Towards a typology of negotiating care in families: a qualitative multiple perspectives study in Austria

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The study explored how family care is developed and maintained in families in cases where more than one family member is involved in care. A total of 43 family carers in Austria participated in this qualitative study. Family care is a process of ongoing communication, in which responsibilities, coordination and conditions are negotiated among the family members involved. Three distinct care network types emerged from the data, which differ in terms of the individual perception of roles and responsibilities, and the distribution of care. Responsibilities for one another, awareness of being a family carer and the availability of resources are preconditions for the composition of these networks.

Key words family care • typology • qualitative research • multiple perspectives design

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Introduction

Over recent decades, various societal and disease-related developments, such as an increase in the number of very old people or the treatment options for severe chronic diseases, have contributed to an increase in the need for care. This process has had considerable consequences for caring families. These families are challenged to constantly change and redistribute roles, and to reorganise their everyday lives (Corbin, 1998). Family care, however, is often reduced to the dyadic of the main carer and the care receiver, without mentioning the roles and functions of other family members, who are often significantly involved in the provision of care (Ceci et al, 2019). This designates family care as a responsibility of multiple individuals, with various actions helping to develop and maintain care for family members in need.
Background

Families are the most important providers of care over the entire family lifespan (Whitehead et al, 2018; Gilliss et al, 2019). Family members have a significant role in any kind of care, such as physical, emotional, social and organisational matters (Ekwall et al, 2004). This can affect the family members’ life situations in terms of burdens and individual health (Bastawrous, 2013; Bleijlevens et al, 2015; Cohen et al, 2015; de Oliveira et al, 2015).

Provision of family care is often described as an individual decision of one main caring person, based on attitudes, affect, normative beliefs and resources (Raschick and Ingersoll-Dayton, 2004; Broese van Groenou and De Boer, 2016). This primarily brings to the fore partner and filial care arrangements in different contexts (Hooker et al, 2000; Penning and Wu, 2016; Dong et al, 2019). Given the growing need for care of people living at home, however, it seems likely that more individuals will take advantage of family care in coming years. It is therefore not surprising that about 34 per cent of the European population in 20 countries can be designated as family carers (Verbakel et al, 2017).

In Austria, the Central European country and welfare state in which this study was conducted, this share was reported to be 21.1 per cent (Verbakel et al, 2017). Based on another national study, an Austrian government report stated that at least 10 per cent of the population is involved in care for family members. From the perspective of those who designated themselves as ‘main carers’, 70 per cent of family care arrangements had more than one family member involved. Three quarters of these care networks were composed of close family members (Nagl-Cupal et al, 2018). This clearly indicates that willingness to provide care within the family is high. It also shows that care networks are often of a considerable size, though the main work, in terms of the responsibility for caring, lies in the inner circle of the family (Vassilev et al, 2013).

In Austria, people in need of care have a legal entitlement to a Pflegegeld (‘care allowance’), set at seven levels, depending on the extent of care required. The higher the need for care, the higher the care allowance level. Care allowance is paid as a cash benefit, ranging from €165 to €1,776 per month (care allowance in the form of in-kind benefits is not provided). Over 60 per cent of those who receive care allowance do not use formal care services (Nagl-Cupal et al, 2018). It is unknown exactly how this money is spent, as care receivers can spend it as they choose, for example, by passing it on to family members who then provide the care.

Family care performed by multiple people can be seen as a conscious use of care strategies, in the sense of protecting, monitoring and planning, as well as of relating to one another and enduring within the trajectory of individual and family life (Eggenberger et al, 2011). Family care is a decision-making process between carers and care receivers, in which individual costs and benefits are incorporated. This has been described from the perspectives of care recipients’ (Sand Andersen et al, 2020), as well as from those of the main carers (Coeling et al, 2003; Wittenberg et al, 2017).

In today’s societies, however, families, their lived relationships and family tasks do not simply exist; rather, they must be permanently created in an interactional process. This relates to the overall development of everyday life becoming more complex – for example, in terms of work and family, or the multilocality of different family members – as well as the compatibility requirements for family members (Jurczyk, 2020). According to the concept of ‘doing family’, the family is not simply something you ‘have’ but something you ‘do’ (Morgan, 2011; 2019; Dermott and Fowler, 2020;
It is a central family task to coordinate different activities into an overall context, based on resources and patterns of action. This involves the coordination of different time logics, the balancing of organisational achievements, the construction of commonalities and the presentation of the family to the outside world. In the sense of the subject-oriented approach, the individual members of a family are not passively bound to particular conditions; rather, they have the opportunity to actively help shape their families and their way of life, and thus to change their environment (Jurczyk, 2020).

Research has shown that family care is very often a matter of multiple family members, including a variety of different people. With regard to our definition of families, we define a family carer as ‘someone who, unpaid, provides help and support to a partner, child, relative, friend or neighbour, who could not manage without their help due to age, physical or mental health problems, addiction or disability’ (Keeley and Clarke, 2003). It is not clear, however, how family care in which multiple family members are involved is developed and maintained.

**Aim**

The aim of the study is to explore how family care is developed and maintained in families in which more than one family member is involved in caring. The study offers insight into family members’ agencies and enhances understanding of how families in which more than one family member is involved provide care for a relative in need.

