



# Designing for Those who are Overlooked – Insider Perspectives on Care Practices and Cooperative Work of Elderly Informal Caregivers

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## ABSTRACT

This paper focuses on the complex and intimate setting of domestic home care. The majority of care for chronically ill people is realized by *non*-professionals, the relatives, who are often overlooked. Many of these informal caregivers are also elderly and face multiple, seriously demanding challenges in the context of informal care 24/7. In order to support this increasing user group, their cooperative work and coordination adequately, it is essential to gain a better understanding of their care practices and needs. This paper is based on ethnography in ten households in Germany. It combines data from the analysis of participant observations over eight months, interviews and cultural probes. Besides detailed descriptions of two cases, the central features of informal care experience and implications for design are discussed: the self-concept of the caregivers as being care experts, the need for social support, timing issues and coordination with other actors in this field.

## Author Keywords

Aging society; caregiver; cooperation; health; ethnography

## ACM Classification Keywords

D.2.10 [Design]: *Methodologies*.

H.5.2. [User Interfaces]: *Theories and Methods, User-Centered Design*.

J.3. [Computer and Society]: *Computer-related health issues*.

## INTRODUCTION

That the population is aging is a statistical fact for many countries worldwide: one in every nine people in the world is 60 years of age or older, and the projected number of people over the age of 60 will reach 2 billion by 2050 [62]. Along with this development, the proportion of elderly people that have to cope with physical and mental limitations or even chronic diseases that necessitate care

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will also increase (for Germany, see [18]: 356-362, [19]). Healthcare expenditure throughout western countries has reached significant levels. The United States spent 18% of their gross domestic product (GDP) on health care in 2013 [12]. In six EU member states (France, the Netherlands, Germany, Denmark, Belgium and Austria) it exceeded 10% by 2011 [17]. The majority of care in Germany is still realised in the private homes of the patients, in most cases by their relatives (spouses, children, etc.): In 2011, two thirds of the 2.5 million chronically sick were cared for at home, against just 30% in professional care institutions [19]. There are several reasons for this: Firstly, the public finance and infrastructure available struggle to meet increasing demand. Secondly (and understandably), many elderly, chronically ill people choose to stay at home in familiar surroundings where they can be cared for by their relatives. Thirdly, the cost of care in a nursing home in Germany, as elsewhere, (see [41] for a comparative review) is nearly twice as high as the cost of home care combined with external care services (e.g. [58]).

The research we describe below is an interdisciplinary research project (“TOPIC”, The Online Platform for Informal Caregivers) undertaken with information scientists, sociologists and media scientists together with partners from professional care institutions. The overall aim of the project is to understand the care practices of informal caregivers and how they relate to opportunities for support by designing a web-based care platform that could integrate various services, including information provision, social networking and coordination tools (e.g. a digital calendar). In this paper, we present the results of a qualitative study conducted in the early phase of the project, investigating the following research questions: 1) The Practice: What are the major characteristics of the routine care and the coordination work of informal caregivers?; 2) The Problems: What are the main issues with which elderly informal caregivers are faced when practicing care?; 3) Challenges & Opportunities: What are the most important challenges for the caregivers in respect to their own well-being? and 4) The Design: What implications for design can we make from learning more about care practice? In our paper, we will present and discuss results from our data analysis of participant observation conducted over eight

months, along with open and semi-structured interviews and cultural probes. After describing the data collection methods used, we will describe two cases in which our informal caregivers and their care situation are detailed. In relation to our first three research questions, the following section will deal with the central features of informal care experience: (I) the self-concept of the caregivers as care experts; (II) their crucial need for social support and (III) timing issues and coordination with other actors. Along with the features, implications for design for such complex situations will be presented and discussed. This work contributes to CSCW not only by providing fine-grained understanding of the work of caregivers and the implications for appropriate support, but also through methodological reflection intended to contribute to the creation of sensitizing concepts for the general purpose of better supporting transferability of findings from a specific context, as in this case [69].

### STATE OF THE ART

Growing awareness of demographic changes in relation to the aging population has led to a blossoming of technology to support healthcare. A large body of work in the general field of health care, and more specifically around coordination and cooperation in domestic home care, now exists. These works contribute both to a better understanding of how healthcare is collaboratively achieved, and to the designing of assistive technologies to support the caregiving. Designing in this field faces subtle yet complex challenges and normally requires a comprehensive requirement analysis and a tailored methodology [20]. Recent research within the CSCW/ HCI purview spans a large spectrum from professional care centres, e.g. hospitals, to the support of individuals suffering from chronic diseases in their own homes. ICT development for institutional care tries to support the intrinsically cooperative manner of institutional care, such as in the case of the introduction of Electronic Patient Records (EPR) [33]. In the home context, research has focused on empowering people so that they can live at home as long as possible (ageing in place). Such work is focusing increasingly on supporting social interaction and the sense of belonging for the elderly [23, 35, 47, 63, 66] in order to for them to continue living independently, even in circumstances where older people experience cognitive and/or physical decline.

