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Negotiating Helpful Action

A Substantive Theory on the Relationship
between Formal and Informal Care

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ACADEMIC DISSERTATION
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Abstract

The purpose of this study was to investigate how family caregivers and nurses consider their mutual relationship and to develop a substantive theory on the relationship between formal and informal care. Interviews (n=88) with family caregivers, nurses and nurse managers have been conducted. Data collection and analysis were performed according to the grounded theory methodology.

The relationship between formal and informal care is an encounter of two quite different perspectives that is focussed on the issue of how a particular amount of caregiving work is performed by means that are considered helpful by the parties involved. The perspectives of family caregivers and nurses on their relationship differ considerably, but both are engaged in a process of *Negotiating helpful action*. While for family caregivers this process is determined by the goal of *Facilitating work and care*, the nurses' everyday reality is focussed on *Shaping different realities* in different households and with different people. How these different perspectives contribute to the negotiation process is influenced by interactive effects between nurses and family caregivers conceptualised as *Mutual dependency*. .

From the caregivers' point of view the beginning of a caregiving situation is conceptualized by the context of *Facing new life circumstances*. For family caregivers the consequence out of this context is *Coming to terms with competing demands. Facing new life circumstances* precedes *coming to terms with competing demands.* Family caregivers engage in a process of *Developing a fitting arrangement*. In this process family caregivers apply strategies of *Managing caregiving*. The strategies for *Managing caregiving* are intended to develop a caregiving arrangement that allows for the goal of *Facilitating work and care*.

From the nurses' perspective *Becoming involved* is an underlying condition of home care nursing. It is a prerequisite for the work of nurses in home care. Home care nursing is framed by three concepts: *Framing home care nursing* which conceptualizes the context and which contains the legislative framework of home care nursing. Beside *Framing home care* nursing, the nurses' professional identity (*Working in home care nursing)* and the nurses' personal identity (*Contributing one's own personality*) influence the nursing perspective. The interplay between the home care framework and the nurses' professional and personal identity results in the consequence of the nurses *Feeling restricted* in their practice. The core of the nurses' perspective is the process of *Shaping different realities.* The concept of *Feeling restricted* influences the process of *Shaping different realities.* According to their professional and personal identities nurses apply professional (*Matching order and reality*) and personal

(*Balancing closeness and distance*) strategies to shape different realities. The goal of the process of home care nursing is *Keeping people at home*.

The substantive theory adds to the understanding of the relationship between formal and informal care in home care. This perspective has the potential to reflect upon existing conceptualizations in nursing science and to provide an expanded view for the investigation of home care and family caregiving phenomena. For nursing practice the substantive theory serves as a tool for evaluating existing practice and reconsider implicit professional assumptions in relation to an existing reality of family caregiving.

Key words: Family caregiving, Formal and informal care, Home care nursing, Nurses and family caregivers, Grounded Theory

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1 Introduction

This study investigates the situation of family caregivers who care for a sick and care dependent relative at home and the relationship these family caregivers have with nurses from professional home care services. The home is the place where most people in need of care are being cared for by their families. The majority receives care from their family members without professional support.

Home care as one component of long-term care is high on the agenda in many countries all over the world. In Western Europe it is an explicit goal of health care policy to face the challenges caused by demographic changes by enabling care dependent people to stay in their homes for as long as possible. To a considerable extent this policy implies the reliance on support provided by family members, friends and neighbours. Public policy is also concerned about the costs that long-term care implies for public funds (Nolan, 1999).

In industrialised countries there is consistent concern that the changes in family structures, the increase of female workforce participation and the growing number of elderly people will result in an increased need for formal services to match the increasing demand for home care. Nevertheless, so far *"...informal care is by far the most prevalent form of long-term care and dwarfs the provision of care in nursing homes and by paid home care workers."* (Wiener, 2003, p. 3). The International Labour Office (Daly, 2001) and the World Health Organization (2003) have recently stressed that problems of long-term care and the prevalence of informal care are not only an issue in industrialised countries, but also in developing and transition countries.

To get a better understanding of the amount, type and patterns of long-term care in families within the European Union, several studies have been carried out. The EUROFAMCARE study focussed on services for supporting family carers of elderly people and called for strengthened support of family carers at EU and national level. It also called for improvement of existing services in terms of coverage, quality and accessibility (EUROFAMCARE, 2005). The SOCCARE project analysed different care arrangements in five European countries. One of the recommendations for formal care policies from this study was: *"Care provisions for older people must in particular go through a thorough self-examination. Why do so many European families see these services as 'last resort' and do not wish to use them? The quality of these services and the responsiveness to needs and values of families are in distinctive need of major improvement all over Europe."* (SOCCARE Project Report 6, 2003, p. 12).

According to the final report of the Commission of enquiry of the German parliament on the demographic change, the extent of the demand for professional nursing care is the aggregated result of decision-making processes within families (Deutscher Bundestag, 2002). Two factors appear to be most influential for the decision-making process: On the one hand, the care performance within families and on the other hand the extent and stability of the informal support network. Within this report it is assumed that the more stable the informal support network is, the lower the demand for professional nursing care will be. This report bases a prognosis concerning the relationship between formal and informal care in the future on a quantified assumption about basic parameters. By doing so, four scenarios are described: The first one considers formal service utilization solely based upon demographic changes. This would mean an increase in the percentage on formal nursing care use from 35% to 40% of all care-dependent persons until 2050. The second scenario additionally takes into account changes in family structures of the elderly and assumes a decrease in the informal resources available to spouses and partners. Following this scenario the percentage of formal service use would increase up to 44%. Scenario 3 considers individualisation and increasing participation of women in the paid working sector. For home care this scenario would mean an increase up to more than 50% of formal service use. Scenario 4 calculates what would happen to the informal resources if the social and political conditions would be improved. It is assumed that within this scenario the percentage of persons moving into a nursing home would considerably decrease and at the same time formal home-care service use would increase up to 58%. This scenario implies the support of informal support networks and in order to do so the need for re-structuring formal home and community services to be more tailored according to people’s needs. It can be seen from these scenarios that an increase in the demand of home care services is inevitable. The report does not say how formal services in general, and nursing services in particular, are going to achieve the goal of supporting informal support networks in a sustainable und effective way. Therefore nurses need to be prepared for how to support family and other informal caregivers. The knowledge of how to achieve this is not part of existing nursing theories, which only to a limited extent provide a background for working with family caregivers in home care.

The core issue from these diverse sources is obvious: Family caregivers need support that is tailored to their needs, but nowadays such kind of support is either not available or services that are available do not match the actual needs. A possible explanation is offered by Gubrium and Sankar (1990) who argue that decision-makers and health care providers appear to conceptualise the home as a kind of black whole into which a range of medical services and conditions can be transferred. Because of this many services do not seem to be tailored to the needs of family caregivers and care-dependent people.

The services that are referred to in the above mentioned studies and reports are not always clearly defined. Long-term care includes aspects of both health and social care which sometimes makes an understanding difficult. The nursing profession finds itself in the intersection between health and social care and this is particularly true for nurses in long-term care either in nursing homes or in home care. Without pretending that the nursing profession is the only profession that contributes to long-term care it can be assumed that it plays an important role. It is an open question, whether nurses contributed to the problems of long-term care services or whether existing policies have prevented nurses from contributing to home care situations in a sufficient way. Moers (1997) has outlined how home care nursing in Germany was subject to various and sometimes contradictory political aims and ideas. These various aims have been associated with aspects of social care and health care as well. The nursing profession itself has not been remarkably active in Germany to develop its own perspective and to present its own approach to the challenges of home care.

Nursing and nursing science need to take the societal development as a challenge. So far these developments have not been addressed in nursing research in Germany and other countries very deeply. Family nursing in the German context is on its way of development, but unlike other countries it develops in the field of home care and from issues of family caregiving in the care of the elderly.

This study cannot give an answer on all issues raised above, but it will contribute to a better understanding of the relationship between family caregivers and nurses in home care. It will address the questions of why and what for family caregivers seek support from formal services and how this support is actually perceived and it will address the nurses' perspective of how they consider their role and contribution in home care with regard to family caregivers.

2 Literature review

The purpose of this chapter is to provide a review over the existing conceptualizations of the relationship between formal and informal care in home care. There is considerable debate about the role of the literature in a grounded theory study. Glaser (1978, 1998) stated several times that a review of the literature in the beginning of a grounded theory study is not necessary and only serves the purpose of getting a preconceived framework for data collection and analysis that does not allow for a real grounded theory study. On the other hand Glaser and Strauss (1967) stated that every researcher must have a perspective to see relevant data and to be able to develop abstract and significant categories from it.

According to Kelle (1994) there are two distinct ways of how theoretical knowledge can influence empirical theory construction. The first way is to not explicate theoretical knowledge, but to use it as implicit knowledge during data collection and analysis and the second way is theoretical knowledge being explicitly available as a heuristic framework that is explicated before data collection and analysis. In this study the second way was chosen, because it reflects the researcher's experience in the field under study. The knowledge about the theories and findings from different studies outlined below reflect existing perspectives on the relationship between formal and informal care. They will serve as sensitizing concepts (Blumer, 1969) that help to guide this research and help in understanding how formal and informal carers construct meaning and interpret particular actions. Sensitizing concepts do not serve the purpose of relying on and referring to this knowledge and forcing data to fit into it, but to question what is going on in the empirical world. They raise theoretical sensitivity and support the labelling of what is going on in the data collected.

The literature was reviewed concerning concepts, theories and studies that describe the nature of home care and the relationship between informal and formal care or, in other terms, the relationship between nurses and families. The purpose of the literature search was to look for conceptualizations from different perspectives that raise the theoretical sensitivity for this study. Leading terms for the literature search were:

- Formal and informal care
- Nurses and family caregivers
- Chronic illness experience
- Home care and utilization, and
- Inanspruchnahme und Pflege (German for Utilization and nursing care)

The literature search was performed using the databases CINAHL, MEDLINE and GeroLit. The search was conducted before the research proposal was written and again after the analysis of the data. The literature search revealed four main areas in which the relationship between formal and informal care has been addressed: within the management of chronic illness, in studies related to family caregiving, from a social policy and health systems perspective and from a professional perspective that often was a nursing perspective, but also implied a general professional perspective including various disciplines. The important concepts and insights from these areas are outlined below. An overview over the literature is provided in appendix 1.

Before the findings from the literature search are presented different terminologies will be outlined briefly which are important for the investigation of the relationship between formal and informal care. Each terminology reflects a particular perspective of how to consider caregiving phenomena. The broader context consists of discussions around care work in general. The terminology 'formal' and 'informal' care stems from debates around the 'informal sector' of welfare production and feminist analyses of domestic labour (Finch, 1993). In this respect informal caring is seen as a normal part of the way in which any society organises the welfare of its citizens. Within this perspective, other labels are public and private care or paid and unpaid caregiving work (Leira, 1993), by which the boundaries between welfare state policy and private responsibilities are conceptualised.

The terminology is also influenced by the fact that 'formal' and 'informal' care have been addressed from a social care perspective and a health care perspective. From a social care perspective, the distinction between 'formal' and 'informal' care has been used to distinguish formal care provision by formal and professional caregivers within the framework of an employment from informal care provision within human, mostly family relationships. Formal caregiving is not attributed to one profession alone, but it embraces professions such as nursing, social work and different kinds of home assistance (Soldo et al., 1989).

From a health care perspective the distinction is not that clear. Health care professionals are mostly concerned with the care of an individual patient while the social relationships of this patient are not in the main focus. Health care professionals basically see themselves in charge and non-professionals are only concerned in terms of how they support and facilitate medical or nursing procedures. Because of this the distinction is often made between 'professionals' who are knowledgable due to their professional education on the one hand and 'lays' who are not knowledgable about medical issues on the other hand (Lewin et al., 2005). In this study these terms are not used, because to attribute the term 'lay' to family members who provide care to another family member often for many years without external support does not seem to be appropriate. Expert-layperson-relationships suggest a clear divide in terms of knowledge, skills and competence with the professionals or experts being the ones to determine the situation. There is no reason to believe that this is true for the relationship between nurses and family caregivers. Recent developments show that the distinction between formal and informal care seems to become more difficult, because previously labelled informal care becomes more formalised and formal care gets an informal dimension as in the case of personal assistants of people with physical disabilities (Allen and Ciambrone, 2003).

In this study it was decided to use the terminology 'formal' care for professional caregivers and 'informal' care for family caregivers as it is the broadest and most neutral one for purposes of distinction between different people who perform caregiving work. It was chosen despite the fact that the people who are labelled as formal and informal caregivers do usually not refer to themselves as formal and informal carers (Twigg et al., 1990). The decision was made, because conceptual approaches on the relationship between nurses and family caregivers have used the terms formal and informal carers. Daly and Standing (2001, p. 7) pointed out that the word 'informal' suggests something casual and outside the ambit of public concern. By using the word informal it is not intended to suggest any value statement. Beside the 'formal'/'informal' terminology in this study it is referred to nurses and family caregivers as they are the ones representing the formal and informal care sector.

2.1 The experience of chronic illness

Studies on chronic illness are included in this review, because the relationship between formal and informal care often is placed in the context of how people cope with and manage chronic illness at home. The chronic illness experience has been studied widely within different disciplines such as psychology, sociology, anthropology and different health care disciplines. The focus of these studies is highly dependent on disciplinary perspectives, theoretical assumptions and concerns. The complexities inherent in the study of chronic illness and the existing knowledge from different disciplines does not accumulate to a coherent general framework of understanding (Thorne et al., 2002). An important aspect of the chronic illness experience is that it is not exclusively related to functional status and symptoms, but also to making meaning for the person afflicted with the illness (Ironside et al., 2003).

The experience of chronic illness has been studied from the individual perspective of the ill person. In this respect the strategies such as gaining control, making demands, non-compliance of the ill person have been addressed (Asbring and Närvänen, 2004). Problems for elders of giving up their independence and the problems associated with becoming dependent on loved ones (Crist, 2005) have also been reported. Important concepts in these studies have been control and balance, but there is no consensus of how control over the consequences of the disease and the balance between different requirements that are caused by the disease are actualised (Piercy and Bliezner, 1999; Thorne et al., 2002).

Despite a range of studies that address the experience of chronic illness on the individual level of the person afflicted there is a growing recognition that the chronic illness experience is hardly just an individual experience, but a joint experience of the individual and his or her significant others and/or family. This perspective resulted in several models such as the trajectory framework (Corbin and Strauss, 1988) or the illness-constellation model (Morse and Johnson, 1991). A common aspect of these models is that the experience of chronic illness always concerns the individual and the respective family. The actual consequences may be different, but the experience never is just an individual one. Another joint aspect of these studies is that chronic illness is always associated with processes of managing the consequences of the illness and organising the work that needs to be done. This involves not only negotiations about who does what, but it also involves redefinitions of former roles, relationships and the establishment of new routines. Families are striving for stability and re-normalisation of their joint family life (Jussila, 2005; Zeman, 1997) and they need to ‘recreate life’ (Conger and Marshall, 1998), because severe illness is usually not anticipated as part of the normal maturation circle of the family members.

Authors have investigated the management of chronic illness at home in terms of phases that the people involved go through (Corbin and Strauss, 1988) and have shown how spouses and families adapt to the circumstances caused by the illness and the adjustments of daily life that occurred. Corbin and Strauss (1988) use the term trajectory that they distinguish from a course of the illness. A trajectory refers not only to the physiological unfolding of a disease, but to the total organisation of the work that has to be done over that course and in addition to the impact on those involved with that work and its organisation. A trajectory focusses on the active role that people play in shaping the course of an illness and it involves the work, the interplay of workers and the non-medical features of management along with relevant medical ones.

An important insight into the management of chronic illness at home is that the key players are the ill people themselves and their spouses and not the assisting medical or other professional staff (Corbin and Strauss, 1988). Other authors have concentrated on types of relationships between the ill person and the family when it comes to providing support and re-arranging daily routines. Steiner-Hummel and Zellhuber (1991) developed a typology on caregiving relationships within families and behavioural aspects related to them. They distinguish between

- caring relationships in which younger family members with often contradictory emotional bounds assume the caregiving role due to high feelings of obligation with a strong influence of female value patterns and role attributions. They take over the main part of the caregiving work and there is only little space for external support,
- Living relationships in which spouses after long periods of caregiving have difficulties in accepting external support, and
- Caregivers who actively draw borders, i.e. they react to demands for support, work actively on finding solutions, but limit their practical and emotional availability and seek for external help.

Similarly Twigg and Atkin (1993) conceptualised the responses of family caregivers to the caregiving situation, but they add the dimension of gaining something positive from the caregiving role.

In summary, the literature on chronic illness reveals the importance of the family in managing chronic illness and the importance of having a focus beyond the actual illness when studying aspects related to it. The sensitizing concepts from the literature on chronic illness are ‘phasing’ in terms of the processes that are associated with managing chronic illness at home, aspects of control and balancing, and the importance of the family.

2.2 Family caregiving

The fact that the illness experience is a family rather than an individual experience is widely recognised. Family caregiving in the literature is addressed as being mostly female (Lee and Porteous, 2002; Navaie-Waliser et al., 2002). Family caregivers are wives, daughters, daughters-in-law and when it comes to children being in need of care the caregivers mostly are their mothers. This common statement from many studies on family caregiving has been challenged by Thorne et al. (2002) who argue that the population in qualitative studies on chronic illness in the majority consisted of white women in their middle ages. The risk of being biased when studying family caregiving has also been mentioned by Schnepp (2006), who states that the neglect of male family caregivers limits our understanding of the complexities involved in family caregiving. Recent statistics from Germany show that 27-37% of all family caregivers were male (Schupp und Künemund, 2004) and confirm the need of being cautious when studying family caregiving with a gender focus.

While there is recognition that family caregiving is an issue that is not only a matter of concern in private homes, it also is in nursing homes (Bowers, 1988; Davies, 2005), in hospitals in general (Astedt-Kurki et al., 1999; Li, 2005) or in intensive care units of hospitals (Verhaeghe et al., 2005). The main location of family caregiving is where people live in their own homes. Therefore it is important to study family caregiving and the relationship between nurses and family caregivers in the context of home and community care, which is neither exclusively related to health care nor to social care.

An overall finding on family caregiving is the hard work that is associated with it and that asks much of the family caregivers. This resulted in many studies that focussed on caregiver burden (Jarrott et al., 2005; Edwards et al., 2002; Pot et al., 2005; Sansoni et al. 2004) and the development of instruments to assess and quantify caregiver burden (McCallion et al., 2005; Schreiner at al., 2006) to have a basis on which to develop interventions to ease caregiver burden. This approach is challenged by some authors (Nolan et al., 2003) who argue that questions on the appropriateness of the 'trial' paradigm in studies on family caregiving did not result in a reconsideration of methodological approaches, but into a call for even more statistical sophistication.

In qualitative studies the burdensome aspects of family caregiving and the life situation of the family caregiver have been referred to as a shrinking life and lack of individual freedom (Öhman and Söderberg, 2004), constant managing, enduring and surviving of day-to-day experiences (Chang, 2006), worrisome in several respects (Li, 2005), and as family caregivers being the hidden patients that are in need of external support themselves (Ostwald, 1997). Bradley (2003) reports that 20% of family caregivers are in need of home care themselves. These findings can be summarised in terms of family caregiving being a strong and hard personal experience. However, an exclusive focus on the problems related to family caregiving does only account for a limited understanding.

Apart from the burdensome and limitating aspects, the processes of taking on responsibility on part of the caregivers for the organisation and work related to the care-recipients caregiving process have been investigated. Taking responsibility involves a redefinition of roles (Morse and Johnson, 1991) between the family members that live together and are involved in the caregiving process. Assuming responsibility is necessary to keep the caregiving process going and to adapt to the new life circumstances of the whole family. It is not necessarily a voluntary process, but more a response to the actual need for it. Öhmann and Söderberg (2004) state that family caregivers are forced to take responsibility while at the same time developing an increased sense of responsibility.

Positive aspects of family caregiving have not been as extensively studied as the burdensome aspects, but there are some indications of positive aspects and the importance of reciprocity within family relationships influencing family caregiving. Blom and Duijnstee (1999) refer to the burden and the strength of family caregiving and they argue that the burden of family caregivers can only be understood by addressing the acceptance of the family caregivers for the caregiving process, the motivation to care and the actual handling of practical tasks involved in caregiving. They stress the importance of the relationship that family caregivers and care-recipients had before the caregiving process started. A positive relationship may lead to a caregiving process that is rewarding and experienced in positive terms by the family caregiver. This perspective is also supported by the purpose of protecting the care-recipient's self as a general purpose of family caregiving (Aberg et al, 2004; Schnepp, 2006). Family caregivers consider this as part of their caregiving role and feel the need to do so due to the emotional relationship they have to the care-recipient.

The experience of family caregivers is important in terms of understanding the life circumstances of the caregivers themselves, but it is also important in terms of the quality of care that is provided. There seems to be a direct link between the ability of caregivers to cope with the situation and the care recipient's quality of care and recovery (Verhaeghe et al., 2005). Although this is a more instrumental perspective on family caregivers, it reveals the importance of searching for interdependencies between family caregivers and care-recipients in several respects such as the history and quality of relationships, the performance of the caregiving process and the impact on the illness and its trajectory.

For the understanding of family caregiving it is important to consider it in terms of a whole family experience that has a range of burdensome and life changing aspects but also includes rewarding parts.

2.3 Nurses in home care

There is widespread recognition that nurses play an important role in home care by providing skilled services to people in need and by working closely with patients and their caregivers (Kane, 2003). Home care nursing may have different connotations in different countries. While in some countries several special qualifications are available for nurses working outside of institutions (e.g. Public Health Nursing, Community Nursing), in other countries home care nursing is the appropriate label that applies to nurses working in extramural settings. This is the case in Germany.

Studies have addressed the nurses' role according to different groups of patients and their relatives. A general perception of the role of nurses is that of supporting the care-recipient's staying at home for as long as possible and the stabilisation of the home care situation (Boes, 2003). Another general perception of the nurse role is related to health promotion and disease prevention (Leipert, 1996). The role of nurses in home care is determined by the context in which nurses practice. This context is often defined by national legislation and regulation on nursing that determines the scope of practice. Therefore the role of nurses is diffcult to compare on an international basis.

Another perspective in studies considers the role of nurses in home care with particular patient populations such as people with learning disabilities (Barr, 2006), people with mental illnesses (Sjöblom et al., 2005), people suffering from dementia (Roelands et al., 2005) or cancer patients (Dunne et al., 2005). Although these studies have taken different approaches in terms of asking nurses what they perceive in their work or what they are actually doing, an overall finding is that nurses recognise the family and family caregivers as being part of their job. However, the actualisation of how nurses work with and for families differs considerably. They face difficulties and dilemmas in the meeting of close relatives (Sjöblom et al., 2005); they recognise the family as element of care (Dunne et al., 2005); and they state emotional support to family members as part of their job (Roelands et al., 2005). This indicates that there is no joint understanding in the nursing profession as how to work with family members and as to the role nurses actually play.

The amount and extent of the nurses' work that is directly related to family caregivers is difficult to determine. Following a study from De Vliegher et al. (2005) who identified self-care assistance, (im)mobility and (psycho)social interventions as the core interventions in home nursing, there is reason to believe that most of the nursing interventions are related to the care-recipients. The above mentioned interventions are basically related to the care-recipient's needs. For the German context this is supported by the fact that the reimbursement scheme for home care nursing services is almost exclusively related to services for the care-recipients (Büscher et al., 2005).

Although the studies on nursing interventions in home care mentioned above seem to focus on interventions for care-recipients, some authors (Jeon et al., 2005; Larson et al., 2005; Magnusson and Hanson, 2005; Tanyi, 2006) have addressed interventions for family caregivers. These studies implicitly indicate the importance of family caregivers and, at least partially, recognize the situation of family caregivers as being stressful. Therefore the focus is on efforts to improve the family caregivers' situation. Interventions that have been investigated embrace respite care (Jeon et al., 2005), the use of communication technology (Magnusson and Hanson, 2005), educational programmes (Larson et al., 2005), and the use of spirituality (Tanyi, 2006).

2.4 Family caregivers and nurses

Beyond the scope of studies that focussed on family caregivers or nurses separately the literature shows several approaches to investigate relationships, mutual perceptions or experiences and interactions between nurses and family caregivers (Jeon, 2004; Nolan et al., 1996; 2001; 2003; Twigg and Atkin, 1994; Ward-Griffin and McKeever, 2000; Ward-Griffin, 2001). These studies mostly collected data from either family caregivers or nurses, but some included both.

From the family caregivers' perspective the services provided by nurses are increasingly subject to evaluation. In Germany, lack of punctuality, no continuity of nursing staff, lack of time, poor performance, unfriendliness, problems with bills and the qualification level of nurses have been identified as concerns and complaints of care-recipients and family caregivers who have been asked about their perception of and satisfaction with nursing care services (Roth, 2001). A lack of influence on what kind of help is provided and lack of flexibility (Holstein et al., 1993) has also been reported.

2.4.1 Professional perceptions

From a general professional perspective Twigg and Atkin (1994) have developed a model of how family carers are perceived by the formal care system. According to this model carers are perceived as resources, as co-workers, as co-clients, or as the superseded carer. Carers as resources are the predominant reality of social care and in this respect carers represent a 'given' reality against which the professionals operate. The carers may be supportive in terms of collaborating with professionals, but they are not recognized concerning their own interests and a conflict between family caregivers and care-recipients is ignored (Twigg and Atkin, 1994). Carers are considered as co-workers when the well-being of the carer is considered as a means of achieving a high quality of care for the care-recipient. That means that the family caregivers' well-being is encompassed by this perspective, but on an essentially instrumental basis. The carers as resources and as co-workers conceptualisation were also identified by Manthorpe et al. (2003) as the models that fitted best the professionals' understanding of needs and circumstances of family caregivers. The carers as co-client perspective regards family caregivers as clients being in need of help themselves. A conflict of interest between the family caregiver and care-recipient is recognized, but the focus is more on the family caregiver. The superseded carer perspective transcends the caregiving relationship rather than supporting it. It either is concerned with the aim of the care-recipient being no longer dependent on the family caregiver or it is concerned with the well-being of the family caregiver that only can be achieved by cessation of the caregiving relationship (Twigg and Atkin, 1994).

The most important aspect from this conceptualization is that family caregivers are mostly considered as being resources for professional or formal carers. This implies the assumption that quality in home care directly links with the quality of professional supervision and the degree to which the caregiver follows the professional care plan (Conger and Marshall, 1998). This viewpoint is supported by several other studies (Bond, 1992; Dill, 1990). Nurses and other health and social care professionals tend to turn the social and physical aspects of home lives into standardised descriptions and classify home care situations according to their pathological implications (Dill, 1990). This aspect has been labelled as medicalisation by Bond (1992). Health care professionals define a problem in medical terms and this implies them being in charge of defining and determining the appropriate answers. For family caregivers this means that they become subject to expert and social control (Bond, 1992).

The problem of how nurses and other health care professionals approach the situation is not necessarily based on the aim of gaining control over family caregivers or home care situations in general. It rather reflects the way of how health care professionals are educated and socialised in their profession. Zeman (1997) refers to this problem as a conflict between the life-world approach of family caregivers on the one hand, for whom the maintenance of family relationships and the status of the afflicted person is the main concern and the problem-solving approach of formal carers on the other hand, who focus on the underlying medical or social problem of the situation and only afterwards, if at all, on the actual person and his or her place in the family. In other words, for formal carers it is a person with a particular disturbed condition that just happens to be a wife or husband or child or parent that is the focus of the home care situation, and for informal carers it is the wife or husband or child or parent that now suffers from any kind of disturbed condition. From this perspective it is obvious that the professional perspective takes it more or less for granted that professional involvement in a given situation should result in a positive outcome, because professionals consider themselves being the experts to contribute to problem-solving. This aspect is addressed by Brown et al. (2001) who argue that the essence of professionalism is power based on claims to specialist expertise. This explains why nurses may consider the work of family caregivers as competetive to their own work (Emmrich, 2002), why they believe that family caregivers in home care are either a resource or a burden (Benzein et al., 2004), or why they suggest a nursing diagnosis ‘ineffective family participation in professional care’ (Lee and Craft-Rosenberg, 2002). Another explanatory factor is provided by Harvath et al. (1994) who refer to different types of knowledge that family caregivers and nurses possess. They describe the nurses’ knowledge as ‘cosmopolitan’ knowledge, which is a generalized understanding of a particular condition, and the caregiver’s knowledge as ‘local’ knowledge, based on their unique understanding of the person suffering from that particular condition.

Concerning the challenge of professional nursing care Zeman (1996) describes it as being on the border between personal and technical care, exposed to expressive and instrumental expectations, and diffuse and specific role plays. This aspect is often neglected in articles on the quality of nursing care that call for normative standards, performances that are accountable for a clear reimbursement policy and can be controlled by external bodies (Mor, 2005). Only slowly it is recognized that quality of nursing care has an interactive dimension. One reason for this slow recognition may be the fact that there is a lack of appropriate conceptual development (Zeman 1996). Possible reasons for problems in the interaction between formal and informal helpers are according to Zeman (2000, p. 216):

- A different judgement of roles and instrumental and expressive dimensions of the relationship
- A problem of compatibility between goals to be achieved, images and conflict strategies
- Differences in the respective definition of what is appropriate action besides functional and task-specific services
- Confusion about the social networks involved

From the families’ point of view the main function of professional nursing care is to stabilise the disturbed reality of the everyday live. Professional helpers will only achieve this if they, on the one hand, add resources to the situation that are exactly tailored to the particular problems, and on the other hand do not increase the complexity of the whole arrangement (Zeman 1997, 1998). Corbin and Strauss (1990) call for a qualification of professional helpers that allows them to gain a clear image of the whole arrangement. Only by doing so they will be able to integrate their own services in an appropriate and effective way.

Although there are various indicators that nurses consider family caregivers as being important for the care of older and chronically ill people living at home, there is obviously a lack of understanding of what this means for the delivery of nursing care. Magnusson and

Lützen (1999) report a conflict of a moral and a professional role of health care workers in home care. Collaboration between nurses and family caregivers is not an issue within the carers as resources model (Twigg, 1993). The caring 'triangle' between nurses, family caregivers and care-recipients has been found to be problematic, because different interests and perspectives need to be coordinated (Bundesministerium für Familie, Senioren, Frauen und Jugend, 2002). From a family caregivers' point of view there is some hope of remaining self-sufficient when external help has been asked for (Savishinsky, 1990), but this seems out of the professional scope. Against existing findings the nursing profession does not seem to have integrated a perspective that recognizes and rewards the work of family caregivers. The main emphasis is on the care of the care recipient and the situation mostly is defined in professional terms. This includes that the services provided are developed according to this professional perspective.

2.4.2 Modelling the relationship between formal and informal care

On a broader level the relationship between family caregivers and nurses has been found to be characterised by tension and uncertainty (Ward-Griffin and McKeever, 2000; Ward-Griffin, 2001) and as nurses being strangers in the families who are on an expedition for the scouting and redefinition of professional care in an environment that is unfamiliar, unpredictable, and often uncontrollable (Coffman, 1997).

Despite the difficulties between family caregivers and nurses outlined above some authors (Fischer and Eustis, 1994; Jeon, 2004; Noelker and Bass, 1989; Ward-Griffin and McKeever, 2000) made an attempt of modelling the relationship between formal and informal care on a more general level. These models are based on different approaches. The typology provided by Noelker and Bass (1989) is strongly based on the tasks that need to be performed in caregiving. The first type, dual specialisation, includes families in which tasks are segregated, meaning that kin caregivers and service providers assist impaired persons with different tasks. The second type, supplementation, includes families in which service providers help with the same tasks as kin caregivers, although the kin caregivers may help with additional tasks. This type assumes that kin caregivers are the major helpers and use service providers to augment their efforts or for respite. The third type, substitution, includes families, in which service providers are the sole source of assistance for the care recipients' needs. The fourth type, kin independence, includes families in which no service providers help with caregiving responsibilities.

The approach taken by Ward-Griffin and McKeever (2000) conceptualises the relationship according to the work and tasks involved in caregiving when family caregivers as well as nurses contribute to it, but unlike Noelker and Bass (1989) they conceptualise the relationship in terms of roles in the work process. Their findings are consistent with other studies in terms of nurses not acknowledging the emotional and intellectual aspects of care provided by family caregivers and nurses tending to give less importance to the caregiver's level of competence and knowledge. Starting from this, four types of relationships between nurses and family caregivers have been identified (Ward-Griffin and McKeever, 2000): In the nurse-helper relationship, the boundaries were relatively unambiguous. The nurse took the time to provide and coordinate the majority of care, while the family caregiver assumed a supportive role. Although only a few dyads currently function in the second type of relationship, the co-worker relationship, most had done so in the past. In contrast to the original nurse-family caregiver relationship, this one was filled with tension, conflicts, and ambiguities. The vast majority of the dyads functioned in the third type of relationship, manager-worker. As nurses gradually transferred their actual caring work to the family caregiver, their supervisory tasks – such as monitoring the coping skills of the caregiver – increased in importance. The fourth type, nurse-patient, occurred almost as frequently as the manager-worker relationship, and as a consequence of it. As a result of their relentless caregiving demands, family caregivers became the nurses patients.

A completely different approach is taken by Jeon (2004) who was interested in investigating the working relationship between nurses and family caregivers beyond the distribution of tasks and roles. He developed a substantive theory on 'shaping mutuality', which describes an essential element of the development of helpful relationships between the nurse and the caregiver that is characterized by high levels of empathy, collaboration, equality, and interdependency.

All three models are challenged by Fischer and Eustis (1994) who state that a) nurses and family caregivers share the two common characteristics of their work being unsupervised and b) their work being similar in scope and the nature of their work. In terms of characterising the mutual relationship between nurses and family caregivers they found caregiving alliances between nurses and family caregivers who jointly managed difficult care-recipients and an integrative relationship in which the professionals were integrated in everyday family life and roles were interlocked in a sense that each provides what the other does not. The most frequent type of relationship that was identified was that there is no relationship at all and that nurses and family caregivers often operate in separate worlds.

While the approaches presented above took a dyadic perspective, Nolan et al. (2001, 2003) addressed the question of how caring relationships can be considered in a triadic perspective and developed the six senses framework. They believe that all parties involved (the ill or disabled person, family caregivers, and paid or voluntary carers) should experience relationships that promote: A sense of security – to feel safe within relationships; A sense of belonging – to feel 'part' of things; A sense of continuity – to experience links and consistency; A sense of purpose – to have a personally valuable goal or goals; A sense of achievement – to make progress towards a desired goal or goals; A sense of significance – to feel that 'you' matter (Nolan et al., 2003, p. 275).

It can be seen from these different studies that the relationship between nurses and family caregivers is understood in parts, but some of the findings obviously are contradictory. Several aspects from these conceptualisations are of importance for this study. The first is the importance of addressing the relationship between nurses and family caregivers from more than one perspective. The second is that a focus on particular aspects of the relationship such as tasks or roles provide important insights, but obviously lack the potential for a more comprehensive understanding of what is going on in home care situations. The final aspect is that of underlying assumptions. The mutuality identified by Jeon (2004) and the six senses framework from Nolan et al. (2003) assume that the relationship between formal and informal care has an implicitly helpful connotation. Ward-Griffin and McKeever (2000) explicitly criticise that studies have addressed the question of how nurses and family caregivers should relate to each other, but not how the relationships between them are actually developed and therefore took a more distanced perspective. Taking into account what has been said above about the problems of putting a professional rather than a joint perspective in the main focus, this is a clear hint of trying to avoid any preconceptions or underlying assumptions when studying the relationship between nurses and family caregivers.

2.4.3 The policy perspective

The fourth area in which the relationship between formal and informal care has been addressed is the social and health policy perspective. The increasing number of people being in need of care is a challenge for many countries in the world. It is not only a challenge for the Western societies, but also for many developing countries (WHO, 2003). The need of care is caused by an increasing number of people suffering from chronic illnesses. Their care poses a problem that cannot be resolved by professional and institutional care alone. For more than 20 years several authors addressed the role of the family and other social networks in providing care and social support to ill and frail family members (Badura, 1981; Brody, 1985) and there is a global agreement that the majority of all caregiving activities are provided by families. While recognizing the role of families in the provision of long-term care on the one hand, there is concern about the problem that due to demographic changes, increased female labour participation and individualisation in modern societies, the willingness to provide care for frail and elderly people within families will decrease and this results in calls for strengthening social policy programmes and the improvement of formal services to cope with these societal changes. Because of this from a social policy perspective there is an interest in learning about numbers of who provides care to whom and in what way. There is also an interest in learning about assumptions and trends on what to expect in the future in terms of how many people will be in need of care, how many informal carers, i.e. basically family members, are to be willing and able to provide care, and how many formal services of different kinds are needed to match the need for care.

In Germany about 70% of all people who receive benefits from the long-term care insurance opted against the involvement of a professional nursing service and provide care on their own (Statistisches Bundesamt, 2005a). Similar numbers are reported from other countries (Crist, 2005; Ward-Griffin and McKeever, 2000; WHO, 2003). This reflects that the majority of caregiving work at home is provided by family members or other informal carers from the existing social network. Professional and formal services only play a minor role and this is an important lesson to learn when approaching home care situations from a professional perspective.

With regard to the relationship between formal and informal care the policy perspective is concerned with social network structures, the utilization of home care services, services for family caregivers and the distribution of care work among formal and informal caregivers.

Social network structures are important to determine the likelihood of formal service utilization. The weaker the informal support structure the more likely is the utilization of professional services. This has been shown by Blinkert and Klie (1999) who identified sufficient, unstable and precarious support networks for people in need of care. Where there is a precarious support network, people were most likely to involve a professional nursing service.

To determine patterns of service utilization during the last decades the Socio-behavioral or Andersen-Newman Model of service utilization was the predominant framework (Andersen and Newman, 1973). It was originally developed to investigate access to health care, but was then used in an expanded sense. According to this model, health service utilization depends on three determinants: societal determinants, individual determinants and the health service system. While societal factors like technology and norms comprise macro-level structures and developments, the health care system has an impact on service utilization because of two aspects: its organisation and its available resources (Gilberg 2000). Resources refer to the total volume of health care resources and their geographical distribution and the organisation refers to access to and structure of the health care system. Societal determinants and the health care system influence the decision on health care utilization via individual determinants, which can be described as predisposing, enabling and need factors (Andersen and Newman 1973). Predisposing factors express the individual's disposition to develop a need for health care services like demographic factors (sex, age etc.) and socio-structural factors (education, job etc.). Enabling factors refer to factors describing individual conditions that enable a person to actually get the health care services needed. Enabling factors are income, insurance coverage, services available. Need factors are determined by the individuals' health status which is taken into account as the perceived illness level and the evaluated illness level (Andersen and Newman 1973).

This model is still widely used, although several weaknesses have been identified. It was criticised for overemphasising structural determinants and failing to specify socio-psychological processes or individual perceptions through which physical health is perceived, evaluated and acted upon (Wan, 1989; Porter, 2000). Another critique concerns the fact that the model overemphasises physical aspects and neglects family-related factors (Bass and Noelker, 1987; Kerkstra and Vorst-Thijssen, 1991; Twigg and Atkin, 1993; Piercy and Bliezner, 1999). Finally, there is evidence that studies using this model provided different and even contradictory results (Porter, 2000)

Other approaches to service utilization support the fact that social network characteristics and family structures influence the decision whether to use a formal care service or not (Gilberg, 2000). This was also found when the utilization behaviour was investigated from an economic perspective (Eisen and Mager, 1996; Mager, 1999).

The question whether and why a formal service is used obviously is not easy to answer. Beyond the focus on utilization authors have addressed utilization with regard to the relationship between formal and informal care. According to Noelker and Bass (1994) there exist three conceptualizations: the hierachy compensatory model, which posits that elders use the support that is closest to them and in which it is assumed that formal care substitutes informal care (Logan and Spitze, 1994); the task-specific model, in which it is assumed that the sources of help are governed by the types of tasks for which assistance is needed; and the supplementation model that has the central feature of task-sharing.

Like the Andersen-Newman Model of service utilization these three conceptualizations have been widely criticised. They were criticised for being focussed only on a limited number of tasks, being too static, and not taking into account factors such as personal characteristics, service environment, beliefs about the efficacy of formal assistance and adequate insurance coverage (Noelker and Bass, 1994). Nevertheless the hierarchy compensatory model was recently used to predict the increased demand for formal long-term care demands in four European Countries (The London School of Economics, 2003).

The hierarchy compensatory model is challenged by the findings of several studies (Pearson Scott et al., 1985; Penning, 2002; Wielink and Huijsmann, 1999; Doty, 1995) that can be summarised in terms of families rarely withdrawing their efforts in caregiving or substitute their informal caregiving by formal services when this was an option offered by social policy. Interestingly there seems to be a trend of a reversed susbtitution model in nursing homes where increasingly former formal support is now provided by family caregivers (Paulus et al., 2005). But also in the reversed sense it is not a simple substitution, but a complex pattern of linkages at the level of separate activities.

The task-specific model is challenged by the problem of determining the actual tasks that are considered important in home care situations. As already mentioned Noelker and Bass (1994) criticised the limited number of tasks that are investigated in the studies. A task based approach can be found in the German long-term care insurance as outlined below. Meanwhile its limited usefulness is recognized and is the reason for studies on possible alternatives (Büscher et al., 2005; Klie and Spermann, 2004). Beside these critiques on any task-specific conceptualizations there is another important finding that needs to be taken into account. Family caregivers were asked how they consider their own actions and it turned out that they defined their actions by meaning or purpose of the action and not by the nature or demands of the action (Bowers, 1987). These findings are supported by Greene and Coleman (1995) and Nolan et al. (1996). In terms of purposes that direct the actions of family caregivers Bowers (1987) identified anticipatory caregiving, preventive caregiving, supervisory caregiving, instrumental caregiving, and protective caregiving. (Re-)constructive and reciprocal caregiving are additional purposes for family caregiver actions identified by Nolan et al. (1996). Other studies support the importance of protection (Aberg et al., 2004) and reciprocity (Schnepp, 2001).

These studies indicate that the hierachy-compensatory approach and the task-based approach imply several weaknesses and only have limited explanatory and predictive power. Other authors (Brömme, 1999; Coe and Neufeld, 1999; Tesch-Römer, 2001) have focussed on particular aspects of service utilization without claiming to develop a coherent and comprehensive new framework. In this respect Brömme (1999) states that potential consequences of policies on long-term care on the relationship between formal and informal care can be a synergy between both, an erosion of informal care, or simply a null-effect on the care arrangements. The impact of gender on service utilization has been investigated (Coe and Neufeld, 1999) and a general call for more complex conceptual labels rather than reliance on singular characteristics has been made (Brandenburg and Zimprich, 1995). It also has been stated that caregiving situations never are static situations, but always change over time (Tesch-Römer, 2001). A general critique on the existing research on service utilization is the limited awareness of the different types of formal services (Bass et al., 1999). In this respect caregiver attitudes have an influence (Pedlar and Biegel, 1999). Often family caregivers express reservations against formal services (Starke et al., 1999) that may change, the more experiences family caregivers had with these services (Badelt et al., 1997). An increase in the general knowledge level about the formal care system (McCaslin, 1998) and knowledge about the quality of services (Collins et al., 1991, Winslow, 2003) can increase the acceptance of the services and lead to more formal service utilization.

2.5 The context for the relationship between formal and informal care in Germany

Decisions concerning the involvement of a nursing service are made within the context of a system of health care and social security. Because this study was conducted in Germany the relevant regulation for this context will be outlined on the following pages.

There are four different ways and regulations that may lead to access to and financing of home care nursing in Germany: a) Long-term care insurance (LTC-insurance), b) Sickness insurance, c) Social assistance, and d) Private funding.

