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SEARCHING FOR THE MEANING OF SUPPORT IN NURSING

A study on support in family care of frail aged persons
with examples from palliative care at home

Peter Stoltz

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<p>Abstract</p> <p>Family carers perform a large amount of the help and assistance that are provided for Swedish frail aged persons who live with one or more chronic illnesses. Consequently, in addition to balancing the Swedish national welfare expenditures, family carers also contribute to the care for older persons in many ways. Parallel to the above, an increased interest for family carers situation can be discerned from research as well as from political decisions. Within these interests, the word support is recurrently used both nationally and internationally. However support for family carers may prove to be a more complex endeavour than it appears. Although there are research in support for family carers, the concept of support remains complex and difficult to conceptualize.</p> <p>It is not unreasonable to assume that the word support can shift meaning across areas where it is used. In nursing, support is highlighted in situations where family carers care for a frail aged person at home. Support is likely to continue to be of importance in these situations as there are no indications of at-home family caring decreasing. To date, there have been little research into understanding the concept of support in nursing. Therefore, support should be further researched in order to be assigned a fruitful and useful meaning.</p> <p>From the general ongoing debate in Sweden on family carers it is easy to conclude that support is “something” that family carers should have or be given. However, it is not as easy to discern <i>who</i> should support family carers, or <i>what</i> the support should entail. As the focus on care for frail aged persons continuously moves towards peoples own homes, it is plausible that nurses will continue to play an important role between informal and formal care provision. Nurses can be expected to be one important group of healthcare professionals that are expected to provide support for family carers even in the future.</p> <p>Proceeding from the above description, this thesis was undertaken with the overall aim to describe, illuminate and understand meanings of support within the nursing context of family care for frail aged persons, as disclosed by family carers, registered nurses and scientific literature.</p> <p>In order to be able to understand meanings of support, it was decided to proceed with the empirical studies in this thesis using a palliative care context. This decision was based on the assumption that the palliative care context would be appropriate for describing meanings of support. Through the four papers underpinning this thesis, the concept of support and its meaning have been studied from differing viewpoints assisted by differing research methodologies. Family carers have narrated on the meaning of support and registered nurses have narrated on the meaning of being supportive. Moreover, the scientific literature was thoroughly searched, synthesized and conceptually analyzed in order to describe, explain and understand the concept of support.</p> <p>The findings from this thesis showed that support in nursing entails two essential dimensions. They were labelled the “tangible dimension” and the “intangible dimension”. The tangible dimension overarchingly represent different services, goods, equipment, information and/or education that, on a general level, can be provided for family carers. The intangible dimension overarchingly is about the quality of the relationship between the family carer and the support provider person. The intangible dimension can be further understood through relationship qualities such as trust, confidence and/or friendship. It moves at a more individual and adaptive level than the general tangible dimension. However, it importantly appears that these two dimensions do not stand in opposition to each other as a dichotomy. Instead, these two dimensions appear to be co-dependents and essentials for support to gain meaning in nursing.</p>		
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MALMÖ UNIVERSITY

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For my parents and all other “everyday heroes” ...

“ – *Varifrån kommer kraften?*, undrar han.
– *Den har vi inombords, men vi har inte sett den förut. Bruset har varit för högt!*, svarar jag.”

Ulla-Carin Lindquist (2004).

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ABSTRACT

Family carers perform a large amount of the help and assistance that are provided for Swedish frail aged persons who live with one or more chronic illnesses. Consequently, in addition to balancing the Swedish national welfare expenditures, family carers also contribute to the care for older persons in many ways. Parallel to the above, an increased interest for family carers situation can be discerned from research as well as from political decisions. Within these interests, the word support is recurrently used both nationally and internationally. However support for family carers may prove to be a more complex endeavour than it appears. Although there are research in support for family carers, the concept of support remains complex and difficult to conceptualize.

It is not unreasonable to assume that the word support can shift meaning across areas where it is used. In nursing, support is highlighted in situations where family carers care for a frail aged person at home. Support is likely to continue to be of importance in these situations as there are no indications of at-home family caring decreasing. To date, there have been little research into understanding the concept of support in nursing. Therefore, support should be further researched in order to be assigned a fruitful and useful meaning.

From the general ongoing debate in Sweden on family carers it is easy to conclude that support is “something” that family carers should have or be given. However, it is not as easy to discern *who* should support family carers, or *what* the support should entail. As the focus on care for frail aged persons continuously moves towards peoples own homes, it is plausible that nurses will continue to play an important role between informal and formal care provision. Nurses can be expected to be one important group of healthcare professionals that are expected to provide support for family carers even in the future.

Proceeding from the above description, this thesis was undertaken with the overall aim to describe, illuminate and understand meanings of support within the nursing context of family care for frail aged persons, as disclosed by family carers, registered nurses and scientific literature.

In order to be able to understand meanings of support, it was decided to proceed with the empirical studies in this thesis using a palliative care context. This decision was based on the assumption that the palliative care context would be appropriate for describing meanings of support. Through the four papers underpinning this thesis, the concept of support and its meaning have been studied from differing viewpoints assisted by differing research methodologies. Family carers have narrated on the meaning of support and registered nurses have narrated on the meaning of being supportive. Moreover, the scientific literature was thoroughly searched, synthesized and conceptually analyzed in order to describe, explain and understand the concept of support.

The findings from this thesis showed that support in nursing entails two essential dimensions. They were labelled the “tangible dimension” and the “intangible dimension”. The tangible dimension overarchingly represent different services, goods, equipment, information and/or education that, on a general level, can be provided for family carers. The intangible dimension overarchingly is about the quality of the relationship between the family carer and the support provider person. The intangible dimension can be further understood through relationship qualities such as trust, confidence and/or friendship. It moves at a more individual and adaptive level than the general tangible dimension. However, it importantly appears that these two dimensions do not stand in opposition to each other as a dichotomy. Instead, these two dimensions appear to be co-dependents and essentials for support to gain meaning in nursing.

ORIGINAL PAPERS

This thesis is based on the following papers referred to in the text by their Roman numerals:

- I Stoltz, P., Udén, G. & Willman, A. (2004). Support for family carers who care for an elderly person at home – a systematic literature review. *Scandinavian Journal of Caring Sciences*, **18**, 111–119.
- II Stoltz, P., Willman, A. & Udén, G. (2006). The meaning of support as narrated by family carers who care for a senior relative at home. *Qualitative Health Research*, **16**, (5), (in press).
- III Stoltz, P., Lindholm, M., Udén, G. & Willman A. (2006). The meaning of being supportive for family caregivers as narrated by registered nurses working in palliative homecare. *Nursing Science Quarterly*, **19**, (2), (in press).
- IV Stoltz, P., Pilhammar Andersson, E. & Willman, A. (2006). Support in nursing – an evolutionary concept analysis. *International Journal of Nursing Studies*, (submitted for publication).

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INTRODUCTION

It is well known that the number of people aged 65 years or older are growing, while the younger section of the population is decreasing (Lagergren, 2004; SCB, 2006). This changing demographics is an international trend where Sweden is no exception. The generally improved standards of living, and developments within the healthcare sector can be seen as contributors to the increased longevity. Almost all chronic illnesses are age related, as their incidence increases with age (Binstock & George, 2001). Consequently, because of the increased number of people who live longer, there is also an expected increase in the number of people who live with one or more chronic illness. In other words, there is an expected increase in the need of care for aged persons. Simultaneously, the focus of care for frail aged persons has shifted from professional institutional care towards a lay informal care at home. Some nations, including Sweden, promote policies to maintain frail aged persons in their own homes for as long as possible (Kinsella & Velkoff, 2001; Socialtjänstlag, 2001:453). Because of this development attention is inevitably brought to family carers, particularly in which way to support family carers. The problem is that support is a complicated concept, that despite its wide use is far from being clearly understood. Therefore, proceeding from nursing, this thesis was aimed at describing, illuminating and understanding meanings of support within the context of at home family care of frail aged persons. However, the focus in this thesis stand in contrast to the, perhaps more traditional, study of social support where peoples' social networks are researched (cf. Finfgeld-Connett, 2005). The latter is not the same as describing, illuminating and understanding meanings of support within nursing, which was the aim in this thesis.

It was decided to proceed from a nursing point of view in order to contribute to the nursing discipline. Nurses belong to one important group of healthcare professionals that will continue to work with family carers who care for a frail aged person at home. Therefore knowledge on support is assumed to be valuable for nurses as well as other healthcare professionals who also work with family carers.

The value of this thesis lies in having empirical roots while also compiling a synthesis of the current state of knowledge on support for family carers. Consequently, this thesis has the potential to move the state of science forward, through the synthesis of insights while using its empirical base to develop understandings of the concept of support in nursing.

BACKGROUND

Increasing longevity and healthcare

Demographers would agree that there is, and will continue to be a significant increase in longevity throughout the world (Lagergren, 2004). This trend inevitably includes Sweden. An aging population follows the demographic changes that most European countries experienced during the nineteenth and twentieth centuries (SOU, 2003:91). One major concern that has received attention in this demographic development, is the expenses for healthcare provision of aged persons (ibid.). Henceforth frail aged persons will be defined as 65 years of age or older. However, there are a multitude of confounding factors complicating prognostications of the effects of an aging population. There is for instance, a high degree of uncertainty as to the correspondence between ill-health and mortality, in relation to potential future developments in medical technology (Lagergren, 2004). Simple linear prognostications show significant increases in healthcare costs, while complex linear prognostications do not (SOU, 2003:91). Then again, increased possibilities to diagnose and treat illnesses may be accompanied by increased costs, which further complicates prognosticative calculations. Consequently, there are not only uncertainties in appraising the healthcare expenditures for aged persons today, but there are also uncertainties about future expenditures (ibid.). Projections speak of an increased volume of health and social services somewhere between 10 and 30 percent during the coming 30-year period (Lagergren, 2002). Nevertheless, much research into healthcare for aged persons is based on the assumption that expenses actually will increase. This study was conducted based on the same assumption.

More specifically this assumption reads; the increasing share of aged persons will contribute to an increased prevalence and share of persons living with ill-health, and thus being in need of help (Blieszner & Bedford, 1995). This assumption is put forward in spite of, that most aged persons in Sweden, even persons aged 80 years and older, do quite well and lead independent lives in their own homes (SOU, 2003:91). These aged persons are not the main concern. Instead, the issues revolve around the increased share of people living with one or several chronic illnesses as a result of the population's increased longevity. Today, almost all illnesses are age-related in the sense that their prevalence increase with age. Example of such diseases are: cancer, dementia as well as vascular and circulatory diseases (ibid.).

The question of who is old, aged or elderly has many dimensions. An illuminative example may be formulated as follows. From a chronological point of view a person of 74 years surely is considered older than a person of 55 years. However, in a more phenomenological sense, the person of 74 years may not feel old, whilst the person of 55 years who perhaps is chronically ill, may perceive herself as being old (Jönson, 2002). This example was used to underline that age is not a straightforward con-

cept. In this study it was decided that a person who is 65 years of age or older is considered old, aged and/or elderly. This demarcation is aligned with the definitions of aged/elderly/older people used by, for example, the World Health Organization (WHO, 2001), the Swedish Council on Technology Assessment in Health Care (SBU, 2003) and the Swedish National Board of Health and Welfare (Socialstyrelsen, 2005a). Furthermore, deciding to use the age of 65 years as demarcation for old, aged and/or elderly was consistent with demarcations and definitions used in the scientific databases Medline (www.pubmed.gov) and Cinahl (www.cinahl.com). Today, Swedish people who have reached the age of 65 years can on average expect to live for another 17 years (men) to 21 years (women) (SCB, 2006). The mean age in Sweden is currently 78 years for men and 83 years for women (ibid.).

Nevertheless, the issue of an aging population has raised and will continue to raise questions at several levels in society. Through out history the Swedish government has attempted to deal with the issue of care provision for aged persons in differing ways. The Swedish state's main influence on policies have been controlled in legislation. Being political issues, the laws and proposals are what govern and direct the Swedish healthcare sector within which this study operated. Hence, these laws and proposals must be taken into consideration and cannot be disregarded. The mid-twentieth century Sweden, marks a point in time when healthcare provision and housing for frail aged persons in need of care was publicly debated and revised (Jönsson, 2002). Since the years that followed the Second World War, there have been different schools of thought on how formal and informal care of frail aged persons have co-existed (Sundström *et al.*, 2002). However, the current consensus appear to be that informal care, in other words family carers, increasingly shoulder a major bulk of care provision for frail aged persons. Meanwhile, public spending on care and services for frail aged persons living in the community has stagnated, institutional care have been shrinking in both absolute and relative terms and public home help services are decreasing even more (ibid.). Families and other informal sources will continue to play an important role in caring for frail aged persons at home. Recently family caring of frail aged persons have even further assumed centre stage in literature, policy making, laws and government propositions (Socialtjänstlag, 2001:453; Socialstyrelsen, 2002a; Jeppsson Grassman, 2003).

One major issue in particular has been where aged persons in need of care should live and reside. The leading answer appears to be at home. Currently, the trend is that focus of care for frail aged persons is shifting away from professional institutional care, towards a lay informal care at home. It is within this focus shift that attention is inevitably brought to the family carers of frail aged persons. The family carers' considerable and important contribution to the health and welfare of frail aged persons has become increasingly salient. However, there has also been a parallel development, namely towards support for family carers. In the family caring issue, support appears to be Swedish society's, municipalities' and voluntary organi-

zations' formal responses to family carers increasing responsibilities (Jeppsson Grassman, 2001). One concrete example of a formal response, was the 300 million Swedish kronor invested by the Swedish government in the years 1999–2001 into the development of support for family carers (Socialstyrelsen, 2002a). However, the increased interest support for family carers is not in purely a government issue. Researchers within several disciplines, including nursing, have also made several contributions to the issue and the ongoing debate about support for family carers.

Family carers and frail aged persons predominantly struggle with challenges such as neurological and cognitive diseases, cancer, cerebrovascular diseases, heart and lung diseases, depression, chronic pain, confusional states, infections and leg wounds (Andersson, 2002; Jakobsson, 2003; SBU, 2003; Larson *et al.*, 2005). Although there is research on issues surrounding aged persons' health and well-being, more research is needed. A systematic review has shown that there is a lack of studies of high quality. Paradoxically the knowledge basis is the poorest where the need is the greatest, which is among the oldest old, i.e. 75 years of age and older (SBU, 2003).

The most prevalent health problems for persons of all ages, but especially for aged people, are those associated with chronic illness (Binstock & George, 2001). In this thesis it was determined that the study and research should be directed towards family carers who care for frail aged persons at home. Therefore, instead of studying any specific disease(s) in relations to family caring the decision was to study a more heterogeneous group; family carers of frail aged persons. This focus have also been forwarded by Nolan *et al.* (1996) and SSF (2004). This may appear an undue diversification which renders the group under study dissimilar. For example, the experience of caring for a person who is suffering from Alzheimer's disease may be very different from caring for a person with cancer at differing stages (Weitzner *et al.*, 1999; Albinson & Strang, 2003). On the other hand, when it comes to support for family carers, it may also be the case that the commonalities are greater than the disease specific differences. For example, on a more abstract level, aspects of support may cohere regardless of disease even if different aspects are more or less in the foreground depending on the family carers individual situation at the time. The appropriateness of support through information or respite care may vary with time as the caregiving trajectory progress, but be commonalities across diseases. Furthermore, there may also be differences in experiences between male and female family carers (Almberg *et al.*, 1998).

Traditionally, there have been differing ways to study support in the community. It is therefore important to underline and illuminate the demarcations for this thesis and study. Although perhaps adjacent, this thesis is disassociated with and autonomous from sociological or epidemiological studies of social support or social network theory. Such studies are concerned with understanding relationships between different social units and their interrelated flow of social support (Nolan *et al.*, 1996). Social support and social network studies can be said to originate from the

pioneering work by Berkman and Syme (1979) and the Alameda County epidemiological data. Psychologists have long recognized the association between social support and health, even if it was not until the effects on physical health were documented that the wider array of researchers and clinicians became interested (Antonucci, 2004). Since then there have been much research activity into the mental and physical effects on health and well-being of social support networks (Asplund, 1983; Cohen & Ashby-Wills, 1985; Bowling & Browne, 1991; Wenger, 1997). Gradually, such research developed into a social network epidemiology of large studies with general outcomes and a social support psychology which focuses on a limited set of specific outcomes in the attempt to elucidate effects on health and mortality (Orth-Gomér, 2004).