Recent studies on healthcare technologies have moved towards a better understanding of the socio-technical facets of the problem [2, 6, 20, 36]. For home-based healthcare, for instance, themes have evolved around the communication and cooperation needs of various stakeholders in chronic illness treatment [5, 42, 51, 53, 56, 61, 70], for example through support for coordination work within a family with the help of digital calendars [3, 4, 5, 12, 34]. Some recent research has shown (in a randomized study) that a group of informal caregivers with access to online support were less likely to suffer from clinical

depression than those who did not [39]. It has been shown that the values and attitudes of each stakeholder play an important role in appropriation and usage of ICT [3]. Research work in the context of cognitive issues has aimed at key problems such as the role of various stakeholders in the care process and has dealt with such issues as “whereabouts” or “biographical” awareness [1, 13, 48, 49, 68] and monitoring [15, 43, 54].

According to the statistics, it is also a fact that informal caregivers do a significant amount of work, and research has shown that such caring places a significant burden on caregivers (see e.g. [9, 14, 16, 40, 65]). Eckwall et al. are primarily concerned with quality of life issues and derived results from a postal survey, as did Van Ruyn et al. In the latter instance, in a study of the care of cancer patients, it was pointed out that 50% of caregivers received no training and 50% also did paid work outside the home. The authors suggest, “*Future research should explore the potentially high yield of addressing caregiver needs*” ([65]: 44) and furthermore stress that little is known about the kinds of social support or community resource that might be available to caregivers. In a similar vein, Deeken et al. [14] review various metrics for assessing caregiver needs and argue “*Many researchers have failed to explicitly define what they mean by a caregiver need.*” ([14]: 937). Such quantitative survey studies (see also [64] and [6]) go some way towards setting out at a fairly general level what caregiver needs might be and how one might measure quality of life indicators, including the stresses of caregiving or the impact of the caregiver’s personality on her/his mental and physical health [34]. There are still, however, relatively few qualitative studies with an ethnographic “sensitivity” [4, 21] or which are geared towards the longer term to fully depict the subtleties and nuances of the field, and how strikingly different the practices of caregiving can be. The studies that exist tend to focus on collaboration between the unpaid and professional caregivers [55], on the “narratives” [37, 38] produced by male caregivers, or on domestic abuse. Most pertinent for our purposes is the study by Gooberman-Hill and Ebrahim [32], which emphasizes the need to think about caregiving in relational terms.

Because of the richly situated, sensitive and continuously evolving nature of healthcare, we have chosen a qualitative research approach here (ethnography). We adopt a broadly Grounded Theoretical perspective for our work, largely predicated on Glaser and Strauss’ early formulations. Their motivation for systematizing their thoughts about qualitative research processes had been largely influenced by their observations in hospitals that resulted in “The Awareness of Dying” [26]. Their research then focused on the social and psychological problems accompanying the *care* of dying patients. They were particularly concerned with the interaction between professionals (medical and nursing personnel), the patients, and their relatives, and developed concepts such as that of the “loss rationale”.

We are proposing something similar here, in arguing that greater attention to the social and psychological issues that accompany long-term informal caregiving is needed when intending to design for this context. This type of informal caregiving is sociologically defined as *“unpaid care, both affective and instrumental, provided in the domestic or private arena, often by women and often for family members.”* ([22]: 196). The gender bias has to be qualified as there are a growing number of men that care for their wives (also comprised in our study). In including male carers, we shed light on relatives (wives, husbands or children) who have to manage a role shift to become an informal caregiver over time. Their way of dealing with these demands is basic to our understanding of the needs of unskilled caregivers who often became care “expert” over time. An important feature of this lies in the “moral career” [29] or identity construction process of caregivers as they move from an untutored position to relative expertise. In other words, how they learn to adopt a new social role and integrate this into their “role-set” [44].

### EMPIRICAL METHODS AND DATA COLLECTION

As stated, we use Grounded Theory (GT) as a research paradigm reference, meaning that we mainly share the epistemological approach associated with Glaser and Strauss’ early works [27], especially in respect to the iterative rationale of our data collection and the desire to conduct comparative work across a number of cases. In this respect, we favour the view of GT as an “abductive” rather than inductive approach. That is, the approach works to generate a “best fit” between data and theory- or category-generation rather than demonstrating a strict logical relationship between the particular and the general. This, we argue, is consistent with Glaser and Strauss’ demand for “plausibility”, and demands less in respect of the coding mechanisms later outlined by Strauss and Corbin ([10]).

The data material is based on an ethnographic stance, composed of participant observation, along with informal and semi-structured interviews. For fairly obvious reasons, there are limits to participatory observation in home care situations; so after some months, we also enlisted “cultural probes” in the sense offered by [11]. These included a variety of different methodological instruments to support self-description and self-observation (see below). The feedback to the cultural probes was considerably more positive than expected. We used this material (diary entries and pictures) mainly as a stimulus in the later interviews to encourage the caregivers to explain their entries in detail.

#### 1. Ethnography and Context Information

This paper is based on data analysis from our first phase of data collection (one year), focusing on care practices, daily routines and the needs of informal caregivers. By paying attention to the high and growing percentage of informal care situations, the research took place not in care institutions, but in the homes of ten families, living in rural areas in Germany.

