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BEING PRESENT IN CARING ENCOUNTERS

- a relational perspective on autonomy for older persons in municipal home help services

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Stockholm 2013

Published by Karolinska Institutet. Printed by E-print ,Stockholm, 2013

ISBN 978-91-7549-262-9

To Leif, Elin and Adam for being there in my lifeworld

ABSTRACT

The care of the old in Sweden and worldwide is developing towards an "aging in place." Older people in Sweden are expected to remain in their own homes supported by municipal home help services. This development has entailed that older people's need of support as well professional carers workload has increased. The older persons need of support is assessed by care managers, and research shows that they are in an exposed position when applying and often do not have their preferences met. In addition research also shows professional carers' difficulties in the care of the old and their need for support. The suggestion is a relational perspective in the care of the old to promote older persons' autonomy due to their increased dependency. Up until now there has been little research into older peoples' experiences of autonomy in municipal home help services. This thesis was therefore considered important to enhance knowledge and understanding of older persons' and their professional carers' lived experiences in everyday life. The overall aim of this thesis was to develop knowledge of older persons' opportunities to make independent decisions and to consider how professional carers can help them to improve their independence. This thesis compromise four studies (**I-IV**) and has a qualitative and a live world approach. In order to deepen the understanding of the meaning of older persons' and professional carers' experiences they were followed over time. Interviews have been conducted with older persons and professional carers before, during and after the professional carers participated in an educational programme. Data was analysed **I-IV** with a phenomenological hermeneutic method. The aim of study **I** was to illuminate the meaning of older persons' dependence on caregivers' help and of their opportunity to make independent decisions. The findings reveal that they are either struggling to make independent decisions or resigning themselves to not being able to do so. The aim of study **II** was to illuminate the meaning of carers' experiences of being in caring situations when a conflict of interest arises with the older person receiving care. The finding reveals that they are ambivalent in conflict situations, weighing older persons' right to self-determination against external demands. The aim of study **III** was to illuminate the meaning of older persons' independent decision making concerning their daily care. The findings revealed how they live with uncertainty as to how to relate to independence and dependence with regard to themselves and others, and how they try to comprehend everyday life. The aim of study **IV** was to illuminate the meaning of professional carers' experiences of supporting older persons' to make independent decisions in caring situations. The findings revealed that they are being torn between respecting independence and dependence and it is therefore complicated to support older persons to make independent decisions. A deeper understanding was reached considering the findings **I-IV** and disclosed; *waiting for others to comprehend their everyday life*, *torn between external and internal demands* and *striving for interdependency in caring encounters.* The conclusion of this thesis is that a relational perspective on autonomy as a shared-decision making could be valuable in the care of the old to enable for professional carers to support older persons in making independent decisions. The implication for practice is a person-centred care in the care of the old to promote a relational perspective on autonomy.

Key words: aged, autonomy, decision-making, ethics, phenomenological hermeneutic, older people, professional carers

LIST OF PUBLICATIONS

I. Breitholtz, A., Snellman, I., & Fagerberg, I. (2013). Older people's dependence on caregivers' help in their own homes and their lived experiences of their opportunity to make independent decisions. *International Journal of Older People Nursing, 8*(2), 139-148. doi: 10.1111/j.1748-3743.2012.00338.x

II. Breitholtz, A., Snellman, I., & Fagerberg, I. (2013). Carers' ambivalence in conflict situations with older persons. *Nursing Ethics, 20*(2), 226-237. doi: 10.1177/0969733012455566

III. Breitholtz, A., Snellman, I., & Fagerberg, I. (2013). Living with Uncertainty: Older Persons' Lived Experience of Making Independent Decisions over Time. *Nursing Research and Practice,* 2013, 403717. doi: 10.1155/2013/403717

IV. Breitholtz, A., Snellman, I., & Fagerberg, I. Professional carers torn between respecting older persons' independence or dependency. Submitted

CONTENTS

1 INTRODUCTION

Writing a thesis is a challenging task and involves a journey compromising many years of hard work. Through my past research related activities as a registered nurse, teacher and my theoretical experiences, I became aware of the present and future need to improve and expand caring sciences. My interest of older peoples' situation in society and how this could be improved developed when I wrote my master thesis in caring science. Due to the increasing older population in our society I was determined that there was a need for development to promote and improve the situation for them. This evoked an ambition and curiosity to start a doctoral education to be a part of this development, to create new knowledge to influence and improve the care of the old. I therefore was inspired when I was introduced to this project about older people's right to make independent decisions in municipal home help services.

2 BACKGROUND

This thesis focuses on older persons, who live in their private homes and are cared for by municipal home help services, and on their opportunities to make independent decisions concerning their daily care. In addition the focus is on how professional carers can support older persons to make independent decisions. In turn this implies opportunities for the older person to become more independent with support from professional carers.

2.1 CARE OF THE OLD

The older population aged 60 and above is increasing worldwide (World Health Organization [WHO] 2011) and older people are expected to 'age in place' (WHO, 2007). In Sweden (Socialstyrelsen, 2008) and several other countries in Europe (McGarry, 2009; Oberski, Carter, Gray & Ross, 1999; Sorbye et al., 2009), United States (Tang & Lee, 2010), Canada (Denton, Zeytinoglu, Davies & Lian, 2002) and New Zealand (Wiles, Leibing, Guberman, Reeve & Allen, 2012) the development is towards a care of older people in their own private homes with support. Wiles et al. (2012) found that the meaning of 'aging in place' is a process, varies and has a strong connection to independency and autonomy. Older people living at home today in Sweden, with support from professional carers, have more complex needs of care and the workload for the professional carers has increased (Socialstyrelsen, 2008). In Sweden the municipalities are responsible for care of the old, and older people apply for help in line with the Social Service Act (SFS, 2001:453) declaring that people's right to self- determination and integrity should be respected. In addition, a national core of values for care of the old has been established in the Social Service Act, stating that older people's dignity and well-being should be respected (Government Offices of Sweden, 2012). In the care of the old the overall aim is a rehabilitation perspective thus older people should use their own resources for as long as possible (Socialstyrelsen, 2012). The older people have to apply for support and care managers assess their needs including cleaning, shopping, laundry, meals, emergency alarms and personal care (Government Offices of Sweden, 2012). There is also a customer choice, for older people to choose between the private sector and public funding, a universal welfare service funded by taxes (Szebehely & Trydegård (2012). However, research shows that older people are in a vulnerable situation and that their preferences are not necessarily addressed in assessment meetings and discharge processes at hospital when applying for home care (Olaison & Cedersund, 2006; Rydeman & Törnkvist, 2006; Rydeman, Törnkvist, Agreus & Dahlberg, 2012) and for long term care (Denson, Winefield & Beilby, 2013). Janlöv, Hallberg and Petersson (2006) found that when older people were assessed for support from public home help they had no opportunity to be involved in decisions. In a study it was found that older people with support from municipal home help services in end of life experienced that a way to maintain dignity was to comprehend by themselves (Andersson, Hallberg, & Edberg, 2008). Dependency has also been found to be a hindrance in everyday life for older people in home nursing care (Ellefsen, 2002). The life situation for older people with mental disorder supported by municipal home help services was found to be that they struggled for existence, and that it was important for professional carers to be aware of this and to not just focus on their mental disorder without considering their lifeworld (Martinsson,

Fagerberg, Lindholm, & Wiklund-Gustin, 2012). From, Johansson and Athlin (2009) found that older people being supported by community care in private homes and sheltered accommodation, experienced good care as being met as a human being by the professional carers and living a normal life in security and safety. Kristensson, Hallberg and Ekwall (2010) found that relationships between caregivers and frail older people were crucial to promote control for older people living at home with support from professional carers, in either health care or social services or both. Research in municipal home help services and older peoples' autonomy is rare. However, studies show that older people in sheltered housing had reduced opportunities to their right to self- determination (Bolmsjö, Sandman & Andersson, 2006; Hellström, & Sarvimäki, 2007; Scott et al., 2003).

In the care of the old Saarnio, Sarvimäki, Laukkala & Isola (2012 found that professional carers had to deal with a troubled conscience, and lack of time was a source of feeling of not giving good care. Their private life was also affected, and the conclusion was that they needed time to deal with these feelings. Ericson-Lidman and Strandberg (2013) found that professional carers in the care of the old, manage their troubled conscience through an inner dialogue and with other people. They stressed the importance of enabling professional carers to share their experiences of their troubled conscience. Stenbock-Hult & Sarvimäki (2011) found that professional carers were vulnerable when caring for older people and meant being human and experienced as both resource and a burden. It has also been found that professional carers in municipal home help services balanced being altruistic and egoistic when caring for older persons with mental disorder, and disclosed how complicated this was for them (Martinsson, Wiklund-Gustin, Lindholm & Fagerberg, 2011). In another study of different professional carers and health care students in the care of the old it was found that they experienced that they had moral distress when their moral and ethical self was affected and concluded the need for support (Fagerberg & Engström, 2012).

2.2 THEORETICAL PERSPECTIVE

This thesis has a relational perspective on autonomy to see older persons as interdependent and not just as independent (Verkerk, 2001) as a shared decision-making (Sandman et al., 2012). An additional focus is to use caring relationship as a tool to focus on self-determination (Sandman, 2004, 2005) in the caring encounter (Snellman, 2001; Snellman, 2009).

2.2.1 Definition of autonomy

In Western societies as well as in Sweden autonomy is highly valued in the context of care and the demand for respecting people's autonomy is a central concept (Agich, 2003; Beauchamp & Childress, 2009; Sandman 2004). The Swedish Health Care Act (SFS. 1982:763) declares that health care should be based on respect for patients' self-determination and integrity, and similarly the Social Service Act (SFS, 2001:453) declares that the public sector approach should be based on the respect for people's self-determination and integrity.

