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Pathways to Care from the Perspective of Family Caregivers

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Abstract

Introduction

For family caregivers, the moment one begins to care for a loved one is key to the caring process: It shapes the subsequent course of care as well as the use of support services. Caregiver self-identification is seen as crucial in this process. This working paper examines how family caregivers experience the beginning of care and the process of self-identification.

Methodology

This investigation was carried out in the evaluation of 33 qualitative, semi-structured interviews conducted as part of the *Digital applications for care provision* (DiVa) research project according to Kuckartz's (2018) content-structuring qualitative content analysis. Participants were grouped into those who retrospectively perceived the start of care as gradual or sudden.

Results

The results show differences in the perception of the start of care, the activities carried out and the use of support between the groups of gradual and sudden caregivers. In some cases, the former did not identify themselves as family caregivers until years later, while in others they tended to take on domestic tasks at the beginning and rarely seek professional support. In contrast, family caregivers who suddenly became caregivers felt overwhelmed by the number and speed of demands placed on them. They were more likely to seek professional help with their care and rely on their private network for support in this exceptional situation. What both groups had in common is a personal approach to the situation and the desire to have a contact person available around the clock, even for minor concerns.

Conclusion

Implications for practice, for further investigation and survey research can be drawn from the results.

Keywords: family caregivers, start of care, self-identification, sudden/slow start of care

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1 Introduction

For family caregivers, one absolutely key moment in the care process is when the care begins. This moment determines the further course of care and use of support. As the need to support spouses or parents increases, family caregivers require a great deal of information (e.g., Bohnet-Joschko, 2020; Büscher, Stelzig, Peters, & Lübben, 2022; Otto et al., 2019), which can be overwhelming given the *"jungle of information"* (T17_43) they encounter. At the same time, family caregivers are uncertain about whom they can turn to with sometimes intimate questions. At this point, family caregivers often lack ways and routines to fall back on when they have questions or must coordinate the activities involved (Hudelmayer, Schütz, & zur Kammer, 2023; Hudelmayer, zur Kammer, & Schütz, 2023; Chapter 4).

Within this process of taking on care, one central factor is that the family member self-identifies as a caregiver. This is because support services can only—or more easily—be found with the corresponding self-designation and keywords. Both private and professional support services can in turn contribute considerable relief, an essential element for the well-being family caregivers in light of the widely documented *burden of care* (e.g., Gräßel & Behrndt, 2016).

This brief outline of the importance of the path into care or the early care phase is a response to the lack of research on this topic to date. It stems from an in-house interview study with family caregivers (Schütz & Hudelmayer, 2023) that prompted a separate analysis of more than 30 interviews conducted on the use of digital support.

For this working paper, the focus was placed on the retrospective perception of the start of care. We left it up to the interviewees themselves to define what "the start" was for them. A further focus was self-identification as a family caregiver. The evaluations concentrate, among other things, on the tasks assumed at the beginning of caregiving and their distribution, as well as the perceived challenges in this early phase of caregiving. This explorative look at the start of care is important for insights into how the initial phase is organised and experienced by the family caregivers. This working paper therefore addresses the following questions in particular:

- How do family caregivers experience the start of caregiving?
- What activities do family caregivers initially take on and what challenges do they face at the outset?
- How do family caregivers experience the process of self-identification

In a first step, the state of research and theoretical concepts on entry into care and identification as a family caregiver are presented below (Chapter 2). The research design and structure of the study are then discussed (Chapter 3), before the results are presented (Chapter 4). In the fifth chapter, the results are interpreted in light of the state of research presented. The working

paper concludes with a summary outlining implications for practice and further research (Chapter 6).

2 Pathways into Care: The Perspective of Family Caregivers

The following chapter provides a brief overview of the current state of research on the topics examined in this working paper. First, it looks at the path to caregiving (Chapter 2.1), i.e., the first steps in how family caregivers plan caregiving and take on activities that they (retrospectively) assign to caregiving. Then, it turns to the process of self-identification and the reasons for and barriers to assuming the family-caregiver identity (Chapter 2.2).

2.1 Perspectives on the Start of Care and Empirical Findings

Empirical studies and the literature show that there is no standardised path to care in the private context, in the sense of family caregivers and loved ones taking on responsibility. The paths to care dependency are just as diverse the ways in which care is assumed; a variety of motives and the life situations of family caregivers is at play (Brandt et al., 2022). Despite an implied connection between the path to care dependency and the assumption of care, these processes do not have to be synchronous. Differences often depend on the care situation, illness, needs, and care network. This article focuses exclusively on family caregivers and their path to becoming caregivers.

There is no uniform picture in the literature of how long the process takes and which aspects or phases it comprises. One reason for this is that there is no uniform understanding of what is meant by family caregivers or informal care and what activities are involved (Schmitt, 2022). Not only do service providers, legislators, and academics have differing understandings, but academics in different scientific disciplines hardly share a common definition (Lichte et al., 2018). One unique issue within the German language is that care is often used to refer primarily to activities that relate to physical and nursing activities, i.e., so-called hands-on activities (Franke et al., 2019; Hielscher et al., 2017; Keating et al., 2019). If the variety of forms of support is being included, such as social and emotional care as well as organisational and housekeeping activities, this is explicitly pointed out, e.g. by referring to the English term care instead of the German term „Pflege“. (Auth et al., 2018).

The majority of empirical studies dealing with the start of care or its early phases have been conducted on specific groups sorted, for example, according to certain illnesses of the person in need of care or only cases of sudden need (e.g., Moore & Gillespie, 2014; Adams, 2006; Kaspar et al., 2019). Kaspar et al. (2019) have noted that “the entry into the role of family caregivers can be gradual or sudden” (ibid., p. 7). Based on empirical data, they further emphasised that the onset is largely determined by how the need for care arises, whether the result of age-related limitations, chronic illness, an accident, or an emergency event. In the

case of a gradual onset, family caregivers provide support in advance, often without being aware of “a new role” (ibid.). Meanwhile, family caregivers take on the tasks immediately in the case of sudden onset. However, reflection and classification of this phase sometimes only take place after the situation has stabilised (ibid.; Chapter 2.2).

This pathway into care is usually viewed as a phase or stage model; however, it should be noted that this is a dynamic process, and not all family caregivers go through these phases, nor is the sequence of phases strictly defined. The characteristics and duration of the individual phases also vary depending on the individual or care network (Kaspar et al., 2019). The number of phases differs depending perceptions of the beginning and end of this process and on which aspects are counted in each individual phase.

Theoretical Concepts for Starting Care

Two concepts are outlined below as examples. The first is that of Kaspar et al. (2019), who expand on a model by Doherty and McCubbin (1985). Their model was differentiated into six separate phases with a focus on supporting family caregivers in the initial, crisis, and emergency situations and thus on possible crises within this process. The process can take varying lengths of time, from a few weeks to several months. As will be explained in detail later, the model considered the first point at which family caregivers take over care and nursing activities to be relatively late. This was followed by the phases of “self-assessment”, “role adjustment”, ”external support”, and a “new everyday life”, while the “crisis” phase could come at any point in the process (Kaspar et al., 2019, p. 4). The process itself was described by the authors as having a “character of the new and unknown; uncertainties, search activities and changes” (ibid.).

Moral-Fernández et al. (2018) developed three overarching phases, as a result of a qualitative meta-synthesis of 19 selected studies. Their first phase was “taking on the role” (ibid., p. 5) and included life changes, uncertainties, confusion, and the associated resistance or acceptance. In the second phase “beginning to realise,”" (ibid.), new needs and consequences arose, and an assessment of the situation took place; finally, the phase of “implementing strategies” (ibid.), included coping with the situation, such as seeking support (ibid.).

Both concepts marked the start of caregiving as the assumption of activities that are assigned to a caregiving situation. However, Keating et al. (2019) argued that family caregiving should be viewed as a phase in the life course and that caregiving should not be limited to the performance of activities but also be understood as a relationship. From a life course perspective, they therefore emphasised the importance of considering so-called “bookends” (ibid., p. 152). By this they mean the initial assumption of care responsibilities and the end of the last care situation, from the perspective of the caregiver. Between these points, there may

be various care responsibilities, so-called care episodes (e.g., several short or also one long and intense period of care). The importance of such a consideration lies, on the one hand, in the fact that the respective care situation is significantly influenced by the amount of care experience that the caregiver already has. On the other hand, the point in time at which family caregivers take over care has an impact on various levels of their life courses. Keating et al. (2019) thus foregrounded the family caregivers and thus move away from a view of care processes that revolves around the health status of the person in need of care. For the future, they called for an analysis of important patterns in order to develop an understanding of the life courses of care work and relationships (ibid.).