This thesis stands in contrast to the multitude of studies in social support performed within the sociological or epidemiological field, as well as studies in search of evidence of effectiveness on health and mortality. The scope of ideas underpinning this thesis is disassociated from initiatives such as surveying or mapping relationships (cf. Due *et al.*, 1999) and discerning the interplay of social support and coping strategies in a stress-coping perspective (Schreurs & de Ridder, 1997; Almqvist *et al.*, 1997a). Instead, this thesis proceeds from two straightforward observations. Firstly, family care of frail aged persons is a contemporary research issue of national and international concern and therefore warrants research and knowledge. Secondly, the concept of support is recurrently used in relation to family carers. However, although it is clear that the concept of support is used within nursing, there has been interestingly little reflection in research on whether or not the concept's movement across disciplines has entailed a slight or larger shift in meaning. Therefore, this thesis set out as a search for the meaning of support in nursing. Differing methodologies were used in order to research the concept of support in nursing from diverse angular viewpoints.

In a way, this thesis can be viewed as approximating basic research, and the onset of this study had similarities to underpinnings in other basic research studies (cf. Andersson, 1994; SSF, 2002). The understanding was that support in nursing should be researched. It was a necessity that the concept of support be given a fruitful substance if it were to be meaningful to continue to claim support as a fundamental for carers (cf. Andersson, 1994 p 19). Without increased knowledge and awareness of its meaning, the concept of support in nursing may be at risk of being weakened, powerless and superficially used. Such a development would be unfortunate, as well as inconsistent, with the increase in contemporary awareness about the complexity of struggles that family carers face when caring for a frail aged person at home.

The complexity of caring for a frail aged person at home

Persons who find themselves in the position of family caring, struggle with several challenges due to the transition in life that their spouse's or relative's health issues have entailed. The below text problematizes some of the issues that family carers may struggle with, irrespective of what the cared-for person's medical diagnosis is.

Undoubtedly, the family carers' situation is surrounded by several subversive factors. For instance, the failure of the medical system to respond adequately to the dominance of chronic care has a particular bearing on aged people. This is because aged persons suffer from chronic diseases to an even larger extent than younger people (Binstock & George, 2001). Consequently, a contributing and complicating factor to the already large caring responsibility that rests on the family may be the way the professional care of frail aged persons is provided. The issues may be attributed to an organizational problem. There appears to be a need for a chronic care model, while the acute care model continues to predominate (Binstock & George, 2001).

Public investments have stagnated and even decreased considerably, in particular as regards frail aged persons living at home. Simultaneously, family carers increasingly assume the caregiving responsibility, and old spouses are particularly alone in their challenge to care for an ill partner (Johansson & Sundström, 2002). In addition, lack of knowledge about formal services as well as inflexibility or lack of availability of services, may impact negatively on people's experiences of accessing and using formal support (Wiles, 2003). According to Binstock and George (2001) the circumstances for patients' decision making is often poor. Furthermore, their source of information may be biased, in other words related to individual health care providers or alternatively news, magazines and popular science. It is not inconceivable that the situation for family carers' decision making also is poor. On the contrary, there are studies indicating that family carers actually are less knowledgeable of community services than patients (Burns *et al.*, 2004). Furthermore, mass media may have contributed to convey a negative image of formal/public services, which potentially influences family carers' attitudes towards using formal services (Lundh & Nolan, 2002). All of which probably does not lessen family carers' struggles.

Adding to the complexity of the situation is the personal history of the people involved. In a wider perspective, the patterns for receiving and providing assistance in old age may be seen as a process of interaction among parents and children and other kin, over their mutual life course and over historical time (Bleizner & Bedford, 1995). Our relations are formed over life, by historical events and by heritage. This in turn may of course affect values in family relations and expectations of caregiving as well as the ability to interact with welfare agencies and institutions (*ibid.*).

Also, studies have shown that family carers are likely to struggle with feelings of loneliness, depression, burden, burnout, poor subjective quality of life, social isolation, vulnerability, enduring stress and frustration (Almberg *et al.*, 1997b; Butcher *et al.*, 2001; Clovez *et al.*, 2002; Beeson, 2003; Proot *et al.*, 2003; Valdimarsdóttir *et al.*, 2003; Given *et al.*, 2004; Ekwall *et al.*, 2005). Family carers appear to have an increased frequency of health related problems as well as an increased mortality risk (Schulz & Beach, 1999; Valdimarsdóttir *et al.*, 2003). They are doubly challenged due to having to deal with their own issues parallel to caring for their spouse or relative (Kirkevold & Strömsnes Ekern, 2002). In contrast, although they are not as prevalent, there are studies elucidating positive aspects of family caring such as feeling stronger as a person, strengthening the relationship, being together, finding meaning and joy (Butcher *et al.*, 2001; Hudson, 2003). One impression close at hand is that support is introduced and held up as key, mainly as a balancer of these negative and positive consequences of caring.

Family carers and support

Hereto it seems Nolan (2001, p 93) and Nolan *et al.* (2003, p 131) are original in publishing an overview of a typology of family carer support. Three of four typologies address information, training, coping, family relationship issues and community services (respite care, finances, equipment), whereas one considers support as any intervention that assist family carers in deciding to take up/not take up the caring role, continue or giving up the caring role (*ibid.*). According to Nolan (2001), the least efforts from healthcare personnel, are made as regards assistance in deciding to “take up/not to take up the caring role” as well as regards deciding to “give up the caring role”. The latter, in particular, may be associated with difficulties and mixed emotions (Lundh *et al.*, 2000). Nevertheless, the main traits of the typologies actually correspond with interventions provided and tested for family cares. Some of which have been researched as information, education or respite care interventions. Nevertheless, how to support family carers remain a national and international issue under ongoing discussion, which is surrounded by several unresolved inconsistencies and quandaries.

At society levels there is considerable room for improvements, as it appears that care and services are given to family carers, rather than being negotiated and individually tailored to their needs (Lundh & Nolan, 1999). One example, which may indicate the contradictions or complexity surrounding support for family carers is that there appear to be a demand of respite care services in Sweden, yet the service is not often granted, nor is it often used by family carers when actually granted (Socialstyrelsen 1998; 2002b). Furthermore, international research on intervention implementation and surveys of family carers’ health illuminate unresolved quandaries in balancing negative outcomes for those who are actively caring for a frail aged person at home (Gräsel, 2002; Schultz *et al.*, 2002).

Assistance available for family carers in Sweden today, is mainly regulated through the Swedish social services act which entail the responsibility of each municipality to provide social welfare services to their inhabitants (Socialtjänstlag, 2001:453). This responsibility includes support for family carers of frail aged persons at home. Differences may exist in the municipalities' support for family carers due to the allocation and decentralisation of this responsibility. However, municipalities principally offer a variety of homemaker services, day-care services, respite care, financial assistance or reimbursement, information, education and group-meetings (Socialstyrelsen, 2005b). All home-help services, including emergency medical alarm and short-term care, are usually associated with expenditures for the individual families. Permission to access these services is usually preceded by an assessment by a social welfare worker. Parallel to formally established services, voluntary organizations may arrange group meetings or visitor services. Voluntary organizations and associations may be related to specific diseases.

The incentive to carry out this thesis, and the consequent research reported as papers I–IV, was initiated by the widespread and recurrent use of the term support. Specifically in relation to family carers or family caring for a frail aged person. Moreover, in spite of research as well as societal efforts on national and international levels, the term support is by no means straightforward, unproblematic or crystal clear. Consequently, further research into support for family carers seemed warranted. It was also noteworthy that support in nursing research did not appear clearly defined and instruments evaluating efforts called support, vary and can be criticized for appearing arbitrary.

In nursing, support is held up as useful within several areas of the discipline. One of which is the area of family care of frail aged persons. There, interventions labelled support have been tested. The objective being to balance the poor well-being, depression or coping ability that family carers struggle with, when caring for an aged relative at home (cf. Larson *et al.*, 2005; Andrén, 2006;). The current state of knowledge concerning support within nursing, leaves many interesting questions unanswered. For example, although there is research into support for family carers (Opie *et al.*, 1999; Higginson *et al.*, 2003; Hallberg & Kristensson, 2004; Lui *et al.*, 2005), the body of research is somewhat unbalanced by the lack of studies seeking a deep understandings of the experience of support such as lived. There appear to be different interpretations and diverging perspectives on support which may obfuscate rather than facilitate research into support for family carers. Consequently, research and increased knowledge in nursing into the concept of support appears warranted.

In this thesis it was decided to let palliative homecare be the empirical context in which to study support and allow for its meaning to become illuminated. This decision was made based on following reasons; it was assumed that palliative home-care is one example where it would be possible to find family carers with lived experiences

of support. Consequently it would be possible to study the phenomenon of support and its meaning as illuminated by family carers narratives. Hence, the existing Swedish advanced in-home palliative care teams (AHC) were seen as an appropriate context which could defensibly be argued as providers of support for family carers. Even if the AHC is primarily for the benefit of the person dying at home, the AHCs can also be recognized as providers of support for family carers (Rollison & Carlsson, 2002). With the way they are organized, the AHCs are able to provide a multiplicity of services which may be considered support for the family carers. Examples of such support is information, education, house calls, respite care, coordinate physical aids or sitting services. Furthermore, support for the family carer, is an integral and explicit component in the World Health Organization's definition of palliative care that these AHCs rest upon (WHO, 2003).

Understandings of key terminology used throughout the thesis

Family carers

In this thesis it was decided that persons calling themselves family, also are family. The family are who they say they are. The understanding is that a family is a group of people who are connected by strong emotional relations, a feeling of belonging and a strong reciprocal engagement in each other's lives (Wright *et al.*, 2002). This definition purposefully reaches beyond traditional boundaries of family membership such as blood, adoption or marriage (*ibid.*). However, in this thesis, family carers should be cohabiting, that is, living under the same roof as the person receiving care. The term family carers was not restricted by age or gender. Examples of terms that were seen as interchangeable with family carers were; caregivers, family caregivers, informal caregivers, informal carers, in-laws (daughters or sons), intergenerational relations, lay caregivers, lay carers, next-of-kin, partners, relatives and spouses (wives, husbands). Such terms could be used in publications that are cited in this thesis.

Cared-for persons

In this thesis the cared-for person should be 65 years of age or older, and for whatever reason be cared for at home by a family member. Examples of terms that were seen as interchangeable with cared-for person were; older person, frail aged person and elderly person. These terms were used to represent the person receiving care.

Home

In this thesis the home was considered the place where one lives. The fixed residence of a family or household, as opposed to an institution or special accommodations for persons needing care, rest or refuge (Allen, 1990).

Advanced Home Care (AHC) and Palliative care

The AHC teams provide, by definition, a physician-led, multi-professional, qualified medical technology service that is available 24 hours a day, seven days a week.

AHC has a hospital bed standing by, has a large reception area and primarily concerns palliative care (Beck-Friis & Strang, 1995). AHC can replace institutional care (SBU, 1999).

AIMS

The overall aim of this study was to describe, illuminate and understand meanings of support within the nursing context of family care for frail aged persons, as disclosed by family carers, registered nurses and scientific literature.

The specific aims were:

To review the available scientific evidence on support for family carers who care for a cohabiting elderly person at home (paper I).

To illuminate the meaning of support as narrated by family carers who care for a senior person at home (paper II).

To illuminate the meaning of being supportive to family caregivers of relatives at home as narrated by registered nurses working in palliative home care (paper III).

To inductively develop a definition of support in the context of family care of frail aged persons (paper IV).

METHODS

Below follows the description of the methodological decisions for the purpose of this thesis, in order to achieve the overall and specific aims. Initially, table 1 is used to provide a brief overview and summary of the four studies (papers I-IV) that collectively underpin this thesis.

Table 1. Overview of the four studies underpinning this thesis.

	Paper I	Paper II	Paper III	Paper IV
Main content	Support for family carers in the scientific literature	The meaning of support as narrated by family carers	The meaning of being supportive as narrated by registered nurses	Concept analysis of support
Sample (n=)	24 scientific publications	20 family carers	20 registered nurses	Encyclopaedia definitions and 38 scientific publications
Method	Systematic literature review	Phenomenological hermeneutics	Phenomenological hermeneutics	Concept analysis
Data collection	Systematic database searches	Unstructured narrative interviews	Unstructured narrative interviews	Database and encyclopaedia searches
Analysis	Quality assessment, classifications and narrative synthesis of research findings	Text analysis inspired by the philosophy of Paul Ricoeur	Text analysis inspired by the philosophy of Paul Ricoeur	Analysis of antecedents, attributes and consequences of support

Frameworks and context for papers I–IV

Framework for the systematic review methodology

Paper I was a systematic review of scientific publications. The value of doing systematic reviews lay in their aim to summarize all appropriate scientific results on a defined health question (Sackett *et al.*, 1997). Initially Sackett *et al.* (ibid.) goes as far as tracing the ideas underpinning systematic reviews down to the nineteenth century. However, later they (ibid.), as well as Cochrane (1972/1999) gives the development of systematic reviews a more recent context, placing these ideas within the twentieth century. Perhaps due to the recency of this development, there appear to be a lack of publications discussing the philosophical underpinnings of doing systematic reviews. More specifically a debate on the theory of knowledge point of view may be warranted? Meanwhile, the natural science perspective and the way axioms like the world and truth is understood within natural science appear to dominate. Positivistic undertones like contrasting the real with the fictious or imag-

ined, the wholesome versus the harmful and the certain versus the uncertain are close at hand (cf. Johansson & Lynöe, 1992). However, it may also be important to underline, that the idea of compiling research results through doing systematic reviews does not seem to resist the introduction of a perspective that is closer to human science underpinnings. The resourcefulness of systematic reviews, in addition to helping clinicians update their knowledge, lay in assisting scientists to direct their research (Sackett *et al.*, 1997). The latter was the case in this thesis. The systematic review identified several research questions which could be pursued in further studies. Hence one contribution of the systematic review was that it gave rise to the subsequent papers II–IV.

Moreover, the rationale behind doing this systematic review was also related to the general growing awareness of the importance to compiling healthcare knowledge. As research on issues surrounding family caring, in particular on support, continues to expand, conducting a systematic review appeared an appropriate thing to do. Systematic reviews generally aim at deriving scientific evidence for best practice, and they are closely linked with the idea of evidence-based nursing. The evidence-based movement by now more or less permeates all healthcare professions, including nursing. Evidence-based nursing is ultimately about integrating the best available scientific knowledge with nurses' personal knowledge, patients' preferences and available resources before making clinical decisions (Willman & Stoltz, 2002; DiCenso *et al.*, 2005). Consequently, as paper I does not entail the integration of knowledge or evaluation of implementation, it makes no claims to the term evidence-based.

There are four overarching patterns of knowing in nursing: empirical, aesthetical, ethical and personal (Carper, 1978), all of which may produce knowledge and theories (Fawcett *et al.*, 2001; Willman & Stoltz, 2002). Paper I focuses on the knowledge derived from scientific studies which has bearing on what was considered evidence. In paper I, evidence was defined as the synthesis of results from scientific studies that were critically appraised for methodological quality (cf. Montori *et al.*, 2003). Scientific studies were defined as any peer-reviewed full-text article that was bannered as research, original paper or when it was indicated in the text that the intention of the authors was to methodologically study a defined health question (*ibid.*).

In order to locate the best and most current evidence on support for family carers it was decided, contrary to custom, that paper I should not focus specifically on studies employing quantitative or qualitative analysis of data (cf. Guyatt & Rennie, 2002). Instead, this systematic review was inclusive enough to incorporate both methodological perspectives. This decision was due to the greater understanding in nursing that evidence for practice may be identified from other research designs than randomized controlled trials (cf. Willman *et al.*, 2005). Instead of being seen as contenders, the qualitative and quantitative methodologies were here seen as

complementary paths to building knowledge within the nursing discipline (Upshur, 2001). This is a recurring standpoint which embraces this thesis as a whole. The argument is that it is because of a difference in the characteristics of knowledge produced from varying research methods, founded in their respective ontology, that the understanding about the world in which we live may develop. An exclusive antagonist view of what has collectively been labelled human and natural science research is outdated. Instead, these points of departure co-exist, complementing each other as two sides of the same coin into diversified and fruitful knowledge about the presumptions of life, the world and the truth.

