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Carers@Work

**Carers between Work and Care. Conflict or Chance?
Results of Interviews with Working Carers**

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1 Executive Summary

The purpose of this sub-project within the project “Carers@Work” is the analysis of the perspective of working carers’ in Germany: their burden, their benefits, their strategies and their suggestions for improvement to be able to better reconcile work and care. Therefore 58 qualitative interviews with working carers were conducted in Hamburg (40) and Dresden (18). The majority of the sample was female, highly educated, caring for a parent with rather high care need and working more than part time. But also 12 caring partners could be interviewed.

Impact of reconciliation

Reducing working hours, stepping back from leading positions, feeling hindered from professional development or becoming self employed has a great influence on further working careers and carers’ financial situation. But also in the daily work situation carers feel confronted with a lack of concentration, conflicts with colleagues and line managers, a decrease of productive efficiency and increasing missing days.

Combining work and care is also a burden to carers’ family life because family members suffer from a lack of time and energy. Conflicts with siblings or partners have a very negative influence on their well being. Carers reported an overall lack of time and a negative influence on their own interests and their social life. This double burden can very easily have a great negative influence on carers’ wellbeing and health, with the potential of cumulating in burn out and break down. Carers’ financial situation can be negatively influenced by a reduction of working hours or losing a job as well as by additional payments for support offers. Also financial difficulties not related to care like high mortgages can negatively influence the possibilities to unburden carers’ situation quite strongly. In cases where carers’ don’t experience any negative influence either the amount of care isn’t that high, carers reduced work already or they are embedded in a good working support network or/and have an understanding employer.

However, reconciling work and care is not only perceived as a burden. Carers also report benefits like personal growth, gaining new competencies relevant also at the work place, improvement of family relations and a new work life balance.

Support and Strategies

Partners and siblings are one of the most important sources of support. Own (grand) children and friends are especially relevant for emotional support and as a source of new energy.

A positive working climate and a general openness for family friendliness are very important preconditions for a successful reconciliation, because it raises the chance of supporting and understanding colleagues and line managers and the arrangement of informal individual solutions for carers. Flexible working hours, possibility to reduce working hours or stepping back from a leading position for the time required as well as time out in case of emergency; all without any negative consequences for their further work life and without additional bureaucracy are seen as the most important support measures by carers.

The existing Long Term Care Insurance is seen as a very important contribution to the possibilities of asking for professional support. Apart from the financial aspects, working carers need the possibility to take a few days off in case of emergency, but the current law is not seen as applicable for carers. Used support services are mainly professional care services, day care facilities, short term care, privately paid home helpers and nursing homes. Which support is seen as the most helpful is depending on the level of care need, the work situation, the familial support and can change over time. Services are seen as efficient and were used by carers when they can rely on staff members, who stay the same over a longer period, arrive in time, are flexible enough to come when needed and provide a good quality of care. Health care providers should treat carers as partners and enable communication and exchange of important information.

Carers demand a better recognition in their role as carers, support which is tailored to meet their needs, the possibility to use flexible work arrangements and an improvement of their financial situation.

Caring is still a female task. Men and women are fulfilling different caring tasks. Whilst female carers are doing all relevant tasks including hands on care, male carers are quite often the main organiser of the care arrangement. The influence a demanding care situation has towards a woman's work life is still very much depending on her partnership. In double earner couples without own children women tend to try working full time whilst caring and get a lot of support by their partners. In typical male bread-winner couples it's often also the task of the wife to reduce work and care for the parent (in law) with rather little male support.

2 Introduction¹

Reconciliation of work and care for an older relative is highly relevant for future societies undergoing socio-demographic change since it affects the future working environment as much as the future provision of care for older people – both areas facing particularly serious challenges in the future. Moreover, the division of labour and roles within the family will also be affected, thereby impacting on an equal “work-life balance” for men and women. Therefore, innovative concepts are needed to exploit the existing capacity of our society. To this end, joint efforts by all societal actors concerned are required. Thereby, family carers and their employers share particular responsibility. Employment and family care are commonly seen as incompatible. The present research wants to show that the reconciliation of employment and family care is possible if accompanied by support measures at enterprise and social policy level. Thus, a forward-looking and sustainable care provision can be guaranteed in an ageing society, and new productivity potentials in form of highly motivated employees can be made accessible.

Aims and design of the whole project

The project “Carers@Work” aims to identify transferable, innovative solutions that promote the reconciliation of work and care in four EU-member states:

- Germany
- Italy
- Poland
- United Kingdom

Hence, this project compares four different “care regimes” regarding typical conflicts and strategies to enable the combination of work and care obligations. The project intends to identify gaps in existing knowledge about successful measures to enable

¹ This introduction was written by Annette Franke & Monika Reichert, project coordination

informal carers to combine paid work and care and to analyse the reconciliation problematic at the enterprise level as well as at the carers' level.

That is the starting point of this research "Carers@Work", which considers both the perspective of family carers and that of enterprises. Thus, the project "Carers@Work" refers to the central challenges of demographic change, namely "ageing workforces" and increasing longevity, which is very likely to result in rising numbers of people in need of long-term care. Furthermore, the research focuses on the "babyboomer" generation to which most family carers belong and changing life courses as an increasing female employment, the necessity to reconcile employment and care in several life phases (this is no longer limited to young parents), extension, differentiation and prolongation of old age, as well as receipt of care as a distinct phase in old age. Finally, the "new reconciliation variant" has been explored in relation to different family and life forms and the resulting new family contexts of old age. Those living in a "sandwich constellation" will still be a small minority – studying them will nevertheless have major implications for the future when their prevalence is likely to increase. The research embraces the following work-packages:

- International literature review²
- Secondary data analysis of survey data (SHARE and EUROFAMCARE)³
- 60 topic-guide interviews with employed family carers in each of the four participating countries regarding individual reconciliation strategies
- Case studies, examples of "good practice", and topic-guide expert interviews with representatives of works committees, trade unions and employers associations as well as documentary analyses of collective bargaining and enterprise agreements⁴
- Social policy report⁵

² Franke, Annette & Reichert, Monika (2010)

³ Principi, Andrea & Perek-Bialas, Jolanta (2011) The reconciliation of work and eldercare: a secondary data analysis. http://www.carersatwork.tu-dortmund.de/download/Carers@work_SDA.pdf

⁴ Kümmerling, Angelika & Becker, Gerhard (2011)

⁵ Franke & Reichert 2011

- Economic expertise as an assessment of the resulting costs for the companies in Germany.⁶

Aims and Research questions of the carers study

The reconciliation of paid employment and informal care is not a rare phenomenon among the workforce and becomes of increasing relevance within the next years. Working carers are characterised by typical factors: They are most often married women between 40 and 50 years, from whom about 25% cohabit with their teenage children. A number of working carers also occupy several roles as spouse, parent and employee. Furthermore, care is mostly provided from daughters to their older mother/ mother-in-law, who is on average 76 years old. On average working carers spent 4-9 hours/week for elder and care obligations are primarily related to "general eldercare". However, nearly 50% of the working carers are also involved in "personal care". All in all, most studies show an overall proportion of about 10% prevalence rate of workers with care obligations.

Even when an increasing number of international researches address the importance of the reconciliation of elder care obligations and employment, most studies emphasise more on the impact on private life and strain of care giving itself. In contrast, there is still a lack of knowledge about how an unsatisfactory reconciliation becomes visible at the working place (e.g., absenteeism, lack of capability, reduced possibilities for career and promotion) and which strategies working carers use to enable the balance between job and care (e.g., working time reduction and re-organisation of work). Some studies also disclose the "respite function" of work, which can buffer the carer's isolation and depression.

The research project "Carers@Work" aims to get a deeper look into the specific conflicts, strategies and demands of working carers. Therefore, semi-structured interviews with working carers have been conducted in Germany, Italy, Poland and the UK to answer the following research questions:

⁶ Schneider & Heinze (2011)

What conflict- and stress-situations between work and care are typical among the carers?

In many cases working carers experience controversial expectations from the work place and the care situation. Thus, they might indicate high levels of physical and psychological burden, which could be the case when caregiving is external motivated and/ or if there is no help available accompanied by interpersonal problems between care receiver and carer. Furthermore, the work-care-situation is vulnerable for unforeseen crises, e.g. due to an decreasing health status of the care receiver. In all, an insufficient reconciliation of work and care has an impact on the carer's health status and wellbeing. Private life is also affected by the combination of work and care in forms of less time for the family, social contacts, hobbies and phases of regeneration. This research question asks for typical stress-situations which occur from an unbalanced reconciliation of work and care.

What strategies do carers use to reconcile work and care for an older individual?

This research question tries to find out which strategies at the workplace, in private life and regarding care are the most common and most successful. To enable the balance between job and care working carers need various strategies to facilitate this reconciliation, e.g. the re-organisation of the work schedule, working-time reduction and seeking for the help of others, e.g. social services as a substitute or in addition to help from the family.

What kind of influence does the qualification level of the carers have with regard to the reconciliation of work and care for an older individual?

A high qualification level is associated with flexible working conditions regarding working time and work organization. On the other hand, lower qualified employees might be more likely to get affected by caregiving obligations in their families. This research question aims to highlight the influence different qualification levels have regarding the possibility

- to combine work and care in general and
- to use different workplace related strategies.

What kinds of influence do the employment status and income situation of the caregivers' households have on the reconciliation of work and care?

It can be assumed that a higher economical status subserves the reconciliation of work and care, because these households might be more likely to purchase

professional help from other, e.g. care service. In addition, the employment status – working full time or part-time – might play an important role as well, when it comes to combine work and care.

Within the context of employment and care, what kinds of gender inequalities are produced by the reconciliation problematic?

Gender is one of the most important factors in determining which family member takes over the role of the main carer and whether an individual alters their working arrangement or give up employment so as to provide care. Thus, eldercare is still marked by gender inequalities, because male carers are usually the “secondary care person” or “the alternative” when no female carer is available. However, the rate of male carers increased within the last years. This questions aims to find differences between male and female carers and/ or how sharing of caring tasks are negotiation.

Which kinds of support at public, enterprise or societal level best enable the reconciliation of employment and care for older individuals?

This question puts emphasis on the carers’ wishes, expectations and demands to the society, their employers as well as social policy makers. Furthermore, this question refers to existing measures, instruments and services on all three levels and their effectiveness for a better reconciliation of work and care.

Are there any specific individual conflicts or strategies related to the reconciliation of work and care for an older individual when comparing different countries?

Against the background of different care regimes the last question highlights the cultural differences among the four countries. On the one hand all four countries share also similar conditions, e.g. the core role of the family, but also there are remarkable differences, e.g. female labour force participation rate. To examine to which extent similarities and differences with regard to overall framework conditions in the four countries influence individual conflicts or strategies is the aim of a comparative report and not of this national background report.

3 Methodology

Data Collection: Problem centred Interviews

To answer the research questions we conducted topic guided interviews with family carers. The semi-structured interviews followed the model of 'problem-centred interviewing' as outlined by Witzel (2001). This approach offered a means of reconciling deductive and inductive research methods as researchers using this method are receptive to the narrative presented by the interviewee yet at the same time are aware of the existing empirical data on the topic which provides the focus for the interviews. Scheibelhofer (2005) argues the approach allows the interviewer to utilise a number of interviewing techniques within one interview in that they begin with a narrative approach, then a thematic interview and finish with the collection of 'socio-statistical information' at the end. In terms of the disadvantages of this approach, it places significant demands upon the interviewer in terms of their ability to employ three styles of interviewing in one session.

A problem-centred interview begins with a preformulated introductory question not unlike the biographical narrative approach. This initial question should be broad and is then followed up with general exploration to draw out more details of particular aspects of the interviewee's narrative. As a result, it is key that the interviewer takes field notes to allow them to return to important issues once the interviewee has completed their narrative. The second type of question included in Witzel's approach are ad-hoc questions. Scheibelhofer (2005) argues their name is a misnomer in that they should actually be prepared in the form of an aide memoir to ensure all topics related to the research question are covered, and to assist with the comparability of results (as a consequence, they are in fact 'supplementary questions' or prompts). These specific explorations utilise knowledge from the literature to produce additional questions on areas that may not have been included in the narrative, but should avoid reverting to the 'question-and-answer game' style of interviewing. Finally, there are questions for understanding whereby the interviewer seeks clarification on earlier statements in the interview. Scheibelhofer argues the interview should finish with a questionnaire related to socio-economic characteristics of the interviewee. For Scheibelhofer, this should be presented at the end of the interview so as to "keep the more unstructured part of the interview as unrestricted as possible" (Scheibelhofer, 2005: 23).

In terms of the interviewers' conduct during the interviews, Scheibelhofer argues the preformulated introductory question "should stipulate a narration without intervention by the interviewer...the interviewer should encourage the interviewees to dwell in their own ideas without making any substantive contribution such as asking additional questions, proposing varying possibilities to answer, etc." (Scheibelhofer, 2005: 23). The ad hoc/ supplementary questions in the topic guide should provide prompts, as opposed to a rigid structure. Indeed, the interviewer should endeavour to follow the narrative presented by the interviewee when asking these ad hoc/supplementary questions. In the final stages of the interview, the interviewer should summarise the main points of the narrative to allow the interviewee to elaborate or clarify any points made. Witzel also advocates the use of a questionnaire to gather data on the interviewee's characteristics. Therefore, in line with Witzel's assertions, for each interview the researcher had:

- A short questionnaire to gather data on the social characteristics of the interviewee;
- Guidelines or 'a supportive device to reinforce the interviewer's memory on the topics of research and provide a framework of orientation to ensure comparability of interviews' (Witzel, 2000: 4);
- Tape recorder;
- Post-scripts to accompany tape recording.

Research questions and topic guide

Based on the aforementioned method, the topic guide contained three elements:

- pre-formulated introductory questions: these were designed to encourage the interviewee to provide a narrative;
- supplementary questions: these followed on from the pre-formulated introductory questions, and should be asked if the interviewee has not already included the answers in their narrative; and finally
- questionnaire: this was presented to the interviewee after the interview as a means of collecting data on their social characteristics without interrupting the flow of their narrative.

The idea is not to revert to a 'survey' format during the interviews, but to encourage the interviewee to provide expansive answers through the pre-formulated introductory questions with the supplementary questions providing prompts if these areas are not covered by the participant's narrative.

By deciding to use the problem centred interview according to Witzel (2001) as the method of collecting data we had to operationalize the research questions into questions usable in the topic guide.

Therefore we transmitted the research question into six main questions in the topic guide, which however, did not simply resemble them. The six questions had to be asked in exactly this way in each interview in all four countries and were meant to give interviewed carers a stimulation to narrate their situation. Each of the main questions was connected with a series of sub-question which should help the interviewer to ask more deeply when the conversation got stuck or answers were not satisfying and make sure that all relevant issues were touched by the interviewed person. The supplementary questions act as prompts for the interviewer to ask the interviewee should they not be addressed organically in their narrative. Thus the topic guide was structured around the pre-formulated questions which allowed the interviewee to provide a narrative. Once the interviewee has answered a particular pre-formulated question, the interviewer could then address the areas that were not been included in the narrative. As a result, the interview did not revert to a 'question-and-answer' game, or necessarily proceed in a linear fashion through the supplementary questions. The idea was not to produce an overly structured interview, yet at the same time we have to collect data relevant to the research questions. Thus the supplementary questions act as an 'insurance policy', in case the interviewee did not include details of these areas in their answers.

As a warm up question which also should enable the interviewer to get a first impression of the care situation and be able to adequately interpret the later mentioned costs and conflicts we asked about care history and care situation.

Care History: Can you tell me something about your role providing care- how did this come about? / Care Situation: Can you tell me something about your actual care situation- how did this come about?

In this context we also directly asked about motivation to care and the reasons for this care arrangement. Usually by asking these questions we got already a first insight into costs and conflicts.

The second block of questions concerned the work and work history, where carers described their actual work situation and gave a short insight into their working career and their educational background as well as a short insight into their partner's situation, if available.

Work and work history: Can you tell me about your current work situation?

With the third package of questions we reached the first core of our research, about impact of combining work and care which mainly provided us with information on research question A, about costs, conflicts and benefits.

Costs, conflicts and care: Could you describe the impact of combining work and care on your life?

This was followed by questions about services carers use and support they receive at home and at their work place. With additional sub-questions we tried to find out strategies carers use.

Strategies: What support/services do you use to overcome these problems (or at least attempt to) and reconcile work and care?

This was followed by questions concerning further improvements of reconciliation:

What could make reconciling work and care easier?

Both questions helped to answer research question B and F. The last block of questions was a wrapping up phase and enabled us to make carers to sharpen and summarize some thoughts developed during the interview, and then slowly fade out of the interview situation

Wrapping up

- What is the most difficult aspect of combining work and care for you? What is the most positive aspect of combining work and care?
- If you look back, what would you have done differently?
- In the light of your experience, if you met someone combining work and care, what advice would you give them?
- What do you do to unwind/ take timeout?
- What are your wishes for the future? In a year's time?

To be able to answer the questions C, D and E we had to do some cross cutting analysis. To receive all relevant information we added some sub-questions to our main topic guide questions. The operationalisation of high and low level of educational qualification was decided to be done with support of the ISCED scale.

Discussing the research questions with our advisory board it became clear that firstly most carers would not be willing to unveil their income to strangers and secondly not only income matters, but also fortune, property and pension. Accordingly it was decided to not ask about the income situation, but more generally about the influence

of the care situation on the financial situation of carer and carer's household. Correspondingly the research question has to be changed here!

Sampling and recruitment

Sampling strategies

Household structure as well as level of qualification have an impact on carers ability to reconcile. It should be assured that carers living in a double earner couple, carers living in a single earner couple and singles having either higher or lower level of education would be included in the study. The emerging six field table was our starting point for the recruitment procedure.

Table 1. Level of qualification and family /household structure

	Couple, both working	Couple, one working	Single	Total
Higher level of qualification (ISCED 4-6)	10	10	10	30
Lower level of qualification (ISCED 1-3)	10	10	10	30
Total	20	20	20	60

Ways of recruitment

In Germany the recruitment was done in the metropolitan region of Hamburg and in Dresden. To be able to collect a good mix of carers from different backgrounds we recruited via very different channels and contacted day care centres, residential homes and care services, hospitals, but also self help organisations like Alzheimer association, Parkinson league, "We care", "Living without barriers" and "Living with a handicap". Besides we informed counselling centres for older people and their relatives, like all eight care access points (Pflegestützpunkte), coordination centre for shared flats for people in need of care, "Social service and advice for the older people from community", self help advice centres in Hamburg, Dresden and Lüneburg (a small town near Hamburg). Further more we included occupational health services in Dresden and Hamburg, care conferences and church congregations, we contacted 60 companies of the network of family friendly

enterprises in Hamburg (www.hamburg.de/unternehmen/117394/start.html) and around 10 companies in Dresden. We published announcements in the newsletter of the “coordination centre of work life balance”, of the “Coordination centre for shared flats for people in need of care” and the “Chamber of Handicraft”, which reaches 6,000 crafts enterprises as well as two big health care insurances.

Last but not least we also spread the information on our project via private contacts of all project members, colleagues and the members of the advisory board. The distribution of leaflets to university, pharmacies and shops for products for the older people was also tried. Despite the fact that we tried very intensive and via many channels it was a quite time consuming procedure to finally find enough willing interview partners. After a few month of not very successfully recruiting we decided to pay an incentive of 20 Euros per conducted interview. Those who were already interviewed got the 20 Euros as a “Thank you” afterwards. Most carers appreciated this gesture of recognition, but it didn’t really help to get more interview partners with lower education, as was intended.

In the table we listed the successful ways of recruitment to show via which different channels we could win our interview partners.

Especially successful were all advertisement with carer’s organisations / self-help groups and family friendly companies.

Table 2. Ways of successful recruitment

Ways of recruitment	Number of Carers
Carers Organisations/Self help groups	13
Companies	10
Welfare Organisations, Associations of shareholders and private associations	7
Private contacts/ Colleagues	7
Health Insurance	5
Local Authorities	4
(Day-)Care facilities	4
Events or Meetings (care related)	3
Parishes	2
Chamber of crafts/ Trade Unions	2
Flyer	2
Total	58

Data analysis

Theoretical approach for data analysis

Qualitative Content Analysis

To evaluate the collected interview material we needed a method which enables us on the one hand to cope with a huge amount of texts (transcribed interviews contain more than 1200 pages) within a very limited time and on the other hand make sure that partner in all of the four participating countries would be able to use a strategy of analysis as comparable as possible.

Therefore we decided to evaluate our interviews with the method of qualitative content analysis according to Mayring (Mayring 2000, Mayring 2008)

Qualitative content analysis is defined “as an approach of empirical, methodological controlled analysis of texts within their context of communication, following content analytical rules and step by step models without rash quantification” (Mayring 2000)

For our purpose the most interesting procedure offered by Mayring is the method of “structuring with regard to content”, which aim it is to “filtering specific topics, contents and aspects out of the material and to summarize it. Which content it is that should be extracted, will be named by categories, (and as far as necessary) sub categories, which were developed theory driven.” (Mayring 2000:89 - own translation)

In the centre of the qualitative content analysis are categories, which can be gained either inductively or deductively. According to the approach of “structuring with regard to content” it made sense to use the deductive category application: “Deductive category application works with prior formulated, theoretical derived aspects of analysis, bringing them in connection with the text. The qualitative step of analysis consists in a methodological controlled assignment of the category to a passage of text.” (Mayring 2000:4)

Typology building⁷

Based on the method of typology building of Kelle & Kluge (1999) we tried to built profiles of working carers. The aim of the method is it to „map complex social realities and grasp contexts and be able to understand and explain them“ (Kelle/Kluge 1999:75) This systematic approach derives from a „process sequence of empirically based typology building“ (Kelle/Kluge 1999:96) within four central steps: „development of relevant dimensions of comparison“, arrangement of all cases in groups and analysis of empirical regularity“, „analysis of the context with regard to content“ and “characterising of the constructed types” (1999: 81). With the aid of a “building an ideal typical construct consisting of several prototypical cases“ (Kuckartz 1988:224 in Kelle/Kluge 1999:95) follows supported by the central categories finally the construction of proto types which are somehow “ideal substitutes” (Kelle/Kluge 199:96) of their group.

Transcription of the interviews

The interviews were transcribed in the style of Kuckartz at al. (2007), as they suggest a quite simple way of transcription, which however meets the requirements of our

⁷ All following citations in this chapter are own translations.

analysis. The most important rule was that transcription was carried out literally and not in vocalisation, expressions in dialect or spoken language expressions are carefully transformed into High German. After every turn taking there should be a blank line for better understanding. Affirmative vocalisations like “oh”, “eyh” were not transcribed. Affirmations which underline the importance of a statement like laughing or sobbing were transcribed in round brackets. Interruptions by the interview partner were set in squared brackets.

In consideration of the fact of anonymisation and the understandable fear of some interviewed carers that somebody would be able to detect them it was decided to anonymise the quoted passages in an adequate way. This means that it was not only necessary to change all names and places but also slightly alter age, disease or number of employees at a company, to make sure that no interviewed carer can be recognised in the citations.

Procedure of analysis

To develop categories according to the deductive category approach, we used the topic guide, which was developed theory driven (see above) as a first structure to establish a system of categories and develop a first draft with the same main categories in all countries. Afterwards two further levels with subcategories were built, which seemed to be relevant in all countries, from the third level on, countries made own decisions.

As demanded by Mayring (2008) the definition of the units of analysis were made, and the code unit (smallest component of the material - *a word*), the context unit (the biggest component of the material - *the whole interview and the evaluation unit* (order of evaluation - *case by case*) was decided. Although the agreements were that quotations belonging to a category should be always as short as possible, but as long as necessary.

In the next step in all countries several pilots were conducted and evaluated with the aid of the theory driven developed system of categories. In doing so not only the topic guide was tested, but also the usefulness and appropriateness of the category systems was proved. After this first passage through the interviews several feedback loops with the whole group were conducted and necessary amendments in the category system were made, following the accepted methodology:

“The aspects of text interpretation, following the research questions, are putted into categories, which were carefully founded and revised within the process of analysis

(feedback loops)” (Mayring 2000:3). In this manner all 58 interviews were evaluated. We altogether have around 4700 codes.

To not loose track on our data, we used two strategies. Firstly we put a headline over each interview which consisted of the most remarkable sentence of the interview. It should be a sentence which immediately would bring the picture of the interviewed carer back to the interviewers / researchers mind.

And secondly we decided to prepare small vignettes on each case as recommended by Witzel, were we describe briefly the main contents of the case, like care situation, work situation, central conflicts and benefits, support services and strategies.

The evaluation of such an amount of interview material in such a limited time was only possible because of computer assisted evaluation methods. In all countries the programme MAXQDA was used. Although it does not do any evaluation, it is of great help in classifying, connecting and combining data.

The function of setting up memos allowed to prepare the key sentences and the short vignettes. The results from our post questionnaire could be set up in an additional list of variables which can be combined with texts and codes as well as exported to SPSS. Especially this list of variables was of great help by developing the different profiles of carers (see chapter 5).

4 Results

Introduction

In this chapter we will present the results of the interviews with working carers. A description of the sample characteristics is followed by an elaboration of conflicts but also benefits experienced by working carers. After the presentation of the impact of the combination of work and care the focus is laid on the strategies carers employ to be able to reconcile.

Socio-demographic characteristics of sampled carers and cared-for persons

Until the beginning of July 2010 we were able to conduct 59 interviews, 40 in Hamburg and 19 in Dresden. One of the interviews turned out to not fit the requirements during the interview, so it was not transcribed afterwards and not

included in our evaluation. The total number of interviews included in the analyses is 58.

The interviews lasted between 24 minutes minimum up to three hours maximum. Most interviews however took about 1 to 1 ½ hours. 23 interviews were carried out at carers' homes, 16 at their workplace, nine in our office, seven via telephone, and three at the Academy for Palliative Care in Dresden. The whole time spent for conducting an interview, travelling and necessary small talk to warm up was of course very much depending on the place where the interview was conducted. For those at carer's home or office the average time was four hours, the maximum six hours, those done by telephone or our office of course shorter.

It turned out that it was very important for all interviewed carers to get the chance of reflecting what happened during the interview, especially to explain and excuse their upcoming emotions afterwards. So it usually took another 30 minutes to discuss purpose and problems of this kind of interviews.

As one can see in table 3 below it was not possible to fill in the cells equally. It was comparably easy to win women, high qualified living in a partnership and caring for a parent. This is not surprising as exactly this group are the majority of working carers in Germany. According to Schneekloth & Wahl (2005) 2/3 of all carers are female (see also Infratest Sozialforschung 2003, Scheider et al. 2006) and 70 - 80% of all working carers are living in a couple (Schneider et al. 2006). Consequently it was a problem to find interested male carers. Although men are catching up in spouse care, intergenerational care is still mainly in women's hand (Gröning & Kunstmann 2008, Radtke-Röwenkamp 2008). We were able to interview eight (14%) male carers, whilst their representation in our society has gone up in the last years to 17% (Schneekloth & Wahl 2005).

It also turned out to be an even greater problem to recruit carers with a lower level of qualification. This may be due to the fact that lower educated carers often quit their job when care need occurs (Trukeschitz et al. 2009). However, even those in our sample with lower level of education all have an ISCED of three, with one exception who has ISCED 2. So, even the lower qualified carers in our sample are still qualified workers. All in all we could include 21 carers being double earners with a higher level of education, and nine with a lower level of education. We interviewed 16 single earner couples, mostly highly qualified, the great majority (10 carers) caring for a spouse. 13 carers are singles (eight are higher educated and five lower).

Table 3. Level of qualification and family / household structure

	Couple, both working	Couple, one working	Single	Total
Higher level of qualification (ISCED 4-6)	21	12	8	41
Lower level of qualification (ISCED 1-3)	8	4	5	17
Total	29	16	13	58

40 of the interviews were conducted in or near Hamburg (27 in the city, 13 in the country side) and from the 18 interviews in Dresden we could do 14 interviews in the city and 4 in the country side near Dresden (table 4)

Table 4. Living area (urban, rural, west, east)

	Female	Male	Total
West urban	23	4	27
West rural		1	13
East urban	12	2	14
East rural	3	1	4
Total	50	8	58

Table 5 demonstrates that most interviewed carers live in a marriage or partnership, only 13 carers are living alone (single, widowed or divorced). This mainly meets the normal distribution in our society (Schneider et. al 2006).

Table 5. Marital status of carer

	Woman	Man	Total
Married /partnership	40	5	45
Widowed	1	1	2
Divorced	3		3
Single	6	2	8
Total	50	8	58

As table 6 shows 20 carers don't have any children, the majority of 33 carers (56 %) has grown up children (> 16 years) and five female carers have children under 16. Official numbers about sandwich carers are widespread. But for Germany Künemund (2006) extrapolates that only 14% of female carers would be in the position to work and care for children and older people at the same time. In our sample several carers live with children older than 16, but still perceiving their presence connected with additional work. If we include all of them there are 18% carers having children under 22 living in their household. This percentage is even greater than in the German society represented.

Table 6. Number of children

	Female	Male	Total
Without children	16	4	20
Children > 16	29	4	33
Children < 16	5	0	5
Total	50	8	58

Table 7 describes the sample according to gender, age, living situation of carer, weekly hours of care, weekly hours of work and the age of the cared-for person:

Table 7. Socio-demographics

Gender	F	50
	M	8
Age	20 - 29	1
	30 - 39	1
	40 - 49	12
	50 - 59	33
	60 - 69	10
	70 - 79	1
Living situation of Carer	Single	8
	Cared-for Person	13
	Partner	12 + 6
	Partner and Children	7
	Partner and Cared-for Person	3
	Partner, Children, Cared-for Person	6
	Cared-for Person and Migrant Care Worker	1
	Own parents and cared-for	1
Weekly hours of care	Once a week	5
	Several times a week	16
	Daily	16
	Around the clock	21
Weekly hours of work	0 - 10	5
	19 - 29	16
	30 - 34	7
	35 - 40	30
Age of cared-for person	59-69	11
	70 - 79	9
	80 - 89	25
	90 -100	13
TOTAL		58

The great majority of all people in need of care is 80 years and older (38 of 58), 13 are older than 90 year. One cared-for person is 59 and in so far doesn't exactly meet the criteria of our sample.

Against our first agreement we also included six carers whose relatives died already several months (up to two years) ago. Five of them got in touch with us because they were interested in taking part of the interview. When we told them that we were asked to interview only carers in the actual situation of caring they argued that we would not get the “heavy burdened carers” by doing so, because they themselves would not have been able to take part in an interview during their caring time. So we decided to not look actively for this group of carers but including them. In one case the cared-for person died in the time between the appointment and the date of the interview.

As presented in table 8, the biggest group are female carers caring for their mothers (26). This is quite comparable to data from Schneekloth & Wahl (2005) who could show that persons in need are cared-for to the greatest amount by their partners followed by daughters. Whilst spouse care is mostly carried out by retired couples, for working carers intergenerational care is much more common (Lamura et al. 2006).

Table 8. Relationship to person in need and gender of carer

	Female	Male	Total
Mother	26	3	29
Father	8	2	10
Mother-in-law	3	1	4
Father-in-law	-	-	
Spouse	10	2	12
Grandparents	2		2
Friend	1		1
Total	50	8	58

Looking at causes of care in our sample, one can see that about half of all persons in need of care are suffering from cognitive impairment. This meets the statistical data in Germany which acts on the assumption of about 1,07 million people older than 60 suffering from middle or severe dementia (Ziegler & Doblhammer 2009) and more than 2,2 million people are in need of care - according to the definitions of the care insurance law (Statistisches Bundesamt 2008). The majority of the others has cancer, stroke/heart attack or carers just mentioned old age or impairment as reasons for care needs. Three cared-for persons are blind:

Table 9. Causes of care need and number of people cared-for

Reasons for Care	Person in Need of Care
Cognitive Impairment (including dementia plus additional mental /Physical problems)	29
Apoplexy / Myocardial Infarction (some also with dementia as a consequence)	7
Cancer	7
Old Age (walk deficiencies, blindness, deafness, falls)	9
Psychological problems (anorexia, depression)?	1
Others (Fibromyalgia, ALS, injury from war, spinal cord disease, genetic disease)	5
Total	58

Table 10 demonstrates the duration of care in years, which varies from 0,5 years up to twenty years. Nearly half of the carers are caring for a shorter time (up to three years) and the other half is caring already for a longer time (4-20 years).

Table 10. Duration of care in years

Duration of Care in Years	Number of Carers
Less than 1 year	8
1 year	2
2 years	10
3 years	7
4 years	9
5 years	5
6 years	5
7 years	3
8 years	3
9 years	1
10 years	2
11years	1
12 years	1

Out of these eight carers caring less than a year, three of the cared-for persons suffer from cancer (HH16, HH30, DD108), the other five carers care for a relative who's need arose about half a year before the interview (HH12, HH14, HH27, HH35, HH39). 12 carers reported caring for two or more relatives at the same time. There

are however several carers who can look back to a “caring career” and cared already for other persons before. We did not put them in the table.

The table Nr 11 consist of a list with the caring responsibilities carers have. Most carers only care for one person, but there are also carers who care for two or even three relatives.

Table 11. Number of people cared-for and their relationship to carer

	Frequency	Person 1		
1 Person	25	mother		
	4	father		
	3	mother-in-law		
	2	wife		
	8	husband		
	2	grandmother		
	1	friend		
	Frequency	Person 1	Person 2	
2 People	1	husband	mother	
	1	mother in law	mother	
	2	father	mother	
	1	mother	mother in law	
	1	mother	father in law	
	2	father	Father in law	
	1	mother	aunt	
	1	mother	father	
	Frequency	Person 1	Person 2	Person 3
3 People	1	father	mother-in-law	father-in-law
	1	husband	father	mother
	1	mother	father	wife

Description of the Care Situations

The description of the care situation covers all tasks carers fulfil to care for the person in need and included main care tasks like ADL and IADL, supervision, appointments with doctors and hospitals, management, bureaucracy and normal visits. The description of the care situation, however, also includes details about the amount of care, reasons for taking over the responsibility and the care history.

Main care tasks

IADL (basic and instrumental) activities of daily living, medical care and activation

All interviewed carers fulfil tasks which belong to (I)ADL or medical care and activation of the cared-for: A majority of carers fulfilled at least parts of hands-on caring tasks (ADL) like showering, changing diapers, supporting on the toilet, with dressing and ingestion as well as observing the intake of medicine, by themselves, sometimes supported by care services. Several carers are doing all hands-on care themselves due to different reasons (mostly because care services are too expensive or don't fulfil carers expectation towards flexibility). These hands on tasks are mainly done by carers who care for the person in need round the clock or on a daily basis.

“And in the morning I take him out of bed and take him to the shower. Presently I take him to the shower in the evenings, but normally I take him in the mornings, personal hygiene, give him incontinence care (...) yes, get him dressed, brushing teeth, washing hair, everything around personal hygiene (...) the whole programme one hour.” (DE, HH3)

Those who are involved in care only several times a week or once a week usually tend to do less physical care. All interviewed carers are supporting the cared-for in one or the other instrumental activity of daily living like housekeeping, cleaning, doing the laundry, going to do the shopping or preparing meals.

“I have only in speech marks to look after my father now, but I have to go to him every day, have to do the shopping, have to do the laundry. He gets meals on wheels, in the evening I prepare his dinner and his breakfast. Well, I need one and a half hours in the evening with the way to and back [yes] and so. On the way there I often do some shopping for him and then I have to do some laundry at home, mending, ironing, these things. And on Sundays he comes to us for lunch (...).” (DE, HH18)

Carers also report that they see it as their task to initiate activities to activate the person in need of care and “keep her going” like walks, support of different rehabilitative therapies or memory training.

„Well, I think that body hygiene and body care and the, the mental care is actually really important for older people. (...) I've also tried that she always gets up and walks some steps and if possible also manages the stairs, because I wanted to keep her fit as long as possible. Fit in speech marks, of course, considering her illness, so that I can do these things with her, going by car and so on and also getting into the car and out. And all these things. I must say, that this is real work, that, two hours are actually not enough.“ (DE, DD112)

„When the physiotherapist comes in a few minutes, she comes three times a week or rather presently twice, they have to prepare my mother in advance. I've got to see that this with the nutrition is exactly coordinated beforehand. It

always means some preparation work and no relief, no. And this concerns many other therapy appointments also in the house, that we still have at present, that are useful, but that don't mean any relief to us.“ (DE, DD112)

Supervision

Carers also report from the requirement to supervise the person in need personally or by phone calls. This is especially necessary in cases of cognitive impairment. Supervision and attendance in these cases is often experienced as very tiring. Depending on the degree of dependency some have to be attended all the time.