There are several moral principles; respect for autonomy, nonmaleficence, beneficence and justice, with respect for autonomy foremost. In the health care context these principles should be followed, though they may conflict with each other, and moral dilemmas will arise as a consequence (Beauchamp & Childress, 2009). However,

Tronto (1993) points out that an ethics of care is a practice and that moral qualities are not a set of rules and principles. Fry & Johnstone (2002) point out that in health care context values such as patients' rights, personal values, cultural values and what professional carers are obliged to do might conflict with one another. It could for example be that a nurse's value to do good for the patient 'conflicts with the value to respect patients' right to make their own choices. A nurse should not base care on own personal values and both nurses and patients are influenced by their own values. Although professional guidelines and codes of ethics provide guidance when conflicts of values arises the nurse has to balance different values against each other in relation to patients' rights and what they are obligated to. If a nurse has a problem solving a conflict of values they should ask for guidance from a substitute nurse.

The concept of paternalism (latin: *pater*) derives from Immanuel Kant's philosophical analyses, which criticized the restriction of the freedom of its subjects. Paternalism always involves any form of coercion, manipulation and exclusion of information, or refusal to follow a person's preferences for their own best (Sandman, 2004). According to Sandman and Munthe (2010) paternalism in health care is decision-making derived from a Hippocratic ideal that the physician knows the patient's interest best. Although in today's health care there are other personnel as well that can be involved in decisions regarding patient care. This implies that health care personnel may exclude patients in the decision making process, with the intention that they know what is in their best interest. Accordingly they disregard the patient as an autonomous and/or rational being and make it a paternalistic action.

The concept of autonomy is well defined in scientific literature and can be understood and used in several ways, and there seems not to be a clear line between different perspectives. The most common is the traditional individualistic perspective and there are also other perspectives, such as the relational perspective, which challenges the individualistic perspective to be too narrow in its definition in the health care context.

2.2.1.1 The individualistic perspective

The word autonomy is derived from the Greek term autos which means 'self' and nomos and implies 'law', 'govern' or 'rule', a person's capacity to self-govern. Accordingly, it is how people make independent choices and decisions to shape their own lives, and other people should respect the person's independence (Beauchamp & Childress, 2009).The concept of autonomy has as its starting point the philosopher Immanuel Kant who developed an individualistic perspective on autonomy. He suggested that individuals have their own laws and control these from inside themselves without interference from other individuals (Kant, 2006).

The concept of autonomy is commonly used synonymous with self-determination. However, Sandman (2004; 2005) argues that the concept of autonomy as used by professional carers includes four different aspects; *self-determination, freedom, desire fulfilment* and *independence* whereas self-determination is the most central aspect. Nevertheless, it is important for health care personnel to distinguish which of these aspects brings value to people since there could be differences, and it should not just be a norm to follow. *Self-determination* concerns decision-making and the fact that people makes decisions according to their own wishes and how they want to live their lives. A person may still self-determine as long as the person has different

options to choose from, even though the options might not be aligned to their own priorities. Consequently, if a person cannot self-determine it means that a person is forced or deceived due to lack of information or has a reduced ability to understand different options. *Freedom* involves having valuable options to choose from in accordance with one's own life plans and if there are no valuable alternatives the freedom is limited. Although, to what extent the freedom is available is dependent on external and internal circumstances, and thus this restricts a person's freedom. Accordingly, how a person values their self-determination is dependent on their freedom to choose from options. Even though there are no valuable options a person is still capable of choosing the most appropriate for themselves. If a person does not have valuable options to choose from they might feel that her/his self-determination is irrelevant. *Desire fulfilment* concerns the final outcome of the decisions and a person might have a reason to decide for themselves if they think it will realize the fulfilment of their own wishes. *Independence* concerns a people's involvement when a decision is carried out so that they can do things themselves. Accordingly it might be valuable for individuals to carry out the decisions and not just hand it over to others. If a person has become dependent on help and no longer able to perform as much as earlier in life it might be valuable for them to carry out as much as possible. Decision competence is based on whether a person is capable to such an extent as possible to realize self-determination, freedom, desire-fulfilment and independence. This implies that a person is capable of valuing different options and how they may influence their lives and take decisions based on that. A person might be more or less decision competent regarding the proportion of the decisions, although is important not to diminish more decisions than necessary (Sandman, 2004; 2005).

2.2.1.2 Shared decision-making

Shared decision-making (SDM) is one of several decision-making models discussed in the literature aiming for the best outcome for the patient and autonomy to change the criticized paternalistic view. Charles, Gafni and Whelan (1997) have further conceptualized the (SDM) model in medical encounters between physicians and patients to explicit clarity. This model (SDM) contributes to a middle way decision between two polars and can be illustrated by a continuum where the paternalistic model (leaves the patient outside) is on one end and informed decision-making model (leaves the physician outside) is set on the other end. The suggestion is that there should be a minimum of characteristics to make it a shared decision-making i.e. involving a minimum of two participants, both parties take part in the decision-making process and both parties agree on the decisions in a mutual acceptance. Charles, Gafni and Whelan, (1999) have further revisited the conceptualization of the (SDM) model (Charles et al., 1997) to make it more flexible, including analytic steps 'information exchange, deliberation, deciding on treatment to implement' in the decision-making process to enhance the respect for the patient's wishes. Sandman et al. (2012) have further explored (SDM) models towards change from a compliance to an adherence paradigm. They suggest nine different (SDM) models and two are preferred to the others (first and second) and one is seen as second (third) choice (only these three will be described here). The first model, 'Shared Rational Deliberative Patient Choice' involves; engagement in a shared deliberation, allows the patient to think through preferences, achieve self-realization and the patient

decides in the end. The second model; 'Shared Rational Deliberative Joint Decision' involves; engagement in a shared deliberation resulting in a consensus in a joint decision and achieve self- realization. The third model, 'Professionally Driven Best Interest Compromise' involve; engagement in a shared deliberation resulting in a conflict and the professional tries to strategically affect the patient to accept the best possible decision (professional perspective), allows the patient to reflect on preferences, achieve self-realization,resulting in an agreement as a compromise.

2.2.2 The relational perspective

In the care of the old the individual perspective of autonomy is presented as an ethical issue, due to older peoples' dependency and reduced independency (Becker, 1994; Collopy, 1988; McCormack, 2001; Agich 2003). It is crucially important to have ethical reflections concerning older people's autonomy due to their increased dependence and vulnerability and accordingly a reduced independence. Further, autonomy is a dynamic process and therefore develops in relation to others (Agich, 2003). McCormack (2001) also argues for a change in care ethics in the care of the old and the need to rethink the concept of autonomy towards a relational approach. The suggestion is an interconnectedness to facilitate for the nurse in the relationship the acknowledgement of the persons in need of care and their preferences. Cordingley and Webb (1997) argue for a movement between independence and dependence for older people towards interdependence instead of viewing them as opposite poles. Verkerk (2001) also advances the concept of autonomy from a caring perspective to focus on a person as interdependent and not only as independent, and to view the concept of autonomy as people making their own decisions with support from others. A commitment to care facilitates for professional cares to be there beside the person as a support. The relational approach enables professional carers to support people receiving care to be autonomous (Verkerk, 2001). Accordingly a relational perspective on autonomy could be useful in the care of the old.

3 RATIONALE

Worldwide the older population is increasing at the same time as the development of care of the old is moving towards an "aging in place". In Sweden older people dependent on help are expected to live in their own private homes for as long as possible with support from municipal home help services. They have more complex needs of care as well as the workload has increased for the professional carers. The older persons have to apply for support and their needs are assessed by a care manager according to the Social Service Act (SFS, 2001:453), stating that the respect for people's self-determination and integrity should be emphasized. The individualistic perspective is an ethical issue in the care of the old due to increased dependency and thus decreased independence. A relational perspective is suggested embodying the importance of having ethical reflections of older people's autonomy. However, research shows that older people are in an exposed situation when applying for home care and that their preference are not fulfilled. Research into older peoples' experiences of autonomy in municipal home help services is rare. However, research shows that for older people living in sheltered housing challenges their right to self-determination. Research also shows that professional carers in the care of the old have to deal with a troubled conscience and that they are vulnerable and it is suggested that they need support with their experiences. To meet the future demands within the care of the old there is a need to increase knowledge and understanding concerning older people's right to be involved in decisions concerning their daily life and how professional carers can support them. It was therefore considered important to study the phenomenon of older persons' opportunities to make independent decisions and of their professional carers to support them.

4 AIMS

The overall aim of this thesis was to develop knowledge of older persons' opportunities to make independent decisions and to consider how professional carers can help them to improve their independence.

I. The aim of the study was to illuminate the meaning of older persons' dependence on caregivers' help and of their opportunity to make independent decisions.

II. The aim of the study was to illuminate the meaning of carers' experiences of being in caring situations when a conflict of interest arises with the older person receiving care.

III. The aim of the study was to illuminate the meaning of older persons' independent decision making concerning their daily care.

IV: The aim of the study was to illuminate the meaning of professional carers' experiences of supporting older persons' to make independent decisions in caring situations.

5 METHODS

5.1 DESIGN AND THEORETICAL FOUNDATION

This thesis compromises four studies (**I-IV**) and has a qualitative and a lifeworld research approach with an epistemological and ontological foundation rooted in phenomenological and hermeneutic. Lifeworld research is an open approach and needs a starting point in a phenomenon philosophy (Dahlberg et al., 2008). In this thesis the phenomenon is older persons' opportunities to make independent decisions and of their professional carers to support them. The focus is the meaning in their lived experiences as it is lived in everyday life according to their lifeworld. To reach the meaning of their lived experiences a phenomenological hermeneutical method inspired by the French philosopher Paul Ricouer and further developed by Lindseth and Norberg (2004) was used. A research approach involves philosophical assumptions concerning ontology and epistemology i.e. what reality and knowledge are (Bengtsson, 2005). The lifeworld is the concrete reality in everyday life that we relate to inseparable together with others (Bengtsson, 2005). According to Husserl (1970) we live together in the lifeworld and thus we consider value, plan and act together.

