

Experiences of being a former young carer: effects in the transition into adulthood and in the present life situation**Experiências de ser um ex-jovem cuidador: efeitos na transição para a idade adulta e na atual situação de vida**Martin Nagl-Cupal¹, Sabine Metzging², Hanna Mayer³

¹ PhD, RN, Postdoctoral Researcher, Department of Nursing Science, University of Vienna, Austria. Vienna, Austria. Email: martin.nagl-cupal@univie.ac.at.

² Junior-Prof., PhD, RN, Department of Nursing Science, Faculty of Health, Witten/Herdecke University. Witten, Germany. Email: sabine.metzging@uni-wh.de.

³ Prof. PhD, RN, Department of Nursing Science, University of Vienna. Vienna, Austria. Email: hanna.mayer@univie.ac.at.

ABSTRACT

This qualitative study aims to describe the experiences of adults with caring responsibilities during their childhood. 16 semi-structured interviews with former young carers were conducted and analyzed using open and axial coding procedures and constant comparison techniques. Being responsible as a child in terms of caregiving has an impact on every person concerned. When entering adulthood, most former young carers maintain the responsibility for the ill person. They feel torn between the effort of trying to arrange their life in a different way and holding on to a life where responsibility is still a dominant concern. They remain silent about caregiving due to the fear of painful memories, or the inability to recognize themselves as former young carers. Knowledge of former young carers' situation can improve the understanding of how caring shapes the transition into adulthood and can help to prevent an inappropriate caring role of actual caregiving children.

Descriptors: Adolescent; Child; Cuidadores; Family Health; Qualitative Research.

RESUMO

Este estudo qualitativo tem por objetivo descrever experiências de adultos com responsabilidade de prestação de cuidados durante a infância. Dezesesseis entrevistas semiestruturadas com ex-jovens cuidadores foram realizadas e analisadas utilizando procedimentos de codificação aberta e axial e técnicas de comparação constante. Ser responsável enquanto criança, em termos de prestação de cuidados, tem um impacto sobre todos os envolvidos. Ao entrar na idade adulta, a maioria dos ex-jovens cuidadores mantém a responsabilidade para com a pessoa doente. Sentem-se divididos entre o esforço de tentar organizar sua vida de uma nova forma e aferrar-se a uma vida em que a responsabilidade é ainda uma preocupação dominante. Eles permanecem em silêncio sobre a prestação de cuidados devido ao receio de memórias dolorosas ou pela incapacidade de reconhecer-se como ex-jovens cuidadores. O conhecimento da situação de ex-jovens cuidadores permite melhorar a compreensão de como a prestação de cuidados molda a transição para a vida adulta e pode ajudar a evitar um papel de cuidador inadequado para atuais crianças prestadoras de cuidados.

Descritores: Adolescente; Criança; Cuidadores; Saúde da Família; Pesquisa Qualitativa.

INTRODUCTION

Children with regular caring responsibility for a chronically ill or disabled family member receive growing attention in the field of nursing and health sciences. These underage children are referred to as young carers⁽¹⁾. The prevalence of informal caregiving by children in Western countries is estimated to be between 2 and 4%⁽²⁾. Young carers are involved in a broad range of caregiving activities, such as household tasks, personal and emotional care, or caring for younger siblings⁽³⁻⁴⁾. They often take over an inappropriate workload of caring responsibilities, which may cause psychosocial problems, problems in school, and restrictions on their social life⁽³⁻⁶⁾. This is likely to increase the more intensively they are involved in caring⁽⁷⁾ and correlates with a poorer health status compared to children who do not provide care⁽⁸⁾. Permanent involvement in caring also shows effects on internalizing problems such as somatic complaints, anxiety, depression, or withdrawn behavior⁽⁹⁾. Young carers report problems and worries more often than others in their age group⁽¹⁰⁾. The more they are involved in caregiving activities, the more invisible is their hardship⁽⁴⁾.

Caring for a family member as a child usually does not end when a child reaches majority. Being a young adult carer is particularly challenging and raises questions of how caring affects normative transitional processes. Thus, unsurprisingly, caring as a young adult is often associated with severe restrictions during transition into adulthood. The need to make educational or private plans is often not compatible with ongoing caring responsibilities⁽¹¹⁻¹³⁾. The responsibility for another family member makes it difficult to leave the ancestral home, which often negatively affects the level of professional qualification, complicates job training or further education, and reduces employment opportunities⁽¹⁴⁾.

