Psychosocial resources contributing to resilience in Austrian young carers—A study using photo novella

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Abstract
Caring for their chronically ill or disabled family members is a responsibility that may be assumed by children and adolescents ("young carers") and may affect young carers’ lives in many ways. Some young carers may experience long-term adverse health effects related to their early caring responsibilities and others may demonstrate healthy adaptation. Little research applying nonretrospective designs, however, has been done from the perspective of young carers regarding the psychosocial resources that enable them to handle the responsibility of caring for chronically ill or disabled family members. The aim of the present study, therefore, was to identify psychosocial resources used by young carers in Austria. Ten children and adolescents (aged 9–17) took photographs to illustrate their everyday lives. The photographs were then used to guide subsequent interviews. Data were analyzed following the principles of directed qualitative content analysis and using the theoretical lens of resilience. We identified two sets of psychosocial resources: (1) Personal resources comprising (a) being able to spend leisure time and (b) finding distraction from sorrows and problems. (2) Interpersonal resources comprising (a) fostering meaningful friendships, (b) receiving support from the family, and (c) bonding with the ill or disabled family member. Young carers largely have the same repertoire of resources as other children and can use them specifically to respond to the care burden. Interventions to support young carers must focus on promoting peer contact and cohesion within the nuclear family as well as bonding with the ill or disabled relative.

KEYWORDS
photo novella, psychosocial adaptation, psychosocial resources, resilience, young caregivers, young carers

1 | INTRODUCTION AND BACKGROUND

Worldwide, children and adolescents under the age of 18 years regularly look after chronically ill or disabled family members (Leu & Becker, 2017). These care providers are referred to as "young carers," "young caregivers," or "children who are next of kin." They provide care, assistance, or support to another family member, often on a regular basis. The person receiving care may be a parent, sibling, grandparent, or any relative with a disability, chronic illness, mental health problem, or condition requiring care.
support, or supervision (Becker & Leu, 2019). Young carers provide a spectrum of care, including physical and emotional care, managing household tasks, and helping siblings (Chikhradze et al., 2017; Dearden & Becker, 2004). International estimates of the prevalence of young carers indicate that 2%-8% of the minors in western countries bear significant caring responsibilities (Hunt et al., 2005; Leu et al., 2019; Metzing et al., 2019; Nagl-Cupal et al., 2014; Office for National Statistics, 2013).

The reasons for providing care as a child or adolescent are complex. They often involve the absence of other informally available support networks, the lack of suitable formal care arrangements, familial preferences, as well as love and natural family bonds with the person in need (Becker et al., 1998; Dearden & Becker, 1998, 2004; Metzing & Schneppe, 2008). Limited financial resources (Cass et al., 2011; Hunt et al., 2005; Metzing, 2007) and, in some cases, cultural motives or religious expectations (Becker & Leu, 2019; Cass et al., 2011) are additional contributing factors.

There are many consequences related to providing care at a young age. Significant caring responsibilities may exceed what is age-appropriate and may lead to serious physical, psychological, social, or academic problems in young carers (Bjorgvinsdottir & Halldorsdottir, 2013; Chikhradze et al., 2017; Kaiser & Schulze, 2015; Moore et al., 2009; Nigel et al., 2003). Although some problems, such as elevated depressive or somatic symptoms, may persist when these young people enter adulthood (Haugland et al., 2020; Shifren & Kachorek, 2003), others are transient in nature.

Young carers also retrospectively report positive consequences of their unique experiences growing up. Among those are high levels of self-confidence, an early sense of maturity, close relationships with their parents, the feeling of being well prepared for their lives (Roling et al., 2019), as well as a sharp sense of responsibility, empathy, and sensitivity (Nagl-Cupal et al., 2015; Szafra et al., 2016). These findings may be viewed as additional tentative evidence for resilience (Masten, 2001; Rutter, 2012) in the lives of young carers. Despite the presence of potentially serious threats to their development associated with their early caring responsibilities, many young carers are still able to grow up to be well adjusted, healthy adults.