In the German system of social security a distinction is made between sickness and ‘being in need of care’. This distinction is important in terms of the benefits that can be obtained for particular conditions. For nursing care this distinction is important, because nursing care under the LTC-insurance for people in need of care is also labelled as *Grundpflege* (which means basically taking care of personal hygiene, nutrition and mobility) and nursing care under the sickness insurance is labelled as *Behandlungspflege* (which means nursing care in relation to medical treatment). This distinction has been criticised (Müller, 1998) and the critique is ongoing, but it still represents the relevant context for home care nursing.

Long-term care insurance

For the study of home care and home care utilization in Germany the Long-term care insurance (LTC-insurance) is the first relevant and important legislative and regulatory framework (Sozialgesetzbuch XI – SGB XI). The LTC-insurance was introduced in 1995 following a 20-year process of discussion (Meyer, 1996). In their first report on the development of the care insurance the German government (Deutscher Bundestag, 1997) summarised the objectives of the implementation of the LTC-Insurance:

1. The risk of being in need of care should be socially insured.
2. The physical, psychological and financial burdens caused by the need of care should be relieved and dependence on Social Assistance should be avoided.
3. The demographic development in the future should be taken into account.
4. It should be ensured that people in need of care remain in their homes and families for as long as possible.
5. The social protection of informal caregivers should be improved to promote the willingness to care in the home environment.
6. A sufficient nursing care infrastructure in Germany was to be established and expanded.

The benefits of the care insurance concern benefits for home care, partly institutional care, institutional care, assistive devices, contributions to the pension and accident insurances of the informal caregivers, and courses for informal caregivers. In home care and partly institutional care (day care facilities, night care facilities and respite care facilities) the benefits are explicitly planned in addition and not as a substitute for family or other voluntary care arrangements. Persons who are eligible for benefits from the care insurance are those who are unable to perform regular activities of daily living due to physical or mental illness/disability for at least six months and are in need of assistance from others. The regular activities are defined by the law and are activities related to personal hygiene, nutrition, mobility and domestic care. The assessment of persons in need of care to determine the dependency level is the responsibility of the Medical Board of the sickness insurances, an official independent consultancy jointly financed by the sickness insurance funds. The assessment is undertaken by doctors and/or nursing staff employed by the Medical Board and takes place in the claimant's home. After the assessment, people are grouped in one of the three levels of need *(Pflegestufen):*

1. Level 1: People on this level are in substantial need of care. They need assistance in at least two of the activities personal hygiene, nutrition **or** mobility once a day and in addition they need assistance in domestic care several times a week. The amount of time required by an informal caregiver to spend on the care of the person in need of care is at least 90 minutes a day.
2. Level 2: People in severe need of care require assistance in their personal hygiene, nutrition **or** mobility at least three times a day on different daytimes. In addition they need assistance in their domestic care several times a week. The time required is at least three hours a day.
3. Level 3: People in most severe need of care require assistance in their personal hygiene, nutrition **and** mobility all day and night. In addition they need assistance in their domestic care several times a week. Time required is at least five hours a day.

In home care, the available benefits are care in kind (*Pflegesachleistung*), cash payments (*Pflegegeldleistung*) and a combination of both (*Kombinationsleistung*). People in need of care are allowed to choose one of these benefits.

After the introduction of the care insurance the majority (about 80%) of eligible persons opted for the cash payments and against the involvement of a nursing service (Deutscher Bundestag, 1997). In the meantime this has slightly changed towards the combination option (Statistisches Bundesamt, 2005a), but still around 70% use the cash payments. The figures for the benefits per month relevant for home care are presented below:

Level of care dependency	Cash payment	Care in kind (usually provided by a nursing care service)
Level I	205 €	384 €
Level II	410 €	921 €
Level III	665 €	1.432 €

Table 2.1.: Benefits for care-recipients living at home in the German long-term care insurance

The combination between cash payments and care in kind works as follows: If somebody, for example, is assessed into Level II and decides that he or she needs or wants some kind of professional nursing support she/he can decide to get 50% of the care in kind benefit, i.e. 460,50 € and gets nursing care up to that price. The remaining 50% will be as cash payment, i.e. 205 €. The decision is up to the care-recipient and may be changed according to needs and/or preferences.

Those people who opted for the cash payments have to call in a professional nursing service for counselling purposes. On Levels I and II this has to be done every half a year and on Level III every three months. The counselling serves the purpose of ensuring the quality of care provided at home and to offer regular support concerning the technical and clinical aspects of the care.

Interestingly the majority of people eligible for benefits from the Long-term care insurance opted for the cash option which according to Zeman (1996) is not the result of selective decision processes on particular services, but more related to problems of acceptance with the formal support system. This is also reflected by the fact that people in need of care express a higher degree of satisfaction when they chose the cash instead of the service option (Zeman 2000). This is especially problematic because the degree of satisfaction decreases where there is only a weak informal support network (Blinkert and Klie 1999) that requires external formal support. Evers (1997) points out that the low utilization of professional nursing care services reflects families' concerns and a lack of trust in professional services. This means that within the discourse of service utilization the subjective meaning and relevance is not taken into account appropriately.

Nursing care services

The long-term care insurance contains a definition of a nursing care service. It is an independently operating company that provides nursing and domestic care services for care dependent people living at home. A nursing care service has to operate under the responsibility of a registered nurse who has received a special course of continuing education. According to the LTC-insurance, nursing care services have to sign a contract with the insurances about type, content and volume of the care provided. With the introduction of the LTC and the so called care-market in 1995, many new nursing care services have been established. Two different types can be distinguished. On the one hand those nursing care services that operate under the auspices of the welfare organisations (e.g. the Red Cross or the organisations of the Catholic or Protestant church) and on the other hand private nursing care services. The private services joined themselves in to larger organisations to have a better and stronger representation in political decision making, in the public, to the insurance companies and the welfare organisations.

In 2005, approximately 10.600 different nursing care services have had a contract with the insurances in Germany and were allowed to offer nursing care to people in need (Statistisches Bundesamt, 2005b). The number is continously changing, because services are subject to general rules of economic markets. They may have to close due to financial difficulties, new ones are going to be established, and services merge with each other. The market in nursing care was politically seen as a means to ensure that a suffcient number of services is available for the care dependent people and their families. It was assumed that competition among different providers would result in a better quality of the services offered.

The reimbursement of nursing services occurs according to a system of so-called performance packages *(Leistungskomplexe)*. Care-recipients decide which packages they want and this is then outlined in a contract between care-recipient and the nursing care service. The performance packages are mostly related to the areas of personal hygiene, nutrition and mobility. Care-recipients can choose between 20-25 performance packages. The catalogues are different in the sixteen *Länder* of Germany and they may be different for private services and services from the welfare organisations. The catalogues are negotiated between the LTC insurance companies and the representatives of the service providers. Services that are not in the contract are not subject of reimbursement in the LTC-insurance.

The insurance companies, the representatives of the communities (see social assistance below) and the different organisations representing the nursing care services negotiated and agreed upon 'Joint principles and measures for quality and quality assurance in home and institutional care'. The nursing care services have to operate according to these principles. The Medical Board of the sickness insurances is in charge of monitoring and controlling adherence to these principles. In case of neglecting the principles the insurances may cancel the contract and the service is no longer allowed to offer services according to the LTC-insurance. For a municipality in Hessia, Evers and Rauch (1998) investigated the structure, ownership and performance of home care services. They concluded that after the implementation of the long-term care insurance changes in terms of structure and characteristics of home care services have occurred: There are more commercial providers, the size of the providers enlarged and the integration of providers into their local community decreased. Services moved from a broad spectrum of support and nursing care to medically dominated performances. The strict reimbursement policies within the sickness and long-term care insurance have an impact on what actually happens in home care situations (Büscher et al., 2005).

Sickness insurance

Beside the LTC-insurance, a significant amount of home care nursing is provided according to the obligatory sickness insurance (Sozialgesetzbuch V – SGB V). Sickness insurance in Germany covers acute medical care. Nursing care may be prescribed by a physician if hospital care would be required, but cannot be provided or if hospital care can be prevented or shortened by home care nursing. It can be prescribed for up to four weeks. Nursing care will also be covered by the sickness insurance, if it is required to ensure the aims of medical therapy.

The board of physicians and the insurances negotiate and agree upon rules on this type of nursing care. In practice this means a catalogue of singular nursing care activities that are subject to prescription and reimbursement under the sickness insurance. The providers of home care nursing are almost the same as the ones operating under the LTC-insurance.

Social assistance

The social assistance act covers help for persons to lead a life in human dignity who cannot help themselves, do not get the support required from relatives, or according to other regulations on social security. Within the social assistance act, nursing care is included. Social assistance benefits are only rewarded if benefits from the LTC-insurance, the sickness insurance and private ressources are not sufficient to cover the needs. The criteria for social assistance nursing care are similar to the criteria in the LTC-insurance.

Private funding

Private funding and demand for a nursing service is always possible for those who can afford it. In case of sufficient financial resources, people can get nursing care above the level of the LTC-insurance. In this case they would have to negotiate the costs of these additional services with the nursing care services, with individual nurses or other people they employ privately.

In practice there exist strong links between these four ways of involving a nursing service. It is not uncommon that people receive nursing care due to the regulations of the LTC-insurance and in addition they are in need of medical care, covered by the sickness insurance. These services are provided by the same nursing care service (even the same nurse). The settlement will be done with the LTC-insurance company and the sickness insurance company respectively. This actually is sometimes confusing for patients, their families and the nurses, too. It is also possible that people receive nursing care within the LTC-insurance and, because of greater need that cannot be funded by themselves, get help that is funded by social assistance.

In terms of service utilization, the German population has the freedom of choice between several nursing care service providers and is free to change the provider for any reason. This implies a real consumer status for care-recipients and family caregivers, but at the same time also makes it complicated to know how to get the services that are most needed in a particular situation and to know about the type and quality of the services. To help with that problem, some policy decisions have been made that ask communites to provide information about services and availabilities. Insurances, consumer organisations and others also run counselling services.

2.6 Conclusions on the literature review

To a large extent the relationship between formal and informal care in general takes place in the context of home care. To stay in their homes for as long as possible is what many people who suffer from chronic illness prefer for themselves. The role of the family for managing chronic illness at home is very important. The management of chronic illness is not a static, but is a dynamic process. Aspects of control and balancing of the ill persons themselves and their family members play an important role. In order to understand the management of chronic illness at home it is important to look beyond the actual illness and to consider the processes applied by families.

What it means for family members to assume the responsibility to care for a chronically ill relative has been widely addressed in the literature, mostly in terms of the burdens associated with being a family caregiver. Family caregiving needs to be considered beyond the burdensome aspects.

Professional nursing services play an important role in supporting chronically ill people at home, but the majority of support is still provided by family members. Although there are some indicators revealing that nurses in home care take the situation of family caregivers into account, their focus primarily is on the care-recipient and family caregivers are considered basically a resource for the caregiving process without a need of support for themselves.

The relationship between nurses and family caregivers has been found to be problematic in practice. Studies often assume an inherently positive effect of nursing care interventions, but evidence for this assumption is limited. From a social policy perspective it is recognised that sufficient relationships between informal and formal carers are important to meet the increasing demand for quality home care. The efforts to address the relationship from a policy perspective focus primarily on task-based relationships and on the question whether formal services undermine the informal care provided by families, friends and others. The literature reveals that task-based conceptualizations are not sufficient to understand the relationship between formal and informal care.

It can be summarised from the literature that the conceptualizations on the relationship between nurses and family caregivers are far from being clear. In order to provide adequate services and to study this relationship the findings are not sufficient.

According to Schaeffer and Bartholomeyczik (1999) the relationship between formal and informal care has hardly been addressed conceptually in nursing science. This viewpoint is also reflected by other authors who have pointed out that the whole home care experience is only dimly understood (Gubrium and Sankar, 1990), and that the research imperative must be shifted from predicting the distribution and possible determinants of home care use to describing the individual‘s experience of home care (Porter, 2000). The overview over the relevant literature revealed that some conceptualisations already exist, but the findings are different and sometimes even contradictory. In addition, the literature reveals difficulties in nursing and nursing science to develop a family-oriented approach to home care nursing that would allow for building partnerships between the formal and informal sector. Methodologically authors have criticised the reliance on cross-sectional and controlled designs that failed to provide a comprehensive understanding of the relationship between formal and informal care. Because of the broad agreement in the literature that family caregiving is a complex issue research methodologies need to address that complexity so as to understand for it and not control for it (Gubrium and Sankar, 1990).

3 Purpose of the study and research questions

This study aims at addressing the complexity of family caregiving by focussing on both the perspectives of family caregivers and nurses as well as their mutual relationship. The purpose of this study is to address the relationship between family caregivers, representing the informal care sector, and nurses, representing the formal care sector. The study aims at generating a substantive theory on the relationship between formal and informal care that contributes to a better conceptual understanding, but also to developing adequate approaches in nursing practice to create a sufficient relationship between formal and informal care. The study was conducted according to the following research questions:

1. What are the concepts used by family caregivers and nurses to describe the relationship between formal and informal care?
2. How are these concepts related to each other?
3. What kind of substantive theory can be developed based on these concepts?

4 Methodology

Methodology as the application of scientific theory is concerned with the question under which conditions insight on a particular area of study is possible (Lamneck, 1988). The area of study in this research is the relationship between formal and informal care in home care. The literature review did not reveal a consistent framework of this relationship that could serve as a guide in this research. Therefore the use of existing concepts from previous research was not an appropriate approach. The research process needed to focus on the empirical reality as it is constructed by family caregivers and nurses themselves. The research methodology for this study needed to take into account the individual's perspective and it needed to allow for reconstructing meaning of two different perspectives onto a mutual relationship. From the perspective of symbolic interactionism, meaning arises out of the interaction between people. Human beings act towards things on the basis of the meanings that the things have for them. The meaning of such things is derived from social interaction and the meanings are handled in an interpretative process (Blumer, 1969). The grounded theory methodology (Glaser and Strauss, 1967; Glaser, 1978, 2001, 2003, 2005) enables the researcher to focus on the reconstruction of social action without having to rely on existing hypotheses. The use of grounded theory is appropriate when the perceptions and experiences of the participants are focussed and the research aims at theory construction based on the participants' concerns. Therefore it is an appropriate research methodology for this study.

4.1 Grounded Theory

Grounded Theory was jointly developed by Glaser and Strauss (1967) as a general methodology to develop theory from data systematically obtained from social research. The background for the development was to contrast grounded theory with theory generated by logical deduction from apriori assumptions (Glaser and Strauss, 1967, 3). Grounded theory was not invented, but it was discovered during a study on the awareness of dying (Glaser and Strauss, 1965).

The aim of grounded theory is to produce a theory that fits, works and is relevant (Glaser and Strauss, 1967) for the area under study. These criteria have been elaborated and a fourth criterion has been added, which is modifiability based on ever-emerging notions from more data (Glaser, 1978).

The two founders of grounded theory took different routes after the joint publication in 1967. In 1992 these different routes resulted in an open controversy caused by Glaser's publication

Basics of grounded theory analysis, in which he accused Strauss of misconceiving the original conceptions of the method and creating a different method that forces the data instead of letting a theory emerge (Glaser, 1992). Several authors have pointed out that actually both ways of conducting a grounded theory study are quite different, but there is no agreement on the extent of the difference. The discussion is particularly difficult as Strauss never replied to the accusations (Strübing, 2004). While Stern (1994) states that both approaches are fundamentally different, Kelle (2005) outlines that Glaser's critique points to existing weaknesses in the Straussian approach, but exaggerates the risks of it. Apart from the question of how different the two approaches are, Strübing (2004) states that Glaser's publication has made visible inconsistencies and contradictions that already existed in the original work. By doing so he initiated a debate that is necessary in the further use and application of grounded theory. Because of the differences it is necessary for researchers to decide which approach they use in their study. This study is based on the work of Glaser as basically outlined in *Theoretical sensitivity* (1978) and further developed in different following publications (Glaser, 1992, 1998, 2001, 2003, 2005). The approach of Glaser was found suitable for data collection and analysis of this study.

The development of a grounded theory is based upon theoretical sampling, the constant comparative method of analysis, the process of substantive and theoretical coding, and constant Memo writing and sorting (Glaser and Strauss, 1967; Glaser, 1978). On the following pages it will be described how this was done in this study.

4.2. Theoretical sampling

An essential part of grounded theory is theoretical sampling. It is *"...the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyses his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges."* (Glaser and Strauss, 1967, 45). Unlike in other research methodologies in grounded theory the sample is not defined before the actual process of data collection starts. The initial phase of data collection starts on a very broad basis with informants who are considered to be knowledgeable on the subject (Glaser and Strauss, 1967). Data collection is continued on the basis of the emerging concepts and conceptual hypotheses from data analysis. Theoretical sampling is a prerequisite for theory construction, because only by guiding the data collection by concepts that emerge and their theoretical relevance data saturation and theory development can be achieved. Theoretical saturation is achieved when no new incidents can be analysed from the data (Glaser , 1978, 1998).

Theoretical sampling directs data collection in terms of deciding who might be the right informants, but it also directs data analysis by posing questions to the previously collected data that arise from the analysis and the emerging concepts. This allows for integrating already existing data sets and analysing these data on the basis of what emerges (Glaser, 1978).

This study was conducted by adhering to the principle of theoretical sampling. Data collection and analyses were performed as a cyclical process in five phases. Initial data collection was performed by conducting eight interviews with family caregivers. After the analysis, three previously collected data sets with nurses were used to do initial coding on the nursing perspective. The third phase of data collection also consisted of a secondary analysis of an existing data set of interviews with family caregivers. In the fourth phase participants were purposefully sought on the basis of first concepts and conceptual hypotheses. The final phase of data collection was performed by conducting interviews with nurses and family caregivers. After the fifth phase data saturation was achieved. A more detailed description of the data collection process follows below.

4.3 Data collection

For a grounded theory study there is no single way of data collection, but several methods can be used. According to Glaser (1978) everything is data. In this study it was decided to use interview data. The reason for this decision was the assumption that a mutual relationship is best investigated by asking the people concerned and let them share their experiences.

For this study seven different data sets were collected at different times. Four of the data sets (n=74 interviews) were collected by myself and three data sets (n=14 interviews) were collected by other researchers in other studies at the Institute of Nursing Science at the University of Witten/Herdecke. In total, the sample consisted of 88 interviews with family caregivers, nurses, nurse managers, care-recipients and a psychologist. As mentioned above data collection took place in five distinct phases and was based on theoretical sampling. In the following the five phases and the seven data sets are presented.

The first phase of data collection consisted of eight interviews (table 4.1) with family caregivers. The criterion for the selection of the first interviews was that the interviewees were willing to share their caregiving experiences and able to express themselves. Due to the assumption that the reasons for the involvement or non-involvement of a nursing service will provide insights into the relationship between family caregivers and nurses, three of the eight interviews were conducted with family caregivers who care without the help of nurses at home. Access to the interview partners was gained by several gatekeepers: two nurses working in home care, a nurse working as a counsellor for family caregivers and two friends facing a home care situation in their own family. This phase of data collection lasted six months.

No.	Interview partner	Caregiver caring for	Nursing service involved	Duration of the interview	Date of the interview
1	Son	His mother with dementia and broken femur	yes	45 minutes	15.07.2003
2	Wife	Her husband following a stroke	Yes	45 minutes	25.07.2003
3	Wife	Her husband with pulmonary emphysema	No	45 minutes	25.07.2003
4	Daughter	Her father with dementia and after myocardial infarction	Yes	25 minutes	30.09.2003
5	Daughter	Her mother with dementia and after a stroke	No	45 minutes	30.09.2003
6	Husband	His wife with dementia	Yes	30 minutes	17.11.2003
7	Wife	Her husband after a stroke	Yes	75 minutes	18.12.2003
8	Daughter	Her mother with hearing difficulties and following knee surgery	No	60 minutes	14.01.2004

Table 4.1: First data set of eight interviews with family caregivers

The second phase of data collection focussed on the nurses' perspective. For this step three different already existing data sets from studies conducted by colleagues from the Institute of Nursing Science at Witten/Herdecke University were used and a secondary analysis of these data sets was conducted.

Secondary analysis is encouraged by Glaser (1978) depending on what emerges in the analysis. However, there are some concerns about secondary analysis in qualitative research, basically in terms of the risk of decontextualization (Mruck, 2005, [2]). The risk of decontextualization and other problems of sharing qualitative data was addressed by van den Berg (2005). He summarises that the feasibility of secondary analysis depends on the research goal on the one hand and the type of textual data on the other (van den Berg, 2005 [45,46]). He proposes some minimum guidelines for contextual information that is required: 1. Information about the discoursive context of the interviewee's responses (meaning audiotapes or detailed transcriptions should be available); 2. the whole interview should be available instead of parts; 3. Information about background characteristics of interviewer and interviewee that could influence the course of the interaction; 4. Information about the place, time and setting of the interview; 5. Information about how the interviewee is/was selected and approached to cooperate; and 6. Information about relevant others known by either the interviewee or the interviewer such as gatekeepers, other interviewees etc. (van den Berg, 2005 [47]).

The data sets were derived from studies in which the researcher of this study was involved in a counselling role. Because of this involvement the use of the interview data from these studies for this research seemed to be appropriate and promising in terms of gaining insight into the nurses' perspective on home care and the relationship between themselves and family caregivers. The principal investigators of the three studies were Boes (2003), Ludwig (2002), and Holle (2004). It was assured that the criteria stated by van den Berg (2005) for secondary analysis were met. The full transcripts of all interviews were available (criteria 1 and 2). The interviewers were familiar to me and in their studies they described the interviewees, the place, time and setting of their interviews, and the way in which they approached their interview partners and their gatekeepers (criteria 3, 4, 5 and 6). For this study only the raw interview data was used that was available in form of transcripts. The interviews were analysed with a different focus compared to that of the original study.

Boes (2003) examined in her study what nurses consider to be their contribution in home care situations. This study consisted of nine open interviews with nurses working in home care, of which eight (data set 2, table 4.2) were selected to be included in this study. One interview was rejected, because the interviewee was not a nurse. Boes (2003) gained access to her interview partners by approaching the management of different nursing care services and asked for permission to approach the nurses employed in the services directly. Ludwig (2002) interviewed nurses on the particularities of home care arrangements of elderly people living alone. These interviews were used to detect differences in the nurses' perspective between single-person households and multi-person households. This perspective served for purposes of contrasting. The data set consisted of eight open interviews with nurses working in home care, of which three (data set 3, table 4.2) were included in this study. The other five were rejected, because they did not reveal anything new regarding the research questions. Ludwig's (2002) approach to gaining access to her interview partners was similar to that of Boes (2003), but she also approached nurses directly. The study of Holle (2003) focussed on the impact of the existing reimbursement scheme for home care nursing delivery from a nursing perspective and was based on six open interviews with nurses working in home care. From the first data set of interviews with nurses the legislative framework of home care nursing turned out to be important and therefore it was useful to analyse this aspect in more detail.

Three (data set 4, table 4.2) of these interviews were included. The other three were rejected, because they didn't contain anything new to the previous two data sets. Holle (2004) gained access to his interview partners by using the same approach as Boes (2003).

Data set	No.	Interview partner	Duration of the interview	Date of interview	Years in nursing/ percentage of employment
2	9	Nurse	85 minutes	08.10.2001	9 years/100%
	10	Nurse	60 minutes	11.10.2001	2 years/100%
	11	Nurse	65 minutes	31.10.2001	8 years/75%
	12	Nurse	80 minutes	13.12.2001	0,5 years/50%
	13	Nurse	60 minutes	17.12.2001	1,5 years/100%
	14	Male nurse	70 minutes	08.01.2002	3,5 years/100%
	15	Nurse	70 minutes	29.01.2002	7 years/100%
	16	Male nurse	55 minutes	04.02.2002	3 years/100%
3	17	Nurse	60 minutes	04.10.2001	12 years/part-time
	18	Nurse	70 minutes	Nov 2001	5 years/no actual employment
	19	Home and family careworker	70 minutes	23.01.2002	9 years/100%
4	20	Nurse	45 minutes	16.10.2003	0,5 years/50%
	21	Nurse	30 minutes	19.11.2003	6 years/100%
	22	Nurse	30 minutes	29.01.2004	4 years/100%

Table 4.2: Data sets 2-4 of interviews with nurses

The third phase of data collection consisted of a secondary analysis of interviews with family caregivers that the researcher conducted himself in another study (Büscher, 2002). The focus of the study was the impact of the German long-term care insurance on home care situations from a family caregivers' perspective. The criteria for secondary analysis were met for this data set, because all the information required was available. The study consisted of twelve interviews of which eight (table 4.3) were included in this study. The other four interviews did not provide any new insights.

No.	Interview partner	Caregiver caring for	Nursing service involved	Duration of the interview	Date of the interview
24	Daughter-in-law	Mother-in-law with dementia	No	75 minutes	22.06.1998
25	Daughter	Father after a stroke and with blindness	Yes	60 minutes	22.06.1998
26	Husband	Wife with multiple sclerosis	No	60 minutes	02.07.1998
27	Daughter	Father with leucaemia	Yes	60 minutes	08.07.1998
28	Daughter	Mother after a stroke	No	30 minutes	17.07.1998
29	Daughter	Mother with unclear liver disease	Yes	45 minutes	29.07.1998
30	Daughter-in-law	Mother-in-law with mobility problems	Yes	30 minutes	30.07.1998
31	Daughter	Mother with cancer	Yes	45 minutes	06.08.1998

Table 4.3: Fifth data set of interviews with family caregivers

The fourth phase of data collection was strongly guided by the concepts that emerged from the analysis. Based on these concepts decisions have been made of whom to interview and for what reason. It emerged from the interviews with the nurses and with some family caregivers that the nursing management plays an important role. Therefore a nurse manager (no. 32) was interviewed. In addition it was important to learn about the perspective of a person who is involved in the relationship between family caregivers and nurses every day, but has a perspective that is not part of the relationship and has a more distanced focus. The leader of a community counselling service (no. 45) on long-term care issues was willing to be interviewed for this study and for this purpose.

The search for additional interview partners at this stage was difficult. Several colleagues were asked to help in getting access to nurses and family caregivers, but only three more interviews (table 4.4) have been conducted in this phase. The fifth interview in table 4.4 (No. 35) was provided from a colleague who knew about this study and had the idea that one of the interviews she did herself might be useful.

No.	Interview partner	Caregiver caring for	Nursing service involved	Duration of the interview	Date of the interview	Years in nursing/ working
23	Nurse and caregiving daughter-in-law	Mother-in-law	No	75 minutes	16.11.2004	22 years/50%
32	Nurse manager			60 minutes	19.01.2005	2 years/100%
33	Couple	Partner after Guillian-Barre-syndrom	Yes	60 minutes	18.02.2005	
34	Nurse			60 minutes	25.02.2005	19 years/part-time
35	Son	Father in a coma	Living in a nursing home	90 minutes	15.07.2004	
45	Psychologist	Leader of a community counselling service		50 minutes	09.03.2005	

Table 4.4: Sixth data set of interviews with nurses and family caregivers

After conduction and analysis of the sixth data set a fifth and final phase of data collection was necessary, because data saturation of codes and categories was not achieved at this point. The relationships between concepts were not completely clear and did not integrate into a substantive theory. Because of the previous phase being difficult in terms of gaining access to interview partners, a different approach was chosen. The fifth and final phase of data collection was initiated by using a press release (see Appendix 2) that was published with the support of the Public relations department at the University of Witten/Herdecke. A short press release was published in the regional part of the biggest newspaper in the Ruhr area. The press

release was very broad as it asked for the willingness of people to report in a 30-60 minute interview on their experiences of the relationship and the collaboration between family caregivers and home care nurses. A phone number and an e-mail address was provided in the press release. The release was intended to gain access to nurses and family caregivers as well.
Accidentally the release was distributed more widely than it was initially intended and it appeared also in several online services and nursing journals. The result was overwhelming. Within two days more than 50 people called and expressed their willingness to share their perspective and to share their stories. The number amounted to more than 70 people in the following three weeks. Due to the amount of feedback within a short time it was impossible to decide if all potential interview partners could contribute to the further development of the theory. Therefore only those offers were rejected where it was clear from the first telephone contact that the situation did not fit into this study. This was true for family caregivers whose experiences were exclusively related to care in the hospital and for nurses who also wanted to tell their experiences from the hospital. Altogether 52 interviews have been conducted in this phase (table 4.5).

It was taken into account that such an approach bears some possible problems. One problem is that people who respond to a newspaper advertisement may represent either a very positive or a very negative perspective on the relationship between formal and informal care. Actually for most of the 52 interviewees this was true, but they all were helpful in modifying the codes and categories that had been developed so far. The positive and negative experiences particularly from family caregivers were used for purposes of contrasting.

No.	Interview partner	Caregiver caring for	Nursing service involved	Duration of the interview	Date of the interview	Years in nursing/ working
36	Husband	Wife with dementia	Yes	45 minutes	01.03.2005	
37	Daughter	Mother suffering from Parkinson disease	Yes, once a week	60 min. Ph	01.03.2005	
38	Wife	Husband after several strokes	No	90 minutes	02.03.2005	
39	Daughter-in-law	Mother-in-law suffering from dementia	Yes, but cancelled	50 minutes	04.03.2005	
40	Daughter	Mother after cranial bleeding	Yes	55 minutes	04.03.2005	
41	Wife (nurse by profession)	Husband after several strokes	Yes, once a week	70 minutes	04.03.2005	
42	Wife	Husband suffering from a mental disease	No	55 minutes	05.03.2005	
43	Wife (nurse by profession)	Husband	yes	90 min. Ph	05.03.2005	
44	Son	Mother with dementia	sometimes	90 minutes	06.03.2005	
46	Wife	Husband suffering from ALS	Yes/self employed	90 minutes	10.03.2005	

47	Daughter	Her mother who now lives in a nursing home	No	60 min. Ph	11.03.2005	
48	Daughter	Her parents	No	240 minutes	15.03.2005	
49	Nurse			40 minutes	15.03.2005	11 years/ 100%
50	Husband	His wife in a coma	No	45 minutes	16.03.2005	
51	Son	His mother	Yes	60 minutes	16.03.2005	
52	Husband	His wife in a coma	Yes		16.03.2005	
53	Nurse			20 min. Ph	17.03.2005	33%
54	Daughter (nurse with academic degree)	Her father with a tumor and after a car accident	Yes	60 min. Ph	17.03.2005	
55	Wife	Her husband with heart disease and in a coma	Yes	80 minutes	17.03.2005	
56	Wife	Her husband with Multiple sclerosis	Yes	60 minutes	18.03.2005	
57	Head Nurse			45 minutes	18.03.2005	21 years/ 100%
58	Daughter	Her mother suffering from dementia	Yes	90 minutes	18.03.2005	
59	Daughter	Her mother with decreased mobility and various diseases	No	45 minutes	19.03.2005	
60	Wife	Her husband with multiple sklerosis	Yes	45 min. Ph	19.03.2005	
61	Husband	His wife with brain damage	Yes	30 minutes	21.03.2005	
62	Daughter	Her mother with dementia	No (nursing home)	70 minutes	22.03.2005	
63	Daughter	Her mother with dementia	No (nursing home)	80 minutes	22.03.2005	
64	Husband	His wife after a stroke	Yes	60 minutes	22.03.2005	
65	Daughter	Her mother suffering from multimorbidity	Yes	45 minutes	23.03.2005	
66	Wife	Her husband with a stroke and cancer	Yes	75 minutes	24.03.2005	
67	Husband	His wife with a rare form of MS	Yes	45 min. Ph	30.03.2005	
68	Nurse			75 min. Ph	31.03.2005	>10 years/ 75%
69	Wife	Her husband in a coma	Yes	50 minutes	01.04.2005	
70	Daughter (nurse by profession)	Her mother with dementia	No	50 minutes	01.04.2005	
71	Daughter-in-law (nurse and nursing manager)	Mother-in-law after hip surgery and with dementia and brother-in-law with MS	Yes	40 minutes	01.04.2005	
72	Husband	Wife with dementia	No (institution)	35 minutes	04.04.2005	
73	Nurse manager			30 min. Ph	05.04.2005	16 years/ 100%
74	Brother and sister	Their mother with dementia	Yes	50 minutes	05.04.2005	
75	Nurse			45 minutes	05.04.2005	9 years/50%
76	Wife	Her husband with dementia	No	55 minutes	05.04.2005	
77	Mother	Her physically disabled child	No	30 min. Ph	07.04.2005	
78	Daughter	Her mother in a coma	Yes	70 minutes	07.04.2005	
79	Nurse			45 min. Ph	08.04.2005	>5 years/

						100%
80	Volunteer Alzh. society			20 minutes	14.04.2005	
81	Brother-in-law	His brother-in-law with a psychosis and cancer	No	60 minutes	15.04.2005	
82	Seamless care manager of specialised home care service			50 minutes	18.04.2005	
83	Niece (nurse by profession)	Her aunt with dementia	Yes	35 minutes	22.04.2005	
84	Nurse			30 min. Ph	25.04.2005	4,5 years/ 100%
85	Nurse manager			45 min. Ph	02.05.2005	24 years/ 100%
86	Nurse manager (owner)			60 min. Ph	02.05.2005	>10 years/ 100%
87	Lähihoitaja	Working in Finland		30 minutes	02.05.2005	
88	Daughter	Her father with diabetes and mobility problems	Yes	60 minutes	28.04.2005 28.07.2005	

Table 4.5: Seventh data set of interviews with nurses and family caregivers

Some of these interviews were conducted on the telephone indicated by the ‘Ph.’ in table 5. This occurred because the interview partners lived in different parts of Germany and it was not possible to travel for one or several days to conduct the interview due to time and economic limitations. As all interview partners expressed their willingness to participate either on the telephone or via e-mail a mutual agreement was made when the interview should take place. For the telephone interviews a time was scheduled, too. After all these interviews were conducted and analysed data saturation was achieved.

4.3.1 Conducting interviews

As it has been mentioned above, data collection was performed by using interviews exclusively. The types of interviews were different in the five phases. How the interviews were conducted was determined by theoretical sampling. The codes and categories that emerged from the analysis guided the decisions on whom to interview next, but also the decisions on what questions to ask (Glaser, 1978, 1998). During the first three phases of data collection the interviews were open interviews. The interviews from the data sets derived from other studies were also open interviews. An open or narrative interview starts with an open question to stimulate participants to share their experiences (Flick, 2002). In this study the initial question for family caregivers was: ”Could you tell me how your caregiving situation developed and how you would describe it now?”. The initial questions in the interviews not conducted by the researcher himself also were intended to stimulate participants to share their viewpoints on the area under study. Boes (2003) asked her interview partners initially about what they are doing in their everyday work and what they would consider as their contribution in home care. Ludwig (2002) asked nurses initially if they could share their experiences in households with elderly people living alone. In Holle's (2004) study the initial question was how nurses consider the impact of the existing reimbursement scheme for home care on their work. After the narration of the interviewee the interviewer asks for parts of the story that have not been fully elaborated and finally asks questions of theoretical relevance for the study. In this study all family caregivers addressed the aspect of the involvement of a nursing service and their relationship to the nurses, but to get a clearer impression at this point, additional questions were asked on why they chose a nursing service, why they chose their particular nursing service and what their experiences with the service in general and individual nurses in particular were.

The interviews in the fourth and fifth phase were no open interviews any more. The interviews with family caregivers started in the same way like the previous ones with the question of how the caregiving situation developed and how the family caregivers would describe it now. The interviews with nurses started with the open question of how they would consider their relationship with family caregivers. The open question in the beginning of the interviews was intended as a stimulation like in previous interviews, but it also served the purpose of searching for new incidents that have not been found before.

After the initial question the interview was focussed on concepts and hypotheses emerged from the analysis of the previous interviews. Family caregivers were asked about their judgment of the nurses' expertise, about responsibility for the entire caregiving process, about the organisation of the work and about the frequency and quality of information on care related issues they got from nurses. Nurses were asked why they think they have been involved in home care situations, about responsibility, organisation of the work, and if and how they provide information. The interviews with the nurse manager and the psychologist in the fourth phase were conducted as semi-structured interviews, during which the interviewees were asked specific questions according to the concepts that emerged. At all times in the interviews they had an opportunity to share their viewpoints beyond the actual question. This was to ensure that concerns of nurses and family caregivers that had not been raised so far, had a chance to be addressed. For the researcher this approach served as a means to stay open (Glaser, 1978) during the entire research process.

As mentioned above some interviews in the last phase of data collection have been conducted as telephone interviews. This type of interviewing has been hardly addressed in the literature, although it seems to be an increasingly used method (Burke and Miller, 2001). The reasons for using telephone interviews in this study were basically practical ones. Family caregivers, nurses and nurse managers expressed their willingness and readiness to contribute to this study and they were ready to do this on the telephone. The telephone interviews were conducted using a list of questions that was derived from the ongoing analysis. These questions were the ones mentioned above and they were related to the codes and categories that had been identified so far.

4.3.2 Data Handling

The interviews from the first and the sixth data set were audio-taped and transcribed afterwards. The interviews from the second to fifth data set were available in form of full transcripts. The interviews from the seventh data set were audio-taped, but not transcribed. Transcription of interviews in general is challenged by Glaser (1998) who states a difference between the traditional use of interviews as complete evidence for a particular finding and the grounded theory use that uses interview data for purposes of conceptualization. Although first in this study full transcription was done, this was rejected for the final set of 52 interviews for theoretical reasons. These reasons concerned the fact that the interviews at this stage were to saturate the categories already developed and to help to conceptualize the relationship between categories and the underlying basic social process. Instead of transcribing all interviews the audio-tapes were listened to and during listening memos on the aspects of relevance according to the previous findings and the participants main concerns were taken down and a summary of the whole interview was written, too. To be sure that all important aspects have been taken into account the interviews were listened to a second time.

4.4 Data analysis

The development of a grounded theory is based upon theoretical sampling, the constant comparative method of analysis, the process of substantive and theoretical coding, and constant memo writing and sorting (Glaser and Strauss, 1967; Glaser, 1978). It has been outlined above how the data collection took place. It was guided by theoretical sampling according to the concepts that emerged from the analysis. Below the process of data anlysis is presented.

4.4.1 Substantive coding

Coding is the process of analysis in a grounded theory study. A code is the essential relationship between empirical data and theory. *"It conceptualizes the underlying pattern of a set of empirical indicators"* (Glaser, 1978, 55). As this study follows the Glaser approach of doing grounded theory (Glaser 1978, 1998), coding was done as substantive coding and theoretical coding. Substantive codes conceptualize the empirical substance of the area under study while theoretical codes conceptualize how the substantive codes relate to each other as hypotheses to be integrated into a theory (Glaser, 1978, 55).

The first step of substantive coding is open coding by which the researcher fractures the data and groups them into codes. Open coding in the first interviews was done by doing a line-by-line analysis of the interview transcripts and according to the questions that Glaser (1978, p. 57) suggested for open coding: *"What is this data a study of?; What category does an incident indicate?,* and *What is actually happening in the data?"*. Open coding involves constant comparisons between incidents, codes and emerging categories. The coding process was interrupted for writing memos whenever necessary.

During the line-by-line analysis incidents have been written on the transcripts and afterwards on a separate piece of paper like in the following example taken from an interview with a family caregiver:

"Just because of what they are doing. They give me freedom, when I want to go away and I know at half past three, four the nursing service is here and I go at one and my husband is still in bed, then I don't need to go back, because I know they will come, get him out of bed and care for him. And they care for him, even if I'm not there, and he has something to drink"(Interview 7: 105-109)

The incidence from this quote was labelled as 'nursing service allows for freedom and feeling safe'. The substantive code derived from this incident compared to other incidents was 'feeling of security'.

In the initial stage of the research process a final decision of how to handle the language issues was still pending. The interviews were both conducted and transcribed in German language. Therefore, the incidents were identified and compared in German first. When it turned out that it would be difficult to translate codes that emerged from the comparison of incidents it was decided to summarize the underlying 'story' of the interviews in English. This was done in a research diary that accompanied the whole research process until the end. The story was then compared again with the German transcript and the incidents identified. From the story open codes were identified as in the following example. The story of interview I was as follows:

"This situation may well be summarised by: making optimal use of services and benefits. The whole caregiving relationship developed over years with increasing physical and mental problems of the mother. Depression, dementia, death of the main caregiver and a hip fracture involved/urged/forced the son to assume the role as the main caregiver with support of his wife. The hospital staff was helpful. The now existing situation started with the hip fracture. The personal beliefs of the son such as feasibility, personal opportunity, external help, and the wish to improve the mothers' quality of life had an influence on that decision. The relationship with the nurses is quite good and with one in particular it is excellent. An active help-seeking behaviour led to gaining knowledge, stability of the situation and appropriate services. The caregiver feels secure and hopes for continuity. He wants to maintain the life he has" (Story of Interview I from research diary on 10 July 2004).

Out of this story the following codes have been identified: Making use of services and benefits, family relationship, help seeking behaviour, feeling of security, having trust, task sharing (with nurses and wife), taking care of oneself, having the personal option, and gaining knowledge and expertise.

The approach of labelling incidents and substantive codes in German during the line-by-line analysis and then comparing them to the summarising story in English was used for all interviews from the first data set. The codes were compared to each other until a set of 26 substantive codes was identified. The data sets two to four of the interviews with nurses were analysed using the same approach. From these interviews 20 substantive codes were identified. For all codes a short memo was written (see Appendix 3). At this point in the research process the substantive codes were not grouped into categories of a higher abstraction level and they were not sorted in any way.

The analysis was done by constant comparison which included incidents compared to incidents, incidents compared to codes, codes compared to codes and codes compared to categories. The labelling of the codes that emerged at this point was either obvious from the nurses' or the family caregivers' own words or the labels were influenced by sensitizing concepts derived from the literature (see chapter 2) and the researcher's theoretical sensitivity (Glaser, 1978).

The original intention to analyse the interviews with family caregivers and nurses together was rejected at this phase of open coding. The list of codes (Appendix 3) reveals the huge differences in the nurses' and the family caregivers' concerns and it was appropriate at this point to decide to analyse and sample the family caregivers' and the nurses' perspective separately.

The interviews from the fifth data set were analysed using the same approach that was used for the previous interviews. This step of analysis allowed for a modification of the codes that had emerged in the first interviews with family caregivers. Six additional substantive codes were identified. First preliminary relations between categories were drawn. Open coding of data set six was also done in this manner.

As has been said the 52 interviews from the seventh data set have not been transcribed and therefore needed to be analysed differently. While listening to the interviews open coding was performed. The listening was stopped when an incident was reported that either matched a code already identified or modified an existing code or revealed new incidents and new codes. After the analysis of all 88 interviews and several hundred incidents 72 substantive codes emerged from interviews with family caregivers (Appendix 4) and 77 substantive codes emerged from interviews with nurses (Appendix 5) .

4.4.2 Memo writing

Memos are essential in doing grounded theory. They are the written form of ideas that come up during the research process. Memos theorize codes and their relationship during the coding process (Glaser, 1978). Memos can be related to theoretical ideas, relationships between codes, ideas on how to proceed in data collection, and integrating sensitizing concepts. Memos are written from the very beginning of the research process and they sum up to a memo fund that is highly sortible (Glaser, 1978).

In this study memos were written starting from the first step of data collection. After the first interviews and during the first analysis memos were written on theoretical ideas such as: 'Decisions in families are initiated', 'positive and negative caregiving experiences in relation to/ as a basis for the decision whether to involve a service or not' and 'constant negotiations with nurses' (see Appendix 6). This was continued during the whole process of data collection. The more codes were identified the more memos served for thinking about relationships between particular codes as can be seen from the following example. For family caregivers the substantive codes 'confidence level' and 'gaining expertise' have been identified and possible relations between these codes were written into a memo: *"In this interview the daughter states restrospectively 'Now I know'. This reflects confidence and expertise on care related issues. How and to what extent expertise is gained may be important* *for the relationship. It may also be important in terms of its contribution to caregivers giving away responsibility to the nurses"* (Memo from 26 June 2004).