When young carers enter adulthood, a prevailing number of affected people show a considerable level of depressive symptoms on the one hand, but also exhibit positive effects related to the former caring situation on

the other⁽¹⁵⁾. Former young carers also report health-related adverse effects, such as back pain, psychic traumata, or other mental problems related to their prior caring experiences⁽¹⁶⁾. School problems experienced during childhood often continue to affect educational and job opportunities in later life⁽¹⁴⁾. Caring for an ill or disabled family member is also associated with various positive aspects arising from early responsibility, including early maturity or the development of life skills^(14,17).

The literature review indicates a growing body of knowledge of young carers in the context of health- and social sciences. Focusing on different life stages of caregiving youth, very few studies reflect on the situation of former young carers and how early caregiving affects their life as adults. Existing literature does also not reflect the temporal and social context of countries outside North America or Great Britain. The main objective of this study is to explore the personal experiences of former young carers and how caregiving as a child or an adolescent affects the transition into adulthood and their present life situation. Contributing to an emerging research topic in German-speaking countries, the study will provide insight into the situation of former young carers, thereby adding to the body of knowledge for preventive action and helping to create need-based programs for present young carers.

METHODS

An exploratory qualitative approach was used to provide a deeper insight into an area that is still largely unexplored. Based on a purposive sample, 16 adults aged 32-60 with previous caring experiences participated in the study in 2012/13. Study inclusion criteria for participants were as follows: adults with caregiving experiences as an underage person for an adult family member with a chronic illness or disability; German language proficiency; grown up in Austria; voluntary participation. Interview participants were recruited by newspaper advertisements, social media as well as leaflets placed at

locations where the researchers expected to get access to the target group, such as insurance companies, hospitals, or medical practices. People who were interested to participate in the study were asked to contact the researchers via email or telephone to obtain more information about the study.

Informed consent was obtained from all participants. Each participant was informed about the aims of the study and the demands and process of study participation, both verbally and in written form. They were informed of the voluntary nature of their participation in the study and the anonymized reporting of the recorded interview data. The study was approved by the Research Ethics Committee of the University of Vienna.

The majority of participants were female (12) (Table 1). Ages ranged from 32 to 60 years, the average age of participants was 45.5 years. Nine interviewees became young carers at a very young age, the youngest being three years old. The others started caring between the ages of 9 and 16. Eleven study participants lived with both parents in the same household, with two of them caring for the grandmother who also lived in the same household. Three participants lived with a single parent who was also the person in need, and two lived with their grandparents, one of whom was in need of care. All participants lived in one of the two most populous provinces of Austria – Vienna and Lower Austria.

Table 1: Characteristics of study participants.

Participant	Sex	Age	Person in need	Type of illness of family member	Duration of caregiving (approximately)
1	f	32	mother	multiple sclerosis and epilepsy	13 years
2	f	48	mother	diabetes	12 years
3	f	44	mother and grandmother	cancer and diabetes	7 years
4	f	59	mother	epilepsy	16 years
5	f	60	mother	mental illness	14 years
6	f	44	father	stroke	3 years
7	f	38	mother	cancer	2 years
8	f	47	grandmother	diabetes	7 years
9	m	49	grandmother	diabetes	10 years
10	f	36	mother	multiple chronic health conditions	13 years
11	f	45	father	mental illness	not specified
12	f	33	mother	mental illness	25 years
13	m	44	father	polyarthritis	14 years
14	f	50	grandmother	diabetes and heart disease	5 years
15	f	49	older sister	epilepsy	20 years
16	m	50	mother	mental illness	not specified

Data collection and analysis were performed in a circular and iterative process. The semi-structured interviews started with the question prompted by the interviewer what it was like to be a young carer. This allowed the interviewees to lead the conversation and determine the starting point of their autobiographical memories. From this initial point, the narratives gradually moved from past experiences to the present situation of the former young carers. The interview guide remained open and was adjusted when relevant topics occurred,

following the assumption that the participants themselves would address and control the topics that were relevant to them.

The interviews were digitally audiotaped and transcribed verbatim. Data were analyzed by constant comparison and with open and axial coding procedures outlined by Corbin and Strauss⁽¹⁸⁾. In the stage of open coding, analysis stayed very close to the original data. Emerging categories were cross-read by the research team and relationships between the categories were

elaborated and discussed. Quotes from the interviews were used to illustrate the categories. The primary aim of the analyses was not theory development, but rather to develop empirical knowledge, extract meaning and gain a deeper understanding of the group under study⁽¹⁸⁾.