„You always have, I live up there [yes], an ear and a foot downstairs [yes, yes] and permanently watch and do and have to be there around the clock, because she can't walk any more, but she always has the feeling she can still do it and then she [yes] always tries to get up [to get up, yes]. Then she sometimes lies in front of the wheelchair or the couch. Well, that means you have to be there.“ (DE, HH26)

Many working carers however report that they use the possibilities of modern communication and call several times a day at the cared-for's home and check the situation.

„She still cooks. But this I have to tell her exactly in the evenings, then we write it down or she writes it down. Then I call her in the mornings and tell her again there and there is lying the paper and you'll have that and that, then I call her in between and tell her, because it won't work otherwise [yes], or else some other thing will be on the table, but she can still manage that all right. [Yes, but that means, how often do you call her in between?] Yes, say three, four times.“ (DE, HH15)

Hospital / doctors appointments

Almost all carers report that they accompany their relative to doctors or stays in hospital.

Now the last two days, I waste them, special leave for initial examination in K. for preparing the narcosis. (...) And there is only one clinic in the whole of northern Germany, namely in K., that does dental treatment under anaesthetic for patients with dementia once a week, on Mondays. There's three to four months waiting time accordingly.” (DE, HH5)

Appointments with doctors are necessary quite often. Due to the fact that doctors don't make nearly any home visits any more, this becomes a quite time consuming issue for carers and usually needs to be done during working hours. Surgeries seem to have no respect for carer's time pressure and time availability.

“The doctors for example shouldn't let relatives wait for hours if they're going to get a prescription. I've waited for two hours to get the prescription for the decubitus mattress and then it contained a wrong diagnosis so that I had to apply again. And had to come again the next day. And had to wait again.” (DE, DD107)

There is hardly any understanding for the special needs of people suffering from dementia in hospitals, so often carers decide to accompany the cared-for person during their stay in hospital.

*„Well there, there I don't demand a great deal, only basic demands of human -, my mother wasn't even washed, there. She didn't get her teeth brushed.“
(DE, HH23)*

Management

Management of the care arrangement means that the carer has to organise the whole network of support beginning with family but also including nurses, doctors and therapies.

This applies especially to the so called long distance carers, who live apart, don't meet each other daily and don't do everything on their own. In our sample we have several carers whose parents live more than one hour away. So they have to travel and arrange days off to be able to meet them (HH4, HH7, HH28, HH34, DD17). The following quotation stems from a caring son with seven siblings who calls himself the manager of the care arrangement of his mother. It shows impressively how many different actors have to be coordinated to keep the arrangement working:

“Yes, meanwhile it's the case, you can say, that many people take care of her. There is the nursing service, I guess that's what it's called, they come in the morning and make this washing and the basic service. And then comes the so-called cleaner at half past ten, but who is much more than that, also an acquaintance of the family. [Employed or on a freelance basis?] as a freelancer and she's cleaning but also warms up the soup or whatever and then the care services workers come at five in the afternoon and then comes my older brother P. at night, mostly, because he then works long always, he comes at about ten half past ten, before he goes home, he drops by. He lives, you need to say, round the corner. (...) I'm sort of playing the family manager (...).” (DE, HH28)

Also those who visit the person in need only once a week, are usually during the week often busy with making phone calls and checking if the arrangement is working.

The following quotation shows to what extent carers can be involved in the organisation of the daily care arrangement also over a long distance:

“If that's, organising from home, now the appointments, the appointments, that are made, when she goes for coffee, then for A I have to, I have to order the taxi, I have to remember that, I'm already typing in my mobile there, 'cause I also have 98 appointments, in my mobile, type a “Don't forget.” then I order taxi, so then I call her: “I have ordered you a taxi”. “Oh yes, that is nice”, I then have to call her half an hour before the taxi comes – or an hour, 'cause she's forgetting it in most cases. (...) “Mum, you've got to go soon. Are you ready?” - “Where do I have to go?” So, I have to remember, that I call exactly then, then I have but here I work and there something happens in between, then I've also forgotten it and then I think: “Well, I can't change it.”

Then she once simply couldn't leave. I call the nurse, who brings her pills in the mornings and in the evenings, regularly, 'cause then there's something organisational.” (DE, HH4)

But also carers who live closer or together with the person in need are involved in management tasks. A daughter who is caring for her mother suffering from dementia expresses the feeling that these organisational tasks never end and when ever one has things gotten organised the next barriers occur and have to get solved.

„And then (...) there was always this barrier to change something, to plan, care – what? Not? And then you had it and then the dementia became worse and you were confronted by the next task. Well I think, over ten years I have the feeling; you never come to rest in the care situation. That's what I felt somehow, that is like the feeling, like a hamster in a wheel, that never really catches up with it.“

A very special and extra intense situation is the beginning of the care situation when the carer who is usually also emotionally involved has to organise sometimes quite all of a sudden the whole arrangement. In almost all interviews carers reported this as one of the hardest times they had with caring. (Except in those cases where the care need occurred very slowly and it is difficult in the retrospect to remember the starting point.) The reasons are usually that carers don't get the information they need, that there does not exist any kind of case management which enables carers to get help from one hand and there is little support from doctors and hospitals. Besides all of this usually the carer is emotionally involved because its his beloved relative who suddenly suffers from an accident or a disease and whose life won't be the same any longer.

“Intensive care unit then, the whole full programme. (...) and then a decision had to be made several times, how to proceed, difficult to adjust, had permanent cramps. Well it was, it was terrible and, then it took a long time until we somehow mastered the situation at home and I would never have thought this, I've always thought, well you know a great deal, you know where to go, but how many contact points are you, going to, that really is a nightmare.” (DE, HH11)

Quite often the beginning of the care situation also requires the dissolving of the household of the person in need of care organise the care arrangement, clear the house of their parent, renovate it and try to rent or sell it, which can also be a quite strenuous job.

“Then I've worked here until Friday afternoon, went there already on Friday or took my free days and went there Fridays and then I did administrative things with her, then dissolved the apartment, packed (...) and then I thought, you have to do this, have to do there, well, from Friday to Saturday I basically always was in A., I always did this moving shit. Sundays I did my own household and I practically went like a, always like a machine. Then went from January to March. (...) But it demands a lot of you.” (DE, HH4)

Or carers have to adapt their own flat or the place where the person in need is supposed to live further on to his/her new requirements. Also a caring son from East Germany reports about these first weeks:

„In the beginning, it was chaotic, when the stroke happened. The mother went to hospital, she went to rehab relatively quickly (...). And then you must act and then you must read different things. I'm able to do this fast and then also to act fast. Well when she came out of rehab, I had her in short-time care for 14 days again, because I had to rebuild something here. And didn't manage all of it. And when she returned from short-time care we were actually ready, so that we knew in which direction to act, and what we had to bear in mind.“ (DD111)

Last but not least a lot of the interviewed carers are also the legal guardians and therefore have the obligation to pay bills, organise the clearing, renting or selling of the former house/flat of the person in need.

“Yes, and then there are, at home there's a bit then of course, yes well paper work I'd say, paying bills and 'cause the house is managed, I suddenly have landlord's tasks, that have to be done and this also takes some time, couldn't give an any figure now.“ (DE, HH13)

It is not unusual that carers of people suffering from dementia have to deal with the fact that the person in need spent all their money or contracted debt.

Bureaucracy

Bureaucracy is a topic which concerns almost all carers; the only difference is that some suffer more than others. In the first hand it means to write applications for the care insurance and other financial support from care or health insurance or social welfare.

“Well permanently, but really permanently there's something to arrange every evening.“ (DE, HH3)

Carers report that it takes them up to half an hour daily to deal with all these applications. Especially in the beginning of the care situation or in case of necessary changes:

„Well concerning the process, 'twas incredibly problematic to find an arrangement with the health insurance. (...)These were eight weeks when I actually, when I took holidays or overtime, did paperwork with the health insurance (...).“ (DE HH30)

One reason for this problem is that they often can't use the opening hours of the administration offices and clarify things on the telephone, because it's during their own working time. Therefore they have to do everything in a written form, which is time consuming.

Very time consuming are also the necessities for entering objections because health insurance rejects to pay for necessary assistive technology like wheelchairs or mattresses to prevent bed sore. Usually after several objections the health insurance pays for the asked help but it needs a lot of time and energy to fight for it.

“And then it came, yes with, struggle with the health insurance, the first small redresses were there and applied for a decubitus mattress, alternating pressure mattress. Really, really long, called again and again, called, it's urgent. (care) Level 1, called again (...) and then we finally, after so and so many objections, got the right one, but by then we already had decubitus level IIII, you could already see the bones. And it was a hard piece of work to get this away and in the end costs the insurance a whole lot of money, (...). All of it costs incredibly much and the insurance had to pay us for this for one and a half years, plus the operations. Well it cost them a lot that they didn't give us this mattress.” (DE, HH5)

Carers deplore that they have to ask for the same prescriptions again and again, although the person in need is chronically ill and will suffer from the same disease for the rest of his/her life and insofar needs the same medical treatment like special physiotherapy for ever. But carers have to organize the same prescription again and again and visit doctors in their consultation hour, which again takes too much time.

“The medical review board should really state, okay we accept this objection by the patient or rather the carer once or twice a week somehow and then it goes automatically. That's what it should be like and then you have your peace and quite and they also have more time.” (DE, HH5)

Carers report that the application for the severely handicapped pass - which simplifies a lot of necessary trips, like to the doctor or the shops and means financial relief - is also very tiring and time consuming if nobody informs you beforehand about the procedure.

To summarize, carers spent quite a lot of their time with bureaucratic procedures and face unnecessary barriers in several application procedures and miss special information already in the beginning of the care situation, which could save them a lot of time and energy and costs for insurances.

Normal visits

Especially for carers who live apart it seemed to be difficult in the interviews to make a distinction between “normal visits” as in former times when the parent was still healthy and tasks which can be defined as caring tasks. They accompany the cared-for, talk with them, listen to them, or go for walks. This isn't really different than with healthy older relatives but is usually additional to all the other tasks and contributes to the amount of time spent with the cared-for person, like this daughter who visits her mother once a week for the whole day:

„Yes, yes. That is, that is a mixture. I'm a daughter, you see, I'm not a nurse,, well I don't have this professional distance. It certainly is a sort of mixture of a normal visit to my mother, as I've done anyway, when she hadn't been in need of care and then plus the things I have to do myself.“ (DE, HH7)

Summary of main care tasks

All carers fulfil some of these main care tasks, but the combination is differing. It's depending on the needs of the cared-for person, the supporting network and other duties, priorities and energy of the carer.

- Some carers provide intensive care in the morning and in the evening including all mentioned tasks.
- Others provide selected support on several days a week like doing the shopping, preparing the meals and giving a weekly shower.
- And finally there are carers providing care on one fixed day per week, because they share the task with others, at those days they do either everything or selected task depending on the arrangement with others. Usually these carers are also during the week in contact via telephone with the person in need and other actors of the supporting network.

Amount of care

There is a huge variation between the amounts of care carers provide. Carers mentioned great difficulties in respect to the invitation to state their hours of care. It is not only difficult to count the average number of hours because it depends on the inclusion/exclusion of different tasks. But it is also difficult because the process of care is nothing statically and changes over time (Pearlin & Aneshensel 2004, Keck & Saraceno 2009). In every single care arrangement these different stages demand different amounts of time. So the hours of care named by interviewees are not very significant, because carers state the similar amount of care with completely different numbers of hours. Therefore it was decided to bunch the amount of hours mentioned by carers to four time spending types:

Carers who care

- Around the clock - these are carers who, apart from working, spend the time at home with the cared-for person in the same household and are often even at night available.
- Daily - these are carers who fulfil caring tasks at least once a day
- Several times a week - carers who fulfil caring tasks not every day, but on several days a week
- One full day per week - usually when living apart and in shared responsibility with other family members

Reasons for taking over care

In most cases there is not one single motive responsible for the take over of the caring role, but a whole bunch of reasons; however, usually one of them is the dominating one. In some cases carers mentioned a special reason but the real reason seems to be somewhat else, not explicitly named, but visible between the lines. In most cases “love” is at least one of the motives: There are however several carers who explicitly pointed to their ambivalent relationship towards their mothers (in law). (HH4, HH16, HH17, HH25, HH29, HH26, HH35)

Carers who justify their dedication with commitment usually argue with the standard of reciprocity. Their parents cared for them so they find it self evident that they care for their parents. But this group can be divided in two. The first group are those carers who would like to return to their parents all the love they’ve got. (HH7, HH12, HH14, HH19, HH21, HH 23, HH24, HH27, H28, HH30, HH32, HH33, HH34, HH37, HH38, DD102, Dd105, DD110, DD111, DD116)

„ Of course that's this gratefulness of the children. The parents are always there for you. In bad conditions your mum was there for you, a very humble woman and humble income, was always there for you. That is such a moral obligation. “ (DE, DD105)

“I love my mother, very simple. And giving her into other hands, as my mother never had many acquaintances herself, actually has always been a hermit, I thought she can't handle this. So, she wouldn't manage. You and mum, that is a close-knit team, that works.” (DE, HH38)

One of the two granddaughters in our sample gave love and the wish to return something to her ill grandmother who was very important to her in her childhood:

“Well it simply was my favourite grandma and so as I've already said, was a sort of down-home person, was a role model for me. Yes and from now on she was a weak person of course. And that was, don't know, was a pity, really. Where you say then 'Now you can return some things.’” (DE, DD108)

The other group confessed during the interview that the relationship towards the cared-for wasn't always simple and easy, but they feel morally obliged to look after their parent or parent (in law). (HH4, HH16, HH17, HH25, HH26, HH35, HH38)

“I also feel responsible for her human wise, because I really think, there's nobody left. Who else if not the children. And my brother is doing nothing, he's completely turned away (...). Well it's a human obligation for me and also one that I'm not doing happily. But one that is, that's the way it is and it's good and there's nothing to add.” (DE, HH17)

Commitment does not only mean commitment towards the person in need. It can also be commitment towards another person. Like this female carer caring for her mother in law confessed that she never had a good relationship to her mother in law

but is now willing to look after her because it's the mother of her partner, and she does it to do him a favour:

"I always had the impression I'm not clever enough or something. Am the wrong one for her son, but I think she's his mother and that's why I'm taking care of it. That's the point, actually." (DE, HH35)

The great majority of carers just never questioned that they would look after the person in need. Not surprisingly it's the caring partners who not even gave reason for the fact that they became the main carer. It seems to be unquestioned and somehow "naturally" for partners to take over this responsibility: (HH1, HH3, HH6, HH10, HH36, HH39, DD101, DD104, DD106, DD114, DD117, DD118).

The others are caring daughters (in law) which take it for self evident that they would do the caring (HH2, HH5, HH9, HH23, HH34, HH40, DD102). The justification as "naturally" does not mean that it isn't connected with love also. It just says that these carers never put into question that they'd take over care.

„Our mother was always right in the middle but it is all of the family. We are in the country here and it should be that way. It's a matter of course for us.“ (DE, HH37)

Several carers decided to do the caring tasks themselves because they experienced a lack of good professional support offers. They reported in the interviews that they were looking for adequate accommodation in nursing homes but there wasn't anything good available. (HH8, HH20, HH22, HH31, HH33, HH28) To belong to this category does not mean that "love" wasn't a central motive too; it's just that they thought about other alternatives first:

"I had said spontaneously I won't care for my mother. (...) Well, we were close to each other, but we also had conflicts. (...) [What made you changing your mind?] Simply the idea that she, or the knowledge that in a facility she would perish and I didn't want to be made responsible for this." (DE, HH22)

A caring daughter fetched her father back home from the nursing home because she couldn't bear to see her father so badly cared-for:

"And when you, just imagine your own father or your mother sitting there. They are put there in the morning, sliding down gradually and sometimes even lying on the ground, when she moves, it's also happened, I found him, it's not their fault. It simply is much work and many people and they can't see this." (DE, HH31)

Every now and then the care arrangement was set up in the existing way because it was the wish of the cared-for. Sometimes children had promised years ago to prevent their parents from nursing home, sometimes the cared-for person just now refuses to accept any other help (HH14, DD103, HH23).

“She's actually also said she never wants to leave, therefore it's also our will to keep her in the apartment as long as possible.” (DE, HH24)

This daughter finally decided to put her mother to a nursing home although she knew her mother would not really like to. Meanwhile it is fine for her mother and a great relief for her daughter:

“In the first place my mother wanted to make me promise that I would never put her in a home, as she called it. And luckily I've never given her the promise.” (DE, HH23)

Especially in cases where there are several siblings usually negotiation processes take place. In a few cases it seemed to be self-evident who would be in charge of the care arrangement because of the special appropriateness of the carer, because she is a nurse by profession or always had the best relationship (HH11, HH16, DD107):

“Yes, after 10 years of living in B. my dad, when mum died, came back to me to D. He surely knew that, as I'm a nurse, he'd be in good hands. Certainly my sister in B. wouldn't have managed as I did.” (DE, DD107)

There is also a group of carers who argue with costs of professional support which prevents them from quitting care and organising a nursing home. Those carers refer to the high costs and freely admit that it's mainly a decision driven by economic reasons. In two cases carers remarked that they never had a very good relationship towards their mother. (HH17, HH29) In the other one (HH18) the carer would very much like to reduce her amount of care but she can't because of financial reasons which don't allow her to buy additional support.

„At that time she was in an old people's home then. And there she actually felt quite well. We've always thought about making it completely so, because. The problem is that it costs a lot of money. (...) But my brother is self-employed, he would have to stump up money and that means he would contribute some € 1200,-.“ (DE, HH17)

“Well, for one thing because of the dosh, for I don't want that the inheritance ends in one of these homes, honestly.” (DE, HH29)

Two carers without own children told that they always planned to take over care for their parents because they never had own children and see it like their societal contribution. (HH13, HH15)

“I have always myself, had an opinion, yes as I had never taken a break, a sabbatical for my own children, I'd do it, when my own parents would need me.” (DE, HH13)

One carer explained under tears that caring would be her purpose in life, because without their dependent relative she would be completely alone in the world (DD112) because all other social networks broke down.

“Positive for me is that I know that they're in good hands, that is the relief for me and also the aim to continue there. And that I have them as long as possible, or else I'm all alone (cries).” (DE, HH112)

One carer confessed directly what others only mentioned implicitly that they decided to take over the care because doctors said it would last only for a very short period and they wanted to accompany their parents in this special period at the end of life. But then the parent recovered and lives now for 10 years. Now she doesn't want to expect her very old mother to move, but she wasn't sure if she would do it again if the long period of over 10 years would be already clear before.

“And it developed this way, well, ten years ago she got serious heart trouble and then the doctors told me that she'd have some six to eight weeks left and then I left the school service, the full school service and said, good, I want to care for her the six to eight weeks and take this time and I took time off without pay. And then she simply recovered and now it's been ten (laughs) years.” (DE, HH32)

The motivation why carers take over the caring task are manifold, but love, commitment and self evidence are the most relevant; obligation, lack of satisfying alternative and financial issues however are present as important patterns as well.

History of care

In this chapter we would like to focus more intensively on the fact that caring is a (sometimes long lasting) process (in the average in Germany about 8 years) in which the involved actors usually pass through different phases.

Carers in our sample divide between different stages, as far as they experienced them already:

- Beginning of the care situation (1)
- Day to day routine after a while (2)
- Special occasions - crisis (e.g. necessity for hospital stays) connected with necessary changes in the care arrangement because of progress of the disease, sometimes leading to institutionalisation (3)
- Terminal phase (4)

“I'm now excluding the phase, that is exactly now, my mother's phase of real palliative attendance and phase of dying since, since the beginning of the year already, where we clearly or the experience are very clear, that the lifetime is coming to an end. This is an extremely demanding time. (...) That is why the situation is currently not typical for the last ten or twenty years. Now we are at the turning point.” (DE, HH8)

Phase 2 and 3 can in some cases occur repeatedly mostly then with increasing progression of the care need and additional adaptations. These phases are a bit different from those of Pearlin&Aneshensel (1994) who split the caring process into three phases consisting of long main support phase (without professional support at

home) escalation phase (what we called crisis) and a phase of institutionalisation, which means that any kind of formal help is included. We disapprove with Pealins & Aneshensel (1994) model because the beginning of a care situation can be quite different and start either slowly almost unnoticed and others start with a huge crisis.

The perspective of carers towards the caring process and the influences on their lives is (next to other variables) also very much depending on the phase carers are actually in. In a cross sectional study like ours, carers of course also report about the care history and summarize their experiences in the past caring process, but we have to be aware of the fact that this interpretation of the past always happens in the light of the actual situation. What makes it difficult to compare carers experience is the fact that they were not all at the same stage in all interviews. We would like to clarify this point with some examples:

Several carers care for a person meanwhile living in a nursing home. In the interviews, however they report about the whole caring history, about the different services they used, the network they tried to establish, the amount of hours they cared and all the difficulties they had to face including the impacts on their own health, but finally came to the point where they weren't able to deal with the situation any longer. We have to bear this in mind, when we look at strategies carers use.

The second example deals with impact of reconciliation on health and well being. There are 11 carers in our sample who had a burn out on a certain stage of the caring process. Most of them were able to arrange serious changes and meanwhile are in much better condition. Our results concerning the reconciling strategies of these carers would have looked very different by that time than now.

Several carers in our sample look back on a kind of caring career within their family because they cared consecutively for several relatives. So the impact on their work live as well as on their private life isn't necessarily only influenced by the current situation only.

So we decided to very closely take into consideration the caring phase at which carers report from certain difficulties and benefits of reconciliation.

Description of work situations

The following chapter describes the sector of activities and the types of enterprises carers' are working in, their status of employment, the kind of work they do and summarises the number of working hours.

Sector of activities

The majority of all working carers in our sample work in enterprises of the free economy (24), in family enterprises (5) and in public institutions like schools, universities, government agencies or trade unions (17). 6% are engaged as practitioners, therapists or pharmacist, in welfare organisations or church institutions.

Table 12. Types of enterprises carers are working in

Type of enterprise	Number of carers
Private sector (free economy, employed workers)	21
Public Institutions (Schools, Information and Assistance Centres, Trade Union)	17
Self employed (family enterprise and free lancer, therapists and doctors)	11
Voluntary sector	6
Without a job	3
Total	58

By the time of the interview almost two thirds of all carers were employees, only four civil servants. A quite big part of 11 carers was self employed, two of them as a response to their caring responsibility. One was still a student and three carers were unemployed by the time of the interview (see table 13). We also included these unemployed carers, because they all are unemployed due to caring responsibilities not being able to successfully reconcile. One of the them quit her job because of caring a few months ago, two are unemployed since a few months because they were not able to reconcile properly. They serve as good examples to better understand the restriction for reconciliation.

Table 13. Status of employment

	Female West	Female East	Male West	Male East	Total
Employee	23	12	1	3	39
Self employed	8		3		11
Civil servant	3		1		4
Student		1			1
Unemployed	1	2			3

To make our results comparable with other European partners we also used the International Standard Classification of Occupations Scale (table 14)

Table 14. SCL - International Standard Classification of Occupations for European Union purposes (ISCO-88(COM))

Type of occupation	Number of carers
Legislators, senior officials and managers	2
Professionals	22
Technicians and associate professionals	11
Clerks	11
Service workers and shop and market sales workers	7
Skilled agricultural and fishery workers	2
Craft and related trades workers	2
Plant and machine operators and assemblers	0
Elementary occupations	0
Unknown	1
Total	58

Kind and quality of work

As described in the recruiting table (table3), the great majority of the interviewed carers is highly educated (37) and consequently works in corresponding jobs. The jobs the interviewed working carers do are very different: 4 CEOs (two of them self employed), 8 clerical assistances (insurance, administration), 5 secretaries, 6 engineers (5 of them female), 5 social workers, 4 teachers, 2 educators, therapists, but also a leader of the human resources development a design draughtsman.

Number of working hours

One criterion for taking part in our study was the precondition that the caring person would also work for at least 10 hours per week on a regular basis. As shown in table 15, a majority (28) of the interviewed carers is working full-time. 27 carers are working part time: half of them around 30 hours, the others at least 19.25 hours (which means half-time) and two of the part time carers are only marginal employed.

Table 15. Working hours of carers

	Female West	Female East	Male West	Male East	Total
Full-time⁸ (38,5 hours/week)	15	9	3	3	28
Part-time -closed to full time (28-34 hours per week)	7	3			10
Part-time 50%⁹ (19,25-27 hours)	12	1	2		15
Part-time less than 50% (4 and 10 hours/week)	2				2
Hours worked per week noted with "0"	1	2			3
Total	35	15	5	3	58

Impact of reconciliation on the life of the working carer

The impact of reconciliation will be demonstrated by typical conflict-and stress situations between work and care among carers, but also by analysing the benefits they face.

Typical conflict- and stress situations between work and care among carers

Impact on Work (Daily and live perspective)

In most cases the care situation has an impact on the work situation, although to quite a different extend. Along with growing demands of the care situation carers

⁸ Its different in different branches, but mostly 38,5, but in some branches full time is only 37 in others 40 hours

⁹ Part time is usually 19,25 hours (also depending on the branch), we subsumed under part time all hours between 19,25-27 hours

usually try to reduce requirements in other areas of their life; in half of the cases also at the work place. These are changes which have an implication also on a life perspective.

Above all almost all carers experience an influence on their daily work; even in cases where they report about a supporting working climate.

Firstly we describe influences of combining work and care on a life perspective and secondly on the daily work life.

Change of work situation (N=27)

One of the first conflict situations coming across by looking at the impact on work are forced changes at the work place to reduce double burden. In table 16 one can see that nearly half of all persons interviewed experienced different types of change.

Table 16. Changes of the work situation because of care

	Female West	Female East	Male West	Male East	Total
Reduction of working hours because of care	9		1		10
Changed (or lost) leading position	1	3		1	5
Lost job	1	2	1		4
Partial Retirement		3			3
Quit job	1				1
Self employment	2				2
Changed job	1				1
Time off	1				1
No change because of care	19	7	3	2	31

Reduction of working hours (N=10)

Nine female carers reduced their working hours, to better catch up with the caring demands. Again these carers have a completely different educational background, work as well in free economy as in civil service, are self employed and employed, male and female (HH1, HH4, HH12, HH19, HH22 HH32, HH34, HH36, HH37).

A female carer e.g. who looked after her mother for ten years now reduced her working hours, which was a real relief to her because she didn't feel capable of fulfilling all requirements of her fulltime job any more and it enabled her to better care for her mother. But she also mentions the negative impacts towards other areas like further development in her job, reduced salary and loss of entitlements to pension:

"Then I had the situation that I realised that you can't handle this with a forty-hour week (...) and then I myself reduced my working time to 30 hours and asked my superior for a free day. (...) The effect is of course, that for years to come I lose some pension, yes and that I've also lost income." (DE, HH19)

Partial retirement (N=3)

Interestingly nobody from East Germany just reduced the working hours, but three East German female carers applied for partial retirement because of their caring duties (one of them using the part time option, the other two using the option to quit the job earlier - DD101, DD106, DD116)

Loss of leading position (N=5)

Four carers quit, one lost her leading position. The four carers who quit their leading position have a quite different educational background and quit their leading position to be able to meet all the requirements from job, care and family. (One man and three women with ISCED 3,4,5,6, two carers from east and two from west - so there could not be found any similarities between the cases DD105, DD109, DD113, HH13).

"Then I had to change something and I put my profession in second place. Well I'm giving up my senior position and I'm reducing work. And these are things that had determined my life before that. And now I have totally different priorities. There's been a cut and I also still don't know what will become of it." (DE, HH13)

Despite of those four, another female carer lost her position as a consequence of the ongoing double burden she could not cope with according to her line managers (DD112).

"Well, until last year, before I went into rehab, I must always say this, I had a management position. Worked for 300 people, who worked in the field. (...) And when I returned from rehab, and I returned on sick leave, because I couldn't find rest at all during that time, I was signed off for some more time, and after that I wanted to return to work. And yes well I my company, my firm, I couldn't find my office any more, because it had been cleared. And my name was gone, and everything had changed. (...) Not able to work under pressure and, not up to the task, as a woman. Yes and then there was a personnel talk, and this personnel talk said, that I should get lost!" (DE, DD112)

One caring son from East Germany reported a career slump because of care (DD111).

“Yes I've never made any progress (...) Then some two, three years ago I had an offer. The market was relatively tight. The company then always know the good field staff. A good field representative is someone who's been there for at least ten years. (...) Yes and I couldn't do this, because I've told myself, with my current, I know what I have. And when I go to him does he tolerate my care situation? Probably not.” (DE, DD111)

So a total of almost 10% faced a career slump deriving from reconciliation.

Self employment (N=2)

Two female carers quit their employment and became self employed to be better able to reconcile (HH8, HH 31)

“Yes, the next effect is that I can't return to my old work, well, to my old life, especially my old life, wandering about, you can really say, that's over. (...) I thought I can commute. But it's impossible in a hotel and then I was watching for some time, a year. Well, all in all my father was in the home for two years. An then I left my job, that is my role then and returned home and took my father home (...) I haven't found a job here. The town has 6.000 inhabitants. I haven't found a job here, also not in M. There are no such hotels, yes, I simply haven't found anything. And simply opened my own shop with my savings and yes (...)” (DE, HH31)

But also self employment is connected to huge efforts. Carers are usually more flexible, but this flexibility is often connected with a quite heavy work load.

“That is a real disadvantage then of being a freelancer, that you're always practically being contacted. Telephone wise [Also at home?], request wise, you have, well, you don't know a weekend in that sense, but we also work at the weekend. That's why time's passing by (laughs). No chance with after work and work, especially not with care but also not with the profession, instead you have a chronic demand.” (DE, HH8)

Job loss (N=3)

Three carers lost their job because of care (HH25, DD107, DD110). One female carer from East Germany caring for her mother in law reported from her husband who lost his job at this moment when he asked about a few days off to organise the funeral of his brother and care for his dying mother:

“Yes, yes, yes, he's just said 'my mother is in need of care (...) and my brother has died and my wife can't organise all this on her own, we have to organise this' and then they said, yes we're sorry, but he has to go, then he was made redundant from one day to the next.” (DE, DD102)

A nurse from East Germany (DD107) reported that she'd lost her job because of care but now she is using this “time out” it as a reconciliation strategy and tries to extend

her unemployment as long as possible to be able to provide the intensive care her father needs herself.

A few days before the interview the employer of a female carer (HH39) caring for her husband, had told her that he would not prolong her fixed term contract again, because she had called in sick too often (either she was ill or she had to join her husband to doctors appointments). (In our sample she was still counted under employed workers, because she still worked by the time of the interview.)

„I have a short-term contract, well, two years, and it was short-term already, was extended for a year, was extended again and now should be turned into a permanent one, but because I've been ill for such a long time, I was told something else, but learned of the mistake today, 'you've been ill too long, you haven't been because of your arm, perhaps you've been because of your husband or so, you've been ill again.' (...) And they knew this, that I have a husband in need of care, it might become even more, so that perhaps I must go to the doctor more frequently and that is not so good for my employer.“ (DE, HH39)

Quitting the job

To quit the job would be an option most carers could not imagine. The majority referred to the necessity to earn their or their families livelihood and the negative impact that early retirement or time out would have on their pension.

Nevertheless also quitting a job can be an option when the pressure of reconciliation becomes too huge. So a female carer in a sandwich position with three children (two of them still under age) quit her job overnight when her mother in law suddenly was in need of intensive care and she didn't see any other solution. In her case at the same time there were great changes at her work place which were connected with growing expectation towards her dedication.

No Professional Enhancement

Several carers also deplore that they were not able to professional enhancement because of a lack of energy:

„When I'm looking back to that time today, I'm also thinking, I've in that time, so to say I've tried to do my work after all. I didn't make any progress for years then, well, the reason was, well, actually you were busy simply managing, what was there, the care as well as the work, but there was no idea of further development any more, at work. I also wouldn't have had the power.“ (DE, HH19)

To summarise, a majority of 32 interviewed carers did not change the amount of work because of care. 21 carers, however, reduced their working hours, took time out, quit their job or lost it. Together with those five carers who reported a slump in their

career we have almost half of the working carers in our sample who reported an impact of reconciliation on their work situation.

Influence on the daily work situation

Carers do not only phase impacts in the long run, but also in their daily work life.

Concentration and productive efficiency

The majority of interviewed carers face an impact of reconciliation towards their daily work, like problems with concentration at the work place and a reduction of their productive efficiency.

Reasons are mainly fatigue and exhaustion, because of sleeplessness and hardly any time for oneself:

“If you only get three hours sleep you're not fit early in the morning or yes, if being afraid has an influence on concentration, quite certainly. With this somehow my routine for years was a help, with which I had some steady, well, no insecurities turned up there.” (DE, HH23)

Another reason for a lack of concentration is thoughts and worries about the depended relative unattended at home:

“(...) and that my mother wouldn't forget turning off the iron or the oven, 'cause then in the end a high-rise building would stand in flames. You're somehow worrying about such kind of things. It's only that she, that perhaps she's lying helplessly on the ground somewhere, this would be the worst but it's also a danger for others. When the dementia increases (...)” (DE, HH35)

Fatigue and worries go usually along with several consequences. Carers report that they observed themselves doing more mistakes at their work:

“And then my line manager asked 'Why have you been making so many mistakes recently?' I say 'Well, I can't tell really'. You can't say 'I've got more things to do at home than usual. That's why I'm making mistakes.' That's actually not the reason. Mistakes simply happen. You can't find a real reason for it. I can't say 'It doesn't happen if I go to bed half an hour earlier. Or 'It doesn't happen if I.' I'm not thinking about my husband when I'm at work doing my job. But nevertheless I'm making mistakes and am forgetting this or that. (...) (DE, DD104)

Another carer reported that she was afraid of changes at her work place and new requirements, because she feels an extreme lack of energy to fulfil new challenging tasks.

„(...) from this feeling of being under heavy pressure there comes the feeling: 'Oh God, not so many cuts and changes', because they then cost some more extra power at work. Well, there I'm not the one who shouts 'Here' and is secretly happy about it. I always realise that I'm happy when everything is going its usual way at work, but jobs aren't like that anymore today. That fits, well, that doesn't fit somehow. Well, it's really difficult.“ (DE, HH19)

“Yes it basically has two things. It makes me dissatisfied, my professional life, in speech marks, makes me dissatisfied because I have the feeling I can't give 100% at work, but I can't ensure the care 100%, and I can't do anything for myself. And that is a situation, a hopeless situation that I can't influence. I can't say I'm doing less at work. The only thing I can say is I organise the care differently.” (DE, DD104)

A female carer who is only partially employed would like to extend her profession but doesn't find the energy because of the care for her mother. So a lack of energy does not only have consequences in the short term but in cases like this also in the long term:

“Well, to reconcile care and job would only be improved for me if my mother wouldn't be. Well, then I'd have the feeling that so to say because my boys have moved out I would have so much power and time, that I could take care of things. And I have neither the time nor, well, I still have the feeling somehow with some rest I could come to an idea in my head, what I really want to do now, where I want to do what.” (DE, HH17)

Eight carers (3 west, 5 east) claimed that reconciliation did not have an influence on their work. Reasons therefore are either that the care situation isn't perceived as so heavy or that they just don't allow themselves to let the care influence their work.

Two carers care for a person in need with comparably little care need:

“Well, between care and job, no, can't say really, well, as I said, between care and private life, but I can't between care and job, I can reconcile them well.” (DE, HH2)

Another reason is that the carer is able to not take the worries to work and rather see the work as a time off. Carers can concentrate on their work when they know that the person in need is in good care.