Also, if care is viewed as a relationship, the beginning can be seen to occur well before the assumption of care activities, and the preparation or discussion of future care can also be viewed as such. This topic is subsumed under “preparation for future care” (Sörensen, 2021, p. 3934), for example. It includes attitudes, actions, and thoughts of aging people and family caregivers to prepare for no longer being able to carry out activities of daily living independently at some future point. Sörensen (2021) described the study situation on this topic as very limited. In summary, she stated that rarely do older people and potential caregivers actively, pre-emptively prepare for care and the need for care. Various reasons are given for this, such as the association of this idea with unpleasant scenarios and future dependencies. In addition, it often requires resources that are not available to everyone (ibid.).

Based on these explanations, research gaps can be seen in various areas. In particular, it is clear that the majority of studies refer to the English-speaking context, that there is little literature in and on German-speaking countries and that the pathways into care are under-theorised overall (e.g., Keating et al., 2019). Furthermore, Sörensen (2021) emphasises that future research should address the impact of care planning on older adults and caregivers.

2.2 Self-identification as a Family Caregiver

In the research literature, there are various perspectives on (self-)identification by family caregivers. It is presented as an aspect or a (partial) phase of the path into care outlined in the previous chapter and can be viewed as an independent process. The research on this has focused on what is expected of people who take on longer-term support and whether or how these assumptions are internalised into role identities (Funk, 2021). This process will be emphasised in this report for the following reasons:

- On the one hand, few empirical studies to date have explicitly dealt with identification as a family caregiver (ibid.). Existing studies and theoretical work in this area mainly originate from English-speaking countries[1] (Funk, 2021; Hensely-Schinkinger, 2017)

[1] There, the topic is analysed and discussed in the context of *Caregiver Identity* (Funk 2021)

and usually focus on the identification of family caregivers with certain illnesses of the person in need of care (e.g., Adams, 2006; Moore & Gillespie, 2014; Hughes et al., 2013).

- On the other hand, the (lack of) self-identification in the care process is also attributed a central importance beyond its beginning, especially in connection with the use of support (e.g., O'Connor, 2007; Eifert et al., 2015; Funk, 2021; Kaspar et al., 2019).

Self-identification as a Prerequisite for Accessing Support

Many studies have attributed a central role to self-identification with regard to accessing support (Eifert et al., 2015; Funk, 2021; Kaspar et al., 2019). Referencing other empirical studies, Eifert et al. (2015) have pointed to a connection between self-identification as a family caregiver and an increased likelihood of taking advantage of support services. They went so far as to identify lack of self-identification as one major cause for low utilisation of outside support (ibid.). With their systematic literature review, they aimed to better understand the process of self-identification in order to develop interventions to improve this process and address possible barriers in this context. Their article concluded with recommendations for action for health professionals and educators, developed on the basis of their findings (ibid.). Other studies have also advocated the perspective that family caregivers should be encouraged to develop an identity as caregivers. The hope is that this will simplify access to support (Hensely-Schinkinger, 2017; Kaspar et al., 2019).

Critically, however, Funk (2021) noted that the evidence on this topic is not clear, referring to Moore and Gillespie (2014). She argued that over-identification as a caregiver can also promote suppression of the needs of the person in need of care (Funk, 2021).

Basics of Caregiver Identity

In Funk's (2021) understanding, the caregiver identity is a mental construct that develops when people characterise themselves as the caregiver for a family member or friend. The support is usually directed towards a person who needs it due to a chronic illness or disability. The identities serve as an interpretative framework and provide norms used by individuals to give meaning to personal experiences, actions, and emotions—and to guide future behaviour. In connection with the caregiver identity, reference is made to other identity theories and the relationship between different theories (ibid.).

Eifert et al. (2015) viewed identity development as a complex, highly socially constructed phenomenon. Following Erikson (1968), one of the first theorists to deal explicitly with identity formation, they described two dimensions in identity formation: the self and the social. While the first is reflexive in nature, the second arises when this self-identity is recognised and supported by others. According to this assumption, people learn who they are by interacting with others and having an idea of how others see them (Eifert et al., 2015;

Erikson, 1968).

While much of the research in this area assumed a developmental or gradual approach to identity development, more recent research has increasingly emphasised the variability and fluidity of self-identification (Funk, 2021). From a developmental psychology perspective, Montgomery and Kosloski (2013), for example, have emphasised that this is an iterative, dynamic process. They identified three main premises on which they have built a theory of caregiver identity. The first is that the acquisition of caregiver identity is systematic and highly dependent on the individual/environment and family. Family *rules*, normative ideas, and the overall context shape this process. Second, caregiving is a dynamic process, whereby the caregiving experience can be characterised at the most basic level by two aspects: the activities in which the person engages and the meaning the person attaches to those behaviours. The third premise is that the change in the role of family caregivers is accompanied by a change in their own identity. Changes in the caregiving context and the resulting discrepancies can therefore be seen as pressure to change one's identity (ibid.).

Accordingly, this identity process is characterised not only by its dynamics but also by the fact that it takes a certain amount of time. Findings by O'Connor (2007), for example, have shown that the majority of family caregivers state in retrospect that it took some time for them to perceive or describe themselves as caregivers (ibid.). This has also been confirmed by the State of Caring 2022 report from the UK. According to an online survey of more than 13,000 participants, more than half of the people took at least a year to see themselves as caregivers, and more than a third longer than three years (Carers UK, 2022).

The Importance of External Influences

Identity development to become a family caregiver is influenced by various factors, which will be outlined in this chapter. Findings on this topic thus far have made it clear that this process does not take place in a vacuum; it is shaped by interaction with others and feedback (O'Connor, 2007). Socially shaped, shared expectations and interpretations of care and the associated tasks play an important role. The process of identification is therefore also influenced by what the respective person understands to be care (or not) and the ideas held by those in their social environment. It is also shaped by gender- and culture-specific expectations of the term care and by identity-forming interactions with others (Eifert et al., 2015; Funk, 2021). Therefore, if identification is influenced by the environment, it can be supported or rejected by outsiders (O'Connor, 2007). Eifert et al. (2015) summarised this as follows: "individuals may be unaware of the label but through interactions with others, they develop an awareness and eventual identity related to caregiving" (p. 364). In addition to the social environment, the person in need of care or the relationship with them is ascribed a particular importance as well. Yet, key barriers to identification can also be derived from this

(Eifert et al., 2015; Funk, 2021), as will be explained in more detail in the following chapter.

To reiterate, one's own understanding of care and family caregivers is central. The aspect outlined above—that the concept of *family caregivers* is very open-ended—also comes into play here. The identity of the family caregiver is not synonymous with the practice of any particular caregiving behaviour. While some people have dealt with the expectations and thoughts of caregiving long before the *objective* start of caregiving, others feel uncomfortable with this term generally and do not identify with it at all, even after years in a de facto support role (Funk, 2021; O'Connor, 2007; Sörensen, 2021). Nevertheless, caregiver identity theory assumes that behaviours or practices also form identities (Funk, 2021; Montgomery & Kosloski, 2009).

In sum, all of the theories outline define identification as a complex and variable process—a personal understanding of oneself and one's role in the family system plays an important role. If we entertain a concept with successive phases of care, however, all of these aspects seem to recede into the background.

Importance of and Barriers to Self-identification

In the following, we will first list some aspects that foster identification highlighted in the literature, and then turn to some reasons for not identifying as or refusing to call oneself a family caregiver.

