Invisible caregivers: The 'hidden lives' of German university students with care responsibilities

Abstract

Since university students increasingly face the need to reconcile studying and caring for an older person this study explores the lives, challenges and coping strategies of caregiving students in Germany as well as the ways institutions of higher education can (or already do) support them. The situation of such students was investigated with eight in-depth interviews with caregiving students, which were fully transcribed and analysed with a thematic coding strategy. Results show that caregiving students in tertiary education are a group that experiences unique challenges that differ from those faced by caregivers in later life, working life or caregiving children. They tend to live 'hidden lives' as caregivers and face exclusion from a 'normal' student life. Findings indicate the importance of raising awareness for the topic among university staff as well as flexibility with regards to regulations in the university context.

Keywords

caregiving students; reconciliation of study and care; qualitative study; chrononormativity, hidden lives

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1 Introduction

Many students today face the challenge of reconciling their studies on the one hand and work and childcare on the other (BOZICK, 2007). A similar, yet under-researched, challenge in the realm of higher education is that of reconciling one's studies and caregiving for (older) adults. Although there is no representative Germany-wide data, various studies assume that up to one in six students regularly provides informal assistance, care and nursing activities for another adult, like a family member, a neighbour or a friend (cf. MINDERMANN et al., 2020). Still research into this area is lacking despite the fact that the number of students who provide informal care to an (older) adult is expected to be growing as demographic aging leads to a growing number of older people both in absolute and relative terms. (Older) Adults receive most of the care from the family. In addition to providing care, these informal caregivers also work or study. The number of students providing care is expected to increase.

We define caregiving students as those, who attend an institution of higher education and simultaneously provide care for an (older) adult, whether it be a family member, neighbor or friend. Studies show that caregiving students, who are part of the group of non-traditional students (CHEN, 2015), face several challenges. A broad definition of non-traditional would be "students who for a complex range of social, economic, and cultural reasons, were either excluded or under-represented in higher education" (ibid., p. 47). Caregiving students often suffer from time constraints (KETTELL, 2018), do not feel like they properly belong to the university they attend, and cannot talk about their caregiving to fellow students or university lecturers and staff ("hidden lives": KIRTON et al., 2012, p. 644). This is exacerbated by split loyalties between their studies and their care tasks, university staff and care recipients (ibid.), as well as the fact that lecturers are often unaware about the care responsibilities of their students. In addition, caregiving students often face financial hardship, as their primary roles of caregiver and student takes all their time, which leaves them often unable to maintain paid employment (KIRTON et al., 2012). Altogether, the reconciliation of studying and caregiving often results in physical and mental health problems as well as a lower quality of life (HAUGLAND et al., 2020).

This study makes three contributions to the literature on the subject: First, it goes beyond previous research by exploring how caregiving students in Germany recon-

cile studying and providing care in a qualitative and in-depth manner. It investigates the challenges they face and the effect that providing care has on their lives. Second, it expands the regional scope of existing studies on the subject (mainly based in the UK and Scandinavian countries) by adding information about caregiving students in the German education system. Third, it explores how institutions of higher education do (not) support caregiving students and what kind of support caregiving students would like to receive.

2 The German context: Education, welfare and care

This section offers a brief overview of the institutional framework in Germany to contextualize the study.

Despite efforts to standardize (higher) education systems throughout Europe, unique features still exist in Germany. A distinctive characteristic of the German education system is that it is very selective. The probability of studying at a university is more strongly linked to the socio-economic background of one's parents than in other countries (OECD, 2018). Moreover, students in Germany spend an average of six years at university, which is comparatively long for Europe, and German students are, on average, older than their peers in other countries (for example UK and US) (cf. LUTHRA &FLASHMAN, 2017).

While the higher education system has a significant impact on caregiving students, their situation is also framed by the national care system. Payments into the state's long-term care insurance, the most recent (established 1994) of the statutory insurances, are salary-based; employees and their employers each contribute an equal share. Benefits for both residential and institutional care are independent of a person's income and everyone in need of care is eligible (DYER et al., 2020).