“Yes, because in my profession I'm, I'm gone and then I don't really care, then she is in day care and if something happens then I always think, yes, ok, fire brigade and police, there's everything, neighbours are there as well.” (DE, HH17)

The interviews with some of the female carers from East Germany give the impression in their diction that they know they are depending on their job and therefore “don't allow” themselves to let the care influence their productive efficiency:

“I have to do my working hours and afterwards I went there and did some things that needed to be done. Always with a bad conscience towards my younger daughter, because she should see her mother off and on. Who's still a teenager. And apart from that, that I have cut back work wise, it's simply not possible. Both things had to work out.” (DE, DD115)

Another caring wife formulates again that she simply has to be functional:

„Yes, well, I really have this, you come to a point where you say 'Oh my God, you won't make it.' And there I thought 'no, the end, you'll make it! You must.' Well, you need to tell yourself, you have to make it and then I have laid out

my scheme properly, what has to be done and you can make it. (laughs) If you want it, you can make it. And the time, it's my time now. Well, otherwise you can't make it. (...) That's why I was thinking at work, that's work, well, I really had it 'Now you're here at work, clear head'. Well, but it takes some effort, well, you can't make it in the beginning. Really not. And yes then I took the effort. (laughs) But I've made it, I'd say. Yes, and that is really important (spoken silently).“ (DE, DD113)

Difficulties carers face at the work place

Some carers face also difficulties which are deriving from the work place and carers often perceive it as a reaction to their life situation. But there are also difficulties at the work place, which have nothing to do with carers personal situation, but intensify reconciliation problems. Reasons seem to be difficulties with the line manager, and no willingness of the company to allow informal agreements with employees.

“You know, you have a superior, and the superior wants the job done. And you can't always go by the book. If you're bound that way, of course, that you have to leave at a certain time and other appointments are more important, that's not always easy. And the superior doesn't like this very much. Ok, let's say the appreciation (...) is a bit left behind. It's not always possible, isn't it, like the motto. (...) Well, it's, it's not really seen as a topic, what is attractive, no, no. I mean, old age isn't attractive anyway, disease is not attractive, disease and both together neither.” (DE, DD116)

Carers who are not allowed to ask for time reduction or some kind of flexibility with their time schedule experience this as great difficulties.

“And had a heck of a trouble at work, because I was away so often and had to leave in between and: 'That's not possible!' And then I said: 'Why? But I'm doing my work.' - 'But if you'd be here all the time you could work more.' Then I only thought: 'You are arseholes!' And then I always tried to explain it to them. - 'Yes, then you must get some help.' - 'Yes, but where from?'” (DE, HH38)

Line managers as well as colleagues sometimes have little understanding for the decision of their employee to take over caring responsibility for a dependent relative. Carers report that they have to listen to the advice from both colleagues and line managers to put their relative into a nursing home and perceived this as very offending.

“I'm alone in this situation. He's already told me, too, I need to become more egoistic and put my mother into a home, perhaps. That's a clear statement, isn't it? (...) No, on the contrary. I can't tell anybody that it's all too stressful for me. I must keep smiling, because if not they say, yes Ms F., if you can't make it, you must put your mother into a home or quit.” (DE, HH32)

In several cases carers had suffered from a burn out which forced them to take some weeks out and after their return they faced difficulties:

„He only said that, until I failed for half a year. When I returned, I was mobbed and that massively also from my colleague.“(DE, HH10)

One reason for difficulties carers face at the work place seems to be a general negative working climate in a company, which leads to bad relationships between line managers and employees, but also between colleagues. Reasons for a bad atmosphere are manifold, but often it seems to have economic constraints. A negative working climate also hampers informal arrangements. The following example stems from a company which is set on short time due to the financial crisis:

“And, apart from that the employer himself, no employer is interested in it today, that is personal bad luck or as you might call it and you have to go through it. Apart from that I hope nothing from him or I expect really nothing from him. That he'd do something, that's the way it is.(...) Well, social, no. (...) [This means your mood is not the best?] Below zero. Well, rather frosty already. Yes, yes and then you rather tell as little as possible at home. [So that it is not, it's not turned against you.] Exactly, then they say, if you don't have time and if you prefer to be at home, then goodbye. You'd have to expect this.” (DE, HH35)

To summarize the impact on work: Carers face several difficulties due to their work situation which affect as well the daily work situation as their working career. The fact that quite many carers feel forced to reduce their working hours, step back from leading positions or become self employed has a great influence on further working careers. In some cases it might become quite difficult for carers to tie in with their former positions and develop their career when the care situation will be over one day. That may be especially difficult because of their age between 50 and 65. Another negative impact of double burden is the fact that they feel prevented from professional development and professional growth because they try to avoid additional challenges at the work place.

But also in the daily work situation many carers feel confronted with difficulties like lack of concentration which leads to mistakes and a slow done in comparison to their usual ability to work. Despite, carers have to face conflicts with colleagues and line managers who have little understanding towards their situation.

Impact on private life

Combining work and care does not only have negative impacts on the work situation but also on their private life. It influences the care situation, family life, social life, own interests, well being and health and last but not least the financial situation.

Care

Reconciling work and care, has – not surprisingly - also an impact on the care situation. Some of these statements are just a mirror inverted to the statements concerning work. Carers would like to spend more time with the cared-for, because

they know that they are missed by the cared-for, who is sometimes awaiting them longingly.

„Because I'm in a double bind, so to say, my husband is alone at home the whole day. And every thirty minutes, that I stay away from home longer, he has to wait. And then you have this moral pressure 'You can't always let him be alone.' He'll go to the dogs if he's alone all the time.“ (DE, DD104)

But also the opposite is reported. Carers are already tired from work; don't find the time to recover after a stressful working day which can evoke strained situations.

“It became most difficult, when I came from work, was basically worn out and tired and when this task was still there. I didn't have enough patience all the time and then we started to have serious quarrel in the first years, because she also couldn't cope with it. When I didn't have enough patience or find the right words or didn't keep calm, then she really (... breaths deeply), yes she sometimes got up, ran away, locked herself into bedroom.” (DE, HH19)

Or the work takes all necessary energy and there is nothing left for the person in need:

„Well, this place in the care home now, it had some effect because of the long time I stayed at work. On the father it had the effect, that he was worse, that I took less care of him, took care of him on a smaller scale, that's how he was taken less care of.“ (DE, DD107)

Asked if they could imagine quitting the caring task, most carers denied referring to their motivation to care. Those who feel obligated or are connected to their relative with positive affection could not imagine quitting the engagement. This may be especially difficult for partners, who would feel left alone.

“Yes and my son then meant, I should go on working, well, he'd rather thought that he'd come into a facility somewhere and then stay there [yes]. Firstly he's not ready, yet, and I wouldn't approve of it. Well, if, then we both go somewhere [yes], but not one here and one there, under no circumstance! I'd think, that's not -”. (DE, HH6)

Others reported that they could not give up because of financial reasons, because professional care in a residential setting would be far too expensive:

„I can't. It's an illusion. And give up care, I can't do it either, I can't cope financially. Not feasible, even if, well, even when working fulltime. When I let him being cared-for permanently, we have reached the point where we have to go to the social welfare office. And that is, well, nobody believes this, but that's what it is. Because I have to, I have to, I have to pay, for the day care I have to pay an extra € 1000,-. And the outpatient care I have to pay completely myself. Well, this won't do. Well, I'm not a manager at Siemens, then I could afford it perhaps. In my profession it's not possible at all.“ (DE, HH3)

Especially for caring wives it can be hardly impossible to decide for institutional care because it would be so expensive that it wouldn't be enough for their own subsistence. Despite these financial arguments especially those carers with a very

high involvement anticipated that they would have to visit the nursing home all the time. This seemed to be much more stressful to some than doing the job at home.

Family Life

Most carers report that their combination of work and care has an influence on their family life, namely the relationship with their partner, their teenage children as well as their grown up children and their siblings - as long as they have either of it.

The great majority of all carers who live with a partner report that their reconciliation has an impact on their partnership, because quite often it's their partner were they first of all reduce their energy. How carers perceive the influence also depends on the support and understanding they get from their partner. In the majority of cases carers reported that their partner is their most important support and therefore don't perceive it under the headline of conflicts. But carers perceive it as a negative impact towards their relationship when they get the impression that they are not able to live up to the expectations of their partner and bothering them with own problems: Like HH4 is putting it, who cares for her mother:

"I can only say, I'm happy, that I have such a tolerant husband. [Yes.] Yes, really! [Yes.] A different one would have left me already, I believe, because I, as I said, I'm not only under a pressure of time but also mentally. [Yes, of course.] I sleep badly, I'm annoying my family with my sorrows and I'm also restrained myself." (DE, HH4)

Conflicts also arise from the fact that partners do not understand and want to get more attention, which the carer is not able to give, because of exhaustion.

"I don't have a life anymore, I still have a friend, but that's only casually. When he comes in the evening and and he's become unemployed presently, and since he also burdens me with his problems, then I, I fly off the handle. I can't cope with it any more.." (DE, HH9)

There are several female carers (those who report that they did not feel supported by their husbands) who report that their husbands were nerved about the fact that the double burden of their wife affects their own comfort.

„And I said, I can do it, but I need a week in advance. I can't change everything instantly, because then I would sit there at the weekend and do the laundry or the cleaning or so and then my husband also won't like it.“ (DE, HH17)

There occur problems between partners, because they disagree about the engagement in care and the kind of organising the care arrangement:

"Yes, that is. My wife has a different point of view, very sceptical. And she often doesn't have the understanding for, how we, the family, manage it. And she's thinking that all this should be organised more strictly, with less

debates, with less disputes. I can only agree on that, but what's the point, reality is different. You can't bake your own situation.” (DE, HH28)

Problems also arise when the partner feels excluded from his wife engagement and worries:

“‘Outsider’, that's what he always accused me of, I always said that I arrange it with my sister. And we excluded our partners, come what may. I didn't let him get involved. And this lead to, this was a point of contention.” (DE, HH37)

In those cases where there are still children living in the family, children are affected, because the lack of time and energy, the tiredness and impatience of their mothers, who are exhausted from caring:

„But of course there are points of friction, of course, that's clear, if you're stressed completely and then comes a remark that you normally (exhales) and you go off the deep end, then the family often doesn't understand [yes, of course]. Well, absolute overload, basically.“ (DE, HH23)

Carers who are also grandparents report that they miss the possibility to intensify the contact to their grandchildren.

“(…) And, yes, and then you're already, you're a grandmother, you're a mother, grandmother and somehow, yes, that you can't simply say at the weekend, oh, yep, look here, that's great, they have time, we're off to visit them or so, no. That is, that's hurting a little, now, well, when I say, it's a pity somehow, that you can't simply live a bit less constrained.” (DE, HH21)

One female carer, caring for 20 years now for her mother very intensely reports a great impact on their family life, because the care need arose already when her own children were really small:

“Yes, that is completely, actually the most bitter part. We always go out only in fragments. The children and I, alternately with the sons, for very short my husband and I, if one of the sons here, but this doesn't work longer than, than a three hour period. (...) But that's, yes, a sad conclusion, that over the years together, well, for example we didn't go on holiday anymore.” (DE, HH8)

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One female carer reduced her caring obligations to find the time to baby-sit her grandchildren.

“And when daughters get children und want to establish themselves in their professions, that isn't easy either. And then you actually need a grandmother

or a grandfather, don't you. (...) And then you actually have to see, now, they sometimes come to us and visit us. Then for a few days, a week or so. But then I can easily arrange it with my job, because my husband is at home. Yes, well, we manage somehow, what shall I say?" (DE, DD116)

Asked about the influence on family life carers don't mention their relationship to their siblings. This is quite astonishing because asked about support through their siblings some carers report huge fights, discords and hurts, provoked through the fact that they have to share the responsibilities for their parents in need of care (more about this see below).

"That's another bad issue for him [yes], he's finished with them for the rest of their lives, what happened there and all [yes]. Well that's, that's getting on my nerves the most, because the children can see this and almost can't hear it anymore and – what, what's disturbing most with all this. Care is in the background, well, I think that's worse." (DE, HH26)

To summarize problems within the family: most carers report that the fact that they care and work is a burden to their family life and causes difficulties because family members suffer from a lack of time and energy also in their relationships.

Own life

Most carers asked about the influence of reconciliation of work and care on their life, do not report the greatest influence on care or on work but complain about a huge impact on their own time, their interests and their social contacts. They seem to use all their energy and their time to keep work and care going. The consequence is that they often neither have (enough) time nor the energy for their own interests. This is a phenomenon all carers seem to be affected from, although with differing degrees.

"Well, we used to have a couch, I've disposed of it meanwhile (laughs), well, not only, because it was old, but simply, because I can't use it. Was only standing around, well, what normal people do, come home, throw off their shoes, lie down on the couch and read a book, well, that they can hang around, I can't do this at all. I come home and first thing my husband makes demands." (DE, HH3)

So several carers (HH10, HH9; HH6, HH14, HH15, HH18) summarize the influence on their life with the statement, that they "don't have an own life anymore" or at least no time for themselves left at all.

„Well, my life's completely changed since then. Well, in the beginning I had the strong feeling of not having an own life any more (...)." (DE, HH10)

In the following we split the answers into an impact towards ones own interest and towards social contacts.

Influence on own interests

“Well, that's certainly, what has changed most: leisure time. (...) Holidays in the sense, that I had some time off, I haven't had since August last year and presumably I won't have any until summer, even if I have a complete week off then. Real holiday is cancelled.” (DE, HH30)

Almost all working carers complain about a negative influence on their own interests.

The reason is mainly a lack of time:

“Well, that, because, even if you say 'I work twenty hours', but I don't have any leisure time somehow. Other people have weekends. I rarely have such a weekend. Such a real weekend. And I also sometimes have, I have to clean or something. Well, I see that all my things are somehow going down the drain, may it be paper work or something.” (DE, HH33)

What is mostly completely missing is the option to do something spontaneously, because carers never can predict the requirements of the care situation or have to organise a substitute.

“What's difficult for me, or let's say, I'd say becomes more and more difficult, that's this growing, it's becoming more and more as well, inflexibility. That you can't say spontaneously 'Look here, the weather is really great, I quickly want to run up a hill', see, something like that. You can't do this anymore, because you haven't planned it beforehand and nobody else isn't there.” (DE, HH21)

Carers know that they could arrange some free time, but - as so many things in their lives - it has to be organised, which sometimes just takes too much energy:

„ It's actually like having a baby, only worse, because you can take a baby with you, for shopping or what do I know. There's Baby-safe and now we're going, but here you have to be there and, yes, I find it more extreme [yes, yes], you're really bound, yes.“ (DE, HH26)

Especially those carers who are cohabiting with a person in need suffering from dementia are often not able to leave the home at nights:

“We have, I used to go dancing in the evening three times a week and now, yes, nothing's left. We've given it up completely. (...) We would have gone on with it, but we had to stop it. It didn't work out, yes.” (DE, HH26)

But carers also give up own interests like reading, which can be actually done at home, because they feel too tired and can't concentrate:

“I'm a Thomas Mann fan, I love Buddenbrooks, but I must honestly say, if I didn't know them, I think, I wouldn't be able to read it through now. I would simply lose the plot.” (DE, DD104)

Only two carers don't report any negative influence on their personal interests, and these are two carers who are relatively little involved in caring.

Influence on social contacts

Statements on the influence on social contacts however vary much wider. Also here quite many carers report a reduction of social contacts and a decline of their social

network, however not everybody. A huge difference between caring for an older person and parenting seems to be the fact that social contacts usually grow with the birth of a child and they decrease with an increasing care need. Quite a lot of carers report about their very small circle of friends. They trace it back to the fact that old age and disease are frightening.

Reasons for reduction are firstly the behaviour of the person in need (because of disease driven behavioural problems) or other difficult consequences deriving from a disease, like an artificial anus, which make it difficult to meet other people (HH1, HH10, HH14, HH15, HH18, HH30, DD105, DD117).

“It hasn't come that far that people cut us or something, not at all, but you notice, nevertheless, we have spoken about this, we can't invite them anymore, it's not possible.” (DE, HH1)

Friendships also break because friends can't cope with the caring situation and rather retreat. (HH8, HH38, HH9)

“Big cut. An extreme cut, because changed totally, well, or we changed. For some very close friends, they have completely withdrawn, (...).” (DE, HH8)

Or friends have difficulties with the behaviour of the carer who seems to be in permanent trouble and never time to meet anyway:

“And one day I was so mad myself, well, with me also – well, my friends, they've all broken up. They said: 'Hey, let us alone, we can't hear this anymore. You never have time anyway and when you have time you sit there crying.' And one day I stood there alone.” (DE, HH38)

The unpredictable health condition of the person in need makes it sometimes difficult for carers to keep appointments with friends, which also can lead to a decline of a social network.

“Yes, well, I'm going out in the evenings now and then. If, but that's really a spontaneous thing. Well, if I see she's fine, then I'm doing it. If I see she's not well, then I cancel. And it's like this, that over time my friends have become less and less. And now there are only two or three friends, yes.” (DE, HH32)

Several carers also explain the influence on their social life with the fact that they are often too tired and exhausted to go out with friends (HH2, HH7, DD105, HH4, HH32)

„Because when I come home I can stand, you can put me against a wall, I sleep. It's not always stressful, but this permanent stress and this constant effort to keep her in a mood. To get things done and then also to work in addition to all this, well, then it's like, when I'm driving myself, sometimes, that in the car I'm afraid of falling asleep. [Yes.] I'm so stressed, it's taking the last energy out of my body.“ (DE, HH4)

“I also need much rest, well, I'm taking it, that I simply, yes, allow me some rest, by reading or doing nothing or, yes. Well, in the beginning I have made

appointments and so and that was really stressful for me. Now it's simply that I go for a walk or, yes.” (DE, HH32)

But there are also carers who don't perceive a decline of friendships. These seem to be all carers who either have rather little caring responsibility - or were able to include their friends in their caring life. (HH20, HH33, HH34, DD111, HH5, HH17, HH22)

“We have many, we have many many friends. And they're also good friends, who, in this situation, are still friends after years. Who haven't turned away somewhere and we are not able to party, but who support us, and where we can say 'Come to my mother. Come for half an hour, I need to go.’” (DE, DD111)

Or the depending relative is forced to accept that also the carer has own needs which have to be treated respectfully:

“No, well, I simply refused this, now it's like, when I'm sitting there with friends, we need to tell her 'You know, I want to sit here alone with U. and chat. Grandma, just go.’ (DE, HH17)

Summary of influence on own life: Almost all carers reported a negative influence on their own interests and their social life and moan about an overall lack of time. Their private time is always the aspect in life, which can be neglected more easily than work, care family or partner; at least for a while. However, in most cases carers don't trace the impact back to reconciliation, but rather to restrictions deriving from caring.

Wellbeing and health

Many carers perceive a negative influence on their health caused by the double burden of reconciliation. The extent, however, varies from very little influence up to a complete break down. We grouped carers in four groups, namely those with “no or very little negative impact”, “psychical impact” esp. sleep disorder, exhaustion and tension, “physical impact”, like backache or herpes and “break down/burn out”.

Little impact on health (N=23)

In seven cases the reason for little health impact may be that the amount of care is still comparatively low. These carers mostly reserved one day per week to look after a parent in need, who doesn't have so much need of support, yet. (HH2, HH7, HH28, HH34, DD115, DD116)

„I didn't get any health problems through this, because I organise enough balance. It's an extra effort, but no, I'd say it hasn't any negative effect on my health.“ (DE, HH7)

Three other carers are at the very beginning of a care situation which slowly becomes more demanding (HH15, HH35, HH14). But a female carer looking after her

demented mother, who still lives on her own, next door, explains the little burden she substantiates with that fact that she completely accepts her caring obligation:

„No, I don't believe so, because I really accept this and cope with it inside in a very positive way. It's no pressure for me. And it's only a pressure that I have fears, could have, what the future will be like, but then I'm telling myself: 'Everything's turned out ok, this will as well.' So therefore, no, I cannot say so.“ (DE, HH15)

10 carers of this group are quite heavily involved in caring and offer round the clock (HH6, HH21, HH26, HH27,), daily care support (DD102, DD103, DD114) or intensive care on several times a week (HH37, HH11, DD114, HH24). The reasons they give for good coping are different, but what most of them have in common is that they are embedded in a supporting network, like HH21 and HH37 who are supported by partner and sister.

“(takes a deep breath) I believe, I've put on weight, because I don't do that much sport anymore (laughs), but concerning health? Well I had insomnia, sometimes. I've also consulted a homoeopath sometimes, if I could get a little, let's say, stimulant or something. I don't know if it was useful, but it didn't really show an effect on my body, it actually didn't, I'd say.” (DE, HH37)

Especially their support network enables them to find abilities to get enough “time out”, do some sports and care for their own well being.

„No, actually not. I manage, I manage alright. I'm going on with my sport all the same, I insisted on this. I say 'I can't reduce it, I need this as a balance, that's what it is.' Otherwise it would effect my psyche, if hadn't the sport, one, two days you have to say 'I can't at the moment.'“ (DE, HH24)

One carers argues that the main reasons for her well being is the ability to sleep in defiance of all worries and challenges:

“Yes, I'd call it a balancing act. Well, there are good days and bad days (...). I certainly have a strong constitution, but I also have my times when I'd rather sit in a corner and say, leave me all alone, please, and luckily that's something I sometimes do. And I sleep, luckily I can sleep very well, that's my capital, I keep telling this. If I'd also sleep badly now, I'd go mad.” (DE, HH11)

And finally there are some female carers who just “decided“ that they would not let care have an influence:

“Well, simply by saying, well pulling the emergency break, that is, early enough and so. Then I say 'No, here's the line for me.' And then I go. I go to my gym and kick off.” (DE, DD113)

Those 23 carers have in common that they have either supporting employers or are self employed or have at least the possibility to work very flexible. One works part time anyway and is in the beginning of the care situation (HH14). Eight of these carers also changed their work load or working situation to make reconciliation

easier, including quitting the job, taking care leave, reducing working hours, stepping back from leading position. (DD106, DD107, DD113, HH26, HH27, HH34, HH36, HH37)

Psychological impact

The great majority of the interviewed carers reports that the reconciliation of work and care has or has had a great impact on their well being and their health. Most often reported impacts are sleep disorder, a great tension and a general lack of energy. A lot of the interviewed carers feel really exhausted (18 carers, 10 from west, 8 from east). This quite often is also related to tears and emotional out bursts:

"(...) in my case the effect was that I got lost in tears quickly, disappeared for myself a long time, at least two hours. You simply sat there and then you simply, it all came out, I don't know why, but it came out." (DE, DD108)

One explanation for the health impact is seen in the problem that the end of the caring responsibility is not to be foreseen:

"And you can become ill fast with this also. And I believe, it's this pressure, it's this pressure and the uncertainty how long it will last." (DE, HH22)

In this context several carers confessed (usually under tears) that they wish the care situation would have an end, by knowing that this will only be possible in connexion with the cared-for's death.

„Well, I've been a carer for over ten years now, I think, worn-out and tired myself somewhere, that I don't let me realise that twice a week is enough. (...) Well, there have just been two situations, where I returned home from my mother or something around this happened again, where I was really sitting here at home crying and saying 'I can't stand it anymore and it should really be over now and she should pass away now' (cries). And then I felt terrible about myself, because you think, she should not – she should die when she wants and not because I can't stand it anymore.“ (DE, HH19)

Exhaustion can also lead to aggressive and nerved feelings, which usually again cause a bad consciousness and stress:

"Well yes, don't know really, if you have this overload situation, well, it often happens to me that I'm absolutely on edge and stressed out. Or the feeling 'that's enough, now, I want to go on rehab and don't want to hear anything from anybody' or so. And of course, this has a strong effect. (...) So that I've often thought, so if my husband tells me now, that we, that he doesn't get enough time from me, I mean marriage wise, that I say then, ok, I can't do it anymore." (DE, HH17)

Also depressive feelings are going along with caring responsibilities:

„And that is, well, sometimes I was so desperate that I didn't have any vitality any more. I simply couldn't laugh anymore.“ (DE, HH10)

“That's something where you must say, I should find some free space for myself. Then I can put something in this free space to give me pleasure, then I'm more balanced inside and have fun and then I can be friendly to my husband again. And the bad thing is, I know it, and nevertheless can't put it into practice. I simply don't have the power and the courage to say, that's the way it is, you have to.. That's difficult for me.” (DE, DD104)

Many carers reported sleep disorders as a reaction to worries and their heavy work load:

„I sleep worse there. So I'm sleeping better now, when I'm at home undividedly, for example. You're simply more tensed, as carer with a job. But what shall I say. It's a colossal time of tension, of course. And I don't know, if anybody could do it single-handed. He would have to rely on help somehow from society, from relatives.“ (DE, DD110)

“In the day I'm a tough one and make and do and struggle [yes, yes] and talk and make and do, but at night fate' coming down on me [yes, yes] and then I don't sleep and then I'm toiling.” (DE, HH4)

Burn out which lead to break down

11 carers reported that they developed of burn out which was so heavy that they couldn't work for several weeks up to half a year. All carers who reported sentences like: “I had a burn out” (HH13), “I broke down” (DD105), “I completely freaked out” (HH4), or “I completely collapsed” (HH16) where subsumed in this group. The main reasons are in all reported cases that carers felt under extreme pressure and overloaded both in the care- and the work situation at the same time. We also included here those carers who reacted with strong diseases to the situation, like a heavy heart disease and the development of a heavy anxiety disorder. Interestingly in the great majority of cases the break down occurred in the first caring phase when carers were forced to quickly arrange the whole supporting system just next to their work.

In four cases a combination of heavy care load, little support and troubles at the working place caused the final break down (HH3, HH10, HH38, DD112).

„That was at the time when my father-in-law was still alive and I had to commute between two houses and care for both men. I reached the point then, where you can't go on, that is, where my nerves were really, well not outside but inside, you know. Always such a humming in my body, where I didn't know at all what was going on with me, but it was the nerves that were purely and simply on edge.“ (DE, HH3)

One caring wife reported that she collapsed because everything was too much and know is only able to continue to work and care because she is set on medication:

“I collapsed, psychosomatic disorders. I was out of the company for half a year. I was in a psychosomatic clinic, I was at my end. (...)Well, I think, I can't manage this all alone. Well, without pills you can't handle it. Otherwise I can't handle it.” (DE, HH10)

One carer even reported between the lines that she was just about to commit suicide or at least put up with her death as a side effect from drug and alcohol abuse. She felt completely overburdened with her demented mother, didn't get any support from her employer, had financial problems and neither private nor professional supporting networks:

"I don't know how other people cope, but I already felt totally alone. (...) I really went to the kitchen, opened a bottle of red wine and without dinner, without anything, I need a wine first. And not with pleasure, but simply down with it – spooky, isn't it? And one day my alarm signals went off. Then I thought, Q., if you're going on like this, you'll become an alcoholic and this won't do. (...) Yes and I quickly had a quarrel with my doctor. Thank God, my neighbour realised it early enough. I had drunken a lot and had taken a whole lot of pills and he dragged me over to my family doctor and she gave me a telling-off. (...) I almost cooked my goose. And worn-out, simply worn-out. (...) I also couldn't sleep. I didn't want to eat, I didn't want anything. I'm a smoker, I puffed like a chimney. Nervous, hectic, unfair, explosive." (DE, HH38)

In two cases carers were working in leading positions with a heavy work load and broke down right after they had organised a complete care arrangement out of a case of emergency (HH13, DD105).

"Well there came a total breakdown. But that was such a fatigue syndrome. [What will be the reason there, where do you suspect the reason for this?] Why, for one thing in the workload. I had two jobs at a supporting organisation since the beginning of the year. (...) Yes and then there came this family load. It began, yes that was an ideal year so to say (laughs tensely). And I didn't watch the first body signals, I must say. (...) Yes and then, at the weekend, it was over. Loss of speech, loss of memory. I didn't care then. I was totally washed-out then (laughs tensely) (...). Yes and then ill for 12 weeks." (DE, DD105)

In three cases (HH1, HH30, HH33) carers had supporting employers or at least no trouble at the work place and were able to deal with the care situation, but then additionally another "critical life event" happened which was the last straw to cause a break down, like in two cases the sudden death or respectively heavy accident of a friend

„I do think, that you're getting ill easier. We had a sudden death between Christmas and New Year and this was the last one, I couldn't take it anymore and I was signed off sick for some weeks at a time.“ (DE, HH30)

HH1 had a strong hard disease which caused a four weeks coma, but he had to care for his wife who became all of sudden more demented, immediately after his return from hospital and so he never had the time to really recover. He perceived this as an excessive demand which made him develop an anxiety disorder, because

"I was, that's why I was ill, short time ago. I had, or still have today, an anxiety disorder. Because I had so many accidents. I never got really fit. I

actually stumbled, from my diseases-situation into care and support and accordingly I stumbled a lot and had cuts all over the place and had blood running into the eye and, oh, I can't list what else, really.” (DE, HH1)

The last two ones just felt completely left alone (HH4, HH16)

„(...) then last year I went, I once went, that was before she moved, I went completely mad. I had a lot of stress here, then I had lots of trouble with my daughter and then on top came my mother and then that was the end of the rope, my body went on strike. Then I went into rehab and four weeks in rehab.“ (DE, HH4)

Physical impact

As well known from literature, carers often suffer from physical disorders, especially backaches:

“Namely they found out that through this tension, my vertebrae, they move. And there I can't [can't straighten up?], I really try but I'm not always thinking about it, just like now, I felt it again, totally tense and cramped and then my spine shifts and then I have pain in the arms, in the legs.” (DE, HH4)

But interviewees also report typical psychosomatic diseases like facial erysipelas or herpes zoster or slipped disk (HH31, HH9)

“Shingles, well, then I'm having my menopause, I'm already over fifty and with growing age all this is difficult for me. Here, I'm also a kind of a perfectionist. I always want everything and at once. That's another story, of course, well, this exhaustion, and then I'm disabled. I have thirty percent severe disability, because I have a herniated disc and then I also have a smashed ankle that means I can't walk normally anymore. Then I'm having arthrosis now, when it's cold, I can't walk. Well, this comes in addition to it.” (DE, HH9)

A quite alarming result is the fact that carers don't look after their own health and health prevention because they are not able or don't find the time to get the medical treatment they'd actually needed:

„I also had a knee injury meanwhile by then, where they said I don't have a cruciate ligament. Actually I ought to had it operated, but would have dropped out for at least two months. This simply would have been, it doesn't work. Well, I can't afford to take care of myself and have to put it aside. Well, sometimes it's really difficult.“ (DE, HH10)

“Unfortunately I had a car accident last year, had injured my cervical spine and this will never really heal again. The doctors suspect, because of this permanent tension, that's why the muscles can't recover really, (...) and I should go on rehab, actually. I can't do that.” (DE, HH32)

To complete this chapter we again have to stress the fact that caring isn't a state but a process with changing demands towards the carer, who has to adjust then again and again to this new demands: As a female carer who cared-for her mother for 10 years put it:

“Well, there are many situations, where I always - , actually, you're often sliding along a breakdown and then you're leading in the next step to avoid it.” (DE, HH19)

To summarize the impact on health: we can state that the necessity to reconcile work and care can very easily have a great influence on people's wellbeing and health. In cases where there is no influence either the amount of care isn't yet that high, carers reduced work already or they are embedded in a good working support network or/and have an understanding employer.

Carers who feel very burdened or even had a break down are usually under great pressure at work and in the care situation at the same time. Or the care situation is very demanding, but they don't get much support.

The worry to lose the job because of health problems is a great fear of a lot of working carers:

“And nothing would be worse than dropping out again for a long time.” (DE, HH4)

Around those carers who reported to feel heavily burdened or had a break down are quite many who also overcame the situation where their own health and well being was seriously threatened by asking for support or reducing their work load or both (HH1, HH3, HH8, HH13, HH22, HH33, HH38, DD113, DD106, DD109 DD105). So by the time of the interview their reported quality of life was much better again. And some of them even had the impression that out of a crisis new chances were born!

Financial Situation

Of great interest was also the impact of reconciling work and care on carers financial situation. To understand the financial impact it is important to know that in Germany all people in need of care with a care need of at least 14 hours a week are entitled to money from the long term care insurance which is not means-tested. The amount differs quite a lot between the three care levels and can be received as an allowance in kind to use it as a substitute for the informal care giver or as an allowance in kind which can be used to pay for professional services. The LTCI was invented as a part insurance cover and therefore usually does not cover all costs deriving from caring. As soon as the LTCI money is not sufficient the cared for person has to pay for relevant services on her own, supported by a partner. Does the person in need not have enough money their children are hold liable for a certain amount and then social help pitches in. (More about the LTCI under chapter “Support”)

There are 32 carers who report negative financial implications and another group about as big as the first one (with 26 carers) who did not.

Out of these 32 carers facing negative financial implications 19 carers are the single earner in their family or are single, 13 carers belong to a double earner couple. From those not facing any negative influence only 10 are single earners, and 16 double earners.

The other big group of 26 carers doesn't suffer from negative financial implications. The main reason therefore is that they either themselves or their partners earn enough money.

"Let me put it this way, luckily we're off quite well financially. I'd be lying if said it was not the case. And I also must say, with the savings we have, it adds. Well, let me put it this way, if you don't have a job, perhaps, and then you have such a nursing case and at home and there's not money, well, I think it would be even worse then." (DE, DD101)

Even more often it is the person in need which has enough funds to cover all emerging costs.

"Also in this case I can say, me and my mother are in a privileged situation. First of all I'm earning a lot, so that I can just spend enough money for my mother anyway. And I'm doing it. And the other situation is, my mother owns a small apartment (telephone ringing) and finally, I'm spending a lot of money, because I know that my brother and I will inherit this apartment for example." (DE, HH2)

A smaller group of persons in need gets social help and /or the payments of the care insurance cover all emerging costs.

"This thing with my mum is critical. This was close to basic existence, then we simply have to apply for housing benefits." (DE, DD105)

There are several reasons for negative financial implications. One important reason is a lower income as a result of reduction of working hours, job loss or arising care need of a partner which leads to his/her retirement. A female carer who gave up her permanent position and became self employed to be able to care for her mother underwent not only a loss of income but also got into depths because she needed to contract a debt for building up her new business.

"Very very tight, because my savings gone, his savings are gone, but not his on me. (...) But they're gone now, can't help it." (DE, HH31)

In another case both partners gave up their permanent engagement to be able to share the caring task and became self employed:

"Yes, a full decrease of our financial earnings by self-employment. Well, an insecurity concerning a return to work, to a paid, regular job. Well, the care situation has basically provoked a material state of emergency. Even if I can

say this here now, if it doesn't look like it at first sight, but with the income it's the case.” (DE, HH8)

Another carer reduced her working hours to part time to be able to accompany her mother during her last month of live - as predicted from the doctors. However, her mother recovered and the care situation goes on for 10 years now, what has a great influence on her loan and also later on her pension.

“The only negative thing, that I really have, is the financial situation. (...) And clearly, I grew into this and initially I had thought, yes ok, if it's only for a short time, then I can bear this with the pension. It's been over ten years now and I'm running short, but I can, I don't have the heart to say now, I'm sorry, I miscalculated, I must work full-time now.” (DE, HH32)

Besides the loss of income also additional payments for the care arrangement can cause financial pressure upon a family. Additional payments become relevant due to different reasons. There can be payment for professional support:

“Mum unfortunately only has a small pension (...). She gets €1100,- and then we have to pay an additional €340, 350,- to the welfare centre. Well, there's not much left, well, the argument we're doing it because of the money, in our case it's not true. But it works, we're really modest, we don't have designer clothes and we don't go out for a meal.” (DE, HH5)

Costs for transportation of the cared-for or their own travel costs between their own flat and the person in need's house:

„My wage is negligibly small for what I'm doing here. I have considerably, well, considerably less money now. Travelling alone costs hundreds of Euros. (...). I'll never compensate this through anything. Well, it simply doesn't work, that's a very big part.” (DE, HH30)

Costs for housing space adaptation:

“When we moved into the apartment, we could afford it and it was ok, but the costs exploded, purely because of additional charges that come. And they really came, well, not extra ones. The reason is also, is also my husband's illness, that I had to do more laundry and my husband and I have to bath him three times. And if it's necessary in between, we then bath again.” (DE, DD104)

In one case a caring daughter took on an additional cleaning job in the evenings just to be able to pay the debts back her demented mother had caused.

“I also had a cleaning job in the evenings in between, because, as I said, my mum's savings book was plundered. Wherever she's taken it, I haven't got a clue. And I said 'OK, we'll manage somehow and then I always put half of the cleaning money on her savings book, so that her funeral would be safe.” (DE, HH38)

The financial situation of caring spouses is often especially difficult because they not only have to pay for additional care support but also lose one income as a couple. And of course those carers who lost or quit their job feel the financial decline

especially. So it is not surprising that eight out of 12 spouses report a negative impact.