5.2 SETTING

The participants were recruited from two different municipalities, one small and one medium-sized, and they were recruited within these municipalities from two respectively three districts. In the medium-sized municipality there was one staff manager of a district and in the small there was the same manager for all districts. In total there were four staff managers involved in the recruiting process who were frequently contacted during the data collection period. In each district the professional carers had an office and in the medium-sized municipality there was one senior housing where the municipal home help services and their professional carers had their office. There were two older persons participating in the study living in this senior housing and two professional carers worked there, thus this accommodation was considered to be a private home and they had help from the municipal home help services.

5.3 PARTICIPANTS

The participants in this thesis were followed over time before, during and after the professional carers' had participated in an educational programme. In order to follow the participants over time they were chosen as a care-couple, thus each older person was paired with one professional carer.

5.3.1.1 Older persons study I, III

The inclusion criteria for the older persons were; aged 70 or more; both men and women; able to speak and understand Swedish; different levels of care needs; and living alone at home with daily help from the municipal home help services. Each older person's cognitive ability was determined prior to enrolment and before study **III**, by a cognitive screening according to MMSE (Folstein, Folstein, & McHugh, 1975). They needed a score of at least 24 out of 30 to be included for study **I** and not to be excluded from study **III**. This screening was conducted by experienced staff that otherwise did

not take part in the project. The participants (**I, III**) lived alone in their private homes, either in apartments or in houses, and they had daily help from municipal home help services The participants had varied domestic help, for example preparing meals, washing up, cleaning, making beds, and care help, such as personal hygiene and other different nursing care according to the Social Service Act (SFS, 2001:453) and Swedish Health Care Act (SFS. 1982:763); Government Offices of Sweden, 2012). In study **I** there were 12 older persons; aged varied between 80-91; eight women and four men; five respectively seven participants from each municipality; varied domestic help, varying between 1-5 times a day. In study **III** there were (after drop outs) 7 older persons still remaining; age varied between 80-91; six women and one man; three respectively four from each municipality; varied domestic help, varying between 1-6 times a day.

5.3.1.2 Professional carers study II-IV

The inclusion criteria for the professional carers were: working in municipal home help services in different municipalities; deemed by their leaders to be experienced and skilled in their work with older people; both men and women; and have an interest in working with older people. In study **II** there were 12 women and one man; aged varied between 31-58 years; six respectively seven participants from each municipality; assistant nurses and enrolled nurses; and their working experiences in municipal home help services varied between 2-17 years. In study **IV** (after drop outs) 7 professional carers still remaining, 7 women; aged varied between 31 to 57; three respectively four from each municipality; assistant nurses and enrolled nurses; and varied working experiences in municipal home help services between 3-15years.

5.3.1.3 Drop outs during data collection

The participants were paired as a care-couple, thus if one of the participant in the care-couple dropped out, the other participant in the care-couple had to be excluded. However, the participant was informed in advanced that this was the procedure. After interview 1 there were 3 older persons (**I**) and 1 professional carer (**II**) and the other part in the care-couple had to be excluded. In total the drop outs after interview 1 were 4 older persons and 4 professional carers. In addition after interview 2 there were 1 professional carer (**IV**) that dropped out and the older person (**III**) was excluded (see table 1).

Table 1. Description of drop outs during the data collection period 2009-2010

	Interview 1		Interview 2		Interview 3		Interview 4	
Study	I	II	III	IV	III	IV	III	IV
Participants	older	carer	older	carer	older	carer	older	carer
Number of participants	12	13*	8	8	7	7	7	7
Drop outs after performed interview	4	4	1	1	0	0	0	0

*One professional carer dropped out (the interview used in Study II) and the older person in the care-couple was interviewed again and formed a new care- couple with a new professional carer.

5.3.1.4 Recruitment procedure

The participants were informed in advance that they were going to be paired with either a professional carer in study II or an older person study I. The time that the older person and the professional carers in the care-couple had known each other before the data collection varied between a few months and several years. Firstly the staff managers in their respective districts gave information about the research project and asked if there was anyone interested in participating. Those who showed interest in participating and were considered by the staff manager to fulfil the inclusion criteria were considered prospective participants. They were given further verbal and written information and additional information was given that they could only be included if they could be paired with an older person or carer. When the staff manager had a prospective professional carer they recruited an older person according to the inclusion criteria. They first contacted the old person by phone and gave information about the project, and if they were interested in participating a meeting was arranged in the older person's home. Further verbal and written information was given and they were also informed that their cognitive ability had to be determined in a cognitive screening before they could be included in the project and before data collection of study **III.** When agreement had been reached they were contacted by experienced staff in order to arrange a meeting to conduct the screening in their homes. The older persons and the professional carers they had been paired with first had knowledge of each other through the staff managers once the older person had been chosen. Information by letter came once a care-couple was decided and I then contacted the participants **I, II** by phone and arranged a meeting for the first interview. This recruiting process was adopted in order to not ask older persons to participate without having an interested professional carer first. The informed consents in study **I, II** were collected before the first interview was conducted. In order to affirm that the older person health had not declined and still wanted to participate and be cognitively screened again, they were contacted by the staff managers before study **III**. Thereafter I was informed by letter again and contacted the participants in study **III, IV** and arranged meetings for interview 2.

5.4 DATA COLLECTION

The data collection for all four studies **I-V** was conducted using open narrative interviews between February 2009 and January 2010. The participants in study **I, II** were interviewed once each between February 2009 and September 2009. Study **III, IV** was conducted between October 2009 and January 2010. All participants, older persons in study **III** and professional cares in study **IV** were interviewed three times each, in October, November 2009 and January 2010. The total number of interviews analysed in this thesis was sixty-seven. Three additional interviews were conducted but excluded from the analysis due to drop outs (see Table 1). All audio taped interviews were conducted by me and all participants were interviewed 4 times each, in order to follow and analyse the meanings of their experiences over time (see Table 2). To enable a deeper understanding of participant's experiences over time the same interview guide was used in all interviews.

5.4.1 Interviews

The interviews were carried out in the older persons' homes and lasted for approximately 40-70 minutes study **I, III**. The same open- ended interview guide was used study **I, III** and the participants were encouraged to narrate as freely as possible their experiences of their opportunities to make independent decisions. The questions asked were: "Can you tell me what it is like when caregivers help you with your daily care? Can you tell me how you experience the opportunity to make your own decisions about your daily care when a caregiver is helping you?" Follow-up questions were asked to deepen the understanding of their narratives such as: "Can you tell me more about what you thought about that? Can you tell me some more about how you felt?".

The interviews with professional carers were carried out at the working place and lasted for approximately 40-70 minutes study **II, IV**. An older person's right to make independent decisions is at stake in conflict situations and they were asked to narrate about conflict situations with older persons. This was done in order to reach the phenomenon of older persons' opportunities to make independent decisions and of their professional carers supporting them. The participants were encouraged to narrate as freely as possible their experiences of giving care to older persons and how to act in situations where conflicts of interest between them and older persons arose. The same open-ended interview guide was used study **II, IV** with open questions: "Can you tell how you help an older person with their daily care? Can you tell a situation when you and an older person did not agree on decisions concerning their daily care?" To deepen the understanding follow-up questions were asked: "Can you tell me more about what you thought about that? Can you tell me some more about how you felt? "

5.5 EDUCATIONAL PROGRAMME

The participants were followed during a period time before, during and after the professional carers' participated in an educational programme. However, it was not the educational programme per se that was followed, the object was to deepen the understanding of the meaning of older persons' and professional carers' experiences over time. Time is individual, subjective and contextual and not linear, but how people move through time is accordingly how people live their lives and focus on the complexity of changes within people (Saldaña, 2003).

Planned meetings with a lecturer experienced in the care of the old, but not involved in the project, took place once a month over 4 months. To stimulate the professional carers to take an active role in the older persons' daily care they discussed and reflected with focus on present research about caring encounter and caring relationship (Halldórsdóttir, 1996; Snellman, 2001; Snellman, 2009). An additional focus was self- determination (Nordenfelt, 2007; Sandman, 2005; Sandman, 2007) and shared decision-making as a relational perspective on autonomy as interdependence (Verkerk, 2001). A study plan was carried out and it was important to have progression throughout the educational programme with a primary focus on self-determination and the caring encounter. However, an additional focus was to use a caring relationship as a tool to focus on self-determination in the caring encounter to achieve "shared decision-

making" (Verkerk, 2001). In the long run this might have implied that the older persons experienced an increased influence over their daily care.

The planned meetings were carried out in each municipality separately with all participants, except one who could not attend the first meeting. Nevertheless, on a few occasions follow-up meetings were arranged in respective municipalities, when a participant could not attend the planned meetings. The meetings took place in respectively municipality nearby the professional carers working place. Data collection for study **I** and **II** was performed during spring 2009 before the professional carers undertook the educational programme during autumn 2009. Data collection for study **III** and **IV** was conducted during and after the educational programme (see table 2).

Table 2. Meetings and interviews performed during data collection period 2009-2010

	Spring-09	Sept-09	Oct-09	Nov-09	Dec-09	Jan-10
Meetings		x	x	x	x	
Interviews with older persons Study I, III	I		III	III		III
Interviews with professional carers Study II, IV	II		IV	IV		IV

5.6 DATA ANALYSIS

The data for all four studies **I-IV** was analyzed using a phenomenological hermeneutic method rooted in hermeneutic and phenomenological traditions presented by the French philosopher Paul Ricoeur (Ricoeur, 1976) and further developed by Lindseth and Norberg (2004).

5.6.1 Phenomenological hermeneutic

The phenomenological hermeneutic method is useful when researching lived experience. To reach the meaning of lived experiences it is appropriate to conduct narrative interviews to reveal the meaning. Narratives need to be written down to become an autonomous text and then need to be further interpreted. To interpret a text when using the phenomenological hermeneutic method involves a movement entering the hermeneutic circle through three steps in a dialectic movement between explanation and understanding. It is a circular process between the whole and the parts to understand what the text says and what it talks about, and the meaning is disclosed in front of the text (Lindseth & Norberg, 2004; Ricoeur, 1976). According to Ricoeur (2007) this movement involves an epistimological and ontological dimension to overlap the dichotomy of explanation and understanding, which has two different epistimological and ontological grounds rooted in natural sience and human science respectively. Accordingly the dialectic movement between explanation and understanding is a complex process referred to as interpretation.