The question of who provides (informal) care is closely connected to underlying societal norms (PFAU-EFFINGER, 2005). Germany's 'care culture' focuses on women in middle or late adult age as the primary family caregivers (ROGGE, 2020). Despite increasing awareness that men also provide care (DOSCH, 2018), this remains comparatively low. Statistics indicate that more than 80% of the beneficiaries receive

in-home care, of which the majority (almost two thirds) exclusively comprises cash benefits and is taken care of by informal, non-professional caregivers such as family members and friends (STATISTISCHES BUNDESAMT, 2019).

3 Methods

This paper draws on eight problem-centered interviews² (WITZEL, 2000) conducted with persons currently enrolled at German universities that are or were engaged in informal caregiving activities to (older) adults. The call for participation was distributed among students at the Goethe University Frankfurt am Main, the University of Applied Sciences Frankfurt am Main, the University of Bremen, the University of Applied Sciences Bremen, the University of Applied Sciences Bremerhaven, the University of Vechta, the University of Applied Sciences Ludwigsburg, the University of Dortmund and the University of Mannheim. Theoretical sampling provided the orientation frame for selecting potential interview partners. For example, we aimed to include persons in different care relationships/care-recipients, in different life stages and different care arrangements. Persons who provided childcare or professional care (e.g., nursing students) were excluded from the study. Table 1 provides an overview over the sample.

² The interviews were conducted and analysed in German, the native language of the participants and researchers involved. Interview quotes in this manuscript were translated by the project team and edited by the GRADE English Language Editing of Goethe University.

Table 1: Overview over the sample

Pseudonym	Care recip- ient	Causes of care needs	Duration	Intensity	Arrangement
Herbert, 49 years	first father, then mother	father: de- mentia; moth- er: dementia	> 10 years	approx. 35h / week	cared for his father together with his mother and then profes- sional nurses
Julia, 30 years	grand- mother	dementia, bipolar dis- order	2 years	full-time	alone
Karoline, 24 years	mother and father at the same time	father: multi- ple sclerosis, cancer; moth- er: cancer	1 year	differs; 5–50h / week	with siblings
Leonie, 23 years	grand- mother	dementia, depression	6 months	approx. 55h / week	with her sisters
Linda, 24 years	grandfather	physical im- pairment	6 years	approx. 10h / week; 100h / week at the end	mainly alone, partly supported by parents
Mia, 24 years	first mother, then father	mother: can- cer; father: cancer	3 months mother, 3.5 months father	differed greatly	alone
Ruth, 32 years	mother	schizophre- nia, cancer	18 years	approx. 5h / week	temporary sup- port of neigh- bors, friends
Susanne, 40 years	adult son	multi-hand- icap	16 years	approx. 25h / week	partly supported by husband

The problem-centered interview guide was constructed based on the results of a systematic literature review (KNOPF et al., 2022) and comprised questions on the care situation, challenges that students encounter while studying and caregiving, positive and negative consequences of reconciling both activities, coping strategies as well as wishes and needs for support. Interviews lasted between 25 and 90 minutes. Due to the Covid-19 pandemic, five interviews were conducted via video communication tools like Zoom, and three were conducted face-to-face. The audio of every interview was recorded and fully transcribed.

Transcripts were coded based on a thematic coding strategy proposed by FLICK (2014) that combines principles from Thematic Analysis and Grounded Theory. Such a strategy is well-suited for phenomena where little research exists, but yet some conclusions can be drawn from previous studies, as it allows to combine both inductive (exploratory) and deductive (derived from existing research) steps in a dialectic manner (ibid.). Categories derived from the literature review conducted prior to the coding process – referring to the care situation, challenges, consequences, and support needs – were used as a deductive framework for coding that was complemented and contradicted in the process with inductively derived codes. The prior four codes proved to be strongly entangled in the qualitative analysis, and thus merged into two meta codes - challenges and consequences on the one hand and support needs as well as existing coping strategies on the other. Within these two meta-codes emerged a division between the university and the caregiving relationship as two contexts that were narrated as both distinct and interrelated, hence codes within the meta-codes were divided between the two. All project members were involved in the coding process and codes discussed in several interpretation sessions. In the following results section, we start by discussing the challenges and consequences, respectively support wishes and needs that caregiving students express independently of their studying situation, and which thus might be similar for other groups of family caregivers; subsequently, we focus on the aspects that specifically concern the reconciliation of studying and providing care.