Although there may be several descriptions of how to conduct systematic reviews, paper I followed an early nationally accepted methodological reference based on a seven-step model which was published in the year 1993 (SBU, 1993). However, the decision to include studies regardless of methodological approach was somewhat unusual. It affected the systematic review in framing the research question as well as the synthesis of results from studies included. At the time, guidelines for the systematic synthesis of results produced from qualitative analysis of data was lacking. Therefore a narrative synthesis of the scientific results included as data was considered an acceptable way forward. From a framework point of view, deviating from the manner in which results are typically synthesized was one of the most important ways paper I differed from conventional systematic reviews. In all other aspects, paper I attempts to follow the rigorous methodology of doing systematic literature reviews, characterized by systemacy at all stages to overcome potential biases (cf. DiCenso *et al.*, 2005).

Framework for the phenomenological hermeneutical research method

There are several similar, but not identical research methods recurrently used within nursing that jointly fall within the category of human science research. Qualitative research is another name, sometimes used interchangeably for human science research although it is not the research *per se* that is qualitative but the analysis of data. These research methods are usable within nursing because of their sensitivity and potential to capture and make sense of descriptions of experiences that people have had. Thus it is possible to understand lived experiences. These experiences could not have been understood in the same way through the use of research approaches proceeding from other ontological underpinnings. The human science perspective is useful in nursing research when the research question, by nature, has a disposition which is about the meaning of lived experiences. This was the case in papers II and III. The kind of knowledge produced and the human science perspective are valued because nursing demands such knowledge and sensitivity to phenomena that occur in people's lives (cf. van Manen, 1990). A sizable part of this thesis was aimed at understanding meanings of support as a phenomenon supposedly occurring in humans' life world. Therefore, the rationale for choice of method was focused on methods derived from the human science perspective and

guided by the dialectical interconnection between research question and research method.

The method preferred in this theses was a phenomenological hermeneutical method as recently described by Lindseth and Norberg (2004) and early researched by Udén *et al* (1992). This decision was influenced by impressions made while completing paper I. These impressions were decisive for how the thesis progressed and developed into papers II and III. What originally guided the ideas surrounding the initiative for papers II and III can be reworded by Kvale's introduction: *"If you want to know how people understand their world and their life, why not talk with them?"* (Kvale, 1996 p. 1). Consequently, interviewing was chosen as the preferred way of collecting data. Also inspired by Kvale's (1996) traveller metaphor, the unstructured interview was chosen as opposed to constricting the interviewer's "travelling ability" with an *a priori* constructed interview guide. The ambition in papers II and III was a sincere attempt to illuminate the meaning of a phenomenon as it revealed itself in people's own narratives of lived experiences.

The phenomenological hermeneutical research method, as described by Lindseth and Norberg (2004), is founded in western philosophy and falls well within the category of human science research approaches and has the potential to make sense of people's lived experiences. In this research method phenomenology and hermeneutics are viewed as symbiotic. Ricoeur (1981) claimed that in human science research, phenomenology remains the unsurpassable presupposition of hermeneutics. Therefore it could be said that phenomenology and hermeneutics are each other's presuppositions. They are interconnected since phenomenology has the ability to describe lived experiences whose meanings hermeneutics illuminates. In other words, hermeneutics makes sense of meanings of the lived experiences that phenomenology describe. Consequently, in the method employed for papers II and III, phenomenology was an inevitable part of hermeneutics and vice versa (Lindseth & Norberg, 2004).

Apart from being a method, phenomenological hermeneutics could also be said to entail an approach, an attitude. The researchers' attitudes while doing the phenomenological hermeneutical studies were characteristic of a lesser interest in establishing whether or not something actually, objectively happened, how often it happened or how common it was (cf. van Manen, 1990). Instead, the researchers' attentions were directed towards capturing the "thing" in question. In this attitude, the phenomenological attitude, no problems were solved and there were no winning concepts or good strategies (ibid.). Instead, the progress was in the researching meaning questions of papers II and III. These questions could not be solved, they could only be more deeply understood (van Manen, 1990). Therefore, a deepened understanding, by way of textual interpretation, was the ultimate objective in papers II and III. In particular it was the assignment of the hermeneutical component to disclose the message in the text, thus overcoming a distance between the reader

and the message. This was possible to do as hermeneutics through differing courses of events has evolved into a science which can be applied to all texts, since it is no longer restricted to biblical or juridical texts, which was traditionally the case (Melberg, 1997).

Earlier the goal was to interpret the author better than what the author could do himself, and understand what he meant or felt when he wrote the text. Now, in contemporary hermeneutics which proceed from Ricoeur (1976), it is instead the text that is central to understand, not the author as a person (Kristensson-Uggla, 1999). The latter approach to hermeneutics was employed in papers II and III. There was no interchange between subjects in the interpretation procedure. Hence, it was not a hermeneutical psychology that was performed but a hermeneutical phenomenology, which is dissociated from psychoanalysis (ibid.). It may be important to underline that the task of the hermeneutic component in paper II and III was not about understanding the author or what was hidden behind the text. Instead, the interpretation process illuminated possibilities that were opened up in front of the text, not behind it (Ricoeur, 1976). As Ricoeur (ibid.) writes: the text speaks of a possible world and a possible way of orienting oneself in it. Inevitably and consequently, there will never be an absolute, true or final interpretation, because “*the nature of the symbol*” (or in this case the text) “*according to Ricoeur lies in its surplus of meaning which makes it virtually inexhaustible*” (Kristensson-Uggla, 1999, p. 182). Hence, for each reading of a text the interpretation process starts anew, which only can lead to that understanding being deepened, and deepened and deepened (cf. ibid.). It was this constant journey towards deeper understanding that was the hermeneutical spiral, not a circle but a spiral, that is virtually without an ending, virtually inexhaustible. When the discourse was liberated from the narrowness of the interview situation, the meaning of the text was potentially opened to an indefinite number of readers, and therefore a likewise indefinite number of interpretations (Ricoeur, 1976). Consequently, the interpretations in papers II and III are just one of many possible interpretations. No single interpretation will ever exhaust the possibility of yet another complementary or even potentially richer or deeper description (van Manen, 1990 p. 31). However, papers II and III sincerely attempted to present the most probable interpretation. The interpretation was not only probable, it aimed at being more probable than another interpretation (Ricoeur, 1976). In comparison with a guess, the researcher guesses the meaning of the text, and while there are no rules for making good guesses there are rules for validating them (ibid.). The “best” guess, or the most probable interpretation, is the one that manages to cover the most aspects (Ricoeur, 1976). These ideas were aimed for and applied in papers II and III.

There are one further important clarification to be made as to the underpinnings of phenomenological hermeneutics. Even though it is generally accepted to write about analysis of text in this connection, it would probably be more accurate to claim to have analysed discourse fixated as text. There are several understandings as

to what discourse is, but the general conception builds upon that peoples entire relationship to reality is expressed through discourses (Nationalencyklopedin, 2005). On discourse Ricoeur (1976) writes: "*if discourse is produced as an event, it is understood as meaning*" (p. 73). In order to capture *discourse as an event* narrative interviews with interviewees were employed in papers II and III.

Narrative interviews

All interviews were tape-recorded and then transcribed verbatim into text. Thus, the discourse elucidated by the interview situation became a text, which in turn was interpreted and so the meaning became illuminated. In the search of a flexible strategy of discovery (cf. Kvale, 1996) the narrative interviews were useful as they were unstructured. The interviewees were invited to speak in their own voice and allowed to control the flow of topics (Mishler, 1986). The narrative interviews are one way of accessing peoples' life world in order to illuminate the meaning of the phenomenon under study in papers II and III. Expressing lived experiences in narrative form is probably the primary way humans use to make sense of their experiences (ibid.). The interviewees disclosed themselves through their verbal communication, in this case their narratives, which were fixated as a text (Andersson, 2002).

The research interviews were dialogues between unequal parties, and had a preconceived structure and purpose. The use of interviewing entailed a returning to the things themselves, "*to return to that world which precedes knowledge, of which knowledge always 'speaks'*" (Merleau-Ponty, 1962/2002 pp. ix–x). As one form of interview technique, the narrative interviews produced knowledge about the interviewees' life world and the narratives were natural and convincing models for conveying meaning (Mishler, 1986). Narratives can be understood in the completeness of their beginning middle and ending. The interviews, in which the narratives and their meanings were conveyed, were more a conversational way of relating to each other than a linguistic event. Moreover, they were also in themselves a form of discourse, and narratives were understood as "*someone was telling someone else that something happened*" (ibid. p. 148). Furthermore the narrative interviews were discursive in as much as someone told someone else about an experienced event that had come to pass. It was in this way that discourse was produced as events in papers II and III. Therefore, it could be understood as meaning. The instance of a dialectic between event and meaning was illuminated and the analysis and interpretation could be based on a theory of discourse and meaning (Ricoeur, 1976; Mishler, 1986 pp. ix & 66).

The unstructured interviews were useful for accessing narratives, because narratives are commonly found where interviewees are invited to relate their experiences in their own way through storytelling (cf. Mishler, 1986). Nevertheless, the narrative interviews for papers II and III were joint constructions between the interviewer and the interviewees (ibid.). Importantly, the interviews were not a series of questions and responses. Instead, they were a circular process where the interviewer and

the interviewee negotiated towards an understanding through the interviewee's narratives of the phenomenon under study (Mishler, 1986). It was through this way of relating, that the non-communicability of experiences such as lived could be transcended (Ricoeur, 1976) for the purpose of papers II and III.

The naive reading, the structural analyses and the interpreted whole

One contribution of applying Ricoeur in contemporary hermeneutics is his methodological way to interpretation and viewing interpretation as a dialectical movement between explaining and understanding, where explanation is a legitimate part of interpreting (Kristensson-Uggla, 1999). In papers II and III the naive reading, the structural analyses and the interpreted whole, are the correspondents to "explanation" and "understanding" in the phenomenological hermeneutical method as described by Lindseth and Norberg (2004). In both papers II and III the naive reading was the initial step in which a first surface conjecture of the meaning of the text as a whole was worded. By writing down the naive reading, understandings, beliefs and assumptions were made explicit. Although influenced by pre-understanding, the naive reading was returned to, questioned and critically appraised. Hence, establishing preconceived ideas could be deflected and the interpretation could expand the understanding of the phenomenon into something more and greater than what the pre-understanding and naive reading contained in the first place.

The next step in the interpretation process was the structural analyses. The initial impression from the naive reading could now be verified, corrected, deepened or rejected. The structural analyses were closer to explanation than to understanding. Structural analyses were therefore accurately labelled *analysis*. This was done to underline that they involved breaking down the text, for instance into sequences labelled meaning units. The structural analyses themselves had more to do with explaining the text than getting a sense of the whole. The latter is closer to understanding the text (cf. Sandelowski, 1995).

The final phase in papers II and III was the interpreted whole. It should be regarded as the result of the interpretation. It was the centre of gravity in the interpretation and took into account the naive reading, the structural analysis and the pre-understandings of the researcher/s. Also, the interpreted whole was mirrored in literature, thus opening up for a widened and deepened understanding (Lindseth & Norberg, 2004). The choice of literature was directed towards the theoretical and philosophical literature that has the potential to widen and deepen understandings of lived experiences. However, when using the literature's perspective the endeavour was to illuminate the text and let the text illuminate the literature, as opposed to forcing literature upon the text (cf. Lindseth & Norberg, 2004 p. 151). The above description may wrongly portray the interpretation as a linear process. Instead, the interpretations in papers II and III were continuous dialectical movements between

the parts and the whole of the texts, and correspondingly between understandings and explanations.

Truth from a phenomenological hermeneutical perspective

The question of whether something is true or not is central in philosophy as well as science and research. Therefore it is an important question to address, even though it belongs to the most difficult questions that can be raised. The whole of theory of science can be seen as an attempt to answer this single question (Söderfeldt, 1985). The essence of this question is whether or not science can provide defensible grounds for actions. Hereof, the problem of causation was formulated, pointing out that it is impossible to *a priori* tell something about the true outcome of any next observation regardless of the pattern's regularity (ibid.). The philosopher Karl Popper attempted to solve this problem through a change in the meaning of truth by claiming that there is nothing absolutely true (Söderfeldt, 1985). Instead, truth simply means not yet refuted.

The point of departure in the interpretation process, the hermeneutic spiral, in papers II and III can be highlighted through Popper's line of reason on falsification when Ricoeur writes: "*An interpretation must not only be probable, but more probable than another interpretation. [...] it is not true that all interpretations are equal*" (Ricoeur, 1976, p. 79). Consequently, as it is not true that any interpretation of a text is valid, working with papers II and III entailed a dialectic where understandings were posed and overthrown. Papers II and III were intentionally directed towards presenting the hitherto most probable or the most likely interpretation of all (ibid.). By lingering with the texts it was possible to come closer to understanding their meanings and hence paving the way for "truth" (Gadamer, 1960/1997). The truth can be revealed by the researcher when s/he takes time to dwell on the question at hand (Dostal, 1994). The key point in papers II and III consequently is that truth was not *there* to be captured. It was not about an objective establishing of facts. Instead it was about presenting the most likely interpretation which was not equivalent to an objective verification of facts. In other words, "*to show that an interpretation is more probable in the light of what we know is something other than showing that a conclusion is true.*" (Ricoeur, 1976 p. 78). What could be achieved through the phenomenological hermeneutical method was one possible interpretation. What adds to the complexity is that truth always simultaneously is revealed and concealed. This is because the phenomenon under study always and constantly relates to the researcher in profile. When a phenomenon is illuminated from different directions, diverging profiles are illuminated but the researcher can not see all sides at once (Dostal, 1994).

Moreover, in phenomenological hermeneutics it is necessary that the researcher be the very instrument for the research. This has considerable impact on the concept of truth, when compared with truth in methods proceeding from other ontological underpinnings. Truth in phenomenological hermeneutics is intimately interrelated

to the researcher as a person. The researcher cannot interpret the material in another way than as an individual person. With reference to the concept of truth, Ricoeur (1965), speaks of being in the truth. There is a prominent moral dimension to the aspect of truth within the human science perspective. The research becomes rigorous when it is “strong” or “hard” in a moral and spiritual sense and conscious of not violating the spirit of human science research (van Manen, 1990; Sandelowski, 1995). These were the key understandings in papers II and III, as regards the concept of truth.

Pre-understanding as regards papers II and III

As the interpreter inevitably is a part of the interpretation process, *bracketing*, meaning putting aside the interpreter’s pre-understanding is impossible from a Ricoeurian perspective. The interpreter cannot understand something as someone other than through the self. Thus, the process of reflecting upon the texts and interpreting the texts had its starting point in the researcher as a person. It was with the point of origin in the researcher’s pre-understanding that the way for deepened understandings could be prepared. Hence, pre-understanding was an inevitable part of understanding. The interpretation cannot begin from nowhere, the point of departure must be from something already given through language (Kristensson-Uggla, 1999). These are the reasons why the idea of bracketing was not considered applicable in papers II and III.

In papers II and III, dealing with the pre-understanding was conscious of avoiding the assumption of *knowing* too much beforehand (van Manen, 1990). Openness was essential and characterized by a humility. The central issue of importance was that reflection did not become a reflection of the researcher’s self (Kristensson-Uggla, 1999). Instead, the pre-understanding was put in to play. Therefore, all authors in paper II as well as paper III, worked together throughout the research process to strengthen the research design. Not by achieving consensus, but by supplementing and contesting each other’s readings as a part of reflexivity (Malterud, 2001). Otherwise, the interpretation may risk to only confirm what is already known, instead of creating a new understanding (Dahlberg *et al.*, 2001).

As regards the researchers’ pre-understandings in papers II and III, none of the authors have been working in that specific context of care, but all were registered nurses with differing experiences from clinical practice. Among the authors there were previous research experiences using the current methodology and some of the authors had previous experience from researching support from a family carer point of view. The pre-understanding consisted of what each researcher could contribute with as a person and their point of departure as a human being when reading the texts. What may influence one’s point of departure as a human being may of course be influenced by past and present life experiences.