"(..) because of this my husband retired with a reduced pension. And my partial retirement was also financially planned. This retirement didn't become less because of the transition from the block model to the partial model, so that practically we had less money twice at the same time. But this didn't lead to, that there were any restrictions, or yes, restrictions of course, not really.." (DE, DD118)

Some carers report financial difficulties which are only indirectly related to work and care but influence the whole arrangement. E.g. there are several carers who bought a house, years ago but still have to pay back for it, which makes it difficult for them to buy additional care support and puts a lot of strain on them (DD117, DD109, HH18). Like a female carer working fulltime, with an own family and three almost grown up children, who cares daily for her father living in the neighbourhood (Whilst her husband is also daily looking after his parents in need of care) and she feels quite exhausted but is not able to pay for any support:

"Then we did it and bought the house and since then we've financially been terribly short to the utmost, my father is old-age poor, he can't, not for him or for us, he couldn't have contributed anything (...), but through this, because of buying the house at that time, which was inspired by the possibility of taking him in, we're financially still at our limits, so that I can't afford a cleaner." (DE, HH18)

And another carer from East Germany in a similar situation because of a divorce reported:

"As I said I had a divorce then, there was financially, because I took the house and paid off my ex-husband and then the financial pressure, it all suddenly came together. (...) This was a tough nut to crack for the whole following year, to compensate." (DE, DD109)

Some carers suffer from a financial loss, because of reduction of working hours, or job loss but their partner earns enough so that it doesn't have any real negative implications:

"Yes, it had financial repercussions, well, and I still have to deal with it, but I don't know at present. Well, this is going to be the next step, certainly with some more things following it, where I have to say, what must I change now. Well, with time, my life oriented towards this. Yes, now I'm lucky that I'm not alone, but with a husband." (DE, HH13)

To summarize the impact on financial situation: we have to distinct between three different factors which can cause negative financial implications in this context.

First of all there are reasons which are directly related to reconciliation. These are at the one hand job related issues like reduction of working hours, quitting a job or a leading position which evoke a loss of income and have an impact on the future

pension. And on the other hand care related issues, like additional payments for day care or other care services which are however necessary to enable carers to go to work and are only partially covered by the long term care insurance.

Secondly there are reasons which are “only” related to the care situation. This can be the early retirement of a husband who became ill as well as care demands like adaption of accommodation to the care needs or other care relevant support, like travel costs to physiotherapies, which demand additional payment.

And finally some carers face financial strains which aren't directly related to reconciliation, like paying back for a house, but have an influence on carers possibilities to reconcile (e.g. it is not possible to pay for the relevant support or to reduce the work load). Or they are only related to work, like the situation of the couple were both partners are working in the same company and are put on short term work for more then a year now which causes quite a loss of income.

Although more than half of all carers report negative financial implications we have to take into consideration that there is a big difference if carers “realise an influence” or if the situation “has a real impact on their lifestyle”.

Benefits from reconciliation

We asked carers directly about any kind of positive impact of reconciling. Apart from two carers, who said that they could not see any positive aspect, all carers were able to mention several important positive outcomes. However, their answers show that the positive impact is not always related to reconciliation, but more often to the fact that they care.

Positive Impact on work

Reconciliation of work and care is often perceived as a double burden. But most carers could not imagine quitting the job. Of course there are often financial aspects which make it impossible to give up a job, but quite often carers see their time at work also as a kind of “time off” from caring. Their work is a possibility to socialise and be confronted with thoughts and worries not related to care.

„But I don't know, when I don't work anymore and both old people are still there and you're somehow trapped between, well with the old people alone (laughs). (...) I'm still going to school, now, and having all those boys, these youngster around me and they're all so happy and full of gags. You can, there you're also still, you are (...). And above all I'm a little afraid that they will say then, now, when I say to my mother or also to my mother-in-law, I must go to my desk or I've got things to do, then they accept this completely, that is, and when you don't have this anymore, then you don't have an alibi

anymore, why we're not playing Scrabble with them or something (laughs).“ (DE, HH21

“But that's how I saw it, when I still went to work, this was my compensation, which also gave me power, so that at home, so that I could do all this at home. Well, this was a (...) a well from which I could take. This was the feeling, that you can do something else, that you can still do things. (...) This was also important for me. And did me good, because you could exchange ideas with others and because you realised, that you were appreciated, you, your opinion was respected.” (DE, DD106)

Carers also see it as a positive factor to work because they assume that the fact they are working allows them to include other support services and family members into caring. They are afraid that if they would not be working it would be seen as their task exclusively:

“First of all I like my job very much [yes], second I can't, I can't manage, 24 hours only with -. Although, I'd marry my husband again any time, also with this illness now, also, if I'd known before, that it would go like this, well, that's no question, but it's also good when it's divided among several people.” (DE, HH6)

The following quotation clearly shows the ambivalence carers often feel about their reconciliation. In the first hand it is seen as a double burden and at certain days carers wish they could just stay with the cared-for person, but back to work they like their job and feel better through their work.

„On the one hand it's a hard pressure, because some days, when I know, he feels bad, I don't like going out, of course. And then I sometimes feel bad on my way to work. I'm sometimes having heartache. Well, I'm afraid that something happens to me. But when I'm there and work, then I'm forgetting it, then I can put it aside and then I like doing my job. Well, I like being there and I think, it actually does me good.“ (DE, HH10

A caring obligation can also reduce the pressure on a work situation because of the change of priorities in live:

“Yes, I think it's simply a bit of, perhaps the pressure from the job, I think this has become less because of this, because it's put it into a perspective, perhaps it's also something else, if you say, well the, you're doing this until Thursday and then in fact you go to your father, you shouldn't go there when being ill, but then I'm not that ill.” (DE, HH34)

In addition there is a group of carers who report a positive impact on work. These are usually female carers working in the social area as social worker, psychologist, doctor or nurse. They report that these new experiences gained through caring contribute to an extension of their knowledge and their ability to work with people in similar situations in their caring jobs.

„Well, for one thing it's a part of experience of life, where I say 'It does me some good.' It's damn important for me, to go to my limits. The experience, that patients always have, that feelings are stronger and faster than the

brain, I had never experienced to such an extreme. Well, I think, it's good, my existence as a human, to experience my limits and it's very good for my job and also, also to see there, to say ok, without reflecting you really can't change anything, because the old reflexes are still there (...). This means, finally, it won't make me worse in my job, but rather better.“ (DE, HH12)

Especially carers who are working in the social sector report that they get a lot of experience and information from their work which enables them to do a good caring job.

„ Well, it was also a relief, to have knowledge there, how I deal with all this paperwork there, where I have to make complaints, where I have to act at once. Where there's a really precarious sphere. Which care needs there are. Well, that's the positive thing, the advantage of my profession, to know all about it.“ (DE, DD105)

Personal growth

A very strong pattern concerning positive impact is the mentioning of personal development and growth. Confronted with the situation of suffering, care need, age and decline many carers reported that they were able to overcome personal barriers. In many interviews carers confessed that they could not imagine before the care need arose that they could deal with the decline of their parents, see them helpless and naked and do hands on care themselves. Realising that they were able to handle the situation made them feel proud and happy. Quite often it was also mentioned that these topics forced carers to face the finiteness of life and their own aging. Therefore they started to think about arrangements concerning their own age.

Also the fact that carers were able to reconcile, to properly work and care, made some of them feel stronger and they reported a growth of self confidence. Especially some of the caring wives mentioned that they were forced to fulfil tasks their husband used to do like driving or looking after the financial issue. Due to his disease it was suddenly the wife's tasks to cope with the new responsibility, what contributed to an increase of self confidence.

An interesting pattern is the positive evaluation of the arisen care situation because carers, usually very work oriented, felt forced to reconsider their work life balance, their values and goals in life. Like a female carer, self employed, managing a family enterprise together with her husband reported that she was used to work a lot and realised already for a while that she should take time out, but never did. By the time her mother developed a severe care need she decided together with her sister to share the task (supported by professional services). Although caring was seen as an additional burden it also gave her the “time out from work” at those days spending

with her mother. So she told about her long walks in the afternoon sun with her mother sitting in a wheel chair, which was perceived as periods of relaxation to her.

“Yes, that I in between I wanted, was somehow burned-out somehow left my job, so that I thought, I somehow should take a break somehow or something, don't know, start something else, change something. And now live brought a change, that's what I hadn't expected at all and as I said, I had these little phases of relaxation with my mother, that that had an effect. I mean, the work wasn't done, but our firm still exists!” (DE, HH37)

In several of these cases (mostly women, one men) it obviously needed a crisis (see the burn out cases above) to make them realise that they had to change their work life arrangement. But then most of them could also see the positive aspect that their life wasn't “only work” any more.

Recognition

By asking carers about improvements concerning their situation quite often the wish for better recognition and acknowledgement of their role as a carer towards employer, own family, friends as well as society as a whole and acknowledgement was named. What hurts carers are friends who don't understand their engagement and line managers as well as colleagues advising them to better put the cared-for to a nursing home. So it is not surprising that those carers who feel that their professional as well as their private environment appreciates their engagement highlight the fact that recognition is perceived as something very unexpected but pleasant.

Support offers

Almost all working carers in our sample receive some kind of professional or informal support. Otherwise they would not be able to reconcile. However, several carers felt overwhelmed by the different kind of support offers or even sympathy they received from their professional as well as private environment. It varies quite a lot what carers highlight as very unexpected support, but it reaches from an understanding employer, medical system or own siblings to strangers at the street. Carers report that this experience to get support offers from people where they didn't expect any attention is a very pleasant experience which they would not like to miss. So they explicitly mention it as one of the good experiences in their situation.

Improvement of family relations

As a positive aspect is also seen that some families report stronger emotional bonds which were developed through the common mission. This can happen between parents and their still quite young children:

„Well no, I must say, it all worked out, we somehow have, all four of us stucked together.“ (DE, DD102)

„And it was really like welding the family together.“ (DE, DD108)

But it also happened between siblings

“Yes, sounds like a cliché, but we moved closer together.” (DE, DD105)

Good relation to the cared-for

Last but not least many carers mentioned that they find it very positive that they were able to establish a good relationship to the person in need. In most cases this is the improved relationship between daughter and mother, which was quite ambivalent over years and now they found ways to get along with each other. In other cases it was always a good relationship, but the caring responsibility for their mother deepened the positive feelings of love and affection, which is seen as a very positive impact of their caring responsibility.

If carers are able to report rather positive or rather negative implications is depending on many different factors, last but not least from psychological ones. But there are some very important influences on the work care arrangement as a female carer from East Germany (DD116) put it who told us, that she would be maybe wrong in our interviews because of her lucky situation: caring for a person with little care need and no cognitive impairment, working reduced working hours and not suffering any financial problems.

Summary

Asked about the impact of the reconciliation of care and work on their life in general all carers mention that it has quite a big impact. We got the impression that carers need to talk about the care situation was much bigger then to report about their work. This was different however, when they had negative work experiences or suffered from the atmosphere at work (Like HH3, DD104, DD112; HH10, HH11, HH19, HH25, HH26, HH30, HH31, HH32, HH38). The kind of influence reconciliation has on carers life varies quite a bit. There is a group of heavy burdened carers who summarize their experience with statements like “it is inhuman”, “I don’t have a life anymore”, “my whole life is attacked”, “I don’t have a life anymore it’s just work and care!”, “it

has an influence of 70%". Asked about the greatest difficulties they are facing a great majority named first of all the overall lack of time which has influence on all areas of their life (work, care, family, free time). Therefore many carers are afraid that they would not be able to keep enough energy for all their responsibilities, especially because of the unpredictable time the double burden will last.

At the work place its mainly inflexible working hours, unsympathetic and little understanding line managers and colleagues, an overload of work, a negative working climate or difficulties with line managers which leads to stress and conflicts. Conflicts are also perceived because carers are tired, not concentrated and suffer from a lack of effectiveness which stems from their double burden and the worries about the person in need they bring to work. Connected to work are usually also financial issues. Half of our sample reports negative financial implications due to reduction of working hours and additional payments for care support. We could also show that a general tense financial situation can force carers to stick to a work - care arrangement which overburdens them, but they don't see a way out, because they are neither able to reduce work nor to pay for additional support.

Asked about the impact on their family life carers often suffer from a bad consciousness because of their lack of time and energy towards their husbands or own children. In several cases this leads to conflicts with partners who feel neglected, but expect full attention. Interestingly this pattern occurs mainly in sandwich cases, were female carers reduced working hours because of their responsibility towards own children. Conflicts with the partner arising from reconciliation are especially burdening for carers. But there were also several carers reporting about improvement of their family relations. Experiences vary to a large extend due to the impact of family relations.

All carers with very few exceptions report an impact of reconciliation on their health. Psychological problems like lack of concentration, sleeplessness and permanent tension are most common, but carers also suffer from diseases known as psychosomatic like problems with their back and herpes. 18% of carers in our sample suffered from a burn out due to their double burden. Very alarming are the cases of carers who neglect their own health prevention and intervention (like dentist, prevention at the GP) because they don't find the time to.

Carers try to keep the influence on work, care and family as small as possible. Therefore it is not surprising that they mostly report an influence on their own needs, interests and social live. Almost all carers with great work load and severe care

responsibility report about an extremely lack of time on their own. In many cases the struggles for ones own life is visible in most of the interviews.

However, as shown above carers also mentioned positive aspects of their reconciliation tasks. In these cases the positive outcomes were much more related to changes in their private life, like improvement of family relations, better relation to the cared-for and personal growth. Carers are also happy with their double tasks because they assume that with out working they would be the only one caring for the person in need without any support of others. In these cases work is also seen as a way of time out from caring.

It becomes very obvious that reconciliation has in most cases both aspects. It has positive and it has negative consequences, as this female carer put it concerning the aspect of the influence towards her family life:

“Yes, there are two moments. One moment is the separation, that, concerning the overall situation, you can't do anything, but also the moment of standing together. Well, the, how shall I say, the qualitative closeness that you gain. (...), which means you always have to take a close look, you can't give a global answer, it's bad or good, but they are very constructive and very straining moments for family life.” (DE, HH8)

Supports and strategies carers use to reconcile work and care for an older person

Support measures

In the first part of this chapter we will describe different support measures carers' use and the amount of relief they receive from it. Afterwards we will show different strategies carers develop to be able to (better) reconcile. As the LTCI is a very important instrument which not only provide financial support for carers and allows persons in need to pay care services it also include several legal regulations especially relevant for carers, we will briefly describe the most relevant aspects.

Family

The support of once own family is one of the most important relieves of the strain. A general interesting perception is that the appraisal of family support seems relatively independent from the effectively provided support. Most important is the kind of the relation between carer and the other family members. In case of a good relationship there is always an excuse also for little support, in case of a bad relationship carers feel more easily left high and dry by there relatives.

Partners

In general partners play a very crucial role as supporters in the caring process. In the great majority of the cases female carers feel supported by their partners and know that they are depending on this support. Usually male partners are not directly involved in caring tasks but are backing their wives up by doing household chores like shopping, cleaning and cooking. This support enables carers to concentrate on their caring tasks. If partners take over hands on care it's usually the "light things" like spoon feeding, assisting or putting the cared-for person to bed. Often partners also take over a lot of bureaucratic tasks.

There are however some exceptions of male partners who are actively and equally involved in caring.

There is a husband who is the main carer of his mother in law because his wife has the salaried position and he is self employed and can work from home. (HH5)

Another husband had to quit his salaried job together with his wife to be able to take over responsibility for his mother in law (HH8).

A male partner supports his wife in caring for her father by taking over her caring obligation, when ever her job forces her to be away from town for a couple of days (HH11).

In those few cases where the husband is the main carer they all get intensive support by their wives. All carers who get support from their partner highlight the important role of their partner as emotional supporter. In some few cases the male partner is not able to actively support his wife because he has own caring responsibilities.

Five male partners were not perceived as supportive by their wives (HH14, HH15, HH16, HH17,HH18). The degree of "non-support" varies. Some partners are just accepting the situation, but not supporting it. The others make pretty clear that they are not appreciating the fact that their wife has a caring obligation, because they have the feeling that their own needs are missed out. This behaviour of their partners is a quite heavy emotional burden for these wives.

„My own health, yes, it went down the drain (laughs). Apart from the overload, where I, in fact, was signed-off sick for three weeks and had to get medical care myself, after this real complete care. One reason was, that, let's say, the support within the family of my, of my family and of my, of my sister then somehow (coughs) wasn't there and I had the feeling 'They leave me alone with all this'." (DE, HH16)

- Our sample contains 10 female and two male carers caring for their spouses. They all report that its not only the care for their partner which burdens them with extra tasks, it is also a problem that they had to take over additionally all tasks

and contributions to the common household which their partner used to do (like bureaucratic work, carrying heavy crates or doing the shopping).

“Yes and this actually also means, that I had to take over more and more, well, actually since his return from coma, he can't relieve me of anything. Well, neither gardening nor housework, shopping.” (DE, HH10)

Siblings

In the care of a dependent parent support of the siblings plays a crucial role. We observed four possible situations. Either the *carer is a single child*, feels sorry that he/she is the only one to take over care and would be happy to have sisters or brothers to share the tasks with them. (HH1, HH3, HH4, HH5, HH10, HH14, HH18, HH35, HH38, DD104, DD106, DD114, DD117, DD118). The second group are siblings who get along quite well and are able to divide the labour of caring in a way which pleases all of them because they support one another in a fruitful way, although the amount of care might be very differently divided. All carers in this group termed their siblings as an important support. (HH7, HH11, HH13, HH24, HH28, HH30, HH36, HH37, DD105, DD110, DD112, DD115)

“We have, my brother and I took it in turns and we drove hundreds of kilometres together and tried to make it somehow tolerable for her, concerning food and body care, but it was more than half of the time I spend with the health insurance, of course. (...) Yes, it changes a lot, sometimes several times a week, sometimes once a week. In other respects my brother cares for the rest and he's been there daily in the last weeks, also simply to drop by.” (DE, HH30)

Sometimes the actual support a sibling can give isn't that big because they live apart, but it helps carers also to get support every now and then:

„(...) and my brother's been here from America for the fourth time this year (...) normally he comes twice a year, that is once in spring and once in autumn, but this time he's been here four times, you see. (...) Then they also managed to relieve me, although they also want to see me, you see.“ (DE, HH9)

Especially in the case of spouse care, carers usually don't expect their siblings to support, but they are of course happy when it happens:

“The situation is now, he's absolutely fixed on me, still, clearly. But I've got a sister and she's taken pains for us. She often visited us, apart from this there, that is, if you have such an ill person in your house, then many people don't come anymore, and you also don't want to have visitors, because you think 'Oh no, who knows what comes next', or perhaps there's some situation, where it doesn't fit or so. But my sister said 'Never mind, I'm coming, I'm there.' Then she came and he got a bit used to her, so that, well now, that she can also stay alone with him for half an hour.” (DE, HH6)

One spouse carer also has an old demented mother and is very thankful that her sister in law took on the main responsibility in her mothers care:

"I have a mother, who meanwhile, meanwhile she's also in need of care. She had to slow down. Well, I also have a good sister-in-law, who lives nearby, who, well, who took a lot of things off me, there." (DE, DD113)

A female carer who works self employed together with her husband divided the care of her demented mother equally with her father and her sister, who all live in the same village. They supported each other very well, shared their sorrow, went together to a carers group and enabled each other to have some time out.

"When my sister said, she would reduce, she would do with less money and that she would reduce, then I said 'Good, then I must also be able to do this.'" (DE, HH37)

Two male carers in our sample stem from a family with many siblings. They both can serve as an example for a good working, large support network of siblings. In one example three brothers care together for their mother and organised a whole care arrangement with different tasks for each brother:

„Yes, in the main we divide this among three people, everybody's not always there and don't have time, but my personality's rather, on Mondays I'm at my mother's, well, actually today [yes], about two hours normally. I go there after work, then my brother and my sister-in-law are there, they're there on Thursdays, normally from one o'clock, cleaning the flat, doing the household, laundry, ironing, and when my mother comes from the day care centre she gets a shower and my sister-in-law prepares her for bed. That's every Thursday and the other brother, he fills the gaps a little, on Saturdays, sometimes Sundays. I'm also normally there every Sunday, in the afternoon, bring some food and then the other brother comes, he's mostly responsible for drinks.“ (DE, HH24)

Many carers, however, are not very pleased with their siblings' contribution to the care situation. The amount of care seems quite seldom to be equally shared between siblings. Its usually one main carer and the others contribute more or less. (sister: HH11, HH16, HH21 brother: HH15, HH2, HH19, HH23, HH25, HH31, HH32, HH34, DD102, DD103, DD108)

Little support is often connected with a bad relationship of this sibling towards the dependent parent or between the siblings. Sometimes old long lasting conflicts break up again in the situation of a parent becoming dependent.

"I have two sisters, one lives near X (...) and actually could do much more. It's a huge conflict between us, she never had a good relation with my father (...) is a difficult character, I might say. (...) And she says, yes why, dad wanted it that way, that you're doing all this, then do it. And she doesn't feel responsible at all." (DE, HH11)

One explanation for little contribution is the assumed fact that the other sibling isn't able to deal with parents decline. Its usually caring daughters who assume, that their brothers aren't able to deal with the situation. Like a carer who describes her brother as "sophisticated." (HH19, HH23, HH31, HH32, DD108)

„(...) another brother can't do it to the present day (...). Well, he hasn't realised to the present day, well, and can't cope with it. And I believe, she's somehow really embarrassing for him or so (...).“ (DE, HH19)

Interestingly there are several cases were the interviewed carer was willing to be the main carer, but the other siblings didn't recognise this, rejected to contribute and expressed their wish for a nursing home:

“So my sister said 'No', she can't take her in and care and had already organised a place in a home. (...) Yes, as I said, I made a decision for myself, I want to care for my mum, whatever my sister says or makes or does about it or not [yes]. And then I didn't, I didn't expect her, I was very disappointed, that I didn't get any support from her, but I didn't demand it from her.” (DE, DD109)

Some carers however reported about a strong tension in their relationship to their siblings, usually at least towards the only other sibling or to one of their siblings (in none of the cases to all others) triggered through the caring situation (sister HH8, HH12, HH26, brother HH17, both HH25). Sometimes the relationship was already always strained. In most cases the care need of a parent was the elicitor of arguments between siblings. Main reasons are that the sibling doesn't want to give enough support (from the point of view of the interviewed carer - we observe that these siblings either don't want to take over responsibility because they had a bad relationship to the parent in need, or because they are not satisfied with the kind of care the interviewed carer decided to provide). In some cases carers don't allow their siblings to take over care, because he/she doesn't do it "right" or he/she isn't able to give enough support (to far away, ill her/himself, own family). In all these cases arguments with siblings are experienced by carers as a huge emotional burden.

“Yes, that was relatively clear, because my brother had, I'd say five years or so ago, when this dementia began, written her a very long letter, where he pointed out why his relation to his mother is not the way he'd like it to be and that he's worked on it for ages, but that nothing has changed and that he's pulling out now, well, I'd simply say, bump, broken off the friendship, end of it. [And he's doing it?] He's doing it. Well, I always get €200,- per month from him, as a recognition of my effort and the whole rest he doesn't care about.“ (DE, HH17)

A caring daughter reported about her sister living in the south of Germany in the same village with her demented mother and had promised to look after the mother on a regular basis. Several times a year the (interviewed) daughter came to pick her

mother up to support her sister. During the last of this visits it was obvious to her that her sister didn't do her caring job "proper enough" and therefore she decided to take her mother with her and not return her to her former home anymore. Her sister was very upset about this "kidnapping" and since then their relationship has extremely cooled down:

„So then I took her with me and I decided inwardly 'I don't let her go there again.' So, I thought 'Then let's see in this fourteen days if she feels comfortable here' and then said to my sister, after about ten days, then she was back, 'Now, under these circumstances and so, I don't see that I let her return.' Yes, she was angry, of course (...). (DE, HH12)

Last but not least there is a group of carers who report that one good thing of the care need of their parent is that it enabled them to *improve the relationship* to their sibling. The fact that they both felt the responsibility to care for their parent enabled them to get closer again after many years of little contact. Those are all relationships towards a brother, who deals with own difficulties resp. a disease which restrains him. (HH22, HH27, HH29, HH33)

„But yes and my brother plaid an important role, well, who lives there, still in the house, always has lived there, had never moved out, is single, is ill to a certain degrade, but can still work. (...) We decided everything together and we learned to appreciate each other and found a bit together again. We came closer together and, I believe, both have, well, find this, well, he also finds it ok.“ (DE, HH22)

To summarize, we observed, that siblings and their support plays a very crucial role for the well being of family carers, especially in case of parental care but also in case of spouse care. However, very often carers don't get the amount and kind of support from their siblings they would like to have. Reasons are most often long lasting conflicts in the family which kindle in case of a parent's dependency.

Own children

In the majority carers have own children but most of them are already adult children. In almost all cases own children are not mentioned as any source of active support. The main reasons are that children have their own life with partners and little children or a stressful job and life apart. But it makes a difference, who the person in need is. Children tend to give more support if the cared-for person is a parent and less if it's a grandparent.

“We have, well, always when I had to make a decision, and I noticed something must happen, then I tried to call my children together or, if not possible, spoke to them separately, what I think, what I reckon is good. What they think about it and they have, were absolutely solidaric, they approved of it mostly, that what I had planned, what I wanted to decide or they said immediately, they would join in or with this or come here or something like

this. And then we, well, said with each step, for me it was all really coming in steps, we decided together how to proceed.” (DE, HH1)

There are, however, some carers who report that their children were great supporters as long as they still lived at home. After their move out, their mothers feel the gap their children left. In some other cases children are not happy with the care situation because they are afraid that the burden of care will be too heavy for their mother and would like her to give up the caring task. Finally there are a few cases where children (all boys!) still go to school and live at home, refuse to support their parents and reject any deeper contact to their grandmother. Only one of the interviewed carers reports about a caring situation for many years where the two children were involved in assistance in their entire youth - but not in physical care - naturally.

To summarise, in general children don't assist their parents in their caring tasks, but interestingly carers never moan about it. Usually they justify it and claim that they are happy that their children are able to live their own life.

Friends

Many carers report a decrease of friendships connected with the care situation. This is seen as a great difference to bringing up children. Young parents usually report a growing network and new relations. Carers however experience quite often a shrinking social network because either friends withdraw from them or they themselves report that they are lacking the time to keep in touch and withdraw from friends and common activities. This is a crucial problem because it happens in a period of life where support from others is extremely important. Friends are mainly important for emotional support. In cases where friends are mentioned they are seen as a source of new energy. However, in direct support friends generally play a rather subordinated role

To summarise, partners and siblings in general play the most important role with regard to support.

Workplace

Asked about their employer a majority of interviewed carers were quite satisfied with them, although they felt under pressure to be able to reconcile work and care. In their opinion their employer did already a lot and was very understanding. However, the important contribution of employers to disburden reconciliation becomes obvious in its range when working carers report about employers who are not supportive.

Against the negative background, in these cases the huge influence of employers on carer's possibilities to combine work and care becomes evident.

Legal framework and company agreements

In Germany meanwhile there exist several formal regulations which are able to ease reconciliation of work and care. Most regulations are rules available for all employees, some only for families and very few for carers. All these regulations can have a legal background, they can be a result of special collective labour agreements or they can be formal regulations of single companies.

The legal regulation only valid for carers is the still quite new possibility of a care leave for working carers invented in 2008. It entitles the main carer caring for a person assessed as "in need of care" according to the LTCI's criteria to take up to 10 days unpaid care leave in case of an emergency, which is defined as a hospital stays, sudden aggravation of the health condition which requires the organisation of a new care arrangement or terminal care.

Our intention was to ask all interviewed carers not only about their knowledge about these regulations, but also if they made already demands on this regulation or could at least imagine doing so. The answers were quite different. Most carers had heard of these possibilities and at least vaguely knew about it. Very few had made demands of the short term leave and none of all 58 interviewed carers had made demands on the 6 month care leave.

In quite a lot of cases interviewers couldn't ask carers if they could imagine to take the time out because it is unpaid and they had told already during the interview about their tense financial situation so that it was clear that they could not do without their earnings. But in general carers appreciate the idea of a care leave but are not satisfied with the actual law.

There is one carer who very much appreciated the possibility of the "short term leave" to be able to organise the new care situation of her parents. Nevertheless she didn't just take these 10 days but combined it with her holidays and spread the 10 days over several weeks so that she could reduce her weekly work load for several weeks to organise the new care arrangement.

"(...) You can take ten or twelve days ad hoc, I think. But they wouldn't have been any use to me. I portioned those ten care days over two months and made my boss a plan, that means a, a real working plan, as I needed it those days, and this were exactly the appointments, that I already had for visiting homes, talks with doctors, with the health insurance and anything around it, I had already made appointments and these days were my care days then,

and then I packed my whole own holiday and remaining days of vacation into it, so that I only had very few working days in the months of November and December.” (DE, HH13)

Several other carers could at least imagine using it in case of an emergency and called it a relief to know that they could use this option.

“I'd make use of it, yes, yes, certainly. (...) Then you don't have to use the holiday. I had, when this care situation came, I had the opportunity to take holiday spontaneously, exactly. It's better that it's not taken off the holiday, but that it's, that you can take it freely, but that it's not paid. Yes, I'd do it, yes [yes]. I very much like this, this regulation, yes.” (DE, HH7)

But the majority was unsatisfied with the fact that this time off is unpaid and claimed the same rights as working parents caring for a sick child, who can make use of 10 days paid leave per year.

Up to 6 month unpaid “care leave” (LTCI)

We also asked carers if they could imagine making use of “care leave” which offers working carers who care for a person in need of care according to the LTCI criteria up to six month unpaid leave from their job if they care for a close relative themselves and work in a company with more than 15 employees. They have the right to get back to their former work place afterwards. Most interviewed carers didn't take it seriously into consideration as soon as they realised that it's unpaid. But also for those interested in making demands of the offer the question is unsolved what they would do when the half year is over but the care need still existing.

“I've heard something, that you can, the lady of the medical service said it, you can get a release for half a year [precisely], but you somehow don't get paid. It's no use.” (DE, HH26)

Those who seriously think about this option found a solution how to compensate the loss of earnings during that time. So in two cases caring daughters could imagine to take the care leave to care for a parent and get financial compensation from them.

“Then I'd practically take my parents' money and say ok, they're paying my salary now. This would work so so. Then I'd be there, but I don't really know, how long they'll live. I'm taking the six months and then they live another five years and what will I do then?” (DE, HH9)

Nevertheless for some carers it is a relief to know that this could be a “last” option if they could not deal with the situation of reconciliation any longer.

“I only know, if I said, 'I must, now it starts', that I could say I'm staying at home. And if everything went wrong afterwards or what, I couldn't care less, I could, if my husband needed me, say 'I'm staying at home'. And that's the only thing, that I know about this act. Apart from that, I haven't thought about it.” (DE, DD104)

Interestingly also one of the male carers could imagine using the option of care leave as long as he would have a guarantee to get back to his former work place. But he also gives cause for concern because work is also seen as a kind of time out (from care) and the option of care leave would reduce his life to care.

"I say, if it was safe that you can return, this would be an option for me, to say 'You are for a while, you can take care of yourself a bit'. On the other hand there's certainly, the centre is care again and nothing but care and you're not distracted by other things.." (DE, DD111)

New suggestions from the Minister of Family Affairs

During the time of our interviews the Minister of Family Affairs made a new suggestion for a care leave law, which would offer a two years reduction of work load to part time (50%) and a reduction of earnings to 75% of the full time wage in this period. After two years the carer would have to return fulltime to his/her job but receive only 75% of his loan for another two years. There was a lot of discussion around this issue because several risks for employers as well as employees are not solved.¹⁰ But we also asked carers about this new suggestion. The following quotation summarised quite well the feedback of many other carers. They appreciate that finally the topic is discussed by politicians and they start to find solutions to a growing problem, but in detail the draft law contains still some difficulties:

"Well, this approach, that was new in the press, I found it ingenious! (...) Yes, yes, that it exists now. On the other hand, I wouldn't know now, when's the right point of time to schedule it for yourself, if it's only two or three years, wouldn't this have to be on the time, it's taking that and that long, those poor people, who then don't know, when does it begin. Right as my idea was: 'Will I actually notice when she dies?' Do I really know when I must start caring? How do I know? And I have a deadline of three years. (...) And please die, finally! How would you do this? Well, I think this time limit is difficult (...) No, I

¹⁰ Meanwhile it is a law, with the additional restriction that carers are not entitled to it if their employers do not agree. More about it under: <http://www.bmfsfj.de/BMFSFJ/Service/themen-lotse,did=168478.html>

It would go beyond the scope of this report to name all regulations. More about it can be read in the policy report by Franke & Reichert (2011), developed within the carers@work project.

Interestingly quite a lot of carers didn't know if there exist any official regulations concerning reconciliation of work and care at their work place. Quite often they have heard something, but never really dealt with the subject.

„It was spoken about, but I didn't really get informed, if it was put into practice already, that for care you can, well, for example if you have to organise something, when one of the parents has become ill (...) or so, then you're entitled to so and so many days per year.“ (DE, HH21)

Carers knew hardly anything about regulations specifically for carers, mostly because they don't exist, but also because they were not informed.

„And I'm telling lies, I believe, that has changed now with our new working conditions. (...) Well, I don't know now, if that's such a, such an internal story, or if that's by rights.“ (DE, HH4)

A carer from East Germany explains that she wasn't really interested in official agreements, because so far she did not need them.

„I believe yes. I think we have a workers' council and so. That's actually all, well, if I had needed support, I think, that, well, that you could have stayed at home for a short time. I think this exists, but I must say, I never put an effort in it. Well simply, because we managed.“ (DE, DD113)

But there exist several agreements for all employees at some companies where also carers benefit from. Overall we found the following company agreements in our interviews.

Legal rights

- Four days special leave for hospital escort

„There's one thing I've claimed. Indeed I didn't know this, because I've never read my collective labour agreement. I have a claim to four days special leave for hospital for example or bringing to hospital or other stories and now, in November, I'm taking the last two, I've already taken two. They are granted by the staff department. That's roughly like the regulation that parents with children, they have ten days per year, we have four.“ (DE, HH5)

- Reintegration into employment after own disease

„Yes, the employer, he has over a thousand employees and they have a reintegration management, which not all companies have.“ (DE, HH13)

- Time out for a few days to organise care arrangement

„(...) that's relatively generous, either with, with these care days, the holiday or the overtime or if necessary with unpaid holiday, which is not really brilliant, but, what produces a lot of work, I think, concerning the

administrative bit. But I think, we as public services have significantly more possibilities.“ (DE, HH16)

- Part time employment

„Well, we're mostly women, well, we have, I believe, 70% women in the company, and yes, consequently more women in part-time. But I think that's what this seal was for.“ (DE, HH34)

- Partial retirement

„No, I had, as I said, this partial retirement then. And I had to comply with the given regulations that you work full-time for this specific period and then retire. There's also the possibility, that you work shorter, but then for a longer period. Those who can do this, it's perhaps not bad as well. This is one possibility then. Well, for me it was very important, that I'm more at home, and he's not alone at home. Despite the possibilities that exist, but this was important for me and also as a reassurance where I could go to work then.“ (DE, DD106)

Company agreements

- Working time account

„But we don't have this anymore since last year, it's, that the hours, that you can work for the hours, so that you [such a working-time account where you can take off hours, when you need them?] Yes, yes, yes. Although I don't really find it a nice thing, because, I don't know, if, well if really something happens or so, then I had this exemption order and then they either wrote yes or no and I must catch up yes or no. I preferred this, because something can really happen at the end of the year, when you don't have any hours left, no holiday left and what could you do then?“ (DE, DD102)

- Sabbatical (Civil service)

„Yes, it's in the debate that you, well, that you can take such a sabbatical and I believe, you could use it for caring. (...) You can work towards it. You can work for half your salary somehow a bit longer whole-time, you could do it that way. But the sabbatical is unpaid.“ (DE, HH18)

- Flexible working hours

„[What are your working times?] They're, luckily, very flexible, that means, I can come and go, whenever I want. [Is this so for everybody or is this due to a special position that you have?] No, it's for everybody. You only have to do your working hours and your work really. I can, as I said, today I left work at a quarter to twelve.“ (DE, HH24)

A carer reported about flextime and flexidays

„We have, which is a real advantage of our company, we have such a flextime it's called. That's a time that doesn't contain a core time, but everybody can come when they like. (...) But in all other cases it's ok and within that limit I can also say „I must go now“ and then it's being subtracted from my time account, but I still have, I always have overtime that is summed up and you can take from that. Well, half a day and a day is no problem. We

have the possibility to take personal days through this time account also into negative hours, if you don't have any hours.“ (DE, HH34)

- Take a month off instead of getting the Christmas allowance

„It had been made possible at the company also in accordance with the collective agreement for a short time. Because also, like now again, there were too many people, however, instead of Christmas bonus to take holiday for everybody. But at that time it wasn't possible anymore, apart from special situations and it's still not in the collective agreement, but it's still in practice. (...) [Caring for a relative would be such a special situation.] Exactly. Well, within the limit of this special situation you can take this one month holiday, at least, but then not get the Christmas bonus.“ (DE, HH27)

- Psycho-social offers like a supervision group where private burden can also be worked on

„Now, it's a formal working group, to reflect anything connected to the counselling process and to learn about innovations. But it's more and more soul massage.“ (DE, DD105)

- Informative meetings for carers (this one is the only offer for family carers - offered in the civil service)

„I went to two trainings on dementia of two hours each and they came from the ZAF central office (...). also by the authorities (...) [And is this paid time or is it free time?] That's work time. Yes, precisely, I found this, I thought (breathes out loudly) that's something at least.“ (DE, HH32)

Wo

Collective labour agreement

- Special offers for civil servants

“You can do that if you have your own serious illness and in perspective of change, of course. You can be graded, half a year maximum, as far as I know, a year on half the, that is on 50% work with 100% pay, if you've worked 100% before. And I used this for half a year and that's law. But then you have to, the situation has not only to be specific, well, because I was exhausted, show the symptoms of exhaustion, so they could grant me this.” (DE, HH1)

- Time out up to 12 years for civil servants

A female carer working in a huge industrial company explains the supportiveness of her employer towards needs of working carers with general openness towards topics which belong to general health management:

“And, of course they are open towards such topics, well, there's also a health management, it's not really perfect yet, but they already have an ear and this was a good help. Well, somebody who has, employer, who hasn't had anything to do with it, yet, would probably be much harder to convince.” (DE, HH13)

Informal offers

Although it was quite difficult to get information on formal company agreements and the knowledge about the legal framework was small, interviewed carers reported a lot of informal and quite creative solutions for caring employees. Carers were mostly satisfied with it because adoption of informal regulations is quite easy to install without any bureaucratic expenses.