Another example illustrates how memos have been used for theoretical sampling and raising the researcher's theoretical sensitivity. During the data collection and analysis Glaser's study on expert-laymen relationships was read (Glaser, 1972). Although this study took place in a different context (Glaser's study expands the expert-laymen-relationship on the patsy and the subcontractor during the process of building a house) it made sense to compare the concepts and look for similarities and needs for modification. Two examples from memos will illustrate how Glaser's study was used for generating hypotheses and for theoretical sampling. The first memo was written after reading in Glaser's study about controlling the quality of the job that was compared with the code 'monitoring and observing' that emerged from the first data set: *"Controlling the job involves inspecting, evaluating and administering the work of an expert (p. 124) which experts do not enjoy from someone less knowledgeable. Experts often do things without asking the patsy. This often leads to errors of a structural nature. The patsy must correct errors immediately, otherwise the errors will chase him for the rest of the job. This is exactly what family caregivers do when they monitor and observe the work of the nurses. It is not yet clear if monitoring and observing is a question of the personal character of the caregiver or if there are particular incidents that cause an active monitoring"* (Memo from 05 May 2005). In the substantive theory this question is answered by the concepts 'triggering struggle' and 'becoming suspicious'.

In terms of theoretical sampling Glaser's study was helpful in reflecting the concept of 'Generalling the job'. *"A characteristic of caregiving work is its non-determined beginning and ending opposed to the patsy from the Glaser study. In addition, it is not possible to hand over the work to a general in home care as family caregivers are always involved somehow. Contracting a general would mean referral to an institution, most probably a nursing home. To be clear about that an interview with somebody who received a 24-hour care in his own home would be helpful"*(Memo from 08 January 2005). During the talks with possible gatekeepers it was explicitly asked if they know a family caregiver caring for somebody who receives 24-hour-care. Interview 33 reflects such a situation.

According to Charmaz (1995) memo writing is the intermediate step between coding and the first draft of the completed study and it actually was like this in this study. For all substantive codes memos have been written. These memos were used in the process of memo sorting and theoretical coding.

4.4.3 Theoretical coding

Theoretical codes in grounded theory have the power of integration, writing about movements over time, enhance the theory and generalize it (Glaser, 2005). As substantive codes theoretical codes are emergent. They emerge from memo sorting and not from preconceived theoretical frameworks, particular structures of a discipline or as 'pet' codes that researchers tend to use when they once discovered a theoretical code that is then applied to all other areas of social research. Glaser (2005) also stresses that theoretical codes emerge from memo sorting and not from data sorting.

Glaser (1978) presents 18 coding families of theoretical codes, which overlap each other and are not mutually exclusive. He asks researchers to learn as many theoretical codes as possible to raise theoretical sensitivity. The list of theoretical codes was expanded by Glaser himself in 'Doing Grounded Theory' (1998) and 'The Grounded Theory Perspective III' (2005). The first step of theoretical coding is to search for integrative patterns that give a structure to the substantive codes and memos and limit the use of possible theoretical codes. In this study this was done by taking the list of substantive codes for family caregivers and nurses and to search for integrative patterns. By doing so some substantive codes were expanded and were treated as categories and others were integrated with other codes and they got a new label. In the appendices 4 and 5 it can be seen how the codes were integrated into patterns that later in the process of theoretical coding became sub-categories or categories.

Memo sorting is according to Glaser a 'by-hand' activity (2005, p. 35) and this advice was followed in this study. A list of the labels of memos and substantive codes was used and by constant comparison they were sorted into patterns that fitted. Because of the researcher being familiar with the content of the memos the list of labels was sufficient in the first place. The more memos were sorted and the more patterns and relations emerged, the more it was necessary to use the full memo and analyse if it actually fitted into the same pattern. The different piles of memos were constantly compared with the list of theoretical codes from the coding families (Glaser, 1978, 1998, 2005).

Kelle (2005, [9]) points out that the coexistence of employing theoretical sensitivity on the one hand and concepts that emerge on the other has conflicting implications that are not yet integrated into each other. He argues that the theoretical codes are kind of an equipment, but there is no idea of how such terms can be used to explain empirical phenomena. He criticises that the coding families lack a distinction between formal and substantial notions. He suggests to use theoretical concepts with low empirical content as useful tools and that 'sensitizing concepts' *"...should constitute (a sometimes loosely connected) 'heuristic framework' of* *concepts (or 'coding families') which helps the researcher to focus the attention on certain phenomena in the empirical field."* (Kelle, 2005, [32]).

In this study the first step of theoretical coding was the sorting of memos and the search for patterns that then have been constantly compared with the coding families. The substantive codes that have been integrated into patterns were analysed concerning the question if a theoretical code actually expresses the underlying pattern. The position of Kelle (2005) was very helpful in so far as the heuristic framework outlined in the literature review (chapter 2) was used at this stage for constant comparison, too. This revealed similarities and differences with existing conceptualisations.

The constant comparison of memos, substantive codes and theoretical codes led to the identification of several theoretical codes that express the respective patterns in the data. It became obvious, for example, that for nurses 'questions of identity' are a pattern revealed in the substantive codes. During the process of theoretical coding the following theoretical codes from Glaser's list of coding families (Glaser, 1978) matched the underlying patterns of the substantive codes: Identity, strategy, context, process, consequence, mutual effects, and goal. In a second step it was differentiated what kind of identities, strategies, contexts, processes, consequences, mutual effects and goals were represented by the memos and substantive codes. This step revealed, for example, the personal and professional identities for nurses that are a main concern for them in their daily practice. During the third step the theoretical codes were labelled according to the family caregivers' and nurses' perspectives. This step aimed at overcoming the difficulty expressed by Kelle (2005) to distinguish between formal and substantial notions in the coding families. The theoretical notion of a process that conceptualizes the relationship between formal and informal care would have triggered the question of what kind of a process is going on. Therefore the labels that have been attributed to the theoretical codes give a substantive notion to them that allows for a better understanding of what actually accounts for the relationship between formal and informal care.

The labelling of the theoretical codes was influenced by sensitizing concepts from the literature and by searching for integrative labels that express the underlying patterns identified from the substantive codes. An example is the goal of family caregivers 'Facilitating work and care'. The coding families were helpful in identifying that the underlying pattern actually is a goal and the sensitizing concepts from chapter 2 helped labelling the goal as 'Facilitating work and care' by keeping in mind the trajectory framework that was published under 'Unending work and care' (Corbin and Strauss, 1988).

For family caregivers the integration of substantive codes and memos into patterns revealed the theoretical codes presented below. By using theoretical sensitivity and applying the researcher's knowledge about existing conceptualisations these codes were labelled and conceptualised as follows:

Theoretical Code	**Label/Concept**
Goal	Facilitating work and care
Process	Developing a fitting arrangement
Strategies	Managing caregiving
Consequence	Coming to terms with competing demands
Context	Facing new life circumstances

Table 4.6.: Theoretical codes and concepts for family caregivers

The next step was to identify the relationhips between the concepts. During theoretical coding memos were written and graphs were drafted to detect the relationships between theoretical codes. By doing so a particular order was identified that started with *Facing new life circumstances,* followed by *Coming to terms with competing demands*. Both lead to a process of *Developing a fitting arrangement* that is influenced by strategies of *Managing caregiving.* The main concern of the family caregivers was identified as the goal of *Facilitating work and care*. This is the goal that is to be achieved by the process of *Developing a fitting arrangement* and it is also influenced by strategies of *Managing caregiving.*

The same procedure was applied to the substantive codes and memos of the nurses. This analysis revealed the theoretical codes and labels/concepts presented in the table below:

Theoretical code	**Label/Concept**
Process	Shaping different realities
Condition	Becoming involved
Context	Framing home care nursing
Identity (professional)	Working in home care nursing
Identity (personal)	Contributing one's own personality
Consequence	Feeling restricted
Goal	Keeping people at home
Strategies (professional)	Matching order and reality
Strategies (personal)	Balancing closeness and distance
Mutual/interactive effects	Mutual dependency

Table 4.7.: Theoretical codes and concepts for nurses

The relationships between these concepts were also analysed. By doing so it turned out that *Becoming involved* is the underlying condition for home care nursing in general. After nurses become involved in home care situations *Framing home care nursing*, *Working in home care nursing* and *Contributing one's own personality* in their mutual interplay result in the consequence of *Feeling restricted.* To match their goal of *Keeping people at home* nurses apply professional (*Matching order and reality*) and personal (*Balancing closeness and distance*) strategies. In contrast to the family caregivers the main concern for nurses is not the goal of *Keeping people at home*. Their main concern, however, is the process of *Shaping different realities* that determines their everyday work. The actual performance of this process is an interactive process that is strongly influenced by *Mutual dependency* between nurses and family caregivers.

In the final step of the analysis it was searched for concepts and the core category from both perspectives. Memos, substantive codes, theoretical codes and the core concepts of the family caregivers' and the nurses' perspective were compared. *Negotiating helpful action* was identified as the core category that integrates *Facilitating work and care* and *Shaping different realities* into a substantive theory on the relationship between formal and informal care. By the analysis described above all substantive codes became a part of the substantive theory of *Negotiating helpful action* (see Appendices 4 and 5).

4.5 Ethical considerations

Ethical considerations in this study took into account the generally accepted ethical codes for conducting research that involves human beings. Those are the principle of beneficence including freedom from harm and exploitation, the respect for human dignity including the right to self-determination and the right to full disclosure, the principle of justice including the right to fair treatment and the right to privacy, and informed consent (Schröck, 1984; Polit and Hungler, 1999).

It was not expected that participation in this study would result in any harm for the participants. Experiences from previous interviews with family caregivers revealed that the interview itself often can be very intense and confronts the family caregivers with their entire situation in a non-familiar way. This actually happened in this study. During the interviews in these moments the tape recording was stopped and the participants were granted the time they needed, before the interview continued. In addition to these situations the researcher was available for the participants to talk about the situation outside of the interview. In some interviews participants shared experiences that were harmful either for themselves or for their care dependent relatives. In these cases the researcher tried to be supportive by informing the family caregivers about possible options to change the situation. In one case a recommendation was given to take the case to court.

Participants were informed about the background of the study before the interview took place. Mostly this was done on the telephone when the first contact was established and when the interview took actually place they were informed again about the study. When access to participants was gained by gatekeepers, these gatekeepers were informed about the study and they got a letter with information about the study for themselves and to hand out to participants. Before the actual interview started the researcher again informed participants about the study and asked for permission to audio-tape the interview.

For the interviews that were used for secondary analysis it was assured that ethical principles were adhered to in the conduction of the respective study. Participants who were interviewed on the telephone were informed about the study before the actual interview took place.

All participants were granted the option to withdraw at any time without stating any reasons. An informed consent form was only signed by very few participants. Most felt confident after having been informed about the study. Particularly after the press release participants stated that they would not have called if they would have any reservations against sharing their experiences.

Confidentiality was guaranteed to all participants. This was also true for the interviews that were used for secondary analysis where the researcher did not know the names and addresses of the interviewees. The participants have not received any financial or other benefits from the researcher.

The proposal of this study was submitted to the Ethical Committee of the Institute of Nursing Science at Witten/Herdecke University and ethical clearing was obtained in June 2001.

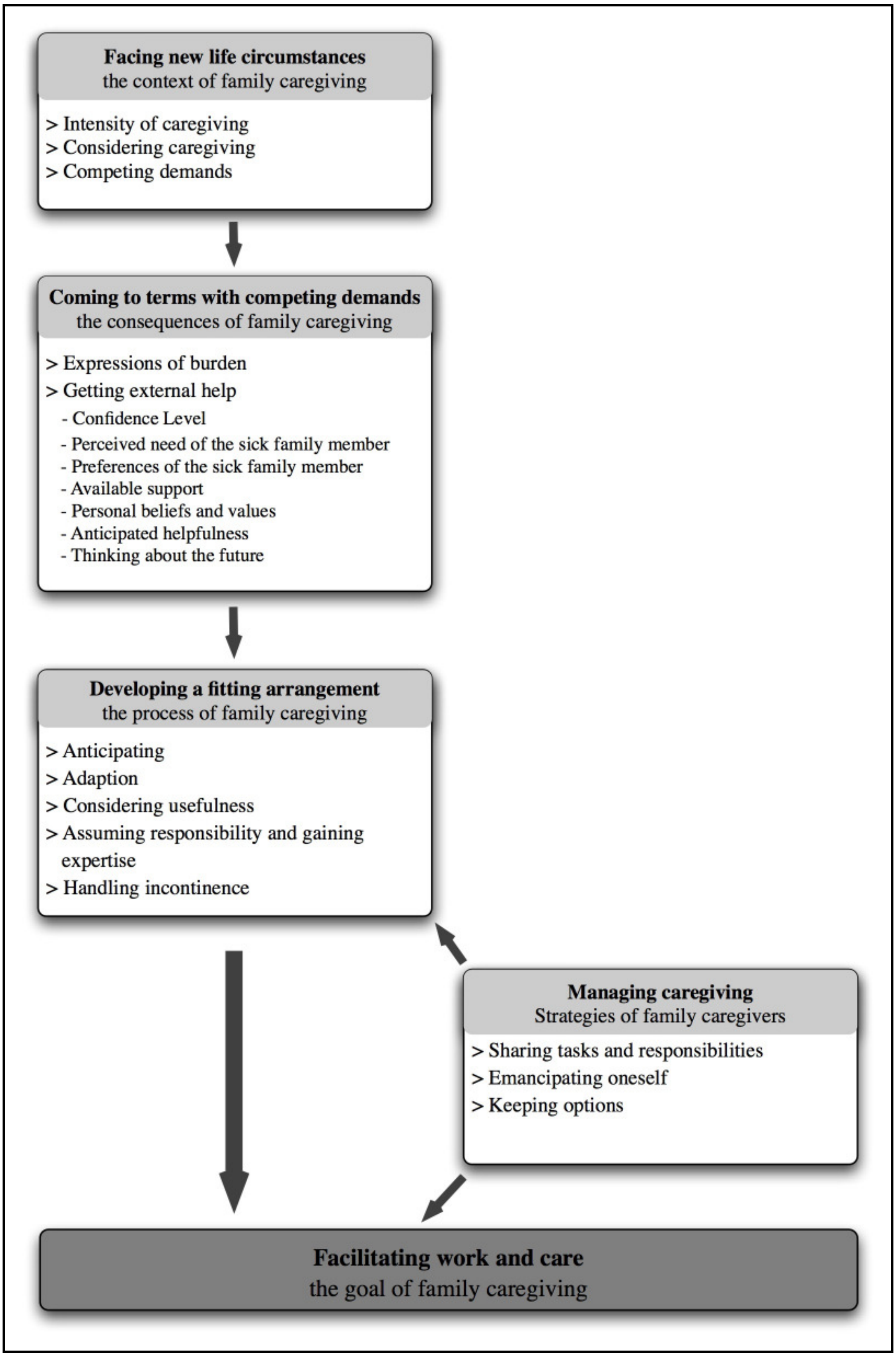
5 Negotiating helpful action – A substantive theory on the relationship between formal and informal care

It has been outlined in the methodology chapter that the perspectives of family caregivers and nurses on their mutual relationship have been analysed and developed separately in the first place. Their perspectives differed in terms of the meaning they attributed to the relationship and in terms of the concepts they used to describe it. The family caregivers' perspective can be conceptualized around the goal of *Facilitating work and care* and the nurses' perspective is conceptualized by the process of *Shaping different realities*. This goal on the one hand and this process on the other hand account for the family caregivers' and the nurses' main concern. The core category that integrates both the family caregivers' and the nurses' perspective is the process of *Negotiating helpful action* to which both contribute according to their different perspectives.

The presentation of the findings follows the logic of the analysis. First, the perspective of family caregivers is presented which is followed by the nurses' perspective. Both are parts of the substantive theory on *Negotiating helpful action* that is presented at the end of this chapter.

5.1 Facilitating work and care – the perspective of informal carers on the relationship between formal and informal care

From the caregivers' point of view the relationship between formal and informal care and the decision whether to involve a nursing service or not is only one part of the whole caregiving situation. The beginning of a caregiving situation is conceptualized by the context of *Facing new life* circumstances. For family caregivers the consequence out of this context is *Coming to terms with competing demands. Facing new life circumstances* precedes *Coming to terms with competing demands.* Family caregivers engage in a process of *Developing a fitting arrangement*. In this process family caregivers apply strategies of *Managing caregiving*. The strategies for *Managing caregiving* are intended to develop a caregiving arrangement that allows for the goal of *Facilitating work and care*. Graph 5.1. provides an overview of the concepts and their relationships that conceptualize the perspective of family caregivers and are outlined on the following pages.



Graph 5.1. Concepts and their relationships of the family caregivers' perspective on the relationship between formal and informal care

5.1.1 Facing new life circumstances – the context of family caregiving

Becoming a caregiver rarely is a process that follows a clear plan in life. It is not something that people actively prepare for. Therefore in the initial phase of caregiving the family caregivers are *Facing new life circumstances*. The new life circumstances are influenced by the way of how the caregiving situation developed. They are also influenced by the *Intensity of caregiving,* the way of how family caregivers are *Considering caregiving* and by *Competing demands* that the new life circumstances imply.

The onset of a caregiving situation occurs either following an acute event or as a slow process. No matter how the situation develops, it always takes place in relation to a family relationship and is influenced by personal values and beliefs of the family members. The family relationship is important in terms of a process when out of a normal family relationship a caring relationship develops. In the case of an acute event which often occurs within a second, the family relationship may face a serious deterioration and a new structure of the families' everyday life needs to be re-established. This concerns both rules and responsibilities of the family that need to be redefined.

When the family relationship turns into a caregiving relationship as a slow process there usually is no clear cutting point where relatives consider themselves as family caregivers. The family relationship is important in terms of ties and emotions that have developed over the course of the family life. Ties and emotions are a property of the family relationship that describe the feelings family members have for and to each other and that determine the relationship during the care process. It mostly accounts for the motivation of family caregivers to care, but it also determines how everyday life is organised and how family caregivers plan the caregiving process. Finally, the family relationship accounts for the supporting network of families. The types of support that different family members provide range from being available just in case and stepping in when necessary to active involvement in particular tasks and joint decision-making concerning decisions about caregiving arrangements.

The beginning of a caregiving process, as either an acute event or as a slow process, influences the relationship between formal and informal care in so far, as in case of an acute event there is an immediate contact to the formal care system, mostly in terms of hospital staff.

The new life circumstances occur within the history of a family life. This implies that personal beliefs and general life decisions that have taken place before the onset of caregiving, influence the context in which the new circumstances actually happen. Personal beliefs concern cultural or religious values about life in general and family life in particular. For many family caregivers these beliefs are driving factors to assume responsibility for caregiving and they influence the actual organisation of the caregiving process. General life decisions have been made in some families before a caregiving situation started and they involve decisions about nursing home use, financial matters and questions of inheritance. They also involve decisions that caregivers made themselves on their own life. Caregivers accept decisions that have been made when the care recipient was capable of participating in such decisions, but these decisions may be subject to change when the care demands are unbearable for the family caregivers.

General life decisions and the relationship within the family are important factors why family caregivers decide to care in their own homes. When talking about their caregiving experiences they express the reasons why they opted for home care in their particular case. Reasons to opt for home care were ethical considerations for some caregivers who never would give their relative into institutional care, but also the anticipated problems that might occur in a nursing home. Most of the caregivers have the care-recipient in mind, but some also prefer home care, because of their own freedom. They feel that home care enables them to make their own choices more easily.

Family caregivers were seldomly prepared for the caregiving process. They face a general lack of knowledge about tasks, processes and procedures of caregiving in the beginning. Because of this they are eager to increase their knowledge on all aspects of the underlying illness and the consequences it involves for the work they have to do. Family caregivers need to work actively and hard to get this knowledge and they complain about the fact that health care professionals (physicians as well as nurses) do not share information voluntarily and that during institutional care there is no active preparation for caregiving at home.

Intensity of caregiving

How family caregivers act and decide in their individual situation is influenced by the intensity and severity of the care-recipient's needs. There are clear indications that strong physical limitations are associated with higher caregiving demands for family caregivers. Being bed-ridden is not described in detail, but serves as a predictor for the involvement of a nursing service. The consequences of the severity of the illness are different. While in one case a husband refers to his wife as a 'living dead', in another case a son is eager to achieve even smallest improvements in his mother's quality of life.

The medical diagnosis influences family caregiving, but only to a limited extent. The exception is the diagnosis of Alzheimer's Disease. Family caregivers caring for a relative suffering from it report some specialities that do belong to the diagnosis. The first thing they say is that they have not taken the situation seriously in the beginning and did not want to recognize and to know what they were up to. Another aspect is that after a while of caring for a relative suffering from Alzheimer, caregivers reach their limits. Family caregivers, who reported retrospectively about their caregiving, say that if they had known beforehand what to expect then they would have made another decision concerning caregiving. Especially caregivers of Alzheimer patients felt left alone from the whole health care system.

Considering caregiving

On a general level family caregivers try to consider their own situation. They do this in terms of accepting caregiving as a natural situation in human life that is characterised by a permanent give and take. Another perspective is the conviction that with the experience of caregiving retrospectively, most family caregivers would make different decisions. They would arrange for more informal or formal help or even not assume responsibility for caregiving at home at all.

Compared to other people some family caregivers see themselves in a disadvantaged position. Because of their work they save money for the society and they do not put any burden on anyone except themselves, but the reward they get for it is next to nothing. This perception is not related to feedback from the care-recipients or other family members. It rather is a statement on the role and status of family caregivers in society.

To make sense for themselves and the outside world some family caregivers try to define caregiving according to their image and their experiences. They state that their caring goes far beyond taking care of physical aspects. In their definition it is important that they are always present, that they listen and talk to their ill family member, and that they supervise the whole caregiving process.

Competing demands

The new life circumstances and the decision to take care for a sick family member involve additional demands for family caregivers. These additional demands are determined by the intensity of the caregiving process, but they are also determined by family obligations and job demands. Family caregivers have to find a balance between these competing demands. Their decisions need to take a variety of aspects into account. Job demands have to be taken into account in terms of the requirement of the family caregivers' income for the overall household income. Job demands determine to a great extent when and how much formal support is going to be involved. But job demands are not only a question of income. For some family caregivers, keeping their job serves as a means of keeping their normal routines and for having something else on their mind apart from caregiving.

5.1.2 Coming to terms with competing demands – the consequence of family caregiving

Within the context of *Facing new life circumstances,* family caregiving bears consequences. The consequences of family caregiving can be conceptualized as *Coming to terms with competing demands*. This concept is actualised and dimensionalised by the categories: *Expressions of burden* and the decision of *Getting external help.* The decision-making process of *Getting external help* in families has different sub-categories that influence and determine the decision. These sub-categories are the *Confidence level* of the family caregivers, the *Perceived need of the sick family member*, the *Preferences of the sick family member,* the support that is available, the *Personal beliefs and values*, the *Anticipated helpfulness* and the *Thinking about the future*.

Expressions of burden

Family caregivers express a range of incidents and experiences revealing how they suffer from the caregiving experience. Suffering results out of the relationship with the care recipient, the work that needs to be done every day, the consequences of the involvement of a nursing service and the perspective that leaves caregivers in uncertainty and with no schedule to follow.

In terms of their own experiences and feelings, family caregivers express the feeling of being alone as really burdensome. Feeling alone is related to the organisation and performance of caregiving work, but also to the expectation of support from anywhere. 'What you don't do yourself, that does not happen' is an expression that highlights how many caregivers feel. Feeling alone results in disappointment that there is no understanding from others, such as other family members, friends or neighbours. Family caregivers feel left alone by their former social network.

Concerning the formal health care system, caregivers are completely disillusioned. Due to several experiences in institutions but also in home care, they lost trust in the professional system. *"Each expectation was disappointed" (46)* states a family caregiver who through all areas of the health care system had the feeling that nobody was there to help her. She felt left alone with her work, her concerns and her hopes.

The involvement of a nursing service or any other kind of formal support not always decreases feelings of burden, but sometimes increases the family caregivers' dependency. They feel dependent and they actually are dependent from the providers' availability and decisions. Other caregivers said that the support they needed in their particular situation simply was not available, either because such a service was non-existent or because they did not have the resources to pay for it themselves. The encounter with the formal social and health care system implies the experience that nothing can be taken for granted: *"It is the permanent fight for the small and simple things that drives you mad" (69).* The involvement of formal support can also imply to lose a part or all of control in one's own house.

Suffering caregiving has an impact on the self-image of family caregivers. Caregiving moves them into a state of permanent alertness. This means that caregivers feel a constant pressure to observe if everything is alright. They need to arrange what is needed for caregiving and they feel responsible for providing care that is alright and serves the care-recipient well. Caregivers are also concerned of preventing any harm or deterioration in the care-recipients state. Constant alertness can result into being under permanent tension and if such a state is reached then for caregivers every single thing can become a stressor, be it a slight deviation from everyday routine or a slight deterioration in the care-recipients' state.

In practical terms feeling alone and permanent alertness limit the caregivers' free movement. They feel bound to the house. They complain about having no life any more and that they are not granted any private life at all. At its worst end a caregiver experienced herself *"I'm not a human being any more, I'm just a functioning machine" (58).*

Many caregivers report the impact of long-term caregiving as themselves becoming crazy or as a stupidisation of themselves. They stress that this has nothing to do with emotional feelings towards the care-recipient, but with them only focussing on caregiving without having a chance of sharing their concerns or just talk to somebody about it. Another impact of the caregiving process is that the management and performance of caregiving interferes with the relationship to the care-recipient. For caregivers it is hard to keep a once good relationship on the same level.

In the retrospective many caregivers state that they had not expected that many obstacles and never thought of the possibility that caregiving woulod be such a stressful experience. They simply had not anticipated what they went through. Another experience from the retrospective is that many caregivers anticipated the occurrence of particular things, e.g. the care-recipient becoming incontinent or being unable to eat on his or her own, they would ask for professional help, but in practice they have not done so. They changed the limits of what they thought of being feasible for themselves.

An additional burden is the administrative work related to caregiving. This involves applications and communication with different officials. A nursing service can be helpful in this respect when it helps and informs on the administrative requirements, but it can also make matters more complicated when a confirmation, an approval or an assessment is required from the service and is not provided in time.

Getting external help

The relationship between formal and informal care starts with the involvement of a nursing service. This involvement is the result of the caregivers and/or care-recipients evaluation of their own situation in terms of the care they need, the individual preferences and the confidence level of being able to care in relation to available external support and its anticipated helpfulness.

As said before family caregiving situations start in two distinct ways. The first route is via an acute event such as an accident that is associated with a cutting point in life and a deterioration of the life of the family. The second way is a slow process in the beginning of which family caregivers perform tasks and activities in the household that are not described as caregiving tasks. Such activities include preparing food, doing the laundry, buying items needed for everyday life or accompanying a family member when visiting friends, consulting a doctor or taking a walk.

In those situations where a caregiving situation starts from an acute event, there is a direct encounter with professionals from the health care system, usually doctors in the first place. Where there is no such event, contact to the health care system depends on active decisions to ask for help or receiving recommendations to involve somebody to help with the caregiving work. Most caregivers are not prepared for what to expect during a caregiving process and mostly they do not have the knowledge of the illness and its related symptoms and problems.

Both routes involve a different decision-making process. While after an acute event the question is if and how home care is an option, in the developing caregiving situations the question is rather at which point external support is helpful and necessary.

Decision making not only concerns the involvement of a nursing service, but the decision on what to do in general. Some families have made general life decisions that they will care for each other and not give somebody away in a nursing home. Others stress reciprocity in their family life where all family members are used to care for each other when one family member is in need.

The decision depends on the following aspects: *Confidence level* of the family caregivers; *perceived need of the sick family member*; *preferences of the sick family member*; *available support*; *personal beliefs and values*; *anticipated helpfulness* and *Thinking about the future*..

Confidence level

The confidence level refers to the family caregivers' trust in their own abilities to handle and manage the caregiving process. The confidence level is no static concept, but it develops over time and family caregivers apply different strategies to raise their confidence level. *"When I got the information that my wife was diagnosed Alzheimer, I started researching"*(72). Others make use of the professionals during the hospital stay: *"In the hospital I insisted on being prepared for my husband's discharge"*(66). The confidence level not only concerns technical aspects of care, but also the ability to combine caregiving with other job and/or family demands. For some caregivers it is impossible to take over the whole caregiving work due to their job commitments. Other family caregivers trust in their abilities as long as particular tasks are not concerned. *"I always thought that as long as she is not incontinent, there is nothing I couldn't do myself"* (40).

The confidence level includes the recognition of limits on part of the family caregivers, which is the actual recognition that not all requirements of the caregiving situation are manageable by themselves. It is mostly related to physical limits coming from the age or own health problems of the caregivers. If the sick family member is bed-ridden, this situation for many caregivers determines their need to ask for external help. The actual recognition of limits determines strongly if and to what extent and for what tasks a nursing service is to be involved.

Perceived need of the sick family member

Caregiving situations after an acute event are associated with a range of technical procedures that have been performed in the hospitals and rehabilitation clinics. Some of these tasks and procedures need to be performed in home care, too. These tasks include sucking secretion of the trachea, wound dressings, positioning and transfering, administering medication, handling medical and assistive devices and others. Depending on their confidence level caregivers assume responsibility for these tasks or they do not. Some actively ask for advice and instruction. *"I always was present at my husbands' side in the hospitals and I insisted on* *being prepared for what I would have to do anyway at home. I always asked questions"* (69). Caregivers are aware of the work they will have to undertake when their relative is discharged from the hospital. Besides the tasks and procedures the estimated duration of the needs of the sick family member plays an important role. As this is often unclear, professionals in hospitals and rehabilitation clinics recommend the involvement of a nursing service to cope with all the work over time that is associated with caregiving at home.

Statements on the duration imply the difficulty of being vague. Caregivers do not recognise this from the very beginning, but over a period of time they will know, whether prognoses have been appropriate or not. *"The physician told me that my mother will only have six more weeks (...), but in the end it lasted for more than 18 months"* (48).

Preferences of the sick family member

The perceived need of the sick family member is a reason for involvement or non-involvement of a nursing service from the caregivers' point of view. The preferences of the sick family member are an important aspect that needs to be taken into account as well. A central issue is the question of how to handle intimate care. *"Strangers make intimate care easier"*(37) is the reality in some caregiving situations, whereas in others the exact opposite is true: *"My mother would never have accepted nurses washing her and helping her on the toilet"* (65). This aspect is referred to by a care recipient himself as *"that is something you don't want to do, to expose yourself in front of strangers, in front of young women"* (3). Caregivers try to avoid exposure of their sick family members if those so wish.

Some caregivers state that they would, at a particular point of time, make a decision against the care recipients' preferences. A daughter who does not provide too much physical care to her mother yet pointed out *"we always had positive feelings for each other and I want to keep the relationship on this level. When you start the physcial care the love will disappear and I would ignore my mother's will in this case"*(8)

Preferences are also related to care recipients wanting to protect and comfort the caregivers. They recognise the work that their relatives do for them and want to decrease their burden.

Available support

The decision to involve a nursing service also has a structural aspect and that is the availability of different sources of support. Most family caregivers refer to other family members that help on particular tasks or just spend their time with the care recipient. *"When we needed to make a decision my daughters assumed responsibility to help me caring for my* *wife and that was the best that could happen as it is the best for my wife if she is being cared for by her family"* (50).

Support can also be available from neighbours and friends and it occurs by various means. While in the situation where the above quote is taken from, the father completely shares the caregiving tasks with his daughters, in other situations it is a neighbour or a friend who steps in occassionally or who is available to talk to or gives a helping hand when needed. *"Having somebody just in case"* (43) is considered to be very helpful by caregivers.

Personal beliefs and values

Personal beliefs and values refer to general cultural and/or religious influences that are important for caregivers to assume responsibility for caregiving and its actual organisation. Beliefs and values in this respect are associated with considering caregiving and keeping sick family members at home as appropriate and giving them away into nursing homes as inappropriate. They are not necessarily related to religious backgrounds. *"Maybe it's due to where I come from and I don't care what other people think, but for me family means family and that involves being there for each other"* (81).

The personal beliefs and values primarily influence the decision to assume responsibility for caregiving at home, but they also influence the decision to involve external help. Caregivers with strong religious and other values and beliefs tend to be more reluctant before they involve a nursing service.

Anticipated helpfulness

The most predictive concept for the involvement of a nursing service is the anticipated helpfulness. It does not refer to a long thinking process with assessing options and cost-benefit-analyses, but it refers to the image or idea that caregivers have about what nurses do and what the involvement would mean for themselves.

Helpfulness of services is associated with the hope of relief. This involves having a little bit of time for oneself, a relief in terms of being able to share a part of the responsibility involved in caregiving, and having the feeling to be on the safe side when nurses are coming regularly and look for the care recipient.

Helpfulness also refers to problems that arose out of the caregiving process. *"Mother was troublesome and refused to get up in the morning when I came in"* (74). This aspect also includes the problems with intimate care already mentioned above. It is related to the care recipients' refusal of help from the caregiver for whatever reason. Emotions between caregiver and care recipient may become problematic and the involvement is considered as helpful in this respect *"with professionals there are no emotions involved"* (59).

Anticipating helpfulness not only is a voluntary process, but it may also be forced through circumstances: *"I had to involve somebody to prevent myself caring for 24 hours on seven days a week and that for months. I needed somebody for the nights to get some hours of sleep"* (46). The caregiver's own health status or low confidence level have an impact on the involvement of nursing services and their anticipated helpfulness for their own individual situation.

For caregivers who have a full-time or half-time job the helpfulness refers to the necessity to keep the job. To perceive the possibility of involving a nursing service as helpful is either a process of self-reflection and changing demands in the caregiving situations or it is initiated by an external impulse, most often by General Practitioners, but also by neighbours or other family members. The obligatory counselling visits by nurses that need to be performed in case of people receiving cash benefits from the long-term care insurance have not been mentioned. The external impulse is no nursing impulse.

A prerequisite for anticipated helpfulness is an idea or image of what nurses in general and home care nursing services in particular offer and what they do. *"I don't know what nurses learn and what they ought to learn"* (74) is a statement of a caregiver that describes quite well how difficult it will be in this case to anticipate the involvement of nurses as helpful in this very situation. Another caregiver is quite clear about the image of what nursing services do: *"Well, they do eating, washing and toiletting and that I can do myself. It's not what I need a nursing service for"* (37).

Finally, very practical considerations concerning the caregiving work influence the anticipated helpfulness and thereby the decision of the involvement of a nursing service. Incontinence is mentioned as a core problem of home care. Apart from the personal aspect of getting used to deal with the incontinence of a family member caregivers complain that there is no service that is a real help with incontinence. *"He usually was wet and I had to change the linen and clean him either before the nurses came or just after they left and if I have to do the work anyway, then I don't need a service"* (48). Incontinence is a problem for 24 hours and it happens at different times. *"I know what services can offer and what they can't. To deal with my mother's incontinence would involve to have somebody ready for 24 hours and this is something that services cannot offer or if they offer it, it is not affordable, so I'm better off with keeping my freedom and do it on my own."* (5).

Thinking about the future

Many caregivers do not have a clear image of what the future might be like when they care for a family member. Their main concern is their own health status which is an indicator of their ability to continue caregiving. What caregivers fear are events that prevent themselves or other family members from being able to care. The caregivers' concern is the care-recipients' well-being. Their hope is a feeling of stability for the caregiving process.

To think about the future is also expressed by becoming fateful which involves letting things go and letting people die. Caregivers state that letting things go is something that needs to be learned in caregiving. It means to let things happen and not to blame oneself or the care-recipient when things do not go in the expected way. Letting things go includes a different understanding of time and it is characterised by caregivers having come to terms with their own life circumstances and those of the care recipients.

Letting people die is expressed by caregivers who experienced a caregiving process after a hospital stay. They know from their own experience what life after resuscitation after an accident may look like. They reflect on their own attitude and while being sure that without the knowledge they have now, they would want all measures taken to save the life of their sick relatives, but with the knowledge and experience their viewpoint changed and they would by far more easily let people die and save them from suffering.

5.1.3 Developing a fitting arrangement – the process of family caregiving

The process of family caregiving focusses on *Developing a fitting arrangement* and it is characterised by *Anticipating, Adaptation* and *Considering usefulness*. Family caregivers *assume responsibility* for the caregiving process and *gain expertise.* A special part of the process is *Handling incontinence* as it involves particular problems within the process.

Anticipating

Anticipating is an activity that is closely related to all caregiving activities. It even becomes a regular part of the caregivers' lives. They have to learn to anticipate potential sources of problems. Therefore, anticipating is also related to the decision for the involvement of a nursing service. Depending on what is anticipated caregivers opt for or against the involvement. One caregiver stated: *"I have involved the service due to anticipated problems. I was sure that the situation with my mother would get worse without somebody to help me" (47)*

Adaptation

The involvement of a nursing service initiates a process that caregivers describe as adaptation. *"Nurses are a relief and additional work at the same time"* (43). Caregivers know already beforehand or they recognize quite fast that the involvement of a nursing service not only implies to get the work at hand done in a way that was anticipated to be helpful. It also implies the need for caregivers to adapt to the new circumstances. They have to adapt to different people that enter their homes. They are usually not in a position to decide who is going to come to do the work and they have to adapt to different people. If they complain about the ever changing nurses, they are dependent on the willingness of the services' management to reorganise the schedule of the nurses and the availability of the individual nurses they favour for their particular situation.

In how far the adaptation is a problem for caregivers depends on their personal characteristics and on the options they have to change the situation. One caregiver states *"When you involve somebody external that automatically means negotiations and arguments and constant adaptation and you have to live with it. You have to adapt to the people and take them as they are"* (41). The dependency also exists when caregivers are in general satisfied with the work performed by nurses. One caregiver chose a particular nursing service for his situation, because this service also offers a short-term care facility and it was very easy when he needed to travel for two or three days to get his wife into short-term care. It was convenient for him and he felt on the safe side and furthermore this facility was close to where he lived. Because of economic considerations the nursing service decided to close the short-term care facility which implied for the caregiver to look for a new one. This increased his burden as he could not rely on the availability of a placement for his wife and he had to negotiate with two different services.

The most burdensome aspects of adaptation are the ever changing people and the timing of the nurses' visits. Having a particular number of nurses coming interchangeably is tolerated by caregivers, because they know very well that nurses have holidays, become sick and have to see to other people's needs at the same time. This number is mentioned to range from 3 to 7 different nurses that are tolerable. A caregiver reports having around 20 different nurses coming and could not stand it any more. The timing is important for caregivers to be able to keep their routines and to make their own plans. In addition many care recipients need their medication at a particular time and have preferences about when they want to get up, to have breakfast and the like.

The extent of caregiver adaptation depends on personal characteristics of what caregivers are able and willing to tolerate on the one hand and the options to change the situation on the other. Caregivers face competing demands and the higher their demands outside caregiving are, the less choices they have. A caregiver who has a full-time job needs to have an arrangement for his or her home care situation that is reliable at first. Even if the caregiver is not satisfied with the service provided by nurses it is a consideration, whether the change of the service would improve the situation and if there is hope of the situation getting any better. Caregivers are reluctant to change a nursing service, because they do not get a guarantee from anybody that things would improve. What they know for granted is that they will have to go through the whole adaptation process again. Finally, caregivers take into account that it is not only themselves who have to undergo the adaptation process, but the care recipients, too, and this involves additional concerns such as exposing the care recipient to even more strangers. If an arrangement is more or less stable, no matter on how low the level of stability is, caregivers are unlikely to threaten this stability by changing the nursing service.

Caregivers who do not have a full-time job commitment and whose competing demands are on a lower level have other options for their adaptation process. They are more free to change the service when they are dissatisfied.

Considering usefulness

The decision for the involvement of a nursing service is based on a process of considering the usefulness of such a step. Family caregivers consider different circumstances of their caregiving situation and evaluate if and to what extent the involvement of a nursing service is useful for them. Considering usefulness does not stop with the involvement, but it continues. If caregivers get the impression that the service is not useful any more then they may decide to cancel the service and look for alternative options that are helpful.

A main concern when considering usefulness are the preferences and characteristics of the care-recipient. Caregivers who believe that the care-recipients would not accept nurses helping them are unlikely to ask for the support of a nursing service. Non-acceptance may be related to physical body care, but also to the general fact of having strangers in one’s own home.

Caregivers are willing to accept additional problems caused by the involvement of a nursing service when the expectations they have towards the nurses are being fulfilled. This shows that it is not only the care-recipients’ perspective that is considered, but also that of the caregivers. Another fact that caregivers are aware of is that the nurses' time is quite limited and they have to consider if the service is somehow useful despite these limitations.

After the decision for involvement was made *considering usefulness* gets a different focus. Caregivers do thoroughly evaluate if their expectations are being met and if the nurses provide the service that was asked for. If the nurses for whatever reason cannot match the expectations the situation is unlikely to continue in the once established way. *"When I'm doing the work while the nurses are present then I don't need them. I don't need a nursing service for being watched while caring for my husband" (56).*

Assuming responsibility

Assuming responsibility involves the active acceptance and recognition that caregivers themselves are responsible for the planning, organising and performing of the caregiving process and the work it implies. They are concerned about the care recipients' well-being and make decisions that they consider supportive for the care recipient and their own ability to care.

Gaining expertise

Gaining expertise is a process that is always associated with caregiving. Caused by the need and motivation to care the caregivers have to achieve a particular level of expertise. They gain this expertise voluntarily or just by chance because of the permanent presence and involvement in the care recipients' needs. The process of gaining expertise may be a joyful or a frustrating one. Many caregivers actively seek for advice from the literature or from professionals such as their General Practitioners. Some caregivers really enjoy the process of learning something new. For many others it is a painstaking process as they experience a feeling of being left alone. *"If I had known beforehand what I do know now, things would have been easier."* (63).

Handling incontinence

Incontinence causes a range of problems for the caregivers in their daily life. Sometimes it is considered to be the most burdensome aspect of the caregiving process. From different perspectives the handling of incontinence determines to some extent the relationship to the formal care sector and influences the perception of the usefulness of a nursing service.

A particular problem reported by many caregivers is the fact that they involved a service with the expectation to get relief regarding their caregiving work, but actually did not get that

relief, because of the incontinence of the care-recipient. Incontinence does not match the times when the nurses are present and many caregivers find themselves in a situation where they either have to help the care-recipient after an 'accident' shortly before the nurses arrive or the 'accident' occurs just when the nurses left the house. Caregivers do not blame the nurses for this, because they know that this is simply bad luck, but they don't know why to pay a service when one of the most burdensome activities has to be performed by themselves.
Another aspect related to incontinence is that it either is the reason for involvement or the anticipated turning point when to involve a nursing service or it is not at all a reason for involvement. Caregivers who have not involved a service state that incontinence might be the turning point that would make them consider the involvement of external help. On the other hand other caregivers state that changing diapers would be no reason to ask for external help. Depending on individual characteristics the management of incontinence has an influence on the relationship and the involvement of a nursing service.

5.1.4 Managing caregiving – strategies of family caregivers

Within their caregiving situation family caregivers develop strategies of how to manage the process of *developing a fitting arrangement.* These management strategies are: *Sharing tasks and responsibilities, Emancipating oneself* and *Keeping options.*

Sharing tasks and responsibilities

The involvement of a nursing service can lead to a situation where family caregivers are able to share parts of their tasks and/or their responsibilities. Task sharing is basically related to the physical aspects of the caregiving process. Family caregivers get a helping hand from nurses or they completely hand over the body care to the nurses. Sharing or giving away tasks also involves medical aspects such as giving an injection. Sharing responsibility is more difficult as it requires trust in the nurses. It occurs when nurses have a key to the home and the caregiver relies upon the nurses' appropriate performance. Helping with important decisions is another aspect of sharing responsibility. Family caregivers ask nurses for advice and hope for helpful recommendations. To engage in a discussion with nurses on important aspects of the caregiving process is the beginning of sharing responsibilities. The question whether the responsibility is actually shared remains an individual impression.