1.1 | Resilience as a guiding concept for studying adaptation in young carers

As both a theoretical concept and field of empirical research, resilience offered a developmental psychology framework for the present study. Resilience emphasizes that healthy adaptation to precarious or challenging life circumstances requires the availability and strategic use of (a) personal resources, such as high cognitive skills and easy temperamental traits, as well as (b) interpersonal resources, that are largely derived from one’s friends and family (Ungar, 2015). Competence in age-salient developmental tasks, such as school attendance/academic performance or absence/presence of delinquent behavior, as well as internal criteria, such as subjective well-being or psychological distress, are used in research as criteria to evaluate healthy adaption or resilience in children and adolescents (Masten & Obradović, 2006; Rutter, 2012).

The broader literature on resilience in children and adolescents growing up under disadvantaged circumstances (stressors such as serious illness within the family) has posited that resilience is ultimately the result of basic human adaptational systems, influenced by personal and interpersonal psychosocial resources, including self-efficacy beliefs, emotion regulation, and supportive interpersonal relationships (Masten & Obradović, 2006; Masten, 2001). If these resources are available and adaptational systems function normally, resilience to developmental threats is expected to be common rather than exceptional or rare (Masten & Obradović, 2006). Nevertheless, much of the research on young carers to date has focused on elucidating the unique experiences and especially the characteristic challenges these young people face (McDougall et al., 2018; Metzing & Schneppe, 2008; Nigel et al., 2003). Although it is important to investigate the exceptional in the lives of young carers, that may set them apart from “ordinary” children and adolescents, researchers may overlook or underestimate more common yet influential adaptation mechanisms and psychosocial resources contributing to resilience.

In addition, researchers have frequently relied on retrospective interviews with former young carers (Roling et al., 2019; Szafra et al., 2016) that may be subject to bias in recalling past experiences. Issues with recall may be especially true when recalling sensitive or traumatic experiences in the distant past (Althubaiti, 2016; Hardt & Rutter, 2004; Hardt et al., 2006; Maughan & Rutter, 1997). Reliance on retrospective interviews in research may be only partially attributed to the difficulty in identifying young carers who often remain invisible in society and thus difficult to recruit for research (Bjorgvinsdottir & Halldorsdottir, 2013; Gray et al., 2008; Nigel et al., 2003).

A major constraint for research with young carers is methodological, as children may have difficulties verbalizing ideas and describing abstract issues in strictly verbal interviews (Zartler, 2014). Complementing verbal interviews with visual media, such as participant-produced photographs, maybe an appropriate methodological response to this problem (Harper, 2002; Zartler, 2014).

The aim of this study was to identify psychosocial resources available to children and adolescents who were currently involved in the care of chronically ill or disabled family members in Austria. By using participatory photograph interviews, we sought to obtain insights from young carers regarding what supports and encourages them in their everyday lives.

2 | METHODS

The present study was designed as a qualitative-descriptive study. Embedded in the interpretative paradigm, qualitative research aims to create a detailed and comprehensive depiction of the perceptions, meanings, and interpretations of the social and cultural reality of the persons involved (Holloway & Galvin, 2017). Qualitative descriptive studies are the method of choice when more data near and less interpretative description of a phenomenon is desired (Sandelowski, 2000).
2.1 | Photo novella

Several methods and techniques applied in so-called “photo elicitation interviews” or “photo interviews” allow researchers to incorporate photographs in verbal interview settings (Close, 2007; Harper, 2002). The current study may be classified as a “photo novella” in which the participants were encouraged to take photographs to illustrate aspects of their lives and also talk and reflect upon them (Close, 2007). Such participant-produced photographs are an especially useful technique in studies with children, as their photographs may help them during interviews to better recall, verbalize, and describe complex situations, feelings, and experiences (Balmer et al., 2015; Close, 2007; Zartler, 2014). Assigning children with the task of taking photographs related to the research topic may also more actively engage them in a participatory research process and be an enjoyable activity by itself (Zartler, 2014). The pictures that are produced, however, do not speak for themselves, but rather require interpretation by and discussion with the photographer to fully understand their subjective perspective, as well as the context and intended meaning of the images (Harper, 2002; Zartler, 2014). When viewing and discussing the photographs with a researcher, the photographs act as stimuli and visual prompt for the interview (Harper, 2002).

2.2 | Sampling and recruitment

A purposeful sampling strategy based on typical cases was used in this study. The purpose of typical case sampling is to describe and illustrate what is normal or typical for a particular group for those who are not familiar with the setting (Patton, 2002). For this study, typical cases were participants who live in a common household with one or more chronically ill or disabled family members and were involved in caring for the family member(s) on a daily or almost daily basis. Children and adolescents under the age of 18 years fitting these criteria were included. From around the age of 10 years, children are assumed to be able to cope with the technical and cognitive challenges associated with photography and interviews (Birney & Sternberg, 2006). The additional inclusion criteria were: (a) voluntary and informed consent/assent to participate in the study (assent by the participants and consent by their parents/legal guardians); (b) willingness and ability to provide information about the research topic; and (c) sufficient German language skills for an interview.