**Methods**

The study used a qualitative research strategy, which allows for openness, flexibility and reflexivity in data collection and analysis (Corbin and Strauss, 2008). This approach facilitates the development of a comprehensive picture of individuals’ subjective perspectives, experiences and practices. A multiple perspectives research design focuses on the subjective views of the people under study, referring to the social-constructivist assumption that individuals fill their social worlds with meaning, while constantly negotiating language and signs (Berger and Luckmann, 1967). According to social constructivism, multiple realities coexist and are retrievable by means of a multiple perspectives research design (Reczek, 2014; Vogl et al, 2018), which is especially useful for gathering insight into the functions of social units and the understanding of social networks (Vogl et al, 2019). We used qualitative interviews, ecomaps and sociodemographic questionnaires to collect the data.

**Sample/participants**

The unit of analysis was a ‘family care network’, in which more than one family member was involved in regular caring for a family member in need of care. The study participants were people who contributed to care for a very close individual, primarily a family member, and who: (1) provided physical, emotional, social and organisational care on a long-term basis; and (2) considered themselves carers or were referred to by other respondents as such. Among these named individuals, we attempted to interview as many as possible and at least two members within a care arrangement. We used a sampling strategy of maximum variation and made efforts to
include networks with members who showed as much diversity as possible in terms of family constellations, durations of care, location and reasons for need of care. We collected data in diverse rural and urban Austrian areas. The study participants were recruited through care organisations and through Austria’s national interest group on family care. These organisations passed our contact details to interested participants. Upon initial telephone contact, we strove to build trust with these persons and to answer initial questions about the purpose of the study and conditions of participation.

A total of 43 family carers, representing 13 family care networks, participated in the study. The number of people interviewed in a network was between two and seven, with their ages ranging from five to 68. Four children below 15 years of age were also interviewed. All participants saw themselves as essential actors in providing care. The number of people involved in the overall care network and contributing to caring in different ways varied according to the views of interviewees between four (in the smallest) and 28 (in the largest) network. Detailed care network information is presented in Tables 1 and 2.

Data collection

We conducted individual, qualitative problem-centred interviews in the year 2018, comprising an open narrative part and a semi-structured part (Witzel, 2000). As an opening question, the interviewer asked the respondent: “How did everything regarding the care of [name of care receiver] start?” and “What has happened since then?” After the initial narrative part of the interview, the interviewer asked questions related to topics the interviewees had mentioned before and that were relevant to our research. The interviewer then asked the participants about topics collected in our interview guideline, which had not been mentioned previously.

At the end of the narrative part, participants were asked to fill in a map indicating the support given to the care receiver, which was based on ecomaps (Rempel et al., 2007). This map had a prepared structure of four fields of support (family, friends, professionals and other). To comprehend individual interviewees’ views on the care situation, each was asked to write the name of the care receivers in the centre of the ecomap. With regard to the amount and intensity of their care, they were requested to arrange all other carers in the network around the care receiver, using ‘post-it’ notes. Participants also visualised the amount and intensity of care provision in the ecomaps by means of their visual distance to the care receiver. The closer an interviewee

<table>
<thead>
<tr>
<th>No. of interviewees; female/male</th>
<th>43; 30/13</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carers’ age range (median)</td>
<td>5–68 years (50.5)</td>
</tr>
<tr>
<td>Carers’ family relations with care recipient</td>
<td>Spouses/partners (3); daughters (13); sons (9); parents (3); daughters-in-law (3); underage grandchildren/siblings (4); adult siblings (2); adult grandchildren (2); nieces (2); stepfathers (1); friends (1)</td>
</tr>
<tr>
<td>Carers’ distance to care recipients</td>
<td>Same household or in the same house (16); within 10 km (8); within 50 km (6); within 100 km (8); within more than 100 km (5)</td>
</tr>
<tr>
<td>Carers’ occupational status</td>
<td>Employed (23); retired (9); non-employed (7); students (4)</td>
</tr>
<tr>
<td>Duration of care responsibility</td>
<td>Up to 5 years (17); 5–10 years (18); more than 10 years (8)</td>
</tr>
</tbody>
</table>
### Table 2: Characteristics of individual care networks