Emancipating oneself

During the caregiving process and in the continuing relationship with nurses family caregivers learn to stand up for themselves. In the very beginning they usually had no idea that this could be an important strategy to manage the caregiving situation. Caregivers express the difficulties they have in learning to stand up for themselves. It starts on a rather low level with learning to resist particular recommendations of nurses and physicians or to resist them acting without involving the family caregivers. In these circumstances caregivers learn to insist on the provision of information, feedback and instruction. They put the professionals under pressure by stressing that they are the ones who know the care-recipient best and, what is even more important, they are the ones to do most of the work. Insisting on getting information and instruction occurs in terms of discussions, but it also occurs by caregivers showing permanent presence during the nurses' visits and by doing so, they emphasize their role in the caregiving process. Standing up for oneself is also expressed by claiming one's rights, where the rights are not anything like written laws, but the right of being respected and acting for a care-recipient who cannot do so her- or himself.

Learning to stand up for oneself is also related to other external people including administrators and insurance people and caregivers stress the importance to learn 'how to deal the officials' (52).

In some situations standing up for oneself is a result of experiencing harm by professionals against the caregivers themselves or against the care-recipient. Caregivers feel the need to express their wishes and perspectives to prevent any further harm for the care-recipient or themselves.

Caregivers who learned to stand up for themselves are very clear on what needs to be done in their very situation. They do not accept a bad performance from the nurses and they do not accept being the victims of the bad working conditions of the nurses.

Emancipating oneself results in the ability of family caregivers to determine the situation. This involves that they are the ones to determine what has to be done in what way and by whom. Concerning the relationship to nurses this implies the caregivers actively instructing the nurses on the activities to be performed. It also implies educating and advising the nurses, which particularly happens in a situation where family caregivers have become very knowledgeable on all aspects of care.

Keeping options

Many caregivers do not ask for the help of a professional nursing service and they are doing so for several reasons. The first reason is that they want to avoid constantly changing people in their homes. They anticipate problems involved in that and try to prevent such a situation.

A second reason is that caregivers see themselves in a position of having to instruct the nurses and that is something they either do not want to or do not feel confident to do. The third and most important aspect is that caregivers are used to help themselves and have difficulties in asking for external help.

Family caregivers develop new strategies when they feel the need or are urged to change their caregiving arrangement. When caregivers ask for external help they first have to learn to accept external help when they were used to do everything on their own.

Other caregivers move a step beyond that and choose different options. Because of a former disappointment with the professional services that were available to them they actively search for another solution which may be to employ somebody oneself. Three main reasons have been stated. The first is the disappointment with professional nursing services. Caregivers have cancelled the professional service for different reasons and searched for the employment of somebody on a private basis. The second reason is related to the inability of the professional service to match the actual needs of the caregiver and care-recipient. In this respect it is more the structural aspect that prevents the professional services to act according to the caregivers' wishes. The third reason for employing somebody oneself is to secure one's own freedom which is much easier, if the caregiver him- or herself determines the rules and minimises the need for negotiation and compromise.

Employing somebody oneself includes that family caregivers themselves set the criteria for the persons to come. Sometimes these persons were nurses, sometimes they had no nursing background, but were interested in caregiving work. A final strategy is to take care of oneself. Family caregivers limit their personal involvement which is expressed as 'I don't give everything' or 'I keep something for myself'.

5.1.5 Facilitating work and care - the goal of family caregivers

The efforts of family caregivers are aimed at the goal of *Facilitating work and care*. The process of *Developing a fitting arrangement,* which family caregivers actively perform is determined by the goal of *Facilitating work and care.*

The work aspect of *Facilitating work and care* accounts for the actual work that is involved in caregiving and which has to be managed by family caregivers. At the same time, family caregivers stress the care they provide and that they consider this to be very important. What good care means may differ in the various circumstances, but all caregivers have a particular idea about it. An overall aspect of *Facilitating work and care* is to protect and comfort the care-recipient. Family caregivers want to do the best for their sick relatives and try to save them from any threats from the outside world, be it by avoiding their exposure to strangers or by protecting them against actions from professionals that are not considered appropriate. Family caregivers' efforts are also related to enhance the quality of life of the care-recipients. Increasing quality of life refers to caregivers' efforts to achieve as much as possible for their relatives who suffer from dependency and illness. Caregivers have the idea that their efforts allow for a better quality of life of the care recipients. They know what they liked and what their preferences were and they try to reconstruct or rebuild some of it.

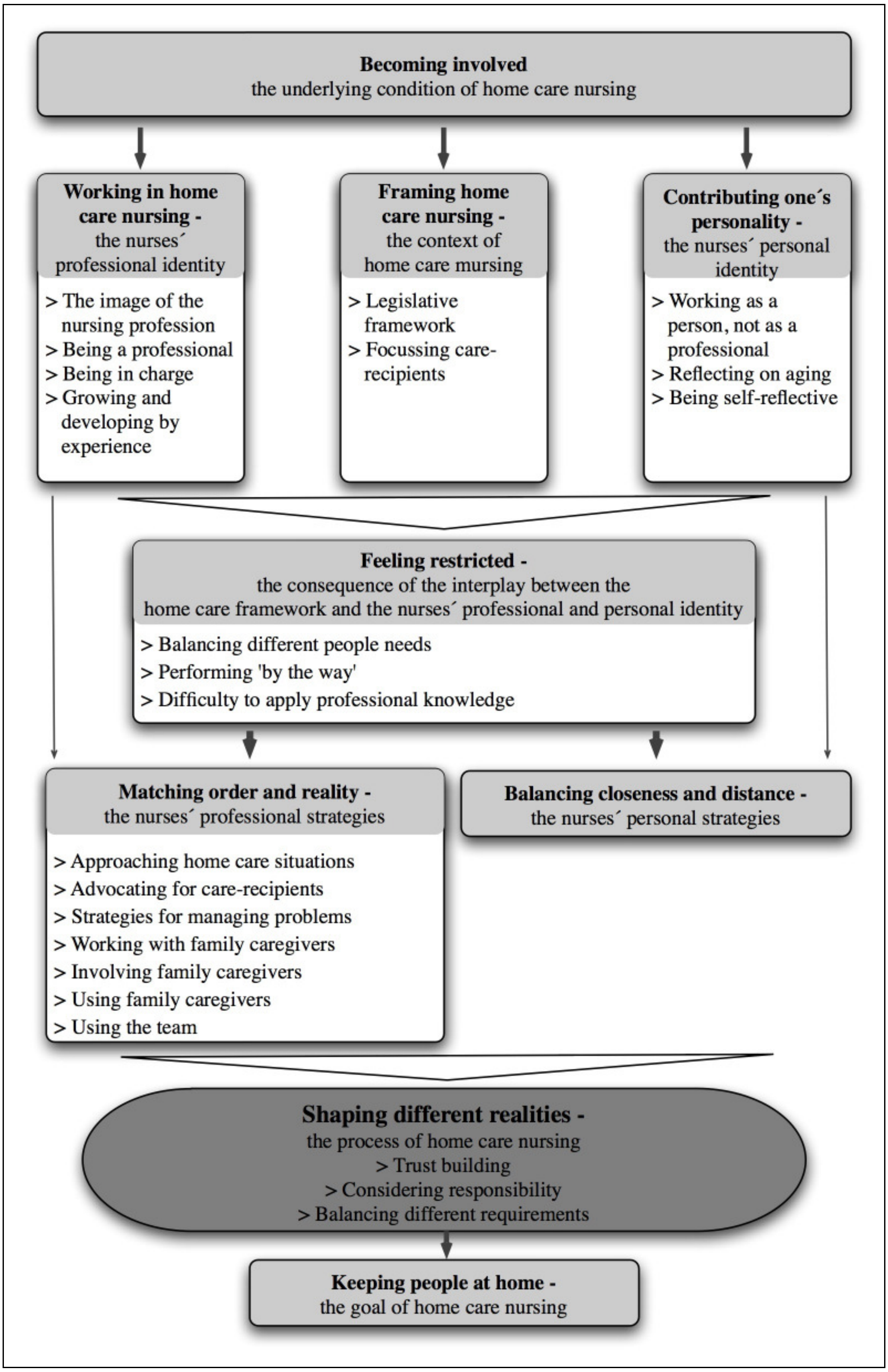
Facilitating work and care is the aim of the caregiving process no matter if a nursing service is involved or not. In addition to the factors that lead to the involvement of nursing services there is the clear expectation of family caregivers that the involvement helps in getting their work done and providing good care.

Family caregivers have more or less clear images of what they expect from nursing services or what would be helpful in their particular circumstances. Helping with decisions is an aspect that is much appreciated as it provides caregivers with the feeling of being able to share responsibility. The same is true for the aspects of providing a feeling of security, being companion and seeking reassurance. For all these expectations nurses can both serve as a real back-up and provide relief to caregivers to a large extent. Being calmed down by nurses also falls into this category.

The ability to talk to somebody and get an opportunity to share one's feelings and the burden of caregiving work is an expectation that is determined by the need for communication and interaction. Caregivers often lack this opportunity and nurses can provide relief in this area, too.

The final image of support is related to the practical and hands-on part of the caregiving work. Caregivers are grateful for practical hints and recommendations that help them to handle the daily requirements. This can be a recommendation to use particular lotions and soaps for skin caring, it can be hints on particular medical or assistive devices, it can involve particular techniques for transferring or mobilising the care-recipient and it can be related to general recommendations on the illness and care dependency.

5.2. Shaping different realities – the perspective of nurses on the relationship between formal and informal care



Graph 5.2. Concepts and their relationships of the nurses’ perspective on the relationship between formal and informal care

Becoming involved is an underlying condition of home care nursing. It is a prerequisite for the work of nurses in home care. Home care nursing is framed by three concepts: *Framing home care nursing* which conceptualizes the context and which contains the legislative framework of home care nursing. Beside *Framing home care* nursing, the nurses' professional identity (*Working in home care nursing)* and the nurses' personal identity (*Contributing one's own personality*) influence the nursing perspective. The interplay between the home care framework and the nurses' professional and personal identity results in the consequence of the nurses *Feeling restricted* in their practice. The core of the nurses' perspective is the process of *Shaping different realities.* The concept of *Feeling restricted* influences the process of *Shaping different realities.* According to their professional and personal identities nurses apply professional (*Matching order and reality*) and personal (*Balancing closeness and distance*) strategies to shape different realities. The goal of the process of home care nursing is *Keeping people at home*.

5.2.1 Becoming involved

Nurses consider their involvement in home care situations as a decision that is externally initiated. Family caregivers and care-recipients get an external hint that the involvement of a nursing service might be an option for their particular situation that could be helpful. Two patterns of these external hints are described. The first follows an acute event, e.g. an accident that results in a great or complete loss of the care-recipients abilities to care for him-/herself and the shock for the rest of the family network, primarily the spouses. Even if family members are willing to care for their sick relative an acute event usually calls for specialised treatment and procedures that they – in contrast to hospitals - are not able to provide. Therefore, they need to rely on the professionals, first of all on physicians and then subsequently on the nurses. The involvement of a nursing service is promoted by the discharge management from the hospitals. The discharge management has a great influence on the family caregivers' confidence to opt for home care. The option of getting external professional help from a nursing service may increase the likelihood of family caregivers becoming willing to accept and take on the responsibility for home care.

Factors outside the health care system also play an important role such as supportive comments by neighbours, friends or other family members. For family caregivers this is helpful because it decreases their fear of being blamed for not being a caring person for the spouse or the parents. Apart from emotional aspects financial implications also play a role.

The higher the amount of the costs covered by the long-term care or sickness insurance is the more likely people are to involve a service.

The second route to involvement is a slow process of family caregivers becoming overburdened by the continuous caregiving work they provide for their relatives. General practitioners play an important role in discussing the option of involving a nursing service to ease the caregivers' situation. Becoming overburdened is either a question of time, i.e. the longer the caregiving process lasts, the more likely caregivers are to become overburdened, or a question of the caregiving tasks becoming more difficult due to a slow deterioration of the care-recipients' condition. Becoming overburdened is a process that often is hidden from the outside world. Nurses find themselves in situations where caregivers are beyond the limits of physical and emotional exhaustion. Caregivers are becoming overburdened when they are convinced of being able to care in the beginning and then miss the point where external help, either for themselves or for care-recipients, would have been appropriate. As this point is highly individualised it is difficult to recognise it, particularly because caregivers often have nobody to accompany them in their work.

When families ask for external help they usually ask for a particular activity being performed which, for whatever reason, they cannot perform themselves. The request is not expressed in terms of asking explicitly for a nurse but rather for just 'somebody'.

The question of involvement is closely related to the question of cancelling a service. While cancelling a service actually is an exception there are many incidents where family caregivers and care-recipients change the pattern of the nurses' visits. This relates to the frequency or intensity of the visits or it is related to the activities being performed during the visits. A reason for changing the patterns of the nurses' visits is an increased self-confidence/confidence level on behalf of the caregivers. They have increased their caregiving abilities either by observation, by active education through the nurses or active insisting on being prepared.

Cancellation includes a change of the service. Nurses report that this happens only occasionally, because a new service means that the whole process of building trust and getting acquainted with new people starts all over again. This process is somehow a 'necessary evil' that needs to be undergone. The process of changing a service and initiating a new process of getting acquainted seems burdensome for caregivers and care recipients and that is why they are reluctant to take this step. They prefer trying to solve existing problems. *"Even if there is disagreement with the nurses for some people it is considered less burdensome to keep the nurses and the nursing service they know compared to involving a new one" (32).*

From the nurses' perspective high costs are stated as a reason for not becoming involved. They have the impression that in times of high unemployment many people are reluctant in spending money on a nursing service. They rather try to care on their own and use the cash benefits from the long-term care insurance.

5.2.2 Framing home care nursing

How nurses can shape different realities and contribute to the relationship between formal and informal care is determined by different factors. These factors are the context of home care nursing conceptualized as *Framing home care* nursing, the nurses' professional identity *Working in home care* nursing and the nurses' personal identity *Contributing one's own personality*. The context *Framing home care* nursing is outlined below, the nurses' professional and personal identities will be presented in the following chapters. Framing *home care nursing* consists of the *legislative framework* for home care and its resulting on *Focussing care-recipients*. The focus on the care-recipients is reflected in the nurses' professional approaches.

Legislative framework

The legislative framework is an important aspect of the nurses' everyday work. It consists of two parts: first, the legislative framework of nursing care delivery constituted by the long-term care (LTC) insurance and actualised by the contract between nursing care service and the care-recipient; second, its impact on the organisational culture of the home care nursing service and the organisation of everyday work.

Nurses have quite different viewpoints on the long-term care insurance. Some worked already before the introduction of the LTC in home care. From their point of view the new framework is responsible for their time-constraints and an increasing economisation of the home care environment.

The legislative framework is not described in detail by the nurses. It is more the effect of it that is their concern. The impact of the regulation on everyday practice has different appearances. For some nurses the contract between service and care-recipient provides a feeling of security: *"Normally we get a contract that is signed by the care-recipient and that allows us to come to his home and to give him a bath, for example. It is to ensure our work. So he cannot say, no, today I really do not feel like having a bath. It is to get us on the safe side." (14: 1249-1256).* The contract also serves as a means for preventing and/or solving conflicts between the nurses and the care-recipient or the family caregiver. This occurs when nurses perceive an expectation of them doing much more than it was agreed upon in the contract. Reference to the contract allows them to limit their availability to care-recipients and their relatives. It is also stressed that the contract accounts for transparency and the nurses as well as the care recipients have something to rely upon.

On the other hand the contract challenges the nurses when they, due to their professional expertise, perceive a greater need of the care-recipient that cannot be matched by them. This aspect is reflected on a broader level with regard to the legislative framework in general and the financial implications in particular. Nurses state the problems that arise because of the scarce resources that are spent on home care nursing and that are available for care-recipients.

"That is work at the assembly line, that is time clock and piece-work and that has nothing to do with nursing, nothing at all. It goes into the complete wrong direction (...). It's getting really dangerous. When we are old we will make the experience that somebody comes with a time clock saying: 'You have ten minutes, what do you want? Do you want to the toilet or do you want to eat?' I think that this unfortunately is the wrong direction, but I don't think that we can stop it, because there is less and less money for ever more older people." (11: 1095-1111).

Another aspect of the legislative framework is that nurses have to communicate the existing regulation and its consequences with care-recipients and caregivers. They consider this rather difficult as the main concern of the people is the crisis they are in and not the legislative and contractual details.

Within the nursing service the legislative framework is implemented by managerial orders on the daily performance that may cause a conflict between individual nurses and the nursing managers. The managers are in charge of organising the work of the nurses according to the different contracts with the care recipients. Usually this is done by compiling 'tours' for the individual nurses. These tours determine how much time the individual nurse has for one care-recipient and for the way to get from one to the next. Nurse managers have to attribute a particular amount of time to each of the care-recipients. The amount of time is determined by the contract.

Nurse managers use different approaches in their planning. How they handle it accounts for the organisational culture and for the challenges of the individual nurses. The different approaches of individual managers reflect their attitude towards the overall long-term care system and their managerial style. They can be characterised between the following two extremes: On the one hand managers who consider the legislative framework to be too strict, accept individual nurses' decisions to work more independently and give them a limited space for individual decisions. They know that the time allocated to individual situations is too short and that the performance packages, the care-in-kind-benefits from the LTC, are by far too limited to match the care-recipients' and caregivers' needs. On the other hand managers who do not think this way, want the nurses first and foremost to follow the plan and the tour and consider activities beyond that as the nurses' private business that is not subject of their employment contract and salary.

Nurses feel the permanent presence of what they call economisation and legal accountability in their everyday practice. This practice is strongly dependent on the managerial style. Nurses state difficulties when they go beyond the contract requirements and involve themselves as a person. The tour, the contract and the nursing manager are often criticised by nurses. This critique arises out of the aspects outlined above, but it also serves as a reason for problems that occur with care-recipients or family caregivers. The external framework may save or prevent the individual nurse from reflecting problems in the everyday work in terms of considering own failures or limits.

Focussing care-recipients

The nurses' perspective in home care is first and foremost focussed on the care recipients. They are the centre of the nurses' work and they are the ones on which the professional education is focussed. This is also reflected by the care-in-kind-benefits from the long-term care insurance. The involvement of a nursing service and the reimbursement of its services are related to services for the care-recipient exclusively. Care recipients are the ones who the nurses feel responsible for and whom they consider the main reason for their job. Care recipients in home care are considered to be different compared to patients in hospitals: "*For me it is not the illness that people have that is the main thing; it is something I have to keep in mind. I want to give them a feeling of being a human being. Not sick people, but a human being like you and me and that they have somebody to talk to on their concerns. So far I always made good experiences with this approach."(9: 34-42).*

5.2.3 Working in home care nursing – the nurses' professional identity

The second influencing aspect for *Shaping different realities* is the nurses' professional identity conceptualised as *Working in home care nursing*. On many aspects this identity was expressed in a very individualised way, however, some general categories express what nurses consider their professional identity. These categories are *the image of the nursing* *profession, being a professional, being in charge,* and *growing and developing expertise by experience.*

The image of the nursing profession

The nurses express their disappointment about the low image the nursing profession has in society and in the minds of many individuals. The low image is reflected in the scarce resources that are attributed to nursing care and results in the nurses feeling undervalued in the contribution they make. They have the impression that their work is being changed more and more into piece-work. The low image is also reflected by the non-willingness to pay for nursing care on part of the care-recipients and their families when the costs are beyond the amount that is covered by the insurances.

Questions of the image of the profession are not only an issue of the society and the nurses' clients. There are issues within the profession that cause different perspectives and viewpoints. There is an emphasis on the distinction between general nursing (which is related to more medical aspects) and elderly care nursing (related to more social aspects). Nurses with different educational backgrounds work together in home care. Coming from the hospital usually implies a stronger focus on the medical aspects of care, although some nurses actually went into home care nursing to put the caring aspect in the focus of their daily practice. Others describe themselves as 'physician' and admit difficulties in caring for care-recipients suffering from dementia or other mental illnesses.

The 'dirty' aspect of nursing care is a contributing factor of the low image of the nursing profession. A nurse reports statements from her friends who have the image of her handling human excrements all day and could not think of doing anything like this themselves. Among the nurses of a particular nursing service problems may arise when 'fine' nursing care (refers to tasks related to medical prescriptions) and 'dirty' nursing care (refers to aspects like incontinence, vomiting etc.) are not equally distributed in the different tours that nurses do every day.

Not all, but some nurses state that the low image of the profession also is reflected in their low salaries. Compensation for low image and low salary is provided by care-recipients and family caregivers. Everytime they express their gratefulness for the nurses' work this accounts for a personal good feeling in terms of one's own person and efforts being valued appropriately.

The image of the profession is also reflected by the perception of physicians. Even if there are only rare physical encounters between nurses and General Pracititioners (GPs) in home care nursing, for nurses conflicts with GPs are a matter of concern. The main source of conflict is a different assessment of the care-recipients actual condition. Nurses feel to be closer to the care-recipients than the physicians and they see the care-recipients on a regular, often daily basis. Therefore, they claim to know the actual condition and the needs of the care recipient better. They refer to their professional knowledge that allows them to judge about a particular condition. The problem is worsened by the fact that nurses feel a dependency from the physicians who are in charge of prescribing drugs or initiating other therapies such as physiotherapy. Another source of conflict is the different frequency with which nurses and physicians visit the care-recipients. Nurses have the impression that physicians do neither like home visits very much nor do they pay these visits regularly. This results in the nurses' feeling more competent and knowledgeable about the care-recipients and the family situation. Physicians are critisised for not taking into account the nurses' reports. Joint case conferences or even discussions do hardly take place.

The low image is finally reflected in the fact that nurses have the impression that sometimes they sit between all chairs and they are the ones who are asked to fill in the gaps that other people create. *"The relatives who maybe want the nurses to do more, because they want to step out a bit of the caregiving process or just get some relief. Between the physicians with whom you have the discussion about the prescriptions about what is going to be prescribed and is that sufficient. But as the person on the spot you maybe see that he needs more. And then between your employer. Actually you are sitting between all chairs." (18: 746-754)*

Being a professional

A wide range of expressions reflects what nurses consider important for *Being a professional*. They state their professional status and put their work into perspective. The nurses consider themselves in terms of professionalism, but have difficulties in determining what exactly that means. Being more knowledgable and competent than family members is assumed to be a part of being a professional. The image about what constitutes *being a professional* varies considerably, but centers around three main aspects: nursing tasks, good nursing care, and characteristics of home care nursing.

When asked about their work nurses refer to a great extent to the tasks they are doing, which include: Grundpflege (which means basically taking care of the care-recipients' personal hygiene); handling and taking care of medical prescriptions; applying medication; arranging for, informing about and using medical and assistive devices; domestic care (that is described as on the border between what a nurse or somebody else should do); counselling and advising on nutrition; incontinence care; and performing interventions for the prevention of pressure sores, thrombosis, and pneumonia.

Besides the description of the main tasks and activities performed by the nurses, they are concerned about the quality of their work. They have an image what good nursing care is and what they can achieve in home care situations. Having done something good to the care-recipient is part of good nursing care. Nurses feel satisfied, when the care-recipients are satisfied. To leave a home without anything left undone is an important part. Grooming activities that result in 'good looking patients' are mentioned as a part of good nursing care. 'Good looking' gives back dignity to the care-recipients and gives them a feeling of being respected as a human being. Promoting mobility is an aspect of good nursing care that has both mental and physical implications. Additional results of good nursing care include the recognition of the illness on part of the care-recipients, increased self-care abilities because of nursing care interventions, enhanced well-being, and motivating care-recipients to becoming more active. For elderly people living alone good nursing care also means being a bridge to the outside world. Nurses are aware of the fact that they themselves are often the only social contact these people have. With regard to family caregivers only one aspect of good nursing care is mentioned and it also involves the care recipients and that is 'sharing experiences from other home care situations'. By sharing experiences nurses believe to help family members to put their own situation in perspective, to know they are not alone, or to get an idea of what to expect in the near future.

The final aspect of '*being a professional*' is how nurses characterise home care nursing. The idea of home care is to work closely with people in their home environment and to use an interdisciplinary approach as indicated by the following quote: *"There are several points on the home care situation. First, there are positive things such as working together with the relatives positively as it should be. Working with the physicians to improve peoples' situation at home or even make their living at home possible at all so that they don't have to go to hospital or a nursing home. Well, but on the negative side it is not always like this of course. Relatives do not always collaborate and, what is a real shortcoming, the collaboration with GPs" (11: 5-18)*

Besides the general characteristics nurses state the problem of irregularities in their everyday routine that actually are no irregularities, because they occur regularly. They are more disturbances of the routine. It is not the 'if', but the 'how' that determines their appearance. Home care is characterised by the need to be aware of the whole environment which includes the care-recipient, family caregivers, physicians, custodians, neighbours. There is a need for communicating with all persons involved in the very environment.

Being a professional is also influenced by the individual educational backgrounds. Particularly nurses educated in elderly care stress their competence in working with the elderly and distance themselves from nursing care in hospitals and its technical aspects. As all nurses have been educated either as a general nurse in the hospital or as a nurse for elderly care primarily in nursing homes, they compare their actual work situation with their work in one of the institutionalised settings. The main distinctive feature is the individualisation of nurses in home care. It includes the need to work and to decide independently. Independent decisions in home care ask for reasoning abilities when decisions are questioned by care-recipients or family caregivers and unlike in institutions the nurse is alone. The individualisation implies the need to relying on oneself. In contrast to institutions there is a great need to improvise in home care. There is no institutional order and there is no stock of medication, devices and other material.

Individualisation does not only concern the individual nurse her- or himself, but also the interactive elements of home care. Nurses use terms of everyday live such as ‘nursing is like love’ to characterise their work. They are also aware of the important role of liking or not-liking a person that influences their performance and the outcome for care-recipients and caregivers. This is not just a one-way street, but it also works the other way round. Nurses stress differences between individual nurses, where some handle the requirements in a given situation better than others and where liking and not-liking a person also plays a role for care-recipients and family caregivers. An important aspect of this is to show consideration for the colleagues. Nurses know that they will not always be the ones responsible in particular situations. Either on weekends or during their vacation other nurses will be involved in these caregiving situations. Nurses know that when they have a good relationship with care-recipients and caregivers it may become difficult for their colleagues. One strategy to handle this situation is to prepare care-recipients and caregivers in time when the nurse will be replaced by a colleague. Another strategy is to limit one’s own commitment either in terms of frequency or in terms of intensity to limit the care-recipients’ and caregivers expectations’ towards colleagues.

Individualisation occurs also on the part of the caregivers. *“They are always focussed on those who were there first. Those who, so to speak, have contributed their personality (...) and it is important, because you don’t want, because you don’t want permanently new people in your house.” (9: 1355-1360.)* Individualisation also is an expression for the fact that relationships with care-recipients are special ones. *"For example, giving a shower. They didn't let everybody helping her taking a shower. And I browsed the wardrobe. I got her new clothes every day. Others were not allowed to look into her wardrobe." (13: 36-41)*

Beside individualisation home care nursing is characterised by establishing routines. Routines serve as a means of matching the time-constraints nurses have to face, but they also help in individual situations to build a relationship and becoming familiar with the care-recipient and/or family caregiver.

With regard to caregivers *being a professional* distinguishes the work of the nurses from those of the family caregivers. Nurses claim to have a professional perspective that caregivers don't have. *"What caregivers don't see at all. It's clear, because they are not used to it. They know the environment and don't recognize it. They only recognize what's there, not what's good for the patient" (14: 1561-1565).*

Being in charge

Being in charge refers to the general responsibility that nurses perceive in home care. The reason for being in charge is the professional competence and the authority for the nurses' actions from the contract.

There is a distinction between single-person and multi-person households. In the latter responsibility may be given away to family caregivers, but basically nurses consider themselves being in charge of the whole process. In single-person households nurses know that they do not have any control during their absence which increases the pressure they feel. Pressure is caused by care-recipients being at risk of low fluid intake, too high or too low blood sugar or confused patients who may be leaving the house and not finding their way back.

Being in charge is disturbed by demanding patients who always ask for more than it is agreed upon in the contract and interfering relatives who disturbe the nurses' professional routine. It is characterised by 'being afraid/feeling safe' in single-/multi-person households. It includes different levels of alertness and awareness of the nurses depending on the given situation in the homes.

Growing and developing expertise by experience

The nurses' statements on what they consider as their expertise differ. There is agreement that it includes the correct performance of particular nursing tasks. Nurses also feel that the correct performance of particular tasks is something that is expected from them by caregivers and care-recipients. Beyond that there seems to be no professional agreement, but different perspectives. For some nurses their expertise includes technical as well as emotional aspects. Home care nursing requires a different expertise compared to nursing care in hospitals and nursing homes. Home care nurses are more requested to prove their expertise while hospital nurses get it attributed or have better chances to work in a team that compensates individual weaknesses. The expertise develops over time which means that experience is a critical issue for developing expertise. Getting a feeling for the life stories of their clients and take it into account is an important feature of the expertise. One nurse states that it is important that nurses keep in mind that their everyday business is an existential and non-usual experience for caregivers. Actual performance is not only related to expertise, but also to the nurses' well-being. Concerning the idea of what is needed for nursing expertise one nurse includes knowledge about the LTC and assistive devices, an appropriate education, the provision of information and technical competence as important.

Interestingly, many nurses agree that many of their colleagues are not considered to be competent or, even worse, considered of being totally incompetent. This fact is explained by stating varying levels of expertise that individual nurses have. The longer nurses work in home care the more confident they are with their work. This subjective feeling results from how they approach their work and how they handle the different requirements of home care.

"In my early years hands-on care, particularly washing a patient, was my main focus. Meanwhile I feel more relaxed, I know about the differences and I don't have difficulties in leaving something out of the daily routine, when it doesn't do the care-recipient in his actual situation any good. (...) The more experience one has, the easier it is to accept that you have limits and the easier it is to negotiate the kind and intensity of care with the elderly themselves or their caregivers." (34).

Growing by experience is on the one hand a matter of years in home care and of the nurses' own age, but it also has other dimensions. One is the duration of the involvement in the caregiving process in the given home care situations. The longer a situation lasts the more nurses feel familiar with the care-recipients and caregivers and feel confident on their approach and performance.

A third dimension of growing by experience occurs when nurses themselves become caregivers. This helps them getting a broader perspective of the complexities involved in home care and it also helps in reflecting the professional role and professional contribution.

5.2.4 Contributing one's own personality – the nurses' personal identity

The third influencing factor for *Shaping different realities* is the nurses' personal identity conceptualized as *Contributing one's own personality.* Personal attitudes and characteristics of individual nurses have an impact on how nurses work in home care. The nurses' personal identity in home care embraces *working as a person, reflecting on aging,* and *being self-reflective.*

Working as a person, not a professional

Nurses want to be acknowledged and respected as a person by caregivers and care-recipients. They know that different nurses have different characteristics and that this is not easy for caregivers and care-recipients. Nevertheless nurses want to have their personality respected. When nurses become involved into a new situation with the objective of building a good relationship with the care-recipients and family caregivers they want to have this relationship on a mutual basis. If this is not possible for several reasons, nurses tend to hide most of their individual personality, put the formal part of their job in the main focus and act accordingly.

Reflecting on aging

Working in home care has a professional perspective and a personal perspective for the nurses. Being involved in a range of quite different home care situations and having to deal with and care for many care-recipients and family caregivers causes nurses to reflect on their own image of getting old. Being confronted with their patients they think of how their own age will be and they have a clear image what they do not want for themselves (being left alone and move to a nursing home).

Reflecting on aging not only concerns the individual perspective for their own age, but it also includes reflections on how society deals with the elderly. The scarce resources available for nursing care are considered according to what the elderly generation did for the society especially after World War II. Some nurses have the feeling that the life achievements of the elderly population and their contributions to the national welfare are neglected.

Complaints about their own work situation are put into perspective when reflecting on aging: *"When I'm feeling bad I'm telling myself to remember my patients and think about how they are. Then you have to say there are thousands of people who are worse than yourself. Every patient I visit is worse off than I am and I'm moaning. By making this clear to myself I feel better." (14: 2178-2187)*

A general positive attitude towards elderly people is something that many nurses express. They have respect for the elderly's lifetime achievements and the richness of their experiences. Often the care-recipients can tell the nurses a lot about history and their own role in World War II.

The concern about the nurses' own age is closely related to the fact that they know a lot about the elderly and feel sorry for them. But it is also other aspects, such as considering elderly people as cute and interesting. If nurses come too close to the care-recipients they need to find a way of not involving themselves too much, because on the one hand it would sooner or later result in having to disappoint somebody they like and on the other hand it would result in themselves having difficulties of distancing. Liking each other also has a mutual dimension when nurses feel treated like grandchildren of the elderly and show interest in a personal relationship.

Working in home care implicitly has a dimension of humour. Talking about life histories or particular events from the care-recipients' or the nurses' life can be very funny. The degree of sharing personal events increases the better the quality of the relationship is perceived. It also works the other way round. The better the relationship develops the more likely personal events are shared.

Being self-reflective

Being self-reflective concerns the nurses' reflection about their profession and about their job. It is related to their relationship with family caregivers and to the differences in the performance of individual nurses.

Concerning the relationship with caregivers a nurse who is self-reflective knows that what constitutes his or her everyday work reality is an exceptional situation for the caregivers. It implies the permanent presence of strangers and the adaptation to the new circumstances that may go far beyond the actual caregiving situation, but may also include limitations in the usual use of the flat or house, or limitations in particular habits that caregivers do not want to share with strangers.

Self reflection is also related to the reflection of their motivation to be a nurse. If structural aspects such as limitations in their options to act as they consider it appropriate accumulate with problems in the relationship to care-recipients and caregivers or with colleagues nurses ask themselves why they are doing this job and consider leaving the profession.

5.2.5 Feeling restricted – the consequence of the interplay between the home care framework and the nurses' professional and personal identity

All nurses report time-constraints in their everyday work. This results in a feeling of always having to hurry-up and being restricted in the professional performance. This feeling is an inner feeling that seldomly is expressed openly towards care-recipients and family caregivers. Feeling restricted is the consequence of the interplay of the legislative framework and the professional as well as personal ambitions and identities. For the work in peoples' homes *feeling restricted* involves: *balancing different people's needs, performing 'by the way'*, and *difficulty to apply professional knowledge.*

Balancing different people's needs

Balancing different people's needs occurs when care-recipients or caregivers ask for something that is not part of the daily routine and this takes longer than the usual visiting time. Incidents include the wish to talk to somebody, or preparation for special events such as birthdays in the family. *"...without the person opposite letting know or recognize, ups, I'm already late a few minutes. When you do your tour you have to stay with somebody for five minutes longer. And you have to save these five minutes at somebody else's home. As long as everything is in balance. It also depends on the need. If someone feels bad, I cannot leave him alone, because if he cries or becomes depressive or whatever. Or if he needs more emotional support while I'm busy with body care. That is different from day to day. You never know how the day will be (...)." (12: 363-380).*

Performing 'by the way'

Performing 'by the way' refers to the nurses' perception that many things have do be done at the same time. One nurse calls it 'efficient multi-tasking'. When physical care, talking, planning and arranging occur simultaneously nurses have the feeling that one or more activities are not in the focus of their attention and happen 'by the way'. *"Yes, it is by the way. It's just interpersonal, you know. It is just ticked of under interpersonal relationship" (11: 1682-1684).* Performing 'by the way' is OK for some nurses while others state that this way of working limits the possibilities for important talks with the care recipients or family caregivers. They see the 'by the way'-phenomenon closely related to the increased economisation of home care nursing where only those activities are accepted that are reimbursed by the insurances. A central criterion for labelling something as 'by the way' is that it is not subject of reimbursement by either the insurance or the care-recipients. *"...that you have an option of billing these talks differently or billing them at all. It is always asked* *for quality and all the paperwork for making everything ready for evaluation. I'm sure that all this has its relevance and I don't want to complain about it, but the patient and the caregiver get lost in this." (9: 125-133)*

Difficulty to apply professional knowledge

The third consequence of *feeling restricted* is the *difficulty to apply professional knowledge*. Nurses have the impression that with more time resources they could do more for the care-recipients, mostly in terms of physical care or medical-technical aspects. They detect incidents where their professional knowledge would do the care-recipient good and where they are not in a position to apply their knowledge and competence. *"Yes, that are, how to say, kind of the bad experiences in nursing. Where you think that actually you are educated and able to judge the situation, but actually you cannot change anything. And that makes you pissed off." (XI: 64-69)*

The intensity of *feeling restricted* has an impact on the dissatisfaction with the job in nursing, although nurses claim that despite the feeling of restriction they would do the best they can for care recipients and would not let them suffer.

5.2.6 Matching order and reality – the nurses' professional strategies

Nurses use different strategies for *Shaping different realities*. The strategies can be distinguished into professional and personal strategies. The professional strategies are conceptualised as *Matching order and reality* and are related to the home care situations in general (*Approaching home care situations, Advocating for care-recipients, Strategies for managing problems*), the work with family caregivers (*Involving family caregivers, using family caregivers*) and the nursing colleagues in the service (*Using the team*).

Approaching home care situations

Nurses use several approaches in home care. These approaches refer to general attitudes nurses need to have when working in home care, viewpoints on what they see as their role and tasks, and strategies on how to handle a situation.

Concerning these attitudes nurses have different ideas and the attitudes reflect a general idea about home care. Nurses know that flexibility is a key competence. They are aware that they need to adapt to different people and circumstances. When asked what they see as their role in home care nurses refer to aspects such as arranging what is necessary and to structure the caregiving process. To wash somebody is considered as a side effect of structuring the process by some nurses.

Other nurses put the relationship with and the work of the caregivers into the main focus. One nurse explains that considering oneself as the assistant of family caregivers and not vice versa helps a lot in home care. A nurse manager states that putting family caregivers in the main focus in the beginning of a process prevents problems later on. An important aspect of putting caregivers in the main focus is to be aware of family rules and family roles. Nurses ought to recognise these rules and roles and contribute to maintaining them. A strategy to get to know what is going on in a family is to make people tell their story. In general a proactive approach is considered to be the right way of establishing a relationship with caregivers that is sufficient.

But it is not always concern about the caregivers' situation that is reflected by these approaches. Another nurse states that making caregivers believe to be in control, but actually deciding herself is the art of home care nursing. This statement reflects an approach that seeks for the prevention of potential problems and smooth collaboration between nurses and caregivers lead by the nurses' expertise.

The basic need for home care nursing is an appropriate timing and planning that accounts for being able to serve the needs and preferences of many caregivers and care-recipients. Timing and planning is followed by the establishment of routines in each household that helps to serve the different needs.

Keeping privacy is considered to be important, because most nurses are aware that their visits for most care-recipients include a very intimate contact. Nurses try not to worsen this aspect by respecting peoples' feelings and property.

Home care nursing is not only related to people, but also to the surroundings in which these people live. Nurses are well aware that living arrangements and habits of the care-recipients and family caregivers influence their work. Habits include cleaning habits and ideas of personal hygiene. There is a need to balance the nurses' ideas with those of the caregivers and care-recipients and nurses engage in arguments to convince the care-recipients about changes when necessary. Taking care of living arrangements is at risk of colliding with keeping privacy.

Providing information on practical aspects of the caregiving process, on technical aspects of the care or on the illness and its course is rarely done actively by nurses. Either they state their time limits or they do not consider it to be their responsibility. Usually nurses are willing to provide information when they are explicitly asked for it. In addition, it is difficult to handle the provision of information. Nurses encounter caregivers who have spoken to several physicians, read a lot of books and articles and are very knowledgeable. For these caregivers nurses usually do not have much expertise at all or they would not rely on it.

Nurses try to create space and flexibility for care-recipients, caregivers and themselves. This involves to deviate from the routine fixed in the contract and to act according to individually changing needs. Mostly creating space and flexibility is related to time for talks and sharing concerns.

An advanced way of how to approach a situation is offered by a nursing service that often takes care for care-recipients for 24 hours. It explicitly awards the right to the caregivers to reject a person that was selected by the management. If caregivers have the impression that a nurse does not mach their expectations they have the right to ask for somebody else. The same applies to nurses who have the right to reject to work in a particular situation. Within this service a three month period is considered appropriate before the final decision is made which nurses are the right ones for this particular situation.

Advocating for care-recipients

In general, the job of a nurse in homecare is determined by an order to care for an individual care-recipient. This strongly reflects how most of the nurses see themselves and their role. They describe strong feelings for patients and see advocating as one of their roles. Advocating stems from the close relationship they have with the care-recipients. Advocating is related to the outside world in terms of claiming more attention and resources for the situation of the elderly. In this respect a congruence of interests between nurses and care-recipients is assumed. Advocating is also related to inner-family affairs when nurses get the impression that family caregivers do not care appropriately for the care-recipients. Therefore advocating involves the justification of their own role in terms of assuring continuity in home care.

Advocating also involves discussions with physicians on part of the care-recipients. *"With the patients it is a question of the generation of the elderly. They do not like speaking up for themselves. Usually they have the same GP for quite some time and they say, well, I cannot tell the physician what to do. It is still this old system. They do not dare saying anything (...) and they ask for my opinion and advice."(9: 640-649).*

Advocating is also closely related to the low image of the profession. Nurses consider themselves as allies of the care-recipients when it comes to the resources available for nursing care. They state that politicians do not know what is going on and therefore make the wrong decisions which in the following make nurses and care-recipients suffer.

Advocating becomes critical when nurses have the impression that the care or the behaviour of caregivers is not appropriate. This may include non-affectiveness, non-loving behaviour or even harmful behaviour on part of the caregivers. Nurses have only limited options for intervention in these situations. As long as they are present they can actively try to prevent such behaviour or try to discuss it with the caregivers. It depends on the experience of the nurse whether a clear communication on such problematic issues an be established. The previous experience of the nurse makes the difference between stepping out of such problems or actively tackling them.

Strategies for managing problems

Problems of different sources and kinds are a part of home care nursing. Nurses report problems that are related to the performance of procedures, problems with particular care-recipients and/or family caregivers on a personal level and problems about different judgements on the severity or intensity of particular aspects concerning the care-recipient. Problems may also be related to disturbances in the daily routine, be it in the professional nursing routine or in the daily routine of caregivers and care-recipients.

Nurses apply different problem-solving strategies which they put into a hierachy. The first strategy is a direct discussion with the care-recipients or caregivers. This strategy often is sufficient. If it doesn't work nurses summarise the problem and put it on record. The record in these instances is the nursing documentation system. Putting something on record serves as a means of covering oneself against potential complaints from caregivers, care-recipients, physicians or insurance companies. Putting something on record does not necessarily lead to a problem being solved. Rather it is a manifestation of the problem where nurses on the one hand and family caregivers and care-recipients on the other hand have their standpoint and are not willing to find a compromise. Depending on the perception of the severity of the problem it is put on record and the situation continues with a disagreement on a particular aspect, or the next step of the problem-solving hierarchy is applied and that is the involvement of the nurse manager. This step implies that nurses see no way of solving the problem on their own. There is no singular reason why they cannot do so. Potential problems that result in the involvement of the nurse manager range from personal antipathy over the outburst of a latent conflict to disagreement over competencies. Nurses withdraw from the conflict and hand it over to their managers, which are considered a higher authority. They can act from a more neutral perspective and have not been involved in the everyday struggle that happened before they got involved. The involvement of the nurse manager is not automatically a guarantee for solving the problem, but it may initiate a problem-solving approach such as re-arranging the tour, sending another nurse in the particular household, meeting with care-recipient and caregiver for a discussion of the problem, or trying to convince the families about medical or technical aspects of the caregiving process. The involvement of the nurse manager may also lead to a cancellation of the contract on part of the nursing care service.

Working with family caregivers

Nursing interventions that are explicitly directed towards family caregivers do hardly occur, if at all. Nurses are not educated in this way, these interventions are not asked from them (in terms of these services being reimbursed) and sometimes they are not appreciated by their management. Only some nurses and nurse managers stress the importance of interventions for caregivers. Either they stress the importance to strengthen the caregivers' capabilities in order to stabilise the whole caregiving process or they stress the importance in terms of accepting the caregivers as persons with problems in their own right.