RESULTS

The present situation of former young carers and how caring has influenced the transition into adulthood can be described with the categories *carrying painful memories, maintaining responsibility, finding one's own identity, and remaining silent*. These effects are influenced by various contextual factors related to the previous caring responsibility, such as the nature of the caring situation, the duration and intensity of involvement, and the experienced effects of caring, e.g. helplessness, temporary or permanent overload, or role reversal. Most participants grew into the caring responsibility and therefore did not know a different life. One woman expressed that she grew into caring bit by bit without realizing that she was a young carer.

This was a normal situation for me. As she [foster mother] got older and her situation got worse, I was about 4 or 5 when I took over the caring activities and so on.

Due to this fact, the duration of caregiving can hardly be specified. Detailed memories of the caring situations were also often hard to recall as the experiences dated back many years. However, specific caring activities were deeply ingrained into the participants' minds, especially those that were performed frequently, experienced as physically strenuous, or associated with shame, i.e. intimate caring activities. A major influencing factor on whether former young carers experienced negative effects in their adult lives was the duration of caring, a long duration frequently coinciding with starting to care at a young age. A long duration is associated more strongly with negative mental or physical well-being and with unaccomplished educational or social goals. Former

young carers also reflect positive aspects associated with their ongoing responsibility. Many feel well prepared for today's life as a result of having to cope with difficult situations or feeling more empathetic and sensitive.

From a retrospective view, caring as a child is a distinctive life situation that leaves its marks on almost every person concerned. One woman summarized her caring experiences as a child with the following words.

I think the entire childhood is slipping through our fingers like liquid from a bucket, and it's slipping and slipping and slipping. I believe all of those experiences shaped me profoundly.

Carrying painful memories

Most former young carers reported a variety of burdens that they traced back to their time as a young carer. These burdens are rarely tangible physical conditions induced by heavy hands-on caring activities, but rather mental strains arising from painful memories of the past. These memories are often associated with a certain illness event of the family member in need. Especially the *feeling of being guilty* of the illness of the family member – which is amplified by the young age of the caregiver – is such a painful memory.

[...] and my mother was so angry with me and then she got her first epileptic seizure. I didn't know what was going on and I thought for many years that I caused this seizure more or less with my own behavior. This does not make me feel real good.

One male participant described his permanent *fear of loss* as a result of the memory of existential fear and worry for the ill family member. Another female interviewee referred to the painful memory of her mother's permanent predictions of not reaching the age of 40. Some of the painful memories come up very often and unexpectedly and cannot be controlled. The memories that weighed most heavily on former young carers were

those that refer to *situational overload* and the *feeling of one's own helplessness* or to the *helplessness of the ill family member* in a specific caring situation. One former young carer and daughter of a mother with multiple sclerosis and epilepsy expressed this as follows.

You can do nothing. It was this incredible helplessness of hers. You stay next to her and all that you can do is to watch it getting worse. [Crying]

These strong emotions that come quickly are also caused by the memories of *grieving* for the loss of the family member's independence and therefore the ability to completely fulfill his or her parental role. Therefore, the emotions are also consequences of the *existential fear* of a child to lose a loved one.

Maintaining responsibility

All interviewed former young carers continued caregiving and maintained the responsibility for at least a while after entering adulthood. It was the need for personal involvement in caring that made it difficult for them to leave. Quite often, they felt emotional pressure to stay at home and continue caring. One woman, for example, who had lived with her ill mother and her grandmother, started a job at a small family business to become more independent. When her mother's condition deteriorated, however, her mother urged her to stay at home.

I said to my mother: 'Look, let me finish this month at my new workplace, just this month, and then they can look for another employee'. And she said: 'If you are going to finish this month, I won't be alive anymore when you come back.' So I resigned from one day to the next.

During the transitional phase into adulthood, former young carers have to balance their individual needs against the need and the necessity to care of the ill family member. Decisions regarding further education or job

training have to be compatible with caring responsibilities. One woman explained that she couldn't promote her educational plans because she was youngest child and she felt more responsible for her mother after her older siblings had moved out of the house.

I would have liked to go to another school, which would have meant moving to another city, too. This was not possible because by this time my siblings had moved out of the house and my parents didn't support the idea either.

For many former young carers, this phase in their life is also often thought of as making compromises for the benefit of the family. Many former young carers maintain the caregiving role, while sharing some of the responsibilities with other people.