Access to this private and sensitive field was very difficult to manage as our research concept aimed not just at interviews on one or two occasions (like most former studies, see e.g. [7, 9, 32, 50, 70]), but at a thorough and detailed participant observation in the homes of the caregivers. Feedback indicated that the care situation is intimate and time-consuming and can, moreover, entail embarrassing and sometimes humiliating circumstances. Linked to this was the presumption that university researchers might be too “distanced”. We eventually made contact with the assistance of “gatekeepers”: Professional caregivers from care services who have daily contact with families affected by care introduced us to families by providing our contact information, flyers etc. Interested caregivers then contacted us and we met in person.

A slow process of trust building, based on numerous meetings in the home and careful explanations of our objectives, eventually resulted in ten volunteer households. The first author, who performed the participant observations and conducted all the interviews, had prior experience with informal as well as formal care situations with patients suffering from dementia, Parkinson’s disease and multiple sclerosis. This seemed to have a positive effect on the development of relationships with the elderly caregivers. Furthermore, the researchers are experienced and trained ethnographers. These experiences also helped us to evaluate situations, react adequately and build up trustful relationships that remain on-going even after a long period.

Older age might be defined in multiple ways, using diverse criteria such as specific cohorts, generations, health issues, employment status etc. (see [22]: 18ff.). In reference to our study, we set the inclusion criteria as age (over 60 years old) and being a full-time, untrained caregiver. Our ten participant caregivers are aged between 60 and 85 years old (most of them in their late 60s), and are retired or gave up their job because of the care situation. All but three are female and had grown-up children. Two caregivers care for a parent and one for her chronically ill, grown up child, but the majority of our informal caregivers care for their spouses. Three of them have dealt with care provision for ten years now (i.e. “long-term” caregivers), the others for a period between two and four years (“short-term” caregivers). Despite these diverse characteristics, one common attribute that we are interested in is care for a relative suffering from a chronic and progressive illness without any realistic chance of recovery: dementia and Alzheimer’s disease (often accompanied by additional medical conditions such as strokes, depression or heart failure), Parkinson’s disease and strokes. We base our insights on data collected from all ten families, but mainly cite data here from eight months’ observational work undertaken with five of them: Three of these are long-term

caregivers (of dementia patients and one case of irreparable brain damage respectively); one of them will be introduced in detail later on (Mrs Wolff\*). The other two participants were short-term caregivers, one of whom will be examined later (Mrs Kunze).

Beginning in October 2013, the first author and one student assistant were engaged in observations and interviewing in the families. This tandem of researchers, one very care-experienced person with another who was less experienced, allowed us to combine and complement two perspectives, observation positions, etc. which resulted in very rich data material (field notes during the observation and observation protocols produced after the visits). It is in the nature of the domestic care situation that such observations are episodic. Typically, visits to caregivers lasted several hours a day (four or five hours on average) and entailed both accompanying caregivers as they went about their tasks and asking questions where appropriate. This participation included going to whatever location in the household where the caregiver and patient happened to be as well contact to other members of the household (like children), friends that visited and professional care staff.

In some cases, we visited the households weekly. Others we visited biweekly or once a month over a period of eight months and also alternated the days to gain a more complex insight into daily routines. Due to the inherent logic of the field and our research position, we didn't schedule the visits for the caregivers, but adapted our observation times to the caregivers' wishes. As mentioned, building trust was critical here and as relationships evolved, observation sessions became longer. Being experienced in sensitive research fields, we were aware of the need to take great care around the interplay between involvement and distance with caregivers.

Our approach, we stress, is an ethnographic [57, 21] in terms of its sensibility, seeking to uncover the meaningful practices of actors, and the attitudes and values that inform them, and combining different qualitative methods. We should mention that nearly all the caregivers in our study raised concerns about standardized questionnaires in early meetings as they associated these with the questionnaires that are used by health insurers to define levels of care.

## 2. Cultural Probes

We used cultural probes [11, 24] as an adjunct to our other enquiries, enabling a degree of self-observation by caregivers during the times that we were not around. We prepared the different probes carefully and with attention to their "look and feel". We explained to our participants that they were entirely free to use any or none of the probes we gave them. In the pictures below (Figure 1-4), some

\* All names and references from the data material cited here are pseudonyms.

examples of the cultural probes are shown: a diary, smiley stickers and Polaroid pictures taken by one of the caregivers (Mrs Wolff). The cultural probes stayed in the families for two weeks. All the families used tools from the box, in some cases across the whole of the two-week period. In most cases, the descriptions of the daily routines remained reasonably consistent over time, with just a few minor alterations in routine. Preferences varied; for example, one of the male caregivers didn't wish to keep a diary, but used the camera, the stickers and short notes, whereas three of the women engaged with the diary enthusiastically (one of them, Mrs Wolff, was writing a care diary anyway).