Nurses, particularly nurse managers, who know about the concerns and the importance of caregivers put them more in the focus. This is reflected by them instructing young nurses to consider themselves as the caregivers' assistants and not the other way round. In this context these nurses stress the importance of assessing the relatives' competence and willingness to contribute to the caregiving process. They consider this to be important because only by knowing about the relatives they can determine their own role, be it the caregivers' assistant, be it a partner to them or be it the person taking over responsibility. Basically, the work with family caregivers is described as *involving family caregivers* or *using family caregivers.*

Involving family caregivers

When working in home care situations nurses speak of involving family caregivers as a central part of what they do. Involving family caregivers is focussed on the care of the care-recipient. Nurses explain to family caregivers what they do and why they do it. By doing so they try to raise the caregivers' confidence and encourage them to actively commit to the caregiving process. Another aspect of involving is instructing and educating caregivers on very practical issues. This is also done for purposes of encouraging caregivers. It takes into account that the nurses' presence is limited to a few hours in the course of the day. Involving family caregivers may be the beginning of a good caregiving partnership between nurses and caregivers. This is especially true when joint decision-making takes place and both seek for agreements. In a positive sense involving family caregivers leads to a reliance on the caregivers from the nurses' perspective and into an active exchange of information about the caregiving process.

Some nurses involve family caregivers as a strategy for providing better care to care-recipients in case the care-recipients are reluctant to accept help or are not willing to be convinced by the nurses. Involving family caregivers is a way of finding an appropriate communication strategy with the aim of performing nursing care in a particular way.

When nurses have the feeling that caregivers do not contribute to the caregiving process as they are supposed to, they try to get them to work or even push them to work. This includes an active request of being helped in the daily procedures. It also includes asking caregivers to take care for a sufficient supply of drugs and material.

Using family caregivers

Different from *Involving family caregivers* is the strategy of using them. Nurses acknowledge the important role relatives can play in supporting the caregiving process in general, but actually they refer more to their own part in it. They use caregivers as resources in terms of providing information about the care-recipient or organising drugs and devices. Using family caregivers is perceived as a positive aspect even if nurses consider them in a particular situation to be interfering.

Some nurses take it for granted that they can use family caregivers. *"If I have to tell relatives over and over again that we are running out of the ointment and I write it down for them – the paper remains unread on the table and I have to write it down again. Well, it is, if the collaboration with relatives is not very good then it is difficult, at least for me it is difficult. (...) If it does not work out with the relatives, for me it is important that my patients are cared for properly and if relatives do not go along with it, I take care of it myself and they pay for it. I put it on the bill. I just write down 'administrative arrangements' or 'visit to physician' and I'm not discussing it any more. For me it is important that my patients are cared for." (15: 593-614).*

Using the team

Within nursing services there are quite different approaches of working as a team. While from some services it is reported that there are no team meetings at all and everything is subject of the individual nurse or eventually the nurse in collaboration with the manager, in other services there are regular team meetings where individual cases or particular problems are being discussed. In general, nurses and nurse managers working in a service with regular team meetings seem to be more sensitive as far as caregiver problems are concerned. These services have an active interest in matching peoples' needs with their services.

Despite working basically on their own in peoples' homes nurses stress the importance of the team. No matter if there are regular team meetings or not, individual colleagues or the team as a whole help to assess particular situations, they provide opportunities to reflect on the work and they serve as means for exchanging and getting hints on how to solve problems or how to handle particular activities. Discussing in the team is considered to be easier than reading a book.

5.2.7 Balancing closeness and distance – the nurses' personal strategies

As mentioned above a professional and a personal identity that influences *Shaping different realities* can be distinguished. Accordingly, apart from the professional strategies of *Matching order and reality* there are personal strategies that are applied by nurses on a very individualised level. The personal strategies are summarised by the concept of *Balancing closeness and distance*.

Involving/distancing oneself describes the everyday struggle of nurses concerning what they call personal involvement. To some extent they are all somehow involved personally in the home care situations. Personal involvement is related to personal feelings for the care-recipients or sometimes even for caregivers. These feelings arise out of personal circumstances in which the care-recipients live, difficulties they have to face due to their illness, sad family histories or simply feelings of liking each other. Personal feelings may also be a result of *reflecting on aging*. Personal involvement embraces all activities that go beyond what is fixed in the contract. This includes taking time for listening to care-recipients, arranging for food or medication, helping with small things in the household, and sometimes sharing a great deal of the nurses' own personal life.

Apart from any professionally or externally determined criteria some nurses work according to 'I try to care for them as I myself would like being cared for' and are aware that this involves different ideas of different nurses and is not always reflected in the legislative framework.

An aspect of involving oneself is to touch the care-recipients. Especially for elderly people living alone a human touch provides warmth and closeness. *"...well, and sometimes it is important to hold somebody's hand or to hug somebody, so they recognize that somebody is really close, because they live alone and don't see much more than their four walls and have a sad view when looking out of the window." (10: 298-305).*

In situations where there is no family or no single relative taking care for the care-recipient nurses find themselves in a situation where they try to compensate for the lacking family. *"With older people who lived with their family or who had good contact to their family it was easier. With them I could give something away. It was clear who is doing the laundry, who is going to the grocery store and on Sundays she was going out of the house for a walk. With Miss G. I always had to plan half an hour or an hour extra when I wanted to take her for a walk." (17: 149-156).*

Depending on their degree of sympathy for the older people living alone nurses feel under pressure of easing their situation and they usually have no back up for this. It is their own decision that, in the worst case, is not considered part of their job by the management, but their own business that is not subject of their salaries or working time. Although they know that they definitely cannot replace the whole family, nurses fight an inner conflict on the intensity of the relationship to their care-recipients and its consequences.

Some nurses work after the official end of their work. They feel responsible for particular care-recipients or feel sorry for them and use their leisure time to do something for them. Doing extra work is not only a matter of responsibility, but it also is a matter of liking somebody or not. If nurses do not like particular care-recipients, they are unlikely to spend some of their leisure time.

Personal involvement causes the need to distance oneself from the work and the particular home care situations, which is not always successful. It is a burden on the nurses' families and relationships. It also causes problems in terms of time-constraints and increasing expectations on part of the care-recipients and caregivers. Especially when they feel sympathy for somebody it is hard for nurses to limit their time and availability, because of their other job obligations.

Different strategies are applied to limit personal involvement. One of these is reference to the contract that allows for a professional distance in case of demanding patients and problems. Another strategy is giving varying time to varying people in the tour interchangeably. On the one day the nurse stays for a couple of minutes longer with one care-recipient and the other day the nurse takes five minutes more for somebody else. Distancing oneself is on the one hand an emotional activity, but it is also supported by structural factors such as changing tours at the weekend which implies to see other people or to have a break from the daily routine.

An important personal strategy concerns the beginning of a new home care situation. Nurses describe various ways on how to start their job in a new environment. They have in common that in the beginning they try to assess what is going on in people's homes. This assessment is not done in any formal way, but is highly individualised. High emphasis is put on the nurses' personality. *"...well, and by means of my own personality, I'm usually quite relaxed and funny and I try to make them laughing and by doing so the relationship develops in a positive way in the long run. They treat me with trust and ask questions that touch my personal life, but they also share some of their personal life such as their last will or how they handle their finances" (9: 56-67).* Activities for getting started include being able to listen, showing interest, being curious and learning about habits.

5.2.8 Shaping different realities – the process of home care nursing

The basic social process of home care nursing is that of *Shaping different realities*. It is influenced by the personal and professional identities and strategies of nurses, by the *Framing of home care nursing* and the underlying goal of *Keeping people at home*. *Shaping different realities* includes sub-processes that will be outlined on the following pages: *Trust building, Considering responsibility* and *Balancing different requirements*.

Trust building

Trust building is stated by nurses as one of the key aspects of home care nursing. Without trust between nurses and family caregivers or nurses and care-recipients the whole caregiving process is at risk of failing. A feeling of trust is a prerequisite for good nursing care.

There is no single way of how trust is built. While some nurses state that it is a 'feeling' and a spontaneous approach, others look specifically for behavioral patterns of patients and families and try to trace cues of care-recipients and caregivers to get an idea of their attitudes and their concerns. There is a wide agreement among nurses that the beginning of a situation is critical for trust building. If for whatever reason the beginning is characterised by misunderstandings or, even worse, disagreements and arguments, it is hard to build trust and to establish a sufficient caregiving relationship on it.

Nurses describe a general mutual understanding on what needs to be done in a particular situation as a reinforcing factor for trust building. Such a mutual understanding helps focussing on the important aspects of care. Apart from a mutual understanding joint attitudes concerning the care-recipients' needs, the performance of particular actions and the way of communicating the caregiving issues is helpful in building trust. Joint attitudes beyond the caregiving process on various aspects of life are another reinforcing factor as it accounts for a good relationship between the nurse and the care-recipient or the nurse and the family caregiver. Mutual understanding and joint attitudes to a large extent are factors related to the personal characteristics of the persons involved. For nurses in addition to the personal characteristics the following professional characteristics are important which are summarised by one nurse as openness, reliability, ability for listening and taking care.

Apart from the personal aspects nurses try to apply different strategies for trust building. The first strategy is to talk to the care-recipients and caregivers while performing caregiving tasks. Usually nurses talk to their clients during the work, but as a strategy it involves to create an atmosphere that allows for trust building. Another strategy is that of arranging for time that is devoted to talk to caregivers. This may occur before caring for the care-recipient or afterwards and it usually implies some kind of small rituals such as drinking a cup of coffee or smoking a cigarette. For nurses an active observing of what's going on in the households is part of all trust building activities. Observing helps getting to know caregivers and care-recipients. It also helps understanding their concerns and their perspectives. This knowledge serves two purposes: On the one hand it helps to adapt to the situation at hand and on the other hand it helps to prevent inappropriate actions.

Despite the difficulties in explaining how trust building occurs nurses are clear on the aspects that prevent trust building or erode trust. The first is not to keep promises that have been made. The second is related to privacy of family caregivers. Nurses need to be careful not to cross the borders of privacy which is not always easy. A manager specifies this aspect by stating that nurses should be careful not to come too close to family affairs, because this is considered an intrusion into a sphere that is none of the nurses' business. A third aspect that prevents trust building is the use of inappropriate terms when communicating with care-recipients or caregivers such as 'don't make such a fuss and get up'.

The way to and the strategies for trust building from the nurses' perspective are also expressed in terms of balancing closeness and distance. Coming too close to people is at risk of crossing borders and keeping a distance may be considered as not being interested and a lack of social competence.

Trust building depends on the care-recipients and caregivers as well. They are the ones to decide if trust building happens and with whom it happens. *"Other patients cry with my colleagues and this one does it when I'm there. That's always different. I mean, it's the patients themselves who decide with whom they can do that." (13: 133-139)*

Trust building is not only a question between nurses and caregivers or nurses and care-recipients. It also is a matter of trust among the family members. Where nurses are involved in a household and the family members obviously trust each other and know how important trust is, it is easier for nurses to be trusted or to trust the family members.

Building a relationship is based on trust and trust is built on the experience of caregivers and care-recipients that the care is provided competently and in the same way each time and takes into account their personal preferences. The challenge for nurses is to take conversations seriously and remember what was discussed and agreed upon. It also implies to remember life histories that have been shared. When care-recipients and caregivers recognise that their concerns and their sharing have been taken seriously this shows them being accepted as a person and it contributes to trust building. Working as a team with caregivers also contributes to a good relationship. Working as a team means both working on an equal level and both viewpoints being considered equally. Working as a team is also described by working in partnership.

Home care nursing from the nursing perspective involves relationships to people. Their work moves beyond a compilation of tasks and involves getting to know the people they are working with. *"Well, a talk is communication and that is the only thing that ought to happen between people anyway. And if I'm to work with somebody very intimately and see him regularly on a daily basis without having any personal relationship that wouldn't make sense to me. Just to wash somebody or to care somehow wouldn't make sense to me." (9: 389-400)*

Getting to know each other also involves that particular problems are best discussed with the nurse who is primarily responsible. Talks about how to handle incontinence for example need a lot of trust to the person one talks to.

The impact of the relationship is taken seriously by nurses: *"If you visit somebody every day without building a relationship you can ruin a lot. The whole independence of patients. If you say, well, I'm washing your back and your feet myself, because this is faster and then I'm out faster, because the time and the next patient is waiting already. Eventually this leads to patients loosing their independence (...) and that is something one doesn't want. You want to keep the patient independent for as long as possible and this is only possible by building a relationship and motivating the patient, which only works when you know how to motivate him" (10: 816-833)*

For the building of a relationship continuity is an important factor. Nurses who work part-time or get different tours regularly state that it is quite difficult for them to engage in a relationship with family caregivers. They are not too familiar with the circumstances in the different households and usually try to maintain the rules and procedures of their colleagues even if they do not fully agree with them. Working part-time includes that being accepted by family caregivers and care-recipients takes some more time.

Considering responsibility

Responsibility occurs differently for nurses and nurse managers. Managers feel responsible beyond the time nurses spend in the families' homes, but their responsibility is not too much related to all the aspects of the direct caregiving process. For the management responsibility starts before the actual caregiving process in terms of appropriate negotiation and planning and it continues after it in terms of being on call and taking care of emergencies. Even if the managements' responsibility is beyond the actual nurses' visit, it is limited, e.g. when the care-recipient falls. The service only can try to detect risks and act accordingly, but never can take full responsibility.

Responsibility also depends on the caregivers' willingness or eagerness to share responsibility or give it away. The more medically oriented the caregiving process is the more likely is a higher responsibility of the nurses. Responsibility is more attributed to them. Another factor for higher responsibility on behalf of the nurses is the frequency of visits. The more visits the nurse pays the more responsibility she needs to take.

For individual nurses responsibility implies their actual visit. Their responsibility is limited to that. Beyond their visit they have to detect and report risk factors, either to the management or to the physician. Nurses state clearly the responsibility that physicians have and that this is not always taken seriously. What makes the nurses' responsibility difficult is their limited scope of practice. They can only negotiate and recommend, but they could, for example, never initiate a referral to a hospital, they could only initiate a GP visit or care-recipients actively calling for a GP.

Responsibility never is clearly defined. It gets difficult when there is a different understanding, e.g. there are care-recipients who would not want an ambulance in case of a deterioration of their condition and it becomes difficult if individual nurses cannot stand this situation. Another difficulty concerns a situation when nurses give recommendations, but people do not accept them. Even if this is put on record, it leaves an inconvenient feeling. *"The extent of responsibility implies an around-the-clock-service. It includes risk assessment and clarification of the issues between the people involved. The limit is when I'm not in the house and people act against the recommendations I have given" (57)*

A final aspect of responsibility is the statement that especially children of care recipients move their responsibility to a larger extent on nurses than would be appropriate. Nurses often are willing to help, but get themselves into trouble when they do not recognise early enough that too much responsibility is something they cannot bear.

Balancing different requirements

Balancing different requirements refers to the various demands in different households that nurses visit during their tour. It is closely related to the different types of family caregivers and their preferences, best described by the dichotomy 'those keeping control' and 'those relying on professionals'.

Especially in the beginning nurses have difficulties determining how to approach the situation. The balance they need to keep is a balance between asking the caregivers and care-recipients too much, as this might be perceived as an indicator of incompetence, and giving clear instructions and orders, which might be perceived as an inappropriate action in other people's home or as an intrusion into a longstanding family life. Nurses also describe their role of being a guest as difficult, because they are usually not invited as any other guest, but because of a particular kind of expertise and expectation that is attributed to them.

Some nurses consider family caregivers who take the initiative as an advantage in a particular situation as they set the scene in which the nurse has to operate. Caregivers acting like this save the nurse from the need for balancing and seeking for the appropriate approach.

Balancing different requirements also includes handling different perspectives of the caregiving situation. Differing perspectives are a source of conflict. Mostly differences arise when neither nurses nor caregivers try to understand their opposites' viewpoint. Differing perspectives are likely to occur when nurses think too strong in technical and professional categories, meaning that they apply their technical knowledge without considering the individual circumstances.

5.2.9 Keeping people at home – the goal of home care

The process of *Shaping different realities* is actualised by a request to become involved in a particular situation. Despite the differences in the individual situations nurses express a common goal that they contribute to the process and try to achieve in their work. This goal is conceptualized as *Keeping people at home*.

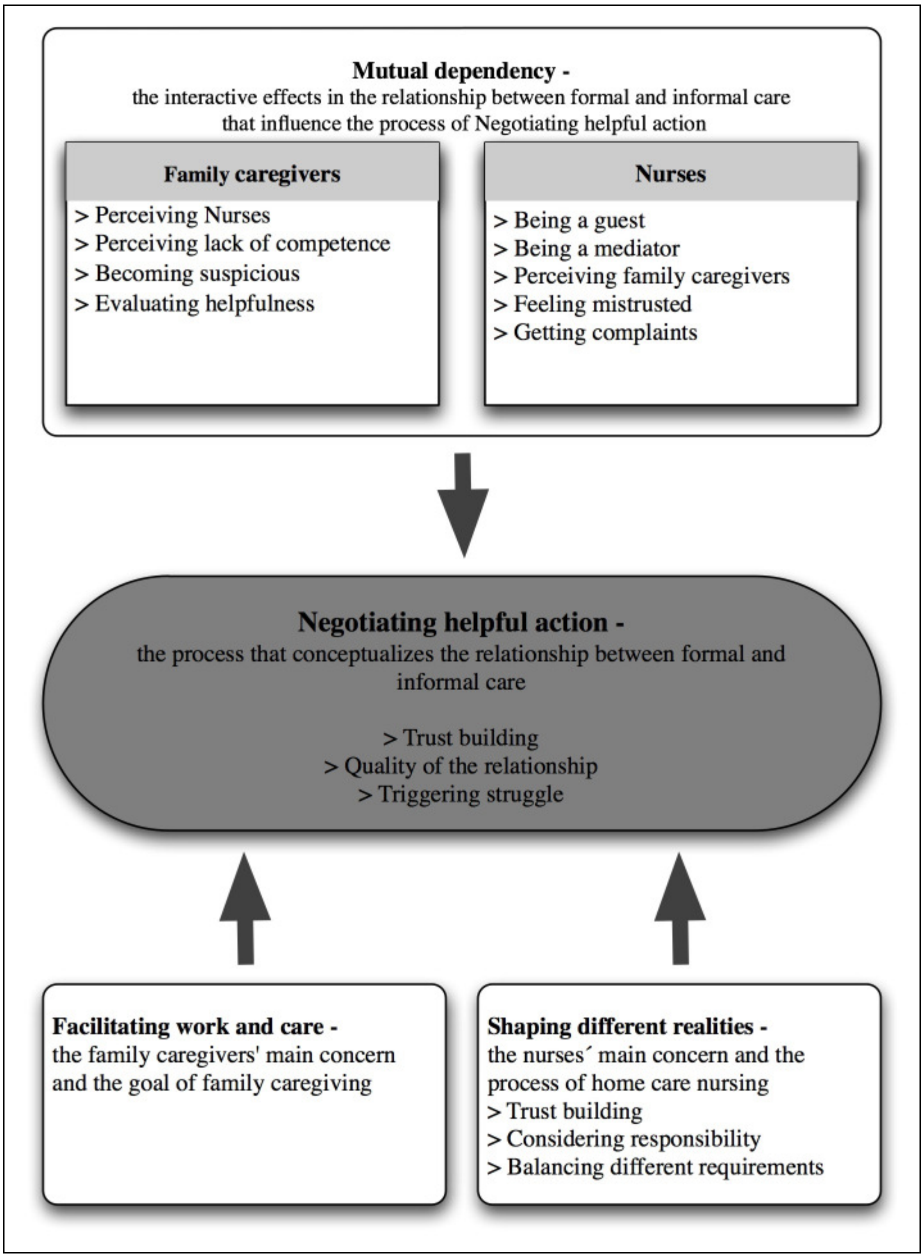
Keeping people at home conceptualizes what nurses consider as their main contribution to home care situations. There is a common agreement among nurses that if they would not be involved in the home care situations of their daily tour, many people would have to move to nursing homes or they simply would be neglected and forgotten. *Keeping people at home* is also considered as the actual expertise that nurses have. It is a key element of their professionalism.

Keeping people at home is done by several means and to a great extent these means are related to family caregivers and not only to care-recipients. The provision of relief is a means of keeping people at home. Providing relief is related to caregivers and care-recipients as well. It includes relief concerning responsibility, uncertainty, arrangements and organisation. Nurses see themselves in a position of being able to help care-recipients and caregivers to ease their situation. Relief concerning responsibility means that nurses can offer support in particular decisions and convey caregivers a feeling of being not alone. Relief of uncertainty concerns the knowledge nurses have and that might be helpful in anticipating possible events in the future and preparing for them. Relief concerning arrangements and organisation is also related to the knowledge nurses have. It includes the activities nurses perform. It can occur in terms of task sharing and providing family caregivers with a feeling of not having to do everything on their own or it can occur in terms of advising on how to organise the caregiving process.

Nurses know that keeping people at home strongly depends on family caregivers and are therefore aware that providing relief primarily needs to be directed towards them. In addition to providing relief nurses consider contributing to the caregivers' confidence as an important aspect. Confidence in one's own abilities is quite helpful when assuming responsibility for a caregiving process. Sometimes caregivers lack this confidence and nurses can achieve a lot in this area. Affirmation of the caregivers' actions, instruction on particular activities and general counselling activities are part of contributing to the caregivers confidence.

5.3 Negotiating helpful action – the relationship between formal and informal care

The relationship between formal and informal care is conceptualized by a process of *Negotiating helpful action.* Graph 5.3. provides an overview of the substantive theory of *Negotiating helpful action*.



Graph 5.3. The process of Negotiating helpful action that determines the relationship between formal and informal care including the family caregivers' and the nurses' perspective

Nurses contribute to this process by *Shaping different realities* and for family caregivers the process is focussed on the goal of *Facilitating work and care.* Nurses and family caregivers are engaged in the same process, but they do so according to different backgrounds. For family caregivers it is the uniqueness of their particular caregiving situation that determines their efforts in *Negotiating helpful action*. For nurses, on the other hand, there are various situations in which they are involved and they have to negotiate within different realities. *Negotiating helpful action* is influenced by various interactive effects in the encounter between nurses and families that are both conceptualised as *Mutual dependency*. This interaction is actualised differently from the nurses' and the family caregivers' perspective.

5.3.1 Negotiating helpful action

The negotiation process is determined by a particular need that is determined by the family caregivers' life circumstances and the condition of the care-recipient. From the nurses' perspective it is determined by the professional context that is based on a legislative framework and the professional and personal identity of the nurses. Nurses and family caregivers have to manage a variety of requirements, but for both these requirements are actualised in a different way. The encounter of nurses and family caregivers is focussed on how a particular type and amount of caregiving work is performed by means that are considered to be helpful.

The type and the amount of caregiving work needs to be negotiated between nurses and family caregivers. The contract between the nursing service and the families serves as a written agreement on the type and the amount of caregiving work, but the contract is by no means exclusive. Nurses as well as family caregivers know that their encounter and their relationship goes beyond the written agreement on particular tasks. The type and amount of work includes not only the individual task, but it includes the way of how a task is performed, the time that is needed for the tasks and the manner in which the time spend together is perceived.

Family caregivers and/or care-recipients are the ones who decide if there will be a relationship between formal and informal care at all, because they decide whether a nursing service is to be involved in their very situation. As soon as the decision for the involvement of a nursing service has been made, family caregivers face the dependency from individual nurses, from professional attitudes, from particular schedules and from other aspects. But finally they are the ones who decide if and to what extent the process between formal and informal care is considered to be helpful and if it is to be continued. Helpfulness serves as the core criterion for evaluating the process. Nurses and family caregivers not always agree on what type of action is helpful. For family caregivers the helpfulness is evaluated according to their indvidual situation. For nurses helpfulness is primarily based on their professional assessment of the situation. The family caregivers actually determine what is considered to be helpful. Different dimensions of *Negotiating helpful action* are *Trust building*, the *Quality of the* relationship and *Triggering struggle.*

Trust building

The main aspect that characterises a good relationship between family caregivers and nurses is mutual trust. It is considered to be a prerequisite for successful negotiations of helpful action. If nurses and caregivers managed to build trust between each other, it is most likely that the relationship contributes to performing caregiving work in a way that is satisfying, helpful and sufficient for everyone involved including the care recipient. Many caregivers and nurses report such good relationships and the core criterion has always been to trust each other, which is seen as one of the key aspects of home care.

There is a joint agreement between caregivers and nurses that for establishing trust the beginning of the caregiving process after the involvement of a nursing service is crucial. Nurses stress that in the beginning the process of trust building needs time and they try to take this time as far as their schedule allows for it. While some nurses state that it is a feeling and see it as a spontaneous approach which depends on sympathy or affection, others look for specific behavioral patterns of caregivers and care recipients and try to trace cues on how the relationship will develop. While there is a general agreement that personal characteristics contribute to trust building, nurses and caregivers both state that it is not only a matter of liking each other personally.

Caregivers stress that for them reliability on the nurses is crucial. They need to feel safe when the nurses care for the care recipient, they need to have the feeling that the nurses are competent in what they are doing. In addition, for caregivers trust evolves from them being acknowledged as a person in their own right including their efforts, their competence, their concerns and their roles. *"It is unbelievable how many stupid people you meet when you care for somebody at home. It was a hard time finding professionals, nurses as well as therapists, with whom everything fits. Everything seems easy now, because there is a mutual understanding of what needs to be done in what way. We don't even have to talk about it. It just happens and we talk to each other as people on the same level"* (78).

Because caregivers know about the time constraints of the nurses, they try to arrange for space and opportunities to talk to each other. Talking about caregiving, but also about other aspects in life is a means of building trust. For caregivers this implies that they are valued as persons in their own right and not just in relation to the care recipients.

Nurses report different approaches of how they try to build trust between caregivers, care recipients and themselves. As they know and feel their own time constraints and the competing demands in their job, one strategy is to try to involve the caregivers in a chat while caring for the care recipient. This strategy may be successful if caregivers take the offer and involve themselves in the chat, too. The strategy also implies the risk that caregivers get the impression of nurses not caring appropriately for the care recipient, because they spend their time chatting and are not doing what they are supposed to do.

Another nurse reports the difficulty he has in the beginning of a caregivíng situation. *"It is difficult to find the right balance. On the one hand I want to make caregivers tell their story and learn about their ideas of how the caregiving work should be done and this may result in caregivers thinking that I'm not competent to decide on my own what is right to do. On the other hand, if I'm too direct and give orders or make new suggestions, caregivers might feel not respected well enough and think that this is not appropriate, because I'm actually a guest in their house."*(49)

One way of building trust is described by nurses as *"balancing closeness and distance"* (85). They are well aware that they intrude in the caregivers' privacy and that people react differently to this. Nurses always have to find out how to best approach the situation. A nurse manager says that it is important *"not coming too close to family affairs and not crossing the borders of privacy. This is very difficult as sometimes just a word can be taken as an assault or can be considered as being none of the nurses' business"* (82).

Joint attitudes concerning the caregiving process and sometimes even beyond it help in building trust, although they are not a necessary prerequisite, because most nurses and caregivers do not want to build a personal relationship. Actually joint attitudes are not that important as long as the caregiving work is done sufficiently.

Another nurse manager states her strategy as *"openness, reliability, listening and taking care"* (49). She tries to be open to the situation and to the people she encounters. She is well aware that she needs to be reliable if caregivers and care recipients are to trust her. Listening involves an interest in people's fears and concerns. It shows that the nurse is not just doing a job, but is also interested in the people with whom or for whom she is doing the job. Finally taking care refers to the need to not just perform a professional routine, but to apply professional competence to an individual situation.

Another concept for describing trust is that of *familiarity*. Familiarity is perceived when trust building was successful and caregivers and nurses work together in a longstanding caregiving process. Familiarity is achieved when *"there is trust, teamwork, partnership and agreements* *are made and kept by all involved"* (57). In addition familiarity involves that caregivers, care recipients and nurses know what to expect from each other. *"Knowing what to expect can be considered as a value in itself"*(32).

Trust building is strongly dependent on how the relationship between nurses and caregivers develops in the beginning. Nevertheless it is not necessarily and exclusively related to the beginning of the encounter. A high impact on trust building is made by caregivers and nurses mastering particular crises together. If a nurse recognises a deterioration in the state of the care recipient and takes the appropriate action such as changing the position, calling an ambulance, or administering medication appropriately this contributes to the caregivers' gaining trust in the nurses' ability to provide appropriate care and be a real help in the individual situation. A nurse describes how she established trust with the parents of a child she was caring for. The family lived in a very rural area with almost no neighbours close. While the nurse was caring for the child one evening the energy system broke down and the nurse and the family were sitting in complete darkness. The nurse stayed calm and helped with finding candles and matches and finally she managed together with the parents to make the light working again. This event served as a means of being able to trust each other.

Mutual acknowledgement is stated by family caregivers and nurses as well as an important factor for a sustainable und sufficient relationship and for working in partnership to care for the care-recipient. From the nurses' perspective mutual acknowledgement is reflected in terms of acknowledment of the caregivers' expertise in their particular caregiving situation and seeking for working in partnership. It includes the assessment of the caregivers' competence to determine the sharing of tasks and responsibilities in the caregiving process.

Acknowledgment is a really mutual aspect. *"It is important to acknowledge the competence of the caregivers and to have one's own competence acknowledged, because this prevents any possible power struggle in the future" (82).* This quote implies that mutual acknowledgment occurs because of different purposes. One purpose is the general attitude of the importance of each others work just for the sake of itself. The next is a more instrumental perspective that calls for acknowledgement in order to prevent possible problems and finally acknowledgement has something to do with the nurses' own feeling of being respected. This is important as nurses feel their efforts and themselves respected as a person and not just as a professional. Particularly for nurses who are or have been caregivers themselves this aspect is important and they spend a great effort on telling their nursing colleagues what family caregiving is like and that nurses need to take this into account.

But also from the caregivers' perspective mutual acknowledgment serves different purposes. Receiving positive feedback from either nurses or physicians provides a reassuring feeling and may contribute to a higher or stronger confidence level. The instrumental perspective of mutual acknowledgment is reflected by the following statement of a caregiver: *"Professionals need to recognise that you care, then they care, too" (64).* Despite the general agreement on the importance of mutual acknowledgement caregivers have the impression that for many nurses there are difficulties in accepting the importance of the caregivers work.

Nurses and caregivers both agree that the best way of handling problems is to address them properly. This involves establishing a way of communication that allows everybody to express concerns. Both have made the experience that if problems have not been addressed immediately they may become even much bigger than they have been in the first place. Beside timeliness the manner by which problems are addressed is important. As soon as one party has the feeling that a problem is addressed as a personal affair or is addressed by using accusations the situation becomes difficult. Repeatedly caregivers call for a direct discussion on the problem. Everything that is hidden makes matters worse.

Caregivers also made the experience that to address a problem properly increases the likelihood of receiving an appropriate service. From the nurses' perspective it is important to keep addressing a particular problem in case they have detected a particular need which is not accepted by care-recipients or caregivers. Addressing this disagreement where and when it occurs serves in the end all parties better than transferring the problem to the management.

The quality of the relationship between family caregivers and nurses

The quality of this relationship is more important for the caregivers than it is for the nurses as they are the ones who have to live in the caregiving situation and have to find their way of how to handle it. For nurses the quality of the relationship has a high importance, too, but no matter if it is a good or a bad relationship, it is a part of their job and they have several options for compensating all kinds of experiences. Nurses have to act within various relationships of different quality and they lead their usual life when they are not on duty. This aspect distinguishes the perspectives and the importance of the quality of the relationship between caregivers and nurses.

Relationship in relation to the care recipient

The quality of *Negotiating helpful action* depends to a large extent on the work provided for and performed with the care recipient. For caregivers their sick family members' well-being and quality of life is in the centre of the whole caregiving process. Even if caregivers have the impression that something of the nurses' performance is not as it is supposed to be, they may hold back their critique in order to protect the care recipient. Expressing complaints and addressing problems is an issue of how far this might put the care recipient at risk for receiving bad care or receiving no care at all. But caregivers also learn to stand up for their family member when they have the impression of their care not being appropriate. *"I know well that the working conditions for nurses are not very good, but that does not give them the right to excuse a bad performance on my husband. If they have complaints they should direct it to the right places and I will join them in their protests, but I will not allow them blaming my husband for it."*(69)

If nurses and caregivers do not agree on what is best for the care recipient this is a potential source of conflict and contributes to struggle concerning the question of who best advocates for the care recipient and who acts in his or her best interest. This struggle develops from different backgrounds. One background is the difference between the professionally and privately defined need of the care recipient. There might be serious differences between caregivers and nurses. This difference often concerns the nurses' professional understanding and their claim to have the expertise. Another source of this conflict is the fact that caregivers do not admit that particular problems actually exist such as bad nutrition of the care recipient, prevention of mobilisation by caregivers or even violence towards the care recipient from the family caregivers. One nurse describes that sometimes the emotions of caregivers for the care recipients are particularly problematic as they prevent the care recipient from receiving the freedom that would be necessary to improve his or her condition and the nurse considers it her responsibility to act as advocat for the patient.

Problematic relationships between formal and informal care are characterised by the caregivers' not feeling safe or even being afraid for the care recipient to be harmed by the nurses. The consequence for caregivers out of this is that they can take no time out for themselves as they feel under pressure to protect their family member against bad influences and bad performances that may result in a serious deterioration of an already weak status.

Relationship on a personal level

Although caregivers and nurses initially do not explicitly want to engage themselves in a personal relationship the reality is that the process of *Negotiating helpful action* also has a personal note. *"These relationships are rarely just professional ones"* (44). Most nurses and caregivers are aware of this fact and try to act accordingly. This implies that mutual respect as human beings is very important.

A nurse manager states that the personal relationship can be a key aspect of the whole situation becoming a satisfying or a problematic one. *"We always take the first three months as a test phase. It needs some time for people to get used to each other. (...) If it does not work on a personal level then we try to involve another nurse in the team. Everybody has the right to reject a person just for personal reasons and this is true for caregivers, patients and nurses as well."* (82). Another nurse manager is well aware that there are many personal things going on between nurses and caregivers that are beyond the scope of his influence and that he does not try to interfere with. *"I know well that nurses and caregivers or patients have their little secrets. There are particular households where they have their coffee and their cigarette and take their time for a chat. I call this their little secrets and as far as I'm concerned I think they should keep their little secrets."* (32)

The relationship on the personal level can turn out into a strength or weakness of the caregiving situation. Positive personal ties and emotions for each other may ease the caregiving work. But when the relationship becomes emotional that may be a serious problem as disagreements will have to be discussed on a personal level and not on a technical level and that threatens the caregiving process becoming or remaining sufficient.

The personal level of the relationship finally involves personal likes and dislikes. This includes a particular way of dressing or behaviour. Caregivers stated that they personally do not like smoking and had difficulties with nurses smelling of cigarettes. Others had problems with too many earrings or piercings of nurses. The personal taste concerning clothing or other things has an influence on the personal level of the relationship, but it was considered to be of low importance.

Characteristics of a bad relationship

A bad relationship between formal and informal care is not as easily described as stating simply the absence of trust. The absence of trust does not necessarily mean a bad relationship. A bad relationship is characterised by permanent arguments and conflicts. The characteristics of bad relationships are more related to the caregivers' point of view. Nurses reported aspects of bad relationships, too, but these experiences did not have the impact on the caregiving process which had the experiences of the caregivers.

For caregivers a bad relationship starts with themselves *becoming suspicious*. *Becoming suspicious* occurs because caregivers get the impression that there is something wrong with the service provided or the individual nurse (see below).

Becoming suspicious also occurs when caregivers have the feeling that nurses hide something. This may be done openly by closing the door when the caregiver wants to enter the room or not openly when caregivers suspect something being wrong (such as a diaper hadn't been changed, the amount of food was not enough, the intimate care was not thorough enough). A daughter reported that bruises on the mother's arm have been explained by the nurses with the mothers bad blood coagulation status. By consulting her physician she found out after a test that the information was not true and that the bruises probably were the results of nurses treating the mother in a rude way. Such events or even to suspect that such events have occured are a shock for family caregivers and it is hardly impossible to get their trust again.

On a more general level family caregivers report that sometimes the professional routine causes problems. The professional routine refers to nurses coming in, not saying a word, doing a piece of work that they can do interchangeably for many care recipients and that is not focussed on the individual care recipient that they are actually treating and finally leaving the house. This professional routine, as caregivers label it, is a disappointment and raises doubts about the anticipated helpfulness of nurses.

Nurses who are unable to accept the caregivers with their concerns may cause a conflict. *"When I complained about some nurses to the management, I was accused of spying the next day"* (74). In another instance the complaints of a caregiver about the performance resulted in her being accused and criticised of being overburdened by the situation. A caregiver who suffered from a bad relationship for several month concluded her experiences with nurses as *"they are so arrogant, they always claim for understanding of their needs, but they never give anything back (...) I wanted to publish my experiences after my mother's death but I couldn't. I was just lucky when it was all over."*(58).

A possible explanation for relationships becoming that worse is provided by a caregiver: *"Problems with nurses arise from peanuts of everyday life, but the caring experience for relatives is everyday life and that's why the peanuts are becoming so important."*(35) For caregivers it was difficult to describe when the bad relationships really started. It is the accumulation of small things or peanuts, how they are called by the caregiver cited above, that turns a relationship into a bad one. A caregiver who is a nurse by profession concludes: *"It is the simple things that made me assess that the service caring for my mother-in-law isn't a good one"* (71).

Triggering struggle

In home care situations where the relationship between nurses and family caregivers is problematic or even worse family caregivers explain this development as a process that was triggered by particular events. There is no clear time frame matched to the triggering of struggle. Often it happens in the very beginning, but it also can develop after a longer period of caring together.

A trigger of struggle are the bills that caregivers receive on a monthly basis from the nursing service and that they need to sign before they are submitted to the insurances for reimbursement. When caregivers have the impression that things are on the bill that have not been done then they want an explanation. Depending on how such a request is handled the problem may be solved or it is the beginning of a struggle. A situation like this may cause distrust on part of the caregivers and them becoming more alert. In the worst case the struggle about bills can result in the accusation of betrayal or the caregivers being left with a feeling of being betrayed.

Complaints are another source of struggle. When there is a reason for complaint caregivers do so. First the complaint is expressed to the nurse, but often the complaint is directly addressed to the management of the service. Depending on how the complaint is handled it is determined if a complaint triggers a longer struggle or not. Caregivers report positive and negative experiences in this respect. When their complaints are taken seriously and they either get a sufficient explanation or their particular problem is being solved soon, then the affair is over. But caregivers also report that their complaints have not being taken seriously and that they were given responses which made the problem worse. Some caregivers made the experience that the management confronted them with an either – or – perspective, meaning that caregivers were given the choice between accepting the performance of the service or the individual nurse as it is or their contract with the service being cancelled. This poses a considerable threat for caregivers, because they would be the ones to undergo the process of getting acquainted to another service and the nurses working for it again, and there is no guarantee at all for them of the situation becoming any better. A special aspect of problems with bills is when caregivers realise that they have been billed for things that they thought would just be a nice gesture of the nurses, such as taking the rubbish down the stairs when leaving. Incidents like this may be the beginning of a struggle, but first and foremost they cause disappointment and they may be the beginning of trust being undermined.

Being threatened or being accused is not only related to bills and complaints. Sometimes it occurs on a lower level during the daily visits of the nurses. Caregivers report that the daily professional routine, e.g. the focus of technical aspects of care and the pretention of competence without engaging in conversation and without willingness of listening or even following what the caregivers are saying, causes problems. Caregivers feel neglected and not respected as a person and this triggers struggle. It is a big effort for caregivers to resist and to address the problem, because they feel how dependent they are on the nurses. The more competing demands caregivers have the stronger the dependency is.

The decision to change a nursing service or not for whatever reason is an individual decision. Despite the highly individualised process some common aspects characterise the decision to change or to keep the service.

Changing the service in general is not very difficult in terms of availability of an alternative. There are many nursing services available and family caregivers mostly have a great chance of getting somebody immediately. Those who have changed the service state that keeping to the schedule as it was agreed upon as the main reason which is important for them.

Caregivers who have thought of changing the service, but actually have never done so, report their reasons more detailed and on a different level. One reason not to change the service is that special arrangements have been made with the service which fit the caregivers' needs and therefore caregivers accept problems that have occured. One caregiver reports on a just-in-case-option that was agreed upon if his wife needed incontinence care.

The main reason for not changing the service is the expectation that the situation would not get any better. Caregivers had to learn that several services are on the market and that it is not easy to receive solid information on what to expect. No matter how difficult the situation is with a particular service at least the caregivers know what to expect. In addition, caregivers are required to undergo the process of getting acquainted to the nurses again and many are reluctant or even desillusioned about the possibilities that a new service might bring about.

The reasons for cancelling a service once involved are very clear and easy. It is a negative result of the process of considering usefulness or it is a situation where the service does not provide what it was asked for or what was agreed upon beforehand.

5.3.2 Mutual dependency

The process of *Negotiating helpful action* is strongly influenced by different interactive effects in the relationship between formal and informal care that are conceptualized as *Mutual dependency*. This is true for the nurses' and the family caregivers' perspective, but for both this *Mutual dependency* occurs differently. For family caregivers it contains *Perceiving Nurses, Perceiving lack of competence, Becoming suspicious* and *Evaluating helpfulness.* For nurses it contains *Being a guest, Being a mediator, Perceiving family caregivers, Feeling mistrusted* and *Getting complaints.* On the following pages *Mutual dependency* is first presented form the family caregivers' perspective.

Perceiving nurses

The way family caregivers and nurses perceive each other has a strong influence on the relationship between formal and informal care and on the way the caregiving work is performed. Perceiving each other is described by caregivers in positive as well as in negative terms. Beside this kind of judgement perception there is also a structural dimension of perceiving each other.

The negative perception is described very broad and general as well as in very detailed terms. On the broader level caregivers have a negative perception when they get the impression that nurses feel under control and act without considering the caregivers' viewpoint. This type of negative perception prevents a good relationship, but does allow for a sufficient caregiving work. The same is true when caregivers feel that nurses do not have family caregivers on their minds, but only focus the care-recipient. *"They cared excellently for my mother, but they never had a word for me" (65).* This leaves caregivers feeling disappointed, but it is still sufficient for continuing the caregiving work with the nurses. Helpfulness is at risk when caregivers perceive nurses working against them and a power struggle is about to start.

The situation becomes even more problematic if caregivers have a negative perception in terms of competence and reliability of the nurses. A cumulation of negative incidents, even small ones, that were not expected undermines the caregivers' trust in the nurses and their abilities. A situation like this becomes even worse if nurses pretend their own sovereignty over the situation, but at the same time prove that they are not able to handle it appropriately.

The most negative perception is expressed by caregivers as follows: *"It is unbelievable how often you have to meet stupid people when caring for a family member" (78)* or *"The nurses were so arrogant, they always claimed understanding for their own concerns, but they never gave anything back (...) They cared for my mother as if she was a piece of meat" (58).* Statements like these stem from situations that have become a severe problem for the caregivers and sometimes also for the care-recipients. A factor contributing to such a situation is the behaviour of individual nurses or a group of nurses from the same service. Caregivers reported a range of incidents in which they were not prepared for the inappropriate behaviour of nurses including not cleaning shoes when entering the house, feeding the care-recipients without heating up the food, dipping a cream cheese sandwich into malt beer, shouting and being rude to care-recipients, declaring caregivers of being stupid, lying to caregivers and openly refusing to help the caregiver despite being explicitly asked for it. Incidents like these were reported in several interviews.

But family caregivers also report a very positive perception of nurses. The positive perception concerns the efforts that nurses spend on the care of individual patients and it is related to the individual way in which they provide the care including the individual pace and taking into account the individual preferences. Another caregiver expressed it as the high standards that some nurses set for themselves. A positive perception includes that family caregivers consider the nursing service to be a relief in their situation. Feeling relieved concerns technical as well as emotional aspects of the burden. The usefulness of professional services compared to informal helpers is actualised by the fact that the professionals have to take care that somebody comes and does the work, even in case of bad weather, in case of illness or other difficult circumstances and this serves as a relief for caregivers.

