Accepted: 5 February 2018
DOI: 10.1111/hsc.12567

ORIGINAL ARTICLE

WILEY Health and Social Care in the community

# Being we and being me: Exploring the needs of Austrian families with caring children

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**Funding information**
Joint Health Objectives of the Pharma Master Agreement, a cooperative project of the Austrian Pharmaceutical Industry and social insurance

## Abstract

Children and adolescents with caring responsibilities are an uncontested reality in our society. Most are hidden from public view, and they perform a broad range of caring activities for chronically ill or disabled family members. The research literature has accumulated a comprehensive body of knowledge about young carers' personal needs. However, knowledge and understanding are limited regarding the needs of young carers' families. This knowledge can contribute to preventing children and adolescents from assuming inappropriate caring roles. A qualitative research approach was used to investigate the needs of young carers' families in terms of managing daily caring demands. Nine family interviews were conducted with 34 individuals including 15 young carers during spring/summer 2015 in eastern Austria. Open and axial coding procedures and constant comparison method were used to analyse the data. The findings revealed that young carers' families need to live in accordance with their inherent family logic. Family logic is generated and maintained via (i) family reciprocity that involves the natural help within the family, (ii) individual developmental space that allows family members to be perceived and act as individuals and (iii) network cooperation that offers formal and informal support and recognition from society in general. The findings contribute to understanding how families with caring children manage the caring demands of their everyday lives. The findings also indicate that formal support for families with young carers should consider the individuality of caring arrangements with respect to the holistic and personal needs and avoid stigmatising families that integrate children into caring.

KEYWORDS
family care, family interviews, family needs, family-centred care, qualitative research, young carers

## 1 | INTRODUCTION

During the past two decades, children and adolescents have been recognised as central to the provision of care within the family. These children known as *young carers* are children and adolescents up to the age of 18 years who regularly provide a significant amount of care for a chronically ill or disabled family member (Becker & Becker, 2008). They help maintaining the household, provide personal care to the family member in need and support healthy family members (Aldridge & Becker, 1993; Dearden & Becker, 2004; Earley, Cushway, & Cassidy, 2007; Metzing & Schnepp, 2008). The involvement in caring is often associated with negative outcomes, and the caring responsibilities of these children often extend far beyond the normal amount of family help provided by non-caring children (Hunt, Levine, & Naiditch, 2005; Morrow, 2005; Warren, 2007).

Only a few countries have gathered data on the prevalence of caring among children and adolescents (Australian Bureau of Statistics, 2003; Hunt et al., 2005, Office for National Statistics, 2013; Stamatopoulos, 2015a). An Austrian study suggests a rate of 3.5% young carers with an average age of 12.5 years and a majority of female young carers (Nagl-Cupal, Daniel, Koller, & Mayer, 2014). This national prevalence data support the notion that the prevalence of informal caring in the underage population is at minimum 2%–4% in all western countries (Becker, 2007).

A growing body of research emphasises the needs and experiences of young carers. However, there is a strong need for information about the illnesses of young carers' family members (Ali, Ahlström, Krevers, Sjöström, & Skärsäter, 2013; Frank, 1995; Newton & Becker, 1999). Young carers need to be aware of the course and consequences of their family member's illness (Elf, Skrster, & Krevers, 2011; Kavanaugh, Noh, & Studer, 2015; Millenaar et al., 2014; Moore & McArthur, 2007). They want to be informed about changes in the ill family member's condition and what those changes imply for the affected person and the entire family (Aldridge & Becker, 1993; McAndrew, Warne, Fallon, & Moran, 2012; Newton & Becker, 1999). Many young carers want to know how to cope with illness-specific issues and how to manage practical concerns in everyday life (Becker & Becker, 2008; Bjorgvinsdottir & Halldorsdottir, 2013; Elf et al., 2011; Kavanaugh et al., 2015; McAndrew et al., 2012; Millenaar et al., 2014).

Research in this area also emphasises the young carers' need to be *ordinary* children, temporarily free from caring responsibilities. Young carers express the desire for private spaces that offer them time to relax and be like any other child (Frank, 1995; McAndrew et al., 2012; Metzing & Schnepp, 2008; Moore & McArthur, 2007; Nigel et al., 2003; Phelps, 2012). These private spaces may also include opportunities for young carers' to interact with friends, pursue their hobbies or just have fun (Elf et al., 2011; Jonzon & Goodwin, 2012).