**Figure 1-4. Examples from the cultural probes in one family (Mrs Wolff): a diary, smiley stickers, and Polaroid pictures of care situations, external care staff, taken and authorized by the caregiver**

## 3. Interviews

As participant observation had certain limitations in the domestic context reported here, interviews were an additional choice. We conducted different kinds of interviews according to specific circumstances [21]: In some cases, interviews were informal and arose spontaneously during observation, for instance when the researcher failed to fully understand unfolding events. These informal talks were noted down in situ. In later stages of our fieldwork, we conducted loose semi-structured interviews after a) collecting the cultural probes back and b) at the end of the data collection phase after one year with each caregiver (one-on-one-interview or sometimes with both the observing researchers). This yielded an additional 20 semi-structured interviews, lasting between one and a half hours and four hours each. All the semi-structured interviews were tape-recorded and later transcribed.

The major subject areas covered in the semi-structured interview guide were based on the initial analysis carried out during earlier observations: care situation, interaction between the caregiver, care receiver, family and external care staff, mobility, time management and monitoring of the health condition of the care receiver.

#### 4. Data Material and Analysis

During the first year, a substantial amount of data was collected from the ten families: extensive field notes and observation protocols, cultural probe material, audio recordings from the interviews and transcripts. As pointed out above, our approach is based on an *iterative* research process without a clear separation of the data collection phase and analysis of the material, but in constant comparison. That means that we started the analysis after the first observations with open coding of the material, went back to the field, analysed again, discussed consistencies in the findings, modified our focus and so on. We collaboratively analysed and discussed the data material in our project team as well as with another qualitative analysis group. We used MAXQDA as a tool to integrate all the data, which allowed us to progressively code the data, add memos to it, and work asynchronously when necessary. We describe some of the main findings below, but first we provide details of the care context of two of our participants in order to illustrate the complexity of such situations.

#### TWO CASES

We chose two examples to reflect the different stages of the “moral career” of the caregivers and the way in which it reflects the progressive learning of a role. On the one hand, we describe the experience of someone who has been dealing with these issues for less than three years (Mrs Kunze) and on the other someone who has been involved in domestic caregiving for over ten years (Mrs Wolff).

##### *Mrs Kunze: Struggling with the New “Normality”*

This family is an exemplar of a short-term-care situation in multiple ways: The 65-year-old caregiver takes care of her 70-year-old husband who was diagnosed with frontal lobe dementia three years ago and additionally with Parkinson’s disease just five months ago. The caregiver has a healthy, sporty and conscious lifestyle. One of her two daughters lives in the house next door with her family and supports the caregiver whenever possible. The caregiver helps her husband with almost every routine activity: washing, getting dressed, drinking/eating, communication, everyday-organization, administrative matters etc. The care receiver is able to walk and to follow conversations in part, but cannot enunciate verbally or manage any of the ordinary manual skills (like opening doors). The caregiver is retired and takes care of her husband most of the time. The family receives financial help for caring and uses this money for external care services such as day care service twice a week. In the talks with her, the caregiver stresses the fact that these times off are essential for her to manage some of the practical aspects of the situation (organization of everyday life), but also for her self-care (sport).

Mrs Kunze, by her own account, struggles with the situation that became a new “normality” in her family. In comparing her previous life with her husband to the present situation, she refers to feelings of shame that she had never anticipated. She finds it difficult to adjust to the changed public behaviour of her husband, for example when he demonstrates his enjoyment for jumping up and down in the street like a child. Feeding him, for instance, when they go to a restaurant, is also embarrassing for her. This learning process whereby caregivers adjust their expectations little by little, struggling with divergence from a previously assumed normality or with dealing with the “stigmatized identity” of her husband as a sick person and herself as a caregiver [31], is typical of the process.

A second, and too-little remarked on feature of domestic caregiving, is that caregivers themselves are often elderly and have to learn to cope with their own deteriorating health at the same time as they learn to cope with their partner’s developing issues. In Mrs Kunze’s case, she fell ill and has recently been diagnosed with diabetes. As she said, until her diagnosis she had not had any significant problems with her health. Up until that point, she had been focused entirely on her husband’s health situation (field notes, July 2014). Mrs Kunze described how she had tried to accustom herself to her husband’s frontal lobe dementia and get the best treatment for him over the three-year period. When he was additionally diagnosed with Parkinson’s disease in summer 2014, she had to start all over again to find out what she could about the disease, but also about her own condition; to re-organize and re-adjust their life in the light of these new circumstances. She explained to us that she sometimes feels that everything is too much, especially with the on-going balance of dependency, with the lack of time for herself, but also the fact that the spouses are no longer on equal terms.

Our purpose in recounting this history is to demonstrate that caregiving is an evolving and dynamic matter. Mrs Kunze is engaged in a challenging and burdensome learning process with few guidelines on how to manage it. She has some limited support for the practical problems she encounters, but little or none for the emotional and social adjustments that she has to make.