„[Do there exists any company agreements, something formal?] No, nothing. Everything is settled in the quiet.“ (DE, DD111)

The disadvantage is that working carers always depend on a good relationship to their line manager. Informal regulations are no claims and can be rejected from line manger without any reason anytime.

Informal offers reported from carers were:

- Reduction of the working hour e.g. reduction to $\frac{3}{4}$ of the normal working time and always on Fridays a day off
- Possibility to take a day off spontaneously
- Home office; for once a week, enables carer to do things like laundry, assistance just next to work
- Special leave
- Compensation for overtime hour

„There's also a special regulation, it's not like, that I have flextime or that it's possible without problems, that for the summer I can, when I also have to do things, simply say, I'm staying two hours longer per day and then take the, the hours off', this is not part of the system. It's an absolute exception and it costs a good deal of talks, that I can do it like this now (...). I'm doing it like this, now, that I have, as an exception, a sort of time account.“ (DE, HH30)

- Special holiday regulation; carer is allowed to take the 30 holiday days in 60 half days, so he always has one afternoon once in a week
- 10 days care leave in combination with holiday of the year, over 2 month; free days spontaneously - for 2 month halve work, full pay - allowed the organisation of the care arrangement
- Respect for carers timetable with regard to advanced training courses which are overnight
- Permission to telephone during working hours to keep contact with the person in need or make appointments with doctors
- Agreement to leave a leading position for the time caring with the option to return
“I certainly got support within the range of that I could quit the position relatively fast, I reckon, but else, no, I couldn't tell. (clears the throat) Actually only because, that my boss said there 'ok', we simply leave you alone for a while.” (DE, DD109)
- Flexibility was seen by carers as one of the most important possibility to enable employees to combine work and care. This argument is supported by self

employed carers who emphasize how important their regular flexibility is for their possibility to reconcile.

- Flexible working time:
- Log-in system and flexible working hours enable carers to care in the morning, to accompany the cared-for to appointments with the GP
- Possibility to leave the working place in case of emergency
- Decide spontaneously to stay at home in the morning and stay longer at night

“Well, that I could always say, when I wanted it. But they also told me, when they would need me. And that's really ok. And of course I tried to arrange this. But they also let me have a work in this, really. But that's independent of the care situation, that's how you do it anyway, that you ask a member of staff 'When would you like to work?'. If you're not working full-time. Yes, but I worked Saturdays, of course, and when I was needed.” (DE, DD110)

Family friendly companies tend to be more open also to carers' needs:

“Yes, yes, our company is said to be a family friendly company and I made an appeal to that, because I also said, family can't only be children, but it's also parents and it's more and more likely to be parents, I think. In our ageing society this is going to be more and more the case, and this was, certainly, this was my argument and I also asked, that you, that you extend the family friendliness also with this.” (DE, HH34)

A general positive working atmosphere is in the carers' perspective the most important contribution of employers because it allows individual solutions:

“I also believe, if you're having problems [yes], that you'll get support. Well, if I go there and say 'Sorry, I simply need fourteen days change, I have to care for my mother intensively.' Then the company would, I believe, meet me halfway and would even say 'Okay, don't take the complete ten days holiday, take five and we can manage the rest.' (...) That's in the structure, it grew historically by the company back then and the company has always been very social in this respect, good attitude.” (DE, HH24)

Attitudes of colleagues

Colleagues and their understanding have an immense influence on the possibility to reconcile work and care and wellbeing at the work place. They can function as active supporters, enable carers to be flexible and act spontaneously. They can even contribute to carer's protection from overstraining. The majority of the interviewed carers are very happy with their colleagues. Asked about the reason for the understanding and support of their colleagues these carers argue that they had a good atmosphere at their workplace and all get along quite well. They themselves tried to support their colleagues and showed their willingness to take over more work in times when the care situation isn't so demanding. And finally especially the older

colleagues often know the situation already because they have been carers themselves or they assume that soon they would be in a similar situation.

There are however also colleagues who envy the “special position” and don’t act in any way supportive. Carers usually explain this with the fact that these people aren’t able to imagine what it means to be a carer, because they have never been in a similar situation. Some carers experienced a lack of understanding concerning their caring responsibility from colleagues as very offending. Several carers reported that their colleagues advised them to put their parent into a nursing home instead of moaning about lack of time, being exhausted and bother colleagues with it. A daughter who’s mother is in need of care for more then 10 years cares for her although she lives in residential care. Her colleagues don’t understand her problems at all. The consequences in these cases are that carers stop to talk about their private situation at all at the work place.

Also at working places in welfare services, were one should expect a greater understanding for social problems interviewed carers missed the opportunity to talk openly about critical live events with colleagues in a protected area.

In a few cases carers who are in a leading position reported about staff members who took advantage of the situation that their line manager was exhausted and caused a lack of leadership. They started to fall back into old behaviour and structures which were obsolete since the interviewed carer was the new line manager.

In summary, most interviewed carers are quite pleased with their colleagues and the understanding and support they get from them. The main reasons for cooperative support in companies seem to be a good working climate and the fulfilling of the norm of reciprocity.

Attitudes of line managers

Line managers play a very crucial role in reconciliation because they are the decision makers and able to support carers and install informal regulations or not. In most cases line managers were portrait as understanding superiors who try a lot to enable reconciliation of their staff members. Carers often explain their line manager’s support and favour with their own full activity at the work place - if not at the moment then in former years. Line managers especially understand if they are or were in a similar situation.

But carers also complain about line managers who are completely lacking understanding. Especially if carers are in leading positions line manager sometimes don't understand why the staff member is taking over caring responsibility in times where it is possible to put family members into an old peoples home. In their understanding caring for a family member is a freely chosen activity and therefore nothing to be considered from the work place. Little understanding from the line manager is usually connected with a strained situation of the whole company or at least the department. In companies which plan to reduce their staff the atmosphere probably isn't too good, staff lives in fear of a dismissal and nobody wants to give reason for critique. So also carers resist asking for work reduction or a day off.

Usually a supporting line manager and understanding colleagues are related. In companies where the line manager is without understanding this is usually also the case with the colleagues. It's usually the atmosphere in the whole company which is crucial for the situation of working carers. A great majority is actually quite fine with the support they receive from their employer. They plead for other kinds of support, like the tailored support offers from the state we described above. But those who are pleased with their employer do have understanding line managers, supporting colleagues and flexible working hours.

Support services

In the following chapter we list all formal support services named by carers in the order of their importance. Considering the fact that in the perception of German carers it not really matters if a service is private, from the state or from social welfare and carers often don't even explain whether their care service is from church, state or private, we decided to focus on the different kinds of services and not on the provider.

Support from Long Term Care Insurance (LTCI)

The possibility of support from LTCI is meanwhile quite well known in the German population, especially the benefits in cash or kind to either pay for support of social services or take it as an allowance for the carer, based on an assessment for the decision on a care level (1 – 3). The benefits in kind for residential care are even bigger, but also never cover all deriving costs.

Carers can apply for a contribution to "hindrance care" once a year which can be spend on residential short term care arrangements or professional home care services when the carers is not able to care due to own health issues or work.

Additionally cared for persons can apply a contribution to short term care in times when they are coming out of hospital and still need care or are suddenly in need of care and are waiting for the care arrangement being established.

Several of the support offers used by carers which will be mentioned further down, can be financed with support from LTCI. These offers were all very well known and used if possible by most of the interviewed carers.

But there are other support measures from LTCI which are less well known. One is the support for people with a special need of supervision because of cognitive impairment who can receive up to 200 Euros per month for special surveillance.

The other one is the already described unpaid short term leave and the six month care leave of the LTCI.

Care services

As expected the majority of working carers in our sample is using home care services especially for support with ADL activities. The satisfaction with the work of care services is very heterogenic among interviewed carers. A majority is quite satisfied with their services, although some carers reported that they had to go through different arguments with their service and even sometimes changed services they weren't satisfied with. (HH1, HH5, HH7, HH11, HH14, HH17, HH20, HH21, HH22, HH23, HH24, HH27, HH31, HH35, HH37, DD102, DD104, DD109, DD110, DD111, DD112, DD115, DD116, DD115) Carers are usually satisfied with a care service if they can rely on it and feel treated as partners and perceive it as a real support:

"(...) that's why we changed the care service [yes] and I can only say now 'It's considerably smaller, this care service, considerably more personal, it works extraordinarily well, they respond to him individually. This man knows what he's doing, calls me automatically if something happens.'" (DE, HH20)

„ I'm so endlessly grateful to this care team, I really must say. Because in many things they took so much weight off me, also with decisions or also simply accepted and respected decisions that wouldn't be so normal in a different situation.“ (DE, DD109)

However, carers also report that the involvement of the care service in the care arrangement was difficult because the person in need of care rejected “strangers” at home.

“He comes in the morning and in the evening (...). Initially he only came in the morning, and it took a long time until my father accepted it, that somebody comes at all, well, he fought tooth and nail. You can only put it that way.” (DE, HH11)

Carers not only asked for support of care services because they were seeking relief from additional burden, but because they did not want to be involved in physical care. Other carers are actually satisfied with the work of their care service but reduce their assignments because of financial reasons:

“And with the care service we arranged it that way that, because the estimate of costs said, if they had come in the morning and in the evening, we would have had to pay about 300 Euro extra from their account and we're simply saving this money now, because I'm doing the evenings [yes]. But not only because of the money, but simply, because then we're more flexible [yes, yes], because she prefers to be able to go to bed sometimes, when she wants to.” (DE, HH26)

The second group of carers however reports that they feel troubled through care services. Main reasons for complains are that care services are not able to handle the cognitive impairment, they are not flexible, staff is changing too often, they are not able to fulfil self-evident tasks and don't stick to agreements related to the treatment of the person in need. Carers who complain in that way can't imagine getting along without this support, but are unhappy about the fact that they don't get that much relief as they expected or probably could have. (HH8, HH16, HH28, HH29, HH37, DD107)

„No, well, we've hired a care service for the care modules in the morning and the evening, since we took her in the house. It wasn't easy integrating the care service in the processes, because my mother's day and night rhythm is very variable, changes a lot, you can't discover any linear developments. It was also very difficult with the care service to agree on a point of time, that has to be written down there, in the morning and in the evening. And in these long years we had to change this point of time in different ways, which had the effect that very different care staff came here, the new staff for intensive care, the knowledge about dementia and intensive care is, to put it mildly, rudimentary with all care services that we contacted, so that, if you're talking about my role, it's rather, yes, well, we were supported by the care service.“ (DE, HH8)

Surprisingly there are 19 care arrangements where there is no care service involved. Reasons are different, either because the care need isn't that large, or support in personal hygiene so far is not needed. (HH15, HH10, HH33, HH34, HH36, HH40, DD106, DD117, DD118)

“Because I don't need the care service for her regularly. She washes herself, ok sometimes she could wash her hair more frequently, but she does it. She gets dressed herself. I don't think, that she would tolerate a care service. But in case of need it would be important.” (DE, HH10)

Another reason is that the person in need of care doesn't want to be cared-for by someone else (HH25, DD114) or the quality of the care service was so unsatisfying

that the carer decided to terminate the agreement (HH3, HH12, HH39). One reason is inflexibility of the service.

"I get 35 minutes, so, shower and all should be done with it. But this absolutely doesn't work! You need an hour to get mother ready." (DE, HH12)

Finally there are several carers who want to do the hands on care themselves and e.g. rather need support in attending the care for during the day. Physical care also can have aspects of love.

"We don't need it. Well, for injections, for Heparin, we had a nurse of the care service coming over ten times that is ok. But for nursing or so, I like doing it." (DE, HH32)

Day care centre

11 interviewed carers use day care as a support service. Those who use it were all very satisfied with this offer. It is seen as very beneficial for the person in need because he/she is involved in sense full activities and gets in contact with other people.

„Well, it's still like that, well, my husband goes to day care from Monday to Friday, he's picked up at 7:30h in the morning, by a driver, and is brought home again at about 5:30h pm. He gets food there and yes, stays there. The blood sugar is measured, blood pressure is taken, he's weighed once a month, then in the house, where he stays, the day care facility, there are therapists. An occupational therapist comes there from somewhere else (...). And there's a programme, events of all sorts, mostly music events, that's good for him and once a week there's a woman with a visit dog or with two visit dogs and then they take a walk, depending on the weather, that's good for him, he likes it a lot, and once a week somebody from the public library comes, they have a voluntary project, they read to them. That's what the care situation in day care is like.“ (DE, HH3)

Also carers themselves seem to benefit very much from this kind of support, because they are able to put their mind at rest during work because they know that the cared-for is under surveillance.

"Well, she's picked up at nine and returns about a quarter to six. [Yes.] And that's the chance why I can go to work at all, otherwise I wouldn't go and it's really – it's a huge relief, well, not every day, from Mondays to Fridays, Saturdays and Sundays they're closed, of course." (DE, HH12)

Also many of those who don't use it so far could imagine doing so, depending on the agreement of the person in need of care. Day care seems to have quite a positive image.

"Yes, I could well imagine this. [But she can't?] I don't know, but I'll think about it. I have to see, if there's something near us." (DE, HH14)

One reason carers don't use day care is the refusal of the cared-for to go there (HH38, DD104).

“But she doesn't want to go out, doesn't she? And I think, it would do her good, because, what I noticed in the old people's home, they also took her to courses. (...) But alone the whole day, getting no stimulation, this can't be it. And I think it's also a pity, isn't it? Although, my mother's always been a lone wolf.” (DE, HH38)

In those few cases of negative comments about day care they are all related to basic conditions like the fact that the travel from and to day care is very stressful for the person in need and /or carer, the costs are too high or persons with heavy cognitive impairment or high care need are not able to be assisted in day care.

“Well this should, well, her pension is completely spent and that, what she's saved, I also let it go into it. Because I keep thinking, ok she's 84, who knows, if she has to go into a home, we would have to have the money, actually. But so she has it every day and it has some use for her, because she feels fine in day care. And I have some time to breathe in the day and I know, she's not spooking about.” (DE, HH17)

Despite, carers complain about long waiting lists, so that it is sometimes not possible to make use of this offer by the time actually needed.

“And then, after about five months, I asked again and I was told, he would be on place 18 and then I felt shattered, because the situation had deteriorated a bit somehow and I thought, I'll never get there, well, actually I could register with the day care, if you're at place 18 or wherever he's now and then I simply had him put on the waiting list wherever it's possible (...).” (DE, HH40)

There are only two disadvantages connected with day care centres. Firstly there are too little day care places available in the neighbourhood of families in need. It would be great if they would exist area-wide. And secondly it is quite expensive and therefore not an opportunity for everybody.

Short term care

In theory the possibility of short term care is very well accepted and carers are happy to know about this option and the possibility to get financial support from the LTCI. Practical experiences with short term care, however, are very different. Satisfaction is closely linked to quality of care, but also to the health condition of the person in need. 16 carers used this offer already, with quite different experiences. Seven carers weren't happy at all because the time there had a very negative impact on the physical and especially psychological condition of the cared-for person. This applies especially to those with cognitive impairment. Carers report that sometimes it took weeks to get the cared-for back in the old health condition. So carers decided to avoid short term care because it indeed allows them time off, but afterwards they had much more work to do.

“Well, we've used short term care several times. And it didn't do him any good at all. Well, it's within hours, that he's completely losing the plot. It's

really serious and tells me things on the phone which are totally confuse and have absolutely nothing to do with reality. Oh, I think, I don't want to take responsibility if he's placed in residential care.” (DE, HH3)

The other nine carers were quite satisfied with the option, confessed however, that it was not always the wish of the cared-for, who were obviously very happy when they could return home again.

“They had offered it in day care there, and I've used it, so that I can do something once a month, or also at the weekend. And then short term care is really useful for me, if, for example, for my granddaughter's school enrolment, I couldn't take my husband. Well, he crashes the whole party there. This won't do. And so I brought him to short term care. And he doesn't like going, well, that's pretty obvious, but he goes and asks me 'When are you going to take me back'. And I write it down on a piece of paper, and then it's ok. And that you also have some short term relief as such.” (DE, DD106)

Especially caring spouses are sometimes hesitating because they rather would like to spend their holiday together with the cared-for than on their own.

„Yes, I'm not that informed, yet, well, I think, ok, there's the possibility of short term care, but I don't know at present, if I'd like it, I'd say, to go on holiday alone and to send my partner to a home then, it's not really, well, I haven't thought about it, yet.“ (DE, HH40)

There are, however, also counter-examples of cared-for persons who felt quite comfortable in a short term care and could enjoy it “like a holiday”:

“You're not there, sometimes, and when I had holiday, then I sometimes gave him into short term care. Looked forward to it. He knew it, it's holiday there. (At the river), at (local tourist attraction), gorgeous, he liked going there. And because it's all Christian facilities, it's also a bit family like.” (DE, DD107)

Short term care is a very important care facility and should be offered further, however, even a very good care facility does not represent cared-for's own home and therefore it is in most cases connected with stress and decline for the cared-for person:

“We also have a relatively good short term care in (name of facility), well, it's not a bad home, it's a decent home, but it's not like being at home and she's also, it's something different. And I need some days until she's the way again, I'd like her to be. And where I'm telling myself, now she's in a condition, where also she feels comfortable. Well, we get her back, and it smells, and her hair isn't washed, and that's unsatisfactory. You must say.” (DD111)

Assisted living

Assisted living is seen as an alternative for parents who aren't able to live on their own anymore because they need some help, but are far from being completely in need of care. It's of relevance only for two of all interviewed carers. Both have a

parent living an hour away from their own home and they come to visit once a week for the whole day. In both cases it's not seen as a possibility for ever because the need for assistance is growing, and offers within the assisted living arrangement are too little.

Residential home

In our research we asked about carers who care for at least 10 hours a week. This criterion often excludes carers whose parents are living in residential care. Nevertheless almost all carers made comments regarding residential care and we can summarize that the reputation of residential care is still quite bad. The image of residential care stems from hearsay, visits of others, stories of friends and the media. This image is so bad that residential care can't be taken into real consideration as an alternative. Carers are afraid of bad conditions like bad hygiene, bad care and bad assistance, but they are also afraid that the person in need wouldn't be able to accustom anymore to new conditions and therefore would die quickly. In many cases carers also report that the cared-for "would not want to live in an old people's home". Another reason carers don't take residential care into consideration is the fact that they would furthermore want to visit the person in need every day and the prospect that they should visit an old peoples home every day is so depressing and time consuming that they prefer to keep the person in need at home. Finally there are several carers who could imagine an old people's home but decided against it because it would be too expensive and the money from the LTCl would not cover all costs.

However in our sample there are also 7 carers whose parent(s) live - meanwhile - in residential care after the carers had a very hard and time consuming period where they tried to find the right arrangement. For these carers the situation was so exhausting that they didn't see another solution anymore. Nevertheless all of them are still very actively engaged in the assistance of their parents. (HH1, HH13, HH19, HH23, DD105, DD115, DD116). All of them seemed to have found facilities they are quite satisfied with.

Low threshold assistance

Low threshold assistance is a quite new offer from the LTCl with special support for people with cognitive impairment with the outcome of a greater need of assistance; a care level is no prerequisite. In case of cognitive impairment the cared-for can get up to 200 Euros per month for special surveillance. These offers allow persons in need of care with a need for special assistance to be assisted for several hours a week in

their own home or in assisted groups, where volunteers look after them and try to find stimulating activities. This is used by 5 of the carers, who all appreciate this offer:

„(...) they were two women, who did it voluntarily: give help relatives, to give some help in the home sphere at home. And they came, as agreed, once or twice a week for two to three hours, depending on (...). And they were also, you could agree on this, if they were to sit down in that time and read something out to mum and simply cared-for her, so that I could look after my own things. Or if we also, because mum wasn't to be looked after, and I didn't have anything to do, or I simply had to talk, I sat down with them and simply talked. Well, this came out of the situation.“ (DE, DD109)

A spouse carer organised voluntary support to be able to join the carers self help group:

„And I had myself then organised a woman, a voluntary worker, a volunteer, who for me was here in the house, that I could go there without hurry. Well, or else I couldn't do this.“ (DE, DD106)

The offers are different in different regions. So far there are only a few assistances in the own home, and for most working carers it is impossible to bring the cared-for to join a group and pick them up two hours later.

And then I called all agencies and they all were sorry but told me that they didn't make this offer yet.(...) So and these low threshold assistance is only offered within institutions and not offered for the own home context, but that is what I actually need.“ (DE, HH3)

Especially carers of male persons in need seem to be doubtful if he would accept volunteers:

“I don't know, if my husband would accept this. My husband is quite (...). He's headstrong, always has been, that's why we sometimes think, if something's odd about him, that, that it didn't used to be different [Yes.]. So, well voluntary, don't know, if he would accept this.“ (DE, HH6)

Sometimes it does not work between the cared-for and the volunteer with the consequences that necessary intervention costs too much of carers' time:

“Yes, of course. Well, we once had a short voluntary story here. The facility V. in D. does visiting service they call it, I believe. And we had this for a while, only, the woman who did it then got into trouble herself and also had with my mother, she couldn't get along with her, somehow. And I noticed this for some time, then I had her as a problem case, too. She wasn't happy then and then I kept saying to her 'You know, you're doing it voluntarily and by your own choice, if you don't get along with my mother, I can understand. I've had problems with her for a whole life. Then you simply don't do it.' “ (DE, HH17)

Often carers organise a whole network of privately paid assistance, volunteers and care service:

“I got myself, so to say, this care subsidy, which had existed since last July. Thank God! I must say. It's a big help. I have, I never use it completely and

then I organised, when she moved then, a second woman (...). One comes Mondays or Tuesdays, they call in the morning and say: 'I'm coming this afternoon' and then they're here for two, two and a half hours and, as I said, they're sometimes playing Ludo with her, do the shopping or go having coffee. The other one comes Thursdays or Fridays and at approximately the same time. They have established themselves, there quite well. They're doing it, she's accepted them as something like a friend and 'my sweetheart' and, well, marvellous. I'm so happy that I have those two women, it's more than I can pay! (...) These two women are a real blessing and I hope, that they're staying for long [Yes.]. I'm also taking care of them, in addition also financially, because I keep saying that it's as if I donated some money somewhere." (DE, HH4)

One negative aspect of a big support network can be that there are sometimes too many different actors involved which means a lot of organisational work for the manager of the care arrangement and under special circumstances also stress for the cared-for:

"But of course, it also has a further aspect. It's already so that, if you take a week, there're ten different or fifteen different people coming in the house. And sometimes partly, when we're not there. And they're all kind and I trust them, but if you've had many new faces, then you don't know who's coming. There's also a certain element of uncertainty involved." (DE, DD111)

This may be one of the reasons why carers refuse to ask for voluntary support.

Privately organised assistance

More than half of all interviewed carers (30) reported that they get support from privately organised assistances. The range and the amount of assistance however is wide spread and includes cleaning women, privately organised driver (for moving the sick person), home help which comes several times a week up to a migrant care worker who is around for 24 hours. In a few cases (HH9; HH31, HH39) privately organised assistance is doing the lions share of all necessary additional care. That can be one person doing all.

„She's there at the moment, six hours a day. No, five hours a day. She comes at half past nine in the morning, takes my mother out of bed, prepares breakfast, if mum hasn't got up already, and then she does, the care service for my father comes at ten, then he's washed, then she also sits down and has breakfast with them. Also prepares lunch and the dinner plate. That's what she can. So, when my work here finishes at four, I go over.“ (DE, HH9)

The task however can also be split between several helpers.

"I started an advert, like posters in a supermarket and that's how it worked, that I found some nice people, who were willing to come over to me for some hours. (...) Well, I have about six hours per day. At the weekends I was at home, I worked 20 hours a week, had to go four, sometimes five hours, sometimes even six (...), in the day I paid myself, of this care allowance and some of my own, of my own savings, simply. [And on how many people did you split it?] I split it on three people, four people, otherwise I wouldn't have

managed, because some people say, no, I can't do it today, and this wasn't really good for me, I had to rely on being able to get to work. (...) This was a big deal of organising. (...) No, I didn't have a care service, because I would've had somebody for only two or two and a half hours.” (DE, HH39)

In most cases private assistance is used as an additional relief for a few hours to enable carers to leave the house for special occasions by knowing the cared-for in a safe situation. They often also have the task to be good company for the cared-for (HH5, HH4, HH11, HH18, HH30, DD107) DD112, DD113, HH21, HH4, HH28).

„Yes, I'm actually organising some relief presently, by, I have a student now, she's 17, she's a natural, she's really great. (...) And, students are quite happy with 6 Euros an hour. It's not hard work. To hold such a bottle like this, until it's empty, or to give a bit of mash, it's nothing exhausting. We don't let her lift, no care things. Only spending time, only this. A bit of holding the hand, caressing, a bit of chatting, changing the TV programme and so. This gives us some space, that we can go shopping, without having to watch the time, also go to get something or get something done. So that we can be away for three hours, for example.“ (DE, HH5)

“And they just gave me the hint, that a pensioner wanted to earn some extra money. I had her come every now and then. It was still ok then, she went to the zoo with him, cleaned a bit at my place and went outside with him, sort of keeping him busy, that he doesn't get lost. It was later, that she gave him the food. She's still doing it. The lady's also a bit older, about 70.” (DE, DD107)

One female single carer describes how she's able to use her private assistance for short term leave. She pays her the money of the respite care allowance and her mother can stay in her known environment whilst the private carer is looking after her;

„(...)or, when I want to go on a short holiday, then I let mum be cared of here at home. And this has worked before. I have different ladies, who are either nurses or geriatric nurses have then or also my brother covered several days. And this have to be people, who stay here overnight and there I'm losing four weeks, so to say. Also part of health insurance pay, because they pay four weeks short term care a year and four weeks respite care. And I can only charge this as respite care.“ (DE, DD110)

Quite a lot of carers occupy a cleaning woman for their own flat or the cared-for's, but interestingly, when asked about support, didn't even mention it, but affirmed it when the interviewer asked precisely about it. That's probably because a lot of them hired cleaning woman already for their entire work life and don't see it as special support for the care situation. As many other support possibilities this is also directly connected to higher income. (HH1, HH2, HH15, HH34) Privately paid assistance can also be a driver, who is driving the sick person to appointments with doctors:

„This driver is invaluable for us. (...) Yes, he charges it directly to the insurance. My husband pays somehow five euro once, every half a year or three months directly to him and anything else the driver does directly with the insurance. (...) But the driver doesn't live here in L. I can call him day and

night, he said, he'll always drive us, wherever he needs to go also to any doctor he would drive. And he can pack the wheelchair without taking the wheels off. The wheelchair's already a bit wobbly and defect.“ (DE, HH10)

It isn't always easy to engage people to look after the cared-for, because one needs special skills to deal with difficult care situations:

“It's not easy for these people. [Yes.] Well, getting non-professionals to do it only works with support. Which means, I don't have the people to win time, but only, that I can sometimes do something else. [Yes.] (laughs).” (DE, HH12)

Migrant care workers

In Germany it is not much known about the use and amount of migrant care workers. It is estimated that round 100 000 migrant care workers from eastern European countries are caring for frail older people in their private homes. In most of these cases the care workers are moonlighting often also their migration status is illegal. The legal framework does not allow private care only private assistance within the household. The official regulations are not very attractive and so most families are looking for migrant care workers at the black market (Döhner et al. 2008)

Only one interviewed carer reported that her reconciliation system is based on the migrant care worker model and she was very happy that she was able to find a male care worker to look after her father, because the carer needs to be strong enough to carry her father down the stairs:

“You know this, they're Polish assistants, that means ladies (...). There were two, two in turns. And they knew, well young people, you had to, but only instruct, not. The, well, the ladies, who came in turns, they were there permanently, for cooking, keeping things tidy and for some company for him, company keepers, in a true sense. [And did you nevertheless have a care service in addition to this?] They yes, always, certainly. Always, always, because of the pills, because the ladies weren't allowed pills. I could also handle it well, also got Pjotr (male migrant carer) quite quickly. Well, a really fantastic person.” (DE, HH31)

Several carers could imagine engaging a migrant care worker. Asked about alternatives in case of an aggravation of the care situation carers often at least confessed that they were thinking about the option hiring a migrant care worker (HH2, HH5, HH11, HH15, HH21)

„If my mother was in need of -, then I would do it this way, that I get a care person in my house (...). I would see to this, because it exists [Yes.] somehow, I believe Poles or somehow they're [Yes, yes.], who you can get home, because my mother always used to say, she doesn't want to go into a home and I also said it. 'This will, we will manage, that you don't need to go into a home.' [Yes.] Today she sometimes says, if it can't be helped.“ (DE, HH15)

Other carers could also imagine looking for a migrant care worker, but are quite realistic about the burden for the migrant care worker to do the job completely alone. Therefore they stressed the fact that they would also contribute in such a case.

“But I honestly can't imagine letting him alone with, with a stranger, who cares for him around the clock. Because I know, what it means and I know what it means if you don't come from the family. To do such a long-term care. (...) I would worry. I could imagine this as an additional support, but then we would have to think about, how to manage it and I don't know, if my husband and I would really say, we would take my father in.” (DE, HH11)

Unfortunately a migrant care worker and additional support from care service would be too expensive for many carers.

“That the care was too difficult, this was really difficult care. [You actually would have nevertheless needed a care service, probably?] Precisely, you couldn't have expected anybody to do this. This would have, for €1000,- or so, this would have been paid too badly. And for one person alone it also was hardly possible.” (DE, HH22)

General practitioners

We also subsumed general practitioners and hospitals under support services because both institutions are in the position to either ease or impede the situation of carers. The great majority of carers complains about the treatment of doctors and hospitals and only 13 expressed positive experiences towards doctors. Those who were satisfied with the treatment met sympathetic doctors who were able to treat the cared-for in the right way, give necessary advice and information and understand carer's situation. Two carers freely reported that they found a quite good hospital where the cared-for has to go every year for a heart check and the family is using this week for a holiday and their time off. The rest had quite bad experiences. Main problem with GP's is that they refuse to offer home visits, they give appointments during the day regardless of carers work, they seem to be not able to prescribe the right medicine and have no understanding of carer's situation.

Hospitals are dreaded by some carers because it usually means that they have a lot of work during the stay of the cared-for person. Carers come and have to make sure that the cared-for gets the right care. In some hospitals demented persons don't get enough food, they dehydrate, suffer from bad hygiene and feel lost during night and day because nobody is able to look after them. As in short term care also after the hospital discharge carers experience weeks of hard work because the cared-for returns home in bad shape. Quite often especially demented persons show heavy behavioural problems, they lose their daily rhythm; they are agitated and are quite weak because of a lack of mobilisation in hospital. Most carers therefore try heavily

to prevent a stay in hospital. Especially in the beginning of a care situation, hospitals quite often are not able to give all necessary advice in matters of further treatment and the right support. So in general carers feel very little supported by GP's and hospitals.

Time out

"Well, I keep dreaming that you put me in a holiday cottage somewhere for a week, far from everything, possibly with five litres of coffee or many books and colours for painting and then simply lock me away and nobody should talk to me." (DE, HH17)

In the chapter "impact on social life" we showed the great influence of reconciliation on carers own time, their interest and their ability to keep social contacts. But we didn't only ask carers about the impact on social life but also on their possibilities to take time out. The evaluation of the statements demonstrates that it is quite important in carers own perception to have some time out. Every carer was able to mention at least some small attempts for time out. The quotations however also show that it is often a real struggle for ones own life! Behind the term "Time out" very different concepts are hidden. Time out can mean as well time for oneself, time for hobbies, and time for family, partner or friends as time for a day trip or a holiday. One special concept is the perception of work as time out from caring (more about it see above).

"Yes, I sometimes flee here, that's simply, it's simply satisfying for me a bit, that I'm needed. Even if it's exhausting, and my work at work has satisfied me just like that. It took my mind off here. Well, I could never exist without work." (DE, DD107)

We can divide carers in three groups. The first one isn't able to go on a holiday trip, but has one or even more activities during the week, which are neither related to work nor to care, like sports, singing in a choir or meeting friends. (HH3, HH27, HH31, HH32, HH36, HH8, DD113) Like the following example of a carer caring for her mother for 20 years and having different activities, but were not able to go on holidays with their children ever:

"That means you practically have your time divided into five parts. That under these circumstances, well, when you see the different legs to stand on, you don't only have two supporting legs, you have five, basically. Family, I consciously name it first, care, traditional profession, voluntary work and passionate job. So and these five spheres are shifting in a different way every day and you must see, of course, that you existentially provide for yourself, that's also clear. You can't do it by cutting back on care because there are care necessities. Well, the spheres family, voluntary work, and the passionate part of your job are shifting." (DE, HH8)

Another spouse carer reports that she is now going to get cosmetically treatment once a month doing herself something good.

“So that has changed, since this happened with my husband, I'm getting myself cosmetics once a month. It wasn't my idea, there's my daughter, said 'Mum, you look terrible'. Then she gave it to me as a present, when Christmas, and I thought, you can treat yourself to it'. So that you can yourself, well, you'd think, that that's really important, that you don't get lost in, because suddenly everything here is you don't have time for yourself anymore. And you need to take it. Well, I think that's quite important. I'd recommend anybody who comes into such a situation.” (DE, DD113)

Carers don't feel able to take time out, when the person in need rejects to be left alone. This may be especially difficult for partners:

“And I believe, he wouldn't be able to accept a short term care. On the one hand he understands, that I'd need some relief, but I also don't know, if he'd allow me a holiday. Or if I announced my wish, I also don't know if I could go easily and if I could unwind, but I think I really could.” (DE, HH10)

The second group consists of carers who do either of it and so hardly have any time out. They aren't at all able to take time out because of different reasons. (HH9, HH38, HH12, HH14, HH16, DD101, DD102, DD108, DD117). Either they are afraid that the person in need isn't well off, when they are away, or because there isn't anybody to look after the person in need or they don't trust those institutions looking after the person. Or they just don't want to let their husband/parent left without their company.

„We sometimes open the terrace door and then we pack her in a wool blanket, that she gets some fresh air. Yes, and we don't do any trips, no, that we go somewhere or what. Leaving her alone for so long, I don't want to do that. Well, you're totally bound.“ (DE, HH14)

“Yes I was really worn out at that time. I must say, because, it's like, the circle becomes closer and closer. Well, I've always had that feeling, that somebody's putting me on a waistcoat and is choking me more and more.” (DE, DD106)

Of course time out is much more difficult to organise for carers who live together with the person in need and look after someone with cognitive impairment. So for their weekly activities carers need often either support from services, volunteers or family to be able to leave for several hours.