The three methodological steps in phenomenological hermeneutics follow a procedure; naïve reading, structural analysis and comprehensive understanding (Lindseth & Norberg, 2004). The methodological step involves a circular process, thus not linear, from a first naïve guess to validation relating to the text (Ricoeur, 1976). In order to reach a first first naïve understanding of the meaning of the transcribed text they were read several times as a whole in order to attain a first naïve

understanding of the meaning. In order to allow for the phenomenon to be disclosed it is crucial to be open to the text and change the natural attitude, i.e. when taking things for granted to a phenomenological attitude. The naïve understanding guided the next step, the structural analysis. This step started with dividing the whole text into meaning units, i.e. any length of text that expressed one meaning. There were parts of the text not related to the specific aims but they were taken in consideration during the preceding structural analysis. All the meaning units were condensed and the essential meaning of each of them was formulated as concisely as possible. The condensed meaning units were then abstracted into sub-themes and then into themes and further to a main theme. This procedure was repeated several times in an on-going process until the structural analysis validated the naïve understanding. To disclose the meaning of lived experiences and to gain a new deepened understanding of being in the world, a text needs further interpretation through critical reflections, and a comprehensive understanding is thus formulated. This commenced with critical reflections as open as possible, where the transcribed interviews, naïve understanding, sub-themes and themes, main theme (**III**, **IV**), the aim, authors' pre-understanding and relevant literature were taken in consideration. To broaden and deepen the interpretation awareness of pre-understanding was achieved, since we understand and revise the pre-understanding while interpreting, and accordingly we cannot liberate ourselves from it. In order to come close to the meaning of lived experiences philosophical literature was useful to disclose a new possible understanding of the phenomenon. Interpretations have not only one meaning, but the findings were considered the most useful amongst other meanings (Ricoeur, 1976).

5.7 ETHICAL CONSIDERATIONS

The project was initially authorized to be conducted in the municipalities by respective municipality managers for the municipal home help services and approved by the Regional Ethics Committee (ref. 2008/256). Ethical considerations have been taken into account carefully throughout the project according to the Declaration of Helsinki (2008). The participants were given verbal and written information of assurance and confidentiality, participation was voluntary and they could withdraw without giving any reason. In order to let the participants consider their participation once more, they signed informed consent which was collected in conjunction with the first interview in study **I** and **II.** Thereafter they were asked verbally for informed consent before each three interviews in study **III,** and **IV.** All audio taped interviews in studies **I-IV** as well as the transcribed interviews were coded for confidentiality. The informed consent, data material and code key were stored in separate locked cupboards at the University. When choosing quotations to illuminate the findings **I-IV** care was taken not to reveal names or places, especially considering that the participants were recruited as a care-couple.

Ethical considerations concerning risk and benefits have been taken throughout the project. The older persons participating were all living alone in their own homes and can therefore be considered to be in an exposed and vulnerable situation compared with older persons living with a spouse or next of kin. An ethical consideration was also made to not ask older persons to participate before there were any professional carers interested in participating. This was done in order to not trouble them with the recruitment process without an assurance that there were interested

professional carers. A risk that may have entailed emotional discomfort for the participants might have been that they were paired as a care-couple and thus in a dependent relationship to each other. However, the risk in relation to the benefits for the participants was considered minor given that the project might entail competence enhancement, which in the long run might improve the older persons' right to make independent decisions. There might also have been a risk for professional carers when participating in the educational programme that they started to reflect on their own care actions with older persons, which in turn might have given rise to feelings of guilt if they considered that they might have acted in a bad way. The professional carers were therefore offered opportunities via their staff manager to get in contact with occupational health services if emotional feelings arose. Another ethical consideration in relation to risk and benefit concerned the older persons needing to be cognitively screened before enrolment in Studies **I** and **III**. There might have been a risk that the older persons felt that this was done in order to check and diagnose cognitive changes and thus be an integrity intrusion and they therefore might not have wanted to participate. In performing the screening, it might also have appeared that the older persons had cognitive changes. In order to promote this the screenings were performed by experienced staff in respective municipalities with authority to take care of possible cognitive changes. I had also an ethical discussion with the managers in the respective municipalities and the staff performing the screenings, in order to consider these ethical issues. The older persons were given verbal and written information by the staff managers about the purpose of the screening in a manner that not was offensive. In order to minimize the risk circumstances the participants were given written and oral information for clarification.

Participants were interviewed four times each over a period of time from several months up to one year. This could be discussed from an ethical point view, especially regarding the older persons who may be considered vulnerable. There was also a risk that their health could decline during the data collection. It has been suggested though that several interviews can be helpful instead of harmful for vulnerable participants since they might appreciate being able to talk about their experiences even if there were sensitive issues (Murray et al., 2009). For the professional carers who participated, it could also be discussed whether their participation over time has affected them from an ethical point of view. Although, it turned out that they appreciated being involved and gaining attention, beyond the interviews and having the opportunity to participate in the educational programme. This enabled them to sit down and discuss and reflect on problematic ethical situations with older persons they cared for, and share these experiences with colleagues and a person experienced in the care of the old.

6 FINDINGS

The findings are presented for each study (**I-IV**) separately.

6.1 STUDY I

The findings **I** of the meaning of older persons' dependency on professional carers' help revealed three themes: "Being facilitated to make one's own decisions" with four subthemes, "Being hindered from making one's own decisions" with four subthemes and "Struggling vs. resigning oneself to losing the opportunity to make one's own decisions" with three subthemes.

The theme "Being facilitated to make one's own decisions" revealed that when the older persons' own needs are fulfilled they are satisfied and feel respected when being supported by a flexible, experienced professional carer. There is a give and take in the relationship in a mutual understanding that develops over time and infuses trustfulness. When knowing what's best for oneself the older people are in control over their own lives and make their own decisions in line with their own wishes and needs. They feel free to accept or decline professional carers' suggestions and tell them how they want the chores to be done. Preserving one's independence the older people strive to manage by themselves as long as possible with support from encouraging professional carers. This infuses confidence in themselves helping to preserve their personalities and independence. When feeling involved the older persons participated in their own care together with the professional carers enabling them to be involved and make their own choices. The theme "Being hindered from making one's own decisions" revealed that the older persons do not having any influence to decide when the decisions are out of their reach high up in the organization and as a consequence their wishes and needs are not met. They have no influence on when the professional carers arrive, and they have lost control, unable to make their own choices or decide over their everyday life, prevented by the organization and with no opportunity to decide. When older persons are not being heard the professional carers prevent or decide over them, without giving them the opportunity to express their own wishes and needs. The older persons are being overlooked when the professional carers are in a hurry and perform the routinized care without asking about their needs. When recognising one's own dependence the older persons are aware that they no longer are able to take care of themselves without support from professional carers. The theme "Struggling vs. resigning oneself to losing the opportunity to make one's own decisions" revealed that when the older persons are defending one's own self-determination they struggle to maintain their independence by guarding their rights and finding solutions to maintain or regain it. When being resigned the older persons have given up their opportunities to decide for themselves and accept and adapt to the care given even if it not is sufficient. This is done out of loyalty towards their professional carers and other older persons in need of help, and thus they diminish their own needs. When waiting for one's turn the older persons do not know when professional carers will arrive or if they have been forgotten, and they try to manage to get things done by themselves. They become uncertain, while at the same time they comply with the situation and do not have their wishes and needs met.

6.2 STUDY II

The findings in study **II** of the meaning of carers' experiences of being in caring situations when a conflict of interest arises with the older person receiving care revealed three themes; "Being ambivalent when facing a conflict of interest" with three subthemes, and "Being guided by doing what is best when facing a conflict of interest" and "Being intuitive when giving care" with two subthemes each.

The theme "Being ambivalent when facing a conflict of interest" revealed that when carers facing a conflict of values they weigh between what they consider is the best and respect for older persons' right to self-determination. They are unsure how to act in conflict situations, when they consider the old do not know what is in their best interests, and wonder whether they are doing the right thing or violating and infringing on the older persons' integrity and self-determination. It is difficult to respect older persons' right to self-determination when faced with time-pressured working conditions and other older persons in need of care, and carers wonder if they should follow routine procedures or cater for older persons' needs and wishes. When being limited by preventive working routines the carers have to follow a working schedule and it is difficult for them, to carry out what the older persons have decided they need help with. They have to deny the older persons help sometimes or help them too much in order to get the chores done faster and face their disappointment when they have to leave. It is difficult for them to solve conflict situations and refer the issue to managers to solve, and it is frustrating to be prevented by the organization from supporting older persons with their needs and wishes. Protecting oneself the carers set limits for the older persons when they demand too much and this gives rise to conflict situations, defending their working environment, although they restrict older persons' right to make independent decisions. The theme "Being guided by doing what is best when facing a conflict of interest" revealed that carers are guided by goodness if they consider that the old person does not know what is best for them. They remind the old person or make the decisions for them, gently so that the old person does not notice it, encouraging their mental and physical capabilities with respect to their right to self-determination. When guided by dialogue the carers are perceptive of older persons' needs and wishes and give alternatives for the old to choose from in conflict situations. If the old person does not know what is in their own interest, they use persuasion and inventiveness calmly and cautiously to distract them. This is time-consuming, and sometimes it is not even possible to have the time, although they still try to support them and do as the older person wants. The theme "Being intuitive when giving care" revealed that the carers are caring in an unspoken way they are affected by emotions and read the older persons' body language, facial expressions and daily mood and do as the old wish until nothing else is asked for. The carers adapt gradually to older persons' personalities and take on different roles where they think it is appropriate to connect with the old. Although it is hard for them, especially when taking on a role they are not comfortable with, this leaves them with uncertainty as to whether they have interpreted the old correctly or not. When personally engaged in the care they use themselves as someone to appreciate the older persons' in caring encounters and this is easier than pretending to be someone else taking on a role. The carers place high demands on themselves and can be personally affected and they need to distance themselves from the old.