##### *Mrs Wolff: Doing Being the Ideal Caregiver*

This caregiver is 64 years old and cares for her 68-year-old husband who has suffered from advanced Alzheimer’s disease since 2003. His medical condition deteriorated dramatically after a stroke in 2006. Since then, the patient has been completely dependent on care, being entirely bedridden, and is completely unresponsive to communication. Her receives the highest level of care in respect of health insurance standards. He relies on help with every aspect of daily life (washing, getting dressed, drinking/eating etc.) and his wife feeds him on liquids five times a day.

The health insurance contributes money and they also have



a care service that supports the caregiver twice a day for washing and dressing. Compared to the other family (Kunze), this family has financial problems and cannot afford any extra care services to relieve pressure on the caregiver. Mrs Wolff just takes one or two “*weeks off*” a year. During that time, the care receiver is based in a professional care institution, covered by their health and care insurances.

Mrs Wolff talks about the physical stresses of caregiving and problems she has with her own significant weight problems as well as knee and back pains that became chronic. She refused to undergo necessary surgery because of her responsibilities to her husband. From her point of view, no one is capable of caring for her husband in the way that she can, that she “*does the best that she possibly can*” in her situation (informal interview, November 2013). This self-positioning underlines, in her view, a level of accumulated expertise. She points out that she knows her husband best, knows how she can cater for his needs. External care, she suggests, would often fail to ensure that the patient gets enough to drink during the day. The point here is that although from the outside such diseases have generic elements, from the point of view of caregivers, they are also unique in their character and require intimate knowledge of the patient’s needs. One consequence is that it is surprisingly difficult to accept outside help. During her time off, for instance, Mrs Wolff tends to choose destinations close by so that she can visit her husband at the nursing home and care for him. Comments such as “*I’m foolish enough not to choose distant destinations.*” (field notes, informal interview, November 2013) suggest the interpretation that she is aware of the costs of her policy, but at the same time she seems to be trapped in her own role as the perfect caregiver. Mrs Wolff, like many of our participants, demands a very high standard of herself, despite the extremely demanding nature of the role she has adopted. She remains highly conscious of what she has lost, including the companionship associated with her previous life and the activities they shared. From her point of view, she no longer has what she calls a “*real husband*” in terms of a communicative human being, husband, father, and sexual partner.

Like almost all our respondents, she confesses to being stressed and has to adjust to her loneliness and lack of freedom. She admits that, at times, she “*wishes he would die*” (field notes, January 2014). She also speaks of the things one gets used to, including silence. It is seldom remarked on that routine family life is a noisy affair. The absence of communication with a partner radically alters that. Mrs Wolff uses YouTube to keep herself and her husband “*busy*” (ibid.).

Another result of our analysis is that long-term caregivers like Mrs Wolff often describe themselves as protecting other members of the family from the daily grind. This self-identified expertise can be further isolating. In Mrs Wolff’s

case, she is keen to ensure that her two sons (aged early twenties) do not have to contribute to their father’s care. Despite the fact that there are potential sources for support in the household, she is not inclined to include them. Here, her other social role (as a mother) is dominant and she wants to protect her children, as she put it.

One last feature that bears a similarity to Mrs Kunze and to other participants is a dependence on computer technology. Mrs Wolff uses online banking because it is useful for the attendance allowance settlement and similar things. This is also in line with her self-perception that she needs “*to be effective*”, cannot afford to let herself go or have times-out. She organizes her life, the care and the household in accordance with very clear, almost ritualized rules. This strategy was also found in our other participants’ routines, which brings us to the next section and the presentation of central aspects of care practices.

### FEATURES OF THE INFORMAL CARE EXPERIENCE

In the data material, we found a wide range of aspects that are relevant for all the ten participants and their care, regardless of the concrete disease or situation. In the following, we will present and discuss three central features, illustrate them with data material and integrate relevant implications for design. The features represented here have been developed as core categories during the process of data analysis.

#### I. Self-concept as a Care-expert

One of the most important findings so far has been the self-description and self-positioning of the informal caregivers as care experts over time. We described this above, after Goffman, as involving a “*moral career*”. Goffman [28, 31] shows, in a different context, how mental patients and other stigmatized individuals experience the stages of their career in a variety of ways but typically in the “*pre-patient*” phase experience “*losing control*”, provoking emotional responses such as anxiety. Moreover, this phase is accompanied by contact with mediators - agencies that affect progress and negotiate a role with family and friends. The “*patient*” phase is characterized by regimentation and routine and the development of strategies to cope with loss of freedom. We will argue, by analogy, that this describes the evolving experience of the caregiver well. Caregivers experience stigmatization, early anxieties and feel a loss of control over their domestic life. Their progress is marked by interaction with professionals and institutions, and the development of coping strategies that are embedded in routines. Goffman also introduces the notion of “*comrades in suffering*”, people who are able to give moral support or tips on how to manage. This, we argue, is something largely absent from the moral career of the caregiver. As we have seen, quite the opposite can be seen, as caregivers attempt to shield family members from the burden.