As explained above, self-identification has been emphasised primarily as a prerequisite for seeking support (Eifert et al., 2015; Funk, 2021; Montgomery & Kosloski, 2013). It has also been assumed that self-identification as a caregiver can trigger a sense of belonging and connection to a certain group or community and thus reduces stress (Montgomery & Kosloski, 2009; O'Connor, 2007). Furthermore, self-identification has been described as a means to a new self-image that redefines one's daily achievements, which results in a form of external recognition (Hensely-Schinkinger, 2017; Moore & Gillespie, 2014; O'Connor, 2007). Beyond the individual level, it has been argued that social visibility is only possible with identification as a family caregiver, as the extensive care activities would otherwise remain hidden (Eifert et al., 2015; Hughes et al., 2013).

Against this background, however, there are a number of barriers to self-identification that prevent identification as a family caregiver. Family caregivers may be conscious of them and explicitly reject this identity, or they may not be aware of these barriers at all or only partially so. According to O'Connor (2007), this second group is more common—at least in her research: "For most, however, not taking on the caregiving identity was not a conscious decision" (ibid., p. 168).

In their literature review, Eifert et al. (2015) came to the conclusion that several factors are associated with the development of a family caregiving identity. They categorised them

into five areas, emphasising that individual factors cannot always be assigned exclusively to one of these areas. The five areas are: role engulfment and losing self, loss of shared identity, family obligation and gender norming, extension of former role and development of a master identity (ibid., p. 7).

Some of these topics refer to how much person identities as a family caregiver alongside or in addition to his/her other identities; how the caregiver role influences the others; and to what extent they are *threatened* or endangered by the caregiving identity[2]. Adoption of this identity can entail a loss of other identities. For example, if the caregiving tasks and the associated burdens take up so much time that there is little left for the other activities and behaviours that had previously defined the person, previous identities may fade or lose significance. The categorisation into these five areas emphasises that other identities often come under pressure when the effort increases and caregiving becomes more important in terms of time and/or psychologically more pressing (Eifert et al., 2015; Funk, 2021).

The loss of a shared identity is similar to this. Most family caregivers share a past with and have a relationship to the person in need of care. This shared identity is also referred to as a dyadic identity. In empirical practice, respondents refer to it by talking about the past before or at the beginning of the care situation, when they talk about we or us as a dyad. This shared identity, whose modes of interaction and behaviour are known to the participants, cannot exist without the participants. If caregiving leads to changes in the established patterns of interaction, the impact on the dyad's self-perception or their own position within this relationship can be quite pronounced (Eifert et al., 2015). With regard to this shared identity, there are indications that the relationship to the person in need of care and/or the shared relationship itself plays an important role in the process of self-identification: Consequentially, a variety of challenges to self-identification may arise, depending on the dyadic identity. For example, O'Connor (2007) came to the conclusion in a study of spouses who explicitly rejected the identity or designation as a caregiver out of concern that they would lose their (familiar/romantic) relationship, their spouse, and their own position within this relationship.

Closely linked to this are the expectations placed on certain people (by society as a whole), as already mentioned. These include, for example, family obligations and gender-specific norms. There are assumptions, beliefs, and values that determine how and who in a family should react to a care situation (Eifert et al., 2015). Ideas about care may differ between families, but there are still overarching, particularly gender-specific ideas about who should take on these tasks (ibid.). Sometimes, taking on care by spouses is also seen as a natural responsibility, such that the care activities are absorbed into this role. This view has been

[2] Behind this the following assumptions are certain understandings of how *identity* is to be understood, what it is, and how several identities relate to each other. However, due to the focus of this working paper, this cannot be discussed further.

supported by Hughes et al. (2013). They showed that those who took on caregiving from a more tangential (and less natural) relationship, such as siblings or ex-partners, were more and likely to see themselves as family caregivers. In contrast, spouses who were expected to take on the caregiving identity did not always feel comfortable doing so (ibid.).

Other reasons mentioned in the literature can also make self-identification more difficult and are related to the aspects already outlined. For example, Hensely-Schinkinger (2017) pointed out that the type of illness of the person in need of care can also be relevant in this regard. For example, the identification process for slowly progressing symptoms and illnesses is sometimes “only in bits and pieces, which in turn makes it difficult to recognise” (ibid., p. 17).

Another aspect that can lead to (active) rejection is the negative connotation of care in general or of family caregivers and those in need of care themselves. The high value placed on personal autonomy and the negative connotation of dependency (e.g., Brückner, 2011) together can lead to family caregivers consciously deciding against calling themselves caregivers. The concern about being reduced to this one identity, outlined above, can also lead to rejection (Hensely-Schinkinger, 2017 with reference to Hughes et al., 2013; Henderson, 2001; Lloyd, 2006; Molyneaux et al., 2011).

Such concerns may lead family caregivers to try to protect the person in need of care and therefore conceal the extent of the informal care they provide. As a result, the family caregivers can go unrecognised in their de facto role. Neither the person being cared for/supported nor people outside the care home network see it, and thus the caregiver does not receive social recognition for their activities (Moore & Gillespie, 2014). On the other hand, the person in need of care may also explicitly reject the designation because it bureaucratises or at least formalises the personal relationship (Hughes et al., 2013), to the same effect. Furthermore, when care activities are not visible to the outside world, interaction and engagement with people outside the network — the importance of which has already been outlined — can suffer (Chapter 5.1). Ultimately, nonrecognition or rejection of the caregiving role leads to isolation and a lack of positive reinforcement and further support.

Challenges for Research and Recommendations for Action

The following chapter discusses how to deal with the barriers mentioned, but it must be mentioned at this point that there are obvious limitations from a research perspective: People who do not see themselves as family caregivers can hardly be recruited as family caregivers for empirical studies. Accordingly, in interviews, they can only report retrospectively on the start of caregiving. Hence, for future research, Funk (2021) has highlighted the challenge of accompanying this process in order to obtain in-depth results.

As explained above, many studies have emphasised the importance of self-identification, partly because a connection is seen with increased use of support, but it is also

seen very critically when people are asked (against their will) to adopt this identity. This can lead to negative emotions and an ambiguous stance. At the same time, (too) strong identification of the caregiver can undermine the sense of identity of the person in need of care (Eifert et al., 2015; Funk, 2021; O'Connor, 2007). This is one of the reasons why recommendations for action also focus on strengthening and thus protecting existing identities that could be jeopardised by the start of care (Eifert et al., 2015; Funk, 2021).

Funk (2021) further pointed out that programs to support family caregivers should be aimed both at those who identify as family caregivers and at those who (consciously) reject such a designation.

In view of the aforementioned gap in research, particularly in German-speaking countries (Hensely-Schinkinger, 2017), the literature points to the need for further investigation. The aim should be to eliminate the discrepancies in previous research and therefore to use new methods to look at different groups (Funk, 2021). In particular, Funk (ibid.) has called for qualitative research to investigate how the self-identification of caregivers is expressed in conversations about their biography or life course.

3 Research Design

Data from the aforementioned *Digital applications for care provision* (DiVa) research project was used to answer the above-mentioned research questions. As part of this project, we investigated the extent to which the use of a digital care solution is perceived by family caregivers and their personal network as support in day-to-day care. The aim of the project was to provide explorative insights into the potential and challenges of a market-ready digital application under everyday conditions (Hudelmayer, Schütz & zur Kammer, 2023; Hudelmayer, zur Kammer & Schütz, 2023; Schütz & Hudelmayer, 2023; zur Kammer et al., 2023).

The following subchapters will outline the process of data collection and evaluation, with a particular focus on the analyses that were carried out explicitly for this working paper. It concludes with a description of the limits of the study for transparency.

3.1 Data Basis and Data Collection

The data was collected in two field phases. In both phases, qualitative, guideline-based interviews were conducted with family caregivers who had voluntarily responded to a call for participation. Following the first interview, the participants were given access to an app designed to help family caregivers with routine organisation of and access to care-related information. They were able to use it for a period of three to five months before reporting on their experiences, challenges, and obstacles to use in a second interview (Phase 2; see Chapter 1). This study focuses on the first interview phase regarding current care-related

everyday life and the associated challenges. One interview chapter focused on the start of caregiving, the decision, and motivation to take on caregiving as well as the development and changes in the care situation since the start. For the interviews, three research assistants created a guideline for each phase, which was tailored to the interviewees' individual situations during the interview, according to the principle of openness (Strübing, 2018).