6.3 STUDY III

The findings in study **III** of the meaning of older persons' independent decision making concerning their daily care revealed one main them: "Living with uncertainty as to how to relate to independence and dependence with regard to oneself and others" and three themes; "One's independence lies in the hands of others" with three subthemes. "One's independence lies in one's own hands" with four subthemes. "Adjusting one's own independence and dependence with regard to oneself and others" with two subthemes.

The main theme: "Living with uncertainty as to how to relate to independence and dependence with regard to oneself and others" revealed that the older persons, over a period of time, were aware of their vulnerability and dependence, but they still wanted to be as independent as possible. This makes it complicated for them when living in a changing situation trying to comprehend every day and living in uncertainty, when they never know what it is going to happen. Although they have attention from one particular professional over a period of time, they still do not know when this person will arrive. The theme "One's independence lies in the hands of others" revealed older persons relying on others to manage one's lives and striving to be independent with whatever support they were able to get from others. They try to organize their lives, to comprehend their everyday life to make it work for all people involved, such as professional carers, relatives or help from the private sector. When deciding for oneself is beyond one's reach it is complicated for the older persons with other people making decisions for them, without the opportunity to be involved and to express their needs and wishes and they just have to accept the circumstances. Waiting for others to come limits the older person's freedom in everyday life when sitting and waiting for professional carers to arrive, and they feel threatened not being able to take care of themselves. The theme "One's independence lies in one's own hands", when deciding for oneself when to become involved, the older persons feel free to express their wishes and needs, to be perceptive and encourage professional carers, and they decide for themselves or together with the professional carers. They are in control of their lives, knowing what is best for them, according to their own wishes and needs. When managing oneself with professional carers as an extended arm the older persons gets support as if they were doing it themselves. The older persons handing over the decisions to others when they feel their own body cannot perform the task and it is comforting to have a reliable professional carer standing near to support them. When giving and taking in the relationship with professional carers in a mutual personal relationship the older persons feel they decide for themselves and it is encouraging and comforting and they become less dependent. The theme "Adjusting one's own independence and dependence with regard to oneself and others" revealed older persons neglecting own needs to allow for the needs of others and showing loyalty to their professional carers. They adjust and accept the circumstances in the organization without any expectations and try to comprehend so as not to burden their professional carers. When withholding ones's thoughts they just observe the professional carers performing the chores and even if they do it incorrectly, complicating their own lives, they still say nothing. The older persons learn gradually to find strategies and to adjust to the professional carers' personalities.

6.4 STUDY IV

The finding in study **IV** of the meaning of professional carers' experiences of supporting older persons in making independent decisions in caring situations revealed one main them: "Being torn between respecting independence and dependency" and three themes; "Being frustrated in supporting older persons to make independent decisions" with four subthemes. "Respecting older persons' independence and dependence" with three subthemes. "Gaining new insight into how to support older persons in making independent decisions" with four subthemes.

The main theme "Being torn between respecting independence and dependency" revealed that it is complicated for them to support older person in making independent decisions, when focus in the organization is to respect independence, while at the same time acknowledging older persons' changing vulnerability and dependency. The theme: "Being frustrated in supporting older persons to make independent decisions" revealed that they are being chased by time in their work as if on an assembly line, with stress constantly present, and making it complicated when the chores are time-restricted and they recognize that the old need time to have their needs met. They weigh up values against each other and there is always someone else in need of help at stake, and they have to consider the older person's right to make independent decisions. Being emotionally troubled when not finding solutions in conflict situations, and defending their actions, and incite conflict. When one's own beliefs do not comply with those of the organization it is hard to support the old in making independent decisions. They appreciate that it is crucial with interpersonal contact with older persons even though it is not prioritized in the organization. The theme "Respecting older person's independence and dependence" revealed that they value independence, when the vision of the organization is that it is good for older persons to do things for themselves for as long as possible. If the old refuse to do things themselves, they question their intentions and encourage or ask them to do it, and this confuses or hinders solutions to conflicts. Being perceptive for dependency they acknowledge older persons' changing vulnerability and dependency from one day to another, do not just focus on independence, and realize that they sometimes need help with things they normally can do. When taking on the decision they recognize that the old are not able to take care of themselves to avoid abandon them, and sometimes the old hand over the decision. It is hard for them to know if they are making the right decision, but at the same time they realizes it is for the best interest for the old. The theme "Gaining new insight into how to support older persons in making independent decisions" revealed that when being present in time they acknowledge how the old fluctuate between dependence and independence. Although being emotionally affected, they regain body control in order to calm the old and solve conflict situations. They realize the importance of creating a meaningful encounter with the old and of taking time and letting go of other commitments. When accepting the person they put aside their own preconceptions, and accept older persons personalities and shortcomings. When they show interest for older persons life stories, it enables to get to know their personality. Coming closer in the relationship when visiting the older persons on a regular basis enables the development of mutuality and trust, and makes caring natural and enjoyable even in difficult situations. When sharing decisions they involve the old in coming to an agreement and this prevents conflict situations, giving alternatives to choose from, not just taking over everything, and allowing the old to decide for themselves.

7 DISCUSSION

7.1 REFLECTIONS ON THE FINDINGS

The overall aim of this thesis was to develop knowledge of older persons' opportunities to make independent decisions and to consider how professional carers can help them to improve their independence. In order to deepen the understanding of the meaning of older persons' and professional carers' experiences they were followed over time. This has made it possible to disclose their common lifeworld and thus a deeper understanding of changes over time was reached. When considering the findings **I-IV** they are intertwined and disclosed as a shared lifeworld over time. The older persons **I** struggling vs. resigning themselves to losing their right to make independent decisions reveals a stressful life situation. A deeper understanding was reached over time of the older persons changing life situation from one day to another. The older persons **III** have to live in uncertainty as to how to relate to their own independence and dependency *waiting for others to comprehend their everyday life*. The professional carers **II** are ambivalent when facing a conflict of interest and they balance between the respect for older persons' self-determination and integrity, and their work demands. Over time the deeper understanding was reached of professional carers **IV** working situation, when they are torn between respecting older persons' independence and dependency. When the focus in the organization is to respect older persons' independence, while at the same time acknowledging their dependence, they are *torn between external and internal demands* and it is difficult to support older persons in making their own independent decisions. The overall deepened understanding of their intertwined shared lifeworld over time when the professional carers had participated in the educational programme is that professional carers and older persons *striving for interdependency in caring encounters*. In order to disclose changes over time the findings **I-IV** were considered as a whole and in part, and discussed as a whole to comprehend how the findings **I-IV** are intertwined.

7.1.1 Waiting for others to comprehend their everyday life

When considering the findings **I-II** it revealed a deeper understanding over time of how complicated it is for older persons to make independent decisions, and how they **III** live in a changing live situation trying to comprehend every day. The understanding is that professional carers **II-IV** has a complicated working situation and it is difficult for them to support older persons to make independent decisions. The complication is further understood, when considering the findings **I-IV** as a whole, as the older persons and the professional carers being embedded in a fixed organization required to uphold routines, and having a stressful situation pulling in two directions. The older persons have to comprehend to make it work for all persons in the organization, to uphold routines and professional carers working routines. They resign themselves **I** and adjust and accept **I, III** the circumstances in the organization out of loyalty to their professional carers. In line with this Wiersma and Dupuis (2010) found that older persons' in long-term care became 'institutional bodies' and that their bodies were adapted to uphold structures in the institution. The older persons **I, III** are aware of their vulnerability and dependence, but still they wanted to be as independent as possible. This discloses a changing life situation, living with

uncertainty as to how to relate to independence and dependence with regard to themselves and others to comprehend everyday life. The older persons **III** changing life situation can be related to Dahlberg, Todres, & Galvin (2009) who argues for an existential view of well-being as a human potential for living where professional carers acknowledge well-being and illness not as opposites but as a movement. In addition Murray (2012) argues going beyond bioethics that view life and the body as an object of flesh and blood, towards a phenomenological perspective situated in the lifeworld in the lived-body. In relation to the findings this highlights the need to acknowledge older peoples changing vulnerability and dependence in everyday life from their perspective, and accordingly caring encounters become crucial to enable professional carers to acknowledge older persons' changing life situation. According to Paterson and Zderad (1988) nursing has to be seen as a phenomenon that arises in the real world where human beings are related to one another in a shared situation as an intersubjective transaction in which both parties are participating. In order to achieve this nursing involves modes of being and doing in interrelation, although it is not only a matter of doing it also involves being with someone, whereas nurses have to be present and acknowledge the patient's lifeworld. Although the older persons **I, III** live in their own homes, they still have to comply with the routines in the organization. In Sweden (Socialstyrelsen, 2008) and worldwide older people are expected to 'age in place' (WHO, 2007) and the meaning of 'aging in place' has a strong connection to independency and autonomy (Wiles et al., 2011). The older persons' opportunities to make independent decisions are hindered by routines and professional carers working conditions, although the Swedish Social Service Act (SFS, 2001:453) declares that people's right to self- determination and integrity should be respected. The older persons **I, III** experienced that they had no influence on decisions made in the organization and this prevented them being involved and making choices. Harnett (2010) found that older persons in nursing homes made efforts to fulfil autonomy or their own wishes and that they were restrained by the institutions inflexible routines. This is further understood as the organization in municipal home help services being routinized which does not make it easier for older person's everyday life, nor respect the older person's right to make independent decisions. In addition the organization also hinders the professional carers **II, IV** from supporting older persons when they have a time-pressured working situation and no opportunities to be flexible for the older person's needs and wishes.