Recruitment relied primarily on cooperation with private and state-funded healthcare and service providers that operated throughout Austria that may have encounters with young carers. This approach was chosen because healthcare professionals working in home healthcare nursing, family counseling, or social services had established relationships with the families with whom they worked. This enabled healthcare professionals to identify young carers and invite them to participate in the study. In addition, a website and social media page were set up and promoted to raise public awareness for young carers and to recruit study participants through a snowball effect. Young carers having previously participated in studies conducted by the researchers were also recontacted. All potential study participants, as well as their parents or legal guardians, received written and verbal information and instructions concerning the present study before written informed consent/assent was obtained.

2.3 | Data collection

Data were collected by both authors. The children were informed that they are invited to participate in the study because they are providing care for a chronically ill or disabled family member. The authors instructed all participants to take photographs that illustrated positive and negative aspects of their everyday lives. First, the participants were asked to photograph situations and things that “make you happy, give you strength, or help you relax and feel good.” Second, they also were asked to take pictures of “what you don’t like in your everyday life, what worries you or makes you sad.” The latter served to acknowledge the challenges that young carers experience and to provide specific contexts in which to reflect on psychosocial resources that enable them to overcome these challenges. The participants were purposely not instructed to document only aspects explicitly related to their role as caregivers. This decision was made in order to obtain a holistic portrayal of the lives of young carers, which specific features are discussed in the following interviews.

The participants were asked to take a maximum of 30 photographs over 2–3 weeks, either with their own cameras or smartphones, or with disposable cameras provided by the researchers. Parents and legal guardians were only actively involved when the participants needed help to send the photographs to the researchers via e-mail or, in the case of disposable cameras, regular mail. A total of 183 photos were taken by the participants, with each participant taking 6–30 photos for the project. The participants provided significantly fewer photographs depicting negative than positive aspects of their lives, but both categories of photographs stimulated discussions during the interviews on adapting to everyday stresses and strains.

The researchers printed and laid out all the participants’ photographs on a table before the interviews started. The interviews lasted between 22 and 94 min (M = 49 min) and took place predominantly in the researchers’ offices (7 out of 10 cases). Interviews with the three youngest participants were conducted at their homes and in the presence of their parents.

After an introduction and some informal familiarization, the participants were asked to pick one of their photographs and describe its contents and context (i.e., what is seen and what it means). Each photograph was discussed in this manner, in as detailed a manner as the participants chose. The photographs were subsequently placed on a green or red piece of paper depending on whether the photo represented a positive (green) or negative (red) aspect of the participants’ lives. Follow-up questions were asked as needed to obtain more detailed insights and keep the interview flowing. Sociodemographic data were collected after each interview. All interviews were audio-recorded. The audio-recordings were
transcribed in full by two research assistants. Both study authors proofread the transcripts for accuracy. All photographs, interview records, and transcripts were only accessible to the researchers and stored in secure locations, that is, on secure and protected servers of the University of Vienna or in a physically locked container.

2.4 | Data analysis

The transcribed interviews and the photographs were imported into MAXQDA 2018 (VERBI Software, 2017) for data management during the analysis by the two investigators. Each photograph discussed in the interviews was linked with the corresponding lines in the interview transcript to illustrate the verbal data.

We used a directed content analysis in which the interview material was assigned to a pre-established concept in a methodologically robust way (Mayring, 2015). This content analysis was very much influenced by our preunderstanding (Hsieh & Shannon, 2005) of resilience as a process of adaptation to significant stresses and strains in life, facilitated by personal as well as interpersonal resources (Ungar, 2015). Accordingly, personal and interpersonal resources contributing to resilience are the two main categories in this analysis.

After becoming familiar with the data, coding rules were formalized around our a priori understanding of resilience. They were primarily aimed at describing and categorizing essential psychosocial resources for adaptation from the perspective of young carers. The psychosocial resources identified inductively from the data were then deductively assigned to the existing categories of personal and interpersonal resources. Data collection and analysis continued until no new insights could be obtained and informational redundancy was achieved (Sandelowski, 2008).