Participants were recruited between September and October 2022, particularly in the region surrounding Kempten, Germany, via flyers, emails from the local university, local newspapers, multipliers from the care and elderly care sector, but also nationally via social media and a project website.

The call for participation did not address the target group directly as family caregivers, but rather the focus was placed on caregiving and the possibility of support. The study flyer was titled "Study on Digital Support for Your Day-to-day Care". In light of the present research question, it can be assumed that only those who already perceived their support activities as care were made aware of the call. The term care was specified in the conditions of participation in the study. In order to avoid a narrow understanding of care, examples were given: "They regularly participate in care (e.g., support in the household, shopping, accompaniment to authorities, regular visits)." Explicit emphasis was placed on the fact participants need not be "caregivers" as such. Although these statements made it clear that a formal designation of the activity as care was not a prerequisite for participation, only people who provided supportive activities and described these themselves as caregivers were addressed. People who did not identify themselves as caregivers or who saw their work as merely providing support, for example, were therefore not included in the sample. Eighteen family caregivers agreed to take part in the study. From this group, 16 family caregivers took part in both interviews, so that data from 34 interviews could be used for the present evaluation. The participants were almost exclusively daughters who supported or cared for one or both parents. They also included a son who cared for his mother, and another interview was conducted with a person who regularly supported their neighbour. The majority of participants were between 45 and 65 years old and mostly lived with or in close proximity to their parents in need of care, who were between 65 and 95 years old. Three of the participants had a commute of 1 to 2.5 hours and could therefore be described as distance caregivers (Franke et al., 2020). A detailed description and reflection of the interview situation can be found in the final report of the DiVa research project by Schütz and Hudelmayer (2023).

3.2 Evaluation Strategy

All the interviews were recorded and then transcribed, creating the conditions for a detailed analysis (Mayring, 2015). All the data that allowed conclusions to be drawn about the interviewees and their social environment were anonymised. Still, it remained possible to link

a person's first and second interview with an abbreviation.

The evaluation was based on content-structuring qualitative content analysis according to Kuckartz (2018). By combining inductive and deductive categories, the analysis can take into account the current state of research as well as capture and identify new aspects relevant to the research question (Kuckartz, 2016, 2018; Mayring, 2015).

For the evaluation of this study, the deductive categories of care biography, care-relevant activities, and burdens as well as the categories developed inductively from the material were used, in particular: resources, reasons for providing care, and support network. The research question for this study was not the explicit reason for collecting the data; rather, its significance only emerged in the course of the evaluation and in view of the results. Thus, all of the already coded material was explicitly reviewed against the background of this question and relevant text passages were provided with memos and coded again. In particular, comparative evaluations were carried out, e.g., between the group with gradual and sudden entry into care.

A coding guide was developed for the respective evaluation steps, which contains a definition, a brief description, and an anchor example of the respective categories and subcategories. In particular, the guide highlights distinctions from other categories. The evaluation was carried out by four project team members using the computer-aided software MAXQDA 2022.

3.3 Limits to the Investigation

The present working paper has limitations that should be presented transparently at this point in order to meet the requirement of contextualisation and critical evaluation of the data (Przyborski & Wohlrab-Sahr, 2021). First of all, it should be noted that the data was not collected explicitly to investigate the issues that are the focus of this working paper. The initiative to take a closer look at this process arose, in particular, from a prior set of initial findings that emphasised the importance of the start of care (Hudelmayer, Schütz & zur Kammer, 2023; Schütz & Hudelmayer, 2023; see Chapter 1). The possibility to evaluate already available data with a new focus on this care phase—and thus directly addressing a research gap identified in the previous evaluations—means that the interviews contained reports and statements of varying scope on the relevant topics. As the relevance of the start of care for the further course of care only became apparent during the first evaluation, no systematic questions were included in the guidelines. Although the topic area was addressed in all the interviews, the lack of a specific question about the start of care in the interview guide has made it almost impossible to compare the statements of the respective interviewees.

Further limitations relate to the study sample. Despite intense recruitment efforts, no older caregivers or spouses of family caregivers were recruited, although wives—along with

adult children—represent the largest group of family caregivers, statistically speaking (Hielscher et al., 2017). The results therefore only provide information about a specific group of family caregivers: the children, or rather the daughters.

With regard to the research results and their interpretation, it should also be emphasised that the research design attracted family caregivers to volunteer for the study in which they were specifically addressed as such. This selection of interview partners means that they were only able to report on the process of self-identification retrospectively. However, this limitation is not unique to this study; it is a challenge addressed as a barrier generally in the current state of research. The need to accompany this process with future qualitative research has been therefore emphasised going forward (Funk, 2021).

As outlined in Chapter 4 and also elaborated, for example, by Kaspar et al. (2019) in their mixed-methods study, the exemplary paths into care (sudden or gradual—as they have been juxtaposed in the presentation of results—can only be clearly separated theoretically. Some of the interviews also revealed combinations of these two constellations.

Finally, it should be emphasised once again that the study had a qualitative research design and therefore a small sample. The study therefore neither claims to nor is it possible to make representative statements about the target group or with regard to the topics investigated. However, the need for research outlined in several subchapters and described in more detail below reveals numerous points of contact and research gaps for further investigations.

4 Presentation of the Results

This working paper opened with the following questions: How do family caregivers become family caregivers? How does the process of caregiving proceed? And when do family members identify themselves as family caregivers? The study has rendered results pointing to clear differences between the group whose entry into caregiving occurs suddenly, *“overnight”* (T8_21), and the group who retrospectively perceive the entry into caregiving as gradual, sometimes over a period of years. Around half of the participants retrospectively reported that they experienced the start of care as rather gradual; the other half described it as a sudden event.

These two groups, which are also frequently distinguished in the literature (Chapter 2; Kaspar et al., 2019), can only be clearly separated from each other in theory. The interviewees’ statements make it clear, however, that some of the study participants cannot be clearly assigned to one or the other of these groups. Rather, the stories reveal unique paths into care that can be seen as combinations of both groups. One interviewee, for example, described how she gradually supported her mother with individual, smaller household tasks at the beginning of her care, but a fall and the resulting sudden deterioration in her state of health led

to a sudden care situation. This example illustrates that the seemingly sudden need for care was preceded by a lesser need for support. Nevertheless, this differentiation between sudden and gradual onset of care is used in the following explanations in order to sort their specific characteristics.

Against this background, the previously discussed question of what is understood by the term care and what tasks it encompasses becomes relevant. The study left open the interviewees' understanding of the concept of care at the beginning. In a narrative-generating question, they were asked to describe their activities in the context of care. During the course of the interview, however, the interviewers addressed the fact that the research was about a broader understanding of care and that care therefore also includes activities beyond the so-called hands-on activities (Auth et al., 2018; Franke et al., 2019; Hielscher et al., 2017).

4.1 Perception of the Start of Care: Key Events and a Gradual Process

As already indicated in previous chapters, the question arises as to who defines the start of care and whether or not it should be equated with one's own identification as a family caregiver. In qualitative research, great importance is attached to the subjective attribution of those affected by giving the interviewees the opportunity to present problems within their system of relevance from their own perspective (Przyborski & Wohlrab-Sahr, 2021). Yet, we will account for further aspects in the explanations that follow. Particularly in the group of family caregivers whose entry into care was rather slow, it became clear that, looking back on their entry into care, they described not yet having perceived themselves as family caregivers at certain times. Retrospectively, however, they would describe themselves as already having been family caregivers at these times. In doing so, they named barriers that stood in the way of such identification (Chapter 4.7), despite recognising themselves already in the role from today's perspective. As one interviewee put it: *"because it happens so gradually, it's difficult for me to be honest, but I definitely (...), I don't know (...) six, seven years like that"* (T19_5).

To arrive at this aspect from a qualitative research perspective, the open narrative prompt on how the care situation came about was used as a starting point to draw conclusions from the narratives about which aspects are seen as decisive for the assumption of care from today's perspective. In this way, structures of meaning and relevance can be clarified as they arise for the interviewees.

In the group of participants who report a sudden entry into care, the assumption of care usually begins with a sudden deterioration in the health of the person in need of care. Triggered by a fall, a stroke or a serious diagnosis, an unexpected need for support arises. While some of the interviewees had already decided years earlier that they would (co-)provide care in the event of a need for care, others only decided to support their parents at the time of the health impairment. These participants identify themselves as family caregivers from this moment on.