The older person **I, III** have no influence on what time the professional carers will arrive to help them with their daily care and chores. However, over time the older persons **III** experiences disclose a deeper understanding of the meaning of how difficult this is for them. They **III** sit and wait for professional carers to arrive, and it limits their freedom in everyday life, and gives rise to a feeling of not being able to take care of themselves. This highlights the importance of continuity among the professional carers so the older persons know who is coming and when so they can feel secure. Hörder, Frändin and Larsson (2013) found that older people in community dwelling experienced successful ageing as keeping a fear of frailty at a distance, and suggest the importance of acknowledging this fear. This is further understood as the organization creating unnecessary worry, and worsening older persons already exposed situation, particularly for those who live alone like the participants in this thesis.

The findings **II,IV** disclose that when the older persons chores are time-bounded every single minute is crucial and the professional carers are constantly under hard pressure. In addition the organization does not prioritize social interactions (**IV)**.This is in line with Mallidou et al. (2013) who found that health care nurses spent less time socializing and interacting with residents than many other activities, and suggest re-organizing routines to enable an increase in the time with residents in order to to shape relationships. Lundin et al (2013) studied special housing for older persons and found that professional carers and older persons share an existence and, as an intersubjective world, they are accordingly subjects for each other. They suggest creating time for professional carers being with the old to support their needs and enhance the quality of care. However, the older persons **III** still have to live in uncertainty and professional carers **IV** are frustrated when the organization hinders them realizing new understanding in practice.

7.1.2 Torn between external and internal demands

The findings **II, IV**over time disclose that professional carers are torn between external and internal demands. The professional carers **II** are ambivalent in conflict situations and weigh between the respect for older persons' self-determination and integrity and their own working conditions. It is difficult when professional carers **IV** are torn between the respect for older persons' independence and dependency and the different perspective of the organization, while at the same time acknowledging older persons' changing vulnerability and dependency. Different values might be in conflict such as patients' rights and professional carers working demands (Fry & Johnstone, 2002). This is further understood as different values being at stake, infusing or hindering solutions to conflict situations, and thus it becomes difficult for the professional carers to support older persons to make independent decisions. In line with this Åhlin, Ericson-Lidman, Norberg & Strandberg (2013) found in a study of care providers in residential care of older people that they experienced that different guidelines do not always correspond with each other . This can further be understood why the professional carers (**II, IV)** are torn between external and internal demands, and why conflict of interest arise, and become so difficult to solve, while at the same time trying to respect older persons' right to make independent decisions.

When professional carers **II** face a conflict of values they weigh between what they consider is best in respect for the older persons' right to self-determination and this makes them feel unsure and alone since they do not know how to act. This is further understood as them needing support as to how to act in conflict situations when different values are at stake. According to Snellman (2001) it is important for nursing staff to reflect on their own values, beliefs and wishes and to be critical of their own actions in order to be more tolerant and open to the patient as a unique person. This can further be related to Fry and Johnstone, (2002) who argue that nurses and patients are influenced by personal values, while nurses should not act out of their own. In conflict situations when values are at stake professional guidelines and codes of ethics should provide guidance and the professional carers should consider different values in relation to patients' rights and what they are obligated to. When the professional carers **II** are situated in conflict situations they have difficulties solving it by themselves and they act as they consider is best. They **II, IV** get emotionally troubled and defend own actions, which in turn incites the conflict. This is further understood in relation to older

persons' **I** struggle to defend their right to self-determination, as it becomes complicated for both of them and it is important to avoid conflict situations and to enable professional carers to get support to discuss ethical issues. However, a deeper understanding was revealed over time of how the professional carers **IV,** although being emotionally affected, could regain their own body control and solve conflict situations. Accordingly when they had participated in the educational programme they gained new insight as to how to solve conflict situations and highlight the importance of professional carers' need to discuss ethical issues to improve the care. Fagerberg and Engström (2012) also found that it is important for health care students and professional carers in the care of the old to be supported in their ethical and moral thinking. This highlights the importance of supporting professional carers in municipal home help services, since they seem lack guidance as to how to balance values to solve conflicts or particularly to prevent them to arising in the first place. It has also been found that care givers in the care of the old are facing contradictionary demands, which can lead to burnout (Juthberg, Eriksson, Norberg, & Sundin, 2008).

When considering the findings as a whole **I-IV** it discloses how difficult it is for older persons and professional carers when they have to follow the decisions made for the older person's needs, at the same time as the older persons fluctuate in their independence and dependency from one day to the next. This is further understood as one reason why conflicts of interest arise between professional carers and older persons. The older people have to apply for support and there is a care manager who assesses their needs (Government Offices of Sweden, 2012) accordingly. These decisions made on their needs are not assessed in everyday care. A consideration is that it would be preferably within the municipal home help services, to have Registered nurses, closer involved in the older persons' everyday care. This could improve the care for the old and support professional carers with ethical issues that arise in their everyday work with the old. Fagerberg and Engström (2012) also stress the importance of involving Registered nurses in the care of the old and the need to enhance ethical and moral implications for both professional carers and leaders.

A deeper understanding of professional carers' **II** ambivalence in conflict situations, when they participated in the educational programmee and reflect on ethical issues, discloses that they became less ambivalent. The professional carers **IV** became rather frustrated when the organization hindered them from realizing their new understanding in practice. Similar findings were found in a study with professional carers working in nursing homes. When they were in ethically difficult situations, they experienced frustration and powerlessness when not being supported by the organization (Jakobsen & Sorlie, 2010). However, it was further understood that when they **IV** had an opportunity to reflect on ethical issues they were more confident and determined in conflict situations, although it was hard for them to know if they were doing right, but still realizing that it was in the best interest of the old. Further, when they acknowledge older persons vulnerability and dependency it seems as if they have started to consider guidelines and reflect on them and become aware of a need to be flexible and to go beyond these guidelines in certain situations. The respect for older persons' self-determination becomes not just a norm to follow (Sandman, 2004) but they are also reflective and flexible from one situation and day to another. When they have started to reflect on ethical issues they also have become more attentive to not just focusing on older persons as independent but as interdependent and they support the

older persons in making independent decisions (Verkerk, 2001) as a shared decision-making (Sandman et al., 2012).

7.1.3 Striving for interdependency in caring encounters

When considering the findings **I-IV** they disclose a change over time where older persons and professional carers are striving for interdependency in caring encounters. A deepened understanding has been reached of older persons' **I, III** opportunities to make independent decisions, and of how professional carers **II, IV** help them to become as independent as possible through a relational perspective on autonomy as interdependence. The professional carers **II** were ambivalent when being in conflict situations and uncertain as to how to act and thus to support older persons making independent decisions. When the older persons **I, III** have an encouraging and trustful professional who is flexible and supporting in a mutual understanding it facilitates them participating together with professional carers to make independent decisions. However, a deeper understanding was reached over time of older persons **III** changing vulnerability and dependency and of how important it is for older persons to have a professional carer acknowledging their changing vulnerability and dependence from one day to another and not just focusing on independence.

The findings **IV** disclose over time that professional carers have gained a new insight into how to support older persons to make independent decisions. This is further understood as when professional carers, are present in caring encounters, it enables them to accept the older persons' personalities. Accordingly they acknowledge older persons' dependency, and is understood as they support older persons through a relational autonomy as interdependence (Verkerk, 2001). Paterson and Zderad (1988) points out that presence in nursing encounters cannot be reached if a person relates to another person as an objective. To become present it must to a certain extent involve; openness, receptivity readiness or availability as a mutual experience between nurses and patients. According to Snellman (2001) it is a prerequisite for an authentic encounter between nursing staff and patient's mutuality, acceptance and confirmation to enable respect for a patient's independence and dignity. When the professional carers **II,IV** and older persons **I, III** share decisions the professional carers involve the old in participating in agreements and give alternatives for the old to decide for themselves **I, III.** When the professional carers **IV** are present in the caring encounter they acknowledge how older persons fluctuate between dependence and independence **III**. In shared decision-making two participants have to take part in the decision-making process in a mutual acceptance and agreement (Charles et al., 1997). This is further understood as the older persons **I, III** having an encouraging and trustful professional carer supporting them in a mutual understanding, and it is comforting and facilitates for them to make independent decisions together with the professional carers. It is also comforting for older persons **I, III** when they feel that their body fails to manage their everyday life, to have a trustful professional carer supporting them, to have someone who acknowledges their changing dependency and to be able to hand on the decision to a professional carer or decide with them.

The findings disclose **III** that older persons live in uncertainty every day as to how to relate own independence and dependence with regard to themselves and others, and this makes it complicated for them to comprehend everyday life. A deeper understanding is disclosed as how important it is for older persons to have attention

from one particular professional over a period of time. However, they still live in uncertainty since they never know when this person will arrive. In line with the findings **I, III** Moe et al. (2013) show that older people receiving help from home nursing care experienced that being dependent on help could restrain or promote dignity, depending on professional carers. They also experienced that being regarded as an equal human, when dependent on help, was supported them in managing everyday life. This is further understood as important for older persons to have trustful professional carers that arrive on a regular basis. A deeper understanding of professional carers' **IV** experiences was also reached, of the importance to visit the older persons on a regular basis and of how this enables the creation of trustful and mutual caring encounters with the older persons. To enable the professional carers to be present in caring encounters and to acknowledge older people's changing vulnerability and dependence in their everyday lives takes time. However, the professional carers are under constant time-pressure **II, IV** and the older persons **I, III** are also aware of professional carers' stress. This time-pressured working situation prevents on the one hand professional carers being present and perceptive for older persons' needs and wishes and supporting them to make independent decisions. On the other hand, it prevents older persons expressing their needs and wishes and thus making independent decisions. Accordingly, when every single minute of older persons' chores are time-bounded, it hinders the respect for older persons' right to self- determination and integrity (Social Service Act (SFS, 2001:453).