2.5 | Rigor

The research process was conducted in a systematic and methodical manner. Data collection and analysis were carried out by the two investigators, both of whom have considerable experience in qualitative research with young carers. This was an important prerequisite for the openness of the participants and thus for the quality of the generated data. During regular meetings, both researchers discussed the ongoing analysis process, reflected on the data, especially on coding issues and the interpretation of the results (Morse, 2015). In addition, reflective discussions were held with other researchers in the field of young carer research throughout the entire study and review process (Whittemore et al., 2001).

2.6 | Ethical considerations

As the study participants were underage, the researchers comprehensively informed their parents/legal guardians and the participants themselves about the study procedures and objectives. Written informational materials were provided to both parties and included the researchers’ full contact details. The participants and their parents were required to provide written assent/consent before the children’s study participation, and either was able to withdraw assent/consent at any time. Study participation was voluntary. The parents and legal guardians were also allowed to be present during the interviews. Additionally, a clinical child psychologist was available to be called in at any time if required. Study participants were given pseudonyms to disguise their identity.

Special consideration was given to the visual data in this project. The participants were instructed not to take photographs of persons without their consent and were informed that photographs containing sensitive information (e.g., identifiable faces or addresses) would not be disseminated in any way. Moreover, to maintain the participants’ anonymity, participants were assured that only a few carefully selected photographs would be used in a study report and scientific publications. The study was approved by the Ethics Committee of the University of Vienna.

3 | RESULTS

3.1 | Participants’ characteristics

Ten participants (four girls and six boys), aged 9–17 years (M = 13 years), from seven families, participated in and completed this study (see Table 1). Six of the ten participants had one disabled sibling each. Three participants had one or more chronically ill siblings. One participant cared for a chronically ill parent. Seven additional children were recruited and gave assent to participate, but dropped out without providing any data.

All participants were living in Vienna, the capital of Austria, and attended compulsory or secondary schools while participating in the study. In 6 out of 10 cases, the participants were living with both of their parents and at least one other healthy sibling. In three cases, the participants had no siblings apart from a care-dependent sibling. In one case, the participant had one chronically ill parent and no one else in the household. Nearly all participants (9 out of 10) had experienced their family members’ chronic illness or disability from birth. Care for the ill or disabled relatives was often provided from an early age: five participants began with caring when they were 8–11 years old and the other five stated they began their caregiving at an even younger age. The care activities included dressing and assisting with mobility devices (especially with wheelchairs and walking supports), giving medication, preparing and assisting with meals, doing housework, providing emotional support, supporting the healthy parent, helping the family member avoid injuries, as well as offering distraction and spending time together.

Most of the participants provided up to 30 min of support per day (6 out of 10 cases), but in two cases, the support amounted to approximately 3 h per day. Almost all families (9 out of 10 cases) made use of professional healthcare service providers, mainly...
were able to draw on personal and interpersonal resources largely comparable to those generally available to other children with intact basic adaptational systems. All following names are pseudonyms.

### 3.2.1 | Personal resources

Personal resources encompassed having leisure time at one’s disposal and being able to distract oneself from sorrows and problems. The young carers used leisure time in many different ways based on their own preferences and needs. Young carers also described conscious efforts aimed at distracting themselves from problematic aspects of the care situation.

**Being able to spend leisure time**

The participants noted numerous personal resources in their leisure time activities. Having obligation-free time and being given the possibility to use this time independently and according to their own interests and needs was mentioned in all interviews, reflected primarily in having the possibility to enjoy one’s free time and being independent. Sometimes, the caring responsibilities had to be delegated first, or as one young carer put it:

"We played games [after delegating caring responsibilities], that was just pleasant. It’s just nice to know that he [disabled sibling] is in good hands, but, like I also have a bit of time for myself." (Layla, 17 years)

A variety of leisure time activities were discussed and illustrated with photographs. These included listening to music; watching movies, TV series, and videos on the Internet; and reading books. The participants were not exclusively consumers of entertainment, as being creative (e.g., doing handicrafts, drawing, taking photographs) was mentioned in every interview as an integral part of leisure time (see Figure 1).