Empirical research context in papers II and III

The rationale behind the choice of research context for the empirical studies (papers II and III) was due to the *a priori* assumption that fruitful narratives on the concept of support could potentially be retrieved from the AHC context. The sampling strategy was purposeful. The line of reasoning behind, and rationale for choosing the AHC context harmonizes with the description of purposeful sampling, in as much as it focused sampling from an information-rich context in order to contribute to the questions under study (cf. Patton, 2002). It may be argued that the AHC context is not representative of the home care of frail aged persons today, or that the context is an extreme outlier. In that perspective, the worth of choosing the AHC context may be underlined by reworded by extreme or deviant case sampling strategy. Valuable lessons may be learned from unusual conditions, extreme outcomes or illuminative cases. Nevertheless, the ambition in papers II and III was to learn from in-depth study of the assumed information-rich AHC context (cf. Patton, 2002 p. 234).

Framework for the concept analysis methodology

According to Rodgers (1989) there are two primary philosophical views on concepts, the entity view and the dispositional view. Concept analysis methodologies recurrently employed in nursing, such as those of Walker and Avant (1983) or Chinn and Kramer (1995) proceed from the entity view underpinnings. There, concepts are viewed as having clear boundaries, being static over time and having a rigid set of conditions (Rodgers, 1989). The entity view has positivistic anchorage in its static and reductionistic approach to concepts, but may be counterbalanced by the dispositional view. The latter has a dynamic, temporal and contextual approach to concepts which are regarded to exist in vast interrelationships with other concepts (Rodgers, 1989; 2000). Hence, the dispositional view may be more adjacent to contemporary assumptions on the nature of knowledge as generally accepted in nursing to date. In the dispositional view focus lies on the use of the concept as opposed to the concept itself (ibid.). Both the focus on “use” in particular, as well as the differences between the entity view and dispositional view in general, had bearing on how the data was collected and handled in paper IV. As concepts are influenced by their use and application, the literature was chosen on the basis of its role of institutionalizing the concept (Rodgers, 2000). A concept in itself was understood as a cluster of attributes which can be identified through examination of common uses. Furthermore, a concept is not a word, but an idea or characteristics associated with the word. Words are used to express concepts but they are not the concepts themselves (ibid.).

The evolutionary approach to concept analysis as described by Rodgers (2000) was considered one appropriate and possible way of dealing with the research question in paper IV. This decision was strengthened by early methods of concept analyses having been critiqued for containing serious flaw, misunderstandings regarding the relationship between concept and theory and for not taking contextual factors into

consideration (Paley, 1996). Also, the essentialist point of view which underpin early methods was considered out of line with the overall theory of knowledge view in papers I–III where temporal, social constructivist and dynamic underpinnings were salient. Instead, the approach to concepts as being without a final endpoint, dynamic, influenced by time and context (discursive, theoretical, cultural, social or disciplinary) as well as the idea of a heuristic cycle of continuously developing results was favoured. The evolutionary approach was considered not only compatible with papers I–III but also compatible with the perspective generally accepted in nursing; where reality, human beings and nursing phenomena are constantly changing, interrelated, overlapping and interpretable only in regard to a multitude of contextual factors (Rodgers, 2000). Furthermore, the procedure of constructing a case, that is an exclusive instance of the concept under study (cf. Walker & Avant, 1983), may be questionable from Ricoeurian point of view where no event is ever interpretable in just one way (cf. Ricoeur, 1976; Paley, 1996). Discovering this difference of viewpoint, further favoured the choice of Rodger’s (2000) method for paper IV.

Samples

Searches for data – papers I and IV

The data in papers I and IV were to a large extent composed of scientific literature identified through systematic database searches. Figure 1 below, was intended as a visual representation, of the subject areas that had to be included in all the scientific publications in order for them to be eligible as data. In other words, it was only if all four “fields” (white) were represented in the same publication, that articles were considered admissible as data (grey). All other articles were ineligible and therefore discarded. These criteria were used in paper I and IV.

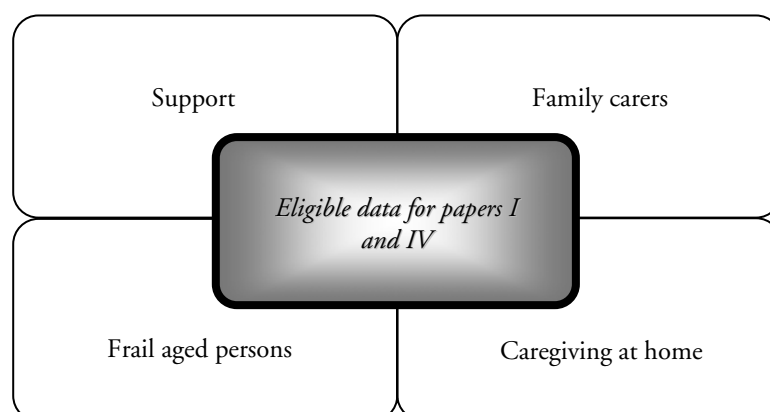


Figure 1. The four subject areas that had to be included in the eligible data, for papers I and IV.

Identifying data for paper I

The identification of data for paper I followed a given pattern with high systemacy in all steps. The method contains seven steps; specify the assessment problem, specify inclusion criteria for studies, formulate plan for literature search, conduct literature search and retrieval, interpret the study evidence, integrate the evidence and formulate recommendations based upon evidence quality (SBU, 1993). Formulating a focused research question was fundamental prior to engaging in the identification of data. Therefore, a structure developed by Flemming (1998) was used when formulating the research question. It was fundamental in order to deduce search words and search terms later employed in the literature searches.

The search strategy was designed to identify as much relevant published research as possible through systematic database searches. Hence, the database searches initially focused on sensitivity rather than specificity (cf. SBU, 1993). One consequence of focusing on sensitivity rather than specificity was that the manual screening of abstracts for eligibility of inclusion became extensive because the searches contained interference in the form of irrelevant citations. The focus on sensitivity was increased by the decision to include studies employing quantitative as well as qualitative analysis of data.

The sources of data were the international databases Medline, Cinahl and the Cochrane database of systematic reviews. The following search words were used and adapted according to the prerequisites of each specific database: family, intergenerational relations, spouses, home nursing, informal caregiver, family carer, family caregiver, family caring, aged, aged 80 and over, frail elderly. A combination of free-text and indexed subject headings was used. The searches created a foundation from which data/studies on support were manually screened and selected.

In addition to the systematic database searches, data/literature was searched for through the Internet, the Netting the Evidence and Medical link websites, Swedish reference databases (Svesök, Libris, Spriline) as well as publications from The Swedish Board of Health and Welfare. Following a pilot search in the Medline database, some minor changes were made to correct the search words. The criteria for inclusion were deliberately non-specific as regards medical diagnosis of the cared-for person, thus creating a sensitive rather than specific image of support for family carers. The outcomes from studies had to pertain to support e.g. efficiency of support or different forms for support, needs for support or experiences from support. Consequently studies measuring outcomes such as caregivers' health status, burnout, burden or strain were not included. Studies in other languages than English or Scandinavian languages could not be included. No limitations regarding publication date were actively used during the database searches. All searches were performed during spring in the year 2001.

Identifying data for paper IV

Potential data for paper IV were identified through extensive searches of encyclopaedias and dictionaries as well as searches of scientific databases. These sources of potential data from encyclopaedias and dictionaries were composed of: The Swedish National Encyclopaedia, Merriam Webster Online, Gale Virtual Reference Library, International Encyclopaedia of the Social and Behavioural Sciences, Oxford Reference Online, The Oxford Dictionary of Current English and the Swedish Academy Dictionary. The scientific databases were composed of: Cinahl, Medline, Psychinfo, The Cochrane Library of Systematic Reviews, Sociological Abstracts and Social Science Citation Index. The searches in encyclopaedias and dictionaries employed the primary search term *support* only, and no combinations were made. However, the searches were limited to the primary search term appearing in the title. The process of pinpointing data for paper IV was in concordance with the identification of data for paper I, in as much as all four subject areas as previously displayed in figure 1 should be included. The primary search term *support* was used in different combinations with aged, aged 80 and over, frail elderly, family care*, informal care*, lay care*, caregivers or corresponding terms depending on the prerequisites of the respective database searched. A combination of free-text and indexed subject headings was used. All search terms used were limited to appearing in citation title and/or abstract. An overview of the progression of data identification and data selection in paper IV is thoroughly described in paper IV.

Sampling and participants – papers II and III

At the initiation of paper II and later paper III in spring/summer the year 2002, AHC was well established at three out of ten hospitals in the southern region of Sweden. This area has 33 municipalities of which 12 had access to AHC through the three hospitals' reception areas (Onkologiskt Centrum, 2003). All three AHCs agreed to participate and collaborated for the purpose of papers II and III.

The sample in paper II was comprised of 20 family carers who agreed to participate. In order to be eligible for inclusion they had to be in the process of caring for a cohabiting frail aged person at home. The family carers were approached in the following way: An nurse working in AHC delivered a letter explaining the aim and procedure of the study (appendix 1). Then the nurse inquired about the family carers' consent to disclose their telephone number to the researchers. If the family carers consented to being telephoned, the first author (PS) rang them up to further explain the study and inquire about their prospective opportunity to participate. Given the sensitive family situation this way of approaching the participants was considered as least intrusive by the researchers. The letter was delivered by a well-known person to whom the family carers did not need to justify a refusal to participate. Also, there was no need to establish any lists of names or addresses of family carers prior to the sampling strategy because of the in-person delivery of the letters. A total of 28 family carers were in telephone contact with the first author. Of these family carers, three did not want to participate due to feeling totally occupied with

caregiving or not regarding themselves as caregivers. Furthermore, one family carer did not cohabit with her charge, two did not care for aged persons and two family carers' charges died before the interview was conducted. Consequently these eight were not included in the final sample selection. All but one of the participating family carers chose to be interviewed in their own home. The person who was not interviewed at home was interviewed in a secluded room at Malmö University. Included families had been affiliated to AHC from three weeks to 96 weeks (median: 12 weeks). Although it was not a specific criterion for inclusion, all participants (n=20) were spouses. Eleven wives and six husbands were interviewed. The family carers' age ranged from 54 years to 84 years (median: 73 years) and the age of the cared-for persons ranged from 66 years to 89 years (median: 78 years).

In paper III, a total of 20 registered nurses were interviewed, of whom three were men. All participants chose to be interviewed in their workplace. The nurses' ages ranged from 32 years to 52 years (median: 43 years), and they had been working as registered nurses ranging from 2 years to 32 years (median: 13 years). The nurses had been working within advanced home care from 1 year to 8 years (median: 5 years). The registered nurses were approached in the following way: at one AHC, five registered nurses volunteered to be interviewed. At the two remaining AHCs, a list of employed registered nurses was obtained, from which every third name was chosen. These nurses were sent a letter (appendix 2) which explained the aim and procedure of the study and also asked them to contact the first author to say whether or not they agreed to participate. Aside from the five volunteers, a total of 23 nurses received the letter asking for their participation, which 15 nurses agreed to. Some characteristics of the participants finally included in papers II and III are collectively shown in table 2 below.

Table 2. Characteristics of the participants in papers II and III

	Paper II	Paper III
Sample (n=)	20 family carers	20 registered nurses
Ages	<i>Family carers</i> 54–84 years (median: 73 years) <i>The "cared-for persons"</i> 66–89 years (median: 78 years)	32–52 years (median: 43 years)
Time affiliated with AHC	3–96 weeks (median: 12 weeks)	<i>Years working as RN</i> 2–32 years (median: 13 years) <i>Within AHC</i> 1–8 years* (median: 5 years)

* Eight years was the maximum, since that was how long the organization has been running.

Data collection

Retrieving data for papers I and IV

Once the literature was identified, a manual screening of abstracts followed in order to identify data that were potentially eligible for inclusion in paper I. The final search resulted in the retrieval of references that potentially met the criteria for inclusion. All database searches were imported into the reference management software program Endnote version 4.0. The software program assisted in keeping track of references.

As regards paper IV, encyclopaedias and dictionaries were searched and potential data were printed out on paper. Potential data from the scientific database searches were imported into Endnote version 7.0. Manual screenings of titles to check eligibility was performed once the scientific literature was identified, but before any full-text retrieval was performed. Thus, the citations that did not meet with all four subject areas (see figure 1 p. 29) could be discarded. This process reduced the number of citations. Besides correspondence or non-correspondence with the four subject areas, reasons for excluding or discarding references at this stage were mainly due to the settings. For example studies conducted in China, Thailand, Malaysia, Hong-Kong, Jamaica, Tanzania, or South Africa. was judged as complex to relate to a European healthcare system context. Citations were also discarded due to no abstract being available, incomplete citations, being in other languages than Scandinavian languages or English. Studies focusing on life-support, intensive care, children or adolescents were excluded.

Based on the prerequisites available to carry out paper IV, a decision was made to further diminish the number of eligible or acceptable citations. This was done by using standard means of probability sampling, which is applicable within the concept analysis method chosen for paper IV (Rodgers, 2000). Thus, the data from each scientific database was organized into two separate reference lists using Endnote version 7.0. One list was created for nursing, containing the databases Cinahl, Medline, Psychinfo and Cochrane. Correspondingly, one list was created for social work containing databases Sociological Abstracts and Social Science Citation Index. The data were then sorted by publication date and a stratified random sample, that was computer generated with SPSS version 12.0, was drawn from each reference list. Each strata then represented 20% of the original (n). After randomization, the 584 acceptable citations within nursing were reduced to 117 citations and the 332 acceptable citations within social work were reduced to 66 citations. All available abstracts of the 117 citations and 66 citations were then manually screened for potential inclusion by two researchers (PS and AW), who worked independently of each other. The selections made by the respective researchers were later compared for matches and mismatches between selections. All matching citations were retrieved in full-text (n=18). As regards the mismatches, the first author (PS) single-handedly reviewed the mismatches again and subsequently an additional 20 citations were retrieved.

Narrative interviews for papers II and III

Before proceeding with the interviewing, the interviewer had again explained the aims and procedure of the study and answered any questions or concerns the participant might have in relation to the study. In the narrative interview situation a sincere attempt was made to let the interviewees narrate their lived experiences as freely as possible, with a minimum of interruptions. Follow-up questions were used to encourage narration, for clarification, to ask for examples of situations and to keep the participant narratives within the aim and scope of the study. Moreover, in order to retrieve as rich and full descriptions as possible the participants were also asked to narrate on experiences from the phenomenon in its absence. If such examples did not spontaneously occur during the interviews, they were asked for. All interviews were tape-recorded on a Mini-Disc player using a small separate microphone with extension cord. All interviews were transcribed verbatim including pauses, weeping, laughter etc.

In paper II, all 20 interviews with family carers were performed by the first author (PS) between September the year 2002 and December the year 2003. The interviews continued for between 30 minutes up to 80 minutes with a median of 48 minutes. The transcripts amounted to a total of 1,143 double-spaced pages. All participants were asked to narrate their experiences of support using the opening question: Please tell me about your experiences of support. The open-ended follow up questions that were used was for example: Can you tell me more?, Can you give me an example?, How did you feel?, What were your thoughts? The follow-up ques-

tions also aspired to keep the focus on the support the family carers received rather than on the support the cared-for person received. The participants were also asked to narrate about negative experiences from support, i.e. to illuminate the phenomenon of support in its absence: Please tell me about a time when you felt that the support wasn't so good.

The interviews, in paper III with 20 registered nurses continued for between 38 minutes to 72 minutes (median: 52 minutes). Transcripts amounted to a total of 628 double-spaced pages. All interviews were performed between October 2003 to December 2003 by first author (PS). Participants were asked to narrate about their experiences of being supportive, using the initial question: Please tell me about your experiences of being supportive towards family carers. Open-ended follow up questions were used to encourage further narration such as: Can you give another example? What happened next?, How did you feel?, Could you tell me about a time when things didn't turn out so well?

All interviews in papers II and III were performed in secluded rooms with only the interviewer and interviewee present, apart from one exception in paper II where the cared-for person was also present. All but one family carer were interviewed in their own homes and all nurses were interviewed at their workplace.