<table>
<thead>
<tr>
<th>Network no. and type</th>
<th>Care recipient (age) (pseudonyms)</th>
<th>Interviewed responsible network members and their relation to care recipient (age)</th>
<th>No. of network members counted by participants</th>
<th>Caring activities within the networks</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 C</td>
<td>Mrs Buechele (76)</td>
<td>daughter (47), daughter (52), daughter (54)</td>
<td>11–20, family members, friends, neighbours, members of the village community</td>
<td>organisation of informal care, being there, monitoring, visiting, no formal care</td>
</tr>
<tr>
<td>2 A</td>
<td>Mrs Clausmeier (78)</td>
<td>son (45), son (51), son (54)</td>
<td>4–12, family members and 24-hour assistance</td>
<td>organisation of informal and formal care, personal hygiene, washing, dressing, household, heating, cooking, custody, preparing for doctor visits, organising ambulance transportation, paying bills</td>
</tr>
<tr>
<td>3 A</td>
<td>Mrs Fuchs (85)</td>
<td>son (57), daughter-in-law (56)</td>
<td>11–12, family members, friends, neighbours, housekeeping, respite care (3 times per year)</td>
<td>organisation of informal and formal care, being there, monitoring, visiting</td>
</tr>
<tr>
<td>4 B</td>
<td>Mrs Gruber (89)</td>
<td>daughter (63), son (50), daughter (57), granddaughter (40)</td>
<td>10–19, family members, friends, no formal care support</td>
<td>organisation of care, being there, monitoring, visiting</td>
</tr>
<tr>
<td>5 C</td>
<td>Mr Jacobs (22)</td>
<td>mother (46), stepfather (50), sister (19)</td>
<td>4–5, family members, no formal care support</td>
<td>personal hygiene, eating, help with changing clothes, social support, comforting, talking</td>
</tr>
<tr>
<td>6 A</td>
<td>Mrs Kastner (65)</td>
<td>partner (67), daughter (37), niece (55), grandchild (5)</td>
<td>4–14, family members and friends, housekeeping, no formal care support</td>
<td>organisational, everyday care, providing entertainment, going to the garden, spending time together, going for walks, preparing and cooking meals, finances, shopping, medications</td>
</tr>
<tr>
<td>7 B</td>
<td>Mrs Lang (92)</td>
<td>daughter (53), daughter (57), friend (63)</td>
<td>17–21, family members, friends, neighbours, 24-hour assistance</td>
<td>organisation of care, being there, monitoring, visiting</td>
</tr>
<tr>
<td>8 B</td>
<td>Mrs Matzeneder (85)</td>
<td>daughter (62), son (52), son (59), sister (68), grandchild (30)</td>
<td>10–28, family members, friends, including homecare service</td>
<td>being there, mental support, making phone calls, emergencies, visiting</td>
</tr>
<tr>
<td>9 C</td>
<td>Nina (10) and Niklas (10)</td>
<td>mother (40), father (47), sister (13)</td>
<td>15–25, family members, school assistance, therapeutic support</td>
<td>any care that is necessary, being there, providing distraction, playing, relieving</td>
</tr>
<tr>
<td>10 A</td>
<td>Mr Ritter (70)</td>
<td>partner (57), daughter-in-law (35), grandchild (12), son (35), grandchild (14), son (34), daughter-in-law (28)</td>
<td>7–16, family members with a little help from friends and neighbours</td>
<td>checking medications, dressing, showering, assistance due to forgetfulness, cooking, doing ‘everything’, being there, laughing, playing, bringing happiness, monitoring</td>
</tr>
<tr>
<td>11 A</td>
<td>Mr Igler (65)</td>
<td>partner (66), daughter (34)</td>
<td>7–9, family members, friends, therapeutic support</td>
<td>everyday life management, going for walks, talking, help with showering, memory training</td>
</tr>
</tbody>
</table>

(Continued)
located themselves to the care receiver, the higher the interviewee estimated the amount and intensity of that carer’s care to be. While filling in the ecomaps, we asked participants to describe how, and to what extent, the individual carers supported the care recipient, recording their explanations. Thus, the participant-led ecomaps were used to enrich our interview data (Bravington and King, 2019) and to generate a systematic comparison of the multiple perspectives on the human resources in the network members’ care situation.

The participants’ basic sociodemographic data were collected using a short questionnaire. We conducted most interviews at participants’ homes and in one-to-one settings. Some interviews were conducted at the research facility or in public spaces, mainly coffee shops. During the interviews with the children, it was left to parents and the children to decide if a parent should be present.

Data analysis

All interviews were recorded and transcribed. Two researchers coded the data. We analysed the data following the open and axial coding and constant comparison procedures of grounded theory, based on its focus on care as an interactional social process (Corbin and Strauss, 2008). In a stepwise process (Zartler, 2010; Vogl et al, 2019), we first analysed the interviews one by one, using a data analysis programme (MAXQDA) to organise the qualitative data. We then compared the codes from the individual interviews within the same network (cross-sectional individual) and integrated the ecomaps comparatively during this second step. The different perspectives of carers within a single network appeared in this second step, enabling us to identify convergent or divergent perceptions of the distribution of care responsibilities within the same care arrangement (cross-sectional within units). Based on these comparisons of the individual interviews within one unit, each individual network (unit) could then be analysed as a case, and we wrote detailed case descriptions of every network (not shown here). In the third step, we compared the case descriptions of the networks (units) (cross-sectional between units). From this

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</tr>
</thead>
<tbody>
<tr>
<td>12 B</td>
<td>Mrs Dichacek (84)</td>
<td>daughter (60), daughter (57)</td>
<td>11–13, family members, friends and neighbours, housekeeping</td>
<td>everyday life, shopping, bringing food, making phone calls, visiting, bringing 'heavy things', chatting, entertaining, providing distraction, helping out, providing neighbourhood assistance</td>
</tr>
<tr>
<td>13 B</td>
<td>Mrs Egger (68)</td>
<td>daughter (50), niece (35)</td>
<td>8–11, family members and friends</td>
<td>shopping, preparing meals, finances, body care, wound care, organising of care, being there permanently and just in case, staying overnight, keeping company, reacting on emergencies and illness</td>
</tr>
</tbody>
</table>
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comparison, it became apparent that the units differ from one another regarding the allocation of care responsibilities (main versus shared responsibilities) and regarding the degree of convergence among the perceptions of the distribution (convergent versus divergent shared responsibilities). Thus, the main comparative dimensions that emerged from our data analysis were the distribution of care responsibilities within the network and the perception of this distribution; within these dimensions, the analysis showed specific patterns in developing and maintaining caring arrangements. Based on an in-depth data analysis of the different levels indicated, three distinct types of care arrangements emerged from our empirical data. These types were described comprehensively and were further validated by systematically comparing relevant dimensions, grouping cases and analysing contextual factors (preconditions). For a qualitative study, we conducted a relatively large number of interviews. Nevertheless, we discussed the subject of data saturation frequently during the research process. We are confident that we have captured the essence of the phenomenon with the interviews we conducted.