**Finding distraction from sorrows and problems**

The young carers explicitly assigned highly differentiated functions to several of the personal resources, going beyond activities to pass the time. As such, being able to play was closely linked to conscious efforts to distance or distract themselves from the sorrows and problems in their lives as young carers. Similarly, practicing sports (e.g., in a sports club) and getting in touch with nature were mentioned as both simple leisure activities and conscious strategies used to find balance in their complex lives. A young carer put it this way when talking about consciously looking for and finding distraction:

"We [referring to himself and a healthy sibling] play video games to just forget about the other stuff. For example, when their [referring to ill siblings] feeding tubes are placed and they are very loud because of it and they cry maybe and the atmosphere is just like different... then we play video games to forget about the whole thing.”

(Adin, 15 years)
Another frequent topic was the need for spending time alone to reflect on their own experiences and thoughts, find peace of mind and relaxation, as well as to pursue their personal interests. Being able to retreat to their own room was important for the young carers to have time of their own as a distraction. As one of the young carers said:

“It’s sometimes good if you do something alone. Leisure time is just for me, so that I can do things that he [referring to ill sibling] cannot do. That he cannot participate in. That is, like, my leisure time.” (Lisa, 11 years)

Although leisure time was the most prominent personal resource in their accounts, some of the participants highly valued the opportunities and the structure provided by attending school. School offered a steady schedule, freedom from worrying about the care-dependent family member, and school trips, all of which served as temporary distractions from their caring responsibilities.

3.2.2 | Interpersonal resources

In addition to individual resources, young carers also have access to interpersonal resources from their social environment. Interpersonal resources encompassed fostering meaningful friendships, receiving support from the family and bonding with the ill or disabled family member.

Fostering meaningful friendships

Friendship was a resource universally addressed by the young carers. They highly appreciated sharing time and activities with friends. Fostering friendships might involve playing and laughing, celebrating events, or simply spending time together (see Figure 2).

Exchanging ideas and staying in contact with friends, either in person, via the telephone or Internet, were addressed often in the interviews. A variety of everyday topics was discussed with friends. By contrast, the challenges of being a young carer were seldom a point of discussion, although the participants did not try to conceal their family situation and their friends were aware of it. Rather, the challenges were discussed while socializing with peers in similar situations. These peers were primarily met while participating in activities organized by healthcare or social service providers (e.g., during supervised vacations or therapeutic group activities). Because of similar backgrounds, many participants talked about an immediate understanding of one another’s situation, sometimes requiring only few words. In some cases, lasting friendships resulted. In the following quote, a young carer emphasized that interactions with other young carers were in fact different than with peers who did not have the same life experiences:

“I know someone, for example, since elementary school, we are very good friends, but he doesn’t understand that [being a young carer] very well. He doesn’t experience such things on a daily basis, but when I’m with others who have siblings [with chronic illnesses/disabilities] then it’s somehow different.” (Adam, 14 years)
Receiving support from the family

The family represents a prominent resource for young carers, as its healthy members can extensively support the young carers as they face everyday struggles, as well as the challenges of caring for ill or disabled family members. The parents and their good relationship with the young carers played a particularly important role here, as the participants consistently described their parents as confidants and a major source of support. Although young carers with ill or disabled siblings were confident that they received enough attention from their parents, they fully understood when their parents, as primary carers, sometimes needed to pay more attention to the children most in need.

If present, healthy siblings were also described as confidants and sources of support, with whom caring responsibilities could be shared. In the words of one young carer: “They [referring to healthy siblings] just understand you best and they help you to shoulder the burden und say, hey, you go out with your friends, I’ll watch over him, no problem.” (Adam, 14 years)

A less prominent topic was the support from more distant relatives who were sometimes contacted in cases of dire need or visited during holidays. Spending holidays together, sometimes also with more distant relatives, was another example of shared activities with the family, which the participants described in great number and detail. These activities ranged from sharing meals with the family, watching movies, and visiting museums, to going on vacations or a hike together (see Figure 3).

Bonding with the ill or disabled family member

The young carers described not only negative but also many positive aspects of their involvement with their ill or disabled family members. All of the young carers reported having a good relationship with the ill/disabled relative, characterized by feelings of love, sympathy, and thoughtfulness. They sought similarities and common interests and attempted to find ways to communicate with their ill/disabled family members, even when verbal communication was not or no longer possible (see Figure 4). When asked about a similar picture depicting two siblings, one young carer explained:

“There I and Kian [disabled sibling] were looking out of the window again. When I consider that you have to help him all the time... he has difficulties concentrating and doesn’t do so many things... then it’s nice to have something in common with him.”