A feeling of security is also described as a good outcome of the work of the nurses. Family caregivers get a feeling of security when the nurses' involvement stabilises the situation. Other positive interactive effects are the appreciation of family caregivers for the nurses' work when they feel that the nurses respond to their very needs and when they feel that their own efforts are appreciated by the nurses.

A final aspect of a positive perception is the 'just-in-case' option. Caregivers appreciate if nursing services provide them with a telephone number just-in-case. This provides a feeling of security. Especially for caregivers who had to use this phone number and actually received the help they needed this raises trust and increases the appreciation of the nurses and the nursing service.

A positive perception can result in caregivers arranging space, time and talks with nurses. This occurs when caregivers acknowledge the nurses' time constraints and try to do their bit to make life easier for both, caregiver and nurses. Creating space basically concerns having time to talk to each other. For caregivers this is a change to the everyday conversation about caregiving and the care-recipient. It allows for getting to know something from the outside world, it serves as a means of sharing one's own concerns and it helps getting to know the nurses better as individual persons. Caregivers know that also for the nurses the possibility to have a break is something they like.

For some caregivers the perception does not stop on the individual level, it also has a structural dimension. Involving a nursing service or being in hospital with their sick relatives often is the first contact they ever had with nurses in practice and they start thinking about the situation of the nursing profession. A common issue is the lack of time that caregivers perceive from the nurses. They get the feeling that nursing work is always under time pressure and this does not allow for talks any more. Caregivers are concerned about the bad working conditions and sometimes call for a societal effort to strengthen the nursing profession. They do not see themselves in a position of initiating such an effort, but many would join it.

Perceiving lack of competence

In contrast to the perception described above a lack of competence is perceived. Family caregivers report a range of incidents where they perceived or experienced a lack of competence on behalf of the nurses. The lack of competence is described in several ways.

The first aspect concerns the nurses' social competence. Caregivers state that many nurses don't have an idea about the situation in the families and what it feels like to care for somebody at home. From their point of view there is a lack of person-centredness from the nurses which implies the application of general techniques and procedures without taking individual preferences into account. This aspect is also described as 'running short of social competence' or 'nurses lacking communicative competencies'. The perception of low social competence is also reflected by the experience of nurses being too medically oriented and the nurses' focus being too much on the physical aspects rather than on the social aspects of the caregiving situation.

Beside the social aspect, family caregivers also expressed concerns about the nurses' technical competence. These statements ranged from general doubts if there is a competence at all to very detailed statements on nurses who weren't able to handle particular devices such as mattresses for the prevention of pressure sores or nutritional pumps. Especially family caregivers who gained a lot of expertise themselves complain about the technical competence. They see nurses applying the wrong techniques when caring for the care recipients and they also express disappointment about nurses who have not learned anything new over time. The experience of inadequate technical competence causes disappointment and mistrust on behalf of the caregivers, but it may also cause serious problems for the care-recipient. Incidents reported included nurses using a wheelchair to transfer a care-recipient rather than activating her, which caused a medium-term immobility and it included the non-detection of stroke symptoms that prevented a timely beginning of the treatment.

In general terms the lack of competence is described as an inability to react adequately to changing needs or as missing theoretical background. Caregivers suspect a lack of competence when nurses do not know what to do in a particular situation. They also stated that a lack of competence is sometimes hidden behind tolerance. Tolerance serves as a means of not revealing that one does not have a clue on what needs to be done in a particular situation.

Another source of perceiving a lack of competence occurs if caregivers experience that the only difference between the nurses' work and their own work is the time when it takes place. On the one hand this gives them confidence in their own caregiving abilities. On the other hand it causes doubts about the role and expertise of nurses and the question comes up if the nurses are of any real help in this particular situation.

The final aspect of perceiving a lack of competence is the experience that procedures and activities have not been performed accurately. A caregiver who is quite disappointed about the nurses' performance states: *"They completely ignore particular needs, they do not provide proper care and they do not provide thorough intimate care for my wife." (67)* Other caregivers experienced inappropriate performance in terms of finger nails not being cleaned, difficulties in changing diapers without making a mess with the bed linen and the like. This aspect is related to very basic technical aspects of nursing care.

Becoming suspicious

Becoming suspicious occurs when family caregivers get the impression that something is not right or is not as it is supposed to be. *Becoming suspicious* occurs when caregivers have the feeling that the bill they receive from the nursing service by the end of the month lists activities that they have not received or have not recognised.

Caregivers also become suspicious regarding individual nurses when they detect failures in the daily performance. This may happen on a very broad level such as the care-recipient being scared, but it may also happen if the body care was not performed appropriately, e.g. finger nails not being clean. Another incident that causes *becoming suspicious* is when utensils were not cleaned or put back into the place where they belong by the nurses.

Becoming suspicious is always related to particular experiences that caregivers made with nurses or nursing services. It can happen in the very beginning of a caregiving situation, but it can also occur after a longer period. The individual background of the caregiver is an important aspect of *becoming suspicious*. Aspects of power struggle between formal and informal care may be part of *becoming suspicious*. One caregiver states that she becomes suspicious every time when nurses stress their professional competence or their professional status. This is because in her experience every time when professionalism was claimed this implied that a discussion was not wanted and nurses felt somehow mistrusted or undervalued or simply could not admit that they did not know how to do a particular activity or were afraid of admitting a mistake.

Becoming suspicious is closely related to doubts about professional competence. It is also related to considering usefulness and it may be related to protecting and comforting of the care-recipient. If caregivers have the impression that things are hidden from them, they become suspicious. Hiding concerns any problems during the care provision of the nurses. It is related to observations of the care-recipients health status, it is related to the accurateness of the nursing tasks, and it is related to openness in communication, meaning that nurses need to communicate when there are deviations from the daily routine, either in terms of time or in terms of persons. *"Problems arise out of the peanuts of everyday life, but caring is everyday life and that's why the peanuts are so important" (35)*

Evaluating helpfulness

A wife caring for her husband decided to reduce the frequency of the nurses' visits. *"I developed a particular procedure of washing my husband in the morning and performing his physiotherapy. The visit of the nurse often only lasted an hour while I needed almost three hours. The nurses were dedicated to their work and they were very nice, but it was not helpful for me, so I decided to reduce their visits from once a day to once a week to help me with bathing my husband. The service arranged for a strong male nurse who helped me transferring my husband into the bathtub and getting him out and that was fine with me".* (66).

Helpfulness is evaluated in very practical terms and according to the caregivers' and care-recipients' preferences. Some caregivers state the limited range of services that are available. *"My brother-in-law does not accept somebody else except my wife and myself and it would be helpful if nursing services would offer something such as establishing contact and becoming familiar with the patients. That would help."*(81). The evaluation of helpfulness occurs before the decision of the involvement of a nursing service or after the decision was made and the service turned out not to be helpful in the expected range. *"I have an expectation when I ask for external help and I want this expectation to be addressed. I don't mind instructing nurses on what to do, but I don't need somebody looking at me while I'm doing the work myself."*(56).

When it becomes obvious that the nurses competencies are limited or the nursing service only offers a limited range of services this may lead to a cancellation of the service involved. *"I* *don't need somebody for changing diapers, that I can do myself, especially as it always is necessary when nobody is present."* (48).

The mutual perception together with reconsidering responsibility and the resulting quality of the relationship have an impact on the evaluation of the nurses' and the nursing services' usefulness. To evaluate the usefulness of services and to make decisions accordingly makes it obvious to caregivers that they will have to take the full responsibility for the consequences such a decision may bring about.

The involvement of a nursing service often occured as a voluntary or externally initiated decision and it was made with the clear anticipation and hope of an external service being helpful. For caregivers the nursing service is just one possibility among different options to organise the caregiving process. *Facilitating work and care* is the priority for caregivers and options are evaluated concerning their usefulness for achieving this goal. *"No matter if a nursing service would have been available or not, the work we would have done anyway and there would have been no other way"*(25). If caregivers have been lucky in finding a nursing service that helps them in getting their work done this contributes to their satisfaction and is a real relief.

If the evaluation of the helpfulness of a service is negative then caregivers make different decisions. If they are personally or financially able to employ somebody themselves and this seems more reasonable according to their situation then they will do so. In three caregiving arrangements this was the choice caregivers made for several reasons. *"I have to make the best out of being dependent because of the care of my wife and guaranteeing my own freedom and that does not work with a nursing service so I decided to use the benefits of the care insurance to employ somebody myself and paid the rest out of my own pocket"* (50). Another caregiver reported it being cheaper to organise the care with privately employed nurses for 24 hours. It saved several thousand Euro a month for the insurance company to pay nurses that the caregiver could select herself instead of getting nurses from a nursing service. The persons who are self employed do not necessarily have to be nurses, but also have a different background as long as they provide what is asked for and do it in a satisfying and sufficient way. The privately organised employment of external helpers requires caregivers that have gained a high level of expertise themselves and a high confidence level beside the financial means. In addition this step requires a good standing to handle the different official authorities such as insurances, employment agencies and suppliers of assistive devices.

Other caregiving situations do not need the support by a person, but only a particular device or a particular recommendation. A daughter reports the relief she felt when she could feed her mother via a gastrointestinal tube. The time she needed for feeding her mother decreased from around seven hours a day to one and a half hours. This allowed for much time on her own and gave her back the strength to cope with the situation. Helpfulness in this case consisted of receiving a helpful information.

Mutual dependency from the nurses' perspective

Nurses do have an active part in the process of *Negotiating helpful action*, they shape the different situations in which they are involved. They do not just react to what they see and perceive. Nurses face the difficulties of *Being a guest*, *Being a mediator,* and they express different viewpoints of *Perceiving relatives.* Depending on the perception of relatives nurses are *Feeling mistrusted* or the nurse management is *Getting complaints.*

Being a guest

With the term 'being a guest' nurses describe a general attitude that is needed in home care nursing. It is the distinctive feature between institutional and home care. First and foremost being a guest includes respect for the care-recipients' and family caregivers' privacy and property. Nurses are aware that nakedness may pose a problem for many care-recipients and they try to handle the situation carefully. Respect for property includes asking for permission before opening cupboards or the like. Being a guest also involves social and interactive elements. *"Well, for me it is a guest role that I'm playing. I'm not showing up like.., saying, well I'm the nurse and you do what I'm saying, because I'm competent and you are lay people. That's not the way I handle it. Well, I'm always involving them and I try to explain why I do particular things. First to the relatives, if patients are not able to decide for themselves and otherwise the ill themselves, of course. And that I'm explaining everything I'm doing, why I'm doing it, why I'm coming, from which institution I'm coming from, if they are able to understand than I usually do so. And if they reject something they do not want at all and that I have suggested, that is OK with me." (11: 80-99)*

Being a guest is also related to staying out of family affairs if possible. Nurses know that they only have limited resources to handle an inner-family conflict, but they also know that there are conflicts they simply cannot deal with because of their lack of competence. In these instances being a guest is a means to save themselves. The status as a guest depends on the individual situation. Not just one approach determines whether the nurse remains a guest, who is welcome or maybe hardly tolerated.

Being a mediator

The same is true for *Being a mediator*. Whether a nurse becomes a mediator depends on the very circumstances in a particular situation. *Being a mediator* is a situation that nurses actively try to prevent. It means mediating between care-recipients and caregivers when they have arguments about conflicting interests. Nurses may become involved in situations where the relationship between care-recipient and caregiver has been problematic for a long time. This problematic relationship might have been characteristic for the life before the care-recipient needed help or it may be the result of the caregiving process. Usually nurses do not actively seek the role of a mediator, but sometimes they cannot avoid being caught in it. They know that they have limits in solving a conflict during the limited time they are present and they do not consider this kind of problem-solving a part of their job.

Especially critical are situations where nurses have the feeling or are even convinced that violence between care-recipients and caregivers occurs. They are aware that several reasons may cause such a situation, e.g. caregivers being overburdened, but they feel an increasing pressure to act in the best interest of the person being violated. It is not always easy to trace if and to what extent violence occurs. A direct intervention from nurses mostly occurs when extreme violence is obvious. Nurses do not see themselves as the right person to find a solution, but try to involve somebody who is considered competent, e.g. a psychologist.

Perceiving family caregivers

When talking about family caregivers nurses use the term relatives. Only seldomly they attribute a ‘caring’ or ‘caregiving’ to them. This reflects the main focus of the nurses’ work which is the care-recipient and his or her needs. Relatives are not the main concern. How nurses perceive family caregivers is reflected in how they label them. Labelling often occurs in a dichotomised way, such as ‘interfering vs. collaborative’ relatives, ‘overburdened vs. those taking nurses as a relief’, or ‘those keeping control vs. those relying on professionals’.

Interfering relatives make matters complicated. They are described as being non-understanding of the nurses’ concerns, demanding in terms of what a nurse ought to do in their particular situation, and they interfere into the nursing actions. One nurse states that they are the worst factor in home care nursing. Relatives are considered interfering when nurses feel themselves in charge. This implies the nurses being convinced to be able to handle the situation on their own. This perspective neglects the relatives’ contribution to the situation. Labelling relatives as interfering reflects a perspective of professionalism on part of the nurses that sees themselves as the experts with others being in the background.

On the other hand collaborative relatives are described as helpful and supportive. They are considered as not knowledgeable, but nevertheless they are used in the caregiving process. They take care of a sufficient supply of drugs and devices, take care of the cooking and the laundry and they provide information about the patient. The dyad of a couple is recognised as the unit of care without specific actions implied. Interfering and collaborative relatives are also referred to as good ones and bad ones. The labelling into interfering vs. collaborative relatives is related to what nurses see as their role in home care. They consider themselves of being in charge and perceive relatives accordingly.

The labelling “overburdened relatives” vs. “those taking nurses as a relief” reflects a nursing viewpoint that basically accepts family caregivers as people with needs of their own. Being overburdened is attributed to those who give everything they have to the care-recipient without taking care of themselves. They are always present and caregiving is the only activity they do in their actual life. The overburdened caregivers have difficulties in accepting help from the nurses and from others. On the other hand those relatives taking nurses as a relief have recognised that nurses can ease their situation and accept the support.

The third distinctive labelling into relatives keeping control and relatives relying on professionals reflects a perspective that arises out of the relationship between nurses and family caregivers. Relatives keeping control determine the caregiving process. They usually have done so before the nurses were involved and they have a clear understanding and image on what needs to be done, how it should be done and who is going to do it. Those relatives relying on professionals act differently in so far as they are willing to share tasks and responsibilities or even withdraw their responsibility and handing it over to professionals.

Criticising relatives occurs when nurses think that relatives do not act appropriately concerning the care recipients. Nurses refer to relatives who do not let care-recipients decide on their own even if they are able to do so. Criticising occurs when nurses think that relatives have wrong ideas about what needs to be done and how it should be done. Nurses also put emphasis on those relatives who opted for cash benefits in the long-term care insurance. These relatives are suspected of not providing adequate care.

Another aspect of perceiving family caregivers is the wish to ease their situation. A prerequisite for this is the recognition of the family caregivers’ situation as problematic and burdensome, which is described as ‘they cross limits, they are caught between love and obligation’. A relief can be provided by giving them time off when the nurse is physically present. Easing the caregivers’ situation is most likely to occur when nurses have the impression that caregivers devote all they have on the care of their beloved relative with nobody sharing their burden. In these cases, some nurses offer opportunities for sharing and relief. This occurs by ensuring caregivers that crying is OK and serves as a means of easing themselves. One nurse states that she offered a caregiver: *"I'm your big basin and I'll take your tears and concerns with me and I'll take them out and pour them into the forest." (34)*

Addressing the caregivers' needs involves a higher workload for the nurses. Due to the time constraints in their daily work nurses perceive that easing the situation is not easy. Their options are stated to be short talks and practical hints. There are concerns that many relatives have difficulties in accepting an offer of support related to themselves. Nurses feel that particular tasks are attributed to them and family caregivers and care-recipients would be surprised of being offered anything else.

Nurses see difficulties for caregivers who place great demands on themselves. They want to do everything perfectly and put themselves under too much pressure. These relatives are at risk to burn-out.

The final aspect of perceiving relatives is to accept the relatives' leading role in the caregiving process. It involves accepting them to determine the amount and kind of nursing care provided. It also includes respecting their role as main negotiators and initiators of changes in the daily routine. Nurses handle the caregivers' expertise quite differently. Some do not have a problem at all when caregivers are more knowledgeable, particularly in case of rare diseases or rare assistive devices. For others this poses a problem and they consider it a sign of their own incompetence when caregivers start telling them how to use a device or how to handle a particular problem.

The mutual perception may result in the negative outcome of acting against each other. A nurse manager states this as her observation. The reasons for working against each other are a lack of appreciation of the caregivers as persons and in terms of the care they provide to their relatives. This manager sees problems more likely to occur on part of the nurses. A problem regarding the caregivers and care-recipients is the idea that nursing care is nothing that needs to be paid for. It still is associated with humanity and humanity is not subject of contracts and settlements. Nurses often find themselves in a position where this needs to be argued about with caregivers.

Feeling mistrusted

In particular home care situations nurses have a feeling of being mistrusted by family caregivers. *"With 95% of the relatives my relationship is very good. (...) The remaining 5% do cause problems in my stomach. They are always after you, the chemistry simply doesn't* *work. The work itself is OK, but there is no harmony. Sometimes these people have changed the nursing service several times. Some have the general attitude that all nurses do betray them."(75).* This feeling of being mistrusted prevents the important aspects of a sufficient and sustainable relationship between nurses and caregivers from the nurses' point of view. They try not to be influenced too much by it when they perform particular activities in these households, but they limit their commitment to what is written in the contract and have no difficulties with it. This kind of 'feeling mistrusted' does not arise out of a caregiving process. It is a more general problem that occurs in human interaction.

Another aspect of feeling mistrusted is a more situative one. When nurses are delayed for a couple of minutes or they do not stick completely to the established routines in procedures, this causes problems for particular family caregivers. Nurses have a feeling that behind these problems there is not just a complaint, but a general attitude of caregivers that they are not doing their work properly and their competence is questioned.

Getting complaints

Relationships between nurses and caregivers and care-recipients differ to a large extent. From the nursing management perspective relationships are not the actual core of the nursing work and according to the individual manager's own perspective they are tolerated or declared the nurses' private business. A nurse manager states the relationships as the nurses' 'little secrets'.

Nurse managers are the ones who get many of the caregivers' and care-recipients' complaints. On this level most of the complaints concern deviations from the schedule that was agreed upon. Complaints about timing occur immediately. They are central to the care-recipients' and caregivers' satisfaction or dissatisfaction with the performance of the service. Complaints about timing stem from the caregivers' and care-recipients' ideas of how to live their lives. In general, the management is challenged by balancing individual preferences with medical-technical requirements (e.g. an insuline injection needs to be given within a particular time frame before breakfast) and the human resources available in the service. The second complaint concerns nurses who are new to particular caregiving situations. Caregivers were used to another nurse and developed a routine that is disturbed and needs to be re-clarified with a new nurse entering the home.

Another source of conflict is disagreement on what has been done by the nurses. This becomes obvious in the nursing record or, more often, with the bills of the service by the end of the month. Less frequently a complaint is made that nurses have not tidied up peoples' homes after their work is finished.

6 Discussion

In this final chapter the conduction of the study and the substantive theory of *Negotiating helpful action* will be discussed. Issues that will be addressed concern the credibility of the research, the theoretical and practical relevance, and finally the implications for nursing science, nursing practice and social policy.

6.1 Credibility of the research

The purpose of this study was to generate a substantive theory on the relationship between formal and informal care. Every research study has to address the question of its own quality and credibility. Usually the terms reliability and validity are used to determine the quality of a research. In Grounded Theory these terms are only of limited usefulness as they are derived from hypothetico-deductive research approaches. The actual question of credibility concerns the path *"...to making a fact scientific or sound scientific"* (Glaser, 2003, p. 129).

In grounded theory this is done by systematically generating concepts from systematically collected data through theoretical sampling and by constant comparison procedures. It has been outlined in chapter four that this study was conducted by doing theoretical sampling in five phases with seven different data sets. It also has been outlined that substantive coding and theoretical coding have been performed by constant comparison.

The criteria for the quality and credibility of a grounded theory study are its fit, workability, relevance and modifiability (Glaser and Strauss, 1967, Glaser 1978, 1998). The appropriateness of the substantive theory of *Negotiating helpful action* will be evaluated according to these criteria.

Fit, according to Glaser (1998), is another word for validity and concerns the question if the concepts adequately reflect the patterns in the data which they purport to conceptualize. Fit is achieved by constant comparison of incidents, codes and categories. The substantive theory of *Negotiating helpful action* was developed by adhering to this principle. Theoretical sampling and constant comparison were performed until no new categories could be identified by substantive coding. The coding process was based exclusively on the data generated during this research. It did not rely on existing theoretical frameworks or on preconceived theoretical assumptions. After substantive coding memo sorting was performed until all substantive codes were integrated into patterns that reflect how the participants resolve their main concern (Glaser, 2005). The process of theoretical coding was based on the integrative patterns of the substantive codes.

The second criterion is that of workability. *“Workability means do the concepts and the way they are related into hypotheses sufficiently account for how the main concern of the participants in a substantive area is continually resolved”* (Glaser, 1998, p. 18). In this study concepts and categories that emerged from the analysis were constantly compared. To grasp the participants’ main concerns their interviews have been summarised into short stories of their situation. The substantive codes and categories have been constantly compared to these stories. By doing so it was ensured that the substantive codes actually represent the participants’ main concern. When it became obvious that a joint analysis of the interviews for family caregivers and nurses would not be sufficient for identifying their main concerns, respectively, they were analysed separately. The separate analysis for nurses and family caregivers ensured that the concerns of the two different groups of participants were conceptualized appropriately, before they were integrated into the substantive theory. The categories and their relationships represent the underlying pattern of what actually happens in the relationship between nurses and family caregivers, while at the same time allowing for inclusion of variation of the different perspectives and the different concerns of nurses and family caregivers.

The third criterion stated by Glaser (1978) is the relevance of the research. *“Relevance makes the research important, because it deals with the main concerns of the participants involved. (...) relevance, like good concepts, evoke instant grab.”* (Glaser, 1998, p. 18). Strübing (2004) says that grounded theory aims at generating theories not for the sake of themselves, but with the aim of an improved ability for action in a particular social area. The objective of theories in a practice discipline is to describe, explain and/or predict phenomena in a particular area. In this study the substantive theory is relevant, because it is based on the participants’ main concerns. The relevance of the substantive theory of *Negotiating helpful action* lies in its power to explain what happens between nurses and family caregivers in home care. It allows for analysing problems that have occured between them by providing theoretical explanations for possible problems. It also allows for explaining factors that contribute to a sufficient relationship between nurses and family caregivers. By doing so it may serve to achieve the aim of an improved ability for action in the relationship between formal and informal care.

The last criterion of modifiability was added later to the criteria for the credibility of a grounded theory. Modifiability concerns the capacity of the substantive theory to incorporate and accomodate new concepts as they emerge. The issue of a grounded theory is not verification in terms of a theory being right or wrong (Glaser, 1998). The important issue is its readiness for modification. The criterion of modifiability reflects that the world is empirically integrated and not logically modeled (Glaser and Strauss, 1967; Glaser, 1978). The substantive theory on *Negotiating helpful action* is ready for modification. Changing patterns of family caregiving, of the management of chronic illness or of social policy decisions might all generate new concepts from data generated after this research. The fact that this study was conducted in Germany in a particular social context did not lead to a substantive theory that is applicable in this context exclusively, but it can be modified with new data from other contexts.

6.2 Theoretical relevance

The theoretical relevance of the substantive theory will be evaluated according to the main categories: Negotiating helpful action, facilitating work and care, and shaping different realities.

6.2.1 Negotiating helpful action

The core category of negotiating helpful action indicates that the relationship between nurses and family caregivers is a process of negotiation. It is not a static relationship, but it has an implicitly dynamic nature. Similar findings have been stated by Evers and Olk (1996) who argue that trust, co-operation and negotiation are the essential aspects for optimum relationships between formal and informal care. Also Ward-Griffin (2001) found that nurses and family caregivers feel the importance of collaborative relationships in that they have constantly to negotiate in an emotionally charged environment. The importance of trust has been stated by nurses and family caregivers as well and both have provided insight into how trust building occurs and is actualized. Nevertheless trust building is not the core aspect of the relationship between formal and informal care. It is a contributive factor. Trust building has been found as a prerequisite for successful negotiation of helpful action. It also contributes to co-operation, but helpful action between nurses and family caregivers can also be negotiated without clear indications of trust and co-operation when family caregivers have a feeling of the care provided by nurses serves the best interest of the care-recipient. If formal care is perceived in this way family caregivers may consider it to be helpful without having a positive relationship with the nurses themselves.

The aspect of negotiation between nurses and family caregivers has been found of importance by other authors, too. Twigg and Atkin (1994) identified the definition of the situation, the conceptualization of need and the acceptability of the care provided to be subjects of negotiation and these findings match the substantive theory of *Negotiating helpful action*.

The core category of this study specifies what the negotiation is all about. The criterion is helpfulness of the actions of formal carers. As it has been shown, helpfulness can only be evaluated according to a given situation and it is the family caregivers and the care-recipients who finally decide what kind of action is helpful. The role of negotiation has also been stressed in other contexts, where patients developed different kinds of negotiation strategies that either were resistant in terms of striving for autonomy and criticising the care or were adjustive in terms of following the rules and building alliances against professionals (Löfmark and Hammarström, 2005). It has also been addressed how interpersonal contexts of negotiating care between nurses and patients can be conceptualized (Spiers, 2002).

Negotiation is an interactive process and the negotiation of helpful action indicates how nurses and family caregivers construct meaning in their mutual encounter. It reflects the basic assumptions of symbolic interactionism (Blumer, 1969). Both nurses and family caregivers are engaged in the negotiation process from their respective viewpoint and this study confirms the work of other authors who stated the completely different worlds in which nurses and family caregivers operate (Fischer and Eustis, 1994).

Negotiating helpful action adds two dimensions to existing knowledge: First, the negotiation process is a tailored one and it is not only professionally determined. In this study it was found that care-recipients and family caregivers actually are the ones to determine if there is any kind of relationship between formal and informal care at all. Second, the negotiation does not only take place with patients or care-recipients, but also with family caregivers. Considering them in an instrumental way as resources (Twigg and Atkin, 1994) neglects the reality of home care situations. Ward-Griffin (2001) states that the opportunities for negotiations for family caregivers are more limited than for nurses, which reflects the powerlessness of the individual whose caring work is not publicly visible. Although this viewpoint cannot be fully confirmed by this study, it has been shown that the negotiation process of helpful action is of higher importance for family caregivers than it is for nurses. Family caregivers play an important role in the decision-making, whether to involve nurses or not, but after they have done so, they find themselves in another dependency. The helpfulness of the formal services is critical for them in stabilising their caregiving arrangement, whereas for nurses it is one of many realities they are involved in as part of their professional performance.

How negotiation works in the triadic perspective cannot be answered by this study. There are indications that from a care-recipients' perspective the relationship between family caregivers and other care providers may not necessarily be important, but access to and the availability of both is considered to be crucial (Fischer and Eustis, 1994).

Negotiating helpful action is not a process that is related to particular tasks. Nurses and family caregivers often perform the same tasks, but at different times during the day. The same phenomenon was found by Ward-Griffin (2001) who labelled it as crossing the boundaries of care that separate 'manual unskilled' from 'intellectual' work. In her study nurses and family caregivers both performed in ways that they themselves attributed not to themselves, but to their counterparts.

The fact that negotiations are tailored on helpful actions may seem a natural insight, but obviously in the existing practice there is a difficulty of implementing such an approach. From a research perspective this study raises the question if studies should be more focussed on the actual processes and how they could be tailored to become helpful instead of assuming helpfulness of professional action per se (Ward-Griffin and McKeever, 2000; Conger and Marshall, 1998).

From a social policy perspective *Negotiating helpful action* confirms that formal and informal care cannot simply be substituted by each other, but that their collaboration offers the chance of a better care (Zeman, 1996). For the German context *Negotiating helpful action* indicates what Ward-Griffin (2001) found for Canada: There is evidence that current home care practices and policies create or intensify problems for family caregivers. Until physical, emotional, and intellectual components of nursing work are formally acknowledged, programmes in long-term care will continue to be geared towards instrumental tasks.

Any approach that focuses exclusively on how particular tasks are performed and tries to attribute the tasks to either the formal or informal sector fails to recognise the complexities of home care. Helpfulness is not determined by the nature of a particular task, but by how a particular action fits into a given caregiving arrangement.

Concepts that represent the reasons why formal services are involved in home care situations are part of the substantive theory on *Negotiating helpful action* and its sub-parts that represent the nurses' and the family caregivers' perspective separately. They all reveal that attempts to predict service utilisation based on structural determinants have only limited use. The question of why, when and to what extent formal services are involved depends only to a limited extent on structural determinants, but is a result of interactive processes of those who actually face the problematic situation. This matches the perspective of Wan (1989) who argues that the overemphasis of structural determinants has failed to specify the socio-psychological process through which physical health is perceived, evaluated and acted upon. This study does not explain this socio-psychological process and it was not intended to do so, but it adds to the understanding the concept of *anticipated helpfulness*.

A theoretical asssumption that is clearly rejected by the substantive theory of *Negotiating helpful action* is those of the hierarchy compensatory model in which formal care substitutes informal care (Noelker and Bass, 1994). As other authors have pointed out this model may be attractive due to its simplicity (Logan and Spitze, 1994), but it actually fails to recognise the reality in families and social networks with one member being in need of care. This is particularly problematic as the assumption that formal care substitutes informal care guides parts of the social policy on caregiving.

6.2.2 Facilitating work and care

The concept *Facilitating work and care* reflects the goal of family caregivers when *Developing a fitting arrangement* in their caregiving situation. The situation of family caregivers has been widely addressed in the literature and the goal of *Facilitating work and care* matches existing findings. Within their trajectory framework Corbin and Strauss (1988) identified three lines of work that constitute trajectory management at home: illness-related work, biographical work and everyday-life work. Because of the family caregivers' being involved in these types of work, they strive for an arrangement that fits into their work and care needs. The involvement of external support implies an expectation of getting support.

Facilitating work and care indicates that the relationship between family caregivers and nurses needs to be considered according to that goal. The relationship is no means by itself. The main concern of family caregivers is to stabilise a disturbed reality of life (Zeman, 1998; Jussila, 2004). They are active in protecting their sick relatives (Schnepp, 2006). The involvement of a nursing service implies a double process of negotiation for family caregivers. On the one hand they negotiate roles and relationships in their existing family life and on the other hand they need to engage in the process of *Negotiating helpful action* with the nurses. Zeman (1996) points out that the negotiations within families are only in parts rational discourses and that they have a less differentiating function, but more a function of reducing complexity. Because of this the sub-categories of *Perceiving nurses, Becoming suspicious, Triggering struggle* and *Evaluating helpfulness* are important to understand how and why the involvement of formal help may contribute to the goal of *Facilitating work and care* or may not.

Concerning the decision, whether to involve formal help or not, the literature documents that this decision is made according to different considerations such as the acceptance of the help for the caregivers themselves and in the light of others (Gräßel, 1998; Starke and Ühlein, 1999) and the subjective meaning and relevance that is attributed to professional carers by family members (Zeman, 1999). Acceptance of help, subjective meaning and relevance will only be attributed to formal services when family caregivers have the assumption or expectation of the services contributing to their goal of *Facilitating work and care.* Nolan et al. (1996) state that from a caregivers' perspective the extent to which support is acceptable and successful depends on the degree to which it is sensitive to the caregiving trajectory and the caring strategies that are employed.

6.2.3 Shaping different realities

The perspective of nurses on the relationship between formal and informal care is conceptualized by the process of *Shaping different realities*. Unlike other studies on the relationship between formal and informal care, this study offers insight into the varying challenges and demands that nurses in home care have to face. In addition, the process of *Shaping different realities* reveals that it is influenced by a professional identity and a personal identity as well. *Shaping different realities* is characterised by the nurses' *Feeling restricted*, meaning that they have ideas of how they could be more helpful to care-recipients and sometimes even to family caregivers, but they state that they lack the means and space to do so.

It becomes obvious from this study that family caregivers rarely are in the focus of a nursing intervention. This has also been found by Twigg et al. (1990) who found that formal services assist the family caregivers to do certain tasks or they relieved the family caregivers from doing them. Nevertheless family caregivers clearly are a part of the complexities of care that service providers have to recognise (Twigg and Atkin, 1994). The focus on care-recipients is part of the context in which nurses offer their services in home care. It is also part of their professional education and their professional identity. According to Nolan et al. (1996), this may be the result of the absence of an explicit policy for family caregivers, because of which professionals rely upon more tacit sources of knowledge such as professional values, 'the culture of the office' and the assumptive worlds of individual practitioners.

Shaping different realities as a sub-process of *Negotiating helpful action* reveals that it is the negotiation process that determines whether the nursing interventions are considered helpful. This indicates the interactional dimension of nursing care quality (Zeman, 1996), but it also indicates that services obviously do not offer benefits that have been documented in the literature as being helpful such as ‘giving family caregivers a day off’ or ‘providing them with a feeling of having free time’ (Starke and Ühlein, 1999). The contractual agreements of home care nursing in Germany force the nurses into normative corridors of action that do not necessarily match the individuals’ actual needs. Stratmeyer (2005) considers the contractual agreements as a burden for the interactive process, because the nurse is obliged on the fulfillment of a basic catalogue of performance. The nurse was not part of compiling this catalogue and does not need to be convinced by it. For the nurse a situative change of the performance catalogue in a given situation would result into a considerable effort and a pressure for justification.

6.3 Practical relevance

The practical relevance of this study concerns two aspects. The first is its relevance for changing contexts of home care nursing delivery and the second is its contribution to tailoring nursing services to become helpful.

Knijn and Verhagen (2003) point out that there is a tendency in Western European Societies to award cash payments to people in need of care and their caregivers in addition to granting reimbursement for formal nursing or other services. This tendency could be observed already in the beginning of the nineties (Evers et al., 1994) and is confirmed by new developments (Klie and Spermann, 2004). Cash payments are a means for contributing to the care-recipients’ independence by awarding a limited amount of money that can be spent on several and diverse sources of help, including payments for neighbours, friends and others. According to Knijn and Verhagen (2003) this development corresponds with implications for formal services who find themselves in a situation where they have to compete with paid informal caregivers for delivering services. Further on they point out that *“...de-professionalization is an ongoing process occasioned by consumerism, the rising education of clients who no longer take professional expertise for granted and by submission of professionals to bureaucratic organisational structures.”* (Stijn and Verhagen, 2003, p. 10).

Although the substantive theory on *Negotiating helpful action* does not take these political developments into account it illustrates that helpfulness of services is the criterion that needs to be matched by professional services and that helpfulness is nothing that can be externally attributed to a situation. It needs to be negotiated and can imply medical, technical, social and psychological aspects as well. Not professional determination, but the ability to identify the key aspects of a situation is seen as one of the core attributes of home care nursing (Nolan et al., 2001)

To be helpful nursing services need to take several aspects into account as it has been outlined by Schmidt (2002): the habits for the basic activities of daily living that have developed biographically are respected, nursing care is considered a process of negotiation which embraces technical competence as well as the individual options and decisions of the caregiving and -receiving household, and the performance of family caregivers is considered as a particular quality that needs to be motivated and productively included, without asking too much of it (Schmidt, 2002).

Apart from this general statement this study shows that developmental work is needed in terms of designing services that have been reported to be helpful such as family training programmes (WHO, 2002), teaching caregivers how to establish routines for caregiving tasks (Albert, 1990), assistance for families to develop skills for problem solving and working together to raise their confidence (Fink, 1995). Furthermore, interventions that allow for caregivers regularly experiencing pleasant activities with friends (Thompson et al., 1993), and nursing interventions that acknowledge and affirm the caregivers' knowledge when it is adequate, try to develop or enhance it when it is inadequate or support family caregivers in applying their local knowledge to problem-solving in their very situation (Harvarth et al., 1994) need to be established. These interventions would also need to be negotiated in the caregiving households, but they have been shown to be more tailored to the family caregivers' needs.

6.4 Conclusions and recommendations for further research

In the introduction of this study reference was made to the European studies EUROFAMCARE (2005) and SOCCARE (2003). Both addressed the need for improvement of existing care services for elderly people in terms of the quality and responsiveness to people's needs. Based on the substantive theory of *Negotiating helpful action* it can be added that the interactive quality of nursing care services needs to be addressed on a broader basis, too. On the other hand professional services operate in an existing social policy context. From a professional perspective as well as from a policy perspective there is a need to investigate the ideas and values that underpin regulatory frameworks for service provision and educational backgrounds of the professionals who are to provide these services.

Regulatory frameworks need to allow for flexibility in service provision. Professionals and service providers only can negotiate helpful action when they operate in an environment that allows for different subjective decisions in situations that may seem similar in the first place, but call for different action. Helping systems need to reconsider the goals and outcomes of current services, particularly in terms of what constitutes ‘success’ (Nolan et al., 2003). From a policy perspective there needs to be a more distinctive view on what kind of services are actually provided. The home as a black hole into which a range of different services can be attributed as pointed out by Gubrium and Sankar (1990) needs a more detailed perspective. When judging about the quality of services it should be clear what particular service is subject to evaluation. Formal care is just a heading that may mean quite different things under different circumstances.

Home care is in the intersection between health and social care and this needs to be taken into account in the political decision-making process. The distinction in many political systems in health and social care has its uses, but it prevents an integrative approach when addressing home care.

The German example shows quite well that a lack of a clear idea of what the nursing profession is able to contribute to health and social care and what it actually should contribute limits the resources that are available for intervention when trying to address the issue of care-dependency at home. If the unclear idea about nursing results in a framework that reduces professional nursing care to the performance of a limited number of predetermined tasks this makes *Negotiating helpful action* actually impossible. It undermines the nursing contribution to caregiving at home and, even worse, it prevents care-recipients and family caregivers from receiving services that they may consider helpful, but that are not part of the political understanding of what this should be all about.

In terms of professional initial and continuing education the focus needs to be expanded beyond the needs of the patient or care-recipient. Home care arrangements only can be understood by taking all people into account who contribute to the arrangement and who have needs on their own. Nursing practice needs to focus more on families and social networks than it has done before. The focus on patients or care-recipients alone limits the ability to be of real help to people who are in need of nursing care. A practice in home care that neglects the care-recipients’ environment will remain of limited helpfulness. The particularities of home care nursing should be included into all kinds of nursing education. Even for nurses who do not work in home care it helps to understand and to address the context out of which they receive their patients and into which they discharge them.

For the German context nursing practice needs to actively work on changing their legislative framework that forces it into a particular scheme of political imagination of what home care is. A change in this imagination will only occur, if nursing practice provides evidence of its contribution to *Keeping people at home.*

Recommendations for further research

On the basis of the substantive theory on *Negotiating helpful action* further research is suggested that will contribute to a broader understanding of the home care experience and ways to sustain caregiving relationships in a helpful way. It has been written a lot about the caregiving experience in families. This research suggests that now studies are required that address the interventions provided by nurses and other formal service providers. In this respect there is a need to thoroughly investigate what kind of interventions have been shown to be helpful and in what way. Intervention studies are needed that address interventions for care-recipients, for family caregivers and for the home care arrangement as a whole.

Research is needed on how nurses can make sense for themselves of the shape and structure of home care arrangements. This can be done by synthesizing existing studies on home care to a coherent theoretical framework that serves the purpose of conceptualization or it can be achieved by developing appropriate assessment tools.

In terms of service provision it needs to be investigated, whether and in what way social policy regulations promote or inhibit the provision of helpful services. A first step in this direction is to detect the impact of social policy decisions on care-recipients and family caregivers on the one hand and on service providers on the other.

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Andreas Büscher

9 Appendices

Appendix 1: Overview over the relevant literature

Subject area: Formal and informal care and health services utilization				
No.	**Researchers, Year, Country**	**Purpose of the research**	**Research methodology**	**Main results**
1	Allen, Ciambrone, 2003, USA	By employing the task specificity framework to explore the implications of using either formal care providers to fill needs that are more typically met by family or family caregivers to provide care that is best provided by the formal care sector.	Qualitative interviews, N=50, analysis of 5 case studies	There are negative implications of mismatched care substitution, but the authors conclude that the task specificity framework is less applicable to emerging systems of community care
2	Andersen, Newman, 1973, USA	To outline a framework for viewing health services utilization which takes into account both societal and individual determinants	Development of a model	A theoretical framework for viewing health services utilization is presented, emphasizing the importance of the (1) characteristics of the health services delivery system, (2) changes in medical technology and social norms relating to the definition and treatment of illness, and (3) individual determinants of utilization. These three factors are specified within the context of their impact on the health care system. Empirical findings are discussed which demonstrate how the framework might be employed to explain some key patterns and trends in utilization. In addition, a method is suggested for evaluating the utility of various individual determinants of health services utilization used in the framework for achieving a situation of equitable distribution of health services in the United States.
3	Bass, Noelker, 1987, USA	To test whether characteristics of the primary and secondary family caregiver influence the elder's use of in-home nursing and aide services	Structured interviews with N=586 family caregivers	The assumption which permeates this analysis is that the primary caregiver influences the elder's use of services directly (as when the caregiver contacts service organizations or professionals to seek services on the elder's behalf) and indirectly (as when the caregiver informally influences the elder's perceptions of illness, need, or the structure of the service system). Data indicated that the use of in-home nursing or aide services for the elderly was more likely when the primary caregiver experienced greater care-related stress effects. In contrast, the amount or volume of service use was determined mostly by enabling factors, particularly household

				income, while elder need characteristics contributed little to explaining amount of service use. Moreover, need characteristics of the primary caregiver had no effect on the amount of services used.
4	Bass, Noelker, McCarthy 1999, USA	To determine how primary kin caregivers perceptions about overall quality of care are affected by characteristics of helping networks and to profile care situations that include formal and/or informal helpers	Face-to-face interviews with N=401 informal caregivers of elderly care recipients, analysis using measures for quality of care, helping network characteristics, care receiver impairment, caregiver strain and caregiver characteristics	Primary caregivers' perceptions of the overall quality of care given to their impaired elderly relatives are more strongly related to the perceived helpfulness of selected formal care providers (home aides, physicians, and social workers) than to the perceived helpfulness of selected kin caregivers. Caregiver race and age, the types of other family members who are helping, and whether a nurse is involved influence caregivers' perceptions of the helpfulness of these formal care providers. In recognition of the essential role played by family members in home-based care, outcome measures also should include characteristics of informal and formal helpers and their interface in helping networks. Although variables representing nurses are not directly related to quality of care, their presence and helpfulness is indirectly associated with quality by altering perceptions of other service providers. One interpretation of these findings is that nurses, particularly in home car, function as a conduit between elderly care receivers and other members of the health care team. These results further suggest that nurses enable or prevent other providers from giving more effective care as perceived by family caregivers.
5	Brandenburg, Zimprich, 1995, Germany	To address the issue of social service utilization of older people living at home in varying life situations	Questionnaire from N= 641 people, taken from a larger study	Levels of independence in everyday life, socioeconomic resources and the extent of family support are the main predictors for service utilization as far as single variables were concerned. Beyond that more complex variables such as the impact of differing life situations on individual decisions of service utilization need to be taken into account.
6	Coe, Neufeld 1999, USA	To explore male caregivers' perception of formal support	Grounded theory, 62 interviews with 24 male caregivers during a period of 18 month	The men experienced a process of making concessions for care in the following four sequential stages: resisting, giving in, opening the door, and making the match. Personal barriers deterred the caregivers from seeking help, and once the caregivers engaged formal help the influence of characteristics of the health care system and individual staff members had both enabling and disabling effects. For caregivers whose use of formal support involved admitting their relative to a long-term care facility, the phase of making the match was followed by

				redesigning their caregiver role.
7	Evers, Olk, 1996, Germany	To investigate from the perspective of nurses, whether and to what extent they recognize the situation of family caregivers, and from a family caregivers perspective, where they experience problems with professional services	Pilot study using qualitative interviews (N= appr. 20 nurses, 30 family caregivers) plus expert interviews	The image of the 'good' family caregiver who contributes to the medical nursing care process is consistently linked to traditional ideas about family solidarity. The significance of negotiation of appropriate and acceptable roles needs to be made purposefully manageable. Service relationships are random relationships in the majority. A sufficient caring relationship from the caregivers point of view is based on trust, collaboration and negotiation.
8	Finch, 1993, UK	To provide a clarification of the concept of caring within the framework of social policy	Literature review, Conference paper	In the British context caring means meeting the practical and personal needs of people who are not fully able to provide for themselves – the chronically sick, people with physical or mental handicaps, those elderly people who can no longer fully take responsibility for their own health and welfare. Normally its use is also restricted to care provided on an unpaid basis. It has to be distinguished between care 'in' the community and care 'by' the community. The intellectual roots of the concept of caring stem from debates around the 'informal sector' of welfare and feminist analyses of domestic labour. Informal caring is seen as a normal, and inevitable part of the way in which any society organises the welfare of its citizens. In trying to pin down the meaning of caring three contrasting words are used: Caring for and caring about, Labour and love, and Duty and affection.
9	Fischer, Eustis, 1994, USA	To examine the interrelationship of two important components of long-term care systems: family caregiving and paid home care	Literature review	Formal and informal care systems seem to represent separate systems of care in that there is often little or no contact between families and workers. Research is needed on the complementary and overlapping roles of paid care and family care and the implications for quality and cost.
10	Gilberg, 2000, Germany	To address empirically and theoretically the amount of care requirement of old and very old people, their utilization of different sources of care, the role of the family, and the transition to an old-age home or nursing home	Using data from the multidisciplinary Berlin Aging Study (BASE), the total research protocol completed by N=516	Care requirement was identified as 56% completely independent, 18% slightly disabled, 14% disabled, and 1% completely disabled. With regard to the care received a difference is shown between objective measures and subjective perception of need, especially for men. Children and spouses living in the same household are a major source of care. The majority of the elderly lives alone and for those most of the help is provided by the private sector. Regarding the role of the family it is shown that family caregivers themselves are often old. The major postponing factor for a transition into a nursing home are spouses rather than children.