The last group, which is also the biggest one, consists of carers who are able to do take their time out. These are carers who either have a good working support network or/and are able to also take their own needs seriously:

„I applied for a rehab in between, and got it (...). I brought my wife to short term care then, for four weeks. She found it impossible (...). And, well, such things I've really done and realised.“ (DE, HH1)

However, also for most carers in this group is not easy and often connected with struggle to get some time out. It is either a fixed date or somehow “holy” or it has to

be arranged carefully in advance. The strategies carers use to organise their time out are quite different. What works in one situation isn't easily transferable to another. Several carers reduced their working hours to get more time, not only for caring but also for themselves:

"It was a great help for me, I can do a lot in those four hours here and then I have the complete afternoon for being at home. Well for me it's a great help. We can't go on holiday, anyway, neither due to financial reasons. Insofar it's a big help." (DE, HH5)

As mentioned above, several carers have good experience with short term care. Others reported that they used the hospital stay of the person in need as a possibility for time out:

"And there's another story, where we have some time off, it's like this, that because of the permanent catheter even with the best application you can't avoid, that there's a bladder infection every now and then or an infection of the urinary tract, at least. And we, with her it's often the case that it quickly rises and then she gets really drained and wrecked and so. And then we always have the ambulance right away and off to one of our nice little hospitals, B or C or so. (...) And this is some time off for us, because in most cases we have doctors who also say, well she's not released on Friday, but on Monday. And then she's had it once, you can say luckily, infection on Easter, that was two years ago, we could go away on a trip over Easter. (...) and then I also know, that she's completely taken care of, then I can relax myself." (DE, HH5)

The general impression is that it isn't so necessary what carers perceive as time out and how they get there, the main point is that they themselves have the impression that there are these "small islands" of freedom as one carer put it.

"Well, you need to, I think, to create such little islands, yes." (DE, HH26)

However there are several carers who changed their life after negative impact on their health and wellbeing and are meanwhile able to take enough time out. (HH13, DD105)

„And then some day we started saying, we must have a day now, we must sort of go to the sauna or something and that became our Friday, the holy Friday.“ (DE, HH13)

Possible strategies to use

In this step we will extract all those supports which are actively used as a strategy to better reconcile work and care. Because we understand strategies as an active action people use to influence a situation in a special way. Not all but most of the above described support measures can be interpreted as strategies for better reconciliation. Carers also gave a great summary of important strategies under the question "which advice would you give someone in a similar situation". Here

interviewed carers either summarized their own strategies or stressed especially those strategies they don't use themselves - for different reasons - but assume that they would be helpful. In the following we summarize the main strategies used by the interviewed carers:

Carers stress the fact that one needs a good working network, consisting of informal help and formal support services. The most important network partner is as we already mentioned above the own family. Most carers with own family try to involve other family members especially partners or siblings. Also those who don't manage to do so give this as an advice. The other side of the coin is that carers experience quite a big burden if this family network is disturbed. Most important formal support partners are seen in care services, short term care and privately paid home helpers. In many cases the main task of the carer is to act as the organiser of the care arrangement and try to keep the network members working smoothly together.

Another important strategy is the development of useful coping strategies. This can be the attitude towards care and the caring task, like "the acceptance of the non perfect", this can also be the ability to enjoy the "little nice things of every day life" (HH12), like flowers and sunshine or the acceptance of the situation. Several carers give the advice not to care if one isn't really convinced that one really wants to do it. Most interviewed carers again and again emphasize that they need sources where they get new energy from, otherwise they could not continue caring for so long. A source for new energy can be the partner, friends, sports, hobbies, what ever it is, important is the ability not to forget ones own requirements. Therein also belongs the willingness in taking time off every now and then.

An important strategy at work is mainly to use the possibility to organise the working time. This can either be reduction of working hours, but also the possibility to use flexitime. For several female carers reduction of work load was a very important strategy to be able to reconcile work and care. An interesting reconciliation model is also the claiming of partial retirement, which is used in our sample by several female carers from East Germany. Also at work informal networks are important.

Understanding and supporting colleagues are very important. In case of a good working atmosphere and family friendly environment carers recommend to be open about the own situation towards line managers and colleagues. In case of difficult work situations carers rather give the advice to hide the private situation.

Finally carers also mention the strategy to sign in ill themselves as a strategy for reconciliation if there is no other option to be able to look after the cared-for on a working day. Several carers reported on using this as a strategy.

To be able to meet all claims of work and care carers recommend asking for help and accepting help from others, where ever possible. Therefore one also should ask for professional care and support for oneself in the role of a carer. Interestingly this is more often given as an advice than put into action.

Several carers referred to the fact that reconciliation is only possible if working carers have a good self organisation. They need to be able to pull all strings in their hand, to organize the care arrangement and be very efficient at their work place. Therefore it is e.g. necessary to have a proper documentation of the caring process or organise a legal guardianship in time.

“Wishes for the future” is one of the questions we didn’t ask in all cases, because they were decided to be one of several possibilities to lose an interview and it was one of those questions were carers who were already emotionally stressed by the interview often burst into tears, so we decided to not always use it. In cases were we dared to ask the question we mostly got the answer that carers wish they will be able to handle the situation and they wish that the care need won’t grow bigger. There are however several carers who wish that the person in need of care would one day “fall asleep peacefully and never wake up”.

Summary: Which kind of support at the public, company or societal level is most efficient for the reconciliation of employment and care for older individuals?

In this chapter we summarize existing measures which are seen as useful by carers at the public, company and family level.

Society/ Public

Family

Closer Family (partner, siblings, own children) is also in Germany in many cases the most important source of support. In 15 cases in our sample one / or several family members are mentioned as being the most important support and responsible for the fact that a care arrangement was working in that way. Most other carers felt emotionally supported by other family members as well as often supported with household tasks.

LTCI

The existing long term care insurance is seen as a very important contribution to the possibilities of asking for professional support, which almost all carers use. Apart from the financial aspects, working carers need the possibility to take a few days off in case of emergency. The actual care insurance law allows now an unpaid “care leave” of 6 month as well as a 10 days leave in case of emergency. The fact that the needs of working carers are meanwhile also known by politicians is very much appreciated by carers. Remarks on further improvements can be found further down.

Support services

There are several support services which are seen as very important to allow reconciliation. This is mainly professional care services, day care facilities, short term care, privately paid home helpers and nursing home. However, due to different levels of care and working situation of the carer not all are “most effective” to everyone and not in all levels of care. Which support is seen as the most helpful is depending on the level of care need and the work situation and can change over time. In general for all services we can state that they are efficient and used by carers when they are of high quality. High quality from carers perspective means that carers can rely on them, that they do their work in time, that they are flexible enough to come when needed and not according to their own time schedule, that the quality of the caring tasks is good, that they send always the same staff members, that they see normal duties without extra advice. Staff members of support services should be able to treat carers as partners and enable communication and exchange of important information. In detail the following services were mentioned as most useful and effective for reconciliation of work and care:

- Day care facilities: especially in the beginning of a care situation caused by dementia day care facilities are seen as a very important support offer. At this stage physical care is not yet needed but carers don't want to leave the cared-for unattended for the whole day. They are worried not only about his/her safety but also about long days were their beloved relative is sitting at home without any society, stimulation and activity. In day care facilities the person in need is under attention and is hopefully able to enjoy the day. Those carers in our sample using day care were mainly very satisfied with the offer.
- Privately paid help: Surprisingly many carers used additional privately paid help as a central strategy to be able to reconcile. Some carers are using privately paid help only a few hours per week as a kind of respite care, which allows them to

have some time out. But in 10% of our cases privately organised and paid help is the most important support carer's use. The models used are quite different and vary from a "round the clock" available migrant care worker to a home helper which does hands on care as well as all necessary home work during the day, to arrangements where several people share the tasks and days of the week. These privately organised solutions are often also financed by the benefits in cash from the care insurance. Privately organised care worker seem to be ideal for many working carers because they are flexible, fulfil the tasks asked for and attend the cared-for, they enable the cared-for to stay in his/her own home and are not too expensive.

- Respite/ short term care: Short term care is seen as a very important facility in two scenarios. It's firstly important in cases of a sudden care need, when a relative is dismissed from hospital with care need, but there was no time left to organise the necessary care arrangement. Secondly it is needed in all cases where the carer is hindered fulfilling his/her caring duties. This can as well be own disease but mostly it is the only chance for a carer to have some time out and go on a holiday trip. Carers are glad that this offer exists, but often complain about the conditions in nursing homes and the bad health and psychological condition their relative was in when returning home.
- Care services: As expected care services are a very often and self evidently used support offer. In our sample their importance increases with a growing physical care need. Due to the fact that staff member come only occasionally, jump in and out not staying with the cared-for, not offering any attendance or activity, they are seen as necessary when physical care becomes too difficult to provide, but they are hardly ever perceived as a support offer enabling carers to reconcile work and care.
- Nursing home: several carers also saw the nursing home as the most relevant strategy to be able to continue working. In most cases these carers tried for a long time to enable the cared-for staying in his/her own home, but were finally coming to an end where their own health and well being was threatened. Nursing homes were never seen as the ideal support, but sometimes due to a lack of alternatives the only possible option. Interestingly the engagement of carers doesn't stop when the cared-for moves to a nursing home. We have several women who even reduced working hours to be able to visit their mothers on a regular basis in their nursing home. So even the fact that there are nursing

homes which guarantee round the clock maintenance does not prevent carers from reducing their own work load.

- Information and counselling: Adequate and at the right time information about care facilities, health and care insurance, self help groups and other financial issues is a very important matter. In some cases it worked because carers knew the right institutions, but still not all people are aware of the relevant institutions. Since 2008 the LTCI reform introduced a right for information and counselling. But many of the new counselling centres are still under development and are not known by most interviewees. Most carers explain that they would have needed counselling services in the beginning of the care situation, but did not really know where to ask for it:

“One day then I found, I think in a newspaper, this dementia advice service. That was quite good insofar, because I got advice there, that I, you think, I thought in between: 'Perhaps you're already not all there anymore'. It's a really funny emotional -, and I learned a lot there, what I didn't have as such, by accident, basically. Also I would have wished that I got a hint by the doctor or by the care service or something.” (DE, HH23)

Carers who were in touch with counselling centres found them very helpful. What carers missed was a good advice in hospitals in the beginning of the care need. To sum up, most successful are support services which are not too expensive, of high quality and able to react flexible on carers and cared-for's needs.

Company level

Supporting and understanding colleagues and line managers are very important preconditions for a successful reconciliation. In companies where carers report about understanding line managers usually is also a positive working climate and carers are able to arrange individual solutions on an informal way. Companies who are generally trying to be family friendly seem to have a greater chance to also be open for work and care arrangements. Most important offers carers mentioned was sympathy of the line manager, flexible working hours, possibility to reduce working hours or stepping back from a leading position for the time required as well as time out in case of emergency; all without any negative consequences for their further work life and without additional bureaucracy.

Suggestions for improvement from carers perspective

Asked about the possible contribution of state, society and employers, main answer of carers was that they would be happy to get support which is tailored to meet their

needs and a better recognition in their role as a carer. Below we list the most important wishes for improvement.

Recognition

Recognition of their role as a carer is one of the crucial aspects carers mention when asked about improvements of their situation. Recognition has several aspects. In the first hand it is has to do with society appreciating the fact that so many people care privately for a relative and are willing to put up with quite great changes in their private and professional live. Recognition however has also to do with acceptance. Carers suffer from the fact that their environment is not able to accept their decision to take the responsibility for a person in need of care. In many interviews carers were hurt by recommendations of friends, neighbours, colleagues and line managers to give up care and put their relative to a nursing home. A lack of acceptance makes it very difficult to ask for help either. So general recognition and acceptance would help many carers a lot to deal more open with their situation and feel free to ask others for support. In our society recognition also has to do with acknowledgement in cash!

Improvements of the financial situation

- More carers would like to reduce their working hours to be able to reconcile and not suffer from a directly loss of income as well as from a lower pension rate. Therefore carers provided several quite different suggestions for improvement:
- The first on is connected with the actual legislation of “care leave” provided by the LTCI. The interviewed carers are not happy with it and don’t use it. Main critical points are that it is an unpaid care leave and that it is very difficult to predict the duration of a care situation. So most carers don’t dare to take the six month care leave, because they don’t know what to do when the care leave ends, but the care need still persists or even increased. If carers take this offer they also need the assurance that it doesn’t affect their working life by any means. Instead carers suggest two different approaches. One demand of carers is that they would like to be treated the same way as parents of young children, who get a parental leave for up to 14 month and get during that time 60% of their last loan. Despite young parents get 10 days paid leave per year in case their child becomes ill. Carers demand to be treated the same way as young parents and get this leave paid as well.

“But that’s why I also believe, it changes, perhaps, if it were both at the same time, which was the drama in our case, simply changes the whole life and

that's why such a sabbatical for someone who has the parents in a care home, can make as much sense as when you care them at home. Because you simply want to spend the rest of you parents' life together with them. And not let you be told: 'Hey, they also took a great of deal of time for you, when you were a baby. And nobody asked them for it and now you follow your career aspirations, what's that supposed to mean?' Well, to balance this, that's what you do in that time. I think there should be the chance for somebody, who decides, to also do this for the parents, just like young parents can make this decision, she wants three years [three years parental leave], yes exactly. Yes, to take parental leave. Well, as non-mother of children this would be poetic justice for me, I'd like to have this, that there's something like this, for all who want to, can claim it." (DE, HH13)

- Another option could be a kind of a “care loan”. This could be the amount of the “benefits in kind “of care level three (which is around 1400 Euros) in cash as an income replacement for the time caring. That would allow those carers with relatives with high level of care need to quit their job for the time caring if necessary.
- And a third version could be to pay carers the same amount of money for their contribution to care that professional services get (same amount as the benefits in kind and not only the level of the benefits in cash), which would be in some cases also in the height of an income replacement. This suggestion is quite close to ideas of the personal budget discussed in Germany (Klie & Spermann 2004), but should be paid to the main carer and leave it open to her/him how to spend it.

Other carers made suggestions how to renew the law and suggested a paid leave combined with the option to use it for a part time leave.

“I could imagine. But I could only imagine, if my employer (...) my direct contact person would assure me, that when I return not everything, so to say, is completely different. (...) I could also imagine much more, to do half a week, well, if, a part-time model I'd call it. Well, that I work from Monday to Wednesday and have Thursday, Friday off, or so.” (DE, HH11)

- In case of reduction of working time carers would like to get financial compensation at least for their loss of pension. At the moment, carers who work less than 30 hours get credits for their pension, but carers who work more than 30 hours don't get those credits because the law says that nobody should work more than 8 hours a day. In fact a lot of carers work full time AND care for many hours. Carers demand to change this law and recognise their additional caring hours!
- People with cognitive impairment should be better recognised in the LTCI, to be able to spend more money on supervision and day care.

- It would be great if one would be able to have enough money to pay for all tasks one doesn't want to do themselves - but therefore one needs enough money.
- Refunding in case of high travel cost to visit relatives in need of care who live far away.

Support services

The majority of interviewed carers agree that there are already a lot of support offers, but quite often the offers don't meet neither the needs of the cared-for person or those of the carer

- Care services should be flexible and of high quality and meet the needs of the cared-for person and the carer.

A variety of suggestions for improvements of support services is linked to the idea that it should not be the cared-for person who has to leave the house and seek for support, but that it should be staff members from out patient services coming more often into cared-for's home.

- Carers ask for flexible applicable care assistance for surveillance and other caring tasks at home. Precondition is that they are not too expensive and come when needed.
- Spontaneously available respite care which comes to the cared-for's home when ever needed - in case of emergency also right in the morning when the cared-for suddenly needs assistance and the carer has to go to work (like the granny service for working parents).
- Possibility of short term care in the cared-for's home. Especially for people suffering from dementia every change of the milieu can cause a deterioration of their health status. But in case a carer would like to take his holidays or other time out, the cared-for has to move to an old peoples' home that offers short term care. Usually his/her condition has worsened during the stay so the carer has much more work to do afterwards and therefore often avoids short term care.
- "And I think, that's the case, the case with many old people, who are brought to short term care. And it's also an organisational question, if I said now, my wife L or Mrs M come over night and stay. This is not accepted by the care services, it's not paid, it's, is it? She's entitled to those three weeks or four weeks, 28 days I think, per year [short term care] short term care, is it, when something happens to the relatives, but when she wants to stay at home and wants to organise, that's,

that's better for them, is it, then nobody pays for it, is it. Then that's simply, yes, a special service that she has to finance out of her pension or so, is it. I think that's somehow, beside the point." (DE, HH21)

- In this connection some carers also plead for the legalisation of migrant care workers who would actually for a lot carer's best meet their needs, because they are flexible, not too expensive and round the clock available.
- Day care facilities are seen as a very important support for working carers, as long as they are not too expensive and open not only for five but for seven days a week and not only between 9-16.00 but round the clock, which would enable carers to decide which times they would like to draw on. It should include out patient over night care. Opening at the weekends would allow carers to use it also for time out for themselves so that they also would have a possibility to recover. All facilities should offer a pick up and delivery service.
- Better offers of activities for the persons in need. Carers quite often feel sorry for the "boring life" of the person in need, where nothing happens anymore. They themselves are away for work during the day and can't provide meaningful activities like singing, going for a walk, play chess or just accompany. So they would be grateful if other people could take over this responsibility.
- Residential homes which have so high quality that they are a real alternative to home care. Carers should be really included in the work of care homes, listened to and welcomed and not only seen as disturbing elements.
- More affordable shared flats for people in need of care, not only for people with dementia, but also for others like terminally ill people in need of care.
- Some carers point to the fact that there exist already quite a lot of techniques which can lighten the physical care or surveillance, but is not always known and often not paid for.
- Carers ask for integrated care and demand a better teamwork of residential care - GP's - hospitals and care services, it should be possible to organise the care arrangement prompt and without gaps
- Carers should be entitled to time off like mothers of young children to go to cure and get new energy - time off is connected to adequate care services looking after the person in need

Practitioners and hospitals

Practitioners and hospitals that are aware of the working carers' situation are of great help. Caring for an old frail person includes a lot of visits at different doctors which means that the carer has to join the person in need to different appointments, usually in the middle of the day. What sounds as a quite unimportant factor turned out to be quite a burden for full time working carers without flexitime, because they therefore always had to take a day off. If surgeries would be prepared to working carers and would offer them appointments at the edge of the day (morning or evening) that would help a lot. An even better solution would be - like in former times - home visits of the doctor in the early evening.

Hospitals are sometimes used as a possibility for time off. Most of the time, however, they cause the carer a lot of work, especially in case of dementia. Hospitals are not prepared to look after this target group what means that the carer has to join the patient and therefore take time off. Secondly patient's condition is usually much worse after discharge than before which means a lot of additional work for the carer. So, hospitals should improve the treatment of demented persons.

Despite carers plead for hospital-pilots who lead cared-for and carer through the hospital routine and give them all necessary advice for afterwards. Nurses from residential care should be allowed to accompany persons with dementia with the ambulance to the hospital. And last but not least all hospitals should be directed to care for people in need of care and be aware of their special needs.

A majority of the interviewed carers complains about the great lack of information especially in the beginning of the care situation. Neither GP's, nor hospitals nor MDK members give them the information required in the beginning of the care situation. Carers experience that they have to collect information in a hard going process and never met an institution where they get at once all information which is necessary to cope with the care situation. So carers demand one counselling centre where they get all necessary information. (Politicians listened already to that for many years pronounced request of carers and invented so called "Pflegerstützpunkte", but they are either known nor used so far)

Interestingly here carers made contributions which sometimes showed that they were not really informed about already existing offers. So they demanded more assistance in the home of the person in need - which already exists. Some mention support offers which don't exist in their environment but exist already in other areas, like self help groups of carers from relatives in residential care or reported from attempts to

hire assistance for the home but it didn't work out. Others would be happy to have someone who comes in the afternoon to do something with the person in need so that it isn't too boring for her/him.

Work place

Some carers recommend enabling all workers to a certain kind of flexibility and the possibility to step down from a leading position for a while without any negative consequences for the further career (depending on the tasks of the company of course) so that carers would not be forced to name the reasons for their usage of the company offers.

Carers would appreciate information sheets from their company with all their entitlements as a carer and may be also further recommendations towards information, counselling and financial issues. Carers stress the fact that they prefer leaflets and sheets they can read without letting the employer know anything about their private situation.

Carers should not be dependent on the good relationship to their line manager but all being entitled to some kind of flexibility and time off. The establishment of these measures could either be the tasks of trade unions or the state. Nevertheless carers announce clearly the desire that line manager should recognise and accept if an employee takes over caring responsibilities, he should be understandingly and make sure that the working carer doesn't have to suffer from any drawbacks. Next to flexibility employers should enable carers to take time off spontaneously in case of emergency without financial disadvantages and disadvantages for the career. There was a kind of controversial feedbacks on the support offers of the employer. In the one hand some carers demand more official offers because otherwise the possibility to time off and flexibility depend on the good will of the line manager. Others warned from more and new bureaucratic procedures in case of new formal offers.

Despite, employers should offer informative meetings to inform carers about all official regulations for working carers in the company. This is only acceptable for employees if they can be sure that they won't have any disadvantages from the confession of being a carer.

Some carers suggested to invent work time accounts where all employees can collect work time and use it for what ever they want. Carers would be happy about the possibility of a sabbatical, which is difficult to plan if one doesn't know when caring

will be necessary - the German family ministry made a similar suggestion -
discussion see under: LTCI reform.

5 Profiles of working carers

Many studies substantiated the assumption that the level of care need is one of the most significant variables influencing reconciliation of work and care (Franke & Reichert 2010, Lamura et al. 2006, Mnich & Döhner 2005). Not only the amount of emotional burden worries about the cared-for person and questions concerning the organisation are depending on the level of care, but also the extent of labour market participation seems to be determined by care related issues. Schneekloth and Wahl (2005) confirmed that especially cognitive impairment has an influence on the ability to combine work and care. At least for England Hutten and Hirst (2001) found that the labour market participation of carers declines with duration and intensity of care. Masuy (2009) could show in her study that with growing care need the probability of women aged 50 and older increases to quit work, whilst women younger than 50 are more likely to reduce work. Obviously the amount of care connected with the amount of work is one central predictor for the ability to cope with the demands of reconciliation.

Therefore we tried to make use of both criteria and built up a four field table, consisting of high and low care level as well as high and low work level. Firstly we defined the terms low and high care need. To make our study comparable with other German studies we decided to use the officially care levels of the Long Term Care Insurance (LTCI) as the criteria for different care levels. A low care need corresponds with care level 1 (>90 min < 3hours physical care and housework/ day), higher care need labels all carers caring for a person with level 2 (>3 hours < 5 hours/day) and care level 3 (more than 5 hours care per day.). To be able to achieve a four field table we put persons without a care level and care level 1 in the same group which consists of 28 carers with low care need, and the second group with high care need (therefore we matched level 2 and 3) consisting of 30 carers.

Within the next step we defined high and low level of work. This was not as easy as with the care levels, because definitions for full time and part time work are quite differing. By looking at our sample we decided to only use 100% working hours as full time, because quite many carers in our sample reduced their working time to 75% to have one day off as a reconciliation strategy. So we defined high level of work as full time employment (which is usually around 38,5 hours/week in Germany). Of course we also counted full time employed teachers as full time workers although they spend half of their working time at home, which might make reconciliation easier. As

low level of work we considered all working hours less than full time (less than 38,5 hours/week). With this definition we have a group of 30 full time workers and 28 part time workers.

Table 17. Profiles of working carers, by workload and care level

Work time and care level	Low care need (LTCI1) (>90min/day) only physical care and housework 28	Middle care need (LTCI 2) (>3h/day) only physical care and housework (20) 30	High care need (LZCI 3) (>5h/day) only physical care and housework (10)
Full time work 30	TYPE 1 (14) Round the clock/daily HH15, HH6, HH18, HH40 DD103, DD104, DD117 D114 Several times/ once a week HH35, HH24, HH28 HH2, DD112 , DD113	TYPE 3 (16) Round the clock/daily HH9, DD102, DD108, DD101, HH1 Several times/ once a week HH38 HH20 HH30,HH13 DD105	Round the clock/daily DD109, DD111. HH5 HH31, HH3 Several times/ once a week HH11
Part time work 28	TYPE 2 (14) Round the clock/daily HH16, HH21, HH32 DD118, HH12 Several times/ once a week HH4, HH23, HH29, HH33 HH34, HH36, HH25, DD115, DD116	TYPE 4 (14) Round the clock/daily HH27, HH14, HH17, HH26 HH39, HH10, DD106 Several times/ once a week HH37, HH19, HH7	Round the clock/daily DD110, HH8, HH22, DD107 Several times/ once a week

With these criteria of low - high level of work and low - high level of care we can quite equally distribute carers to the four occurring types and have carers with “high work - low care”, “low work - low care”, “high work - high care” and “low work - high care” (14 - 14 - 16- 14). We then consulted items influencing the ability to reconcile work and care according to literature (Franke & Reichert 2010) and included cognitive impairment, spouse care, amount of time spend with caring, duration of care and age of carers, main support, changes of work situation because of care, level of education, household structure, gender, strong health implications (break down) into the profile building.

Table 18. Distribution of items between the four profiles of working carers

	High hours of work - low care level (Type 1) N = 14	Low hours of work - low care level (Type 2) N=14	High hours of work - high care level (Type 3) N= 16	Low hours of work - high care level (Type 4) N= 14
Person in need with dementia	6	6	9	12
Partners in need of care	5	1	3	3
Age of carer (50 and older)	11	7	10	13
Gender				
woman	11	12	13	14
men	3	2	3	0
Duration of care 4 years and more	7	7	9	7
Carers who care round the clock/daily	8	5	10	11
Level of education				
high	10	12	10	9
low	4	2	6	5
Household structure				
partner, both working	4	9	9	8
partner, one working	7	2	3	4
single	3	3	4	2
Carers main support				
no support	9	4	0	1
family support	3	4	6	2
day care	1	1	2	2
privately paid support	0	2	2	1
care services	1	0	1	6
nursing home	0	3	3	2
Change of work situation				
reduction of working hours	0	4	0	11
loss of leading position	1	0	0	0
giving up leading position	0	0	3	0
self employment	0	0	1	0
Break down, strong health implications	3	2	9	3

Type 1 (n = 14): Low care need and high level of work. No cut backs in the work situation - comparatively little care effort needed

- Cut backs in the work are not yet necessary due to comparatively little amount of care (although carers feel burdened and are working towards a change).
- Carers have rather no other support so far or found informal solutions with family.
- There was no need for changes of the work situation so far.

From 14 carers belonging to this group five are caring for a spouse and six are caring for a relative suffering from dementia. The majority of those carers in this group caring on a daily base doesn't use (m)any support offers. Some reported about additional support from care services or private help on an hourly basis, but 10 out of the 14 carers provide the main tasks themselves although working fulltime. In most cases this is still possible due to the comparatively little amount of care need.

However, several carers are thinking about a change of their situation, like a cut back in their work situation or additional support, because the care need is increasing, and they feel quite burdened by the actual situation. Its eye catching that there are quite many spouses in this group who are forced to work fulltime because of their financial situation. They are also the ones who report about round the clock care need although they have "only" care level zero or one. This is often the case with spouses who live together with the cared-for and feel responsible for their partners' well being round the clock. But that is also the case when the cared-for is suffering from dementia and in need of attendance. Half of all carers caring once or several times a week shares the task equally with siblings, a fact which doesn't make it necessary for them to contribute to care every day. All carers in this group have in common that changes in their work situation were not reported yet. 11 out of 14 carers which are almost 80% in this group are 50 years and older.

Type 2 (n = 14): Low care need and low level of work. Private life oriented - Low level of work due to other priorities

- Type two carers are by majority younger female carers caring for a parent, living in a partnership where both are working or at least have income from pension. They are sandwich carers who reduced their working hours already due to other family obligations or own health.
- A subgroup felt the need for a reduction of working hours to be able to cope with the care situation without negative impact towards own health and private life.

- Caring once a week up to several times a week and get support from family, day care, privately paid care, but also from nursing home to be able to also have a social and family life.

In this group we gathered 14 carers with rather low care need and a low level of work. But all are working at least 19,25 hours (which is half time) up to 32 hours per week. One would expect that carers in this group do a lot of care themselves, however only 5 carers care without further support, 9 carers report about important main support offers from family, day care, privately paid care and nursing home. This probably correlates with the fact that only four carers reduced their work situation due to the arising care necessities. All the others worked already part time due to other family obligations or own health problems and don't have the capacity of caring without further support. Due to the fact that the percentage of sandwich carers is the biggest here it is not surprising that they are the youngest group of carers (half of the carers are younger than 50 years) and less often care around the clock (one third). Carers in this group are mainly female living with their working partner or having a partner already retired but receiving pension. Care services are not seen as really relevant support in this stage of the care need, because usually heavy physical care need is connected with a higher care level.

What is interesting is the fact that in this group the percentage of carers with a high level of education is the biggest (71%). This might be explained with the fact that for employees with high income the salary is still interesting also by reduced working hours. For workers with little income it often does not make sense anymore to work part time, have all the effort with organising support and get very little salary.

Type 3 (n= 16): High care level and high level of work. Work oriented carers - support for care organised

- Type 3 carers care in situations with high care need. Therefore carers need somebody to replace them whilst working. They all use intensive support from day care, partner or sibling, privately paid help (like migrants) or nursing home.
- More than half of type 3 carers report about a break down or disease which forced them to look for alternatives and support.
- Changes in the work situation are related to rather stepping back from leading positions or change to self employment, but not towards a reduction of working hours.

The 16 carers in this group are only able to work fulltime and deal with high care need because they use a lot of different support offers. There isn't anybody not using support. Care need is so extensive in many cases that carers who are continuing working fulltime need either a person or an institution replacing them whilst working. Solutions are quite different: caring partners are mainly using day care, others rely on their partner or sibling with whom they are sharing responsibility, but also privately paid help (like migrants) or nursing home is chosen as a support offer. Nevertheless, 71% reported that they themselves care round the clock as soon as they return from work.

Several carers in this group gave up their leading position or changed their work place to be able to cope with their responsibility as a carer. In this group a majority reports about a huge burden, break downs or other diseases as a consequence to the overburdened situation especially during the time where the arrangement had to be organised. By the time of the interview they had found new solutions in asking for additional support.

Type 4 (n = 14): High care level and low level of work. Care oriented carers - cut back at the work situations

- Type 4 carers are only women, caring in the majority for a parent suffering from dementia. To fulfil these tasks they reduced their working hours to a large extent.
- The amount of low qualified workers is the highest here as well as of those who lost their job due to their caring responsibility.
- Because of the intensity of the physical care need, care services are an important source of support. Type 4 carers subordinate their working life to care.

Type 4 carers are caring in a high percentage (85%) for relatives suffering from cognitive impairment, most of them round the clock. Most of the 14 carers (79%) decided to change their work situation actively to be able contributing to care themselves. Interestingly they not only reduced their working hours to half day, part time, a majority of those caring round the clock reduced working hours very strictly. One carer uses partial retirement, one care leave and two work very little weekly hours, one quit her job. But in this group are also two carers who lost their job due to difficulties with reconciliation. A majority of type 4 carers works in jobs with not too high income like a nurse or a (medical) secretary. Those 3 carers who reported caring "only" several times a week are all working 30 hours which is close to full time. Two carers after many years of caring decided to put their parent to a nursing home,

but nevertheless reduced working hours to be able to spend at least one day per week with their dependent mothers.

The majority does also a lot of physical care themselves. Therefore they quit work, they lost work because of care, they used their unemployment as a strategy to be able to care, they became self employed or asked for care leave. Apart from the caring partner in this group all others also use care services as supporters in the heavy physical tasks they have to fulfil.

Conclusion to these profiles

We can confirm that the level of care need has a great influence on the reconciliation strategies of carers. As long as the care level is still comparatively low, carers often try to handle the situation without additional support. When the care need increases they are forced to ask for further support which replaces them also during the day when they are away to work or they have to reduce their working hours. Especially dementia is one of the reasons why carers feel more often forced to reduce working hours. Very interesting however is the fact that we have “round the clock carers” as well as “several times a week carers” in all four fields. This is firstly an effect deriving from the definition of care levels in the system of the LTCI. Care levels are mainly depending on the need for hands on care, and not in the need of attendance or emotional support. Therefore especially the needs of persons suffering from dementia are often not incorporated. And secondly it also shows that the commitment of carers is different. So is a caring spouse usually more willing to spend many hours together with her partner than the caring daughter, living with husband and children.

However, it's not only the level of care need which influences carer's behaviour towards their employment situation. Carers not only reduce working hours due to severe care need, but also due to other reasons. As we could show with type 2 carers they reduced working hours due to other reasons like family obligation or personal growth. Vice versa severe care need does not stringently lead to work reduction. Carers who reduce working hours and spend the time with full time caring tend to be lower qualified workers or workers who had to face some difficulties at the work place.

Negative health implications can occur in all situations because the feeling of overburden has very different influences. However, the group of full time workers with high care need is obviously most often affected. Care services are especially used by carers who are dealing with heavy physical care and who reduced working hours already to cope with the situation.

There are, however, also a lot of similarities between the types and variables which are no feature for distinction. The level of education as well as the household structure is quite equally distributed in all four groups. However, there are small differences which have to be treated carefully due to the small number of cases. Most interesting according to our recruitment scheme is the household structure. We could show that those carers reducing their work load more often are living in a double earner couple. Single earners seem especially threatened from job loss due to overburdening. Those carers reporting to care round the clock in type one are mostly spouse carers.

Also the distribution of age is quite equally, because 43 carers of our sample are anyway 50 years and older. Therefore it's especially interesting that half of all younger carers are type 2 carers.

This typology was of huge help to get an overview over the amount of data. After conducting the interviews we were overwhelmed by all these individual destinies and had difficulties to see similarities and differences. After building these profiles we were able to show that amount of care need as well as household structure do have an implication on carers' strategies for reconciliation. It also showed that employers understanding and formal as well as informal support offers are of great relevance in all four different types.

6 Discussion

What conflict- and stress-situations between work and care are typical among the caregivers?

In this chapter we will discuss the conflicts and stress situations carers of our sample face because of reconciliation in the light of the literature and discuss the influence of factors known from the literature. Caring for a dependent relative can touch all areas of life, which under certain circumstances can cause negative impact on health, private life, work place and social environment. Cause and effect, however, can't be looked at in isolation because they determine and influence one another (Franke & Reichert 2010).

Our research confirms several findings from other studies. Also in our sample carers mentioned the overall lack of time as one of their central problems with reconciliation, which has an influence on all areas of life (Schneider et al. 2005, 2006). However, carers usually try to keep the influence on work, care and family as small as possible. Therefore it is not surprising that they mostly report a great negative influence on their own needs, interests and social life. Almost all carers with great work load and severe care responsibility report about an extremely lack of time on their own.

Although carers try to keep the influence on their family small, especially female carers in sandwich positions often suffer from a bad conscience because of their lack of time and energy towards their husbands and children. Conflicts deriving because male partners feel neglected and expect more attention, although their wife is working, caring and raising the children, are experienced as especially burdening for female carers.

Very amazing were the reported conflicts between siblings, with sisters as well as brothers. Although the closer family relations were not our main focus, several carers described the bad relationship with a sibling, usually rooted in the childhood, but now worsened through common responsibility for a depending parent, as the most burdening aspect in the whole issue of work and care. This is a topic also in other studies, but usually only at the edge of reconciliation research. In this light we can support Franke & Reichert (2010:85) who state that as helpful support of family and social environment can be for a carer, as burdening is ignorant behaviour, little recognition and understanding as well as the lack of active support perceived.

A bad relationship to the cared-for person seems to be as burdening as conflicts with siblings. Other studies found that the relationship between carer and cared-for is threatened by a change for the worse due to a general stress and double burden working carers are facing (Kröger 2003). In our sample also several carers reported about a bad conscience towards the cared-for because of a constant lack of time and several carers confessed an already live long quite ambivalent relationship towards a parent which made the care quite difficult for them. And others experience sorrow and grief because of the change of a demented parent's personality. But no carer reported about a worsening relationship because of the care need. This could be assumed to be a result of socially expected answers. But the very open atmosphere in most interviews where carers talked very openly about difficulties and conflicts speaks against it as well as those carers who openly confessed their difficulties. In the opposite, most carers named the bettering of the relationship as one of the very few positive aspects and this were very trustworthy answers.