Sociologists are familiar with the structured nature of familial roles and have noted the way in which changes in household structure, gender roles, and so on have impacted

on the family. This is just as true, if not more so, for caregivers as they learn how to negotiate new roles. They experience a “role shift” [28, 31] from being mainly a wife/husband, mother/father or daughter, to new and, to begin with, ill-defined obligations as full time caregivers. They receive no professional training in that field of work and so are forced into the “learning” of new practices. Such learning is evolutionary and takes place over a long period of time. It is, in large part, composed of two equally important elements. The first entails “coping” with the new reality, especially as there is little or no chance of things changing for the better. Coping here refers not only to the obvious burdens but also to new experiences of stigmatization. This includes shame, feeling uncomfortable or being embarrassed by a partner. Mrs Kunze, for instance, points out that she tries to avoid certain public places that do not offer any intimacy (like big restaurants) (field notes, November 2013) or – if that is impossible – she positions her husband with his back to other members of the public so his behaviour is relatively invisible (field notes, February 2014). This, it scarcely needs to be said, also entails radical revisions of relationships with relatives, friends, neighbours and acquaintances.

Over time, this new reality becomes more fixed. There seems to be, in other words, a progressive acceptance of a role. Where short-term caregivers are engaged in coping with the novel situation, learning what that role might be and adjusting to changing circumstances, “old hands” have acquired a self-image of a clearer and arguably more fixed kind. As described above for Mrs Wolff, our long-term caregivers position themselves as care-experts, also in contrast to professionals. Mr Jacob (80 years old, caring for his wife with dementia for ten years now) even stressed his perfect care of his wife’s body and that her condition “*would be significantly worse if she was in a nursing home*” (informal interview, January 2014). Mrs Hermann, the mother of a nearly fifty-year old man suffering from irreparable brain damage and severe epilepsy, also often referred to negative experiences with external care institutions. From her point of view (as was also expressed by many of our other caregivers), nursing homes and their medical staff in particular do not have the adequate framing conditions and competences to really understand individual needs and respond to them properly. They only perform their “run-of-the-mill” procedures as she says, she has experienced more than once with her own son (informal interview, Mrs Hermann, October 2013). An exception to this observation is the fact that most of our long-term caregivers report positive relationships with individual external care professionals who visit regularly and who seem to share their understanding of the necessary care routine. Most of the time, these people do their job in the family over years and stick to the care routines and preferences the informal caregivers have established over time (field notes from Mrs Wolff, Mr Jacobs and Mrs Hermann).

## II. The Crucial Need for Social Support

One major aspect of informal caregivers’ lives can be identified as their social isolation. Caregivers often spoke about their reduced opportunity to chitchat with other people on a regular basis, but also to get in contact with other people facing a similar situation. In large part, this has to do with increasing isolation, for short-term as well as for long-term caregivers. It becomes even more difficult to share experiences, identify common problems and solutions and gather information. There is, in short, an absent network in this sense, despite the fact that our participants have offline social networks consisting of close family and friends. These networks can sometimes be activated as support networks in order to afford time off for the caregivers; Mrs Kunze and Mr Jacob, for instance, both place great value on the two or three hours a week when they meet acquaintances in their respective sports clubs. All the contacts with the nuclear family and friends are important for them and represent a kind of “self-care” for informal caregivers; but they also expressed the desire to communicate with people outside their own family and network without any obligations or on a more “anonymous basis”.

Care staff visits are also opportunities for caregivers to retain some social contact outside the family. As pointed out before, all of the long-term caregivers rely on cooperation with professional care organizations that support them on a daily basis. The level of intensity varies amongst the observed families, but in most of the cases, professional caregivers visit the families twice a day for some minutes. As the work of the professional care staff is highly regulated due to economic/financial restrictions based on the individual care level of the patient, the time available in the respective household is low. Consequently, the shared care work is underpinned by very clear rules and routines (organization of the equipment, roles, etc.). Here, mutual understanding and trust between the involved actors is most important to maintain a functioning and satisfying situation not just for the patient, but also for the responsible informal caregiver. Often, the informal caregivers prefer a certain professional caregiver who, in their view, shares an understanding of the individual and the sensitive situation often due to a long period of collaboration.

These limited opportunities do not, however, solve the major problem of organizing free time for meeting friends and keeping up regular appointments. Options for meeting people outside the house are limited – which is particularly difficult to manage in rural areas, and for elderly caregivers who are not very mobile. The feeling of being isolated from life and feeling lonely accompanies most of our long-term caregivers; for instance Mrs Hermann, who has cared for her son for decades: “*Sometimes, one feels like one is buried alive, if one doesn’t see anyone else or talk to anyone else but the professional care service in the morning.*” (Mrs Hermann, field notes, October 2013). Over the month of observation in her home, we recognized that

her motivation to participate in our study was mainly driven by the hope for more communication with other caregivers in the long run.