With a gradual onset, on the other hand, the need for support increases slowly and sometimes unnoticed. Often, the primary focus is not on a specific illness, but rather, for example, impaired mobility or an increasing lack of strength, so that support in the household appears necessary from the perspective of one or more actors. Diseases that can have a slow progression, such as dementia, are also found in this group. One participant described how she noticed a change in her mother, and the associated need for support, but only associated a possible dementia illness with it a year later: *"But something was wrong with my mother, until we thought 'Wow, it could be dementia', a year had passed"* (T20_5).

Two other participants also described how the current care situation became acute due to the death of the spouse of the person now in need of care and how the care situations merged seamlessly. In both constellations, the parents cared for and supported each other.

It was clear that the parents, even if both were severely restricted, adapted well to each other as a team and were able to compensate for or cover the support needs of the other. One participant described this with the following words: "*Well, it's the story of a blind, a deaf, and a mute. (laughs) So according to the principle. So mom's hearing is very, very poor [...] but her mind is really up to scratch and she's tiptop [...] With dad, he doesn't have combat dementia, but he does have dementia where he can't be alone. [...] And everyone does something for each other to a certain extent"* (T7_5). With the death of a parent, this intrinsically functioning system then collapsed, which led to the children (i.e. the study participants) who had previously only supported their parents a little becoming more involved in the care from this point onwards. Only in retrospect did they begin defining themselves as family caregivers: "*So for my mom, I can say it was dominant in that, of course, after dad died, it was then exclusively about mom, so to speak. Before that, it was a bit more diffuse"* (T19_5).

4.2 Type of Activities at the Start of Support and Care

These briefly outlined differing starting situations at the beginning of care also revealed differences in terms of the activities that family caregivers took on at the beginning of care. For example, the interview evaluations showed that, while the sudden-onset group often took on care directly, so-called hands-on activities from the outset, the other group tended to only perform smaller household tasks at the beginning. For example, one participant described how she gradually took her parents' laundry home to wash and went grocery shopping for them. Housework or accompanying them to important appointments were also repeatedly mentioned in this context. It should also be emphasised that providing company and the opportunity to participate in society were activities mentioned exclusively in this gradual-onset group. The social or societal withdrawal of parents was seen here as the trigger for an initial need for support.

However, activities could also be identified that were undertaken by members of both

groups. These include, for example, obtaining information, particularly on statutory benefits or medical care. For the gradual-onset group whose or those who did not (yet) define themselves as family caregivers, it may have been a matter of searching for explanations for their parents troubling behaviour or initial considerations about how to help aging parents with certain tasks. The actors in both groups also began to organise and, in some cases, accompany their parents to appointments.

4.3 Distribution of Tasks within the Care Network

As explained above, with an increasing need for support or care, new tasks arose or additional ones, in the context of home care, and had be taken on or organised by family caregivers[3]. With regard to the groups of sudden and gradual onset, differences in the distribution of tasks in the private network became clear.

Interviewees who reported a sudden entry into care described the sudden changes as an exceptional situation. From one day to the next, many activities arose that were perceived by the interviewees as care activities. These new tasks tended to be divided among those involved. Although the distribution of activities within the potential support networks depended on various factors, such as distance or the relationship to the person in need, most of the activities that suddenly arose and for which no one had been prepared seems to have led to several members of the network feeling responsible and figuring out how to contribute.

In contrast to this description, a slow entry into care means that the tasks were gradually taken on. As will be explained in more detail elsewhere, some family caregivers were unsure of which tasks they (must) feel responsible for and which tasks the parents can (still) continue to do themselves. In this sense, both the tasks and the identification of the family caregivers themselves were unclear. For example, if they did not identify themselves as family caregivers or if the parents were not perceived as being in need of care, it also seemed to have been more difficult to specify the tasks involved and distribute them accordingly. Due to the lack of designation as care, there did not appear to be a *phenomenon* that could be divided up. As the tasks in these constellations tended to be more gradual, it could also become more difficult to identify the point at which support from other family caregivers, such as siblings, was required. Physical distance or the relationship with the parents played a particularly important role in the early phase of support for the gradual group. Family caregivers who were nearby more often seemed to be in a better position to recognise a need for support, e.g., that housework was becoming difficult for the parents. The children would then do this on the side when they dropped by and sometimes did not see this as care. In this way, they took on more and more tasks over time.

[3] There may be differences as to who identifies which activities as necessary. Due to the limited scope of this study, it is not possible to go into this in more detail.

In summary, it could be seen that when care suddenly starts, the unexpected tasks that arise tended to be shared between several family caregivers, also due to the sudden volume of need. The exceptional situation appears to have overridden previously established intra-family patterns of taking on responsibility. On the other hand, these pre-existing patterns seemed to become more entrenched as the need for support slowly increased and people who were already more involved in care or felt responsible for taking on the tasks themselves gradually took on more tasks. This may also be attributed to the type of activity, among other things. For example, the activities involved in gradual entry tended to be housework, which were less often perceived as *traditional* care.

However, the disruption of established habits within the family associated with a sudden onset of care in which, for example, all the children participated in providing support after a fall, appeared to be only temporary, at least in some family constellations. While the sudden onset was perceived as an exceptional situation, families sometimes fell back into familiar patterns as soon as the situation improved or routine set in. This was exemplified by the statement of one interviewee: *"it [is] a bit difficult because basically the previous relationship and power constellations, I would say, have started to re-establish themselves within this family. [...] And it's going back to the way it used to be"* (T2_3-5).

4.4 Making use of Professional Support

While the previous chapter focused on the distribution of tasks within the private network, this chapter will look at similarities and differences in the use of professional support. Sudden-onset caregivers made use of a higher level of professional support from the outset. The interviewees assigned to this group were more likely to use a care service, day nurses, and support from so-called live-ins[4].This can be attributed to the fact that, as explained above, this group also took on hands-on activities, in particular, from the outset. These are the types of activities that eventually are more likely to require professional support. However, it also seemed to be the case that gradual-onset interviewees, who slowly take on household and then care activities, also made less use of professional care over the long term.

Accordingly, the sudden-onset group was more concerned with organising a suitable form of care from the outset. With the sudden onset and the excessive demands described, they actively looked for care homes and considered partially assisted facilities, among other things. The family caregivers who gradually took on more and more tasks did not mention such

[4] With reference to Aulenbacher et al. (2021), Schabram and Freitag (2022) defined the term *live-ins* as people "who are employed in a private household and also live there […]. The term comes from the English language and refers to the correspondence between the place of work and place of residence. The terms 24-hour caregiver or simply caregiver are also commonly used" (Schabram and Freitag 2022, p. 15).

considerations. Inpatient facilities were not a concern at the beginning. Instead, they mentioned wanting to enable their parents to age at home for as long as possible. They often expressed uncertainty about the right time to take such a step. One interviewee reported on her communication with an inpatient care facility: *"Since [in the care home] I have to let them know every January whether he should stay [at home] or not. And I've been sending them this email regularly for seven years: It's still okay thanks"* (T20_53). In the course of care, considerations about inpatient facilities were discussed in individual cases and usually in connection with events that represent a major break in the care situation, for example, a (sudden) deterioration in the condition of the person in need of care or a strain on the family caregivers.

4.5 Challenges at the Start of Care

There were also similarities and differences between the two groups with regard to the challenges faced by the participants. For example, the sudden-onset group experienced the speed at which the demands were placed on them as particularly stressful. One of the participants summarised this as follows: *"What was and is super blatant is simply the speed at which these things, so to speak, so I'll put it this way, the speed at which these things came at me"* (T2_31). This was associated with the challenge of having to deal with many activities at the same time and the associated (sudden) concern for loved ones. Accordingly, many of the participants described how difficult it was to support their parents in this stressful situation and to find a suitable way of dealing with it themselves.