**Ethical considerations**

We provided detailed written and verbal information to all participants prior to the study. Since we also included children and adolescents in the study, age-appropriate information letters were formulated. Study participation was voluntary and informed consent was obtained from all participants. For the participating children up to the age of 14, approval from their legal guardians was sought before obtaining informed consent from the children themselves. For reasons of data protection, we pseudonymised all data (transcripts and ecomaps) for further processing and documentation. All data were kept secure from third-party access. Before data collection, the study obtained approval from the Ethics Committee of the University of Vienna.

**Validity and reliability**

By using a collaborative research approach, we strove to enhance the confirmability of the data, characterised as the congruence between multiple researchers’ interpretations. All four researchers had broad expertise in interviewing both families and children. We documented the analysis process by using fieldnotes to ensure utmost dependability. At periodic meetings, the research team discussed the ongoing analysis process and reflected on the data, with special emphasis on the coding process and interpretation of results (Morse, 2015). We also had reflective discussions on the findings (Whittemore et al, 2001) during three presentations with some 60 healthcare professionals who were case managers in homecare settings. As a result, they were able to relate well to, and to recognise their professional experience in, the findings.

**Findings**

Family care that includes more than one carer can be described as a process of ongoing communication and negotiation, in which responsibilities and conditions are negotiated among those involved. Taking into account the basic conditions of awareness as a carer, mutual expectations and motivations, and resources, the carers negotiated which responsibilities and which activities were assumed by the individuals.
The process of establishing the care arrangement was also an adaptation achievement on the part of each network member, which had to take place in accordance with their own resources and needs. Three different types of family care networks emerged from the data: Type A – the main responsibility network; Type B – the convergent shared responsibility network; and Type C – the divergent shared responsibility network. These networks differed in terms of the distribution (and the perception of the distribution) of caring responsibilities and the management of boundaries. The process of developing and maintaining family care with more than one person involved is shown in Figure 1.

**Preconditions**

Besides the need for care, the presence of a close relationship in which a basic responsibility for the family member in need of care persists is a causal condition for the emergence of a family care network. This remained the case regardless of the degree of kinship, and it could also include neighbours or friends. When a loved one needed care, the development of the care network required certain conditions: awareness of being a carer; expectations and motivations; and available or required resources.

**Awareness of being a carer**

Our analysis clearly indicated that awareness of being a family carer was established in a complex and sometimes long-lasting process. The transition from a family relationship to a care relationship appeared to be fluid. The beginning of this process could typically only be identified retrospectively, as Barbara illustrated: “So, looking back, I would say since 2013. So, that’s what I’ve come across now, that I’ve already started … now when I’m doing the cleaning in the apartment, I’ve started to write things together, so that she knows her way around” (Barbara, 47, daughter, Network [NW] 1). Konrad described that, as a caring partner, he had only realised through an

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**Figure 1: The process of developing and maintaining family care with more than one person involved**

![Figure 1](image-url)
Towards a typology of negotiating care in families

external stimulus that he was predominantly a carer in his relationship with his wife and no longer primarily a partner:

‘Four years ago, three, four years ago, when it started, I got— how was that? I came across the [names organisation] through seven corners with detours, don’t ask me how. And then someone recommended that I go and see a psychologist. And then I went to see her, and she said a sentence to me that was very important: ‘You are no longer the husband, but you are now a carer.’ And if you can internalise that, then you can handle it, right?’ (Konrad, 67, husband, NW 6)

The responding carers had different levels of awareness of being carers themselves. This was associated with the extent to which the person in need of care perceived that need, which, especially in the case of dementia, often does not correspond to that of the environment.

**Expectations and motivations**

Different expectations regarding the care responsibility of family carers for one another, for the care recipients and for the social environment were included in this negotiation process. A normative hierarchy emerged regarding the question of who was ‘responsible’ for providing care, which followed the criteria of degree of kinship, gender, spatial proximity, own family situation and available time resources. Caspar (51), one of three siblings whose father had recently passed away and who was organising 24-hour live-in care for his mother at the time of the interview, described this in terms of both parents’ situations: “I live in a partnership now, but previously, that was always the reason, everyone said, ‘You’re single, so you take care of her’” (Caspar, 51, son, NW 2). The analysis revealed that the expectation of care shifted to the next-younger generation when persons to whom the expectation of care was first directed dropped out due to their own illness or death. Raphaela described her own clear understanding of who was obligated to provide care and in which family constellation as follows: “Because, as I said, I had to care for my grandfather because my parents just weren’t available anymore, because they would have actually been the ones who should have cared for him” (Raphaela, 35, daughter-in-law, NW 10).

As indicated earlier, the fact that caring for relatives is often not a question of voluntariness was also evident from the fact that people often talked about ‘having to’ provide care in the interviews. However, this did not mean that care motivations and expectations were experienced as negative. In most cases, family carers described their motivation to provide care as a combination of a sense of personal responsibility and external circumstances that made alternative options difficult or impossible to realise.