				Important predictors for the different sources of care are the level of physical limitation especially dementia-related symptoms, socioeconomic resources, the living arrangements and age
11	Gräßel, 1998, Germany	To identify predictors of use of professional support	Standardized questionnaire completed by N=1911 informal caregivers	Predictors of whether use of professional help is made or not are – independent of the reasons why help is necessary – the extent of the help that is needed and the absence of support with the family. Sociodemographic vaiables such as age, sex, income, and education have no influence.
12	Harvarth, Archbold, Stewart, Gadow, Kischling, Miller, Hagan, Brody, Schook, 1994, USA	To address ways of how to establish partnerships with family caregivers	Literature review and integrative review of four different studies	Caregivers have important information that is unique to their care receiver and essential to his or her care. This information is called local knowledge in this article, a concept from anthropologic theory. Gerontologic nurses have cosmopolitan knowledge, a term used in anthropology for universal forms of knowledge. The family's local knowledge is derived from experience in managing the older person's chronic illness and is embedded in the context of the family culture and relationships. The nurse's cosmopolitan knowledge is derived from his or her educational background and experience. It is important to blend local and cosmopolitan knowledge in thinking about the problems and concerns of family caregivers and their frail relatives. Only in the areas of meeting physical needs of the care receiver and setting up services for the care receiver did caregivers report learning more from health professionals than any other source.
13	Holstein, Holst, Due, Gert, 1993, Denmark	To address the question whether formal and informal services replace each other or supplement each other and what are the consequences for the family	Literature review, overview article	The category of the elderly who receive most informal help from their social network are: rural, female, oldest age group, living alone, many social contacts, poor health, poor functional ability, low social class and poor financial situation with the strongest predictor: poor functional ability. Most of the elderly anticipate help from their social network in case of acute, but not in case of long-term illness. Spouses are the category that is most expected to provide help. Criticisms to the formal support system: Changing home helpers are a source of dissatisfaction. Lack of information from the social services department, too. Problems regarding the lack of influence on what kind of help is provided and how, Decisions were made by the professional staff, Lack of flexibility in solving the problems, because of applying standard solutions to the elderly

				problems, Inadequate follow-up, Lack of professional skills in dealing with psychic problems among the elderly, Lack of services: The system gives priority to care but not to rehabilitation and training.
14	Jeon, 2004, Australia	To examine processes through which community mental health nurses work with families of older people with depression	Grounded theory based on observational data and 19 interviews (six nurses and seven family units of caregivers and patients	The process of 'shaping mutuality' emerged as the central feature of a substantive theory of the working relationship between nurses and caregivers. Mutuality was a concept that was firmly grounded in the research data reflecting both nurses' and caregivers' accounts and interactions. The concept describes an essential element of the development of the helpful relationship between the nurse and caregiver that is characterized by high levels of empathy, collaboration, equality, and interdependency. The process, shaping mutuality, comprises three developmental phases: 'lack of mutuality', 'partial mutuality', and 'constructive mutuality'.
15	Kerkstra, Vorst-Thijssen, 1991, The Netherlands	To identify factors important in explaining the nature of community nursing care received by patients in their homes.	During a period of 2 weeks a representative sample of 137 community nurses and 49 community nurses' auxiliaries at 47 different locations paid a total number of 12.847 home visits to provide care to 3.315 patients. For each visit patient characteristics, the nature of the care delivered and the length of the home visit were recorded	The results suggested that three groups of patients could be identified in terms of the nature of nursing care received at home. First, patients who were older, who were also receiving informal care and did not suffer from psychosocial problems, were most likely to receive assistance in their activities of daily living. Second, patients suffering from multiple disorders, whose situation was assessed as unstable, and those who did not suffer from psychosocial problems were most likely to receive technical nursing care. These patients were visited most often. Finally, male patients suffering from multiple disorders, whose situation was assessed as unstable, especially when new mental or social problems emerged, were most likely to receive psychosocial support and education from the community nurse. These visits appeared to be the most time-consuming.
16	Leira, 1993, Norway	To address the concepts of care: loving, thinking, doing	Literature review, Conference paper	Welfare state ideology project the welfare state as a caring state. The first part of the paper examines recent conceptualisations of care, focusing particularly on Scandinavian contributions, in which caring is commonly discussed in terms of work. Care-giving work is not necessarily considered to be a labour of love, but a from of work demanding special skills. The next is a look at the institutional differentiation of care and the introduction of a typology of care-giving work. Scandinavian studies often argue the necessity of analysing different forms of care, public and private, formal and informal, paid and unpaid within the

				same negotiation of boundaries between welfare state policies and private responsibilities. The last section briefly discusses the division of labour between formal and informal care-giving systems.
17	Logan, Spitze, 1994, USA	To study older persons' use of formal services in the context of one medium-sized metropolitan area with a principal focus on the relation between formal service use and informal help	Personal interviews with 554 persons aged 60 or older, multivariate analysis using measures of services use, informal support, need, predisposition, and enabling factors. In addition 99 interviews with service providers	Most services are used by only a minority of older persons. There is some evidence of both compensatory processes (where family support substitutes for formal care) and bridging (where the informal network helps link the older person to services). Service users are distinguished partly by their greater functional disability. Use of some services is affected by indicators of predisposition, such as sociability and age identity. Enabling factors, such as availability of services or their accessibility by the respondent, have little effect. Theorists have not agreed on how to think of the relationship between formal and informal support. There is the hierarchical model that argues that the use of formal services is diminished by the availability of a supportive family and friendship circle. This model has been criticized for its simplicity that also makes it attractive. There are reasons to believe that the hierarchy of potential caregivers depends upon particular tasks that need to be provided.. Others note that people's informal network may act as a bridge between the older person and formal services, bringing the person into contact with public service providers and thus facilitating informal care. From this perspective, informal support is seen as a possible enabler of formal assistance. The complexity of the relationship between formal and informal support shows that application of the needs-enabling-predisposition framework is not always straightforward.
18	Manthorpe, Iliffe, Eden, 2003, UK	To explore professional attitudes to family members supporting an older person newly diagnosed with dementia	Focus groups interviews with four focus groups of 20 participants each. For the analysis the typology developed by Twigg and Atkin was used.	The primary care workers' understanding of the family caregivers needs and circumstances fitted best with Twigg's models of carers as resources and co-workers. There was only limited awareness of family caregivers' responses and attitudes to caring.
19	McCaslin, 1988, USA	To clarify unresolved questions about service use	Four different studies with different designs were integrated	Indicated by consistent findings was that general knowledge and acceptance of the formal service system are better predictors of use than are the demographic and functional capacity variables usually studied. Whether older persons will actually utilize available health and social services is a function of many factors beyond

				objective, professionally defined need. Frequently identified influences on service use by elderly persons have included race, socio-economic status, strength of kinship networks and other informal supports, objective and self-defined need, affiliative tendencies and knowledge about available services. Perhaps the most useful marker of potential new questions is the highly consistent finding that self-perception of service knowledge and need accounted for a large amount of previously unexplained variation in service use.
20	Noelker, Bass, 1989, USA	To investigate how personal care and home health services are used in relation to assistance from primary kin caregivers	Semistructured interviews with N=519 caregivers, analysis based on a self developed typology	Four models derived from the literature indicate that there are various types of relationships between informal and formal caregivers. The first type, dual specialization, includes families in which tasks are segregated – kin caregivers and service providers assist impaired persons with different tasks. The second type, supplementation, includes families in which service providers help with the same tasks as kin caregivers, although the kin caregivers may help with additional tasks. This type assumes that kin caregivers are the major helpers and use service providers to augment their efforts or for respite. The third type, substitution, includes families in which service providers are the sole source of assistance with care recipients needs. The fourth type, kin independence, includes families in which no service providers help with caregiving responsibilities. The kin independence type was predicted by lower levels of physical impairment and care-related health change in the primary caregiver. Conversely, higher levels of physical impairment and care-related health change were predictive of formal service specialization. Other predictive determinants were caregiver gender (supplementation type), relationship to the care recipient and care-related activity restrictions. The dual specialization type seemed more characteristic of male (Husband) primary caregiver and those with higher care-related stress, as well as care recipients who were less functionally impaired.
21	Noelker, Bass 1994, USA	To promote conceptual and empirical attention to the relationship between informal and formal helpers	Review of three existing conceptualizations of the relationship between formal and informal care	Conceptual and empirical interest in the relationship between informal and formal helpers is driven by policy and program development issues as well as theoretical concerns. Research findings consistently suggest that the fear of service substitution is groundless in the majority of family care situations
22	Paulus, Raak,	To investigate the	Quasi-experimental	Integrated care did not bring about the

	Keijzer, 2005, The Netherlands	relationships between informal and formal care, changing relationships over time, and the impact of integrated care.	design in a traditional care comparison setting and an experimental setting. Care activities were recorded by informal and formal caregivers at three different measurement points.	expected major changes. There was a limited amount of substitution of formal care with informal care. There were limited changes in the extent of dual specialization, in which informal and formal caregivers perform separate activities. There was little supplementation of formal care with informal care. Furthermore, relationships changed over time, resulting in a complex pattern of linkages at the level of separate activities.
23	Pearson Scott, Roberto, 1985, USA	To identify patterns of use of informal and formal support networks and factors associated with their use	Comparison between a group of 245 older adults with low incomes and a group of 235 adults with higher incomes	The transactions that occur in support networks are primarily in the form of supportive ties or exchanges among some set of individuals. Two patterns of familial networks are discussed: the substitution and the shared-functioning kinship model. The substitution model seems to apply to other informal support networks (Neighbours, friends), whereas the shared-functioning model seems to be more suitable for informal and formal support. With regard to the first hypothesis – that a shared functioning pattern of support would be found between informal and formal networks of rural elderly poor sample – this held true only for persons exhibiting the greatest lack of socio-economic resources. In summary the results regarding this sample of rural elderly poor suggested three patterns of network support for the poor that did not confirm strictly to the hierarchical or shared functioning patterns. This study provides empirical evidence that formal services, when used, are being used in conjunction with support from children and friends rather than to take the place of informal assistance.
24	Pedlar, Biegel, 1999, Canada	To examine the role of caregiver attitudes in explaining the use of homemaking services, personal care services, transportation, caregiver services and the number of services	Face-to-face interviews with 82 family caregivers, analysis using an explanatory model resulting in five outcome measures of community services use, seven scales to measure caregiver attitudes toward service use and seven control variables	The study establishes four hypotheses: a) More favourable caregiver attitude toward family responsibility will be associated with lower levels of community service use. Only limited support for this hypothesis through the findings; b) Favourable attitudes or perceptions of service quality will be associated with higher levels of community service use. Same result as in Hypothesis 1; c) Caregiver attitudes will play a role in explaining the use of services that are defined as discretionary, but not personal care that is defined nondiscretionary. Same result as in Hypothesis 1; d) Attitudes, taken together, will improve the explanation of the amount of services used. Hypothesis supported by the findings.

				Consistent with previous research, this study found that factors pertaining to both care recipient and caregiver health need play the most important role in explaining the likelihood of using services and the number of services used. Spousal caregivers were more likely to use services if they trust providers. This suggests that agencies should focus on strategies to build trust
25	Penning, 2002, Canada	To examine the relationship between the extent of formal in-home care received and levels of self- and informal care	Two-stage least squares regression analysis on data drawn from interviews with N=661 older users and non-users of publicly subsidized home care services	No evidence to indicate that more extensive use of formal services is associated with less extensive self- or informal care. The extent of self-care practiced and informal care received are most strongly related to the overall need for care as indexed by the number of chronic conditions and levels of functional impairment. Policies that restrict formal services in order to ensure that they do not undermine self- or informal care or as a means to enhance levels of self- or informal care appear unnecessary and are likely to be ineffective. There are indications that for individuals receiving publicly funded home care services only, more extensive formal care is associated with more extensive self-care.
26	Piercy, Blieszner, 1999, USA	To examine the links among adult children's perceived responsibility to care for elderly family members, other family needs, and their use of formal services	N=28 interviews with family caregivers analyzed by using a multistage process designed for long interviews	Participants stated that it was the family's responsibility to provide an environment that was safe and comfortable for the parent. They felt it was imperative to be sensitive to parents' emotional needs and their desire to have as much autonomy as possible. When it was evident that parents behaved in ways that might harm themselves or others, family members stepped in to perform housekeeping, financial management, and transportation activities – these interventions were labelled paternalism. Although family caregivers did not make distinctions between types of services (discretionary and non-discretionary) when discussing their reasons for obtaining services, the data suggested that use of nondiscretionary services was discussed most often in the context of care recipient need and eligibility for service, whereas use of discretionary services was mentioned most often in the context of caregiver issues and the need to spend time with other family members. Respondents did not appear to make decisions about formal services based on solitary considerations such as perceptions of filial responsibility alone or reactions to formal services alone. Rather, they evaluated the total situation and attempted to balance the needs of

				multiple family members. Such a perspective often led to the desire to use outside help and efforts to make satisfactory arrangements.
27	Porter, 2000, USA	To provide a critical analysis of the pre-eminent approach in the research on home-care utilization	Literature review	Understanding any complex phenomenon requires attention to these problems: (1) identifying the phenomenon's parts. (2) determining relationships among the parts, and (3) identifying changes in the phenomenon. Focused on population risk factors rather than individual behaviors, epidemiologic tests of the Andersen model have not yielded an empirically valid construct of home care need (a critical part of the phenomenon). Tests of relationships among such constructs have not produced conclusive predictions of use. Analyzing changes in use has thwarted in part because prospective longitudinal designs have seldom been employed. Employing these basic arguments this critique of the epidemiologic study of home care utilization is presented as a rationale for descriptive phenomenological study of the experience of home care. The Andersen model was developed and refined within a behaviorist research tradition. With the advent of epidemiological research on health services use, researchers have sought to explain the distribution and determinants of a condition, such as home care use for a 'population at risk'. In theoretical frameworks few home care researchers have differentiated between the behavioural and epidemiologic interpretations. The article then focuses on the problems concerning the definition of constructs/concepts like 'illness', 'need' and 'illness-need'. Concerning the variable 'home care use' it is difficult to dichotomise an entity that has diffuse boundaries. Critique on the Anderson model concerns its limited ability in predicting home care use, the problem that individual determinants, and the contribution of predisposing and enabling factors to explain home care use has been limited, and that the results of various studies have been contradictory. A major problem is that most studies have been conducted as cross-sectional studies although prospective and longitudinal studies have been claimed to have priority.
28	Soldo, Agree, Wolf, 1989,	To consider the prevalence, correlates, and	Literature review	It is concluded that this field is at a nascent stage of scientific study and that the knowledge base is sketchy and, on

	USA	consequences of horizontal integration of formal and informal care systems		some major questions, contradictory
29	Twigg, Atkin, Perring, 1990, UK	To review evaluative research that has been undertaken on different services for family carers	Review of the research	Knowledge concerning the relationship of services to informal care is still deficient and this is true for three areas: policy and practice; levels and patterns of provision for carers, and the effectiveness of services
30	Twigg, 1993, UK	To suggest four ideal types or models of how public service agencies conceptualize their relationship to carers and to examine the implications of these models for the major streams of discussion concerning informal care	Literature review, and own study (see below)	This papers suggests four ideal types or models of how public service agencies conceptualise their relationships to carers: carers as resources, carers as co-workers, carers as co-clients, the superseded carers. There are streams of the debate around the critique concerning informal care. The first one is the feminist critique. It centres on a criticism of the resource model. The second one is the rationalisation of community care. Because of cost implications because of the rising older population policy statements increasingly have emphasised 'the caring capacity of the community'. This approach is exemplified by the carers as resources model. The superseded carers model is completely absent from this stream of debate. The co-worker model only appears in an instrumental fashion, as a cost-effective means of maintaining input into the care system. The third stream of debate is the disability critique. From this viewpoint the superseded carer model is the only appropriate model and within that only the route that emphasises the disabled persons' right to live a life that gives them the maximum of independence and control.
31	Twigg, Atkin, 1993, UK	To analyze factors mediating the relationship between carers and services and address processes that lead to some carers receiving service while others do not.	Literature review, Conference paper	The Andersen/Newman approach assumes that everything takes place in a single mind – that of the potential client – and that he or she is the prime mover in the matter. Three modes of response to the caregiving situation: to be engulfed; balancing/boundary setting, and symbiosis
32	Twigg, Atkin, 1994, UK	To explore the reality of how service providers like doctors, social workers and community nurses respond to carers	Qualitative interviews with family caregivers (N=90) and service providers (N=125)	Family caregivers have been categorised in three main ways: in terms of features of themselves, in terms of features of the cared-for person, and in terms of their relationship.Carers exist off-centre to service provision and they are perceived in terms of carers as resources, carers as co-workers, carers as co-clients and the superseded carer
33	Wan, Thomas T.H., 1989,	To review current knowledge of the determinants of	Literature review	There are methodological problems inherent in the conduct of health services research. The causal specifications of the

	USA	health service use by older persons		Andersen Model were not fully identified in most studies. For the improvement of utilization research, efforts should be directed toward formulating rigorous measurements and conducting longitudinal studies. The relationship between institutional-based services and ambulatory/community-based services utilization needs to be carefully examined.
34	Ward-Griffin, McKeever, 2000, Canada	To describe and analyse the relationship between nurses and female family members caring for frail elders in the home	38 interviews with 23 nurse-family caregiver dyads	The relationships that develop between community nurses and family members caring for frail elders are complex, dynamic, and multifaceted. Shifting boundaries in caring work leads to changes in nurse-family caregiver relationships, which can be categorized as four distinct, but interconnected types: 1) Nurse-helper, 2) nurse-worker, 3) manager-worker, and 4) nurse-patient.
35	Ward-Griffin, 2001, Canada	To describe and analyse the relationship between nurses and female family members caring for frail elders in the home	Critical ethnographic method in a socialist-feminist framework, in-depth-interviews with N=23 nurse-family caregiver dyads	Relationships were characterised by uncertainty and tension. Nurses and family caregivers functioned within and resisted current home-care arrangements, but they engaged in an ongoing process of negotiating cultural assumptions about ‘private’ and ‘public’ caregiving
36	Wielink, Huijsman, 1999, The Netherlands	To address the evaluative criteria of elderly community residents regarding their preferences in cases of long-term care decision-making	Qualitative interviews with N=8 older people, and a quantitative sample of N=76	A good relationship with informal carers appears almost pre-conditional to a preference for informal support. The desire not to burden acquaintances, as well as a positive previous experience with this type of care, are the most important reasons stated for choosing formal or private services. Insights into criteria that are used to evaluate different care arrangements clarify and refine our perspective on future developments.
37	Winslow, 2003, USA	To describe the experience of the use of community services, including benefits and barriers, by family caregivers of relatives with Alzheimer’s disease or a related disorder	Qualitative, descriptive design, interviews with N=21 family caregivers, analysis by using qualitative content-analysis techniques	Family caregivers received benefits of renewal, sense of community, and new knowledge and believed that their patient benefited from the services. Barriers to service use included care receiver resistance, reluctance of the caregiver, hassles for the caregiver, concerns over quality, and concerns over finances.
38	Zeman, 1996, Germany	Clarification of the collaboration between professional and private carers	Literature review, Observation of and discussions with professional and private carers, N= not indicated	Optimal collaboration in mixed care arrangements calls for tailored and systematic efforts of professional carers. Structural problems need to be abandoned on a structural level. The perception of professional carers needs to be sensitive to informal caregiving processes and professional carers need communicative competences. The study calls for a stronger focus on the micro-sociological perspective.
Subject area: Family caregiving and chronic illness				

No.	Researchers, Year, Country	Purpose of the research	Research methodology	Main results
1	Aberg, Sidenvall, Hepworth, O'Reilly, Lithell, 2004, Sweden	To explore perceptions of informal caregivers of very old (80+) relatives regarding the purpose of caregiving	Semistructured interviews with significant others, N=14, analysis according to the thematic framework approach	The general purpose of informal caregiving is: Protection of the care recipient's self. Caregiving categories have been identified as social-emotional, proxy, and instrumental
2	Asbring, Närvänen, 2004, Sweden	To determine strategies that women with uncertain illness trajectories use to gain control over their situation	Qualitative interviews with 12 women diagnosed chronic fatigue syndrom and 13 with fibromyalgia	The women apply various strategies of managing the illness and influence caregivers. They gain control by acquiring knowledge about the illness. They also describe power strategies they use in their interaction with the caregivers to take command of their situation, and those were: exiting, noncompliance, confrontation, persuasion/insistence, making demands, and demonstrative distancing
3	Astedt-Kurki, Lehti, Paunonen, Paavilainen, 1999, Finland	To find out how families experience the hospitalization of one family member and to chart the participation of the family in the treatment of the hospitalized family member.	Questionnaire to family members (N=70) of patients on a neurological hospital ward	The study demonstrated a variety of negative sentiments in the families, such as worry, fear, shock, anxiety and depression at the hospitalization of their family member. The families also expressed neutral and positive sentiments, such as approval, relief and faith in the help given. Nearly 80% of the families' statements dealt with emotional responses. Changes in the everyday life of the family caused by the hospitalization of a family member were also reported, with most changes affecting the immediate family. Hospital visits gave a rhythm to family life. There were changes in the sharing of housework and taking care of affairs, as well as in relationships within the family. Family members spoke of their loneliness, fear and longing. External changes in family life were present in 13% of statements. Helping the patient in hospital involved functions like participation in nursing care, taking the patient to the cafeteria and rehabilitation. Only 20% of statements dealt with emotional support for the patient.
4	Blinkert, Klie, 1999, Germany	To investigate under the conditions of the new long-term care insurance the significance that living in informal social networks has for the selected or emerging care arrangement of elderly people in need of care	Interview with a random sample of 1.234 people	The book provides a 20-page summary of the results

5	Bond, 1992, UK	To review some of the literature on caregiving from social policy and on professionalisation from sociology	Literature review	The context of the article is the care of dementia sufferers with particular reference to the role of family and other informal caregivers. The theoretical contributions on informal and formal caregiving have been dominated by the gender order and the professional order to the detriment of other aspects of structure. In the light of these theoretical contributions the article explores the inherent contradiction in society's desire to provide care to dementia sufferers without compromising the position of informal and formal caregivers. A distinction is made between the sociology of care and the sociology in care. Health professionals have medicalised the care of people with dementia which implies four aspects: Expert control, social control, individualisation of behaviour, and depoliticisation of behaviour.
6	Bowers, 1987, USA	To generate a theory of intergenerational caregiving	Grounded Theory, based on interviews N=60 with 27 parents and 33 of their offspring	Five conceptually distinct, overlapping categories of caregiving were revealed (anticipatory caregiving, preventive caregiving, supervisory caregiving, instrumental caregiving, protective caregiving). Only one of these includes what is generally considered to be caregiving in terms of hands-on caregiving behaviours or tasks. The other four types are not observable behaviours, but are processes crucial to intergenerational caregiving and to an understanding of the experience of intergenerational caregiving.
7	Bowers, 1988, USA	To study family perceptions of nursing home care	Grounded dimensional analysis (a combination of grounded theory and dimensional analysis) based on interviews (N=28) with relatives of nursing home residents	Relatives attributed responsibility for most tasks to nursing home staff, but held themselves responsible for monitoring and evaluating the quality of care, teaching staff to deliver high quality care, and providing direct care intended to preserve the residents 'self'.
8	Brody, 1985, USA	Memorial lecture		It is argued that parent care has become a normative but stressful experience for individuals and families and that its nature, scope, and consequences are not yet fully understood. Some of the complex factors that interact to determine filial behaviour are explored. A hypothesis is advanced that may explain in part the persistence of the myth that adult children nowadays do not take care of their elderly parents as was the case in the good old days. Some of the ways in which social policy responds to knowledge about filial behaviour are noted.

9	Brody, 1995, USA	To explore prospects for family caregiving in the context of policies for family caregiving	Book chapter, based on literature	It is now understood that the 'substitution theory' has no foundation. The field is now engaged in three additional and interrelated stages of research: we are beginning to address diversity among caregivers, there is awareness of the need for longitudinal studies that address change and continuity, and respect for the value of qualitative study has re-emerged.
10	Chang, Horrocks, 2006, Malaysia	To explore the meanings of the lived experiences that Chinese family caregivers in Malaysia ascribed to the care they provided to relatives with severe and persistent mental illness	Qualitative interviews with N=19 Chinese family caregivers,	The impact of the stigma of the relatives' mental illness on family caregivers and families is pervasive and strong. As a result, family caregivers tried to avoid talking about their relatives' mental illness with extended family or friends in order to protect their families from 'losing face'. In addition, most family caregivers believed that adopting positive behaviours and attitudes helped them cope with caregiving.
11	Collins, Stommel, King, Given, 1991, USA	To understand and to measure the attitudes of family caregivers toward community services through the development of the Community Service Attitude Inventory (CSAI)	Focus-group interviews with five focus groups with 6-8 caregivers each, followed by qualitative interviews (N=10) with family caregivers of individuals with dementia	A consistent finding in family caregiver research has been that individuals in the caregiving role, many of whom are providing intensive home care, make little use of community services. Two categories of caregiver attitudes have been reported so far: a) attitudes regarding the acceptability of using the formal service system; b) attitudes about the quality of services. For the development of the instrument three attitudes were identified form the literature: caregiver independence, preferences for informal versus formal care, and caregiver confidence in the community service system. 47 items were used for factor analysis. Five attitude subscales have been developed: Concern for Opinions of others, Confidence in service system, Preference for informal care, Belief in caregiver independence, Acceptance of government services Preference for informal care was the attitude measure with strongest predictive power, the belief in caregiver independence showed itself to be a modest predictor of the frequency of current service use.
12	Conger, Marshall, 1998, USA	To explain some processes used by family caregivers and care recipients with acute conditions to develop and maintain satisfying care relationships in home settings	Grounded theory, Interviews with 9 dyads (care recipient and family caregiver) once, 4 dyads twice and 1 dyad three times	The substantive theory of recreating life that emerged suggests that caregivers and care recipients respond to disrupted realities caused by illness trough redefining self and redefining the relationship. Four mitigating factors affecting the developmental process were identified: a) prognosis, b) progress, c) social support, and d) professional support
13	Corbin, Strauss 1988,	To develop a theory about chronic illness management and to	Grounded theory based on qualitative	The book examines how chronic illness is managed at home, how the management of home care and the illness itself affect

	USA	describe the experience of it	interviews with 60 couples, of which at least one and sometimes both had a chronic illness or disability	the lives of married couples, and how the domestic adjustments made to accommodate chronic illness, in turn, affect the management of the illness. It has been realized that the key players in the drama of accommodating chronic illness at home are the ill people and their spouses, rather than the assisting medical staff. The central concept is that of trajectory. It embodies a sociological perspective on events that are ordinarily and primarily interpreted in medical terms or a combination of medical and psychological terms. The term trajectory focuses on the active role that people play in shaping the course of an illness. It captures implicated aspects of the temporal phases, the work, the interplay of workers, and the nonmedical features of management along with relevant medical ones. Trajectory shapes have two important properties: variability and phasing. Variability is determined by a combination of a) the nature of the illness and the person's physiological and emotional response to it and b) management schemes instituted by health professionals and the ill. The term trajectory denotes not only the potential physiological development of an illness but also the work involved in its management, the impact of illness, and the changes in the lives of the ill and their families that in turn affect their management of the illness itself. A vision of the potential path that an illness and its associated work might follow is termed a trajectory projection, whereas an envisioned plan to manage all of that is called a trajectory scheme.
14	Corbin, Strauss, 1990, USA	To describe the meaning of arrangements in home care and to explore their role in care of the ill at home	Based on the same study as mentioned above	Unlike hospitals the home is not an institution established for the purpose of caring for the ill. When it takes this function, its members must learn the skills, gather the equipment, find the services, and carry out the work as best they can. Home care of the chronically ill is aimed at keeping the illness course stable and managing any associated disability Making of arrangements refers to the process by which agreements are reached and maintained between persons for carrying out the tasks associated with home care. Arrangements can be classified into two broad categories: standing or routine (those that are in place and with them there is no need to work things out each time such resources are

				needed) and temporary (that must be worked out each time they are needed or desired) Arrangements are interlocking, interdependent and in a fragile and complex equilibrium. While many arrangements are based on clear negotiations, persuasion and even coercion, others are more in the nature of implicit understandings. Unsatisfactory arrangements put other family members in the uncomfortable positions of acting too frequently or openly as control agent, reminding the ill of what they are supposed to do.
15	Crist, 2005, USA	To broaden nurse clinicians', policy-makers' and researchers' understandings of what it means to elders to receive family care	Hermeneutic interpretative phenomenology, observations in naturalistic settings and N=9 interviews with elderly people.	Elders living at home were found to incorporate help from family members confortably into their lives. They viewed themselves as autonomous and able to maintain balance between autonomy and dependence on loved ones. Receiving family care may have positive meaning for elders, especially when the care is provided within the context of positive relationships with family carers. These findings are in contrast to previous reports.
16	Davies, 2005, UK	To explore the extent to which Meleis's mid-range theory of nursing transitions is supported by the findings of a stduy exploring relatives' experiences of the move to a nursing home	Secondary analysis of a constructivist study of relatives' experiences of nursing home entry, N=37 qualitative interviews and observational case studies in three nursing homes	All domains of the theory of nursing transitions were supported by the data. The model failed to represent adequately the interactive and dynamic nature of relationships between formal and informal caregivers in the nursing home context.
17	Doty, 1995, USA	To explore implicit and explicit influences on decision making with regard to family caregiving and access to publicly funded home care	Book chapter based on literature	Families rarely withdraw their efforts or substitute formal for informal help when publicly funded home care is made available. Improved access to formal help via public programmes only rarely inspires or encourages families to provide more informal care or to maintain family caregiving for longer periods than they would have otherwise. The best case managers can hope to do is to acknowledge informal resources in such a way that publicly funded help does not mindlessly duplicate or wastefully supplement care already being provided while failing to meet other needs that the family is unable or unwilling to serve.
18	Edwards, Zarit, Stephens, Townsend, 2002, USA	To compare employed and non-employed caregivers of cognitively impaired elderly family members	Using two competing positions derived from role theory, role conflict and role expansion it was explored	No differences between employed and non-employed caregivers on measures of role overload, worry and strain and depression were found. For working caregivers greater conflict on the job was associated with higher role overload and worry and strain while beneficial work

			whether holding the positions of both caregiver and worker led to greater role overload and psychological role conflict, or provided an outlet that helps caregivers better manage the demands placed on them	experiences were only weakly associated with lower role overload and worry and strain. The was an interaction effect between positive work experiences and role overload when predicting depressive symptoms.
19	Eisen, Mager, 1996, Germany	To address inter- and intragenerational decision models with regard to long-term care	Literature and a mathematical calculation model	Family decisions concerning care for the elderly must be viewed as a continuous process in the life cycle of the family. Families or households are regarded as exchange organizations where the members cooperate and produce (Household) specific commodities, especially personal services. A basic characteristic of these personal commodities or services is that they cannot be acquired in external markets or acquired in the desired quality or only at high prices. A distinctive feature of families is the low costs of the intrafamiliary welfare production. Based on this problems with ADL or IADL can be specified as losses in household productivity.
20	EUROFAMCARE, 2005, EU (co-ordinated from Germany)	To provide a European review of the situation of family carers of elderly people in relation to the existence, familiarity, availability, use and acceptability of supporting services	The EUROFAMCARE project consists of several major parts. National Surveys and a Trans-European Survey Report operate on the micro-level of concrete experiences of family care. National Background Reports and a Pan-European Background Report cover the macro-level of national and European policies and their implications. The study is complemented by a Socio-economic Evaluation and a European Policy Analysis.	There is a 12 page summary of the Trans-European Survey-Report available that addresses why family carers do provide care, what the older person’s needs for care are, how the needs are matched to care provision, and who provides what types of support. Policy implications are stated with regard to the EU and the national level, to service providers and to family carer organizations.
21	Fink,	To test a theoretical	Non-random	The hypothesis that the family’s internal

	1995, USA	model developed to explain strains and well-being in families providing care to an elderly patient	sample of N=65 families using the Family Social Support Index (FSSI) and the Family Hardiness Index (FHI)	resources and resources from their social network would enhance family well-being was supported. The hypothesized direct effect of resource variables on family strains was not supported
22	Greene, Coleman, 1995, USA	To address the negative consequences of caregiving and to review services developed to respond to these needs	Literature review, Book chapter	Task-based definitions of caregiving may be inconsistent with the experience of caregiving. Instead caregiving should be defined by its purpose and not by its tasks.
23	Ironside, Scheckel, Wessels, Bailey, Powers, Seeley, 2003, USA	To study the lived experiences of chronic illness	Heideggerian hermeneutical phenomenology	The pattern, Experiencing chronic illness: Cocreating new understanding, and three themes emerged during the analysis of the data. The themes were: a) focusing on functional status does not adequately account for the experience of chronic illness, b) decentering the focus on the treatment of symptoms makes way for equally important discussions of meaning making in the context of chronic illness, and c) the objectified language of healthcare covers over how chronic illness is experienced.
24	Jarrott, Zarit, Stephens, Townsend, Greene, 2005, USA	To focus on the effects of change in the amount of formal and informal instrumental assistance on caregivers' distress	Questionnaire	Increases in formal but not informal levels of assistance were associated with improvement in each measure of distress.
25	Jeon, Brodaty, Chesterson, 2005, Australia	to review research literature over the past 10 years on respite care for people affected by severe mental illness	Literature review	The majority of family caregiving studies identified a need for greater quality, quantity, variety and flexibility in respite provision, and the literature has remained largely silent in relation to those affected by severe mental illness. There are contradictory findings on outcomes of respite care services and a lack of controlled empirical studies and evaluative research on effectiveness.
26	Jussila, 2004, Finland	To explore families' living with a parent with cancer and to develop a susbtantive theory to explain how they solve the main concern in their lives	Grounded theory, 32 joint couple conversation with 13 families and 26 hours of observation in five families	The main concern of families living with a parent with cancer was stabilising of life through facing of hardships and assuming an attitude towards the future which patterned out as detaching from the disease, fighting against the disease, adjusting to life with the disease and submitting to the disease.
27	Lee and Porteous, 2002, Australia	To examine the impact of family caregiving among middle-aged women	Questionnaire on specific items about family caregiving (N=1.775) and open-ended comments (N=185)	The quantitative analyses showed that caregivers experienced more financial difficulties, poorer physical and psychological health, higher levels of stress and higher use of health care services. Content analysis of the comments supported these findings and in addition identified emerging themes including

				difficulies with travel, inadequacies in health and welfare systems, a sense of exploitation and fear for the future.
28	Li, 2005, USA	To explore the kinds of worries that family caregivers experience when their older relatives are hospitalized	Qualitative study based on N=10 intensive interviews and participant observation	Family worry was defined as family caregivers' feeling difficulty in fulfilling their roles because of worry. Four categories of family worry were identified as a result of this study: 1) worry about the patient's condition, 2) worry about the patient's care received from the health care team, 3) worry about future care for the patient provided by the family caregiver, and 4) worry about finances.
29	Löfmark, Hammarström 2005, Sweden	To analyze from a gender perspective how elderly women and men responded to treatment and care after stroke in the acute care setting	Grounded theory based on interviews with 7 women and 5 men	In the hierarchic medical context, the participants used four kinds of negotiations. These negotiations were either resistant (striving for autonomy and criticizing the care) or adjustive (following the rules and building alliances) to the hierarchic structure.
30	McCallion, McCarron, Force, 2005, USA	To focus on the development of a measure of subjective burden, The Caregiving Difficulty Scale – Intellectual Disability (CDS-ID)	An existing caregiver burden scale – the caregiving hassles scale (CHS) was adapted for use with 203 staff caregivers of persons with Alzheimer's disease and intellectual disabilities	On the existing CHS items, staff carers appeared to experience greater subjective burden than has been reported for family caregivers. The psychometric properties of the CHS found with this population were poor. Factor analysis produced a revised scale, the CDS-ID with three subscales with Cronbach alphas ranging from 0,75 to 0,93 and 38 items overall.
31	Morse, Johnson, 1991, Canada	To explore the illness experience	Theory building out of five grounded theory studies on the experience of living with chronic illness	The Illness-Constellation Model views illness as an experience that affects the sick person and his or her significant others. The ramifications of the individual's illness experience cause profound changes in the interactions, roles, and relationships of those involved in the illness experience and result in a loss of normalcy. The task of regaining normalcy, of regaining former roles and relationships with others is a legitimate task that must be resolved before the person regains a high level of wellness. In the Illness-Constellation Model the illness experience is defined as a four stage process: Stage I: Stage of Uncertainty; Stage II: Stage of Disruption, Stage III: Stage of striving to regain self, and Stage IV: Stage of Regaining Wellness
32	Navaie-Waliser, Spiggs, Feldman, 2002, USA	To examine gender differences among informal caregivers in caregiving activities, intensity, challenges, and coping strategies and to assess the differential effects of	Cross-sectional design using telephone interviews with a representative sample of N=1.002 informal caregivers	Compared with men caregivers, women caregivers were significantly more likely to be 65 years of age or older, black, married, better educated, unemployed, and primary caregivers. They provide more intensive and complex care and they have difficulty with care provision and balancing caregiving with other family and employment responsibilities. Women

		caregiving on their physical and emotional well-being		caregivers suffer from poorer emotional health secondary to caregiving and cope with caregiving responsibilities by forging respite participation and engaging in increased religious activities.
33	Öhmann, Söderberg, 2004, Sweden	To elucidate the meaning of close relatives' experiences of living with a person with serious, chronic illness	Phenomenological, hermeneutic study based on narrative interviews with 13 spouses and 1 daughter.	Three major themes were revealed: A shrinking life, forced to take responsibility, and struggling to keep going. Close relatives in this study seemed to be living lives characterised by a reduced sense of individual freedom and an increased sense of responsibility for the care of the ill person. It means struggling to obtain the strength to manage their duty and an inner sense of community and of solidarity.
34	Ostwald, 1997, USA	To investigate caregiver exhaustion and its negative consequences for the caregivers themselves and their loved ones	Questionnaire, N=245 family caregivers	56,4% of caregiver exhaustion was predicted by three factors: lack of personal time, employed in a paid job outside the home, and frequent behavioral problems in the care recipient.
35	Pot, Zarit, Twisk, Townsend, 2005, The Netherlands	To examine the associations between transitions in paid home care and stress appraisals and psychological well-being of family caregivers of dementia relatives	Longitudinal study with N=264 caregivers who completed up to 3 interviews during one year	The onset of paid home care was associated with increases in feelings of worry and strain and a worsening in positive effect. Ending paid home care was strongly associated with a decrease in depressive symptoms, whereas sustained use of paid home care was related to reduced overload.
36	Sansoni, Vellone, Piras, 2004, Italy	To examine anxiety and depression among Italian Alzheimer's caregivers	The situation of N=34 caregivers was investigated over 816 caregiving days by using a descriptive, repeated measures design	Caregivers suffered high levels if anxiety (76%) and depression (42%). Statistical analysis showed that the anxiety and depression scores were positively correlated with hours of care, physical and psychological illness scores, and negatively correlated with level of education and time for leisure activities. No significant correlations were found with the Mini Mental State Examination scores, demonstrating that the burden of care is large, irrespective of the extent of mental impairment.
37	Savishinsky, 1990, UK	To consider the conditions faced by dementia sufferers and their family carers and to formulate programs and policy initiatives	Anthropological research	Many families hoped to remain self-sufficient in providing home care, but they then wanted quick, sensitive responses when they did turn to others for aid. It was found that the first attempts of carers to get help could affect their future attitudes toward community ressources and that their feelings about the responses they got could shorten or lengthen the time it took for them to get meaningful assistance. People consistently presented a self-image that stressed their family role rather than emphasize a primary or even distinct identity as a caregiver („I'm a wife who cares, not a carer who just happens to be a wife")
38	Schnepp,	To investigate how	Grounded theory,	Caregiving among Russo-German