4 Results

Our interviewees have very different caregiving and studying situations (see Table 1). Whereas Leonie, Linda and Mia describe their care tasks as rather minor and mainly about shopping, cleaning and keeping the care recipient company, Herbert, Julia, Karoline, Ruth and Susanne are involved in care tasks like providing food and mobilizing their relatives as well as helping them use the toilet. Despite these differences, every interviewee mentions two themes: (1) the challenges and consequences involved with caregiving and studying, and (2) the support they either receive or wish they did, to cope with these difficulties. Each of these sections can be sub-divided further into general or university-specific aspects.

4.1 Challenges and Consequences

Caregiving students deal with numerous challenges regarding their studies, personal wellbeing and social network. Their reports indicate several negative and some positive consequences of reconciling caregiving and studying.

In general, caregiving requires permanent engagement that caregivers must incorporate into their routines and often experience as overwhelming. On a personal level, negative consequences include physical and mental health issues. For example, Susanne, who has been providing intense care for her adult multi-handicapped son, reports that

Caregiving is physically exhausting and it really takes it out of you psychologically. [...] it is really hard work, to change the diapers of a young adult man and place him on the toilet [...] and caregiving, in this sense, really means 24-hour care.

Exhaustion, stress and anxiety can manifest as physical pain, aggressiveness or even burnout. Our interviewees talked about emotional struggle, shame, sadness and fear of the future.

The physical and mental burden is especially hard for those who did not volunteer to give care but regarded caregiving as a family commitment. One student experienced the care task being delegated to her.

And then um it [the caregiving] was somehow just stealthily handed over to me. Um 'yeah, you know more about this than we do'. (Linda)

Maintaining relationships with friends, fellow students and family while communicating one's wishes and needs in the caregiving situation towards them is another major challenge. Caregiving students report tensions within the family and in friendships. The inability to work in addition to caregiving and studying can lead to financial hardship. Also, caregiving generally means less or no holidays and leisure time.

Since this study focuses on caregiving students, challenges related to the university are of particular interest. According to the interviewees, a lack of time and energy to attend classes, engage in group work and meet the required deadlines are the primary challenges that arise from studying and caregiving together. Others mention that they have extended and rescheduled their studies, failed or postponed exams, relocated a planned semester abroad and felt generally insecure about completing the degree successfully. As student and caregiver are both demanding roles in terms of time and energy, students feel the need to prioritize one or the other and feel guilty either way.

Given the often time-consuming and demanding caregiving situation, students in this position often find themselves having to neglect their studies:

Studying just becomes so unimportant. It quickly fades into the background. Because you suddenly think to yourself, 'Okay, that's no longer important right now.' What's important is that your grandmother doesn't lie in feces, that she doesn't put herself or others in danger. (Julia)

Students also report choosing their classes and examinations according to their caregiving obligations:

It was impossible to take courses after 4pm because he got home by 5pm and I was responsible for caregiving from then on. (Susanne)

In their experience, the study workload exceeds their capacities. Challenges arise from the university staffs' expectation that students are able to manage full time studies at any given time.

They feel dependent on the lecturers' goodwill to be more flexible with rules, such as mandatory attendance or deadlines for course work. The interviews reveal that they feel discouraged from speaking openly to their lecturers or administrative staff about their situation. In line with this, caregiving students reported a lack of understanding for their situation by lecturers:

Um, that um, the difficulty was that the lecturers also required a lot [...] And um yes, because some lecturers did not really show much empathy, to say 'okay, I understand that they also have other worries'. (Leonie)

Beyond lack of empathy, another reason for hesitating to communicate openly is that caregiving students fear being confronted with the stereotype that their caregiving obligation makes them less productive and less reliable. They report little understanding from the university in general for any kind of challenge that students might face beyond their degree program.

Moreover, caregiving students report that getting involved in clubs, volunteer work or other types of extracurricular activities in addition to studying and caregiving is difficult. Lack of time for university is regarded as a driving factor in exclusion from relationships to peers.