**Available or required resources**

Available and required resources refer to resources on hand and those not yet available, which must be generated within the networks. Both included material resources (for example, adaptable housing and money) and immaterial resources, such as particular abilities to deal with conflicts or stressful situations that require high frustration tolerance. This was more strongly pronounced in some individuals.
in the networks than in others and was why they took on specific tasks, as described in the following: “Nadja, my wife, is extremely insistent in demanding certain goods and financial support. I wouldn’t be, I can’t do that, because this begging in certain institutions is very humiliating to me” (Norbert, 47, father of underage children in need of care, NW 9).

Learning about formal support services and working out individual solutions was an enormous communicative achievement within the support networks. This also required a great deal of time, commitment and perseverance. Care networks in which there was a higher level of socio-economic resources (education, financial resources or vocational status) and time were at an advantage in this regard. The resource of vocational status was addressed, for example, by Caspar (51), who lived about 100 km away from his mother who needed care. He organised and managed her care from this distance, and visited his mother every Saturday:

‘And then it was not so easy to get a medical judgement right away because there are not so many neurological institutes that take a patient immediately, right? But because of my status at the state, we then went to [named place], and that’s where [the disorder] was diagnosed right then and there.’ (Caspar, 51, son, NW 2)

Providing increasingly more care for someone was described by respondents as a process that also required enormous time resources, which had to be allocated within the network. At first, the time resources allocated for care were those most readily available, mainly leisure time. When these time resources were no longer sufficient, additional resources had to be deployed, which led (in eight networks in the present sample) to a significant reduction in, or to the complete withdrawal from, employment of at least one family carer in the network.

**Network types**

Based on negotiating these preconditions, a care network can be developed and maintained over time, as long as it is functional in regard to the care situation and no significant changes are needed in terms of the persons involved or the care situation. Our data revealed three types of networks, which essentially differed in how the main responsibility for care was distributed and how this distribution was perceived. The focus in all networks was on the person in need of care and their needs. The main characteristics of the network types are shown in Table 3.

**Type A: Main responsibility network**

In this network type, the main responsibility for care, especially for the organisation of care, was in the hands of *one person*. This was clearly defined and perceived equally by all respondents. This network type can thus be described as centrally organised and coordinated. It is typical for this network type that the other respondents indicated that they provided support for the main carer, rather than for the care recipient. In the development and maintenance of this network type, a partner or spouse often bore the main responsibility. The structure of a partner relationship and the first changes that came along with a need for care, and therefore primarily affected the two
Table 3: Main characteristics of the care network types

<table>
<thead>
<tr>
<th>Type A: Main responsibility network</th>
</tr>
</thead>
<tbody>
<tr>
<td>One person perceived as mainly responsible</td>
</tr>
<tr>
<td>Coordination of care by this person</td>
</tr>
<tr>
<td>Support of others for the main responsible care provider, rather than for the care recipient</td>
</tr>
<tr>
<td>Care perceived as an act of love</td>
</tr>
<tr>
<td>High expectations of oneself and of the person in need</td>
</tr>
<tr>
<td>Tendency of main responsible person to do more than they can</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Type B: Convergent shared responsibility network</th>
</tr>
</thead>
<tbody>
<tr>
<td>More than one person perceived as mainly responsible for care</td>
</tr>
<tr>
<td>Allocation of care responsibility among network members described similarly and perceived as fair</td>
</tr>
<tr>
<td>Relatively clear communication and common decisions</td>
</tr>
<tr>
<td>More formal planning and organisation of care with a longer-term perspective</td>
</tr>
<tr>
<td>Care perceived rather as labour than as an act of love</td>
</tr>
<tr>
<td>Mutual assistance and relief</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Type C: Divergent shared responsibility network</th>
</tr>
</thead>
<tbody>
<tr>
<td>More than one person perceived as mainly responsible for care</td>
</tr>
<tr>
<td>Allocation of care responsibility among network members described differently</td>
</tr>
<tr>
<td>More ad hoc planning and organisation of care, with a less long-term perspective</td>
</tr>
<tr>
<td>Care perceived rather as an act of love than as labour</td>
</tr>
<tr>
<td>Mutual assistance but additional negotiation processes based on different views of care needs</td>
</tr>
<tr>
<td>More vulnerable and liable for conflicts</td>
</tr>
</tbody>
</table>

partners, have a special dynamic in terms of awareness as a carer. The transition into a relationship in which care is needed is long-lasting and emotionally challenging. In addition, such a transition is frequently aggravated by a dementia-related care situation. However, care provided by spouses was not a prerequisite, as in the case of NW 2 and Carl, one of four siblings who cared for their parents: “There are four of us, and the main responsibility is on one brother. And he has actually managed everything. So, everything is very centrally managed” (Carl, 54, son, NW 2).

Most of the care activities, such as organisational care, household activities and emotional care, were seen as activities that had already been present to a greater extent in the relationships of primary carers compared to other carers before the need for care had arisen. Therefore, the increase in different areas of everyday support was particularly difficult to distinguish from those that were already part of the relationship. This can be considered as indicative of why formal support was available in this type of network but was often taken up at a very late stage. Strains, as well as the caring activities themselves, are increasingly interpreted as being part of the relationship.