	2001, Germany	Russo-german resettling families experience and perform caregiving and which factors influence the experience and the performance of caregiving	58 interviews with 81 informants and field observations	resettlers is to be seen as part of comprehensive family care and support. They stem from the collectivistic family orientation. The need for family care is perceived as simply given and is experienced as a *must*. Because of the biographic experiences and the experiences of immigration the caring behaviour of Russo-German resettlers is not necessarily congruent with those practised in Germany and not at all congruent with those of professional carers. This has an impact on the utilization of professional support. In order to provide helpful and meaningful support professional carers have to take into account the whole system of family carers and have to avoid the separation of the family.
39	Schreiner, Morimoto, Arai, Zarit, 2006, USA	To determine a statistically valid cut-off score fort he Zarit Burden Interview (ZBI) in order to identify family caregivers at risk for depression and in need of further assessment and intervention	The ZBI and the Geriatric Depression Scale were adminstered to three different groups of family caregivers: stroke caregivers (N=80), COPD caregivers (N=48) and general disability caregivers (N=70)	The findings suggest that a cut-off score ranging from 24-26 has significant predictive validity for identifying caregivers at risk for depression. A ZBI cut-off of 24 correctly identified 72% of caregivers with probable depression.
40	SOCCARE, 2003, Finland, France, Italy, Portugal and UK (co-ordinated from Finland)	To discover how public policies and social services can more efficiently and responsively help families to cope with their care responsibilities and to combine these with employment.	The project interviewed almost 400 European families in detail about their opportunities and difficulties to make flexible and responsive care arrangements and to combine these with participation in paid employment. The interview data was analysed mostly at the national level and then compared.	According to the final and most general recommendation of the SOCCARE Project, it is highly necessary that policies do away with strict dichotomies. Citizens of Europe are not either workers or carers. They are both at the same time. As well, children, disabled people and older people are not in need of either informal or formal care. Both are essential and practically always, there is a need to integrate both at the level of everyday family life. To face the challenges of the future, an integrated policy perspective on work and care is required in Europe.
41	Starke and Ühlein, 1999, Germany	To investigate a) how the situation of family caregivers determines, whether, to what extent and when professional help is asked for; b) which types of burden are considered particularly serious; and c) in which areas	Qualitative approach, Problem-centered group interviews, 20 participants	Family caregivers are due to their caregiving tasks close to exhaustion, at the same time they are reluctant to use existing support options, and particularly in those areas, where they perceive the most burden, there are no services available

		the readiness to utilize professional support can be identified		
42	Tanyi, 2006, USA	To propose a guideline for spiritual assessment and interventions for families while considering each family member's unique spirituatlity	Guideline development based on literature and exemplified by case studies	The paper argues that despite the rhetoric about incorporating spirituality as part of total family assessment there is a dearth of such guidelines. As a beginning solution guidelines are proposed for spiritual assessment and interventions for the family as a unit, and the category of spiritual interpretation to represent diagnosis is introduced.
43	Tesch-Römer, 2001, Author from Germany on a European Study	To explore the topic of caregiving and intergenerational solidarity	Literature review	Caregiving is not a static situation, but a process in time. This is true for both care recipient and caregiver. The process of caregiving is related to somatic, personal and social factors of the care recipient. There is a decision process within the family concerning the involvement of 'outsiders', either as bringing social care services to the home of the care recipient or as moving the care recipient into a long-term care institution. On the family level it is still unclear which factors influence the decision process of involving formal services outside the family.
44	Thompson, Futterman, Gallagher-Thompson, Rose and Lovett, 1993 USA	To investigate whether different types of social support are equally associated with burden and whether the different types of support correlate with different types of burden	Measurement instrument for caregiving context, social support and caregiving burden were used (N=217) and analysed via multiple regression analyses	All types of social support for frail elders are not equal. Engaging in social interaction for fun and recreation appears to be the most important in diminishing the burden of caregiving. Interventions that focus on caregivers regularly experiencing pleasant activity with friends and other family would seem to go a long way toward managing the burden of caregiving.
45	Thorne, Paterson, Acorn, Canam, Joachim, Jillings, 2002, Canada	To report insights obtained from an extensive and exhaustive metastudy of qualitative studies of chronic illness experience	Metastudy of 292 qualitative studies on chronic illness	To read research reports between various disciplines and theoretical perspectives is to read the narrative text of each discipline's interest in chronic illness, perhaps of each discipline's interest in human nature and life experience itself. It is important to acknowledge that the very notion of chronic illness is itself contested, both by those who experience it and by those who study it
46	Verhaeghe, Defloor, Grypdonck, 2005, Belgium	To structure the available information on the psychological reactions of family members confronted with traumatic brain injury	Literature review based on the theoretical framework of systems theory and stress-coping theory	The level of stress experienced by family members of patients who have traumatic brain injury is such that professional intervention is appropriate, even after 10-15 years. Not the severity of the injury but the nature of the injuries determines the level of stress. Partners experience more stress than parents. Children have specific difficulties. Young families with little social support, financial, psychiatric and/or medical problems are the most vulnerable. Coping with traumatic brain injury can be described in phases. The

				better family members can cope with the situation, the better the patient's recovery. There are functional and non-functional coping mechanisms and coping is influenced by such factors as gender, social and professional support and the possibility to have reciprocal communication or an effective relation with the patient. Support from professionals reduces the stress being experienced and encourages people to cope effectively.
47	Verhaeghe, Defloor, van Zuuren, Duijnstee, Grypdonck, 2005, Belgium, The Netherlands	To structure the available scientific knowledge on needs and experiences of family members of intensive care unit patients with particular extension to coma patients.	Literature review	Needs are divided into four categories: cognitive, emotional, social, and practical needs. The need for accurate and comprehensible information that leaves room for hope is universal. Family members want to speak to a doctor every day about the condition of and the prognosis for the patient, and want a nurse to explain to them about the care, the unit, the equipment and what they can do for the patient during visiting hours. Family members place great importance on being called at home if the condition of the patient changes. Emotional needs as hope, reassurance and being able to remain in the vicinity of the patient are crucial
Subject area: Home care nursing				
No.	**Researchers, Year, Country**	**Purpose of the research**	**Research methodology**	**Main results**
1	Barr, 2006, UK	To provide an overview of the changes in the caseload and working practices of community nurses for people with learning disabilities (CNLDs) over an 11-year period within one region of the UK.	survey design,the total population of CNLDs within one region was asked to complete a postal questionnaire.	Results showed less involvement with children, more focus on adults with physical and mental health needs and nurses often appeared to have a monitoring rather than an active clinical role. Data also identified an increasing caseload size
2	Benzein, Johansson, Saveman, 2004, Sweden	To explore district nurses' beliefs about families in home care	Explorative, descriptive design using focus group interviews with five district nurses on three different occasions	District nurses hold two distinct beliefs towards families in home care: families are a resource or a burden. Resource refers to being a resource for the patient, for other family members and for the nurses. Families were considered a burden when they were experienced as demanding in various ways, e.g. when family members did not act in the way that pleased the nurses or when they showed their suffering.
3	Boes, 2003, Germany	To illuminate and understand the contribution of nurses in home care according to their own viewpoint	Grounded Theory, interviews, N=9	Nurses aim at keeping the care recipients at home for as long as possible. In order to achieve this, nurses perform interventions voluntarily such as managing household work and emotional support. These actions depend on the

				relationship between the nurse and the care recipient, the situation itself and the professional attitude of the nurse.
4	Bradley, 2003, USA	To assess the health of family caregivers	Questionnaire, data collected from 51 family caregivers by nurses	Appr. half of the caregivers reported poor or fair health, with a third reporting a decline in their health over the previous 6 months. Unmet health needs included the need for blood pressure monitoring, mammograms, PAP smears, and prostate examinations. Further needs included referrals to other health care providers or community agencies, health teaching, and home care for the caregivers themselves
5	Büscher, Boes, Budroni, Hartenstein, Holle, 2005, Germany	To investigate the impact of an alternative reimbursement scheme for home care on nursing care delivery	Case study and action research design, 40 interviews with nurses, nurse managers and older people in need of care	The impact of the alternative reimbursement scheme were different for nurses and care-recipients. While nurses had the subjective perception of having more time to provide care, the care-recipients stated that the new scheme does not change the amount of time that the nurses have for them. Six activities emerged as being different from the are nurses provide under the regular reimbursement scheme: performing negotiation processes, continous evaluation of the situation, organising everyday life, being a social contact person, promoting abilities and resources, and providing security.
6	Coffman, 1997, USA	To explore the experiences of nurses working with families of technology-dependant children and to gain a deeper understanding of the meaning of home care nursing in long-term care situations	Phenomenology, 10 interviews with nurses working in home care	As the overall theme 'stranger in the family' was identified. Essential themes included: advocating for the child, blending with the family, maintaining family boundaries, empowering the family, working as a team, and holding a job. Although nurses commented on their increased autonomy and satisfaction in the care of the child, they also acknowledged their status as employees of parents and agencies. They described difficulties in relinquishing control over the child's care and the resulting feelings of vulnerability. Home-care nursing can be compared to an exploratory expedition in which nurses are sent out to discover an redefine the boundaries of contemporary professional practice.
7	De Vliegher, Paquay, Grypdonck, Wouters, Debaillie, Geys. 2005, Belgium	To gain insight into the core interventions in home nursing	Descriptive, quantitative, cross-sectional study using two questionnaires based in the nursing intervention classification, N=501 nurses	Self-care assistance, (im)mobility and (psycho)social interventions are the most frequently performed interventions in home nursing, but they are performed and can only be interpreted in combination with other, more technical interventions. These interventions can be considered the core interventions in home nursing.
8	Dill, 1990, USA	To examine the care planning process of home care services and to analyze ways	Ethnographic study, participant observation over 18 month on a	In making judgements about client needs and decisions regarding their care, case managers were guided by two sets of interpretations: those derived from

		in which service providers interpret the homelives (the experiential and symbolic dimensions of life at home) of clients	caseload of 250 clients drawn from one district of a major metropolitan area	clinical perspectives and those engendered by the logistics of service delivery. There were certain predictable variations in the perspectives of the nurses and social workers. The nurses focused more on the physical functioning and medical conditions of the clients while the social workers were more concerned with family relationships and socio-emotional functioning of clients. A central element in the mutual clinical perspective was that both classified the home situations according to their pathological implications.
9	Dunne, Sullivan, Kernohan, 2005, UK	To explore district nurses' experiences of providing palliative care for patients with cancer and their families	Husserlian phenomenological approach with a purposive sample of 25 female district nurses, analysed using Colaizzi's seven stages of data analysis.	Four themes were identified: the communication web; the family as an element of care; challenges for the district nurse in symptom management and the personal cost of caring. District nurses' experiences of providing palliative care to family units was challenging but rewarding. The emotive nature of the experience cannot be under-estimated, as many district nurses were touched by the varying situations
10	Emmrich, 2002, Germany	To investigate the meaning of the work of family caregivers from the perspective of home care nurses	Ethnomethodology according to Spradley, 30 participant observations in 14 households and 8 interviews with home care nurses	Three domains were analysed: ways to perform care, ways to perform 24-hour care, and ways to determine care. Those domains reflect the actions of nurses and family caregivers as well. They also reflect how ways of caring performed by family caregivers were integrated into the nurses' professional procedure.
11	Evers and Rauch, 1998, Germany	To investigate the aspect the personal help and support aspects of formal care provision and the communication and interaction with the recipients of the formal services	A) Qualitative approach, semi-structured interviews with managers of nursing homes and home care services, N=16 B) Based on A development of a questionnaire for all home care services in the community, N=20	The structures and characteristics of the service providers have changed. Brochures of services pretend more different services than actually are provided. Home help services and supplementary services only play a marginalized role, but there is an increasing need that probably is met by the 'grey market'. While LTC- and sickness insurance are the main funding organisations for home care delivery private payments don't have any significance. The nursing staff consists of qualified personnel in terms of nurses and elderly care nurses. Collaborations between different providers and between nursing care and medical care services are not the result of planned efforts.
12	Larson, Franzen-Dahlin, Billing, Arbin, Murray, Wredling, 2005,	To determine the impact of a nurse-led support and education programme for improving the spouses' perceived general quality of life, life situation,	Longitudinal, randomized controlled trial. 100 spouses were randomly assigned to intervention or control groups, 50 in each group. Both	No significant differences were found, between intervention and control groups, over time. In the sub analyses, we found that the group attending 5–6 times had a significant decrease in negative well-being and increased quality of life over time, while the group attending fewer times had a significant decrease in

	Sweden	general well-being and health state.	groups were followed for 12 months.	positive well-being and health state, similar to the control group, which also had a significant decrease in negative and general well-being.
13	Lee, Craft-Rosenberg, 2002, Korea	To discuss the label, definition, defining characteristics, and related factors of a proposed nursing diagnosis 'ineffective family participation in professional care'	Literature review	Although a number of family related nursing diagnoses exit, none really addresses the problems encountered if family members are unwilling or unable to participate in patient care. The proposed nursing diagnosis 'ineffective family participation in professional care' has been submitted to the Nursing Diagnosis Extension and Classification for consideration.
14	Magnusson, Hanson, 2005, Sweden	To describe a cost analysis of a home-based support service for frail older people and their family carers using information and communication technology	Case study methodology involving five families, part of a larger project called ACTION (Assisting Carers using Telematics Interventions to meet Older Persons' Needs)	Cost savings were achieved in all cases, and the benefits to older people and their carers were also considerable. As a result of the cost analysis and overall evaluation data, ACTION has been implemented as a mainstream service in the municipalities involved..
15	Magnusson, Lützen, 1999, Sweden	To identify and analyse ethical decision making in home of persons with long-term mental illnesses	Interactive dialogue in three focus groups was anlysed using constant comparison analysis	As a central theme the moral symbolic meaning of 'home' was identified. Health care workers experience a conflict between their professional role and their moral role, which they perceive as unclear.
16	Peden-McAlpine, Tomlinson, Forneris, Genck, Meiers, 2005, USA	To discuss the design , evaluation and outcomes of a reflective practice intervention (RPI) on how to incorporate family intervention	Phenomenology, based on interviews with N=8 nurses	Three interrelated themes describe changes in the nurses' experiences as a result of participating in the RPI: 1) acknowledging and re-framing preconceived ideas about families, 2) recognizing the meaning of family stress, and 3) beginning to incorporate the family into nursing care. The RPI stimulated double loop learning that changed pediatric critical care nurses' attitudes about family, enhanced their communication and ability to build trusting relationships with families and brought about a new appreciation of the uniqueness of family stress. There was a new integration of family care into the nurses' practice as a result of the intervention.
17	Roelands, van Oost, Depoorter, Verloo, 2005, Belgium	To describe some of the conditions for effective counselling	Postal questionnaire developed within the organising framework of the Theory of planned behaviour was sent to home nurses and home care workers, N=168 home nurses and N=601	Formal caregivers indicated that knowing the diagnosis was important, but it could facilitate or hinder caregiving. The were able to describe behavioural characteristics which are indicative of dementia, but only in a limited way, and their strategies to uncover the diagnosis were also limited. Formal caregivers reported that they supported family caregivers emotionally, advised about communication with the person with

			home care workers were included in the analysis.	dementia and informed family caregivers about services.
18	Sjöblom, Pejlert, Asplund, 2005, Sweden	To examine nurses' view of the family in psychiatric care.	Four focus groups, with four to six carers in each group, were conducted and interpreted using content analysis.	The results present four themes: compassion for and understanding of close relatives, the carer as the recipient of negative feelings, difficulties and dilemmas in the meeting with close relatives and preconceptions of mental illnesses in the family and in society. The results were interpreted as meaning that the carers found themselves in something that can be described as a double-bind situation.
19	Spiers, 2002, Canada	To describe interpersonal contexts of negotiating care in home care nurse-patient interactions	Qualitative ethology for video-based research, based on 31 videotaped visits	The interpersonal contexts were negotiation of a) territoriality, b) shared perceptions of the situation, c) an amicable working relationship, d) role synchronization, e) knowledge, and f) taboo topics. The study demonstrates how both nurses and patient are both empowered and made vulnerable through everyday conversation.

Appendix 2: Press release for gaining access to ínterview partners in the fifth phase of data collection for data set seven.

WAZ „Aus dem Ruhrgebiet"
Mo. 28.02.2005

Uni Witten sucht Pfleger und Pflegende

Für eine Studie über das Verhältnis von pflegenden Angehörigen und Pflegekräften sucht die Universität Witten/Herdecke Betroffene. In einem 30- bis 60-minütigen Gespräch sollen sie über ihre Erfahrungen sprechen. Die Interviews finden im Rahmen einer Doktorarbeit am Institut für Pflegewissenschaft statt. ☎ 02302/926-360, -301 oder E-Mail: buescher@uni-wh.de. (WAZ)

WAZ, Witten, Mo. 28.02.2005

Uni sammelt Auskünfte über Pflege

Für eine Studie über das Verhältnis und die Zusammenarbeit von pflegenden Angehörigen und professionellen Pflegekräften werden Betroffene gesucht, die bereit sind, in einem 30- bis 60-minütigen Gespräch von ihren Erfahrungen zu berichten. Die Interviews finden im Rahmen eines Promotionsprojekts an der Uni Witten, Institut für Pflegewissenschaft, statt. Die Studie wird durchgeführt von Diplom-Pflegewirt Andreas Büscher. Information und Anmeldung: ☎ 926 360 od. 926 301.

Translation (text on the left):
University of Witten looks for Nurses and Caregivers
For a study on the relationship between family caregivers and nurses the university of Witten/Herdecke is looking for interview partners. They are asked to share their experiences in an interview of 30 – 60 minutes. The interviews are conducted as part of a PhD study at the institute of nursing science. Telephone: 02302/926-360, -301 or E-Mail: buescher@uni-wh.de
Published in Westdeutsche Allgemeine Zeitung, 28 Feb 2005, Section: Aus dem Ruhrgebiet ('from the Ruhr area') – regional part

Translation (text on the right):
University collects information about nursing care
For s study on the relationship and the collaboration between family caregivers and nurses it is looked for people who are willing to report on their experiences in a 30-60 minute interview. The interviews are conducted as part of a PhD study at the institut of nursing science at Witten/Herdecke University. The study is conducted by Diplom-Pflegewirt Andreas Büscher. Further information and contact: 926-360 or 926-301.
Published in Westdeutsche Allgemeine Zeitung, 28 Feb 2005, Section: City of Witten – local part

Appendix 3: Substantive Codes from data sets 1-4

Codes from interviews with family caregivers		
No.	Label of the code	Memo on the code
1	Perception/Knowledge of the illness/dependency	There are clear indications of strong physical limitations associated with higher demands for the caregiving relatives. Bed-riddenness is not described in detail, but serves as a predictor for the involvement of a nursing service. Consequences of the degree of illness/dependency are quite different as in one case a husband refers to his wife as a 'living dead' whereas in another case a son is always eager to achieve even smallest improvements in the quality of life of his mother.
2	Gaining expertise	This concept could also be labelled as 'becoming knowledgeable' or 'becoming an expert'. Caused by the need/motivation to care the caregivers have to achieve a certain level of expertise. This is done voluntarily and involuntarily. It may be done alone, within the family network, with the nurse, in contrast to the nurses. It is a process over time that due to the particular circumstances in a given situation is joyful or burdensome.
3	Competing demands	Competing demands conceptualize the actual circumstances of caregivers and refer to demands between family obligation, family caregiving and job demands. They are voluntarily as well as involuntarily.
4	Assuming responsibility	refers to the caregivers responsibility for the caring process and the tasks involved. They involve the care recipients well-being. In general caregivers assume full responsibility. There are incidents where shared responsibility with nurses leads to a relief of burden and others where it leads to monitoring of nurses.
5	Confidence level	The confidence level refers to the caregivers trust in their own abilities to handle and manage the care process. It is not a static concept, but it develops and is expressed in different ways.
6	Recognition of limits	is the perceived or actual recognition that not all requirements of the care situation are manageable by the caregivers. Mostly it is related to physical limits. Bed-riddeness is mentioned as the driving factor where the limit is reached. The recognition of limits is somehow determining if and to what extent and for what tasks a nursing service is involved.
7	Cultural/personal beliefs	involve cultural and/or religious influences that are a driving factor for the caregiver to assume the responsibility for the caregiving process and its actual organisation.
8	Distancing oneself/limiting personal involvement	is expressed in terms like 'I don't give everything' or 'I keep something for myself' or 'I take care of myself'.
9	Help-seeking behaviour	involves the active search for help and support and includes the role of self-help groups. Caregivers act differently on this. While some are eager to learn about the broad range of services and make optimal use of them others are more reluctant to search for and involve external help.
10	Making use of services and benefits	refers to the use of different options that are available on the care market.
11	Perception of the sick relative	is related to the relationship that caregivers and care recipients have/had to/with each other. It is the driving factor why caregivers take over the care, their motivation.
12	Exposure to strangers	is expressed by a care recipient who wouldn't like to be exposed naked to strangers and where the caregiver tries to respect this wish.
13	Protecting and comforting	is what the caregivers do for/to the care recipient. It's a strongly expressed aim of what they want to achieve in the whole process.
14	Trust building	Trust building involves a process between family caregivers and nurses. It depends on general attitudes towards nursing services on the one hand and to various considerations on the other (such as practical arrangements and the perception of the impact of particular actions on the care recipient). It results in complete mutual trust in which the nurses are considered 'part of the family', smooth integration of the nurses into

		everyday life, and awareness on part of the caregivers that leads to monitoring and observing of what the nurses are actually doing.
15	Perception of/experiences with professional behaviour	This concept is related to the perceived or actual behavior of nurses and nursing services. It is also related to actual experiences in one's own home or other peoples' homes. It occurs in positive as well as in negative terms.
16	General attitudes towards nursing services	refers to a matter-of-fact estimation of what nursing services have to offer and what not. It is a very neutral statement that considers nursing services first and foremost as public services that underlie particular rules and are not always available when they are needed. The expectation of expertise is one of the attitudes expressed by caregivers.
17	Sharing tasks and responsibilities	between caregivers and nurses explains on the one hand how the work involved in the caregiving process is organised. It also explains how tasks are distributed among different family members. Sharing of responsibilities may be a kind of relief for caregivers as the involvement of nurses allows for sharing of responsibilities while the caregiver never gives up the main responsibility.
18	Monitoring and observing	occurs where there is a more distanced relationship between nurses and caregivers. Caregivers observe carefully the nurses actions and interfere when they have objections or doubts.
19	Different perceptions of need and situation	This code refers to the definition of the situation from the caregivers point of view. There are incidents for a different definition between nurses and caregivers that lead to negotiating, struggling, or arguing. Caregivers refer to different levels of knowlegde between them and the nurses with the former knowing more about the patient. One puts it as: I knew, they didn't.
20	Feeling of security	is described as a good outcome when the involvement of a nursing service leads to a state that is considered stable.
21	Differentiating between individual nurses	includes the fact that caregivers perceive individual nurses' actions, behavior and performance differently and leads to preference for particular nurses coming into the home. The process of differentiating follows no clearly defined criteria. It occurs during the direct encounters that caregivers and nurses face.
22	Family relationship	The family relationship is an underlying pattern or an openly expressed concept in the interviews. It occurs in three differents ways: a) Processural: It is referred to as a process when out of a normal family relationship a caring relationship is established. This may happen as an acute event within a second, which results in a general **Life deterioration**, out of which a new routine of everyday life has to be re-established. Or it may happen as a slow, hardly recognizable process in which there is no clear cutting point at which relatives turn into caregivers. b) emotions and ties: This property of family relationships involves the feelings that family members have for each other and that determine the relationship during the care process. It mostly accounts for the motivation of caregivers to care, but it also determines how everyday life is organised and how relatives organise and plan the care process. c) supporting network: The family relationship is described in terms of how support is provided. This ranges from being available and stepping in to active involvement on particular tasks and finally joint decision-making.
23	Cutting point/Life deterioration	refers to the home care situations where it all starts with an acute event. It marks the begin and has different implications compared to the slow process that can be traced in other situations where there was sufficient time to make the arrangements necessary.
24	General life decisions	have an influence on the caregivers actions. They involve decisions about nursing home use, financial matters and questions of inheritance. They also involve decisions that caregivers made themselves on their own life. Caregivers accept decisions that have been made when the care recipient was capable of participating in such decisions, but they may be subject to change when the care demands are unbearable.

25	Practical considerations and arrangements	involve the planning and circumstances of the care process. They have an influence on the relationship between formal and informal care as they are related to **Trust building** and **Confidence level**.
26	Control and predictability	refers to the question of who is in charge of the situation. Predictability helps to make arrangements concerning the whole caregiving process. Being in control is quite important as it determines the confidence level. It also refers to everyday tasks and routines that need to be in control.
Codes from interviews with nurses		
1	Legislative framework for nursing care	This framework is not described in detail. It is more the impact of it that concerns nurses. They have to face scarce ressources which are reflected in the contract between the patient and the service and the monthly settlement. Within the nursing service the framework is implemented by managerial orders on daily performance that may cause a conflict between individual nurses and the head nurses. Nurses' options are determined by the 'tour' they have to do every day and that is usually planned by the head nurse. From the nurses' perspective the patients are at risk due to the resources. This is reflected in statements such as 'they have the option between eating and toiletting' or 'our performance is based on purse rather than needs'. Beside these more burdensome aspects the framework provides security in everyday work and it distinguishes between what is considered a nursing problem and what is not.
2	Feeling restricted	All nurses report on time-constraints in their everyday work. This results in a feeling of always having to hurry-up. This feeling is an inner feeling that seldomly is expressed openly towards patients and families. Feeling restricted is a result of the above mentioned 'legislative framework'. For the work in people's homes the consequences of feeling restricted are: balancing different patients' needs, performing 'by the way', and unability to apply professional knowledge.
3	Being a professional	The low image of the nursing profession is reflected in a tendency towards piece-work and in the non-willingness to pay for nursing care on part of the patients and families. There is a strong emphasis on the distinction between general nursing (which appears to be related to more medical aspects) and elderly care nursing (related to more social aspects). The nurses consider themselves in terms of professionalism, but have difficulties in determining what exactly that means. It may be distinguished in: **3. a) Nursing tasks:** Grundpflege (basic care, which in the German system basically means taking care of the personal hygiene of patients), taking care of medical prescriptions, drugs, assistive devices, prevention, domestic care, counselling/advising on nutrition, incontinence care, 'fine' nursing care (refers to tasks related to medical prescriptions) and 'dirty' nursing care (refers to aspects like incontinence, vomiting etc) **3. b) Good nursing care** is described in terms of: having done something, good looking patients, mobility, recognition of illness, increased self-care, well-being, bridging to the outside world, happiness, motivating **3 c) Characteristics of (home care) nursing:** Nursing is like love, conflict between being a human being and being a professional, balancing competing demands, improvising, individualising patient situations and nurses performance, stressing of differences between nurses, role of sympathy and antipathy. In addition the following aspects were mentioned: reasoning about decisions, working independently, relying on oneself, independent decision-making, establishing routines, performing multi-tasking.
4	Being in charge	refers to the general responsibility that nurses perceive in home care. There is a distinction between single-person and multi-person households. In the latter responsibility may be given away to relatives, but basically the nurses consider themselves of being in charge of the whole process.
5	Reflecting on aging	Nurses consider their work in terms of thinking of aging in general and

		their own age in particular. Being confronted with their patients they think of how their own age will be and they have a clear image what they don't want for themselves. Reflecting on aging serves as a reason for 'feeling for patients'.
6	Involving/distancing oneself	describes the everyday struggle of nurses concerning what they call personal involvement. To some extent they are all involved personally somehow. Because of that all state the need to distance themselves from work which is not always successful. This causes burden on the nurses' families and relationships. Different strategies are applied to limit personal involvement. One of those is reference to the contract that allows for a professional distance in case of demanding patients and problems.
7	Feeling/advocating for patients	Nurses describe strong feelings for patients and see advocating as one of their roles. Advocating stems from the close relationship they have to patients. It involves justification of the own role in terms of assuring continuity in home care. Non-involvement of nurses would mean a risk of degradation and neglect for the patients. Feedback from patients helps with own feelings and the own role.
8	Being a guest	in peoples homes is a main feature of home care nursing. It includes respect for patients' and relatives' privacy and property.
9	Building of trust and relationship	is stated as one of the key aspects of home care nursing. It is not clear how it occurs. While some nurses state that it is a 'feeling' and a spontaneous approach, others look specifically for behavioral patterns of patients and families and try to trace cues on how the relationship will develop. A feeling of trust is a prerequisite of good nursing care. In general, how the process evolves depends strongly on the attitudes and characteristics of the persons involved. On part of the nurses, creating an atmosphere is a strategy for the process of trust-building. It involves listening, being interested and observing.
10	Handling/managing problems	problems occur with patients and relatives. They are related to disturbances in the daily performance or in the relationship. There seems to be a problem with patients with mental disorders. Nurses state a hierarchy of problem-solving approaches: direct discussion with patients/relatives, putting it on record, involvement of the nurse manager.
11	Perception of physicians	is problematic in terms of different assessments of the patient situation, initiating the involvement of a nursing service, doing the prescriptions necessary
12	Interfering relatives	are those who make matters complicated. They are described as non-understanding, demanding, and the 'worst factor of home care nursing'.
13	Collaborative relatives	are described as helpful and supportive. They are considered as not knowledgeable, but they are used in the caregiving process. They may take care of sufficient supply of drugs and devices, take care of cooking and laundry and they provide information about the patient. The dyad of a couple is recognised as the unit of care without specific actions implied. Interfering and collaborative relatives are also referred to as good ones and bad ones.
14	Involving relatives	includes giving explanations, getting them to work, pushing them. The perspective is on the care of the patient. It also involves exchanging observations and reliance on the family on part of the nurses. On the positive side it asks for a good partnership, joint decision-making and finding agreements.
15	Criticising relatives	applies to those who opted for cash benefits. They are suspected of not providing adequate care.
16	Being a mediator	includes mediating between relatives and patients in case of arguments or conflicting interests. Nurses tend to stay out of those problems, but feel sometimes caught in it.
17	Easing the relatives' situation	A prerequisite is the recognition of the relatives' situation as problematic and burdensome, which is described as 'they cross limits, they are caught between love and obligation'. A relief can be giving them time off when the nurse is physically present. Addressing the relatives' needs involves a higher workload for the nurses.

18	Accepting the relatives leading role	involves accepting them to determine the amount and kind of nursing care provided. It also includes respecting their role as main negotiators and initiators of changes in the daily routine.
19	Considering home care situations	includes judgements and comparisons of single-person and family households, where the latter is considered to be better for the patient as the family serves as a relief. For the nurse communication is different when there is a relative or a family.
20	Replacing the family	is sometimes asked of nurses and includes providing warmth and closeness. Nurses state that this is in general not possible for them.

Appendix 4: Substantive codes from interviews with family caregivers and how they were sorted into categories and sub-categories

No.	Substantive Code	Sub-Category	Category
1.	Addressing problems properly		Trust building
2.	Anticipating	Anticipating	Developing a fitting arrangement
3.	Arranging space, time and talks		Trust building
4.	Assuming responsibility		Facing new life circumstances
5.	Avoiding exposure	Getting external help	Coming to terms with competing demands
6.	Becoming suspicious		Becoming suspicious
7.	Being confronted with Alzheimer's Disease	Intensity of caregiving	Facing new life circumstances
8.	Being fateful	Thinking about the future	Coming to terms with competing demands
9.	Being motivated		Trust building
10.	Being reluctant to change the service	Changing or cancelling the service	Triggering struggle
11.	Burdened by administration	Expressions of burden	Coming to terms with competing demands
12.	Cancelling involvement	Changing or cancelling the service	Triggering struggle
13.	Changing patterns of nurses' visits		Becoming involved
14.	Characterising professionalism		Perceiving nurses
15.	Competing demands	Competing demands	Facing new life circumstances
16.	Confidence level	Confidence level	Coming to terms with competing demands
17.	Considering caregiving	Considering caregiving	Facing new life circumstances
18.	Considering options		Evaluating helpfulness
19.	Considering usefulness	Considering usefulness	Developing a fitting arrangement
20.	Control and predictability	Expressions of burden	Coming to terms with competing demands

21.	Cultural/personal beliefs	Personal beliefs and values	Coming to terms with competing demands
22.	Cutting point/life deterioration		Facing new life circumstances
23.	Defining caring	Considering caregiving	Facing new life circumstances
24.	Determining the situation	Determining the situation	Managing Caregiving
25.	Differentiating (between individual nurses)		Perceiving nurses
26.	Different perception of need	Perceived need of sick family member	Coming to terms with competing demands
27.	Distancing oneself	Keeping options	Managing caregiving
28.	Doing it alone	Keeping options	Managing caregiving
29.	Employing somebody oneself	Keeping options	Managing caregiving
30.	Emancipating oneself	Emancipating oneself	Managing caregiving
31.	Emergency backup		Perceiving nurses
32.	Engaging in a relationship	Relationship on a personal level	Negotiating helpful action
33.	Evaluating the nurses' work		Perceiving nurses
34.	External hint		Becoming involved
35.	Family relationship		Facing new life circumstances
36.	Feeling safe	Relationship in relation to care-recipient	Negotiating helpful action
37.	Feeling of security		Perceiving nurses
38.	Formalisation of relationship	Legislative framework	Framing home care nursing
39.	Gaining expertise	Gaining expertise	Developing a fitting arrangement
40.	General life decisions		Facing new life circumstances
41.	Getting the work done		Facilitating work and care
42.	Handling incontinence	Handling incontinence	Developing a fitting arrangement
43.	Having fears about the future	Anticipated helpfulness	Coming to terms with competing demands
44.	Having somebody at hand	Available support	Coming to terms with competing demands
45.	Help-seeking		Managing caregiving

	behaviour		
46.	Images of support/expecting support		Facilitating work and care
47.	Increasing quality of life		Facilitating work and care
48.	Instructing on what to do		Evaluating helpfulness
49.	Joint planning		Facilitating work and care
50.	Lacking knowledge		Facing new life circumstances
51.	Learning to stand up for oneself	Emancipating oneself	Managing caregiving
52.	Limiting difficulties	Getting external help	Coming to terms with competing demands
53.	Making use of services and benefits		Managing caregiving
54.	Monitoring and observing		Becoming suspicious
55.	Mutual acknowledgment		Trust building
56.	Nurses perceived		Perceiving nurses
57.	Opting for home care		Facing new life circumstances
58.	Perceiving lack of competence		Perceiving lack of competence
59.	Perception of professional behaviour		Perceiving nurses
60.	Perception/knowledge of sick relative	Perceived need of sick family member	Coming to terms with competing demands
61.	Practical considerations and arrangements	Anticipated helpfulness	Coming to terms with competing demands
62.	Protecting and comforting		Facilitating work and care
63.	Reasons for changing/non-changing of the service	Changing or cancelling the service	Triggering struggle
64.	Recognition of limits	Confidence level	Coming to terms with competing demands
65.	Responding to caregivers’ needs	Changing or cancelling the service	Triggering struggle
66.	Saving oneself	Keeping options	Managing caregiving

67.	Service as relief		Evaluating helpfulness
68.	Setting priorities and having preferences	Determining the situation	Managing caregiving
69.	Sharing tasks and responsibilities	Sharing tasks and responsibilities	Managing caregiving
70.	Suffering caregiving	Expressions of burden	Coming to terms with competing demands
71.	Triggering struggle		Triggering struggle
72.	Trust building		Trust buidling

Appendix 5: Substantive codes from interviews with nurses and nurse managers and how they were sorted into categories and sub-categories

No	Substantive Code	Sub-Category	Category
1.	Accepting limits	Being self-reflective	Contributing one's own personality
2.	Acting against each other	Perceiving family caregivers	Mutual dependency
3.	Addressing problems properly		Trust building
4.	Advocating for care-recipients	Advocating for care recipients	Matching order and reality
5.	Applying different strategies	Strategies for managing problems	Matching order and reality
6.	Approaching home care situations	Approaching home care situations	Matching order and reality
7.	Asking for somebody		Becoming involved
8.	Arguing about hospital care	The image of the nursing profession	Working in home care nursing
9.	Assessing relatives' competence	Working with family caregivers	Matching order and reality
10.	Attitudes towards home care	The image of the nursing profession	Working in home care nursing
11.	Balancing different people's needs	Balancing different people's needs	Feeling restricted
12.	Balancing different requirements	Balancing different requirements	Shaping different realities
13.	Becoming overburdened	Expressions of burden	Coming to terms with competing demands
14.	Being a guest	Being a guest	Mutual dependency
15.	Being a mediator	Being a mediator	Mutual dependency
16.	Being a professional	Being a professional	Working in home care nursing
17.	Being familiar with households	Trust building	Shaping different realities
18.	Being in charge	Being in charge	Working in home care nursing
19.	Being self-reflective	Being self-reflective	Contributing one's own personality
20.	Building a relationship	Trust building	Shaping different realities
21.	Caregivers expertise	Perceiving family caregivers	Mutual dependency
22.	Caring as oneself would like being cared for	Being self-reflective	Contributing one's own personality
23.	Changing patterns of nursing visits		Becoming involved
24.	Characterising home	Being a professional	Working in home care

	care		nursing
25.	Creating space and flexibility	Approaching home care situations	Matching order and reality
26.	Degradation and neglect of care-recipients		Keeping people at home
27.	Developing expertise	Growing and developing expertise by experience	Working in home care nursing
28.	Differing devices	Perceiving family caregivers	Mutual dependency
29.	Different perception of need	Relationship in relation to care-recipient	Negotiating helpful action
30.	Differing perspectives	Balancing different requirements	Shaping different realities
31.	Difficulty to apply professional knowledge	Difficulty to apply professional knowledge	Feeling restricted
32.	Distinguishing relationships	Perceiving family caregivers	Mutual dependency
33.	Doing extra work		Balancing closeness and distance
34.	Economisation and legal accountability	Legislative framework	Framing home care nursing
35.	Engaging in a relationship	Relationship on a personal level	Negotiating helpful action
36.	Feeling mistrusted	Feeling mistrusted	Mutual dependency
37.	Feeling restricted		Feeling restricted
38.	Focussing caregivers	Working with family caregivers	Matching order and reality
39.	Focussing care-recipients	Focussing care-recipients	Framing home care nursing
40.	Getting complaints	Getting complaints	Mutual dependency
41.	Getting help from the team	Using the team	Matching order and relity
42.	Getting to know each other	Trust building	Shaping different realities
43.	Getting started	Approaching home care situations	Matching order and reality
44.	Good nursing care	Being a professional	Working in home care nursing
45.	Growing by experience	Growing and developing expertise by experience	Working in home care nursing
46.	Having somebody at hand		Becoming involved
47.	Image of the profession	The image of the nursing profession	Working in home care nursing
48.	Impact of relationship	Trust building	Shaping different

			realities
49.	Individualisation	Being a professional	Working in home care nursing
50.	Initiating involvement		Becoming involved
51.	Involvement of a nursing service		Becoming involved
52.	Involving/distancing oneself		Balancing closeness and distance
53.	Involving relatives	Involving relatives	Matching order and reality
54.	Keeping people at home		Keeping people at home
55.	Keeping privacy	Approaching home care situations	Matching order and reality
56.	Labelling relatives	Perceiving family caregivers	Mutual dependency
57.	Liking each other	Reflecting on aging	Contributing one's own personality
58.	Managing problems	Strategies for managing problems	Matching order and reality
59.	Mutual acknowledgement		Trust building as a prerequisite for successful negotiation of helpful action
60.	Non-involvement of a nursing service		Becoming involved
61.	Nursing tasks	Being a professional	Working in home care nursing
62.	Obstacles for building a relationship	Trust building	Shaping different realities
63.	Perceiving relatives	Perceiving family caregivers	Mutual dependency
64.	Perception of physicians	The image of the nursing profession	Working in home care nursing
65.	Performing 'by the way'	Performing by the way	Feeling restricted
66.	Providing information		Approaching home care situations
67.	Reflecting on ageing	Reflecting on ageing	Contributing one's own personality
68.	Replacing the family		Balancing closeness and distance
69.	Shaping responsibility	Considering responsibility	Shaping different realities
70.	Sitting between all chairs	The image of the nursing profession	Working in home care nursing
71.	Structural ordering	Legislative framework	Framing home care nursing
72.	Taking care of living arrangements	Approaching home care situations	Matching order and reality

73.	Taking the initiative	Balancing different requirements	Shaping different realities
74.	Trust building	Trust building	Shaping different realities
75.	Using relatives	Using family caregivers	Matching order and reality
76.	Using the team	Using the team	Matching order and reality
77.	Working as a person, not professional	Working as a person, not a professional	Contributing one’s own personality

Appendix 6: Memos on theoretical ideas during first phase of data collection and analysis

Decisions are initiated

Different ways and types of how a decision-making process was initiated were described. In some families there have been talks and discussions about what should be done in case one family member becomes sick or care dependent. These discussions don't take place because of a clearly defined need for action or decision. They are more considerations about potential important life decisions to be made. In one interview (6) it was stated that the whole family agreed that no one should ever be transferred to a nursing home as long as care at home is possible. 'As long as possible' was not clearly defined but implied for family members that they would have to put considerable effort in managing a care situation at home.

In other cases the decision-making process was initiated by professionals. This commonly occurs when the sick and/or care dependent family member was referred to a hospital. Before discharge the patient and the caregiver was asked by a physician or a social worker (nobody said it was a nurse) how they will manage the situation at home and if the involvement of a nursing service is something they would consider.

The third way of making decisions arose from a situation where relatives already cared for family members and where they felt an actual need of getting support. By chance they established contact to a counselling service (in the community) or a self-help group. This contact provided them with information on what kinds of support are available and with opportunities to share their experiences with others. To see that others' situations were comparable eased the perception of burden.

Experiences of informal caregivers on which the decision for the utilisation of a nursing service is based

Negative experiences that lead to the involvement of a nursing service were characterised as being helpless, being unsecure and being exhausted. Helplessness refers to a situation where the caregiver has to take responsibility, has to handle job requirements and is faced with a situation where the care receivers' problems get worse, e.g. he starts walking out of the house or is not able to take medication himself. Helplessness is closely related to unsecurity about what will happen in the future. One caregiver puts it as 'Caring is risk-related'. They are fully aware of this and their everyday struggle is characterised by efforts on how to make the situation manageable and by hoping that the situation keeps stable. In case of increasing demands and decreasing abilities of the care-recipient this leads to exhaustion of the caregiver.

Special events have a strong influence on the decision for a nursing service. These events are either events that lead to stronger dependency (accidents or problems with nutrition) and to the referral to a hospital or events that take place during the home care situation. Hospital stays often, but not necessarily, result in the involvement of a nursing service.

The central experience is that of being able to handle and manage the situation. This is influenced by different aspects. One is that of available support in terms of personal support by other family members and neighbours and in terms of material support by having assistive devices. Another one is that of having made own decisions. Where caregivers had the option of deciding on their own what to do and how to handle and arrange the situation this leads to confidence to manage the caring situation.

A central problem seem to be conflicting demands. While some caregivers point out to be able due to their personal situation to assume full responsibility (being there all the time) other simply cannot handle the demands between job and care.

There are also many experiences that go beyond the caring situation. Among those are religious and cultural influences that cause a high level of acceptance of being a caregiver for a family member. The former relationship between caregiver and care-recipient also has a strong influence on the perception if the situation is manageable or not. Where there was a good relationship caregivers refer to reciprocity, meaning that they would have been cared for, too, if necessary and this increases their own commitment.

The perception of the sick family member is an aspect that influences the decision for a nursing service. One caregiver refered to his wife as a ‘living dead’. That didn’t mean that he rejected any caregiving task in any way, but it influenced his decision for a nursing service in so far as he could not think of being able on his own to care for a ‘living dead’. The perception of the sick father as a wonderful person also lead to the involvement of a nursing service, because the caring daughter wanted the best care possible for her father.

Many caregivers did not just refer to the perception of their sick family member. They also put emphasis on the fact that caring is not just a burden. One caregiver said that ‘it probably is the most sensible thing he did in his life’. Another mentioned that she could think of worse life conditions and a third one stated, that she enjoys every minute she has with her husband.

Experiences related to the background of the German care insurance are twofold: On the one hand they have a positive impact because they allow for making use of the different benefits of the care insurance that fit perfectly into the individual situation. On the other hand the procedures required to get benefits prevent others from asking for help, because of feeling ashamed and to feel like a beggar. It’s a prerequisite to ask for the benefits, they are not offered without application and depending on personal characteristics this may prevent people from using them.

Constant negotiation

Formal and informal care are involved in a process of constant negotiation of the care situation. This negotiation has different dimensions. The first one is that of continuity of the formal carer. It could be detected that where there is continuity of the nurse from the nursing care service it is easier to establish routines concerning who does what and in terms of organising communication. In other situations often changing nurses meant that these routines had to be constantly re-negotiated.

The central focus of negotiation is the daily routine. Caregivers reported various instances that were of a helping or of a disturbing character for their everyday caring. As being helpful were stated: helping with physical tasks and providing practical help. Caregivers know that physical care has to be provided and considered it to be convenient when these tasks could be shared with the nurse or completely taken over by the nurse.

Beside feeling convenient negotiations about daily routine often are of a disturbing character. Caregivers described different conflicts that arose in the relationship. These conflicts concerned different viewpoints on tasks and performances. A caregiver said that it was OK in the beginning but that soon it started to put an additional burden on her, because she felt that the nurses did not judge her father’s situation appropriately. She engaged in permanent discussions with the nurses and the head of the nursing service on what ought to be done. She stated: ‘I knew the situation, they didn’t’. The formal services were not at all a release for her, they mainly changed her caregiving role.

In another case it turned out to be difficult that the nurses did not follow the time scala that was agreed upon. The caregiver could not rely on the time when the nurses came to his house and this was not acceptable in the long run. He decided to involve another nursing service.