However, the interviews show that caregiving students experience these challenges to different degrees. Some caregiving students even associate studying and caregiving at the same time with positive aspects and resiliency. They report that they are better organized than fellow students and have learned to put things into perspective. Moreover, they perceive reconciling different tasks improves their creativity as well as time-management abilities. One interviewee mentions that it was fulfilling for her to give back support that she had received from her grandfather when she was a child.

While some students indicate that caregiving strains their relationships, others find it tightens their family bonds and friendships. A student reports that her relationship with her family member as care-recipient improved. Another stated:

In a way, it was good that I wasn't getting up to nonsense at night like I used to, but was at home [with my parents] (...). We grew closer as a family during that time. (Karoline)

4.2 Support

The following section outlines the support that caregiving students mention receiving and that they wish they would. Overall, the study participants draw on few sources of support.

The care and support arrangement, i.e., the network of informal and professional caregivers among whom care tasks can be distributed, strongly affects students' involvement as caregivers. It is striking that hardly any interviewee receives support from professional nurses. In Leonie's case, for example, the (foreign) live-in caregiver could not re-enter the country during the first Covid-19 related lockdown in spring 2020, leaving her mother and sisters to take care of her grandmother. In Linda's case, her grandfather denied professional support:

My grandfather (laughs) was not, well, he wasn't willing to have other people around him. [...] There's this old-fashioned way of thinking in our family that families support each other, so the younger generations help the older ones. And that was my grandpa's opinion as well.

How strenuous the students perceive the care situation largely depends on how much support they receive from the rest of the family. Some can share tasks with parents or siblings, while others suffer from being completely left alone with the responsibility. Karoline remembers sharing tasks with her siblings: "I think none of us could have done this alone, but together, we were a team", but Herbert did not have the same resources: "Yes, as an only child, I can't say to a sibling 'take over today' or 'step in for me tonight, one day".

While professional care and family support is crucial, we focus on support provided in the university context. In general, caregiving students report they receive little support from the university. Universities often lack action plans for caregiving students, impeding applications for concessions (e.g., financial support or scholarships), and staff is unaware of the phenomenon. Equal opportunity commissioners and family offices often focus on students with children. The caregiving students feel unseen as there are no offers specifically tailored to their needs "I mean I looked [for support] but found nothing" (Karoline).

What caregiving students find instead are psychological counseling, stress relief courses and sports classes, which the universities offer to all students. One reason

that they prefer the 'anonymity' of support structures for students in general is that many caregiving students feel ambiguous towards opening up about their care obligations with university staff or their fellow students. Mia also mentions that emotional support from university staff would make her feel uncomfortable. "So I didn't want to demand emotional support from someone who works at the university". In line with this, few interviewees mention receiving support from fellow students.

In addition to the general support structures for students, caregiving students also negotiate 'individual solutions' with individual lecturers or administrative staff. These include, e.g., deadline extensions and alternative forms of exams, which greatly depend on the individual's goodwill and understanding. Karoline mentions a clerical assistant in the registrar's office.

The guy in the registrar's office – a clerical assistant I guess – who I always gave certificates and official forms to during my studies. He just helped me again today. I would never have finished my studies without him. He was so flexible with deadlines.

One support structure caregiving students wish for is awareness by lecturers and administrative staff about the challenges of reconciling studying and caregiving. This would make them less dependent on the decisions of individual lecturers. "Sensitizing the people who work at the university about the issue. That would be a good thing" (Susanne). Linda sees potential in implementing a special week highlighting the situation of caregiving students, in which the university informs its staff and fellow students about the issue through various activities. "Yes, I think the idea of a week of the caregivers is super. It doesn't matter if 50 or 200 people come. Finally, something would be done about this topic." A second wish of these students is greater access to flexible, remote learning, which would ease their burden of being restricted by lecture times. The interviewees hope that the experience of remote teaching during the Covid-19 pandemic will serve as a steppingstone for permanent remote learning.

Flexibility was mentioned frequently when the caregiving students were asked about what support they needed – the flexibility of deadlines, attendance, type of exam, as well as the choice of lectures.

Finally, day-care centers at the university are also worth considering. "And those responsible for a person with dementia, like me. They can then drop them off there [Day-care centers at the university], for example." (Herbert).