(Layla, 17 years)

The young carers greatly appreciated the shared time and activities with the ill/disabled relative and the positive experiences with them despite the illness/disability. Often, this was achieved by conscious efforts on the part of the young carers to realize that their cared ones, with their help, were living happy and fulfilled lives, despite their limitations.
FIGURE 4  Finding, sharing, and enjoying common interests and activities with the ill/disabled family member

4 | DISCUSSION

The children and adolescents in this study offered a variety of insights into their lives as young carers who were living with and caring for chronically ill or disabled family members. Stimulated by the task of taking photographs, positive as well as negative aspects of their everyday lives were addressed in photo novella interviews. A basic framework of resilience (Ungar, 2015) was used to organize the findings into personal and interpersonal resources. This approach enabled us to highlight different supportive psychosocial resources that are available to the young carers and enable them to deal with caring responsibilities at a young age. In line with this framework, we identified a variety of personal resources that can be attributed to the young carers themselves, as well as interpersonal resources that can be traced back primarily to their friends and families. This indicates that young carers can largely draw on resources comparable to those generally available to other children. In other words, their adaptational systems remain largely intact, which is a major finding of this study.

There is a difference, however, between young carers and other young people in regard to the specific circumstances under which the resources are used and the functions they perform. In particular, young carers make use of their resources, sometimes very consciously, to deal with the consequences of their caring responsibilities and find relief. A few additional resources appear to be more specific to young carers. These resources include being able to bond with the ill or disabled family member and fostering meaningful friendships, both with ordinary peers and with young people from similar backgrounds, whom young carers primarily meet during supervised vacations or therapeutic group activities.

Having the time, space, and options for recreation are basic prerequisites for the healthy development of all children. These prerequisites are all the more important for children who have greater responsibilities. The young carers in this study reported a multitude of leisure time activities. Being able to spend their leisure time according to their own ideas and needs must be viewed as a vital chance for exploration, curiosity, and self-reflection, as well as to develop social and problem-solving skills (King et al., 2009). Some of the activities described in this study, such as being able to play or being creative, have already been shown to foster resilience in children with developmental risks and also reflect efforts to spend time in constructive ways (King et al., 2009; Ungar et al., 2005), both independently and by participating in structured programs, like extracurricular school activities (King et al., 2009; Masten & Coatsworth, 1998; Ungar et al., 2005). Accordingly, having the necessary time and space to follow personal interests and having access to recreational activities are fundamental resources for the well-being of young carers. A specific characteristic of young carers is that some of them regard and use leisure activities as conscious strategies to alleviate the burden of their care responsibilities.

Young carers also need to be able to retreat and distance themselves from everyday strains and stresses, as well as those related to their caring responsibilities (Metzing & Schnepp, 2008; Moore et al., 2014; Nagl-Cupal & Hauprich, 2018; Stamatopoulos, 2015). This need must not be mistaken for an expression of maladaptive coping or denial (Bonanno, 2004), but viewed as an indicator that resilience requires time for reflection and regeneration (Ungar et al., 2005). Being able to spend time on their own enables young carers to cope with their familial responsibilities (Chikhradze et al., 2017) and sustain individual as well as familial well-being (Doutre et al., 2013). Having their own rooms is an asset in this regard, as is having access to green spaces and opportunities to spend time in nature (McCormick, 2017).

At the same time, interpersonal resources are indispensable for young carers. Spending time and interacting with friends is an essential resource for them. Friends are often prominently involved in leisure time activities of young carers, whether it may be playing together, going on excursions, or spending time together outdoors (Elf et al., 2011; Jonzon & Goodwin, 2012). This conforms with the literature that highlights the importance of social bonding and meaningful relationships for fostering resilience in children and adolescents (Ungar et al., 2005). Additional social structures can serve essential supportive and compensatory functions for young carers, which may not be adequately covered by friends or the family. School may be regarded as a structuring element in young carers’ lives which may offer respite from their situation at home (Moore et al., 2006), as well as being a member of an association (e.g., a sports club) or youth group. In addition to the actual function of these institutions and services, they also offer the opportunity for children and adolescents to establish good relationships with socially competent adults outside the family (Masten & Coatsworth, 1998).