Maintaining responsibility is also induced by the experience that people from outside the family are barely ever able to replace the young carer. None of the interviewed former young carers fully relinquished their caring responsibilities if the person in need was not able to take care of him or herself or when alternative caring arrangements had been established. Even then they would continue to fulfill certain caring responsibilities, however, not in an instrumental way, but rather as a "back-up" or in an anticipatory capacity.

Finding one's own identity

The lives of former young carers were shaped by a strong sense of responsibility for another person when they were a child or an adolescent. Some participants said that they didn't even know what a normal childhood was, since certain activities, such as going out whenever they wanted to or having sleepovers, were impossible because of caring. Looking back, caring was an essential part of their identity when they were young. However, there was a point when caring for another family member was no longer necessary, usually when the cared-for person had passed away. If that occurred, not only did this mean the loss of a loved family member, but the responsibility the

young carer had was suddenly gone, leaving behind a vacuum that could not be easily filled. When the sense of being responsible was suddenly missing, an important part of their identity went missing, too.

Everything seemed so meaningless to me. Not because she [mother] was gone, but my task was gone as well. I had no idea what to do with my free time. So what I missed was to care for her.

In that sense, the loss of caring responsibilities confronts the former young carer with new and often unexpected challenges. As they are forced to give up caring, their near future is marked by efforts to fill the gap caused by the loss of the fundamental caregiving experience. At that point in their life they are often confronted with reflecting on their own needs. This can be very challenging, especially when they realize that they had been putting their needs aside for a very long time. It is in this situation of not knowing their own needs and constantly being confronted with questions such as “who am I” or “what do I want in life” that they have to find their own identity. A male former young carer reflected on this as follows.

I am just learning to care for myself and that my own needs are important too. I am withdrawing into myself to find out what I want? I try to take time on this ... because many situations in my life are really unfamiliar.

The loss of responsibility for the ill family member often gives them a feeling of being a seeker without direction. Often they are torn between efforts to rearrange their lives and living differently than before, and an urge to once again take responsibility for someone in need of care and support, a situation they are familiar with and which thus gives them a feeling of security. While some try to catch up on everything they weren't able to do during their childhood – e.g. traveling or hanging out with friends – others frequently and unintentionally

choose a life with strong responsibilities again. Therefore, many of former young carers choose to enter nursing education programs or search for employment in the health and nursing sector or in other social professions, even if they have tried other jobs before.

Remaining silent

Former young carers mostly do not talk about their previous caregiving experiences. Sometimes they feel ashamed or are afraid of discrimination due to the stigma associated with a family member's illness, especially in the case of mental disorders. They also do not talk about it because caring was part of their normal lives when they were young, which is why they do not call it into question. Another reason for their silence is that they want to protect themselves from being overwhelmed by the painful memories. They attempt to suppress their feelings for a very long time.

I mean, that was a special subject. I didn't talk about it for a very long time, I mean about that. I always started to cry when I was talking about my mother.

Regardless of why they chose to remain silent, for some participants the interview in the course of this study was the very first time talking about their childhood experiences. For some participants, the strain imposed by suffering builds up over the years and talking to someone becomes an important way to release the pressure, especially when there is distress in the form of mental anguish.

I must say I have been in therapy for more than ten years now because I realized that all of that must get out of me. It is somewhere in me and it's draining me. It has to get out of me and it needs an outlet for that.

Talking about their situation required a certain degree of awareness of their former role as young carers. Some of the participants were unaware of their role until

reflecting on their experiences during the interview. Becoming aware of one's role as a former young carer is an important process; many of the interviewees, however, had the feeling that something was wrong with them without being able to identify the origin of this feeling.

DISCUSSION

This study gives one of the first glances into the situation of adults who provided informal care as a child or adolescent. It can be assumed that caring during this phase of life has an impact on every person concerned, and affects the transition into adulthood as well as the later life as an adult. Findings from this study are consistent with findings from other studies where participants reported both positive and negative effects related to past caring experiences^(14,17). While positive aspects, such as the ability to master their life as a result of having to cope with difficult situations during their childhood, were a recurring topic, negative physical effects associated with caring, as mentioned by Frank et al.⁽¹⁶⁾, were reported far less frequently in the present study. Concrete negative effects were, in fact, only reported when specifically addressed by the interviewer.