From the interviewees’ perspective, other actors involved in the greater care network were potentially numerous and diverse, ranging from a 24-hour care service to be coordinated by the main responsible carer to neighbours or the larger part of a village. In a main responsibility network, however, everything came together in the hands of one person. Konrad reported on this when neighbours or the property owner called him because his wife, who suffered from dementia, had once again lost her way: “And they call me now, ‘She’s with me now’, or ‘I’ll bring her to your house’, or something like that. That works quite well, I must say. And that’s a great help, there are just many, many, many helpers, I don’t even know who’s at work here” (Konrad, 67, husband, NW 6).

In this network, the motivation to bear the main responsibility was very much based on love and reciprocity between the main responsible carer and the person in need of
care. This led to high expectations to maintain care on the part of both the person in need of care and the main responsible person. As a result, the main responsible persons in this type of network often tended to demand too much of themselves and, in turn, experienced this as burdensome. Support was expected, and usually given, from within the family. Particularly in rural areas with little infrastructure, simple purchases of medication or food, and “everything that goes with the house and yard” (Caspar, 51, son, NW 2), proved to be a challenge that had to be met predominantly by other family members. Comprehensive formal support was also used in this network and provided considerable, yet in no case complete, relief for family carers.

Type B: Convergent shared responsibility network

In this network type, the main responsibility was shared among several individuals to a balanced extent. Responsibility for care was coordinated in a communication process and was characterised by mutual agreement and convergent perceptions, such that the involved carers perceived the allocation of care tasks as mainly fair and largely agreed upon this. As with Type A networks, shared responsibility included other means of informal and formal support involved in caring. This network type typically evolved from Type A networks when the main responsible carer became unavailable for caring, for example, due to their own age-related difficulties.

Respondents in these networks perceived the decision-making processes as transparent and clearly communicated. For example, Mrs Matzeneder (85) needed care due to a previous stroke. Her three children provided most of the care, coordinated the care arrangement and shared the responsibilities in this regard. This allocation of responsibilities was specified in the same way by all interviewees, describing certain responsibilities and competences, as her son Maximilian outlined:

‘And then the responsibilities were shared out. My sister is mainly responsible for this social aspect, and I am mainly responsible for the house and garden, and the technical and financial side of things, and my brother is there a bit more often because he is more flexible because he doesn’t have a family of his own. Yes, that’s just the way it is now.’ (Maximilian, 59, son, NW 8)

The other two family members interviewed – Mrs Matzeneder’s sister (68) and a grandchild (30) – described this distribution in the same way. Compared to the Type A network, the main characteristics of this network type are more long-term planning, more consistent routines and a more formal organisation of care. The carers’ own obligations or long distances to the place of residence of the family member who needs care led to a clear, duty schedule-like division regarding physical presence. The main carers had similar motivations for, or expectations about, taking on caring activities. Equal sharing of responsibilities did not necessarily mean equal sharing of all details of care. Additional work provided by one of the main carers could be compensated by other benefits, such as payments, which were also perceived as fair, as described by Mrs Gruber’s (89) eldest daughter:

‘We siblings agreed on it, but we didn’t do it for free. How should I say? We agreed on a daily rate and whoever cares for the mother gets so and so much money per day. At the end of the month, we settle the bill. And in the
beginning, I got the most, because in the beginning, she was almost always in our house.’ (Gerda, 63, daughter, NW 4)

The interviewees in this network type had a similar awareness about how much care the person in need required. As a result, the definition of the situation was barely a subject of negotiation. The awareness of shared responsibility – “I’m not alone in this; we’re in this together” (Margarete, 62, daughter, NW 8) – underscored the extent of mutual interdependency, as well as the need for cooperation with, and consideration of, additional supporters in the network. The equally responsible carers tried to respect as much as possible the mutual need for time off described by Margarete, in whose network all the siblings, with the support of others, also shared caring for their mother on weekends: “When it’s our weekend, we try not to involve the others at all, so we really try to leave them alone. Ah, because we also take care of one another” (Margarete, 62, daughter, NW 8).

The decision-making and negotiation processes in Type B networks, as well as in the other network types, are not free of conflict. However, because caring was considered more of a labour task than a service of love, these were perceived less as the result of family or emotional difficulties at the relational level than as a result of the current care situation that the carers needed to manage together.

**Type C: Divergent shared responsibility network**

The Type C Network, as well as the Type B network, shared the care responsibilities among several family members. In contrast to Type B networks, perceptions of the sharing of care responsibilities in Type C networks diverged among the responsible carers. Compared with Type B networks, the main difference was that the family members interviewed did not consistently see the same actors as the main responsible carers. Their perception of whom they shared responsibility with was often very divergent. In the care network of Mrs Buechele (76), who was diagnosed with dementia, the main responsible carers appeared to be her three daughters: Barbara (47), Bianca (52) and Birgit (54). While the youngest and the oldest daughters considered themselves as bearing more responsibility and performing most care activities, Bianca perceived all three sisters’ care activities as evenly allocated. While filling in the ecomap, she stated: “I'd like to put the three of us equally in the map. My sisters perhaps won’t” (Bianca, 52, daughter, NW 1).

The negotiations of responsibilities and tasks in this network type were described as being more emotional and conflictual between the interviewees than in the other network types. The amount of care provided was perceived and reported differently, and, in some cases, assessed as unfair. This was the case in Mr Jacobs’ (22, autism) network, in which his sister Johanna (19) expressed that because of the care responsibility for her brother, she always put herself behind. Her stepfather, however, perceived her care contributions to be only quite minor compared to her brother Jan’s (24) contributions.