Young carers also express a strong need to talk about their experiences and feelings and to be recognised as a young carer. Depending on their individual experiences, they seek exchanges with like-minded peers or with friends who are not involved in caring (Aldridge & Becker, 1999; Ali et al., 2013; Kavanaugh et al., 2015; Nichols et al., 2013). Some young carers need to talk with adults, either those in their families or others adults such as teachers or social or healthcare professionals (Kavanaugh et al., 2015; Nicholson, Hinden, Biebel, Henry, & Katz-Leavy, 2007).

Many young carers express the need for immediate support (Frank, 1995; Grant, Repper, & Nolan, 2008; Kavanaugh et al., 2015; Phelps, 2012), which involves practical support or the sharing of caring responsibilities (Moore & McArthur, 2007). Depending on their age and education history, they may also need support for school or job training. Thus, more flexibility and understanding from teachers, school management or supervisors may be required to enable young carers to fulfil their caring responsibilities and to prepare them for employment (Elf et al., 2011; Frank, 1995; Heyman & Heyman, 2013; McAndrew et al., 2012; Moore & McArthur, 2007).

**What is known about this topic**

- Research on young carers is increasing worldwide.
- The personal needs and experiences of young carers are well understood.
- A family-centred perspective contributes to a broader understanding of families and of family-tailored interventions.

**What this paper adds**

- Caring in families involves reciprocity among family members, providing personal space and using formal support structures according to the families' own values.
- Families have an overall goal of living in accordance with their inherent logic.
- A family-centred perspective with respect to the needs of individual family members is essential to preventing children and adolescents from assuming inappropriate caring roles.

The literature has accumulated a comprehensive body of knowledge about the personal needs of young carers. However, there is a gap in our knowledge and understanding of the needs of young carers' families. Efforts to address this knowledge gap are crucial, however, and align with emerging worldwide recommendations to focus on both, care providers and care recipients within the family system (Cass et al., 2011; Fives, Kennan, Canavan, Brady, & Cairns, 2010; Frank & McLarnon, 2008; Schlarmann, Metzing-Blau, & Schnepp, 2011). In theory, this family-centred focus aims to reduce the level of children and young people's involvement in caring and ultimately prevent underage children from assuming a substantial amount of caring responsibility (Clewett, Slowley, & Glover, 2010; Frank, 2002). Therefore, the aim of this research was to investigate the needs of young carers' families with respect to managing the caring demands in their everyday lives.

## 2 | METHODS

A qualitative research approach was used to explore a phenomenon that is largely unknown in many countries. Qualitative research focuses on the insight view of the people involved and their perception, meanings and interpretations (Holloway & Galvin, 2017). The current study was part of a larger project that aimed to develop a family-centred intervention for families with young carers.

### 2.1 | Sample and participants

We included families in which at least one young carer and either an adult carer or the chronically ill family member of the young carer were willing to participate in the study. The families were recruited with the help from social or home care organisations and one organisation that offer a summer camp for young carers. Adult family members were asked to contact the researchers, who informed these family members about the study aims and the interview procedure. Based on the assumption that "family is who they say they are" (Wright & Bell, 2009), the members of each participating family were asked to determine who should participate in the interview. This enabled the families to nominate extended family members and/or good friends in addition to immediate family members. We did not include families with members suffering from severe mental health problems or substance addictions based on the presumption that the ability of such individuals to take active responsibility for their own care is at least somewhat limited (Nigel et al., 2003).

All the participants received detailed written and verbal information prior to the study. The participants were informed that their participation was voluntary and the anonymised reporting of the recorded interview data. Due to the different ages of the individuals involved in the interviews, the information was presented in an age-appropriate manner for adults, adolescents and children. At least one minor child participated in each interview, and the legal guardian signed the children's informed consent form. The Research Ethics Committee of the University approved the study.

## 2.2 | Data collection and analysis

The data were collected via family interviews in spring/summer 2015 in eastern Austria. According to Åstedt-Kurki and Hopia (1996), a family interview is a method in which members of a family unit are interviewed in a group setting with the purpose of gathering information. It is an appropriate method for collecting family information because the participants not only talk about their lives in the family but also communicate simultaneously as a family (Przyborski & Wohlrab-Sahr, 2014).