ANALYSES

Reviewing and synthesizing data

A total of 333 full-text articles were retrieved and assessed for paper I. The assessment process was performed in two phases by two independent reviewers (PS, RN). First, a specific protocol was developed for the screening appraisal. The screening process was designed to make sure that the studies met all inclusion criteria and determined whether or not the studies should be further assessed in phase two. After an initial screening process of the 333 retrieved articles, a total of 37 remained as collectively agreed upon by the two reviewers. The remaining 37 articles were subjected to a deeper classification and quality assessment. In this second phase of the assessment process, specific protocols for studies with qualitative as well as quantitative analysis of data or systematic reviews were used. The protocols were developed from literature on research assessment (Guyatt *et al.*, 1993; 1994; Oxman *et al.*, 1994; Willman & Stoltz, 2002). After this final review process 24 articles remained. The reviewers collectively agreed upon the classification and quality assessment of each article. A three-point scale was used in order to reflect the scientific quality of studies included: high (I), medium (II) or low (III) quality. A medium (II) grade was used if studies did not meet criteria for high (I) or low (III) quality in full.

Due to the pursuit of sensitivity, the results in paper I draw upon studies employing quantitative and/or qualitative analysis of data. This led to a methodologically heterogeneous mix of studies that should be synthesized into a comprehensive cohesive description. As tangible proposals of methodological guidelines to synthesizing and/or integrating qualitative and quantitative studies were lacking, a narrative synthesis was performed as opposed to a meta-synthesis or re-analysis which perhaps are more common in systematic reviews of more homogeneous data. Conclusions were drawn following the synthesis of data. These conclusions were classified as A (high) or B (medium), depending on the scientific strength underpinning each statement. High-strength statements (A) should not easily be overthrown by counter-evidence from individual studies other than perhaps systematic reviews.

Phenomenological hermeneutical analysis

All data eligible for analysis in papers II and III consisted of narrative interviews. The transcribed interview text was analysed and interpreted in three recurring phases: naive reading, structural analyses and comprehensive understanding. The structural analyses reflect the *explanation* of the text, whilst the naive reading and the interpreted whole reflect the *understanding* of the text. The latter two are however at differing altitudes of understanding on the hermeneutical arch (cf. Ricoeur, 1976). First a thorough reading of each interview was carried out, in order to naively capture a first surface conjecture of the text as a whole (Ricoeur, 1976; 1991;

Lindseth & Norberg, 2004). The naive reading was then followed by the structural analyses, which allow for a deepened understanding of the initial naive reading. All structural analyses were thematic. They involved an identification, condensation and organization of meaning units, which are selected sequences of text that convey meaning. Meaning units could be one or more sentences that conveyed meaning according to the aim of the papers. The meaning units were lifted out from the initial text into tables and gradually condensed according to the following sequential order. The meaning units were transformed into one or two sentences, condensed as closely to the initial text as possible. Then, the meaning units and transformations were taken into account when subthemes, themes and core themes were formulated. Furthermore, the structural analyses also prepare way for a widened and deepened understanding of the text as a whole, labelled the comprehensive understanding or interpreted whole. Although the process of analysing and interpreting the interview text is not linear, the interpreted whole gives the impression of being the final phase because it represents the results and centre gravity of the analysis process.

Concept analysis

The data in paper IV were collected with the emphasis on inductive discovery with focus on identification of relevant aspects of the concept. The literature was analysed to identify attributes of the concept and its contextual features (antecedents, consequences and temporal variations), surrogate terms, related concepts and application of the concept (Rodgers, 2000). The identification of potential changes over time was taken into consideration by sorting the lists of the scientific literature by publication date, prior to the random selection process. Hence, the random sample contained early as well as later publications. The identification of attributes was the primary objective of the analysis. The intention was to inductively derive a definition of the concept of support. The identification of attributes was facilitated by keeping in mind and asking the following questions of the data: “*What are the characteristics of the concept? i.e. What is the ‘thing’ the writer is discussing?*” (Rodgers, 2000 p. 91). Similarly, the contextual basis identification of the concept was facilitated by keeping in mind while reading: “*What is happening when an instance of the concept occurs?*”, “*What happens before/after*” and “*Is the concept used differently in different situations/by different people?*” (ibid.). Surrogate and related concepts were also noted during the analysis phase. In order to structure the analysis phase a data collection sheet was constructed and filled out for each scientific publication. This allowed for verbatim passages to be noted whilst collecting data. Data was also easily organized by the categories antecedents, consequences, references, surrogate and related terms.

The data analysis entailed the breaking apart of “a thing” to identify its consistent components (Rodgers, 2000). The analysis of data in paper IV could be labelled thematic analyses. Each category of data (i.e. attributes, contextual information,

references) was examined separately to identify major themes presented in the literature (ibid.). This phase entailed a process of organizing similar points in the literature until a cohesive and comprehensive system of descriptors was generated. Once data are organized under labels of major aspects of the concept, theoretical analysis took place. That included areas of agreement and disagreement across disciplines and changes over time.

Before the thematic analysis of data, an exemplar of the concept was identified using data which was originally collected for the purpose of paper II. According to Rodgers (2000) the exemplar should be identified rather than be constructed in order to be consistent with the philosophical underpinnings of the evolutionary concept analysis view. The exemplar was intended to illustrate the characteristics of the concept in a relevant context, thus leading to enhanced clarity.

The overall objective of using this method was to identify a consensus derived from the literature. In turn, the consensus potentially creates an important foundation for further research. The results should therefore not be regarded as a definitive answer. Instead, the results are powerful heuristics that promotes and gives direction to additional and future research (Rodgers, 2000).

ETHICAL CONSIDERATIONS

In paper II family carers of frail aged persons were asked to narrate their experiences from dealing with the specific life situation of caring for a dying relative at home. This life situation may include a wide range of different feelings including upsetting and subversive emotions. Hence, asking the family carers to narrate experiences in relation to, or because of, this specific life situation may awaken negative or painful feelings for the participants. Interviews are intrusive and affect people as interviewers lay open thoughts, feelings and experiences which the interviewees perhaps did not intend to share in the first place (Patton, 2002). Therefore a series of precautions during, and surrounding the interview situations were contemplated in a sincere attempt to minimize the risk of harm being inflicted upon interviewees.

All interviewees who participated in paper II gave their consent to be interviewed. They could abstain from being interviewed, pause the interview or withdraw their recordings once the interview was finished. Also, during the interviews the participants narrated freely and therefore had some influence on which issues were addressed in the interviews (cf. Strandberg, 2002). Participating in the interviews for paper II could cause negative emotions, reactions and/or be too time consuming for the interviewees. The research for paper II could be quite intrusive as it involved working with feelings and experiences (cf. Wilkie, 1997). Furthermore, there are still moral discussions and concerns on a general level as to whether or not research should be done in palliative care settings (de Raeve, 1994). Consequently, there was a risk that interviewees experienced negative emotions because of the interview. However, no negative responses caused by the interviews were, or has later been, conveyed to the researchers. Instead, the impression was that interviewees generally felt okay about the interview experience, and about sharing their experiences in that they may benefit someone else. This has also been seen in studies on research participation experiences within palliative care (Barnett, 2001; Hudson, 2003). Before leaving their homes, the interviewees were again provided with the telephone number of the interviewer and informed of the possibility to withdraw the recording even though the interview was finished.

Before attempting to contact any family carers, the aim and procedures in paper II were approved by the clinical directors of all included AHC units as well as by the research ethics committee at Lund University, LU 233-02. Thereafter, the potential interviewees were approached with a request for their participation in the least intrusive way conceivable. Potential interviewees actively decided to disclose their personal information (i.e. telephone number) to the researchers or not. Therefore the law about personal information (SFS 1998:204) did not apply. No lists of names were necessary and none existed. If the family carers agreed to participate, they decided the date, time and place for the interview. All family carers who participated had the opportunity to contact the first author before, as well as after, the interview

itself. All participants were guaranteed confidentiality and that any material such as recordings and transcript be kept safe and away from unauthorized persons.

The aim and procedures in paper III were also approved by the clinical directors from all included AHC units as well as by the research ethics committee at Lund University, LU 370-03. The nurses who agreed to participate in paper III were interviewed with the same general conditions as the family carers in paper II. All interviewees in paper III were given written and oral information about the aim and procedures. All consented to be interviewed and all were guaranteed confidentiality. However, as all nurses were interviewed at their workplace it may be locally known who actually participated in the interviews. However, it is not known what was said or by whom.

All communication and information concerning paper II as whole were directed to the family carers only. Consequently, the cared-for persons did not receive any written information, nor was consent obtained by the researchers from the cared-for persons. This may on the one hand be viewed as unfair or inconsiderate towards the cared-for persons. On the other hand, family carers may be considered as autonomous individuals, capable of and suitable for deciding whether or not to inform the cared-for person about their eventual participation. Actually, one interviewee decided not to inform the cared-for person. As a result the interview took place at a another location than the home. This interviewee would not have participated, had information been sent to the cared-for person.

There can be a risk that some interviewees in both papers may have felt obliged to participate, either as an expression of gratitude (paper II) or due to peer pressure (paper III). Whether this actually was the case is unknown. If so, the principle of autonomy (Beauchamp & Childress, 1983) could have been jeopardized. However that may on the other hand have been counterbalanced by all the other precautions taken. Overall, papers II and III were performed in accordance with the principles of autonomy, beneficence, non-maleficence, justice and with respect for the protection of human rights (Beauchamp & Childress, 1983; Polit & Hungler, 1991; Vetenskapsrådet, 2002; 2003).

RESULTS

The results from each individual paper (I-IV) have been organized into the text below. Four subheadings are used to interlacingly report the results from papers I-IV. The description contain the main traits of the results whereas further detailed may be found in the individual papers.

The incentive to support family carers

The diversity of studies on support for family carers complicate cross-study integration. However there appear to be high consistency as regards the incentive to why family carers are in need of support in the first place. Countries national initiatives to support family carers are brought on by the large extent of care that family carers provide (paper IV). It is clear that family carers experience a high degree of negative emotions such as burden, stress and worry when caring for a frail aged person at home (paper I). Family carers' situation can be described as disruptive and subversive. Struggling with feelings of loneliness, helplessness and hopelessness alongside a fear of loss of control, relationship role changes with loss of reciprocity are some of the challenges family carers may be faced with (papers I & IV). Feelings of loneliness, helplessness or forsakenness may be particularly subversive, and feeling there is no support can be expressed as being overwhelmed by responsibility, experiencing insecurity and aloneness (paper II). Family carers can experience the period following the cared-for person's discharge from the hospital as particularly troublesome and speak of being forsaken left to fend for themselves. They may feel as if there is nowhere to turn to for help, and that nobody cares about what happens with their family. They may try to find pathways to call upon professional help, but seemingly nobody wants to assume responsibility in making sure that service provision or medical attention is appropriate. Family carers may experience this as being unable to attract attention to their situation. Although family carers may want to help the cared-for person, they may sometimes feel unable to do so without the aid of healthcare professionals. Also, being passed through the hands of all the relevant authorities without an appropriate response to resolve any issue at hand, may generate a feeling of being met with thoughtlessness, without deference. Finding someone who would help family carers take on the difficulties arising from caring, instead of offering temporary solutions may be a very real challenge for family carers. Similarly, the instance of determining whether or not it may be appropriate to seek professional help, for example if the condition of the cared-for person worsens, can likewise be difficult and trying for the family carer. That involves assuming responsibility for the well-being of another person (paper II). Also, witnessing the suffering of the cared-for person, while feeling able to do nothing can give rise to powerlessness, feeling insufficient or perplexed. These feelings, or the feeling of being alone with responsibility, may never fully be erased, as family carers can feel irre-

placeable and ultimately responsible for standing by the cared-for person regardless of the support provided or attempted (paper II).

The tangible dimension of support is about services and education

Within the tangible dimension, support can be understood through research as the total level of assistance or any input provided for family carers (paper IV). The support may be more or less directly aimed for the family carer as a service that tangibly can be given and received. Hence, this dimension represents the formal services defined by tangibles such as visits, telephone calls, home help services, planning care, financial services, day-care services and training (paper IV). Several scientific studies on support for family carers appear really to be about increasing family carers' caregiving capacity or competence. For instance through providing respite care, maximizing community resource utilization or through a teaching-learning process based on education and information (paper IV). Hence, support for family carers may appear as a means to meeting an alternative objective, which is increased emotional and physical health of the cared-for persons (paper IV). Nevertheless, it can be asserted from the scientific literature that family carers desire respite care, although the evidence of its effectiveness remain unconvincing. Furthermore, it would appear that caregiver education programmes would be good and effective ways to support family carers (paper I).

Reviewing the scientific literature reveals that the stress-coping or stress-buffering conceptual frameworks prevail in support for family carers (paper IV). Support is mainly portrayed as positive for family carers, therefore it is noteworthy that researchers seldom discuss or mention negative or adverse effects of support. For example that supportive persons, or relations can be a potential source for conflicting wills. Family carers can also feel discouraged from having attending support groups where less autonomous persons than the ones they care for themselves are discussed (paper IV).

When asked about their experiences of being supportive, nurses narrated one aspect that appears to gravitate around the tangible, concrete or hands-on dimension (paper III). Family carers are, in the nurses narratives, partially portrayed as needing to realize what is reasonable to expect of caring at home. Furthermore, what the nurse can relate to them through nurses' experience and knowledge. The nurses related aspects pointing towards attaining a preparedness in the family carers' ability to deal with the situation at hand. This was, at a higher level of abstraction, understood as "striving to keeping caregiving at home". In contrast was an unpreparedness in the family carer, which appeared desirable to avoid as it potentially involved the family carer giving up caregiving (paper III). Experiencing the situation as manageable was understood in relation to feelings of togetherness and involved trusting surrounding resources and a shared responsibility (paper II). Hence, through tangible supports, family carers can feel that they are no longer alone in managing the situation. Con-

sequently, meanings of support may further be illuminated and understood through the concept of manageability (paper II).

According to the nurses' narratives, feeling confident in caring at home was about promoting self-confidence in the family carers and reassuring family carers that caring at home is feasible. Moreover, promoting family carers' confidence in the nurses was also about: that the nurses actually would make sure family carers' needs were met (paper III). The nurses taught ways to handle caregiving. They discussed tangible proposals with the family carers of ways of dealing with issues arising in caregiving. The issues ranged from handling and administering painkillers to helping the cared-for person with her/his own hygiene (paper III). In knowing how to deal with situations that otherwise could feel unfamiliar, there was no need for the family carers to feel powerless to act or worry. The nurses were working for the family carer to feel in control and assured by knowing what to do and how to get in touch with the nurses. Hence, nurses were seeking a sense of security and safety for the family carers through knowledge and ability to act in different situations (paper III).

Integral to reassuring family carers of the feasibility of caring at home was, according to the nurses, to prove one's own worth through the performance of promises. Being supportive was not just about uncovering family carers' needs but also translating words into deeds, for instance, putting their contribution to the family carers' situation into action as soon as possible (paper III). Keeping appointments, coming when called for. Honouring one's promises was illuminated by the nurses narratives as a part of being supportive, through fostering a reassurance of responsiveness to the family carers needs (paper III). Consequently, investing in family carers' self-confidence in managing caring at home, preparedness through understanding, reassuring and affirming the family carers were some of the salient features. These can be understood and interpreted as traits of professional caring in a nurse–person encounter. Therefore, the meaning of being supportive may be further and deeper understood in close relation to or approaching the concept of caring (paper III).

The giving and receiving of affirmation did not come through as coincidental in the nurses narratives (paper III). Instead, encouraging the family carers and telling them how good and capable they were in caring for their relative, was an aware part of being supportive. Nurses were mindful of commending family carers and acknowledge their worth and value in caring and caregiving (paper III). The confirmation and affirmation expressed by the nurses, to some extent, could keep the family carers caring and managing to go on a little longer. After all, according to the nurses, it was thanks to the family carer that the cared-for person could stay at home. However, the nurses also spoke of the confirmation they themselves received from patients and family carers. In turn that kept the nurses going and sustaining continued work within this particular health service field (paper III).