On the other hand, interviewees belonging gradual-onset group described how difficult it was for them to figure out how much support the parents needed at the beginning or in the process of taking responsibility for their care. For example, parents tended to be overburdened in specific areas and, especially when parents refused support, family caregivers did not know where they could or should intervene. The situation with person's health and the degree of independence rarely improved. Family caregivers experienced a slow physical and mental deterioration of the parents in the course of the care biography, which they had to accompany, as one participant put it: *"then the process was so gradual that it got worse and worse"* (T9_3). While the state of health certainly can improve after a sudden fall, for example, the interviewees gradual-onset group said improvements were rare or that they assumed the situation would not improve: *"And everyone knows that dementia doesn't get better"* (T4_79). This in turn led to the challenge that both groups faced: Almost all of the interviewees discussed the psychological and emotional aspects of dealing with the care situation and with their parents' ailments and illnesses.

This was illustrated by the following quote*: "So the most difficult thing, that's still the case now, is that my mom—has such an attitude. Now she… Well, in this case, because I'm there,*

she's a burden, and she's so whiny. [...] And that always really freaks me out. And sometimes I can swallow it. But it's a mother-daughter thing [...] that kind of thing, it takes a realty sucks me dry" (T19_19).

This also clearly distinguishes private care from professional care: Not only the demarcation of the activity was perceived as difficult; the fact that the people being cared for were part of decades-long dyadic relationships, where often also emotional closeness and concern play a role: "From the professional to the family caregiver, it is important to realise that there is a world of difference. That one has nothing to do with the other. [...] And that is sometimes irritating and sometimes, it's a total mishmash and you really have to find your way around it first" (T5_33-35).

Regardless of whether the assumption of care was based on normative obligation, emotional attachment or the desire for reciprocity, the family relationship was the decisive factor for the assumption. This involved not only a biological relationship, usually, but also a shared or family biography that shaped the care setting and the assumption of responsibility. In this sense, finding one's own role with its tasks and responsibilities in a new structure, in which the parents increasingly need support, was also described as challenging. In the interview, one participant commented on this as follows: "*the challenge was just also // that she was very insecure, that she was also more anxious and rather unsure, and we first had to find out: How is this going to work? Then it's the mother-daughter thing. At first it was a total role reversal; before, she was the worrier and she was in charge, 'yes mom,' and now suddenly I have to look after my mother"* (T16_59).

4.6 Developments in the Further Course of Care

While the previous chapters focused in particular on the initial phase of caregiving, this chapter will look at the extent to which the initial phase shapes the further course of care. In order to assess the following results, however, it must be emphasised that the family caregivers were in different phases of care at the time of the interview or had been involved for different lengths of time.

In the group of interviewees with a sudden start to caregiving, it is clear that they perceived the start of caregiving as an exceptional situation in which the family rules and division of tasks were suspended (chapters 4.2 & 4.3). As time went on, it became clear that this situation, in which the division of tasks appeared to be shared between several people, is not necessarily permanent. Over time, old patterns of family division of labour crept in (again), so that old relationship dynamics—perceived as destructive—also came to the fore again. One interviewee gave a vivid description of how she was very supportive of her parents during her father's stroke and her mother's cancer diagnosis, and also felt valued in this relationship system. However, as her father's health improved, old patterns returned and she felt excluded

from the system. As a result, she withdrew out of self-protection: *"And that's why I keep asking myself how [...] this will continue and how I can really bring everything down to a minimum level, the support of my parents, so that it is mentally and emotionally okay for me"* (T2_3).

The situation was different for family caregivers who had slowly grown into the care situation. In these interviews, the family caregivers reported that the care routine helped to stabilise the network and the division of labour. Nevertheless, this group also perceived the care situation as dynamic, in which slight adjustments (have to) be made again and again due to changes in the parents' state of health.

4.7 Barriers to Self-identification

As shown, the self-identification of family caregivers played a central role in the context of the start of care and the use of support. In some cases, caregivers only availed themselves of support after this self-identification. It may also be important to differentiate between self-identification and merely presenting or describing oneself as a family caregiver to the outside world. However, since no such differentiation was made during the interviews, this distinction cannot be discussed further below. The interviews did reveal a number of barriers to identifying as a family caregiver, nevertheless.

Barriers linked to the activity became clear, on the one hand. For example, the classic hands-on activities were predominantly seen as care, while all other support services were less often associated with this term. This view became particularly clear when other family caregivers took on these activities and the interviewees mainly performed administrative tasks. Both in these contexts and in constellations in which other people invest more time in care, it was difficult for the family caregivers interviewed to describe themselves as family caregivers, as they themselves, according to their interpretation, only provided additional support. In this context, individual interviewees seemed to have an inherent image that only allows one person to be a family caregiver.

Another barrier—also related to the type of activities or the understanding of care— was the (normative) self-image of support within the family. Particularly at the beginning, when only a few tasks or, as described above, a few specific activities were undertaken, these were not defined as care. The activities and the effort involved were discussed as a matter of course; they were unquestioned. This was exemplified by the following quote from an interviewee: *"We don't present it as care when my cousin, my father, goes to physiotherapy or something. [...] And then they say 'oh, then we'll go to the DIY store or something later.' That's not perceived as care or anything"* (T12_147).

A further obstacle was related to the negative associations associated with the term "care dependency." Both with regard to their own designation as a family caregiver and to the person in need of care, the term as such was avoided. With regard to their own situation, it appears

that this was partly in the hope of maintaining a distance from the tabooed and negatively connoted topic. Parents, too, had to be protected from the entire topic—by avoiding the terminology—in the hope that they would not have to face it. In this context, the negatively connoted term must not be associated with the person. In some cases, certain statements by the interviewees could be interpreted to mean that they were afraid the term itself could change the parents' inner attitude and behaviour: The expectation being that such talk would lead to a deterioration in their state of health.

5 Interpretation of the Results

In the following, the results presented descriptively in the previous chapter will be interpreted against the background of the current state of research and the need for further research will be highlighted. In a first step, the commonalities identified between the groups differentiated in Chapter 4 will be highlighted before moving on to the processes of entering care and self-identification in light of the current state of research.

5.1 Identification of Similarities and Differences and between Sudden and Gradual Entry into Care

Just as the literature essentially identifies two possible paths into care (Kaspar et al., 2019), a distinction was also made in this study between a gradual and a sudden entry into care (Chapter 4).

The comparison between these two groups illustrates fundamental differences in the way family members experience the start of caregiving, the activities they perform, and the challenges they face. This not only results in different needs, which should be taken into account when providing support services, for example (Chapter 6.2); it also shows how central this phase appears to be for the perception and self-image of family caregivers. The findings thus support the need for research on this topic, which has also been emphasised several times in the literature (e.g., Funk, 2021; Eifert et al., 2015; Chapters 2 & 6). Furthermore, combinations of these two exemplary paths into care have been presented in practice and in the interviews; thus, the heterogeneity among family caregivers and the unique nature of their care biographies is also evident (Brandt et al., 2022).

In addition to these differences, however, there are also similarities between these groups, which could be found among almost all the family caregivers interviewed in the study. Overall, it can be seen that both groups have high demands for information at the beginning and invest time and energy in searching for it (Hudelmayer, Schütz & zur Kammer, 2023; Chapter 4). Family caregivers who do not (yet) see or describe themselves as such also need information. This includes the search for information in the event of troubling parental behaviour, for example, or looking for support with household tasks. Funk's (2021) findings reinforce these

results, emphasising the need to prepare information in such a way that it can be found by and also appeals to both groups.

Another common aspect that ran through almost all of the interviews was the challenge of dealing with the care situation or the parents on a personal-emotional level. This is already evident from family caregivers' characteristics. All of our interviewees had a personal/familial relationship with their parents in need of care, which was also the reason for taking on the care. The relationship also shaped and influenced the care process and was named as a decisive factor in the stress experienced in the care situation. Reasons for this included high personal expectations and a strong focus on the wishes of the person in need of care (Schütz & Hudelmayer, 2023). It became apparent that with the entry into care, on the one hand, the need for care changed old and established patterns of behaviour in the family. On the other hand, the relationship was clearly shaped by the shared past. Interpretations may differ between the family members and (future) people in need of care. On one side, this process changed the family's' support roles, which were now directed towards the parents; on the other, the relationship remained strong, and closeness was shaped by the (shared) past. These old and new demands may therefore clash and lead to an emotional challenge. In addition, the interviewees also felt burdened by worrying about their parents in crisis situations and by witnessing the deterioration in their health and thus worrying about how long their parents will live (Chapter 4.5).