The interviews began by asking the family members to draw a genogram and an ecomap of their family and their extended social network. In qualitative research, these are useful paper-pencil tools when generating data about multiple individuals within one interview. These tools served as the basis for formulating the interview questions and ensured that every person was involved in the interview (Helling & Stovers, 2005). The family members were also asked to describe and draw their supportive networks as well as hindering social structures in order to develop a comprehensive picture of the entire family and how the family members are interrelated with their social environment in the context of chronic illness (Rempel, Neufeld, & Kushner, 2007). To initiate the conversation, the interviewer suggested broad *family topics* such as describing experiences with the ill family member's illness or an ordinary day of caring. The family "as a whole" was emphasised to acknowledge the perspectives of individual family members. The interviewers who were experienced in interviewing children paid specific attention to the age-appropriate formulation of the questions. The children were often encouraged to contribute to the conversation as they rarely actively participated in the interview.

The interviews were audio-taped and transcribed verbatim. The data were analysed using open and axial coding procedures and constant comparison method according to Grounded Theory Methodology outlined by Corbin & Strauss (2008). Grounded Theory was selected as the methodological background because formulating needs from a family perspective involves a social negotiation process between the participants and their environment both, in actual family life and during the immediate interview situation. The data collection and analysis were performed using a circular/iterative process. During the open coding procedure, the data analysis adhered very closely to the original data. The emerging codes and categories were cross-checked by the research team, and the relationships between the categories were elaborated and discussed. The coding procedure involved writing theoretical and code memos and diagrams to structure and consider the relationships among the theoretical categories and to document those relationships. Quotes from the interview participants were used to illustrate the categories. Data saturation was reached when the categories were sufficiently dense and no new patterns emerged from further interviews. The analytic software Atlas.ti was used to undertake the analysis and to identify both the emerging themes and the relationships among them. To ensure the trustworthiness of the data (Steinke, 2004), the researchers held group discussions during the analysis stage and performed communicative validation with the interview participants.

# 3 | FINDINGS

Nine family interviews were conducted with 34 individuals, including 15 young carers (mean age = 12.6, age range 9–18). The interviews took place in families' homes and lasted between 55 and 145 min. There were broad variations in the composition of relationships and number of participants in the interviews (Table 1). The interviews comprised between 2 and 8 individuals.

Data analysis shows that in order to manage caring demands, families with caring children want *to live in accordance with their inherent logic*. This inherent logic is defined as the shared understanding about practice, behaviour, norms and values typical for the family. A family's inherent logic influences how the family copes with or tries to cope with its specific caring situation. From a family perspective, the family's inherent logic is developed through the three concepts *family reciprocity*, *individual developmental space* and *network cooperation*. Whereas family reciprocity reflects upon the needs of the family as a whole, developmental space refers to the needs of family members as individuals. Both phenomena are equally important, and they are interrelated. In addition to this dyad, network cooperation refers to family-external help and an understanding of the family's situation. These three components including their sub-components are described in turn.