### III. Timing Issues and Coordination

In our field of research, the importance of daily *routines* is evident. Even when caregivers are themselves retired (as in our study), they are faced with multiple, demanding tasks due to the nature of full-time care. These embrace mainly care-related activities such as the personal care of the patient's body (washing, dressing, moving from one side to the other and feeding several times a day, giving medicine etc.) which is time-consuming and challenging because most of the patients are (completely or partly) immobile, bed-ridden all the time, unable to interact or even respond to their caregivers and so on. All other activities such as appointments with doctors, professional care staff or insurance companies, organisation of medical aid, the patient's financial and legal issues, cooking, shopping, washing clothes, cleaning the house/flat, etc. also have to be managed by the informal caregiver. Not forgetting her or his own needs. Mr Jacob (80 years old), for instance, pointed out that *"he is now controlled more by outside influences and busy with the care job than he was during his working life"* (informal talk, January 2014), especially because he is "on call" 24/7 whether his wife is feeling unwell or whether her medical condition has deteriorated etc. Consequently, a common characteristic of all the participating caregivers is their intense need to structure time in detail and to coordinate their activities with others (the relatives, their social network, the professional care staff etc.). Most of them accomplish this by using a calendar (in paper form) to keep track of all their activities.

Our respondents consistently report that they find the management of time very difficult. Firstly, long-term care of patients with progressively deteriorating conditions involves considerable coordination with professionals of one kind or another. Professional people, unsurprisingly, have an entirely different set of commitments to deal with; they cannot easily "drop" one patient in order to deal with another and often have fixed commitments. A significant part of the formal support given involves visits to external clinics. This means that for the most part, informal caregivers must fit in with professional schedules rather than the other way round. Secondly, the provision of medication in a systematic and controlled manner; the management of exercise regimes; dealing with sanitary requirements, organizing meals and so on all require careful planning, especially when the caregiver is, more often than not, solely responsible. Thirdly, depending on their condition, the cared-for person often cannot be left alone for more than a few minutes at a time and thus caregiving has to be carefully dovetailed with other activities such as meetings with relatives and friends, shopping times, employment or the minimal leisure time of the informal caregivers themselves (for sport, time-off etc.). This is even

more important for elderly caregivers and the maintenance of their own health.

The paper calendars are full of scribbled detail. Our participants all described the calendar as an essential tool for their time management. The tasks, activities, other actors and routines that have to be managed are highly complex and – as Mrs Kunze pointed out – they have to be managed by the caregivers themselves as their partners, the care receivers, cannot support them: *"in partnerships, one could divide the tasks etc., but that's not possible any more"* (informal talk, February 2014). This quote also underlines the difference in coordination and collaboration in families as such; in childcare, for instance, as – ordinarily – these tasks can be divided between the parents/partners. In this situation, time management is a far from trivial matter. Deviation from the plan, in this context, is often very consequential and disruptive. Most of our participants stressed that they depended as much as possible on predictability, especially of the professional care staff. Contingencies that arise (e.g. the late arrival of a support worker or a cancellation by a supporting family member) may result in an avalanche of defaults, like Mrs Kunze pointed out: *"a delay of the day care bus will provoke panic in the whole family."* She described a scene from the week before, when the bus that should have picked her husband up from day care was late by over an hour. Her daughter was waiting for Mr Kunze (the patient) at home, but had to leave due to other obligations. (field notes, November 2013).

Most caregivers we observed emphasized the need for circumstances to be as controllable, or organized as possible. Some of them also pointed out that they would like to improve the coordination between their own schedule and that of the professional care staff organization, for instance with automatic notifications about delays etc. Daily routines are essential for coping successfully with the demands of the care situation; plans are, in most cases, precise to the minute, especially when professional external care is involved. All of our caregivers communicated their lack of "time for themselves", the lack of freedom and spontaneity in their lives. Mrs Wolff summarized her situation with the characteristic comment that *"even spontaneity has to be organized"* (interview after the collection of the cultural probes, February 2014).

### DISCUSSION & CONCLUSION

As stated at the beginning, we refer to Glaser and Strauss' early works about the "The Awareness of Dying" and their interest in the rationales of caregivers, but we go beyond that by addressing a specific group of unskilled (informal) caregivers and their way of coping with their situation, learning a new role as a caregiver and cooperating with professional caregivers. As we have pointed out, existing literature has tended to focus on quantitative measures of quality of life or on limited "one shot" interviews ([7, 9, 32, 50, 70]). Here, long-term ethnography provides us with



extensive insights into the highly complex and evolving situations of domestic care and in so doing addresses precisely the “missing what” that Van Ruyn et al. [65] point to.

The experiences described above are not stable or fixed, but dynamic in multiple ways. This is important, for there can be no generic application that fits the needs of all caregivers. Progress over time and the learning curve typical of their experience, we believe, is the most important dimension to consider. Learning, as we have seen, is a major feature of the moral career of the caregiver and all of our participants express reservations about the kind of help – social and symbolic as well as material – that is available to them (see for instance the aspect “self-perception as a care-expert”). The learning process of the new, additional social role of an informal caregiver is mainly realized and accepted over time. Along with this goes the observation that people who have been caregivers for a short period and who still struggle with this new role, situation and routine, also partly show what Goffman calls “role distance” [30], meaning a more critical view of the caregiver role (such as Mrs Kunze). That might also be an important perspective to design for such situations in the sense of supporting the establishment of a “virtual community of practice”.