The findings **IV** disclose that when the professional carers have gained a new insight it is easier to find a balance to their personal commitment and not take on a role **II.** Travelbee (1971) stresses that there is a risk for nurses and patients to categorize and stereotype one another when judging by the first impression. This is understood as when the professional carers take on a role **II** they are not present in the caring encounter. Paterson and Zderad (1988) argue that the meeting between human beings has a mutual purpose through intersubjectivity and has a meaning and both have expectations of each other. When relating they enter a genuine dialogue which is needed for human existence through an intersubjective transaction, in relationship with others' human potential to be viewed as a unique individual. This is further understood in relation to the findings that when professional carers **IV** and older persons **III** are present in caring encounters it enables them in a natural way to be personal to a certain extent and for a mutual respect to emerge. In a review of the literature of the concept of caring presence Covington (2003) worked out a definition: 'Caring presence is a way of being that allows for nurse and patient to connect in a human-to-human experience that promotes healing' (p.313). Accordingly, the holistic nurse needs to form a safe space in the relationship through a caring presence, where the nurses are being there and are attentive and available for the patient's experiences of suffering and illness. This is further understood as when the professional carers **IV** take their time, and let go of other commitments, they are present and this enables them to accept the older persons' personalities and shortcomings. This can be related to Cameron's (2004) suggestion that an ethical moment in health care situations reveals when acknowledging and responding to other vulnerable persons' call for help. Paterson and Zderad (1988) also stresses that nursing involves a call and response responsibility, thus the patient is calling for help and the nurse responds to help this call for help. This is a process that comes about simultaneously in a dialogue between nurses and patients. Older persons in nursing homes experienced that being acknowledged by nurses in encounters was

connected with well-being (Westin & Danielson, 2007). When there is a mutual give and take in the caring encounters and the professional carers **IV** are present, it enables them to acknowledge older person's calls for help and to respond and support them to make independent decisions. This enables also for the older persons **III** to feel free to express their needs and wishes, and thus to make independent decisions, with support from professional carers.

When considering the findings **I-IV** a valuable approach would be a person-centred care in the municipal home help services. This would enhance professional promote ethical issues that arise in the everyday care and enhance professional carers' opportunities to support older persons to make independent decisions. McCormack and McCane (2006) have developed a framework for person-centred nursing involving a process to work with patients' beliefs and values, engagement, sympathetic presence, shared decision-making and taking care of physical needs. To accomplish person-centred practice it is important to have professional carers with professional competence and for them to develop interpersonal skills. In addition they need to be committed to their work, to clarify beliefs and values and to know oneself. However, it is important according to Bullington and Fagerberg (2013) to be critical and to philosophically conceptualize the meaning of concepts, such as person-centred care and holistic care, to put focus on the patient's lifeworld to avoid a reductionist perspective on human beings. In line with this it is understood that when the professional carers **IV** participated in the educational programme they gained new insight into person-centered care and how to support older persons to make independent decisions. When they are present in caring encounters they acknowledge older persons **III** changing vulnerability and dependence from one day to another. Thus they focus on the older person's lifeworld and this enables a relational perspective on autonomy as interdependence (Verkerk, 2001) and shared decision-making (Sandman et al., 2012).

7.2 METHODOLOGICAL CONSIDERATIONS

To enhance trustworthiness methodological considerations have been made throughout the project and need to be discussed further.

7.2.1 Design

7.2.1.1 Lifeworld approach

In order to deepen the understanding and the meaning of older persons' and professional carers' lived experiences over time the same qualitative and lifeworld research approach was chosen and data analyzed with a phenomenological hermeneutic method for all four studies **I-IV** (Lindseth & Norberg, 2004; Ricoeur, 1976). The epistemological and ontological foundation of this project has been defined in order to enhance quality (Walsh & Downe, 2006) and can therefore be considered as a strength. The lifeworld approach is open and flexible to reveal meanings of phenomenon (Dahlberg et al., 2008). The lifeworld is complex with its diversity characteristics often intertwined (Bengtsson, 2005). Therefore it can be considered a strength to follow the meaning of the participants' lived experiences over time, in order to reach a deeper understanding of the complexity of their lifeworld.

7.2.1.2 Study over time

To design a research project over time presupposes careful planning and being prepared for unpredictable occurrences to arise. Further the purpose is to reach a depth and breadth of the participants' life experience and possible changes over time (Saldaña, 2003). Throughout this project there has been careful planning with the persons involved. In addition I have had continuous contact with my co-researchers and when an issue has occurred we have considered it and solved it. However, overall the process has been relatively unproblematic, which may be due to the careful planning, even though not everything can be predicted, and this can be considered as strength with the project.

In order to reach a deepened understanding of the participants' **I-IV** experiences they were followed over time as a care-couple before, during and after the professional carers participated in the educational programme. However, it was apparent during the data collection and data analysis that this would be difficult to achieve. There was some older persons who were hospitalized for short periods and professional carers working conditions prevented them occasionally visiting the old. This made it difficult occasionally for the participants to tell of their common experiences. Therefore, the educational programme was not studied over time per se; the intention was to stimulate and encourage the professional carers to take an active role in the older person's daily care. This could be seen as a weakness, but when following participants over time, there is a risk that older people's health changes as well as the working conditions for the professional carers. However, the interviews were considered rich and several interviews enabled a deeper understanding of the meaning of the participants' experiences over time. Using serial qualitative in-depth interviews to reach changing experiences is considered to be valuable to achieve a deeper understanding of an ongoing relationship between participants and researcher (Murray et al., 2009). To follow and deepen the understanding of the meaning of the participants lived experiences over time repeated interviews were conducted with each participant; once for study **I, II** and three times for study **III, IV**.

7.2.2 Data collection

7.2.2.1 Participants

With the participants recruited as a care-couple the recruitment process required continuous careful planning with the staff managers, both verbal and in writing. The recruitment process was complicated due to that a presumptive carer needed to be recruited first and then an appropriate older person. However, the staff managers were cooperative and made efforts and the recruitment process continued until the educational programme started. There were twelve older persons (**I**) seven still remaining (**III**) and thirteen professional carers (**II**) and seven still remaining **(IV**) and the number of participants could be considered a weakness. However, the number of participants is not crucial in lifeworld research, varied characteristics of the participants being preferred to reach a variation of the phenomenon (Dahlberg et al., 2008). The participants (**I-IV**) had varied experiences and were recruited from two different sized municipalities and accordingly variation was achieved.

7.2.2.2 Interviews

When conducting narrative interviews the purpose is to reach lived experiences. Through narratives we free ourselves from judging that we already know and therefore narrative interviews are useful for disclosing lived experiences (Lindseth & Norberg, 2004). Researching lived experiences has been found to promote ethical discussion and ethical decision in the health care context (Dierckx de Casterle et al., 2011) and narrative interviews with older people to improve practice and service development (Hsu & McCormack, 2011). It is crucial for the interviewer to create a climate so the participants feel comfort to freely tell and express themselves (Lindseth & Norberg, 2004). The fact that I have conducted all interviews (four with each participant) can be assumed as an advantage because I have had the opportunity to meet the participants several times. This in turn may have contributed to the fact that participants felt more secure as the data collection period proceeded and thus be seen as strength. In addition, it can also be seen as strength that I have carried out all the interviews, which has enabled me to develop my interview skills to deepen the interviews. Before each new interview was conducted, with each participant, I listened through previous tape-recorded interview to thereby also deepen the next interview. This made it possible to critically listen and examine myself and thus develop my skills as an interviewer. I conducted and transcribed verbatim all the interviews, which has been time consuming. However, it can be seen as strength, as I have been able to begin the data analysis at the time of the interviews and the following transcription. To transcribe interviews is a way to get closer to the analysis and therefore can be considered as a part of the analysis process (Kvale & Brinkmann, 2009). The interviews were rich narratives of participant lived experiences, and were in total sixty-seven, and therefore considered sufficient and a strength. However, it could be seen as a weakness considering the number of interviews, when using the phenomenological hermeneutic method, since it is a delicate task and time-consuming.

7.2.2.3 Educational programme

The purpose of the educational programme was to increase professional carers' knowledge of how in caring encounters to support older persons to make independent decisions in matters affecting their daily lives. In order to achieve this the meetings focused on the professional carers' own experiences reflected on, related to the study literature. They were asked before meeting three and four to briefly write down an experience with a problematic caring encounter concerning the older person's self-determination. Ekebergh, Lepp, and Dahlberg (2004) found that reflective learning in drama based on student's own experiences is a way to enhance a new understanding to overcome the gap between theory and practice. In the educational programme during the fourth and last meeting the intention was to use the included experiences in role plays. It turned out that none of the participants were interested in the role play and preferred instead to reflect on the experiences, and this could be seen as a weakness. However, the focus with the meetings was to encourage them, not to put pressure on them and therefore it was important to be flexible according to their wishes. The participation during these meetings can be considered high since all participated (except one participant for the first meeting) and follow-up meetings were arranged on a few occasions in order to achieve high participation.

7.2.2.4 Data analysis

The data **I-IV** has been analyzed using a phenomenological hermeneutic method (Ricoeur, 1976; Lindseth & Norberg, 2004) grounded in a lifeworld approach (Dahlberg et al., 2008). It could be discussed whether using the same analysis method grounded in a lifeworld approach could represent a weakness in this thesis. However, Bengtsson (2005) points out that it is an advantage using the same research approach to achieve a common knowledge that can be integrated, and thus provide a cumulative mass of shared knowledge. However, it could also be seen as a weakness to use the same data analysis for all four studies in the thesis. To reveal the participants' lived experiences requires patience to let the text open up to disclose the meaning. The phenomenological hermeneutic steps; naïve reading, structural analysis and comprehensive understanding are not a linear process but a circular one where the three steps highlight one another in a dialectic movement between understanding and explanation (Ricoeur, 1976; Lindseth & Norberg, 2004). It was an on-going process and required several naïve readings and structural analysis **I-IV** until the structural analysis validated the naïve understanding. This meant that I have become familiar with the data and the method and, so to say, have it within me. I have used a phenomenological method **I-IV** and it can therefore be considered a strength that I have had the opportunity to develop and deepen my analytic skills.

