulthood. The experiences affect the psychological, physical and social areas of the caregiver’s life. This includes feeling guilty, a great fear of loss, an

increased sense of control or due to former chaotic life a strong sense of organisation and order. Some of them never led a “normal”, child-like life or never had the idea how other families organise and create an ordinary family life. In extreme cases some are missing a reference value of what a “normal” life is. Additionally some report heavy back pains, in connection with heavy lifting in the past.

### ***Recalling inner images***

Wherewith everybody always struggles are returning inner images and memories from special formative situations from the past. Therein the affected find themselves in a situation, which used to be quite straining in the past. These images are filled with memories of fear, helplessness and being excessively over challenged. There is no kind of defence mechanism against these images from the past. They simply appear and diffuse themselves among the person’s thoughts. They contribute a fundamental amount of strain and stress in the caregiver’s present life.

On the contrary the care experience is often reflected as something positive. Particularly life problems are handled more relaxed nowadays and that through this care experience, in the childhood, many feel well prepared for today’s life. Many state that they feel more empathetic and sensitive.

### ***Taking over responsibility remains***

That sense of responsibility, gained through the experience during the childhood, doesn’t usually end with the end of the care but rather continues. Even though most affected people decline/refuse to take over responsibilities for others, they eventually return to this position as an in taker of responsibility. This characteristic is frequently described as a positive development by the former caregivers. But this can also be quite a burden, especially when the amount of responsibility is too massive and the concerned person feels too responsible for everything, even for other people’s mistakes.

## **How do they cope with the impact of caregiving on their lives?**

Former caregiving children handle the care experience differently in their adulthood. This can be understood as a chain of processes and this also requires a certain development of their awareness through their past life and their role as a caregiver. This awareness is not

developed or formed by everyone and for those who eventually do this only happens after many years.

### ***Not talking about it vs. the need to talk about it***

An essential characteristic of caregiving children is that they often won't talk about their situation. This often continues until they have reached adulthood. For many of those people the interview situation was the very first occasion to talk about their (early) care experience. Some of them even mentioned that this was never a topic of conversation, not even with the closest family members or friends. The reason for this lies in the past. It was always handled as not worthy of talking about it, because this used to be "normal" or it is connected with great vulnerability, grief or fear. In the present life most of them don't talk about it because they still don't view themselves in the role of a former caregiving child or because they don't want to be reminded of their past. So they block everything out because of the fear of negative emotions that could come up and therefore would be difficult to handle for them. For many the strain from the past is considerably great and some of the former caregiving children take on some form of conversational therapy in effort to deal with the past. This would certainly imply that they themselves recognize their role as a caregiving child respectively as a child of a chronically ill family member, or their willingness to share that past and memories with someone else.

### ***Resolving the own identity***

Many young carers learned to put on hold their personal needs in their childhood because everything was focused onto the illness. With this background many resolve their own identity issues and needs not until they have reached adulthood. They start very late with the search of who they are as a person and what they want from life. Frequently, psychotherapeutic help supports this stage. A considerable amount of former caregiving children often return, through round about ways, for instance through their professions, to the familiar role of a supporter and caregiver. This is because they know this role very well, find sense in it and sometimes they even want to make up for something.

### ***Make it different and experience a “normal” everyday life***

The experience in the past serves today often as a model to create an own life. The former carers do and carry out things with a different awareness than they did in their past. This is often reflected in their own family life or how they bring up their own children. Many seek for a so-called „normal life“ because in their childhood normality, as we know it, was not experienced.

### **Demand of support for present young carers from the perspective of young carers**

Many former caregiving children were able to name plenty of areas, where they needed and wished for support and help, when they were children or adolescents: Primarily better knowledge about the illness and the symptoms. Moreover the practical support and help in the daily life as a caregiver, especially concerning the very physically straining and disgusting caring activities/tasks.

From today’s perspective many wish a certain amount of consultancy with regard to the organisation of everyday care. Additionally many would have wished, from today’s point of view, a contact-point for emergencies in the area of homecare and later on a special place or refuge, where they could have received help in special, burdening situations, such as death or grief. Many of them occasionally wanted to just “be a child” for some time, without any responsibility towards somebody.

To let professional care into the family, to receive support and help, used to be something unthinkable for many. Either, the children didn’t view themselves as caregiving children, because it used to be something shameful, or they didn’t rely on appropriate external help or the parents didn’t approve. Many didn’t know, that professional help even existed, which needs to be viewed in a temporal context, when professional support systems, for example home-based nursing care in Austria, were seldom.

If external support and help would have been imaginable then only through a trustworthy person that the family would know. In combination with a help and support structure that would rather contact you instead of you contacting them. Caregiving children and adolescents feel responsible for the ill family member and would only demand for own support if they knew that the ill family member is taken care of. The parents always need to be integrated, because they are the last instance of the decision making process, whether external help and support is claimed.

## Aims and recommendations concerning the support of young carers in Austria

Young carers can be found in every country and every layer of society. It is difficult to identify them as a group and even more difficult to identify them as affected persons. Some of the caregiving children don't view themselves like this and don't want to be identified from others. The status as a "caregiving child" doesn't end with the age of consent. Frequently the care situation is taken beyond the childhood days and the entire impact is often only shown in later adulthood. Provisions to support young carers should pursue the following aims:

1. Perception and acceptance of caregiving children as a social reality in Austrian society
2. Removal of taboos concerning "young carers"
3. Protection of the children's rights and children's participation in all age relevant areas of life
4. Promotion of the health and wellbeing of children through preventive activities concerning an inappropriate role as a caregiver, which could constrain the personal development
5. Help and support for the entire family

The recommendations in terms of the support of young carers are directed towards various protagonists on all levels of responsibility. Especially the one's in direct contact with caregiving children, through their work. The recommendations tie in with existing structures but also emphasise the creation of new and towards the target group specifically adapted structures. Given the results of the research, the relevant literature and the fact that caregiving children, up until now, are a hardly perceived group in Austria. Following essential recommendations can be evaluated:

- *Formation of awareness by the population including the affected children and the avoidance of stigmatization of children's care*  
...through medial campaigns with a focus on information and education

- *The right of identification of affected caregiving children in their proximate environment*  
...through people that are close to their living environment, such as people in contact with them like professionals at school or health-care providers.
- *Education and information about the illness that is suitable for children*  
...to discharge fear and lack of security
- *Caring support in everyday life through available, low-threshold offers of help*  
...to support, guide and relieve  
...through a Case Management or Family Health Nurse approach  
...through a contact point in case of emergency
- *Development and constitution of child and family orientated help and support programmes*  
...to be able to talk to like-peers and adults  
...to be able to just be a child  
...that are promoted effectively and are evidence based, as well as financed on a long-term basis

Furthermore accompanying provisions are recommended such as,

- explicit reference to young carers, in specific the greater and wider definition of the term care-giver as well a informal care-givers
- to put a focus not only onto children and adolescents but also onto young adults, as caregiving relatives
- a continuous news coverage on the situation of caregiving children, adolescents and young adults in effort to establish research sector

References used in this study are listed in the main report.





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