Nadja, a mother of two children with severe congenital disability (Niklas, 9, and Nina, 9), saw especially herself and her older daughter Nadine (13) as the main responsible carers and at the centre of the network. In turn, Nadine did not at all see herself as a carer; rather, she perceived herself as a sister in an especially close relationship with her siblings. For Norbert, the father, caring in the family was instead performed by a strong team working together:
‘So, the way I feel is that the network has simply become bigger, where you simply hold together several parts, where there isn’t just one knot that holds everything together in the middle, but where there are simply more than one, where something can also be dropped, where there’s always someone there, you always have the feeling that you’re getting support.’ (Norbert, 47, father, NW 9)

In this network type, perceptions regarding the overall size of the network were also quite divergent. While Norbert described the network as consisting of 25 people, Nadja mentioned a lower number, that is, 14 network members. In contrast to Type B networks, this network type was marked by more ad hoc and less long-term planning of caring, a more informal coordination process, and often independent and separated provision of care. Among other private or professional responsibilities, this was mainly due to the fact that the acting persons perceived the extent of the need for care differently, as Barbara, one of three sisters in Mrs Buechele’s (76) network, stated:

‘She [sister] said that she [mother] was just pretending and that she [mother] just needed more attention and we weren’t going to do that now. And she [sister] just didn’t care about her for a long time. And then, when she realised how much my [other sister] and I do for my mother, all of a sudden, she [sister] felt hurt and insulted because she [sister] felt excluded.’ (Barbara, 47, daughter, NW 1)

Short-term and occasionally spontaneous decisions and planning can lead to a dynamic in which the most flexible carer, who holds the most resources, often performs the largest share of care and fills the care gaps, if needed. The different perceptions of the need for care, the main responsibility, the distribution of care and the additional negotiation processes involved make this type of network appear to be more fragile and also more vulnerable to conflict.

**Responding to changes**

As shown in the typology, the main responsibility for caring in the networks was negotiated and distributed among multiple family members. Nevertheless, once established, networks do not have a static form but rather require adaptations to changes. This requirement induces a process of renegotiation of the caring arrangement. Such changes are induced by a significant change in care needs, sometimes caused by a deterioration of health, as the wife of a person in need explained: “And that’s now become extremely worse in the last three months, really extremely. And our son is now fixing up the second apartment, which is empty. He’s fixing it up for himself, and then he’ll move in next door to me. That will also be easier” (Renate, 57, wife, NW 10). Yet, adaptations can also be due to situational changes among the caring family members, such as a job change, retirement, divorce, illness or sometimes death. Both, however, can result in the need to renegotiate preconditions and change the caring arrangement. It becomes evident that family care always includes the management of family boundaries, in terms of which network members are allocated and which positions they adopt within the system.
Discussion

The aim of this study was to elaborate how care is developed and maintained within a family care arrangement in which more than one person takes responsibility for the care of a family member in need. Understanding the process of establishing and maintaining care includes comprehending the distribution of care responsibilities and all other activities that contribute to the individual needs of the care-receiving person and are performed by a wider network of care. Both the main responsible carers and all other supportive individuals within an extended network contribute to the stability and to the flexibility that is required to maintain the care arrangement over time.

Care networks and typologies have been the subject of several studies, mainly focusing on information about the size, composition and utilisation of formal support services (Keating et al, 2003; Dunér and Nordström, 2007; Vassilev et al, 2013; Broese van Groenou et al, 2016; Girardin et al, 2018; Varda and Talmi, 2018). Our study goes beyond the existing typologies. Using a multiple perspectives approach, our study revealed that the size and composition of the networks were rated quite differently by different respondents, even significantly so in some cases. This implies that the size of a network and the number of people contributing to care in that network can hardly be objectively represented. The perception of roles and responsibilities in care networks can vary substantially between different network members in terms of both their own contributions and those provided by others. Which informal care contributions help to maintain the care arrangement may also be a highly subjective matter. This was shown, for example, when one person in a network saw the next-door neighbour who regularly came over to have a chat as an important part of the network but another person in the same network did not.

In the analysed care networks, the main responsible persons were always close family members, while the extended network consisted of very different people, such as friends, neighbours or distant relatives. Some networks had formal support installed in order to keep the care arrangement stable, while others were exclusively formed and maintained by informal entities, without any contact with formal support services. These networks primarily included adults, though also, and often unnoticed, involved young children. It was surprising to see the openness with which the children and adolescents spoke about their help for another family member; yet, at the same time, they were often not aware of their caring roles. Even more so than for adults, supporting a family member arises from a feeling of family responsibility that young carers do not automatically associate with the concept of kinship care (Nagl-Cupal and Hauprich, 2018). Although it can be assumed that some 3–6 per cent of all minor children are involved in care, this fact is hardly taken into account in research on home-based care arrangements and is barely the subject of healthcare (Nagl-Cupal and Hauprich, 2020).

One of the main findings of this study is that the establishment and maintenance of family care in which more than one family member is involved is a dynamic process that is created within the availability of a set of conditions in a permanent process of communication and negotiation. This emphasises family caring as being an act of negotiation between several people involved. In that vein, family care always includes matters of boundary management, that is, setting the boundaries of who is involved in which ways to which extent and from which perspective. In line with the concept of ‘doing family’ (Jurczyk, 2020), we would argue that based on family
challenges like family caring, family consists in the performance of construction, in which relationships, roles and boundaries are interactively negotiated. It is family care that binds family members in mutual responsibility. Thus, it is the care for a close person and dynamic change in the care situation that contribute to the family being constructed and reconstructed, over and over again. In the context of developing and maintaining family care, family is therefore not only something you have but also something you ‘do’.