Again, learning might be mistakenly thought of as *simply* a cognitive matter- that there are certain things one needs to know about a medical condition in order to provide care and so on. We have tried to show that this significantly underplays other important aspects of the learning process. Not least, support needs to be provided to enable caregivers to manage their own identities over time. This includes support, for instance, for feelings of shame and stigmatization, and the sharing of experiences of this kind. Isolation and the moral commitment to “managing on one’s own”, and managing one’s own psychological and physical health turns out to be a major feature of the caregivers’ burden. We interpreted these changes as a “moral career” for caregivers, one in which their identities and social as well as their more detailed practices and their cooperative work undergo change. Informal caregivers have to face these changes and have to adapt themselves to new and evolving conditions. Consequently, the technical support we envisage will have to reflect this variety of conditions.

The most significant challenge we as designers face, is how to make the envisioned product capable of covering the entire process that caregivers undergo. This not only requires the platform to be easily accessible for users with various levels of technical experience, but also requires the features and contents of the platform to cover caregivers’ needs during the various phases of their moral career.

In respect to experience with technology, most of our users have zero to little experience with smart devices and online social networks. Prior to our device rollout, only one of our users had a smart device (Tablet) and only one (other) user

was registered on Facebook. This of course creates great challenges for the user group to accept and appropriate technological interventions. Additionally, the likelihood of being subjected to age-related impairments such as reduced eyesight further complicates the situation. Carefully designed interfaces and elderly-oriented design are just the first steps. The platform needs to have a site-wide guidance system to walk users through early sessions and support them at various points. We argue rather, that we need to understand the complex and evolving assumptions that inform their practices as they move from “novice” to “expert”. And, of course, we need to learn how, when and what kind of help might be needed, both on a technological and care level. From the methodological perspective, we need to take a concerted approach to bring the technology to our users, breaking what can look like monolithic complexity into little milestones. For example, rolling out smart devices earlier than the prototype is ready, we will give the users enough time to first get acquainted with a device and consequently reduce hindrance when the software is later rolled out separately. In addition, long-term personal training is essential for elderly users. Overall, we need to think of our platform as a service rather than a software product. This means education in how to use the platform, individual adaption of the service, and the work of a reliable support team will all be as important as the platform itself.

The definition of the content and features the platform should provide is, of course, another major challenge. Considering the diversity of experience, and the evolving progress of each individual, the platform will need to have both great flexibility and extensibility to be able to cover a large range of needs/interests. A modular design philosophy would seem to best fit these varied scenarios, providing easy extensibility by add-ons. In respect to content, it will provide an editor-friendly interface to allow easy content maintenance; so content providers will not have to bother with source code and can focus on delivering great content to the platform continuously. We see several potential contributions our platform will bring to informal caregivers and we would like to illustrate and provide further considerations in relation to:

**Information Support:** The confidence informal caregivers develop of “owning” the best care practice is based on the fact that they have gone through a long (normally painful) learning process, sometimes receiving relatively little external help from professionals along the way. The envisioned platform should provide information to support this learning process and make channels for information exchange available. Our results underline that informal caregivers need not only credible information from professionals (e.g. information about a disease), but also information from other peers (caregivers facing similar challenges) to provide orientation in their moral career. The platform will contribute information channels from both professionals and the “unprofessional” users. Of course, the

validity of user-generated content here could be a concern; a certain need for moderation by professionals on these channels may be necessary. How this might meet the needs of our users will be examined in the next phases of the project. Last but not the least, the platform needs to structure information in such a way that different levels of knowledge and expertise are catered for.

**Social Support:** Our results illustrate that, so far, our users do not use online social networks, and even their real-world social connections are decreasing due to limited time, energy and options. Building a dedicated community for informal caregivers has been our ambition since the foundation of the project. Yet, with more understanding of the field, we are ever more aware of the need for social support for this population (e.g. experience on fighting stigmatization and shame, psychological counseling, social inclusion, online/offline events, and care for one's own situation). Considering the lower-than-average physical mobility of this user group, especially in rural areas where offers are even more limited, the platform might also provide mobility support (e.g. public connection, taxi, car sharing [45]).

**Coordination Support:** In our users' paper calendars, we observed intertwined, compactly crowded plans that involve multiple stakeholders such as family members and care professionals. The communication channels with these stakeholders, for now, are maintained solely "by hand". "Spontaneity has to be organized", but as the current coordination lacks efficiency and responsiveness, and stakeholders are not able to react to contingency in many cases. Coordination support on our platform, we think, goes well beyond merely providing a digital calendar. The challenge lies in creating and integrating coordination channels and the automation of communication "backstage". It is, we argue, essential that all stakeholders are integrated into the coordination process, and that the platform should, proactively where possible, inform all stakeholders about contingency and support the re-negotiation process when stakeholders react to unexpected changes. To achieve this goal, technical development is just one part of the objective. It would also require a lot of effort in the integration process on the part of "big players" in the healthcare system, e.g. care service and health insurance.

Informal elderly caregivers might have been relatively overlooked as an ever growing user group up till now, but we believe that long-term micro studies contribute towards an understanding of the evolving complexity of this kind of cooperative and coordinative care work.

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