**TABLE 1** Sample description: the participants' real names were changed to pseudonyms

| Family | Interview participants, other family members in the household and support function | | Age | Cause of need for care | Duration (min) |
|---|---|---|---|---|---|
| 1 | 1 | Klaus, father, ill family member (if) | 58 | Hemiplegia | 122 |
| | 2 | Hannes, son, young carer | 15 | | |
| | 3 | Susi, daughter, young carer | 13 | | |
| | 4 | Maria, mother, adult carer | 44 | | |
| | | Lisa, daughter, young carer, no participation | 21 | | |
| 2 | 5 | Franz, father, if, no participation | 62 | Dementia, blindness | 60 |
| | 6 | Sabine, daughter, young carer | 16 | | |
| | 7 | Sybille, mother, adult carer | 47 | | |
| 3 | 8 | Sarah, mother, if, single parent | 44 | Multiple sclerosis | 100 |
| | 9 | Peter, son, young carer | 11 | | |
| 4 | 10 | Thomas, father, if | 56 | Hemiplegia, epilepsy | 108 |
| | 11 | Sabine, mother, adult carer | 44 | | |
| | 12 | Paul, son, young carer | 16 | | |
| | | Richard, son, young carer, no participation | 18 | | |
| 5 | 13 | Elisa, mother, if | 43 | Breast cancer | 92 |
| | 14 | Tina, daughter, young carer | 13 | | |
| | | Markus, son, young carer | 9 | | |
| | | Gerhard, father, adult carer, no participation | 44 | | |
| 6 | 15 | Johann, father, if | 45 | Paraplegia | 143 |
| | 16 | Kathrin, mother, adult carer | 38 | | |
| | 17 | Sarah, daughter, young carer | 10 | | |
| | 18 | Tom, son, young carer | 11 | | |
| | 19 | Martin, son, young carer | 13 | | |
| 7 | 20 | Lukas, young adult, if | 22 | Myasthenia gravis | 76 |
| | 21 | Birgit, sister, young adult carer | 22 | | |
| | 22 | Bernd, brother, young carer | 14 | | |
| | 23 | Helga, mother, adult carer | 47 | | |
| | 24 | Peter, cousin, regular support | 14 | | |
| | 25 | Agnes, aunt, regular support | 45 | | |
| | 26 | Heinz, neighbour, regular support | 55 | | |
| | 27 | Gerlinde, neighbour, regular support | 55 | | |
| 8 | 28 | Hans, father, if | 54 | COPD | 208 |
| | 29 | Irene, mother, adult caregiver | 33 | | |
| | 30 | Michael, son, young carer | 14 | | |
| | 31 | Lisa, daughter, young carer | 12 | | |
| | 32 | Tobias, son, young carer | 11 | | |
| 9 | 33 | Andrea, mother, if | 42 | Multiple sclerosis | 62 |
| | 34 | Elsa, daughter, young carer | 11 | | |

### 3.1 | Family reciprocity

Family reciprocity represents a central element of the inherent logic of a family. Within the family, this concept involves the natural help that each family member offers to the others without being asked. It consists of the sub-components *mutual support*, *being in good hands*, and *live a normal family life*. *Mutual support* is the need, in which family members assist each other in daily life. This support is both, expected from and provided to each other as a matter of course. It is a natural support between the care recipient and caregiver as a young carer explained:

> *You do not have to say anything, for them it is self-evident. They don't mind, you can count on them any time.* *(IV 4, 568f)*

Mutual support provides families with a feeling of security and enables the family members to act autonomously. Mutual support is the element that constitutes and stabilises the family system because "(…) it is the family that knows how it works and that knows how the ill family member feels and what he needs" (IV 7, 845). The family members' relationships with one another and their respect for family customs convey a sense of security in the performance of caring.

The second aspect of family reciprocity is *being in good hands*. This implies that family members have confidence that the best care is being provided in order to meet the ill family member's needs.

> *Because I know okay, she has someone who knows what to do, she can depend upon her hundred percent.* *(IV 7, 491)*

It is also an important precondition for family members to allow themselves a respite from caring. If it is not sufficiently addressed, the carer cannot stop focusing on the ill family member. This, for instance, can cause problems with concentration in school or in the workplace. It can also have more far-reaching consequences. For example, a young carer dropped out of school because her impaired brother was not receiving the level of care that she believed was appropriate.

> *At that time, I dropped out of vocational school. I have left aside everything.* *(IV 7, 53)*

To know that the ill family member is in good hands also prevents family members from feeling guilty. Feelings of guilt can arise when family members are absent from work or school and worry that their ill family member is not receiving sufficient support. Guilt can also emerge when family members believe that they should be grateful for the help they receive from outside the family:

> *You feel completely inferior and guilty when you think that you have to beg for everything.* *(IV 8, 400)*

The third aspect of family reciprocity is the need to *live a normal family life*. This involves family members endeavouring to maintain or rebuild their family routines. These routines may include common activities or simply lunch or dinner together. Due to the demands of caring and the ill family member's inability to participate in family activities, it may be difficult, for example, to engage in leisure activities as a family or to manage other typical family issues.

> *Our dad used to go hiking with us. He guided us and made things with us (…) all this has changed over time.* *(IV 4, 211)*

The partial or occasionally complete incapacity of the ill family member may also prevent that individual from fulfilling his or her familial roles, which often leads to sharing of those roles among other family members. Therefore, normal family life also involves attempting to maintain normative roles as long and to the greatest extent possible. Adult care recipients may also attempt to fulfil at least some aspects of their parental role. In addition to practical aspects such as preparing meals, the effort to maintain a parental role also has symbolic aspects. For example, during the family interviews, an ill father endeavoured to present himself as the head of the family by being the first to answer the questions and by having the last word.