In summary, the results indicate that emotionally coping with the care situation and dealing with parents is a key challenge. The interviewees expressed a desire to have the option of contacting help to accompany the process and provide guidance during this phase. These results also support work by Kaspar et al. (2019), who also emphasised that the need for flexible accessibility of a specialist was expressed in their research, especially in times of crisis. While support services have so far mainly focused on passing on information, such as care advice (Wolff et al., 2023), our results indicate that it is also important to discuss (new) ways of dealing with the support situation and family relationships. Sharing experiences with other family caregivers could also play an important role here. However, the interviews already indicated that, so far, this has played only a limited role in family caregivers' everyday lives of, partly because the topic tends to be taboo in society as a whole.

5.2 Determinants of Care Pathways: Key Events at the Start of Care

The literature presents an inconsistent picture of when caregiving begins and when family caregivers are perceived as such by others and/or identify themselves as such (Chapter 2.1). The phase models presented as examples by Kaspar et al. (2019) and Moral- Fernández et al. (2018) describe the start of the process with the assumption of the first activities assigned in the context of care at a certain point in time or retrospectively. Montgomery and Kosloski

(2013) specified that these activities go beyond the normal scope of the original family role. This already highlights the importance of intra-familial or individual expectations and practices that shape how one interprets their entry into caregiving (ibid.).

However, the interviews showed that when family caregivers were openly asked about the start of care, they talked about how their motivation to provide care came about or what their attitude towards care was like before the need for care arose. They also talked about how it may have changed over time. Thus, family caregivers saw these topics as relevant and worth mentioning, at least in the extended context of the start of care, because they established a connection to the care situation in the interviews. The present results thus confirm the perspective laid out by Keating et al. (2019), who have argued that the care process should be defined more broadly and not be limited to the phase of classic hands-on activities or the assumption of externally visible activities. This point can be confirmed by the need for research emphasised by Funk (2021) to accompany the entry into care with qualitative studies in order to identify the early phases of care and the process of first taking over activities. Based on our results, this wider perspective on the start of caregiving importantly also covers the mental load[5] that may already be growing before the assumption of visible practical activities. For example, thinking about care and the associated considerations are part of the preparation for future care (Sörensen, 2021). And although Sörensen (ibid.) concluded that few people deal with the topic of care in advance, our interviews made it clear that some family caregivers did entertain potential care before taking on practical activities and also acted and made decisions on based on such forethought.

In addition, our empirical results make it clear that the start of caregiving by family caregivers does not necessarily run parallel to the path to care dependency. This was shown in the two interviews cited above (Chapter 4.1) where the children (daughters) were next in line to take over care. Indeed, both reported becoming (primary) caregivers of the remaining parent following the death of the other parent.

5.3 Differences with Regard to Self-identification and the Definitions of ‘Care’

The results of this working paper reflect many aspects that have also been identified in other empirical studies and taken up in this paper as part of the state of research (Chapter 2.2). The present results also enable a more differentiated view by providing a more in-depth insight through the comparative evaluation of family caregivers with a gradual or sudden onset of care.

[5] *Mental load* has been defined as “the thinking, planning, scheduling and organizing of necessary everyday tasks, as well as the feeling of having to take care of or be responsible for them and the emotional consequences of this work” (Lott & Bünger, 2023, p. 3 with reference to Dean et al., 2021). *Mental load* is a concentration of cognitive and emotional work that is perceived as a burden or overload (Dean et al., 2021).

Our evaluations thus allow conclusions to be drawn about the kinds of barriers that affect which groups in particular.

The study results underline that the duration of the process, as reflected in the literature (O'Connor, 2007), was particularly relevant for the group whose entry into care can be described as slow or gradual. Various reasons for this have already been covered in Chapter 4.2. It became clear, for example, that the type of tasks undertaken by these family caregivers plays a central role. They increasingly took on domestic tasks, which are less often regarded as traditional care tasks. The comparatively rapid self-identification as a family caregiver in the group of sudden caregivers was due not just to the type of activities but also to the increased use of professional support and contact with medical and nursing professionals[6]. The aforementioned reasons for a sudden onset of care, such as a fall or a diagnosis, result in more frequent visits to clinics, rehabilitation facilities, etc. People are then addressed as family caregivers in these contexts and are almost automatically referred to support services for family caregivers (Hudelmayer, Schütz & zur Kammer, 2023).

Another central aspect mentioned by family members retrospectively as a reason against self-identification with the caregiver role was "protecting" the person in need of care. While the literature has primarily addressed the aspect of protecting a shared identity that may be threatened by formalising and designating the relationship as a caregiving one (Eifert et al., 2015; Hughes et al., 2013; O'Connor, 2007; Chapter 2.2), our interviewees focused on the desire not to confront the person with their need for care (Chapter 4.7). The focus on non-confrontation may be due to the fact that only the children, especially the daughters, of the person in need of care were interviewed in the study, and not the persons' spouses (Chapter 3). It appears relevant to differentiate the relationship in this context, as described in Chapter 2.2. The interviewees repeatedly mentioned that they found it difficult to give up their previous relationship with their parents, especially at the beginning. One interviewer noted that she felt uncomfortable and embarrassed about everything she does for her parents. As exemplified here, there is a risk that such embarrassment could lead to a lack of recognition for the care activities that family caregivers take on (Chapter 2.2; Moore & Gillespie, 2014).

On the other hand, the interviewees hoped that designating the care would prevent the cared-for person from being confronted with their need. One participant justified this with the hope that it would have a positive effect on her father's health if he were spared from thinking about his age or his need of care.

The barriers mentioned so far indicate that the terms "care" and "care dependency" as well as "family caregivers" are explicitly avoided within some care networks and externally, but

[6] In this context, it should be noted that family caregivers who saw themselves as such also availed themselves of professional support more often.

that the family caregivers were at least partially aware of this. It is not clear from the study results whether and to what extent this was a protection from the outside world, or to what extent they did not see themselves as such. If they did identify as family caregivers, potential for support-seeking behaviour rises, at least theoretically, even without the corresponding external designation. This proved to be more difficult if the interviewees did not see their support in the context of care at all. This applies in particular to activities that relate to support with everyday chores, such as washing and cleaning. These activities, in turn, were mostly found among participants whose entry into care was described as gradual (Chapter 4.2).

There are many possible reasons for this rejection of the term care, which have been mentioned both in the literature and in some of the interviews. These include, for example, a narrow understanding of care to refer to hands-on activities and not organisational or domestic support (Franke et al., 2019, Hielscher et al., 2017; Chapter 4). In addition, support with these activities was sometimes taken for granted within the family. In this context, ideas about how families should be and function and which expectations are associated with which people are important (e.g., Brandt et al., 2022; Eifert et al., 2015; Funk, 2021). In the interviews, further aspects became clear as to when care is spoken of in this context. This could be, for example, a diagnosed illness or support that exceeds a certain limit in terms of time or emotional demands. This aspect was not explored further in the interviews, but it appears to be relevant for further studies.

6 Summary and Practical Implications

This working paper has focused on the beginning of caregiving and the early caregiving phase in order to examine the question of how family caregivers experience the start of care and self-identification process. The focus has been on how they retrospectively perceive the process of taking responsibility for care, which activities they take on at the beginning of caregiving and which challenges they are confronted with.

Based on a key finding of the DiVa study (e.g., Schütz & Hudelmayer, 2023) that the start of caregiving is of central importance for the organisation and use of (digital) support, qualitative interviews were evaluated through the lens of the start and the early caregiving phase. The relevance of this phase became clear on several levels:

- On the one hand, the interviewees mentioned a great need for information at the beginning of care, which results, among other things, from the multitude and complexity of the requirements with which they are confronted in this new situation. At the same time, they were uncertain as to who they could turn to with questions.
- On the other hand, the family caregivers reported that they had initially lacked strategies and ways of accessing information and managing administration and coordination.

The interviews thus revealed not only a high need for support but also an openness to accepting support services in navigating the new and confusing landscape of care (Hudelmayer, zur Kammer & Schütz, 2023; Schütz & Hudelmayer, 2023). Against this background, the start of care also appears centrally important to the way forward.