Unlike the prevailing tone in scientific results from accessible studies (papers I & IV), the nurses' narratives illuminated dilemmas from supporting family carers. This was specifically elucidated in situations where the family carer's and the cared-for person's needs and wishes were in opposition (paper III). Then nurses found themselves in the dilemma of having to choose between family carers' or patients' wishes' and the solutions were rarely optimal for all. This was exemplified in situations when the family carer felt they could no longer go on caring, but the cared-for person wanted to stay at home (paper III). If the family carer did not feel at ease with caring at home or did not feel capable of managing, then interactions and actions taken by the nurse to keep caregiving at home was potentially coercive. However, correspondingly if the family carer felt willing and confident in caring at home, interactions and actions taken by the nurse to actually keep caregiving at home could be favourable for everyone (paper III).

Also underpinning the tangible dimension of support was the nurse acting as liaison between resources and the family carer (papers III & IV). Using their resourceful knowledge in what public authorities in Sweden generally are able to assist with practically, financially or emotionally to help family carers the nurses explained about financial compensation or acted as an intermediary between the family carer and other professionals who potentially were better suited to meet family carers' needs (paper III). Professionals like, for example, priests or almoners could be such persons.

The intangible dimension of support is about the quality of relationships

The intangible, dimension of support appear essential, but is perhaps not as salient as the tangible dimension. It comes through in published research studies that use adjectives such as individualized, adaptable, accessible, responsive, convenient, suitable or tailor-made (paper IV). Through the intangible dimension, the necessity to individualise support is highlighted. For instance by recommendations such as adaptability, flexibility or support needing to be attuned to family carers' needs for usefulness. Studies also underscore the provision of support as a recognition of family carers' needs and entailing to follow through in the continuum from problem identification to help provision (paper IV). In contrast to the previous more tangible dimension, support now emerges more as pertaining to the protection or safeguarding of family carers' relationships (paper IV). Symmetrically and/or reciprocally balanced relationships are highlighted as optimal since support is portrayed as equally good to receive as it is to give, regardless of the relationship constellation or parties included (paper IV). However, studies rarely address the consistence of the quality or specific aspects of relations. Instead, a significant amount of research exist on support as overreachingly assessed in family carers' meetings with professionals or peers, individually or in groups (paper IV). However, studies have actually shown that family carers wish to satisfy learning needs in groups with peers or to otherwise network in social support groups (paper I). More specifically, support

appears to be created by instances when family carers have the opportunity of sharing emotions, experiences, knowledge and feelings, in other words, being allowed to verbalize, voice and express current happenings in their life by un-troubling their minds to a dedicated other (paper IV). This can be understood as translating into the interspace between human beings, or support as a co-created occurrence between humans. The latter stands in contrast to the tangible dimension where services could be given and received. Instead, papers II and III give weightiness to the quality or aspects of relations and the interspace between human beings, or support as a co-created occurrence between humans. Nevertheless, the tangible and intangible dimensions of support do not appear to exist independently of each other. On the contrary, examples like the quality or aspects of relations may serve as dialectical interconnection points between the two dimensions. Learning how to maximize community resources, for instance, knowing whom to call for warranted help may be understood as adhering more to the tangible dimension, whereas the feeling that this person cannot be just “anybody” but should be “somebody” that the family carers feel they can trust can be understood as adhering more to the intangible dimension and quality of an interpersonal relationship (papers III & IV). Both dimensions coexist, and together they can contribute to the experience of support.

In paper II one meaning of support was understood as sensing togetherness. The understanding was deepened by writings on the idea of friendship, since that could illuminate the quality of the togetherness between the family carer and a potential supporter. Friendship and togetherness border on each other. However, there are different kinds of friendship, and the case in point here may be a conditioned friendship. In such relations the friend is not endeared for who he is, but for his favours (paper II). This condition to the friendship seems to revolve around a sense of security and certainty of assertive action. The family carer must feel able to depend or rely on the one who supports, but regardless of whether s/he is a trained professional or not (paper II). The idea of friendship in relation to support for family carers illuminates a dimension, which hitherto has received little attention within this particular research area (papers I, II & IV). There may exist a dimension about the depth or level of engagement in support. It is this level of engagement that here has been understood in a broader sense through the idea of friendship (paper II). Its boundaries can be outlined by the concept of goodwill, which is the beginning of friendship but not identical with friendship itself. Persons you have goodwill towards you only wish well, but you are hardly a participant in their endeavours or go to any lengths on their behalf. Instead, what is characteristic of a friend is that he benefits others, in particular if they are in need of it but did not ask for it themselves (paper II). Healthcare professionals’ humanistic attitudes in their demeanour towards families, specifically seem to influence family carers’ possibility to be involved in a meaningful way in caring (paper II). At the highest level of meaningful involvement the triad of the staff, relative and patient may form a partnership in caring. However, the meaningful involvement can be undermined by a

lack of commitment from staff, which was previously outlined by the idea of goodwill (paper II).

The effort or aspiration to form a relationship, was elucidated by the nurses' narratives in paper III. Building a trustful relationship, involved the contrasting cases of, on the one hand, striving for a connection and wanting to get to know the family. On the other hand, also experiencing a distance was an impediment that prevented the nurses from excelling in their care. These two contrasts were most clearly illuminated in narratives where nurses perceived themselves as being out of time (paper III). The experience of having time therefore seemed essential for forming a relationship. When there was no time, the nurses narratives expressed that their support to the family carers was not as optimal as it could have been. In addition to the prerequisite of time, the effort of building up the relationship also illuminated dimensions of confidence and trust. These were recurring dimensions throughout the interview text.

Once the forming of the relationship was in motion, possibilities were opened up for within the relationship. This was here formulated as "becoming attentive" (paper III). The nurses were perpetually becoming attentive for how the family carers were feeling. Nurses' narratives also illuminated courage as a dimension of attentiveness. Being close and attentive to the needs of a family carer involved courage, as opposed to dodging or giving way to difficulties. The nurses spoke about daring to open up for conversation, daring to engage in discussions about topics that can feel difficult to touch upon (paper III).

As regards being attentive, the nurses' narratives furthermore illuminated that being supportive also entails an attentiveness to what the situation requires. In other words it is necessary to harmonize with the family carer's needs and shape the intensity or diversity in measures for helping the family carer accordingly (paper III). One thing the nurses knew for sure was that their aid to the family carers was individual, as opposed to general. No two situations were the same. The support needed to be tailored to the caregiving trajectory, increasing in intensity and/or diversity as the person being cared for became more severely ill (paper III). "Giving family carers undivided attention in time and space" was an aspect of being attentive which was exemplified when nurses prioritized taking time, and making time to hear the family carer out. One nurse labelled this as "*...being 100 percent present...*". These narratives were illuminated by examples where nurses were part of creating an undisturbed space where they could be with and listen to the family carer (paper III).

As the forming of the relationship had begun to take place, the nurses experienced gradually winning the family carers trust (paper III). Gaining the family carer's trust and becoming a person who can be trusted illuminated aspects of confiding and confidence. Through time the nurses were moving within the confidence of the

family carers and becoming more able to excel in their support. Getting to know the family carers was fundamental. Confidence and being a confidant appeared as most of all concerning sharing in the family carers' emotions through their storytelling (paper III). This was exemplified in situations where the nurse gave the family carers an opportunity to really express feelings and get things off their chest. The overall case in point from the perspective of nurses' narratives, may be what is called responsive relationship (paper III). Hence, the significance of an immediate response on the nurses behalf to attend to family carers' needs was underlined. For example, as a genuine dialogue appear unable to plan for in advance, it must be caught opportunistically in the moment as an immediate response (paper III).

Returning to paper II, the meaning of support was also illuminated when the family carers tell about being in relation with others as well as being in relation with oneself in the challenge of giving care. The latter meaning of support was understood through family carers' narratives and disclosed a dimension of resourcefulness residing within (paper II). This aspect of support, or in any relation to support whatsoever, has hitherto only been found in one lexical definition in paper IV. There, "to support yourself" is synonym with resting, leaning. However, in paper II this meaning of support instead seem closer to phenomena like inner strength, or an inner capacity. This was elucidated by way of how meanings of inner strength have been formulated (paper II). Nevertheless, a feeling of togetherness appears to involve trust in others as well as in oneself that there will be enough resources if something happens. One major trait in the family carers' narratives illuminated the meaning of support as "experiencing a sense of togetherness".

Being supported – support and its attendants

As regards the attendants to support, scientific studies are high in conformity (paper IV). Many of the words used as descriptors in antecedents are again found as descriptors of consequences or endpoints. However, their fundamental interconnection with the intervention itself, if one is attempted, is not seldom unclear (papers I & IV). The attendants to support as described in the scientific literature are described as improvements in for example quality of life, understanding, communication, physical and mental health and social interactions (papers I & IV). Moreover, researchers also assess successful support in relation to decreased institutionalization, anxiety, depression, loneliness, isolation, anger, strain and emotional pain. Tools employed to capture outcome effectiveness of interventions called support are recurrently depression scales, quality of life scales, general health questionnaires (paper IV). Discussion on the exact relation of support interventions to these outcome measures is rare (papers I & IV).

However, studying support from a human science point of view opened up for multifaceted descriptions of attendants to support in comparison to the predominant way attendants hitherto have been described (cf. papers I & IV). For instance,

paper II reports a buoyancy in family caring, described by interviewees who could sense themselves feeling encircled by an action potential. Their sensing of a network that would step in, should they need it, was a great asset and reassurance (paper II). Family carers rested assured that they could and would get help or more help should they need it. They were no longer the sole accountable bearer of the well-being of their relative or responsible for making decisions pertaining to the health of the cared-for person (paper II). The experience of support is invigorated by immediate responses from professionals, children or friends when in need. Likewise, situations may be experienced as supportive where healthcare professionals witness and acknowledge family carers' values, feelings or struggles, recognized their situation, pay attention to and notice or respect them (paper II).

The meaning of being supportive was further investigated in paper III. There, being supportive entailed salient but interlaced tangibles and intangibles. More precisely, the theme "facilitating caregiving" alludes to nurses' doing/actions while for example the theme "being attentive" has more to do with the nurses' way of being. Support again comes across as a phenomenon which interweaves the two dimensions of tangibles and intangibles. Furthermore, the phenomenon seems to involve a direction from one person to another. The results from paper III brought attention to the concept of caring and uncaring behaviours when studying the meaning of being supportive. More specifically, paper III illuminated the very delicate balance between support and unsupport in the light of caring and uncaring as a part of being supportive. The "responsive relationship" can be the framework that opens up for these caring behaviours. After all, the nurses' narratives elucidated that willingness to support may border on unsupportiveness if the wills of the family carer and the cared-for person are contending. Then matters are brought to a head. Such cases were about whether or not the family carer could accept the idea of caring at home. If the family carer felt willing and confident in caring for their relative at home, the situation could become favourable. However, if the family carer did not feel at ease with caring at home or did not believe themselves capable to manage, the situation could turn into coerciveness towards the family carer. Then the turn of events can end up in that caring takes place at home, against the family carer's will.

DISCUSSION

General discussion of the findings

By studying support through differing methodological approaches, it has been possible to illuminate different aspects and two dimensions of support in nursing. The detailed findings are reported in papers I–IV respectively, whereas this discussion return to distinguishing overall features of the findings. The objective is to attempt to advance the debate towards fruitful discussions on meanings of support in nursing. The findings underlined that there were at least two identifiable, but inseparable, dimensions of support: the tangible and intangible dimensions. These dimensions appeared to co-exist, and resembled a continuum more than a dichotomy in their interaction. There are early research that has recognized the multidimensionality of support. For example, Twigg and Atkin (1994) acknowledge small-scale and large-scale systems levels to support, as well as specific or mainstream levels. In another study, Bass *et al* (1998) concluded that support cannot be uniform, and therefore cannot be expected to have uniform effects. However, the impression remain, that most attention has been directed towards what in this thesis have been called the tangible dimension of support. Therefore, the discussion here will instead favour the intangible dimension, in order to underscore it as one worthwhile contribution from this thesis.

The qualities of the intangible dimension of support, were elucidated in this when attention was brought to related concepts such as friendship and confidence (papers II & III). The contribution of introducing these concepts in relation to support, lie in their potential to reflect relationship qualities that may be crucial in order for support to gain or loose meaning. In addition to highlighting concepts such as for instance friendship and confidence in relation to support, this thesis also has heuristic potential founded in its inductive approach towards illuminating further understandings of support in nursing. Hence, the general discussion of the findings can also be seen as a starting point into further research, rather than the ending of the same. Reflections on warranted progression towards understanding support in nursing will be interweaved throughout the discussion of the findings. However, these reflections and the conclusions that can be drawn are dependant on papers I–IV study limitations.

The qualities of the intangible dimension of support, based on papers I–IV, directed attention towards the importance of how meanings of a concept are created in the first place. Ideas of concepts and how they are formed through objects, terms, definitions and their relation to contexts can be said to have been in focus in this thesis. However, traditionally such thoughts have belonged to linguistics and semantics (cf. Laurén *et al*, 1997). Language does influence thoughts, and words can mean different things to different people in different situations (Ogden &

Richards, 1923/1989). Therefore, the meaning of support as researched within the nursing context through this thesis, can contribute with reducing the ambiguity and plethora of understandings of support which hitherto appear to have hindered rather than facilitated research and best practice development.

The findings from this thesis in part pointed out an intangible dimension of support, where relationship qualities and happenings within relations to others were found. For example, formulations such as networking in support groups for social purposes and room for verbalizing emotions as found in papers I and IV can be said to indicate this intangible dimension of support. Likewise, but perhaps more specific, understanding support as sensing togetherness through the relationship qualities friendship and inner strength were illuminated in paper II, while qualities such as confidence, trust and attentiveness were found through paper III. In order to make further sense and enhance understanding of these qualities of the intangible dimension of support, the terminology of the “Senses Framework” (Nolan, 2001; Nolan *et al*, 2003) was used but reworded to underscore and illuminate meanings. The Senses Framework formulations (*ibid.*) were reworded into the following three formulations:

- ~ A sense of confidence – trusting and/or confiding in others and/or yourself
- ~ A sense of belonging – to feel part of something
- ~ A sense of reciprocal significance – to feel that you matter

These formulations and findings from papers I–IV and a combination of literature which underscore the intangible dimension are used here to further convey understandings, in the search for meanings of support in nursing. In addition to the findings from this thesis as well as the work of Nolan *et al* (2003), the importance of focusing on relationship qualities between healthcare professionals and family carers, has also been underlined by other researchers. For example, in their development of a theoretical framework, Andershed and Ternstedt (2001) described a beneficial attitude of staff, using relationship qualities such as openness, sincerity and confirmation. The descriptors used by Andershed and Ternstedt (*ibid.*) appear adjacent to the “sense of confidence” as well as the “sense of belonging” that were forwarded here as relationship qualities, and further understood through the concept of friendship.

According to Blieszner and Adams (1992) qualities such as sharing, commitment, respect and trust can be seen as underpinning a friendship. Of the major structural aspects to the friendship structure, emotional closeness (solidarity) appear decisive. In paper II, the concept of friendship was used to underscore one important quality for support to gain or loose meaning. However, as also illuminated in paper II, through the work of Aristotle (1967), the case in point here may be a conditioned friendship. In such friendships, the friend is endeared for her/his favours and not for who s/he is. Furthermore, there may also be an hierarchal difference with high

inequalities between the healthcare professional and the family carer. This hierarchical difference can also have bearing on the friendship structure (Blieszner & Adams, 1992). There are activity on friendship studies in nursing (Silfverberg, 1999; Sousa & Frizzell, 2005), but none have hitherto been found in relation to support for family carers. However, an increased awareness of relationship aspects between healthcare professionals and family carers further understood in relation to conditioned friendships may be fruitful and widen understandings of support for future researchers and professionals.

In paper III relationship qualities such as confidence, trust and attentiveness were used to describe understandings of the meaning of being supportive. Here, they may all be seen as adhering to the “sense of confidence” and having to do with trusting and/or confiding in others. These relationship qualities directed attention towards ethical and moral dimensions, since trust and confidence in relationships appeared close to what in everyday language can be called a person’s character. In their work Beauchamp and Childress (1983) have described ethical aspects of the professional-patient relationship. The rules of fidelity, virtues and character (*ibid.*) still appear useful, even though the issues here revolve around the family carer – professional relationship.