However, for caring family members, taking on these additional roles can cause role conflicts or overload. In particular, the caring adults in a family may feel torn among the competing roles of being a good parent and a good partner and fulfilling caring responsibilities:

> *I really want to spend more time with my husband, but I also want to spend more time with my daughter. Time is flying, and after a while she will move out.* *(IV 9, 47)*

## 3.2 | Individual developmental space

Living in accordance with the family's inherent logic also implies having *individual developmental space*. This enables each family member to be perceived and act as an individual person. Individual developmental space consists of the sub-components *asserting a non-carer identity*, *communicate about normal things* and *communicate about the family situation*. *Asserting a non-carer identity* represents the need to develop and pursue individual interests. For children, it contributes to the efforts to do all those "normal" things what non-caring children do. One young carer expressed his desire for leisure activities, respite time and a place where he could be himself: "I need something to find balance in my life" (IV 7, 475).

However, needs such as these, must often be set aside because they are not compatible with ongoing caring responsibilities. For example, one daughter often missed her driving lesson because of her ill father's need for help. It is, therefore, unsurprising that school represents a central location for asserting a non-carer identity for young carers. School is a place where young carers can be like other children and experience a part of life that does not involve caring:

> *School is not about illness. This is my own realm where I don't talk about illness stuff.* *(IV 5, 196)*

At this point, another need becomes apparent: the need to *communicate about normal things* with others. These exchanges are not related to family or the family's illness situation. When asked what he talks about with his friends at school, one boy responded as follows:

> *I don't think that anybody knows about my situation. I don't talk about it either. There is a lot of stuff more important, though. Car engine, diesel, gasoline engine, spark plugs. All that boy's stuff.* (IV 1, 204)

Parents, therefore, feel responsible for maintaining developmental spaces for their children. To ensure that children have these developmental spaces, parents often endeavour to arrange respite times; for example, weekends when children leave the house for recreation and "(…) doing things without worry and just for themselves" (IV 4, 213).

The provision of individual developmental space, however, requires family members to be able to *communicate about the family situation*. These exchanges are intended to encourage self-reflection about the family situation. Families often prefer "(…) someone from outside with a neutral view (…)" (IV 1, 204) to facilitate such exchanges. Depending on the family's preferences, this can be someone who is experienced with illness or caring, with neither, or with both.

### 3.3 | Network cooperation

The third aspect of living a life in accordance with the family's inherent logic is the need for *network cooperation*. This refers to cooperative arrangements with *informal* and *formal support networks* and to the *recognition from the society in general* in order to cope with the caring situation. A key element of network cooperation is that families want to determine the nature and extent of network support and to maintain the overall responsibility for caring. This implies the creation of an individualised family support model that is co-produced together with formal and informal support systems. It is important that informal and formal support networks respect and assist the family in generating their inherent logic.

*Cooperation with informal support networks* refers to help from and integration into the community. Informal networks can be composed of friends, neighbours or even religious communities. Similar to support provided within the family, support from informal networks is frequently offered as a matter of course, and family members also do not feel guilty when asking for help.

> *You don't have to ask them. It is natural that they help us. We can call them any time; they are there for us.* (IV 4, 569)

As family carers spend most of their time at home, their spatial proximity or distance to their informal networks is a contextual condition that can facilitate or hinder immediate or low-threshold support.

*Cooperation with formal support networks* includes healthcare or social care organisations that provide various types of caring, household or bureaucratic support for activities that cannot or will not be performed by the family or their private networks.