Some studies have argued, however, that there is little to no negotiation about care, even when the care situation changes significantly. Willyard et al (2008) investigated care arrangements carried out by adult siblings. They found that: (1) they all saw themselves as primarily responsible for care; (2) there was nearly no communication between the siblings regarding care; and (3) cooperation occurred only in specific situations. In several aspects, this is similar to the Type C network in our study. For this type, different perceptions of the same care arrangement emerged most clearly. The differences were related to the subjective perception of responsibility for care and its organisation, as well as the size of the care network and thus the people who contribute to successful care in the caring arrangement. In turn, the multiple perspectives approach in this study allowed us to show that there are both differences and consensus in terms of the perception of care responsibilities, and that negotiation among the individuals involved is essential to developing and maintaining care arrangements.

Still, in our study, the objective of negotiation was to distribute the responsibility for care, taking into account various expectations and resources. From the perspective of the main responsible family carers, decision making and its prerequisites are addressed, for example, in the informal care model (Broese van Groenou and De Boer, 2016). Beyond this, negotiation focused on the needs of the care recipient and aimed at keeping the homecare situation stable, taking into account the dynamics of temporality and trajectory of illness, and the related adjustments of the family members (Nolan et al, 1995; Corbin, 1998). These issues, however, can be understood as the central goals of family care at home (Köhler et al, 2021).

Changes in the state of health or the situation of the contributing carers show the temporary nature of a care arrangement when transition-related negotiations in that arrangement become unavoidable. These ‘tipping points’ in the context of caring by and for older people lead to systemic transformations (Crist et al, 2019). As shown in our study, this makes renegotiating care arrangements between the main responsible individuals unavoidable, while the need for transformation within a network over time is highlighted (Carpentier and Ducharme, 2003).

Beyond this micro-level, negotiation is influenced by the broader structural context, that is, how the welfare state is designed in terms of the role of family care and the provision of financial resources for the homecare sector (Zechner and Valokivi, 2012; Andersen et al, 2020). As shown, care recipients in Austria have a legal right to care allowance, which they can use to fund support from formal care providers. Such allowances, however, do not (by a long way) cover all the costs of care, and there is a widespread lack of formal support to integrate and coordinate different care services. This also explains why families are reluctant to hand over control for care responsibilities. This fact applies to many European countries (Montoro–Gurich and Garcia-Vivar, 2019), regardless of their welfare state characteristics.
Strengths and limitations

The article has presented new empirical findings based on methodological innovations and is of interest to academics, non-governmental organisations and healthcare professionals. As far as we know, this qualitative study is the first of its kind to incorporate the perspective of multiple responsible individuals in order to explain how care is developed and maintained in family care networks. Therefore, the findings considerably exceed snapshots of individual carers (Moen and DePasquale, 2017). The developed typology is highly generic, as it considered various care events. Therefore, it also has a low level of specification. The situation would have been different with an exclusive focus on paediatric care. Attempts were made in the interviews to take account the time course of caring. This issue could have been better addressed in a case-based longitudinal study. We tried to sample according to predefined criteria. However, no theoretical sampling was employed during the research process. Our perspective was limited to ‘traditional’ family constellations, which is a restricted reflection of reality. Networks among sexual- and gender-minority persons were not observed in this study. Moreover, it is difficult to transfer the results to countries where certain aspects of care, such as organisational tasks, are rather delegated to the formal care sector. In most families, individuals were named who also contributed to care but did not want to participate in the study. The participation of additional persons would have given a different picture of the perception of care in the family.

Conclusion

This study has offered insights into family care arrangements in which more than one person is responsible for care. Family care is a dynamic process that demands permanent adjustments of the involved individuals to maintain care. It is based on communication and negotiation among those involved as an important tool for ensuring care. Despite the different network types, care recipients’ needs are critical to all the identified care arrangements. Professional support for caring families must take into account their internal dynamics and structure. To keep the networks stable, and to relieve persons already involved, professional organisational support may be required, which may differ by situation, family or illness event. The perspective on family caring as a network task can balance the focus between exclusively considering single carers and drawing the attention to a broader range of contributions and resources in terms of a family system approach. This shift may fuel a resource-oriented perspective, thus supporting healthcare providers to sustain informal care at home over longer periods. Our study also showed that, at times, the size and composition of a care network cannot be objectively determined from the view of multiple perspectives. In turn, this could imply that differences in perceptions of network size and composition have a substantial meaning for the perceptions of opportunities of potential support for those who provide care.

Insight into the typology at hand can help healthcare professionals to develop network-type-specific support. In the main responsibility network, opportunities for the temporary relief of the main responsible person can be addressed. The convergent shared responsibility network is not necessarily in need of practical support or relief but more in need of the recognition and appreciation of the
caring family members. Finally, the divergent shared responsibility network may require support in mutual communication in the form of family assessment or family conferences in order to avoid conflicts and to align the individuals towards joint action.

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**Conflict of interest**

The authors declare that there is no conflict of interest.

**References**


Towards a typology of negotiating care in families


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