5 Discussion

Our results show that the experiences of caregiving students partly resemble those of other informal caregivers, like young adult carers, spouses, adult children or inlaws: mental stress and anxiety as well as physical strain are common outcomes in the literature on caregiver burden in general (KASCHOWITZ & BRANDT, 2017; JOSEPH et al., 2020). However, we also find that caregiving students in tertiary education are, in fact, a group that experiences unique challenges. This can be traced back to the concept of the institutionalized life course (KOHLI, 2007) and the norms and expectations associated with the different phases of the life course that Elizabeth FREEMAN (2010) coined as 'chrononormativity'. In Germany and many Western societies, tertiary education is traditionally framed as a stage of freedom from many social obligations as well as of discovering and experimenting (cf. STAUBER & WALTHER, 2016). Due to their caregiving obligations, our interview partners reveal that caregiving students are often not able to engage in this idealized 'student lifestyle'. Furthermore, caregiving students 'violate' the 'care culture' in Germany, which dictates that female relatives in middle or old age should provide care (ROG-GE, 2020).

In deviating from normative expectations, caregiving students feel ashamed about their situation and try to conceal it from fellow students or university staff. In a qualitative study on caregiving students in the UK, KIRTON et al. frame this phenomenon as "hidden lives" (2012, p. 644). This refers to their finding that many students do not want staff, lecturers and fellow students to know about their caregiving duties, even though explaining their situation might increase understanding of it, and perhaps even buffer some of the negative effects that it has on their studies and social integration at the university.

Study participants were quite outspoken about the support they wish their universities would give them to prevent both short and long-term damages to caregiving students' lives. They suggest several measures that universities can take, including awareness trainings about caregiving students' situation (and even their mere existence) for university staff, more flexible teaching arrangements in terms of time, place and format of performance reviews for caregiving students, and on-site (elder-) care services – all of which would, in turn, contribute to the visibility, integration and normalization of caregiving students.

Although all the study's participants are enrolled in Germany universities and, thus, the findings may only apply to Germany, there are still some implications for caregiving students' situation in general. As previous research on the topic outside of Germany (KIRTON et al., 2012; KETTELL, 2018) finds exclusion from a 'normal' student life as well as the issue of hidden lives, one can assume that the support that our participants desire is also transferrable to caregiving students outside of Germany. Raising awareness for the topic among university staff as well as flexibility with regards to regulations are the two main tools mentioned here. In addition, more research on caregiving students should be conducted globally.

We must acknowledge several limitations to this study: Participants were only recruited via universities, so the sample only includes enrolled students. Thus, we did not reach students who were forced to drop out due to care duties. Participation in the study also required these individuals to self-identify as "caregiving students" – a term that exists in neither academia nor the community (unlike family carers). Our findings indicate that a fear of being stigmatized by university staff may have also prevented some from participating in the study and participating in interviews is time-consuming and might hinder heavily occupied caregiving students from taking part in the first place. Finally, we so far have not yet investigated how the care and study situation interacts with potential arising challenges and consequences.

Despite these limitations, we outline two pathways for future research on caregiving students: First, we still have scarce knowledge about the percentage of students who provide care. While studies have been carried out for specific universities or departments (cf. ALSOP et al., 2008; BOUMANS & DORANT, 2018; HAUGLAND et al., 2020; MINDERMANN et al., 2020), no national data exists about how many students in higher education provide informal care for an adult. Yet, as outlined above, caregiving students might not always identify with the term 'caregiver' and not classify the support they provide as 'care'. Thus, we need to develop instruments to operationalize caregiving in this context before we can collect further data on caregiving students. In our opinion, mixed-methods approaches are best for developing such measurements. Second, while existing research hints at some characteristics among caregiving students and factors that might increase the likeliness to care (e.g., gender or family constellation; cf. ALSOP et al., 2008; HAUGLAND et al., 2020), we hardly know anything about the long-term consequences of studying and caregiving. Cumulative advantage/disadvantage theory (DANNEFER, 2003)

posits that these outcomes may be severe and contribute significantly to the reproduction of social inequalities across the life course. Hence, for our knowledge on social inequality, it is crucial to approach the situation of caregiving students from a life course perspective.

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