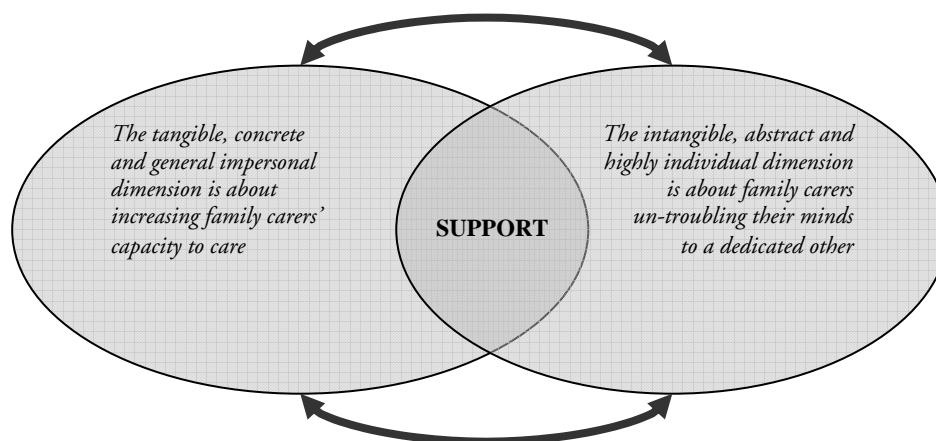
According to Beauchamp and Childress (1983) issues of fidelity revolve around the meaning of faithfulness, the importance of promise-keeping and not to withdraw from responsibilities. The relationship qualities adhering to fidelity, illuminated meanings of support and being supportive in this thesis. In particular, meanings of being supportive as acting faithfully, and the performance of promises was found in paper III. There, it was further understood through literature on honouring commitments and moral attitudes on behalf of healthcare professionals (Milton, 2000; 2002; cf. Nâden & Eriksson, 2004). Trust and confidence therefore appear as fundamental relationship qualities regarding meanings of support and being supportive. The willingness to trust a healthcare professional appears dependant on confidence and reliance upon them to act in certain ways, and on opinions of that person’s character (Beauchamp & Childress, 1983). This again underline the importance of promise-keeping, or in other words: fidelity.

However, through the findings of this thesis, trust also appeared essential for sharing emotions and unburdening oneself through conversation. In paper III, this was seen through the lens of Buber’s (1953/1990) work, who elucidated that trust creates an atmosphere of confidence that is the breath of life of the authentic conversation. Therefore, trust can be an essential quality for family carers when networking in groups with peers, as forwarded in paper I. However, a “genuine dialogue” may be difficult, perhaps even impossible, to plan for in advance (*ibid.*), which illuminates the dynamical and adaptive qualities to the meaning of support. For the nurses in paper III, it was the establishing of a relationship that opened up for attentiveness, confidence and trust, and the nurses could be supportive through en-

tering in dialogue with the family carers. However, in sharing emotions through storytelling it appeared that telling did not come easily for the family carers, and nor did the listening for the nurses. The nurses narratives reflected a dimension of having courage, which on a more abstract level also may be seen as belonging to virtues, character and ethics. In their response to the uniqueness of each situation, the nurses seemed to choose a deliberate steadfastness as their valued priority (cf. Bournes, 2000), even though it could be challenging for them to witness the family carers' storytellings. Overall, several of the identified qualities within the intangible dimension appeared to direct attention towards morals and ethics. Therefore, approaching ethics and moral philosophy, may further widen the understandings of meanings of support in nursing, perhaps through the reflection on the rightness or wrongness of attitudes and actions (cf. Drummond & Embree, 2002). In continuing to deepen understandings, research and professional practice on support for family carers in nursing, it could be fruitful to proceed from an ethical and/or virtue framework to elucidate healthcare professionals supportive attitudes, dialoguing and actions (cf. Scanlon, 1998; Ramirez & Silfverberg, 1999; Silfverberg, 1999; Croona, 2003).

The flow from the morals of attitudes, towards the morals of actions illuminate the essential dialectical interconnection between what was here labelled the intangible and tangible dimensions of support. Actions taken by healthcare professionals to support family carers appeared to balance between being favourable or coercive for the family carers (paper III). Hence, there also appear to be a moral and ethical dimension to healthcare professionals supportive actions. The value of highlighting the idea of dialectical interconnection points between the intangible and tangible dimensions of support is to underscore their essential coexistence for support to gain meaning. In paper IV, a visual display of the two dimensions labelled the intangible and tangible dimension was used in an attempt to illustrate the necessary intersection of these two dimensions for the meaning of support in nursing to appear (Figure 2).

Figure 2. A visual display of the two intersecting dimensions that are inevitably and dialectically integrated in the here derived definition of support.



As shown in the visual display above, there can be areas where the two dimensions do not intersect. Therefore, even if the general discussion of the findings here hitherto has favoured the intangible dimension of support, these two dimensions seem demand the other and vice versa. It may be that support increasingly loses in meaning through a horizontal movement from the central intersecting core of support in figure 2. In other words, support in nursing appears unable to be exclusively tangible nor exclusively intangible. Both dimensions are warranted.

Also, continuing to proceed from the relationship issue, and seen through the lens of a theoretical framework, the meaning of being supportive can be considered as approaching the concept of caring (cf. Halldórsdóttir, 1996). Meanings support can be related to the concept of caring. One possible explanation for this is that being supportive is a larger, more intricate and important dimension to nurses' work than previously have been acknowledged. Relationships and aspects there of, like attitudes, have been highlighted as central issues in attempts to define caring itself. For example, Brilowski and Wendler (2005) acknowledge caring as proceeding and developing from affection and concern for another, much in resemblance to friendship. However, whether or not the concept of caring may be fruitful for further understandings, research or practice into support for family carers can be uncertain. The concept of caring itself, is subjected to debate within nursing and may be located at an unduly high level of abstraction in order to further convey useful meanings to understanding support.

Methodological considerations

The papers in this thesis and study are associated with strengths as well as limitations. These will be discussed and acknowledged in the text below. Papers I and IV touch upon each other in their similar strengths through their high methodological systemacy. The identification and management of data, chiefly consisting of scientific articles, was rigorous and meticulous in order to minimize the introduction of researcher bias. Correspondingly, papers II and III are high in methodological rigour and are alike as they share the same methodology.

The systematic review and the concept analysis papers

The systematic review corresponding to paper I, may be considered research upon research in as much as it follows a given set of systematic and methodological steps. The review addressed a clearly focused research question based on the structure published by Flemming (1998). This may be considered a contribution to validity in as much as it created prerequisites for identifying relevant literature. Correspondingly, the systemacy of database searches may also enhance validity by accurately identifying literature. Moreover the systemacy of searches increases replicability, which may contribute to the reliability of paper I. However, there are limitations to paper I as regards retrieving all relevant literature. Searching the database Psycinfo was overlooked, journals and reference lists were not hand searched and

experts in the area were not contacted (cf. DiCenso *et al.*, 2005). These limitations may have affected the sensitivity of the searches negatively, as well as hampered the avoidance of publication bias. Nevertheless, included databases were searched in an extensive, up-to-date and methodologically sophisticated way. Highly sensitive and inclusive search strategies were used although it was inevitable that some studies be missed.

The aim in paper I was not exclusive in producing evidence of effectiveness for best practice. Instead, the aim also allowed for a more descriptive approach as regards support for family carers. In retrospect, the aim could have been more clearly defined and less ambiguous. However, if more focused on evidence of effectiveness, some of the descriptive power in paper I might have been lost.

The criteria for inclusion and exclusion of studies were set to match the aim of the study. On the one hand it was necessary to fit these criteria as closely to the aim as possible in order to formulate conclusions that were applicable for this particular group of family carers. On the other hand, this resulted in the exclusion of several studies, in particular if the studies participants did not exclusively consist of family carers, at-home care or if the mean age of family carers were below the age of 65 years. This consequently had bearing on the sample selection of studies finally included. Also, as the selection criteria were unspecific regarding medical diagnosis of the cared-for persons, the sample may have been unduly heterogeneous.

The reviewers assessments of the quality of the included studies, may be seen as enhancing the strengths of paper I. The quality assessment contributed to the veracity and solidity of the conclusions drawn on the basis of the included studies. However, the inexperience of the reviewers may be a potential unit of quality assessment error. More experienced and senior reviewers may have used other limits for quality criteria.

One further advantage in paper I, was the combination of studies applying qualitative and quantitative analysis of data. This was in line with a contemporary call for acknowledging qualitative and quantitative traditions as a continuum as opposed to a dichotomy (Rolfe, 2006a). In contrast to exclusively focusing on either, the combination of these two ways of analysing data may have assisted in approximating the most possible complete image of support for family carers. However, due to this combination, the focus was somewhat shifted away from evidence of effectiveness of interventions. Also, methodological guidelines for synthesizing studies using qualitative analysis of data, could not be identified at the time when the review were completed (cf. Upshur, 2001). The technique of synthesizing studies using qualitative analysis of data is still developing and contested areas remain (Walsh & Downe, 2006; Zimmer, 2006). Issues have been raised by researchers into procedural, analytic and interpretative techniques as regards synthesizing studies using qualitative analysis of data as well as highlighting the valued contribution of doing

such reviews (Popay *et al.*, 1998; Greenhalgh, 2002; Sandelowski & Barroso, 2002; 2003; Barroso *et al.*, 2003; Sandelowski *et al.*, 2003; Thomas *et al.*, 2004). Nevertheless, due to the combination of qualitative and quantitative analysis of data, the conclusions drawn appear generally formulated which is jarring from a qualitative research perspective. The narrative synthesis used in paper I, was considered to be one conceivable way forward at the time. However, it may have undermined the systemacy of the review as narrative reviews are summaries of research that lack an explicit description of the systematic approach (Montori *et al.*, 2003).

The concept analysis of support represented by paper IV was based on the presumption that the state of the science surrounding the concept may produce knowledge on the maturity of the concept, its use and meaning (Rodgers, 2000; Penrod & Hupcey, 2005). An important part of the data in paper IV was derived from the scientific literature through database searches. Hence, the selection of disciplinary literature becomes one potential strength or pitfall as regards the validity and reliability of the findings. Similar to paper I the validity of the searches are dependent on systemacy and accuracy in pinpointing relevant references. In paper IV, as in paper I the searches were inclusive and sensitive by using overarching search words which were high in subject headings lists and hence low in specificity. Consequently the manual sorting was extensive in order to discern which references that potentially could be included as data. Also, the methodological progression in paper IV was highly systematic which should have contributed to the reliability of the concept analysis by enhancing its replicability. The selection of scientific literature as data was partially done using SPSS version 12.0. which should have decreased researcher selection bias. The use of systematic means of sampling, such as the selections drawn from computerized data bases has increased the likelihood that the analysis of data has been representative (cf. Rodgers, 1989 p 333). Furthermore, the analysis of data was postponed until near end of data collection. Thus avoiding the introduction of bias by premature thoughts and jumping to conclusions (Rodgers, 2000).

There is a possibility of important studies being missed through the selection process of the scientific data for paper IV. However, the highly rigorous and systematic way the concept analysis was carried out, should contribute to the unlikelihood of the findings being completely overthrown by another similar paper. This is due to that the definition, which is one endpoint of the findings, was derived opposed to intuitively or creatively formulated (Rodgers, 2000; Penrod & Hupcey, 2005). Other strengths of paper IV were the emphasises on the heuristic value of the findings and using an analysis based on literature as well as interview data. The interview data examples were intended to illustrate the characteristics of the concept in a relevant context, thus leading to enhanced clarity and knowledge (Rodgers, 2000).

The phenomenological hermeneutical papers

As the theory of science framework for the phenomenological hermeneutical studies, represented by papers II and III, proceed from a human science perspective it has implications for the way the trustworthiness of the research may be discussed (Rolfe, 2006a). Therefore, the terminology as forwarded by Lincoln and Guba (1985) will be used here to discuss and appraise these issues. One strength of papers II and III was the innovative and sensitive way that support for family carers was studied facilitated by the use of this specific methodology. As regards papers II and III, the high degree of systemacy may be seen as contributing to the trustworthiness of the research. Specifically in terms of credibility, thus enhancing the authenticity of the findings (Lincoln & Guba, 1985). The explicit methodological detail and rigorous reporting of the methodology was intended to enhance the possibility of critical appraisal of papers II and III (cf. Hoddinott & Rosin, 1997; Rolfe, 2006a). In addition to the choice of methodology in light of the aims, another strength of papers II and III was the choice of context. The appropriateness of choosing the palliative care context in order to illuminate meanings of support and being supportive was increasingly strengthened throughout the research process. However, questions may be raised as regards the transferability of the findings into other settings or groups (cf. Lincoln & Guba, 1985; Mill & Ogilvie, 2003). Even though there is a universality to the findings and the credibility of the procedure should enhance the dependability of the findings, it may be important to underline that the objective was never to draw general conclusions from papers II and III. Hence, the question of transferability may be further illuminated only if the aims of papers II and III were to be revisited in other settings.

There were however some difficulties in the onset of both papers. Their opening questions of the respective interviews were formulated in a way that discerning and focusing on lived experiences were perhaps not immediately evident. The consequences of this presented themselves in both papers mainly through the interviews. The family carers' and the nurses' narratives on support did not flow in a continuous and coherent way. Instead their narratives on support appeared interlaced with or dissolved in, the experience of being a family carer or being a nurse in these specific contexts. Furthermore, the interviews were joint constructions between interviewer and interviewee (Mishler, 1986). Consequently the quality and tone of the interviews, which were data, were partially tied to the interviewer's person and experience as an interviewer. For example, a more experienced interviewer may have been more successful in the circular process where the interviewer and the interviewee negotiate towards an understanding through the interviewee's narratives of the phenomenon under study (Mishler, 1986). Hence, through this way of conversing illuminating the non-communicability of the interviewees' experiences such as lived (cf. Ricoeur, 1976). The issues surrounding the interviews may have limited the confirmability, that is the neutrality and objectivity, of the data (cf. Lincoln & Guba, 1985).

A sincere attempt was made to clearly describe the data analysis in papers II and III, as well as how sub-themes and themes were derived. The rigour and adequate description of the analysis and interpretation procedure should enhance the credibility and dependability of papers II and III. In the condensations the choice of words aimed at representing an abstracted and deeper level of understanding without losing sight of the meaning of the text, that is, the utterance meaning (Ricoeur, 1976).

During the analysis of data in paper III, an alternative way of proceeding with the structural analysis of the meaning units was discovered. In proceeding with the structural analysis, it was found that the nurses narratives on the meaning of being supportive, abstractly entailed both a doing and a being. Their "being" referred to their own persona, behaviour and performance, but also entailed a "doing". In other words: actions. Hence, the question could be raised if whether some of the meaning units could be treated as "action units". Since the point of departure which is underpinned by linguistics, the case in point here may be reworded into revolving around the so called locutionary and illocutionary acts (Ricoeur, 1976). Or in other words "the doing of the saying" (ibid, p 14). For example the doing of the saying in one example could entail praising the family carer or confirming him or her or even making a promise to him or her, which would be the locutionary act. The illocutionary act, the actual "force" or meaning of praising could perhaps be understood [sic] as an expected continued caring from the nurse. By praising s/he expects a continued caring from the family carer or by saying "I promise" the nurse actually puts herself under the obligation to do what she says she will do (Ricoeur, 1976 p 14).

The interplay between what is said and the doing of the saying resembles the dialectic between event and meaning. According to Ricoeur (1993), there is no resistance in moving from texts to actions. The theory of actions give rise to the same dialectic between understanding and explanation as the theory of texts (ibid. p. 88). Hence, in paper III the interviews could also have been analysed from the alternative route of an action theory point of departure. However, this would have had profound implications for the entire project because to begin to talk in terms of action requires a continuance in terms of "project, intentions, motives, reason/inducement and action" (Ricoeur, 1993). Consequently, it would seem improper to integrate text with action theory. In paper III it was decided to discontinue with a theory of action analysis. However, this insight may in the future contribute to the Lindseth and Norberg (2004) description of phenomenological hermeneutics. According to Ricoeur (1993) the writings of von Wright could be useful for understanding discourse from a theory of action point of view. The analysis in paper III could have taken other directions, which could have illuminated different perspectives and levels of understandings. This could have been useful as multiple perspectives and multiple levels of understandings may contribute to theory building.