Quite a lot of research is done already on the effect caring has on work (Franke 2010:45). Our study mostly confirmed these results, although in some areas we have interesting differences. Reconciliation can have an impact on the daily work situation as well as on the entire work life. Also in our research we found that impacts carers are facing in their daily work are a lack of concentration and effectiveness (Schneider et al. 2005). They can't concentrate because they feel exhausted, overburdened or are in constant worries about the care situation at home (Phillips 1995, Keck & Saraceno 2009). This situation is usually worse for those working carers who aren't able to take a time out and use the weekends or their holidays for relaxation (Schneider et al. 2006). The additional stressful worry to not be able to fulfil all employment requirements (Franke & Reichert 2010:57) was especially reported in our sample by caring wives from East Germany. This difference may be explained with the different meaning of employment in women's lives in East and West Germany, as well as the much higher unemployment rate in East Germany.

We could, however, not confirm results applying to long distance carers. Whilst the Metlive study Caregiving in the U.S. (Metlive & NAC 2004, Metlive 2006) found out that long distance carers are suffering especially and report a persistent lack of concentration and permanent feelings of guilt, these carers in our study - with one exception - belong to the ones, one could easily define as balanced. They reported about a good work live balance and very little influence on health, work and private life. The difference may derive from the fact that long distance carers interviewed in the Metlive study usually continued working full time whilst carers with caring

responsibility for a parent living apart in our sample all worked part time already or reduced working hours to be able to better reconcile. So we can agree with Phillips (2007) that the impact on work in these cases is great - because carers reduce working hours - but the carers in our sample don't feel burdened by the fact. This may be the case in our sample because these carers reported an informal supporting network or the care need wasn't so extensive yet and they were satisfied with their decision to reduce, because the financial implications were of course visible, but didn't entail financial difficulties.

According to Phillips (2007) not only long distance but also no distance between carer and cared-for can cause problems. However, we could not confirm this result. 12 of the cohabiting carers are spouses who mainly tried to live together as long as possible. In almost one third of the cases children and a parent are living together. In some of the cases the care need is very high, but still we could not trace back the burden of the carer to the fact of living together or apart. This was only a topic for those daughters living in an ambivalent relationship and explaining that they'd mainly care due to financial reasons. For the others the influence towards burden is more depending on the general degree of the care need, the support carers can get and the overall work load they have.

In the already mentioned Metlive et al. (2006) study 80% of the interviewed carers reported about missing of working hours, because they came in late, had to leave early or were forced to interrupt their working day usually due to a sudden crisis or appointments with doctors. Carers in our study also reported about these effects of their caring responsibility, however the appraisal of their own behaviour was a bit different and the majority did not declare this absentism with missing working hours. This may derive from the fact that most carers in our sample have very flexible working hours, which allows them to arrange their days quite flexible. However, in cases where flexibility was not possible this missing caused also problems. Missing of working hours was mainly caused because carers sign in ill although it is the cared-for person which needs support. If this happens to often carers get into huge troubles and as a consequence several carers in our sample lost their job because of too many missing working hours.

Besides the effects of reconciliation on the daily work situation it also can have consequences on the long run and influence carers entire work life. This starts with limited abilities to further training and education, because carers can't take part in additional training (Schneider et al. 2005, 2006). Interestingly this was not mentioned by any of our carers, however several carers reported a "slump" in their career they

did not connect it with little advantage of taking part in further education. Our assumption is that carers in our interview situations were so involved in the actual situation and trying to cope with every day business that most of them didn't think about further education or career, but just reported about their actual situation. Despite of this most of our carers are between the ages of 55 - 65 and therefore belong to a group of employees often anyway excluded from further training in Germany.

The already manifold broached issue of the overall "lack of time" leads carers in many cases to a reorganisation of their working time, which can consist in quitting a leading position, reduction of working hours, taking care leave or, ask for partial retirement or even quitting the job¹¹. As a consequence of ongoing conflicts between employer and employee working carers also can lose their job.

We don't have longitudinal data in our study so we don't have any general information on the influence of these changes on the entire work life. But we can conclude from the consequences it has on parents taking child leave and assume that a career slump will be a consequence or the career will even be ended if employers in the age between 55 and 65 are too long away from the work place or are not able to fully work under pressure. And it's obvious that a reduction of working time and income loss will have an influence on the amount of the pension. The European Community Household Panel (Kilpeläinen 2005) confirmed the percentage of working carers ending their career due to caring obligations with 4,3 % for the 55 and 59 year old ones.

The question why in some situations conflicts occur is depending on different preconditions. Conflicts at the work place in the sight of the carer are mainly caused by inflexible working hours, unsympathetic line managers and colleagues, often deriving from a negative working climate in a company and an overload of work. However, it is also related to issues which have nothing to do with the work place but

¹¹ To avoid double descriptions the reader will find more about the different ways of work organisation models under the chapter strategies. Although time changes at the work situation can cause problems esp. in the long term, we still rather consider different solutions carers find as strategies.

nevertheless have an influence like the severity of the care need and the support system a carer can establish. Connected to work are usually also financial i Half of our sample reports negative financial implications due to reduction of working hours and/or additional payments for care support. According to Reißmann (2005) every tenth carer has to face a loss of income mainly due to reduction of working hours. 40 % of Canadian working carers have additional costs due to work and care (Williams 2004). So tried Metlive & NAC (2004) to extrapolate the financial burden of long distance carers and came to the amount of \$ 392 per month. Long distance carers in our sample affirmed this and complained about the enormous financial burden caused by expenditures for fuel or train tickets. According to Franke & Reichert (2010) there exist very few studies on financial problems caused by lacking reconciliation possibilities and hardly any German data which we could use for comparison. However, Rothgang et al. (2006) estimated an average income loss of carers in labour market participation due to care-giving issues of 688 Euros for restricted carers within the Eurofamcare sample. What we find alarming in our results is the fact that there are carers who are forced to stick to a work - care arrangement which overburdens them due to financial strains. These carers don't see a solution, because they are neither able to reduce work nor to pay for necessary additional support. The other group are children who, due to ambivalent feelings towards their parent, actually don't want to care but feel forced too because of financial interests. These latter constellations are very prone to negative family dynamics, overburdening of the carer (Lynette & Yardley 2003) and even run the risk of abuse or neglect of the cared-for person.

As highlighted already in several other studies also carers in our study regard a lot of bureaucratic barriers as quite unnecessary additional burden, which needs a lot of their time and their energy (Lamura et al. 2006)

Difficulties and bad supply of patients suffering from dementia by doctors and hospitals are already described in several studies (Angerhausen 2008), but as far as we know not in the consequences for working carers. Despite working carers suffer from conflicts with GP's who often are not willing to take working carers timetables into consideration and make appointments in the middle of the day, because dates at the edge of the day like in the morning or evening are often reserved for "working patients", which does not apply for a working carer who is only a companion of a not working person.

According to Buckner & Yeandle (2006) working carers have a three times as high probability of health impairment than non caring workers. A result we also found in

our study. A great majority of carers reported a negative influence towards their health and well being. Psychological problems like lack of concentration, sleeplessness and permanent tension are also among our carers most common (see also Brückner 2008, Höpflinger & Hugentobler 2005), but carers also suffer from diseases known as psychosomatic like problems with their back and herpes. Very alarming are the cases of carers who neglect their own health prevention and intervention (like dentist, prevention at the GP) because they don't find the time to.

Little is known about suddenly occurring care related situations of crisis (Sim Gould et. al 2008). A crisis can force the carer and her network to adapt to the new situation, make changes, include new support and figure out if reconciliation is still possible. Usually the greatest crisis is a sudden begin of a care need, e.g. after a stroke, an accident or otherwise caused necessary stay in hospital. At this time usually no arrangements are made and carers are forced to act quickly and effective in a time of emotional state of emergency and usually still very little information about the necessary steps (See also Schneider et al. 2005, 2006) is available. So it is no surprise that those 18% of carers mostly suffering from a burn out developed it in the beginning of a care situation. All of them had to face a sudden care need combined with heavy demands at the working place. Its also interesting that the group of carers who suffered from a burn out are not the same who we declared as the heavy burdened carers who summarized their experience of reconciliation with statements like "it is inhuman", "I don't have a life anymore, its just work and care", "my whole life is attacked". This also may be depending on the time of the interview. The "burn out carers" where all forced to make adaptations towards their arrangement to be able to further cope with the situation. So they reduced working hours and asked for more support. Those who care already for many years however, and just always "balance at the abyss" in relation to their energy and seemed to be much more in danger of developing serious diseases and the feeling that they sacrifice their life to care than the first mentioned.

A very important result by looking for typical conflict and stress situations was the experience that there are not only negative aspects, but reconciliation of work and care has also some positive impacts. Although positive outcomes seem much more related to aspects in carer's private life, like improvement of family relations, better relation to the cared-for and personal growth, it's often overlooked that many carers perceive work as a time out from caring (Au & Sowarka 2007, Grammar 2008, Keck & Saraceno 2009, Schneider et al. 2005, 2006.) Also in our research we found that being at work gives carers the feeling to take part in "normal life", to think about other

issues than caring, to socialise and get acknowledgement for fulfilling their tasks. To speak with Reichert (2007) working also has a kind of respite function. Another reason why several carers seem satisfied with their “double burden” is the assumption also found by other researcher (Keck & Saraceno 2009, Schneider et al. 2005) that without working they would be the only one caring for the person in need without any support from others. And finally we have some high educated female carers in our sample who worked always fulltime their entire life and now saw one advantage in caring that it forced them to find a new work life balance. Therefore they reduced their work and interpret their caring responsibility as a kind of societal contribution.

It becomes very obvious that reconciliation has in most cases both positive and negative aspects. Which one prevails depends on the amount of care, the informal and formal support at the work place and in private life as well as the quality of the relationship with all persons involved.

What strategies do carers use to reconcile work and care for an older individual?

Under strategies we subsumed all activities carers undertake to be able to fulfil their tasks. Networking and including other family members and colleagues belongs to it as well as asking for formal or informal support, using coping strategies and reorganise the work place. Strategies carers can use are also depending on possibilities offered by state, society, employer, and own family.

One of the most successful strategies is the establishment of a well functioning network, consisting of informal help and formal support services. The most important network-partner is as we already mentioned above the own family. Most carers with own family try to involve other family members especially partners or siblings. This strategy also depends on the ability to ask for help and accepting help from others, where ever possible. The other side of the coin is that carers experience quite a big burden if this family network is disturbed. Most important formal support is seen in care services, short term care and privately paid home helpers. In many cases the main task of the carer is to act as the manager of the care arrangement and try to keep the network members working smoothly together.

The other important strategy next to network building and asking for help is the possibility to organise the work life in a supporting way. This can either be reduction of working hours, stepping back from a leading position, using partial retirement or

taking care leave. 18% of the female carers in our sample were reducing working hours to be better able to reconcile, which matches exactly the percentage in the representative research of the MUG III study (Schneekloth & Wahl 2005) which came up to 18.2% of female and 6.6% of male carers. The 12,5% of male carers in our sample reducing their working hours is not significant, because it leads back to the one man out of 8 in total who reduced his working hours to care for his wife. This confirms the findings from Bitmann et al. (2007) also for Germany who found that men rather tend to stay full time employed whilst women are more likely to reduce their working hours¹². What is interesting in our sample is that no carer from East Germany used reduction of work to meet the conflicts. Here also female carers seem to try to stick to their fulltime employment as long as possible. If this does not seem possible anymore they rather choose a model the American Medlife study (2003) discussed as a typical male strategy: early retirement in the form of partial retirement.

Not very often but still used is the possibility to take a care leave. According to Metlive (2003) - which is not unproblematic to cite because it's connected to the US social policy - it is about 10% of female and 5% of male carers who are making use of usually unpaid time out options. First preliminary results of a study (Deutscher Bundestag 2010) estimate that within the first 1 ½ years around 9000 carers used the short term leave and 18 000 the six. About 55 % of all carers didn't even know the new legislation and their right. Also in our sample nobody used the new abilities, mainly because it is unpaid. But two female carer (4% of the female sample), came up to a special informal arrangement with their line manager which enabled them to have some time out ¹³

According to Schneekloth & Wahl (2005) for about 10% of the main carer quitting their job is a strategy to face the double burden they are in. In our definition quitting the job wasn't seen as a "successful" strategy in terms of reconciliation, because quitting the job is the end of work life balance. Due to the fact that we did not

¹² More about the gender differences see down below in the chapter of gender inequality

¹³ More about the different care leave models see in the chapter strategies and LTCI above

explicitly ask for carers who quit the job because of care we don't have any data about it. But although we did not plan to include them we still have one carer who quit the job and three who lost it. Strategies at the work place are also helpful like using the possibility of flexitime or home office (see also Spiess & Schneider 2003; Trukeschitz et al. 2009, Metlive 2003), dealing with understanding and supporting colleagues and line managers, by being open about the own situation but also demonstrate the willingness to support other colleagues.

Finally carers also mention the strategy to sign in ill themselves as a strategy for reconciliation if there is no other option to be able to look after the cared-for on a working day. Several carers reported on using this as a strategy. So far we didn't find this in the literature as a strategy but rather as a conflict.

Another important strategy is to develop useful coping strategies. This can be the attitude towards care and the caring task, like "the acceptance of the non perfect", this can also be the ability to enjoy the "little nice things of the every day life" like flowers and sunshine or the acceptance of the situation. Several carers give the advice not to care if one isn't really convinced that one really wants to do it. Most interviewed carers again and again emphasize that they need sources where they get new energy from; otherwise they could not continue caring for so long. A source for new energy can be the partner, friends, sports or hobbies. What ever it is, important is the ability not to forget ones own requirements. On this also belongs the willingness in taking time off every now and then.

Several carers referred to the fact that reconciliation is only possible if working carers have a good self management. They need to be able to pull all strings in their hand, to organize the care arrangement and be very efficient at their work place. Therefore it is e.g. necessary to have a proper documentation of the caring process or organise a legal guardianship in time.

Strategies carers use are often very effective and appropriate, sometimes however carers also use strategies which are neither reasonable nor helpful or health promotive, but rather self exploiting. They were used in situations were carers don't see any other way out.

To the latter category belong especially strategies which lead to the fact that carers "don't have a life on their own" anymore. These working carers are able to keep going and balance work and care by ignoring their own life. This can be either physical or emotional needs and mostly applies to carers who hardly ever rest and don't take enough time out. Main reasons for ignoring own needs are mainly severe

care needs combined with little formal but mainly also little informal support, a tense financial situation and strict demands of the employer.

What kind of influence does the qualification level of the carers have with regard to the reconciliation of work and care for an older individual?

Literature on reconciliation demonstrates that carer's labour participation is closely connected with their level of educational qualification and employment (Franke & Reichert 2010). Therefore we included the level of educational qualification already in our recruiting table and tried to find as many carers with high level of education as with low level of education. As high level of education we defined all working carers with an ISCED of 4 or higher. Employees with lower education are those with an ISCED of 3 or lower. In our sample we were able to include 41 (70%) working carers with higher education, but only 17 (29%) carers with lower education. It was very difficult recruiting interview partners with lower education. And also out of those with lower education, 16 have an ISCED of 3 and only one person has an ISCED of 2, which means that also the lower educated carers in our sample are still quite well qualified employees. We were not really able to include poor educated carers working in precarious work situations. The reason for this difficult recruitment situation may be twofold. First of all it may be traced back to the fact that participating in an interview conducted by a university may be something were less educated workers are rather hesitating. Another reason may be due to the fact that lower educated carers in less well paid jobs tend to quit their employment in case of occurring care need because they are sometimes better off in taking the care allowance and caring themselves than in earning low salaries and paying for additional support. Whilst high qualified carers try to combine work and care as long as possible, because the financial impact of their job loss is much higher. So probably the greatest difference between lower and higher education is that lower educated carers more often don't try to reconcile but quit their job (Engstler 2006, Masuy, 2009, Scharlach, Gustavson & Dal Santo 2007).

Researchers assume that working carers with a higher level of education usually belong to a higher class milieu, where it seems to be much more common to buy additional support services than in traditional lower class milieu where carers tend to organise care within their own family (Blinkert & Klie 2004, Heusinger 2006). This different behaviour however, is not seen as a question of differences in moral values but first of all a question of costs of opportunity. Carers with a higher level of

education usually also have a better employment and income situation, which enables them to buy additional support services (Blinkert & Klie 2000, Hasseler & Görres 2005). Besides they are usually working in jobs with more flexibility and freedom concerning work which allows a better reconciliation (Trukeschitz 2009). Secondly, quitting a well paid job has other consequences than quitting a low paid job. Payments like the benefits in cash of the LTCl which can be seen as a kind of income replacement in cases of poorly paid jobs are not seen as a compensation for income loss of better earners (Mnich & Kohler 2008).

Lower education, however, does sometimes but not always correspond with lower income. In our sample several lower educated working carers are working in own companies being quite successful earners whilst others with high educational level are in financial troubles. But this may also have to do with the fact that also the lower educated carers in our sample are qualified workers, earning enough money to buy additional support, be easily able to get the necessary information and deal with all bureaucratic issues. So it's probably not the level of education creating the difference but employment and financial situation.

But we also analysed if the level of education would have an influence on other reconciliation strategies carers use. Among those who changed their work situation like reduction of working hours, stepping back from leading positions or becoming self employed are only 4 carers with a low level of education. Two of them lost or quit their job, one became self employed and one took some kind of care leave. But no one of the lower educated carers reduced their working hours. This corresponds with the fact that in the group of carers with lower care need and lower hours of work we found only two rather low educated carers, one working part time due to own health issues and the other one never worked full time due to other family obligations. In cases where gender differences interfere our results do not confirm the theses that orientation towards work correlates with the level of education (Schneider et al. 2001).

But in the other hand 9 (53%) of these lower qualified carers are quite unsatisfied with their employer, because they feel put under pressure, mobbed, threatened with dismissal or indeed lost their job. (more about it see under employment situation 6.4.1.)

So in our relatively high educated sample we could not find any great differences between lower and higher educated carers, mainly because we didn't find any "really" low educated carers working as blue colour workers or in precarious jobs. A fact that

is mainly confirming the above discussed theses that low educated carers rather tend to quit their job and therefore did not meet the requirements of our study.

What kind of influence do the employment- and income situation of the carer and carers' households have on the reconciliation of work and care?

Influence of employment situation of carer and carers' household on the reconciliation of work and care

Research results about influence of the household structure on the abilities to reconcile are ambiguous (Franke & Reichert 2010). As described above a partner is seen by many carers as one of their most important supports. Nevertheless we assumed that there would not only be a difference between singles and couples, but also a difference according to the employment situation of the partner. Therefore we explored the cohesion between household structures including other family obligations, level of care, carer's employment situation and - if existing - partner's employment situation.

The assumption was that especially civil servants would be quite easily able to reconcile, because they have very secure jobs and a wide range of official regulations for their servants, especially different models for family leaves. Although there are only four civil servants within our sample, all of them reduced their working hours. Two of them reduced their working hours already due to earlier family obligations and their partners were both civil servants too. One male carer was caring for his wife and therefore reduced working hours for a restricted time and one female carer doesn't have a partner, but reduced work to be better able to care for her mother.

On the other hand there are 11 self employed carers - three of them male carers, who have an apparently unsecure job. Five carers however, have their own business (with a range of employees between 1 and 120) and are rather successful sales(wo)men. Four carers are offering their abilities and try to get errands or projects for themselves and two carers have own surgeries as therapists. As different as their companies are as different are their income situation and social environment. Whilst four carers are in real financial strain, four others are doing perfectly well and three without greater impact.

Research results about the capabilities of self employed carers are quite contradictory. According to Sarkisian and Gerstel (2004) self employed workers are less often engaged in caring because they are usually forced to work more than full

time. In our study however we couldn't confirm this result. The majority of the 19% self employed carers in our sample stressed the fact that they are self employed as the main reason for their ability to work and care, because self employment usually allows a greater flexibility and independence (see also Keck & Saraceno 2009).

Two carers became self employed as a strategy to better combine work and care. And it indeed enabled them to better care, but they are both struggling with their income, one of them with a self employed partner the other one single. Five of the self employed carers are working reduced hours; three of them due to care, six carers are further working full time. Nine of these carers have partners, three of them are self employed as well, the other six are working as employees. But here of course it depends very much on the kind of work self employed carers are doing. Those carers who work in their own family enterprise with own staff are usually better (not only in financial aspects) able to reconcile then those who singularly try to sell their abilities and quickly would loose costumers as soon as they are not able to fulfil their needs in time. So it depends also for self employed carers on the branches they are in.

From literature it is known that also branches have an influence on reconciliation. Workers employed in the public sector or even employed as civil servants for example have a very secure work place and a lot of additional possibilities to work flexible or take some time out (Franke & Reichert 2010). As a result their probability to quit their job declines around 30% in comparison to others (Döhner et al. 2008, Masuy 2009). So we tried to include working carers from different branches and sectors, from small family enterprises as well as huge world wide operating companies and with/without formal support offers for carers.

There could not be found any coherence between the branch of work and/or the size of the company in relation to the change of the work situation. Reduction of working hours and quitting of a leading position is equally distributed between different branches. It seems like these changes are rather related to the amount of care and support availability of different formal and informal support systems. But of course the situation at the work place can enable or hinder carers from making use of different models of working time reduction.

Although we could not locate any differences between sectors with regard to reconciliation we found that those carers working in family friendly companies were all quite pleased with the support by their employer. This is a result of the fact that in these companies there is usually a general openness towards questions connected

with work life balance and the generally established framework to improve the work life balance of employees also helps working carers to better reconcile (Franke & Reichert 2010).

Finally we focused on carers working under unsatisfactory conditions in their company. Although in the beginning of this report we stressed the fact that in our sample there aren't hardly any carers working under precarious conditions, we interviewed several carers who feel very much under pressure to perform. Either because their line managers aren't understanding and try to get rid of employees not working sufficient enough (too many mistakes or absence from work) or because employers threatened the whole staff with dismissals due to economic decline. We also included several carers who lost their job because of caring. Some of them had only temporary contracts and therefore were easily to dismiss after the end of their contract. For us the enormous influence a company can have on working carers well being become obvious when we interviewed the first carers suffering because of their employment situation. Interestingly half of the carers unsatisfied with their employer belong to the lower qualified workers. Looked at the lower qualified workers only, the amount of carers suffering because of their working place conditions is 53%. So it seems to be confirmed also by this study that lower qualified caring workers have a weaker position at the work place.

Out of these 18 carers (30%) who complained about not supportive employers, seven live in East Germany. If we only look at the East German participants, 38% are complaining about unsupporting employers. The reasons for carers' dissatisfaction were different. One group of carers has to cope with the situation that their employer isn't understanding at all and consequently also not very supporting. These employers have in common that they don't want to be bothered with personal problems of their employees, and therefore also hesitate to adopt informal solutions like more flexibility. A second group reports about mobbing at the work place by line managers mainly, but also by colleagues as soon as they signed ill for several weeks due to a burn out caused by the double burden. Both carers with this experience reported about strong trials of their line manager to dismiss them. A third group of carers suffers from an immense pressure to perform at their work place and feel often overstrained and not able to fulfil all requirements properly. This often happens in companies which are in quite bad economic shape. Carers working in a company threatened by economic decline and the announcement to dismiss employees are put under constant strain and fear of job loss. The last group finally consists of carers who lost their job because they were not able to reconcile properly - in the eyes of

their line manager. Especially in cases where employees have temporary contracts, it is quite easy to get rid of them. But in our sample there were also carers with standard contracts who got their dismissal. An unsecure employment situation as well as bad climate at working place is very burdening for carers. So it's not surprising that 14 out of the 18 carers reported about quite negative impacts on their health condition (5 burn outs, 7 exhaustions, 2 physical diseases).

Employment situation of the household members

29 carers (50% of our sample) are working full time. 12 of them have partners also working full time, in eight cases the partner is the person in need, seven don't have a partner at all. In one case the partner is working only 20 hours and has the main caring responsibility, in one other case the partner is retired. 23 carers live with a partner working full time. In 13 cases out of these the partner is working full time and the carer part time. Six carers work fulltime whilst their working partners reduced working hours due to care, seven carers were working anyway reduced because of children within their family (or former times having children). In three cases the partner is working only part time. In two cases the male partners are equally engaged, in one case he reduced working hours to improve his quality of life.

Conjecturable employment of both carer and partner plays a decisive role in the process of establishing the care arrangement and making decisions about own involvement. So we expected that carers within rather secure jobs or with partners in secure jobs would more easily and often feel able to adopt their job situation to their needs and reduce working ours or take a care leave. Therefore we looked first of all carefully at the combination of different forms of employment between partners.

Table 19. Employment structure of carers household

Partner Carer	Employed partner	Civil servant partner	Self em- ployed partner	Partner cared-for	No partner	Partner retired	TOTAL
Employed carer	12	2	6	10	6	4	39
Civil servant carer		2		1	1		4
Self - employed carer	2		3	2	2	2	11
Others					3	1	4
Total	14	4	9	13	12	7	58

We then were interested in the question if the employment situation of the partner would have an impact on the strategies of working carers towards their own employment situation. One hypothesis was that carers with partners in need of care or single carers rather stick to their full time employment whilst carers of a partner working (full time) him/herself would be more likely to reduce working hours or even quit their job.

Table 20. Changes of work arrangement and partner employment situation

	Partner working	Partner in need of care	Partner retired	Self employed	No partner
Reduction of working hours	6	3	1	3	
Quitting / loosing a leading position	2	1		1	1
Partial retirement		2	1		
Became self employed				1	1
Quit/lost job		1	1		4
Care leave	1				
No change	9	6	3	4	6
Total	18	13	6	9	12

The first glance at the table shows that working carers make changes towards their work situation in about half of all cases. Interestingly there are no differences visible relating to partner employment patterns. Working carers change their work situation in half of all cases no matter whether they are singles or have a partner working (full time, self employed), a partner who is retired or in need of care. However, by having a closer look at the table we can see that there are differences with regard to the kind of work changes. So it is very illustrative that in all groups there are carers reducing their working time except in cases of the single carers. This may be explained with the fact that single carers are depending completely on their own income whilst couples also have the partner's income or at least his/her pension or retirement money. The more it is alarming that it is mainly single carers who lost a job because they were not able to make the grades of all. Partial retirement was taken by women who's partner also wasn't working anymore, because of a disease or own retirement.

Those female carers in West Germany living in a sandwich position with own children in the same household all work only part time. (HH14, HH16, HH17, HH 26, HH 29)

This is different in East Germany where the mother with an under age child works fulltime, but worries about the fact that she hasn't got enough time and energy left for her daughter in puberty. The negative side of the coin is that relatively often especially those female carers with reduced working hours (and in a sandwich position with own children) don't get much support from their husbands. It seems that in these families the traditional division of labour is more unquestioned than in those where both partners worked full time and in the consequence both partners also shared the caring responsibilities more equally. Those carers with reduced working hours also often get lesser support from their siblings (more about it see under gender inequalities). Those male partners who directly support their wives also in caring (9) are almost all partners of wives working full time. Only exceptions are those couples where the partners shared the care equally (HH8, DD102) anyway.

To summarize we could show that carers are working full time when it is possible because of little care need or when they receive enough support from family or services. If carers reduce working hours then they can rely on a full time working partner or at least a partner with income from pension. Single carers in our sample did not reduce their working hours however in quite high percentage lost their job because they were not able to fulfil all the different requirements from work and care. Female carers also reduce their working hours for other family obligations, mainly children. In these cases the male partner is working full time. So the employment of

other family members esp. partners does have a great impact on the decisions of carer's reconciliation strategies.

A lot of companies are on the right way and have good support offers to enable carers to better reconcile. Of course improvement is possible and necessary, and at the moment it is mostly up to a company which offers they provide. But companies will probably make changes voluntarily. Due to demographic changes especially high qualified workers are missing. A fact that will force companies to make endeavours to be attractive for high qualified employers and make them to stick to the company. Therefore they will probably try to be family friendly companies and also install measures for carers. That will be an advantage for high qualified workers.

Really difficult becomes the situation for carers working in companies with little employment protection and without the influence of trade unions, who fight for employees rights. Unfortunately they increase and dismissal protection disappears when employees are only temporarily and project connected employed. This development may hit especially lower qualified workers. Low qualified workers aren't that valuable for companies because they are more easily to replace. An increasing number of companies try to pay very low wages, soften labour protection measures and hire workers only with temporary contracts. The policy discussion of the last years made it obvious that in the future we will probably have a contradictory movement depending on employee's qualification. Society and government have to be aware of the fact that maybe in the near future these changes may also contribute to the fact that relatives don't dare to take over caring responsibility because of their own job insecurity.

Influence on the financial situation of carers household

One research question concerns the impact of reconciliation on income. The income situation of the carer and the household is very important because it has an influence on the organisation of the care arrangement as well as the work situation. We decided to broaden the approach and ask about the impact of reconciliation on the financial situation of carer and household instead of only income. Firstly income is a very private issue and people usually don't like to talk about it. The second reason was that the impact of income is not the only influence on the overall financial situation of the household. The financial situation is not only related to own employment and income, but also to own fortune and property as well as the financial situation of the partner, the cared-for or other family members. Possibilities to pay for

additional support as well as the ability to reduce working hours or quit the job usually depend on the overall financial situation.

We interviewed 30 carers living as a couple, both working, 16 carers living with a partner not working. 13 out of these 16 single earning carers are living with a spouse in need of care. Three of the single earners live with a retired partner (HH7, HH12, HH28), who gets quite high pension after life long working as an academic. 12 carers live as singles, caring for a parent. Asked about the impact of reconciliation on their financial situation about half of the carers experienced a serious negative impact due to reconciliation, the other half did not. One important reason for little influence is the fact that in about half of all cases the person in need of care is in possession of enough money to come up for own needs and is sometimes even able to compensate carers loss of earnings. Usually carers experience a difficult financial situation, when the cared-for is not able to financially contribute at all to his care arrangement.

In the other half interviewed carers reported financial implications of reconciliation, because they quit or lost their job, reduced working hours or have to pay for additional support offers. But only 14 carers experienced a “great negative financial impact”. Stephens et al. (2001) found out that especially women with a low level of qualification, low employment status and little income experience their caring role as seriously conflictive. Financial difficulties can prevent carers from asking for enough professional support (Scharlach, Gustavson & Dal Santo 2007) which can lead to further conflicts and overburden.

We had a closer look on those 14 carers and detect that the majority (10) of them were singles (6) or single earners (4). The other four carers are double earners, where two feel financial pressure deriving mainly from the fact that they have to pay back the credit for a house, one family because both partners quit their employment and became self employed to be able to share the caring obligations and the last couple are both working on the same company and put on short term work. The fact that the majority of those in really great financial strain are single earners shows already the great impact the household structure can have.

This assumption can be confirmed if we have a closer look on those 12 caring spouses in our sample, two male and ten female carers. Not all of them reported difficult financial situations, but all of them are captured in a situation where they definitely feel forced to continue to work and care: at the one hand usually spouses feel responsible to care for their partner as long as possible, but at the same time

they are forced to continue to work (fulltime) to earn their common livelihood and be able to pay the additional support services which are necessary to reconcile. Nine spouse carers are working full time, one was just under the notice to leave her job, one reduced working hours, three asked for partial retirement and one gave up her leading position (still working full time). For the majority this is quite a show of strength. (Only three don't report any impact on their health, all the others do.) Most of them report about a financially difficult situation which forces them to work because otherwise they could not afford all necessary support services. In East Germany three caring wives applied for partial employment to be able to spend more time with their husbands. One carer said (HH3) that she would stop working immediately if she could look after her husband but she can't because they would be forced to apply for social aid in that case. Of course also early retired people receive a certain amount of pension, but in the average its lower because the cared-for didn't work until the retirement age and therefore lost an amount of pension.

It's also worth to look more closely at those 12 singles in our sample who care for one of their parents. Most of them are working close to full time, one lost her job, one is self employed and works part time and one reduced to part time. But half of them reported "great financial implications". (The same carers don't feel supported by their family - or they don't have any). It's a similar situation then with caring spouses that the impact on their financial situation is much bigger as soon as they reduce their working hours because they are responsible for their income alone. Four of the single carers and the single earner carers also had to deal with a job loss during their caring career which even strains their situation. For both cases it's not only that they are forced to continue to work and earn enough money but they also have to deal with the fact that there is no partner supporting them with household or caring tasks.

However there are also single earners where there isn't such a huge negative impact, because of the general financial situation which can also be influenced by property, heritage or other kinds of assets which can belong to a family independently of their employment status. We also found the pattern that a granddaughter "has to care" for her grandmother because she inherited her house in exchange for the promise to have life long right to live there and received care from her granddaughter.

Last but not least we would like to focus on those living as double earner couples. Nine carers in West and five in East are working full time whilst living in a double earner couple, the other 16 carers work between four and 34 hours per week. 12 of these carers report about changes by choice in their work load (reduction of working

hours, quitting a leading position, quitting the job). They were able to do so because they had either highly paid jobs and/or lived with a partner with high income. The others, who still work full time, care for someone with rather low care level or get a lot of support from either their partner or other family members.

To summarize: The income situation of a household has a great impact on the reconciliation of work and care. Half of the sample did not report financial difficulties, the other half did. Those carers who reported a negative financial impact reported three different causes: lack of income, additional payments for care support and financial difficulties not caused by care or work however influencing the whole situation in a negative way.

Singles and single earner couples report more often about a difficult financial situation and feel forced to continue to work (fulltime) because they are reliant on the money. Financial difficulties can also prevent carers from asking for more professional support.

Only half of all double earner couples are working full time, the others part time. Twelve of all carers in double earner couples changed their work loads, which was possible because their husband contributed as well to the family income.

The income and employment situation has a great impact on the reconciliation of work and care, because it leads to little money, forces carers to work full time and care with little professional support or enables carers to work reduced working hours but therefore “punish” the carer with little informal support.

Within the context of the actual parameters of employment and family-work, what kind of gender inequalities are the results of the reconciliation problematic?

In Germany 90% of all compulsory insured care persons in the pension insurance are female. This affects all informal carers working less than 30 hours and caring for more than 14 hours a week (Backes, Amrhein & Wolfinger 2008) These statistics underline the fact that caring is still mainly a female obligation (Infratest Sozialforschung 2003, Schneekloth, Wahl 2005, Schneider et al. 2006), especially when a higher amount of care is needed. Responsibilities of caring for a relative as well as the associated tasks are still very unequally distributed between men and women.

In this chapter we would like to first analyse female arrangements concerning the division of labour and then confront it with male strategies.

The first and most obvious outcome is that it is still mainly women's work to care for their relatives and therefore women are forced to reconcile more often than men. In our sample about half of all female carers are continuing working full time the other half is working on reduced hours. We were very interested to have a closer look on similarities and differences between those working full time and those working part time and figured out that we could divide them into three different groups: those working full time, those reducing work to improve their work - care - life balance and finally those who worked already part time due to other family obligations. Schneider et al. (2001) found that women have an increased probability of quitting work in case of a close relatives' care need. We are not able to analyse an increase or decrease of working hours within our study, but we there are women working fulltime in our sample although they have to deal with high care need of a relative. The most interesting question is: what enables these women to continue working full time and be able to care?

23 female fulltime workers in our sample are all either having a partner also working full time (11), a partner in need of care (6) or are single (6). There is only one case where the male partner is working on reduced hours to be able to care. By looking closer at this subgroup we found several similarities among these female carers. Firstly they all have very supporting partners and a quite strong supporting network. The 10 carers living in a couple both working full time generally report that they feel supported by their partners as well emotionally as in deed and stress the fact that they could not imagine getting along without this support. Mostly in these cases husbands don't contribute in caring, but take over other responsibilities esp. housework and administrative work, which supports their wives. The care need does not seem to have an influence on this arrangement, because we can find both low and high care level types in this pattern. Usually they also have resources for additional payments. But the most important factor is that they never had own children and were due to this fact able to always work full time during their entire work life and insofar have a "typical male career". These results not only underline the thesis of Flieder (2008) that women who raised already children are seen as somehow especially capable of caring for a relative in need of care, especially when the work life is already marked by several gaps. But it also shows that men seem obviously more willing to support their wives /partners and equally contribute to caring when they live in a couple with a life long dual earner role model. The exceptions from this module are women from East Germany who always worked full

time although having had own children. This result probably has to do with completely different value of work in the former DDR.