Nevertheless, with regard to the current state of research, there are relatively few articles that have explicitly dealt with the path into care or focused on it. Various authors have called for further study on the topic. Empirical challenges have also been identified, as this process usually can only be studied retrospectively (Chapter 2). Concepts and models that describe the care process or entry into care equate the beginning with the assumption of initial care activities (often a hands-on activity). At the same time, some studies have addressed the question how much people prepare themselves for future care situations. These authors have argued for a broader understanding of care beyond the assumption of externally visible activities (Chapter 2.1). The identification of family caregivers has been examined in the literature primarily with regard to the question of how the self-identification of family caregivers can be promoted and which barriers exist in this context, as identification is seen as a prerequisite for accessing support (Chapter 2.2).

The results evaluated with the help of qualitative content analysis (Chapter 3) have been presented here using two exemplary courses of events, a sudden and a gradual entry into care. Similarities and differences between the two groups were identified (Chapter 4) and will be summarised in the following.

Presentation of Results: Differences between Gradual and Sudden Onset of Care

With regard to the activities at the start of caregiving, it can be seen that the group that described the start of caregiving as rather gradual or step-by-step mainly took on household tasks and rarely performs hands-on activities right from the start. They explained that they gradually took on more and more activities for their parents and thus became family caregivers, sometimes unconsciously. Both the type of activities and the gradual addition of individual activities can be identified as the reason why this group sometimes only saw themselves as family caregivers at a late stage, as the interview participants described when looking back on their entry into caregiving. In comparison, family caregivers who started caring suddenly tended to see themselves as caregivers from the outset. This can be attributed to the fact that they increasingly took on activities that are traditionally considered care. On the other hand, sudden entry was also more likely to be associated with stays in hospital and/or rehabilitation facilities. In their interaction with the professionals there, they were not merely addressed as family caregivers but also given information about care-related services and assistance, which in turn can impact their self-image (Chapter 4.2).

There are also differences between these two groups in terms of support from the

private network. While the interviewees with a sudden onset of care in this exceptional situation divided up the many tasks that arise all at once, there was rarely a concrete reason to involve the potential participants of a care network for the tasks that arise in the case of a gradual onset of care. Instead, the everyday tasks that gradually arose were taken over by one person. A similar picture emerges with regard to the use of professional support. Among the study participants, the group describing a sudden onset of care was more likely to use outpatient services and day care (Chapter 4.3 and Chapter 4.4).

Presentation of Results: Similarities between Gradual and Sudden Onset of Care

In addition to these differences, however, there are also similarities with regard to the entry into care and the associated challenges. For example, almost all family caregivers described feeling challenged on a personal and emotional level by caregiving. This referred to both the concern for family caregivers and the associated helplessness as well as the relationship level, which changed in the context of a changing dependency and support situation. In this context, the interviewees also repeatedly mentioned biographical experiences and associated emotions that seemed to become relevant in the context of early care. This addresses the core of home care: the personal relationship with the person in need of care. As is known from empirical studies, this relationship is what shapes the entire care situation and, as these results illustrate, also the beginning of care. As the personal relationship and the relationship of care and dependency shifts particularly strongly in this phase, this seems to be a particular focus (Chapter 4.5).

Another common feature associated with this is the desire for a contact person to whom family caregivers can turn with concerns, even minor ones, particularly but not exclusively, at the start of care. In addition to specific information about the care situation, they were also essentially interested in being able to talk about the relationship and concerns of the person in need of care. This desire may also result from the emotion described several times by the interviewees of feeling alone or being abandoned in and with the care situation.

With regard to identification as a family caregiver, the results show that there were obstacles at different levels. They ranged from a conscious rejection of this identity in order to protect the person in need of care, to protect the shared relationship, or to protect themselves all the way to unconscious identification—if the activities are not assigned to care, for example.

In this context, the results of the study indicate that the group with a slow, gradual entry into care in particular tended to find it more difficult or later to identify themselves as family caregivers and were less likely to make use of private or professional support. This is not least because, due to their specific care needs, they were rarely in contact with medical and nursing professionals who, on the one hand, addressed them as family caregivers and, on the other, pointed them towards further help.

Due to the exploratory character and the small sampling as well as the data basis not explicitly collected for the present research question (Chapter 3.3), our working paper can only provide initial starting points. However, it illustrates the relevance of the topic and need for further investigation in this field. Further studies should focus on entry into care from a broader perspective that does not begin with the assumption of care responsibilities.

Conclusions and Implications for Research and Practice

Against the background of the importance of the start of care for family caregivers, this study has identified similarities and differences between the group of family caregivers with a sudden and gradual start of care. The study thus addresses an identified knowledge gaps, and in doing so it points to the need for further research in this field. Implications for professional practice and research can be derived from the results of this study.

Implications for Practice

There are numerous reasons why family caregivers, especially spouses and partners of the person in need of care, do not identify themselves as family caregivers, or only at an advanced stage of the care process.

> *Support services should therefore be aimed at both those who identify as family caregivers and those who do not see themselves as family caregivers. In particular, it* ***should be examined in the future how information services*** *can be designed so that they are also appealing and easy to find for those who do not identify as caregivers.*

With regard to the support options for family caregivers, it is clear that the group that gradually takes over care tends to seek professional help later and less frequently in the study. This is partly due to the fact that they are less likely to be in hospitals, rehabilitation facilities, or with medical specialists at the start of care and can hardly be made aware of support services there.

> *For family caregivers with a gradual entry into care,* ***alternative places to medical and care facilities should be identified*** *where they can be made aware of support services. To do this, it is necessary to* ***identify the key events*** *for this group and align the support services with them.*

Almost all family caregivers identified caring for the person in need and the relationship dynamics resulting from the changed support and dependency relationships as a key challenge at the beginning of caregiving. In this context, there is a desire for optional contact with people trained to accompany the process and provide orientation and exchange.

> *Support and advice services should increasingly* ***address (new) ways of dealing with the care situation and family relationships****. With regard to the desire for trustworthy contact persons for exchange or for questions, one avenue could be to see how likely* ***support groups with other affected persons/former family caregivers*** *could be to help to relieve the burden.*

The path to care dependency can, but does not have to, run parallel to the start of care for family caregivers: The death or loss of a parent, for example, can lead to the collapse of a functioning care system whereby the children/daughters suddenly become family caregivers.

> *Support and information services must therefore not (exclusively) be geared towards the course of the illness of the person in need of care; systems must (also)* ***take into account*** *the* ***individual care biography of the family caregivers*** *in order to provide them with targeted support at an early stage.*

Implications for Future Research

The results confirm the need for more information identified in relation to the start of care and self-identification as a family caregiver and point to a need for even further research as well as challenges ahead.

The results show that the majority of family caregivers do not identify themselves as such, or only do so at an advanced stage of the caregiving process. For survey research, this poses the challenge of identifying this group at an early stage in order to recruit them for surveys.

> ***When recruiting family caregivers for studies, there is a need for alternative ways and possibilities to identify family caregivers*** *prior to the process of self-identification in order to be able to map events and burdens in this phase. To this end, self-descriptions and key events must be identified and integrated into surveys.*

The results show that the concept of care often conceals a narrow understanding of care that is reduced to hands-on activities. In addition, the term has negative connotations, so it is sometimes rejected by family caregivers and those in need of care.

> *In order to also identify family caregivers in the early stages of care and those who mainly perform domestic tasks,* ***alternative terms to "care" and "persons in need of care"*** *must also be* ***used*** *in the surveys and calls for participation in the study*.

While the start of care has so far often been equated with the assumption of initial care activities, when interview partners were openly asked about the start of care, they referred to their motivation for taking over care and thus to the fact that they are now in a position to provide care related decisions in the context of the planned/future assumption of care.

> *Future research should* ***take into account*** *the* ***broader context in which the start of caregiving occurs*** *in order to be able to map both the (mental) preparations for caregiving and the associated stresses.*

Late self-identification as a family caregiver means that they can only report retrospectively on the start of their caregiving, if at all. This means that the reports on the early phases are always influenced by the later or current care situation.

There is therefore a need for (qualitative) studies that ***accompany the process of care entry*** *and thus record the early phases of care and the process of taking on initial activities*.

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