In order to understand we use our pre-understanding and revise it when interpreting (Lindseth & Norberg, 2004). However it is suggested that it is important to have a self-awareness of pre-understanding (Drew 2001). I have experience as an enrolled nurse in long term care and as a registered nurse I have cared for many older people within health care in a clinical medicine department. I have no experience as a registered nurse in the care of the old and above all not within municipal home help services. This could be seen as a weakness, although it can also be seen as strength, to not have pre-conceptions, and thus allowing me to be open to the phenomenon. Throughout the data analysis I and my co-researchers have considered our different pre-understandings in order to enhance and reach trustworthy interpretations. Interpretations have different meanings and the findings in this thesis were the most conceivable. However, using qualitative research the aim is not to generalize the findings. When considering the transferability the findings **I-IV** in this present thesis can be transferred to other contexts with older people dependent on help, if the reader refigures the interpretations (Lindseth & Norberg, 2004).

8 CONCLUSION AND IMPLICATION

The findings in this thesis disclose that older persons are vulnerable and dependent, and this is a changing life situation from one day to another. When professional carers have time to listen to the old, it enables them to unite in the caring encounter to fulfil the older persons' needs and wishes through sharing decisions. When the professional carers are just there being present standing next to the old it enables for them to acknowledge their vulnerability and to be perceptive to their dependency. To be present in caring encounters takes time and commitment and enables professional carers to accept older persons as persons. In this way professional carers acknowledge how older persons value their independence and enables them to support older persons through interdependence as a relational perspective on autonomy as a shared-decision making. The conclusion is that a relational perspective on autonomy as a shared-decision making could be valuable in the care of the old to enable for professional carers to support older persons in making independent decisions. The suggestion is that the decisions assessed by care managers concerning older persons' needs and care within municipal home help services is taken too far removed from daily care. The suggestion is that these decisions should come closer in everyday care to make it easier for professional carers to support older persons in caring encounters. It would be preferable to have Registered nurses, more involved in older persons' decisions in every day care. The implication for practice is to change the perspective of the organization towards a person-centred practice to enable professional carers to acknowledge older people's lifeworld and accordingly to focus on the interaction in caring encounters between older people and their professional carers.

The proposal of this project was that older people in need of care are not solely independent but interdependent. This thesis implies that older people gain a more profound influence over the care needed through professional carers' further training. Additionally, the project implies that professional carers got support to seek new solutions in order to gain a mutual understanding and to strengthen the older persons' self-determination. An increasing older population is a worldwide problem. Therefore, this thesis presents knowledge that creates a foundation for further implementation in other groups of older people and their professional carers worldwide.

9 FUTURE RESEARCH

This thesis has created knowledge and understanding that a relational perspective on autonomy as a shared decision- making can improve older persons' opportunities to make independent decisions. The older persons participating in this thesis were considered decision competent. A future research area of interest to further study is the relational perspective on autonomy in care for older people with dementia. This relational perspective could be valuable considering that older people with dementia have reduced decision competence and there are ethical issues concerning their autonomy. Accordingly, it could be useful to improve autonomy for older persons with dementia and for the professional carers to solve ethical issues arising with the older persons.

10 SWEDISH SUMMARY

Vården av äldre i Sverige och världen över utvecklas mot ett ’åldrande på plats’. I Sverige förväntas äldre personer att bo kvar hemma i sina ordinarie bostäder med stöd av kommunal hemtjänst. Denna utveckling har medfört att äldres behov av stöd har ökat likaså de professionella vårdarnas arbetsbelastning. De äldre personernas behov av hjälp bedöms av en biståndshandläggare och forskning visar att de är i en utsatt situation när de ansöker och får inte sina preferenser uppfyllda. Därutöver visar också forskning att professionella vårdare har svårigheter i vården av äldre och deras behov av stöd. Det som föreslås i vården av äldre är att ett relationellt perspektiv av autonomi bör antas för att främja äldres autonomi på grund av deras ökade beroende. Fram tills nu har det varit lite forskning kring äldre personers erfarenheter av autonomi inom kommunal hemtjänst. Denna avhandling ansågs därför viktig för att öka kunskapen och förståelsen för äldre personer och deras professionella vårdare. Det övergripande syftet med denna avhandling var att utveckla kunskap om äldre personers möjligheter att fatta självständiga beslut och att överväga hur professionella vårdare kan hjälpa dem att förbättra sin självständighet. Denna avhandling innefattar fyra studier (**I-IV**) och har en kvalitativ och livsvärlds ansats. För att fördjupa förståelsen av innebörden av äldre personers och professionella vårdares upplevelser följdes de över tid. Intervjuer har genomförts före, under och efter det att professionella vårdarna deltagit i en utbildningsinsats. Data analyserades (**I-IV**) med en fenomenologisk hermeneutisk metod. Syftet med studie **I** var att belysa innebörden av äldre personers beroende av professionella vårdares hjälp och deras möjligheter att fatta självständiga beslut. Resultatet visar att de antingen kämpar för att få fatta självständiga beslut eller resignerar för att inte kunna göra det. Syftet med studie **II** var att belysa innebörden av professionella vårdares erfarenheter av att vara i vårdande situationer när intressekonflikter uppstår med den äldre personen som får vård. Resultatet visar att de är ambivalenta i konfliktsituationer och väger mellan äldres självbestämmande och yttre krav. Syftet med studie **III** var att belysa innebörden av äldre personers självständiga beslutsfattande kring deras dagliga vård. Resultatet visar hur de lever med ovisshet hur de ska förhålla sig till oberoendet och beroendet i relation till sig själv och andra och hur de försöker att förstå sitt dagliga liv. Syftet med studie **IV** var att belysa innebörden av professionella vårdares erfarenheter av att stödja äldre personer att fatta självständiga beslut i vårdande situationer. Resultatet visar att de slits mellan att respektera oberoende och beroende och att det därför är svårt att stödja äldre personer att fatta självständiga beslut. En djupare förståelse nåddes **I-IV** då resultatet övervägdes och visade; väntar på andra för att förstå sitt dagliga liv, att slitas mellan externa och interna krav och strävar för medberoende i vårdande möten. Slutsatsen i avhandlingen är att ett relationellt perspektiv av autonomi som ett delat-beslutsfattande kan vara värdefullt i vården av äldre personer för att möjliggöra för professionella vårdare att stödja äldre personer att fatta självständiga beslut. Implikationen för praktiken är en person-centrerad vård inom vården av äldre för att främja ett relationellt perspektiv på autonomi.

Nyckelord: autonomi, beslutsfattande, etik, fenomenologisk hermeneutik, professionella vårdare, äldre personer, åldrig

11 ACKNOWLEDGEMENTS

I would first of all thank the older persons and the professional carers who participated in the project for sharing your experiences with me.

During this journey there have been many people involved supporting me to make it possible to get through these last years. I would like to thank:

Karolinska Institutet, Department of Neurobiology, Care Sciences and Society (NVS), for giving me the opportunity to pursue my doctoral education.

Mälardalen University, School of Health, Care and Social Welfare (HVV), who made it possible for me to pursue and funded my doctoral education.

I would like to especially thank my main supervisor Professor Ingegerd Fagerberg and my co-supervisor Associate professor Ingrid Snellman. You have always believed in me and have been patient, encouraged me and pushed me to dare to take a step further both in my doctoral education and my personal development. You have always given me quick response and given me constructive criticism. I think that both your profound knowledges complemented each other and enriched me to develop throughout my doctoral education. Thank you for giving me the last courage and strength to finish writing up my thesis.

My external mentor Eva Norin, you have always been there for me when needed, supported, encourage and believed in me.

The doctoral students, Professor Per-Olof Sandman and others participating in seminaries "forskarforum" at KI, NVS, for interesting discussions. I would especially thank doctoral student Anna Swall for encouraging me and supporting me along the way.

The doctoral students in the doctoral meetings initiated by professor Ingegerd Fagerberg at Ersta Sköndal Univeristy.

My colleagues at Mälardalen University, HVV, which in one way or another have supported me. I would like to especially thank Camilla Schmidt Birgersson, Lena Marmstål Hammar, Heléne Appelgren Engström, Pernilla Avelin, Marita Summer Meranius, Cecilia Rydlo, Monica Dahlgren, Katarina Bredenhof Heijkenskjöld, Maria Harder, Karin Weman, Christina Kantola and Lena Jonsson. I would also like to give a special thanks to earlier colleagues Kerstin Dubbelman and Ann-Kristin Aava, Gunnel Gustafsson and Per Ekstrand.

Mälardalen University Library for supporting me and special thanks to Peter Hedberg.

Michael Cole for linguistic revision of studies I-IV and the final thesis. Thank you!

All persons involved in the project in the municipalities for your cooperation.

For financial support to the project: Mälardalen University, School of Health, Care and Social Welfare (HVV), The Swedish Society of Nursing (SSF), Uppsala Hemsyster-skolas fund, The Solstickan foundation and Rune Ljundahls foundation.

My closest friends Pia Lindberg, Maria Sigges and Lena Eliasson for being there for me in both upturns and downturns.

My mother-in-law Barbro Karlsson, for supporting me and sharing your experiences with me.

My brother Peter Breitholtz, my sister Elisabeth Breitholtz Sjölinder (with family) and my brother Magnus Breitholtz (with family). Thank you for always encouraging me, believing in me and supporting me whenever needed.

My dearest parents Ulla and Bo Breitholtz for your unconditional support throughout these years, it would not have been possible without your support. Thank you for always believing in me and giving me the strength to finish this thesis.

Lastly I would like to sincerely thank my dearest family Leif, Elin and Adam for being in my lifeworld. Without your love this would not have been possible. Thanks for giving me the time this summer, to be in our cabin at Yxlan with its beautiful landscape. This gave me the last strength to finish writing up this thesis.

Yxlan, August 2013
Agneta Breitholtz

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