> *We need someone to take care of the rest.* (IV 4, 774)

In addition, it can offer a temporary respite from caring activities. However, family routines are extremely susceptible to disruption, particularly when formal support is involved. Families often argue, for example, "that there are always different people coming into our house" (IV 4, 1248). In addition to the cost and availability of services, trust and continuity are the most significant considerations for families when accepting formal support. Discontinuity of care is a common reason that families do not take advantage of formal support. Families often feel that they are entirely at the mercy of others, as one family described:

> *Every 3 or 2 days we have dialysis. This is a collective transport, and we don't know if it takes 45 min or 2 hr. It would be easier if they would say something like, "The patient will come home later this day" because we sit here and have to wait until he comes home, or he doesn't come at all.* (IV 1, 225)

*Recognition from the society* relates to family members' concerns about being recognised and valued as an important member of the society. It also relates to society's general awareness of caring families and that families do not want to be stigmatised for involving children in caring. When asked what he hoped from society regarding his caring contributions, one boy responded as follows:

> *When other people do not exclude me.* (IV 7, 864)

It is important for families to emphasise that children or adolescents play an active role in caring for a chronically ill family member. This is due to the inherent logic of the family—*a well-balanced* need between family reciprocity and individual developmental space.

## 4 | DISCUSSION

The findings contribute to the understanding how families where children and young people provide care manage caring demands in their everyday lives. The overall goal of those families is to live a life in accordance with their family's inherent logic. This logic represents the family's norms for how they cope with caring situations. Family reciprocity and individual developmental space contribute to those norms and must be addressed equally by all members of the family. The role of informal and formal support networks is to respect and assist the family in generating this inherent logic as well as to respect that families want to determine the nature and extent of support and to maintain overall responsibility for caring.

Family reciprocity, as described in this study, makes an essential contribution to maintaining family functioning. In studies of adult family care, reciprocity is defined as a mutually beneficial exchange that contributes to well-being and family functioning (Carruth, Tate, Moffett, & Hill, 1997). The children's perspective of reciprocity refers to children's self-image regarding the support they provide to parents or other family members when necessary. However, an ill family member not only receives but also provides care for their children or others in many situations. A mother with severe multiple sclerosis, for example, may not be able to prepare breakfast for her son, but she may maintain her parental role by putting him to bed and cuddling him. This aspect of reciprocity is usually overlooked in families with caring children, as the focus is often solely on the young carers' situation (Aldridge & Becker, 1999). As the findings of this study illustrate, the act of reciprocity is applicable to caring arrangements that include children and adolescents in which caring can be considered an independent intergenerational exchange involving mutual benefits for healthy and ill family members. Therefore, family reciprocity can be perceived as the glue of family cohesion that helps to stabilise family functioning and as the basis for coping with everyday life demands in families with caring children. Consequently, family members are encouraged to see their relationship as normal (Aldridge & Becker, 1999; Rolland, 1999; Smyth, Blaxland, & Cass, 2010).

The second aspect of the findings, the need for individual developmental space, refers to individuals' need for temporary respite from caring responsibilities and time to act as an individual person. Many studies have highlighted the importance of responding to these needs (Moore & McArthur, 2007; Nigel et al., 2003; Purcal, Hamilton, Thomson, & Cass, 2012; Stamatopoulos, 2015b; Watson, 1999). However, it is often difficult for children to ensure their own developmental spaces. Our study reveals that responsibility for providing developmental space often rests on adults, who endeavour to maintain a balance between caring responsibilities and having a normal life for themselves and their children. This is consistent with McDonalds' finding that "balancing and trading off" is a significant strategy that parents use to ensure that each family member's needs are met (McDonald, Dew, & Cumming, 2010). Our study suggests that for young carers, school is an important "carefree island" that enables them to maintain their own developmental space. Young carers can interact with their friends and communicate about normal things in life (Cluver, Operario, Lane, & Kganakga, 2012; Moore, Morrow, McArthur, Noble-Carr, & Gray, 2006). The literature also indicates that caring can have a considerable influence on young carers' education and can lead to various problems such as bad grades, fatigue or low educational aspirations and outcomes (Dearden & Becker, 2002; Lloyd, 2013; Siskowski, 2006). Therefore, it is important that schools recognise and understand the needs of young carers and develop a positive culture that allows young carers to balance school demands with their caring responsibilities (Moore, McArthur, & Morrow, 2009).