Throughout the analysis and interpretations of papers II and III the authors worked closely together, not to control the analysis, but to strengthen the interpretations by contesting and supplementing each other's readings as a part of reflexivity (Malterud, 2001). This process of reflexivity was undertaken to enhance the dependability, confirmability as well as credibility of both papers. Thus contributing to their collective trustworthiness (cf. Lincoln & Guba, 1985). Discussions on trustworthiness may depend on their frame of reference (Rolfe, 2006b) Here, reflexivity was key in lending the research an authenticity and honesty that is a distinctive characteristic for human science research (van Manen, 1990; Walsh & Downe, 2006). Also the reflexivity may have been a precaution due to the risk of losing meaning while condensing meaning units to higher levels of abstraction (cf. Graneheim & Lundman, 2004). The rigorous method, the credibility of the researchers involved as well as their philosophical belief in the value of qualitative inquiry should have contributed to the credibility of papers II and III (Patton, 2002).

CONCLUSIONS AND FURTHER RESEARCH

This thesis showed that support for family carers who care for an frail aged person at home entails two essential dimensions. One dimension was here labelled the tangible dimension, which overarchingly stood for the different services, education and information that can be provided for family carers. The other dimension was labelled the intangible dimension, which illuminated that the meaning of support is also about qualities of the relationship between the family carer and the potential support provider person. The intangible dimension was regarded as needing to be individualized for family carers, but also appeared abstract as regards understandings. Nevertheless, these two dimensions seemingly must coexist in order for support to gain meaning. The one dimension cannot do without the other and vice versa.

One contribution from this thesis, as regards healthcare professionals, as well as researchers interested in support for family carers, may be the advancement of knowledge and focus on the intangible dimension of support. Studies in this thesis (papers II & III) illuminated qualities that can play a central role for support to gain meaning. Further research that evaluate and test implementation of increased awareness of meetings, attitudes and/or communication training for healthcare professionals using the findings from this thesis may reveal implications for advancing best practice (cf. Gryssels *et al*, 2004; Bergh, 2002).

Research similar to the phenomenological hermeneutical studies on support that were incorporated in this thesis has hitherto not been found to a great extent within nursing. One interesting finding of this thesis was made in paper II, where the meaning of support was put in relation to “inner strength”. Greater knowledge in this area is required, in order to discern any relation between inner strength to understanding support.

In papers II and III understandings of meanings of support appeared appropriate to put in relation to abstract concepts such as caring as well as moral and ethical dimensions. Therefore, it seems important to further explore these concepts and their appropriateness in relation to support in nursing. Similarly, it could be fruitful to further investigate how or if, the concept of support relate to the concept of consolation.

This thesis approximated basic research in its attempt to approach a “real definition”, meaning to describe the essential nature or the core attributes of support in nursing (cf. Binstock & George, 2001). Therefore, further research may be warranted on how the findings from this thesis would perform when instead applied closer to an operational definition.

In this thesis it was decided to use the palliative care context to study the meaning of support and the meaning of being supportive. Future research in the form of similar studies using examples from care contexts where persons are suffering from for instance dementia or cerebrovascular accidents, may further contest and diversify the knowledge on the phenomenon of support for family carers in nursing. Such studies are welcomed.

Also, comparative studies across care contexts where persons in palliative, dementia and stroke care are found, may be able to discern organizational structures that facilitate or nourish the tangible as well as intangible dimensions of support. This could be valuable for family carers who care for an frail aged person at home but outside of the palliative care context that exemplified in this thesis.

Future research may also further explore the complexity of being a family carer. This may be warranted as the concept of “family” appears constantly reshaping/reforming. Changes in the configuration of family may lead obligations in complex relationships including several degrees of step-kin and in-laws, single-parent families, adopted persons and “other” relatives (cf. Binstock & George, 2001).

SVENSK SAMMANFATTNING

Anhörigas insatser utgör en stor del av den hjälp och assistans som ges till Sveriges hemmaboende äldre personer som lever med en eller flera kroniska sjukdomar. Anhöriga bidrar också till den nationella välfärden genom att balansera hälso- och sjukvårdens kostnader. Det kan skönjas ett ökande intresse inom forskning så väl som i politiska beslut för anhöriga som vårdare. Stöd till anhöriga som vårdar tycks vara ett mycket aktuellt begrepp inom flera intresseområden, både i Sverige och internationellt. Men stöd till dessa anhöriga kan bli ett mer komplext uppdrag än vad det initialt ger sken av. Trots att det finns forskning om stöd för anhöriga, kan begreppet ändå anses komplicerat och vara svårt att föreställa sig innebörden av.

Ordet stöd är gammalt och har fornsvenskt ursprung. Den engelska motsvarigheten support är inte heller nytt. Vad som är anmärkningsvärt och intressant är istället i vilket sammanhang ordet används. Idag används det bland annat inom IT-branschen, militären, juridiken, konsten, arkitekturen, medicinen och omvårdnaden. Inom omvårdnad och omvårdnadsforskning blir begreppet stöd särskilt aktuellt i de situationer då en anhörig vårdar en äldre närstående i hemmet. Antalet sådana situationer förväntas inte minska i framtiden och begreppet stöd kommer därför att fortsätta vara aktuellt. För att ge stöd, förbättra stödet och lära nya sjuksköterskor stödja, måste begreppet förtydligas, eftersom det idag finns väldigt lite forskning om begreppet inom omvårdnad.

Från den allmänna debatten i Sverige angående anhörigstöd kan slutsatsen dras att stödet bör finnas. Det är emellertid inte lika självklart vem det är som ska stödja eller vilket innehåll stödet bör ha. Allteftersom fokus för vården av äldre flyttas mot vård i hemmet är det rimligt att anta att sjuksköterskor även i fortsättning kommer att spela en betydelsefull roll i kontakten mellan anhöriga och professionella vårdare. I gruppen professionella vårdare förväntas sjuksköterskor ha en betydelsefull roll som anhörigstödjare. Eftersom det finns så lite forskning om innebörden av att vara stödjande, beskrivs genom en av delstudierna innebörden av att vara stödjande så som det berättas av sjuksköterskor. För att kunna förstå innebörden av fenomenet stöd, har de empiriska studierna i avhandlingen genomförts inom den palliativa hemsjukvården, eftersom fenomenet stöd förväntades kunna tydliggöras och beskrivas där. Genom de delstudier som ingår i denna avhandling beskrivs begreppet stöd för äldres anhöriga med hjälp av olika forskningsmetoder. Anhöriga har berättat om sina upplevelser och erfarenheter av stöd och sjuksköterskor har berättat om innebörden av att vara stödjande. Dessutom har den vetenskapliga litteraturen också använts för att beskriva, förklara och förstå begreppet stöd.

Det övergripande syftet med avhandlingen är alltså att inom omvårdnad, så som det visar sig med hjälp av anhöriga, sjuksköterskor och den vetenskapliga litteraturen beskriva, belysa och förstå innebörder av stöd för anhöriga som vårdar en äldre närstående hemma.

I den första delstudien identifierades former för och vetenskapliga bevis om stöd till anhöriga som vårdar en äldre närstående hemma. Detta genomfördes som en systematisk litteraturstudie. Metoden baserar sig på en känd modell om sju steg för att identifiera, klassificera och kritiskt värdera bästa tillgängliga vetenskapliga bevis inom området. I studien inkluderades 24 artiklar som visade att anhöriga som vårdar en äldre närstående i hemmet räds social isolering samt önskar att träffas i gruppnätverk med jämlikar antingen av sociala skäl eller utbildningsskäl. Anhöriga efterfrågar i hög grad avlastning/växelvård. Trots en omfattande mängd litteratur inom området är det oklart om anhörigas situation förbättras genom dessa insatser. Den vetenskapliga kunskapen om hur insatserna bäst tillhandahålls/ges är otillräcklig.

För att kunna belysa innebörden av stöd, så som det berättas av de anhöriga själva genomfördes den andra delstudien. Denna delstudie inleddes med förhoppningen om att bättre kunna förstå anhörigas upplevelser och erfarenheter av stöd utifrån deras situationer. Metoden som användes var en fenomenologisk hermeneutisk metod, baserad på Paul Ricoeurs filosofi. Inledningsvis genomfördes tjugo narrativa intervjuer med anhöriga som vårdar en äldre närstående hemma inom den palliativa hemsjukvården. Dessa intervjuer utgör grunden till en text som analyseras och tolkas på ett strukturerat och återkommande sätt. En del av resultatet utgörs av två övergripande teman som kunde formuleras efter det att intervjuerna hade analyserats. Med temana avses att beskriva innebörden av anhörigas upplevelser och erfarenheter av stöd. Temana som formulerades var: "Att uppleva en känsla av samhörighet med andra i vårdandet" och "Att känna samhörighet inom sig själv i vårdandet." Den samlade innebörden av stöd förstods i denna studie som "Att känna samhörighet." För att fördjupa förståelsen av detta och tolka helheten reflekterades denna innebörd genom exempel i litteratur om begreppen vänskap, inre styrka och hanterbarhet. Det senare knyter an till teorin om känsla av sammanhang.

För att kunna gå vidare med att belysa begreppet stöd genomfördes delstudie tre. Denna avsåg att belysa innebörden av att vara stödjande så som det berättas av sjuksköterskor. Exemplet hämtades även denna gång från den palliativ hemsjukvården. Den metod som användes var densamma som tidigare beskrevs för delstudie två. Totalt tjugo sjuksköterskor från tre olika sjukhus i södra Sverige deltog genom sina berättelser om att vara stödjande gentemot anhöriga. Flera subteman och teman formulerades från det rika och omfattande intervjumaterialet till två huvudteman: "Att forma en relation" och "Att hålla vårdandet hemma". I den tolkade helheten diskuterades även denna gång innebörden av att vara stödjande i förhållande till exempel ur litteraturen.

I den fjärde och avslutande delstudien avsågs att inom omvårdnad induktivt utveckla en definition av begreppet stöd med avgränsning till området anhöriga som vårdar en äldre närstående hemma. För att framgångsrikt uppnå syftet med delstudien användes den så kallade evolutionära metoden för begreppsanalys. Denna innebär ett systematiskt genomsökande av vetenskaplig litteratur och uppslagsverk med avsikten att identifiera samstämmighet om det aktuella begreppets innebörd. Delstudien genomfördes genom att i första hand analysera den litteratur som kan sägas institutionalisera begreppet. Med sådan litteratur avses huvudsakligen vetenskaplig litteratur varför denna utgör en stor del av data i delstudie fyra. Flera olika elektroniska uppslagsverk samt databaser innehållande forskningslitteratur genomsöktes. Efteråt gjordes ett urval av litteratur och urvalet analyserades. Det var möjligt att formulera följande definition; *“Delvis innebär stöd tillhandahållandet av generell handgriplig hjälp, så som information, utbildning, ekonomiskt bistånd, hjälpmedel och extern service. Det skapar förutsättningar för att underlätta anhörigas kompetens eller kapacitet att vårda. Dessutom innebär stöd nödvändiga kvaliteter som individuell anpassning, föränderlighet, långsiktighet, utrymme för att ge uttryck för känslor såväl som en idé om ett ömsesidigt och jämbördigt utbyte mellan de involverade personerna.”*

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APPENDIX

Letter requesting participation (paper II)
Letter requesting participation (paper III)

Malmö, den 10 november 2002

FÖRFRÅGAN
- om deltagande i forskningsprojekt:

'Anhörigas upplevelse av att vårda en närstående i hemmet'

I allt större utsträckning vårdar anhöriga sina närstående i hemmet, med eller utan hjälp och stöd från samhället. Utvecklingen innebär att en alltmer kvalificerad vård bedrivs i hemmet och detta ställer nya krav på de anhöriga. Trots dessa nya krav är litet känt om de anhörigas situation. Vi vill därför undersöka anhörigas situation som vårdgivare i hemmet.

Syftet med forskningsprojektet är att beskriva anhörigas situation genom deras egna berättelser kring upplevelsen av att vårda en närstående i hemmet. Projektet utgår ifrån Malmö högskola, Hälsa och Samhälle. Förhoppningsvis kan resultatet av undersökningen leda till att anhörigas situation och behov av stöd förtydligas och på sikt underlättas.

Det här brevet har överlämnats till Dig konfidentiellt (vi känner alltså inte till Ditt namn eller Din adress) med hjälp *Kvalificerad Vård i Hemmet* (KVH). Du har fått brevet eftersom Du vårdar en svårt sjuk närstående i hemmet och därför befinner Dig i situationen som vårdgivare till en familjemedlem. Vi vill gärna fråga Dig om Du har möjlighet att delta i projektet, genom att berätta om Dina upplevelser och erfarenheter.

Deltagandet är helt frivilligt och Du har möjlighet att avbryta Ditt deltagande när som helst, även om Du tackat ja från början. Din berättelse kommer inte att kunna härledas till Dig som person. Berättelsen kommer inte heller att läsas i sin helhet av någon obehörig person.

Om Du är intresserad av att delta, eller om Du önskar ytterligare information, så ombedes Du ringa Peter Stoltz; 0703-56 98 00. Du kan också uppge Ditt telefonnummer till sjuksköterskan, så ringer vi upp Dig.

Om Du väljer att delta så kommer legitimerad sjuksköterska Peter Stoltz att per telefon berätta lite mer om projektet samt komma överens med Dig om en tid och plats som vi kan träffas för en intervju.

Med vänliga hälsningar

Peter Stoltz
Leg. sjuksköterska
Doktorand
Hälsa och Samhälle
Malmö högskola

Ania Willman
Leg. sjuksköterska
Filosofie doktor
Universitetslektor
Hälsa och Samhälle
Malmö högskola
Biträdande handledare

Giggi Udén
Professor i vårdvetenskap
Hälsa och Samhälle
Malmö högskola,
Vetenskaplig handledare

Malmö, den 7 november 2003

FÖRFRÅGAN
- till deltagande i forskningsprojekt:

*'Sjuksköterskors berättelser om att ge stöd till anhöriga,
som vårdar en äldre närstående i hemmet'*

I allt större utsträckning vårdar anhöriga sina närstående i hemmet, med eller utan hjälp och stöd från samhället. Utvecklingen innebär att en alltmer kvalificerad vård bedrivs i hemmet och detta ställer nya krav på de anhöriga. Trots dessa nya krav är litet känt om stöd för anhöriga i denna situation. Vi vill därför belysa fenomenet stöd, för anhöriga som vårdar en närstående hemma, genom att sjuksköterskor berättar om sina erfarenheter av att ge stöd till anhöriga. På så sätt kan redan befintliga former av stöd till anhöriga förstärkas och/eller kan nya stödformer utvecklas.

Studien förväntas ge en samlad bild av sjuksköterskors upplevelser och erfarenheter av att ge stöd till anhöriga. Projektet utgår ifrån Omvårdnad vid Hälsa och Samhälle, Malmö högskola.

Du har fått denna förfrågan eftersom Du genom Ditt arbete kommer i kontakt med anhöriga som vårdar närstående i hemmet och ger stöd till dessa anhöriga. Det är Dina upplevelser och erfarenheter av att ge stöd till anhöriga som vi vill att Du berättar om.

Intervjun tar cirka 30-60 minuter. Det är godkänt av verksamhetschef Magnus Kåregård att intervjun äger rum på arbetstid, om så önskas.

Deltagandet är helt frivilligt och Du har möjlighet att avbryta Ditt deltagande när som helst, även om Du tackat ja från början. Din berättelse kommer inte att kunna härledas till Dig som enskild person. Din berättelse kommer att spelas in på kassettband för att sedan skrivas ut till text, som inte kommer att läsas av någon obehörig person.

Om Du önskar ytterligare information, så ombedes Du ringa Peter Stoltz. Tfn: 0703-56 98 00.

För besked om deltagande/icke deltagande vänligen ring Peter Stoltz, så kommer vi överens om en tid och plats som vi kan träffas för en intervju.

Med vänliga hälsningar

Peter Stoltz

Leg. Sjuksköterska
Doktorand
Hälsa och Samhälle
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Ania Willman

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Universitetslektor
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Maud Lindholm

Leg. sjuksköterska; dr. med. vet.
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PAPERS I-IV