Young carers may share and discuss everyday sorrows more freely with others than their specific problems as young carers, which peers without the same life experiences may not easily relate to (Cluver et al., 2012; Moore et al., 2004). Participating in more specific programs provided by healthcare or social organizations (e.g., supervised vacations or clubs), designed either for young carers or children growing up in any kind of precarious circumstances, may
thus be especially important to them (Black & Lobo, 2008; King et al., 2009; Masten & Coatsworth, 1998; Purcal et al., 2012; Ungar et al., 2005). Apart from intended therapeutic effects, such as strengthening the children’s resilience (Cunningham et al., 2016) or temporary relief from caring, they enable young carers to meet peers living in similar circumstances and offer life-enriching opportunities otherwise potentially unavailable to them. Consequently, social interactions with peers in similar life circumstances may be meaningful for young carers. Enabling such interactions should be a major consideration in interventions to foster resilience in young carers.

Perhaps the most fundamental resource for young carers, however, is the extensive support they receive from their nuclear family. Apart from healthy siblings, parents and legal guardians (“surrogate caregiving figures”; Masten & Coatsworth, 1998) are children’s main source of support and advice. At the same time, at least one parent of young carers frequently acts as the primary carer for the ill or disabled family members. By providing most of the care, the parents reduce their children’s caring responsibilities, which may still be substantial (taking up to 3 h per day in this study). Parents try to maintain a balance between their children’s caring responsibilities and being “normal kids” in an attempt to ensure that each family member’s needs are met (McDonald et al., 2010; Nagl-Cupal & Hauprich, 2018). Overcoming these challenges requires family cohesion, problem-solving skills, and educational competencies within the family (De Jong & Schout, 2013; Schout et al., 2017), as well as strong family bonds facilitated by family routines, rituals, and shared time, in addition to recreation (Black & Lobo, 2008), all of which were frequently illustrated in this study.

Consequently, interventions to support young carers appear most promising if they are equally aimed at the individual needs of the healthy as well as ill/disabled members of the family (Purcal et al., 2012). Although the ill or disabled relatives themselves, as part of the family, may not always be a source of support for young carers, bonding and building good relationships with them is a crucial resource.

5 | LIMITATIONS

The authors acknowledge several limitations of this study. First, there was a relatively high drop-out rate. In total, 17 children and adolescents were recruited as potential participants. Seven of these children and adolescents, however, dropped out before they were able to provide any photographs. No specific reasons were given for this although in one case, the ill family member died during the study period. This resulted in a fairly small, yet still adequate sample size in this study. Second, we did not confirm objectively whether the participants meet all criteria for positive adaptation implicated in the concept of resilience. We relied on the expert judgment of the recruiters, parents, and ultimately the participants themselves to ascertain that none of the study participants were severely distressed and exhibited significant behavioral or academic problems during the study period. Third, with a single exception, the participants all cared for ill or disabled siblings alongside two parents or legal guardians. Thus, the results of this study may not be as relevant for young carers living in different family constellations, especially in the case of ill or disabled parents, which may lead to a certain (temporary) role reversal of the given child and parent. Fourth, parents/legal guardians were present during three interviews, although they remained largely passive. Their presence, however, may have affected the conversations with their children (Coad et al., 2015). Fifth, all participants lived in the metropolitan area of Vienna. Accordingly, the results of this study may most accurately depict the situation of young carers in urban rather than more rural settings in which health and social care services may be less accessible.

6 | CONCLUSIONS

The young carers reported having a range of psychosocial resources at their disposal that enabled them to deal with challenging life circumstances and contribute to their resilience. Supporting them effectively in this endeavor requires a systemic approach from health and social care professionals involving all family members. Supportive interventions for young carers should address the problems and needs as much as the resources of the family and thereby essentially help them to help themselves. Supportive measures must aim to promote family cohesion, problem-solving skills, and empathic educational competencies within the family to enable the family as a system to adequately and flexibly manage the challenges of providing care. Ill or disabled family members are not only to be understood as recipients of care from the family, but as a part of the family, which is why it is vital to foster good relationships between them and their young carers. Consequently, it is important for health and social care providers to actively recognize the often-concealed role children and adolescents may play in caring for relatives and to form supportive and trusting relationships with them. It is neither exclusively uncommon nor rare qualities that allow young carers and their families to confidently deal with the challenges of their lives, but rather basic, yet effective, adaptational systems that may be cultivated and promoted with systemic support.

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CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

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