The third aspect of the findings focuses on families' cooperation with formal and informal support networks. This is a frequently discussed issue in research and policies related to young carers (Becker & Becker, 2008; Berggren & Hanson, 2015; McAndrew et al., 2012; Metzing & Schnepp, 2008; Moore & McArthur, 2007; Nichols et al., 2013; Stamatopoulos, 2015b). This study suggests that cooperation with formal and informal networks is important. Families, however, do not make use of this cooperation at any cost. To achieve effective cooperation, families with children and young people who provide care must not feel stigmatised and must retain control over the nature and extent of the support provided as well as overall caring responsibility. Positive relationships based on trust, understanding and acceptance are a central precondition of accepting support, what has also been highlighted in the literature (Aldridge & Becker, 1993; Frank, 1995; Grant et al., 2008; Newton & Becker, 1996).

Since the release of early research on young carers, a large number of dedicated support services have been developed. The majority of these support interventions are intended to provide direct relief such as respite or peer-based activities, for example, clubs or summer camps, as well as more support-based activities such as person-to-person counselling or web-based information services (Stamatopoulos, 2015b). These approaches appear to be the preferred strategies for supporting young carers in Austria, whereas family-based support programmes for young cares do not exist at present (Nagl-Cupal, 2017). This is also applicable in an international context. With the exception of parents with HIV/AIDS and cancer such programmes appear to be rare (Berggren & Hanson, 2015). Programmes that approach support from the family perspective are crucial, however, as they place more emphasis on preventive aspects rather than direct support or relief for young carers. According to Purcal et al. (2012), prevention aims to avoid the entrenchment of children's caring role or, if the role is already established, to help young carers achieve a level of caring that is not associated with negative effects. Our findings support Purcal and her colleague's notion that preventive services are a combination of formal and informal support tailored individually to each family that reflect the needs of all family members (Purcal et al., 2012). According to our findings, these services should assist families to maintain a balance between family reciprocity and individual developmental space and should respect the inherent logic of the family. At least in theory, the imbalance between these two aspects may be a key reason for the inappropriate involvement of children in caring and for negative effects.

Strategies such as "family group conferences" can involve nuclear and extended family members as well as formal healthcare or social care providers. These conferences can facilitate decision making about caring arrangements and ensure that the decisions do not conflict with the interests of other family members, especially the interests of children (Aldridge & Becker, 1999; Nixon, 1999).

## 4.1 | Limitation

One of the main challenges of this study was gaining access to families with caring children. All the participating families were associated with an organisation that coordinates support programmes for young carers. Therefore, we cannot say how families without any formal support cope with their daily lives, even though these families are presumed to represent the vast majority of caring families (Nagl-Cupal, Daniel, Kainbacher, Koller, & Mayer, 2015). Furthermore, the term "family interview" must be interpreted with caution due to some restrictions: for a variety of reasons, not all family members who were involved in caring participated in the interviews.

Consequently, we may have overlooked some important perspectives of family needs. Family interviews have been demonstrated to be an appropriate method for this type of research. When family interviews are successful, they can closely resemble a "real-life situation" (Eggenberger & Nelms, 2007). Nonetheless, the tendency of families to display unity towards external parties can paint an erroneous picture of harmony and can conceal conflicts or differences. Conducting one-to-one interviews in addition to family interviews could have enriched the findings of the study and may also have illuminated "push and pulls" (Becker, 2007) that contributed to forcing children into a caring role. This, however, can especially be relevant for children of parents with severe mental health problem, drug or alcohol problems—a group, we did not include in this study.

## 5 | CONCLUSION

This research emphasises the importance of a family-centred view to understand the impact of caring responsibilities. Any intervention should include all family members and should attempt to avoid an exclusive focus on any one person. Respecting and supporting families in living in accordance with their inherent logic is a cornerstone of maintaining the stability of caring and family functioning and the wellbeing of individual family members. The assumption of caring responsibilities by children and adolescents in families is a societal reality that cannot be avoided. Emphasising a family-centred approach and fostering families' empowerment and autonomy without stigmatisation represents an essential contribution to ensuring the healthy development of young carers and their families as a whole.

## ACKNOWLEDGEMENTS

This research was financially supported by the Joint Health Objectives of the Pharma Master Agreement, a cooperative project of the Austrian Pharmaceutical Industry and social insurance. Many thanks to Natasa Prajo for transcriptional work and for helping with the literature review.

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**How to cite this article:** Nagl-Cupal M, Hauprich J. Being we and being me: Exploring the needs of Austrian families with caring children. *Health Soc Care Community*. 2018;26:e532–e540. https://doi.org/10.1111/hsc.12567