The second group consists of carers working part time already before the care need arose. They show a quite traditional pattern of labour division. In our sample that's mostly those families where children still live in the household and wives are working part time anyway to be able to fulfil the household tasks. Here wives not only do not feel supported by their husbands, but also feel under pressure to not disadvantage the husband due to caring obligations. As one woman put it, that her husband is earning the biggest part of their livelihood, he is working hard to keep their standard of living but therefore he is expecting to not being bothered with household or caring duties. In another case the wife is caring for her mother in law living in the same household. When the care need became too severe it was she who quit her job and now she feels chained towards the house, whilst her husband is working outside in the farm. But it seems to be out of question that it was she who had to take over this part, although her husband is already retired and working voluntarily on the farm. An already existing unequal distribution of labour seems to be a very important promotive factor for an unequal distribution of caring responsibilities (Flieder 2008). Housework and caring is still assumed as a female obligation in these families. This ascription is underlined by the sociostatistical and social security legislative terms of "main bread winner" (which is usually the husband) and "main carer" (which is usually the wife). Backes (1999 in Backes 2008:23) calls this a "hierarchical complementarity", because it fixes the traditional gender roles with different ascribed tasks and defines the main task of women being the caring/household part.

Another promotive factor for this inequality, closely linked with the traditional division of labour is the generally lower income of women. Especially in cases where women always had reduced working hours and neglected their own career due to family obligations they usually have smaller salaries compared to their always full time working husbands. Another reason for smaller income is the averagely worse payment of female employers in general (Pfau-Effinger 2005, Pfau-Effinger et al. 2008). Looking at this precondition it seems only reasonable for families to reduce the working hours of the person with the lower income. This however leads to increasing financial dependency of women (Gröning 2007; Himmelweit & Land 2008). Additionally the discrimination of women in the labour market increases their discrimination again when it comes to caring. In these configurations female carers are double disadvantaged. Women disclaim their own career and income and receive lesser caring support from their partners.

A third group of female carers in our sample reduced working hours for better reconciling. These women either had a quite heavy care load or belong to the group of long distance carers, who reserved one day per week to spend with their parent in need. Their decision to reduce their work load may also have to do with the fact that they are mostly married to already retired partners, having quite a lot of time. These partners are supporting them emotionally and with homework, but not with caring. These women all have in common that they reduced their working hours to improve their work life balance and are financially rather well off. Their decision to not reduce their whole life to only working and caring but allowing themselves also enough time for recovering and time out can be interpreted as a way of life in opposition to typical male full time working model into a more balanced model which includes all important parts of life. Obviously financial preconditions to do so have to be given.

Several studies indicate that men's contribution to care increases (Buboltz-Lutz 2006; Schneekloth & Wahl 2005; Keck & Saraceno 2009). In our study, however, the proportion of men is only 14 %. This has probably not only to do with the little amount of men caring, but also with the fact that for men it is much more a taboo to confess their caring obligation than for women. This conclusion seems to be at the first glance a contradiction to the result from Philips (2007) who states that female care is something rather taken for granted whilst male care has a very positive connotation. But our experience with recruiting showed that this may be true for the private context, but within the working environment men seem to be even more hesitant than women to confess their obligation. An assumption which can be confirmed by data of the Metlife Mature Market Institute et al. (2003), who found out that male workers are much less willing than women to openly talk about their caring obligations with colleagues and line managers. This may derive from the fact that care is still seen as a typical female task and therefore perceived as something "atypical" for men with little value (Backes, Amrhein & Wölfinger 2008).

It was very difficult to find any male carer willing to take part in our investigation. But we finally could include eight caring men. Aside we also can compare men and women in their different roles around a usual care arrangement as a partner of the main carer or a sibling of a carer because we got a lot of information about men's contribution from the point of the interviewed female carers.

The eight interviewed male carers in our study were involved in very different arrangements: Two men are caring for their wives. The first one was in a very heavy physical and emotional burdened situation looking after his demented wife and fulfilled all caring tasks including hands on care himself, but organised successively a

lot of support services until in the end he decided to reduce his own amount and arranged her living in a shared flat with other demented people. The other husband is looking after a wife which is not demented and still able to do a lot of things herself and is able to spend the day on her own, but looks back on a life long history of care needs from her husband (HH1, DD117). One male carer (Hh36) is together with his sister, who is the main carer, supporting his parents. He isn't able to take over the main responsibility because he is also caring for his wife, who is in care need of level one and needs daily support, because she suffers from amyotrophic. His wife was too young to fulfil the recruiting criteria for our investigation; nevertheless he does all the necessary support including all hands on care and reduced his working hours to be able to look after her.

Three men caring for their mothers presented themselves as the "manager of the care arrangement", although they all offer also instrumental help, like shopping, dealing with the doctor and care services. None of them does any hands on care himself (HH24, HH28, DD105). Interestingly two of them are part of a network of many siblings, who share the task of looking after their mother. (HH24, HH28). All three of them are working full time in demanding jobs and are heavily engaged in supporting their mother. One caring son (Hh25) is insofar an exception as he also has several siblings and tries to arrange and organise help for his parents, but neither feels accepted by his sister and brothers nor does he get the necessary support from them. Which in the end leads to the fact that he isn't able to prepare the support he thinks would be relevant.

A different pattern is visible at this son from East Germany who is also working in a quite demanding job and at the same time is strongly involved in caring (managing as well as instrumental help and hands on care), however, supported by his wife and other family members. He seems to be an exception, because he's also offering hands on care (DE, DD111). At the first glance quiet astonishing is the fact that these carers are very little supported by partners. But we then figured out that there are no wives able to support, because they are either in need of care (HH1, DD117, HH 36) or the male carer doesn't have a wife (HH24, HH25). Two male carers from East Germany caring for their mothers (DD105 and DD111) equally share the caring obligation with their wives. Only one caring son (HH28) reports that his wife does not actively support him in caring. However, he has a large network of siblings sharing the caring tasks, so it is simply not necessary to include another person. In comparison to the female carers it is noticeable that none of the male carers caring for a parent reduced his working hours because of caring or other family obligations.

5 of them never had own children. There is only one carer from East Germany who quit his leading position because of a break down due to overburdening with reconciliation. However, also he continues working fulltime.

Although it wasn't possible for us to include more male carers directly into our study, we got a lot of information about men in their role as a sibling in case of a parent in need of care, through caring daughters who reported about the (non-) contribution of their brothers and partners. As described above quite a lot of women report about a brother who isn't willing to really contribute to care. And one of their explanations for little contribution is the assumed fact that the other sibling isn't able to deal with parents decline. Its always caring daughters who assume, that their brothers "aren't able to deal with the situation". Like a carer, who describes her brother as "sophisticated" (HH19, HH23, HH31, HH32, DD108).

Astonishingly this statement is accepted as a reasonable excuse where nobody can change anything about it. The fact that men can't cope with the situation seems to be something women find they have to live with. Interestingly there didn't occur a single case in our sample where the refusal to care by a daughter (which was reported quite often) was justified with the fact that she was "not able to deal with the situation". This argumentation is based on the assumption that there exist typical female and male attitudes which can't be really put into question. So the stereotype that women are somehow better capable of caring seems still vital. As described above there is this interesting pattern of brothers who strongly contribute to care, but all have to deal with own difficulties resp. diseases which restrain them and makes work life balance anyway difficult for them (HH22, HH27, HH29, HH33). Three of these brothers are bachelors without own family responsibilities. These brothers are willing to share the task or at least contribute as much as they are able to. The fact that they don't participate in the labour market and/or don't have own family responsibilities makes them in the eyes of their sisters capable of sacrificing their energy to care.

A very common and probably wide spread pattern is this of brothers trying to contribute in line with their possibilities which are usually depending from their own work life arrangements (work and family) and the distance between the parent in need and own place of residence. In these arrangements it's usually the sister who is the main carer and brothers contribute something, depending on their own work load rather little than more. So there is only one case in our sample where a brother with own family obligations and a sister both working full time share the amount of care equally (HH30). In this case the brother is living at the same village with his mother whilst the daughter is a long distance carer. The other two cases where brothers are

contributing equally are those arrangements where the male main carers are the network organiser. Here also brothers are equally involved. Sisters of course also not always work properly together and as described above suffer from ambivalent feelings towards each other. The difference is that they give different reasons for not contributing and more often also report about an equal share of work.

We hardly found any men, willing to be interviewed, caring for a parent in law, whilst women often feel responsible for their mother in law. In our sample we interviewed only one husband caring for his mother in law (he also cares for his mother, who lives in another town and is mainly cared-for by his sister). Also his wife is equally included in caring for her mother (DD105). But we interviewed three caring daughters who reported about their husbands supporting them very much in caring for their mothers in law: One daughter (HH5) lives together with her husband who is self employed and works from home. He is looking after his demented mother in law during the day whilst his wife is fulltime working as an employee coming home from work at night. Her justification for this division of labour is that she is the one with the definite salary whilst her husband as a self-employed never can rely on his income. Despite she argued that she as the outgoing type of personality needs her colleagues and other people much more than he as a quite introvert does. When ever she is at home she takes over most responsibility for her mother. The other example is a family where both partners gave up their employment and became self employed to be able to share the care of the wife's demented mother. This arrangement led to a strain and uncertain financial situation but enabled both to equally take part in other life activities and didn't burden only one partner with care. Both cases seem to be an example that slowly also new patterns of labour division seem to occur where men and women take over the same amount of responsibility. Finally there are two other cases where caring daughters report about a lot of support in the (hands on) care of their parent. In both cases their husbands are male nurses who are very familiar with the caring topic. In both cases their support was traced back to their special qualification, but also to their general willingness to support their wives and equally share all arising tasks.

What was found in other studies is also visible in our data, namely that men's contributions increase primarily within spouse care (Census 2001, Schneekloth und Wahl 2005). In these cases also male carers are doing hands on care, reduce their work load, take time out and feel completely responsible. It seems that caring for a wife meanwhile also became an obligation for men.

This seems to be different in case of parents care need. Caring sons are often not contributing a lot as long as there is a sister involved. A result confirmed by Johnson and La Sasso (2000) who could show that the existence of a sister lowers the probability of a woman to become the main carer of a parent, the existence of a brother however doesn't lower her probability of becoming a carer. The interviewed male carers in our sample act mainly as care manager, not doing hands on care and have a great support network. Consequently we also could not corroborate the statement of Backes et al. (2008) that men are caring less often than women, but in case they do care, they spend the same amount of time as women. The difference to our study can maybe be explained by the fact that this ascription applies to all male carers including those already retired, but working carers are different.

None of the sons in our sample reduced working hours due to the care need of a parent. This corresponds with other results of Backes et al (2008:58) who claim that men are usually caring in advanced positions: Because also in case of being the main carer men usually can fall back on more informal and formal support, which also allows a better reconciliation of work and care.

Nevertheless there is some hope visible that this will change because we also found the pattern that men start to feel as responsible as women and take their turns in caring. In our sample one situation was reported where a husband together with his wife became self employed to be able to care together with his wife for his mother in law.

Several facts underline the assumption that caring is still seen as an obligation of the daughter (in law). So we found different patterns, which almost all stress the fact that – if siblings are available - as long as there is a sister it is mainly her responsibility to care for a parent. As already stated by others (Gröning & Kunstmann 2008; Radtke & Röwenkamp 2008) we could also show that brothers contribute, but with different tasks and to a lesser degree and fulfil rather administrative or instrumental tasks than hands on care (see also Schneekloth 2006).

As described by Grammar (2008) also in our sample women are the ones who are more often willing to reduce their work load or work already part time due to former family obligations.

Only female carers lost their jobs because of their caring obligations and are the ones who got lesser support from family members than men. Women also report greater negative financial implications and more often have to face an influence on their pension (Himmelweit & Land 2008). So also in our study we could show that it is

still women who more often have to balance work, care and own family life and have to cope with consequences in their private and their work life as well as their financial situation. In our research we found several reasons for this still unequal share of work in times of an increasing contribution of women in the labour market. But we also found hints that role appreciations are changing only slowly.

But also partners are not always supporting their caring wives in a fruitful way. As long as the traditional division of labour was clear, it was obvious that caring would be women's task because they were the ones responsible for household and family work. Interestingly, although all women we interviewed are - or at least were - engaged in the labour market - the old role models and responsibilities are still quite lively. The fact that amount and kind of care are still not equally distributed between men and women also has an impact on reconciliation for work and care. In the pattern we found women care more often and intensive than men. They are usually the ones who are more often willing to reduce their work load or work already part time, they are the ones who lost their job because of their caring obligations and the ones who got less support from family than men. They also are the ones who report greater negative financial implications and more often have to face an influence on their pension.

Another reason why women take over main responsibility is often because they are the ones who still have the lower income in comparison with their husbands. So it is obvious that if someone reduces the work load it must be the one with the lower income. Whenever men take over main responsibility they are spouse carers, or have a lot of support and act mainly as a care manager or there are other reasons why they can't work full time and therefore are capable of taking over more responsibility, or they are the ones worse salary. In these cases the factor "employment" can neutralise the factor "gender" (Sakisian and Gerstel 2004). In our study men had the main responsibility for caring or at least contributed equally to care when they earned lesser money than their female partner, had the more unsecure job, were less qualified or worked already reduced working hours due to other reasons (own health problems) or were unemployed and therefore capable of taking over more responsibility, by own means but also by means of their female kin, esp. wives or sisters.

From a feminist perspective also several instruments of the LTCI are heavily criticised of supporting existing gender inequality and underlying power structures. Critics point to the fact that especially female low income workers tend to quit there job and take the benefits in cash as a kind of income replacement (Mnich & Kohler

2008). But also the regulation that contributions to the pension insurance are only paid, if the main carers is working less then 30 hours a week and the option of care leave¹⁴ would rather turn women into part time work or quitting their job (Backes et al. 2008; Brückner 2008; Dräger et al 2003).

In our study we did not find any of these consequences happen. But this may be due to the fact that we were not able to include any real low income earner in our study. One reason why we could not find these situations might however be the fact that female carers with low wages quit their job already when care need of more then 10 hours a week arose.

Those rather high qualified women in our sample did neither reduce working time to get insurance payment nor did any of them take the six month care leave from LTCl. Due to the fact that it is a time off without income replacement it does not seam to be attractive.

But the question remains: what could be done to get more men into care work? When we look towards other areas of reconciling work and family life we can observe that financial incentives can be one solution to combat inequality under certain circumstances: For many years the German society tried to get more fathers into parental leave, but fathers were never willing. Meanwhile parental leave is connected with an allowance but its full amount can be kept by a couple only when they share the parental leave and the father takes at least a two month leave. Since then participation of men in parental leave increased significantly. Maybe something similar could be an option to make more men participating in care.

Which kind of support at the public, company or societal level is most efficient for the reconciliation of employment and care for older individuals?

In this chapter we discuss already existing political, operative and societal measures perceived as useful by carers as well as their suggestions for further improvement.

¹⁴ More about the actual legislation on care leave as well as suggestions from the Ministry of Family Affairs towards a “new care leave” see under chapter “support by the German LTCl

Recognition of their role as a carer is one of the crucial aspects carers mention when asked about improvements of their situation. A result interestingly also gained by other research done in Germany (Schneider et. al 2005 and 2006) but as far as we know not in other countries. Recognition has several aspects. In the first hand it is related to the fact that society as a whole appreciates that so many people care privately for a relative and are willing to put up with quite great changes in their private and professional live. Recognition however has also to do with acceptance. Carers suffer if their environment is not able to accept their decision to take the responsibility for a cared person. In many interviews carers were hurt by recommendations of friends, neighbours, colleagues and line managers to give up care and put their relative to a nursing home. A lack of acceptance makes it very difficult to ask for help either. So general recognition and acceptance would help many carers a lot to deal more open with their situation and feel free to ask others for support.

In our society recognition also has to do with acknowledgement in cash! Carers who reduce their working hours to be able to reconcile not only suffer from a directly loss of income but also from a lower pension rate. Several carers therefore claim a loan for carers who quit their job for caring in the height of the amount of benefits in kind in care level three (which is around 1400 Euros).

The existing care insurance is seen as an important contribution to the possibilities of asking for professional support, which almost all carers use. Working carers need the possibility to take a few days off in case of emergency. The LTCl allows now an unpaid "*care leave*" of 6 month as well as a 10 days leave in case of emergency. The fact that the needs of working carers are meanwhile also known by politicians is very much appreciated. Nevertheless are the interviewed carers not happy with the actual legislation and don't use it. Main critical points are that it is an unpaid care leave and that it is very difficult to predict the duration of a care situation so most carers don't know when to take the six month care leave and what to do when it ends. If carers take this offer they need the insurance that it doesn't affect their working life by any means. Carers demand to be treated in the same way as parents of small children, with paid care leave and 10 days paid care leave in case of disease or stay in hospital. This request is also discussed by political parties. Several authors (Blinkert & Klie 2004, DGB 2005, Meyer 2006) showed that especially conservative parties plead for different modules of care leave with the intension to strengthen informal care relations, whilst socio-democrats and trade unions are rather opponent, because they are afraid this model would consolidate women's domestic role and

rather plead for better adjusted support services, short term reduction of working hours and better dismissal protection.

There are several *support services* which are seen as very important to allow reconciliation. This is mainly professional care services, day care facilities, short term care and privately paid home helpers. Interestingly support by volunteers was neither used nor requested by most carers. This hesitation towards volunteers has mainly to do with the size of a good working care arrangement. Too many involved actors make it difficult to organise and handle the arrangement, cause additional stress for the carer and easily overstrain the cared-for person (Schneider et al. 2005 and 2006, Sims-Gould et al. 2008).

To improve the situation carers need reliable and flexible care services of high quality, who meet carers and cared-for's needs. Day care facilities are seen as a very important support for working carers. However, they should be cheaper, extending their opening hours to 7 days, round the clock and install pick up and delivery service. Schneider et al. (2005 and 2006) also found that day care facilities and short term care as one of the most important support offers for carers, however as in our study often only used by high qualified carers with better income due to the high prices. Surprisingly shared flats for people suffering from dementia - recommended in literature as an innovative idea which should be expanded (DGB 2005) were rather seldom mentioned, although one carer in our sample used it and was very satisfied. The reason for little usage is probably the fact that they are unknown to most people and still a quite expensive option.

Short term care is seen as a very important facility in case of the beginning of care need when carers are still busy with organising, or to allow carers a time off. An improvement would be to allow short term care in the cared-for's own home by nurses who would stay round the clock.

In this connection some carers also plead for the legalisation of migrant care workers who would actually for a lot of carer's best meet their needs, because they are flexible, not too expensive and round the clock available. To seriously react to this request and even change it into a recommendation would go beyond the scope of this study, because it not only touches legal or financial aspects, but is also linked to ethical and moral issues and therefore has to be discussed in depth and separately at another place. But the request should be taken seriously by politicians and the discussion put on the political agenda.

Quite a big issue for many carers in our sample was the (non)-support by doctors and hospitals. Interestingly we didn't find similar complaints and discussions in other articles on reconciliation. Although it is quite an issue in research dealing with people suffering from dementia and their carers (Angerhausen 2008, Kleina & Wingenfeld 2007). *Doctors and hospitals* that are aware of working carer's situation are of great help. Caring for an old frail person means a lot of visits at different doctors. If surgeries would be prepared to working carers and offer them appointments at the edge of the day (morning or evening), that would help a lot. Even better would be - like in former times - home visits of the doctor in the early evening. Hospitals are sometimes used as a possibility for time off, most of the time however they cause the carer a lot of work, especially in case of dementia. Hospitals are not prepared to look after them what means that the carer has to join the patient and therefore take time off. Secondly patient's condition is usually much worse after discharge than before which means a lot additional work for the carer. So, hospitals should improve the treatment of demented persons and establish an environment suitable for these patients.

Many recent studies dealing with carers needs deplored the lack of adequate and at the right time information about care facilities, health and care insurance, self help groups and other financial issues (Blinkert & Klie 2004, Lamura et al. 2006, Döhner et al. 2008, Schneekloth & Wahl 2005). Also carers in our sample suffered from a general lack of information and counselling especially in the beginning of the care need of a relative. Although the German government tried to react on this demand and put the right for advice in form of the "care access points" in the last reform of the LTCI, still most carers never heard about these facilities.

Efficient support services from carer's perspective are offers which are not too expensive, of high quality, round the clock available and able to react flexible on carers needs.

Measures at the company level are existential for working carers (Franke & Reichert 2010) although it didn't even seem to be self evident for carers themselves at the first glance. How important an employer's attitude towards carers is becomes usually obvious when missing. Also at the company level recognition eases carers work - life balance, because it means a lot of stress to working carers if they have to justify their engagement as a carer. Therefore also supporting and understanding colleagues and line managers are very important preconditions for a successful reconciliation. In companies were carers report about understanding line managers usually is also a positive working climate and carers are able to arrange individual solutions on an

informal way. Companies who are generally trying to be family friendly seem to have a greater chance to also be open for work and care arrangements.

Most important offers carers mentioned was sympathy of the line manager and colleagues, flexible working hours, possibility to reduce working hours or stepping back from a leading position for the time required as well as time out in case of emergency. These requests were made already by many other studies (Mestheneos & Triantafillou 2005, Meyer 2006, Schneider et al. 2005 and 2006, berufundfamilie 2007 and 2009). Franke and Reichert (2010) summarize that very helpful is a work organisation tailored to employees needs, which are as flexible as possible with however constant structures. Especially important is a balance between space for enough flexibility at the one hand and predictability at the other hand. Next to flexibility the possibility of reduction of work load and working hours are both seen as quite important by carers. As in our sample also in other studies researcher come to the conclusion that carers are especially pleased with 75% work load because they can take a day off but the income loss is still bearable (Franke & Reichert 2010).

We could confirm in our study the finding that often informal agreements are of more help and better adjusted to carers needs then - if existing - official formal regulations (Schneider et al. 2005 and 2006). Nevertheless carers should not be depending on the good relationship to their line manager but being entitled to some kind of flexibility and time out. The establishment could either be the tasks of trade unions or the state (DGB 2005 and 2006). Some carers recommend enabling all workers to a certain kind of flexibility and the possibility to step down from a leading position for a while without any negative consequences for the further career (depending on the tasks of the company of course) so that carers would not be forced to name the reasons for their usage of the company offers.

Carers would appreciate information sheets from their company with all their entitlements as a carer and may be also further recommendations towards information, counselling and financial issues (berufundfamilie2007 and 2009). Carers in our study however stressed the fact that they prefer leaflets and sheets they can read without letting the employer know anything about their private situation.

To summarize this discussion on most effective support offers we can state with Franke & Reichert (2008) that relief for carers is not to win with single offers, but needs a connection between political, societal and operational measures.

7 Policy recommendations

These recommendations derive from the evaluation of the carers interviews. However, they do not consist of carers' suggestions for improvement only, but represent the view of the evaluating researchers. Additional remarks which were not expressed by carers but seem to be relevant from the viewpoint of the researchers were made explicit. We divided the recommendations into those valid for the government, the society, the employers and the service providers. But as recognition is crucial for all mentioned target groups, we start with this general point.

Recognition

Carers need a private and professional environment which accepts and appreciates their decision to take the responsibility for a person in need of care. Better recognition prevents carers from feeling forced to defend their decisions for their individual care arrangement. A better recognition and acceptance would help many carers a lot to deal more open with their situation and feel free to ask others for support.

Recognition can be achieved in many ways. It is a form of recognition when employers stop asking employees to make a decision towards a nursing home and everybody has an idea what it means to be a carer. But it is also a contribution to better recognition when politicians and employers put the topic more often on the agenda and the issue expands into a public discourse. Recognition however has in our society also to do with acknowledgement in cash!

Government / society

A lot of the already existing offers and legal aspects concerning carers are regulated and anchored in the (health) care insurance law. Therefore the majority of our recommendations are directed to government and society but have to be implemented with the insurance law.

Personal budget

Working carers feel overburdened when they have too little support or have to work too much. The desires of carers however are quite different. There are carers who would like to get additional support from care services, others would be helped with a privately paid home help and the next ones would like to reduce working hours, but

loss of income and a lower pension rate would lead to extreme financial strain. Therefore we recommend a personal budget for the cared-for in the height of the benefits in kind from the LTCl which would allow families to use the money for the kind of support they need: to pay for formal support, to employ a private home help or take the money as a kind of income replacement.

Contribution to pension payments

Connected with the suggestion for a personal budget is the demand for a contribution to pension payments for all working carers working less than full time. At the moment only carers working less than 30 hours per week receive contributions to their pension payments from the LTCl. Carers who work more than 30 hours are excluded although often caring round the clock.

Care leave

The actual discussion of unpaid and paid care leave is appreciated, although not all problems connected with the time limit seem to be solved. Care leave isn't a possibility for all carers. It might however firstly be a good option for carers who be in funds due to own salary or partners earnings. And secondly for those carers caring in a situation where the duration of care is rather predictable or where they can imagine to hand over the main responsibility to other persons /institutions after this two years. Additionally carers should be treated the same way as parents of young children who can get 10 days paid leave per year in case a child becomes ill. That would enable carers to better act in case of emergency without painful loss of income.

Possibility of treatment at a health resort for carers

As for mothers there should be the possibility for carers to apply for a treatment at a health resort. Many carers feel extremely exhausted and would need a time off where they can gain energy again. Sometimes however, carers don't want or can't leave the cared-for behind. Therefore cures should be offered for the carer only, or as a holiday where carer and cared-for can spend the time together, but the cared-for person is looked after during the day so that the carer has time to recover. The later options exist already but should be extended.

Information and counselling with easy access

As already mentioned in many studies also we demand a better system of information and counselling for carers. The newly invented care assess centres (Pflegestützpunkte) are a positive step in the right direction. Unfortunately they are

still quite unknown by carers. It is too early to report about the acceptance and success, especially as these institutions work very different in all federal states. Here we need research to monitor this innovative approach.

Reduction of bureaucratic demands

Many carers suffer from a lot bureaucratic demands for health and insurance companies. Several procedures are useful and important, but it would be worth rethinking if all paper work required at the moment is entirely necessary. It could be a real relief for carers to have less bureaucratic work and could maybe also save some money to the insurance companies if they could reduce some operating procedures. Despite carers often complain about a disrespectful treatment by insurance consultants, who seem to be holding relevant information back or giving too little advice. It would help carers a lot if their insurance consultant would understand their situation and act sympathetic and friendly.

Gender equality

Last but not least the gender issue should be considered. Caring is still a female task, therefore also much more women are hit by the need to reconcile. From other areas - like child care and parental leave - we know that financial issues are one possibility to get more men into childcare. So it would be worth trying to connect financial incentives on a more equal distribution of care work.

Employers

Flexibility

The probably most important precondition for successful reconciliation is the possibility to be flexible in time, place and amount of working hours. Flexibility does not only mean regulations like flexi-time - which is a very crucial option - but also the possibility to take home office days (as far as possible) or reduce the work load for a certain time, by working part time or quitting a leading position for a fixed time. Flexibility means also that employers enable carers to leave the work place in case of emergency and make up for the lost working hours at a later date. Additional bureaucracy should be avoided and negative consequences for further work life excluded.

One possibility to prevent carers from disadvantages from line managers and envy of colleagues because of their "special treatment" would be to offer several regulations

to all employees without asking for reasons, like the option to work part time, flexible working hours or a “sabbatical”.

Family friendliness

Some formal regulations seem to be necessary and helpful to prevent working carers from depending on the sympathy of a line manager, like right to work part time or take a care leave. However, a company which attempts to be family friendly is often also open to informal solutions adapted to individual needs of employees. A positive working climate, supporting line managers and understanding colleagues are a central precondition for a successful reconciliation.

Option of part time work

Employees should generally get the possibility to reduce their working hours and work part time for a defined period. Part time should not only mean 50% reduction but also offer more 75% jobs, which seem to be a compromise between work time reduction and income loss. A reduction of working time has of course to go along with reduction of work load, which is not always the case. Connected with the part time option should be the right of a return to full time after a defined time.

Information within companies

Carers are especially in the beginning of a care situation in the need of information about their rights, their duties and possibilities relating to support offers as well as their work place options. Companies have very different experiences with offering information, counselling and advice towards their assumed employees with caring responsibilities. Very often carers don't use the different offers. This probably has to do with the fact that carers have to out themselves as carers by making use of an offer and this is something many carers avoid as long as possible, because they often fear negative consequences. Nevertheless carers wish to get information from their company. So we recommend providing this in a way which enables employees to use the material or join an event without being forced to admit that they are caring.

Legislation for companies

Many companies are doing already quite a lot to become a family friendly company and support work life balance of their employees. They are doing this mainly to be capable of competing. Especially high qualified workers are becoming rare in some branches and companies are aware of the fact that they have to do something to be attractive for employees. This, however, is very different for low qualified workers working in companies where their labour is easily replaceable. In these companies

often very little is done to support the work life balance of their employees and our legislation does not force companies to be family friendly. On the contrary, also long lasting old privileges fought through by trade unions are abolished in many companies, like agreed wages, number of holidays and dismissal protection. Precautious work places however are very bad preconditions for a successful reconciliation. The prevention of further recess of employee protection is a task of government and a question of priorities within our society.

Care service providers

Quality of the services

Working carers need services of high quality to feel relieved and able to concentrate on their work. Services should be reliable and flexible enough to meet carers' time requirements, they should provide care work of high quality and don't send too many different staff members to one client. Staff members should be smart enough to also fulfil matters of courses without extra request. Staff members of support services are appreciated when they treat carers as partners and enable communication and exchange of important information.

Day care facilities

Day care facilities are one of the most important relieving measures for working carers. They are very much appreciated as long as they are not too expensive. It would be of great importance to have more day care facilities with shorter waiting lists, which are open seven days a week, if possible round the clock. Opening till late or overnight would also enable single carers or spouses to work full time or shift worker to better reconcile. Open weekends would give carers the possibility to recover. All facilities should offer a pick up and delivery service, so that carers don't have to hurry in the morning before or late after work.

Nursing homes and short term care facilities

A nursing home is often the last option when all other possibilities are exhausted. Nursing homes in general still have a quite bad reputation. The same is valid for short term care usually placed in nursing homes. Nursing homes should try to develop into facilities which are real options for older people, by creating home like atmosphere and not resembling an institutional character.

More in-home attendance

Carers plead for more in-home attendance, some for migrant carers. It should not be the person in need who is forced to leave the house to be looked after and often returns confused and in bad shape. Carers need much more affordable 24 hours attendance coming to the cared-for's home for the short term as well as for the long run. Where this stuff could come from and under which circumstances they could be allowed to fulfil this task is an issue the government is instantly asked to deal with.

Manageable support networks

Meanwhile there are quite a lot of very good support offers available in Germany. Carers can have care services, home help, day care and volunteers looking after the cared-for. The problem is that often too many different people are involved in the network. It is difficult for the cared-for to deal with sometimes up to 10 different persons looking after him/her and it means a lot of additional work for the carer to organise an arrangement consisting of so many different people. Therefore it could be of some help if professional staff would be able to fulfil several different tasks and not send new different members for each task.

Hospitals

Hospital stays of the person in need cause a lot of work and energy for working carers, especially in case of dementia. Hospitals are not prepared to look after this target group and often don't care for them properly. That forces many carers to join the patient for the whole hospital stay. Therefore they have to take time off. Secondly patient's condition is often much worse after discharge than before, which also means a lot of additional work for the carer. Our demand is that hospitals should improve the treatment of persons in need of care and adapt the environment to these patients special need and adequately care for them.

Often the beginning of the care situation is connected with a stay in the hospital, because an acute crisis made medical treatment or examination necessary. Carers are then forced to organise the arrangement very quickly and are often neither informed nor prepared about financial issues and support options. Social workers in hospitals could have a very important function as first advisor and informants for carers.

Practitioners

Caring for an old frail person includes a lot of visits at different practitioners which means that the carer has to join the person in need to different appointments, usually

in the middle of the day. What sounds as a quite unimportant factor turned out to be quite a burden for full time working carers without flexitime, because they therefore always had to take a day off. If surgeries would be prepared to working carers and would offer them appointments at the edge of the day (morning or evening) that would help a lot. An even better solution would be - like in former times - home visits of practitioners in the early evening.

8 Literature

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9 Annexes

Description of the 60 cases

Table 21. Description of the 60 cases

	Gender	Age	Cared-for person/s	Causes of care need	Level of qualification	Family / income structure	Kind of work
HH1	Male	60	Wife	Dementia	High	Couple, one working	Civil Servant
HH2	Female		Mother	Old Age	High	Single	Employee
HH3	Female	58	Husband	Stroke	High	Couple, one working	Employee
HH4	Female	59	Husband	Dementia	Low	Couple, both working	Employee
HH5	Female	51	Mother	Dementia	Low	Couple, both working	Employee
HH6	Female	70	Husband	Dementia/ cancer	High	Couple, one working	Self employed
HH7	Female	58	Mother	Old age	High	Couple, one working	Employee
HH8	Female	60	Mother	Dementia	High	Couple, both working	Self employed
HH9	Female	54	Father and mother	Old age/ dementia	Low	Single	Employee
HH10	Female	57	Husband	Cancer	Low	Couple, one working	Employee
HH11	Female	44	Father	Stroke	High	Couple, both working	Employee

HH12	Female	60	Mother	Dementia	High	Couple, one working	Self employed
HH13	Female	51	Mother and Father	Old age	High	Couple, both working	Employee
HH14	Female	59	Mother	Dementia	Low	Couple, one working	Employee
HH15	Female	57	Mother	Dementia	Low	Couple, both working	Self employed
HH16	Female	49	Mother	Cancer	High	Couple, both working	Civil Servant
HH17	Female	52	Mother	Dementia	Low	Couple, both working	Self employed
HH18	Female	56	Father	Old age/ blindness	High	Couple, both working	Employee
HH19	Female	54	Mother	Dementia	High	Couple, both working	Employee
HH20	Female	47	Friend	Heart attack	Low	Couple, both working	Self employed
HH21	Female	58	Mother and Mother in law	Dementia	High	Couple, both working	Civil Servant
HH22	Female	59	Mother	Stroke	High	Couple, both working	Employee
HH23	Female	45	Mother	Dementia	High	Couple, both working	Employee
HH24	Male	51	Mother	Dementia	low	Single	Employee
HH25	Male	47	Mother/ Father	Dementia	High	Single	Self employed
HH26	Female	51	Mother	Dementia	Low	Couple, one working	Unemploy ed
HH27	Female	57	Mother	Cancer	Low	Couple, both working	Employee
HH28	Male	63	Mother	Old age/ blindness	High		Self employed
HH29	Female	54	Mother	Dementia	high	Couple, both working	Employee
HH30	Female	33	Mother	Cancer	High	Couple, both working	Employee
HH31	Female	54	Father	Dementia	Low	Single	Self employed
HH32	Female	48	Mother	Hart	High	Single	Employee

				disease			
HH33	Female	50	Mother/ father	Depression	Low	Single	Employee
HH34	Female	55	Father	Limited mobility	High	Couple, both working	Employee
HH35	Female	44	Mother	Dementia	Low	Couple, both working	Employee
HH36	Male	53	Mother/ father	Depression	Low	Couple, one working	Self employed
HH37	Female	48	Mother	Dementia	High	Couple, both working	Self employed
HH38	Female	51	Mother	Dementia	Low	Single	Employee
HH39	Female	56	Husband	Dementia	High	Couple, one working	Unemploy ed
HH40	Female	47	Husband	Dementia	High	Couple, one working	Employee
DD101	Female	49	Husband	Dementia	Low	Couple, one working	Employee/ partial retirement
DD102	Female	46	Mother in law	Cancer	Low	Couple, both working	Employee
DD103	Female	46	Grandmoth er	Old age/ blindness	High	Couple, both working	Employee
DD104	Female	61	Husband	Neurological disease	High	Couple, one working	Employee
DD105	Male	52	Mother in law/ mother	Dementia	High	Couple, both working	Employee
DD106	Female	65	Husband	Dementia	High	Couple, one working	Partial Employe ment
DD107	Female	55	Father	Dementia	Low	Single	Unemploy ed
DD108	Female	27	Grand- mother	Cancer	High	Single	Vocational training
DD109	Female	47	Mother	Neurological disease	High	Couple, both working	Employee
DD110	Female	60	Mother	Dementia	High	Single	unemploy ed
DD111	Male	56	Mother	Stroke	High	Couple, both working	Employee
DD112	Female	57	Mother /	Limited	High	Single	Employee

			Aunt	mobility			
DD113	Female	61	Husband	Stroke	Low	Couple, one working	Employee
DD114	Female	59	Mother	Dementia	High	Couple, both working	Employee
DD115	Female	56	Mother	Dementia	High	Couple, both working	Employee
DD116	Female	61	Mother	Cancer	High	Couple, both working	Employee/ partial retirement
DD117	Male	55	Wife	Neurological disease	High	Couple, one working	Employee
DD118	Female	62	Husband	Stroke	High	Couple, one working	Employee