Considering caregiving youth from a family caregiver position the transition into a later life shows certain analogies to the concept of post-caregiving transition (PTC). As Ume and Evans⁽¹⁹⁾ stated, this particular time addresses the period beyond adult family caregiving, usually terminated by death or placement in the nursing home of the loved one. Larkin⁽²⁰⁾ investigated this transition and identified three phases. At least two of these phases can be identified in the post-caregiving transition of former young carers as well. "Post caring void" is the immediate phase after caregiving and is characterized by a sense of loss of responsibility, feelings of emptiness and disequilibrium of live. Many former young carers express the same feelings just when the responsibility they had as a young carer was suddenly gone. In the phase, called "constructing life post-caring",

family caregivers return to their previous life they had before. Former young carers usually do not have a previous life they can go back to because caring was part of their youth. Anyway, the category "finding one's own identity" in our study fits very well into this phase because "construction life post-caring" is based on something new or unknown. It seems to fit even better than in the original concept were the construction seems to be more a "reconstruction" of something that was already there before.

The study also showed that, from the retrospective view of a former young carer, caring as a child or adolescent affects educational and social life decisions as a consequence of the ongoing caring responsibility. In accordance with other study results⁽²¹⁾, we cannot predict that these effects are necessarily always negative or lead to deprivation in later life. Caring responsibilities, however, do affect later life decisions in various ways. If educational goals are incompatible with caring responsibilities, a lack of freedom to make a conscious choice becomes apparent. In this case, the distance between the place of education or work and the family's home plays an important role to combine both caring, and education or career⁽¹¹⁾. Similar to other studies about young adult carers^(15,22), the present study also shows that former young carers often refer to certain abilities they acquired during childhood and carry into later life. This, often unconsciously, influences their occupational decisions, and many former young carers see themselves working in a caring or other social profession⁽¹⁶⁾.

It is well known that young carers do not talk about their situation due to the fear of stigma or family disruption^(4,23). They also do not talk about it because caring responsibilities are part of their normal life rather than exceptional work that distinguishes them from others⁽²⁴⁾. Former young carers also do not talk about their prior situation, often not even to friends or family members due to the same reasons. A significant finding of this study is that, even with a time lag, former young carers are often unaware of the specific role and

responsibility they once had. This awareness often occurred during the immediate interview situation, when talking about it.

Therefore for many participants, the interview was the first time ever they had talked about their caring experiences. According to positioning theory⁽²⁵⁾, this suggests that, in contrast to adult caregivers, former young carers cannot recognize themselves as caregivers because they do not interact with other young carers. The lack of awareness of children and adolescents who care for an ill family member on a regular basis as well as a legal definition of what constitutes a young carer and what this means in the context of family care hinders affected persons to recognize themselves as a former young carer. Ultimately, this also provides a strong explanation for why it was particularly difficult to get access to the group under study.

Limitations

At the time of the interviews, most of the caregiving situations dated back approximately 15 years. A younger sample with a maximum individual age of 40 years would likely lead to different findings, as it can be argued that children supporting their families were more self-evident and socially tolerated or even desired in the past, especially in a post-war generation. Data saturation was not achieved, as there was not enough variation in the sample. Although more interviews do not necessarily lead to more insights, they can contribute to a better knowledge of important contextual factors that may affect participants' actions (e.g. family background, gender, socioeconomic status, etc.). Nevertheless, the study's approval period required us to finish data collection at a predefined time.

CONCLUSION

This research highlights the situation of a hidden group in our society. Focusing on former young carers and reconstructing their past may help to develop preventive actions for present young carers and may also help to

improve existing young carers programs. From the researcher's point of view, some former young carers are still in need of help. This indicates the problematic nature and inappropriateness of caring activities during childhood and adolescence and raises the necessity to assess the situation of actual young carers and support and relieve them in their daily lives. It also indicates the right to identify young carers in their immediate surroundings and the creation of a respectful and non-discriminatory environment that facilitates the coming out process of caregiving children. Even though the research focuses on former young carers as individuals, it highlights the need for a systemic view of the whole family structure and to provide family support services. Nurses as the largest group of health care providers are often the first contact point for families in need of support. This puts them in a special position to look out for young carers' well-being and prevent them from assuming inappropriate caring responsibilities.

Adult carers services largely ignore the specific transitional needs of young adults, who are also less likely to know their legal rights as a carer. Therefore, the transition of young carers into adulthood requires specific support to assist them in their educational, professional, and social goals. Several agencies in countries such as Great Britain or Australia have introduced new policies to support this group of former caregivers during the last decade. Unfortunately, there are almost no such support programs, no specific legal rights frameworks, and hardly any political or professional awareness in German-speaking countries yet.

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