Detection and Assessment of Pain in Dementia Care Practice

Registered nurses’ and certified nursing assistants’ experiences

Christina Karlsson
Psychometricians try to measure it
Experimentalists try to control it
Interviewers ask questions about it
Observers watch it
Participant observers do it
Statisticians count it
Evaluators value it
Qualitative inquirers find meaning in it

-From Halcolm’s *Laws of Inquiry*

To my beloved mother and father
Abstract

The overall aim of this thesis was to explore and describe registered nurses’ and certified nursing assistants’ experiences of detection and assessment of pain in older people with cognitive impairment and dementia. A further aim was to evaluate the Abbey Pain Scale-SWE (APS-SWE) in dementia care practice.

A sequential exploratory design was used. First, qualitative methods using interviews were applied to explore and describe registered nurses’ and certified nursing assistants’ experiences of pain assessment in people living with dementia. Subsequently, quantitative methods using observation, instruments, and questionnaires were applied to evaluate reliability of the APS-SWE in dementia care practice among older people living in special housing accommodation, and face validity for pain assessment by registered nurses and certified nursing assistants.

Eleven registered nurses working in municipal elderly care participated in focus group interviews, 12 certified nursing assistants working in special housing accommodation participated in individual interviews, 13 registered nurses and ten certified nursing assistants working in home healthcare setting participated in individual interviews, and 96 older people living in special housing accommodation and their caregivers of five registered nurses and 70 certified nursing assistants participated in evaluating the APS-SWE in dementia care practice.

Registered nurses in special housing accommodation settings experiences that pain assessment in people with dementia is challenging primarily due to their changed registered nurse role into nurse consultant advisors, which to a great extent is directed into administrative and consultative tasks rather than to clinical bedside care. This has led to decreased time in daily clinical nursing care, preventing recognising symptoms of pain. This has also led to that they are dependent on information from certified nursing assistants who are front-line staffs providing routine care. Certified nursing assistants’ perception of pain in people with dementia emerges from being present in the care situation and alert on physical and behavioural changes in the
person’s usual pattern, and from providing the care in a preventive, protective, and supportive way to prevent painful situations occurring. Registered nurses and certified nursing assistants working in home healthcare team use an array of strategies to detect and assess pain. A trustful work relationship based on staff continuity and a good relation to the person in need of care facilitates pain assessment situations. Systematic observation of older people in special housing accommodation during rest and mobility using the APS-SWE demonstrates that the scale has adequate internal consistency, reliability, and face validity for pain assessment.

This thesis concludes that recognising pain involves a complex interaction of sensory, cognitive, emotional and behavioural components, and that experience-based methods rather than evidence-based pain tools are used. Registered nurses’ and certified nursing assistants’ detections and assessments of pain rely on robust cooperation, staff continuity, and good knowledge of the person cared for. The APS-SWE show adequate internal consistency, reliability, and face validity and can serve as a useful pain tool to assist in detection and assessment of pain in older people who are limited in verbalising pain recognisable. Further evaluation of how the person-centred perspective is applied in pain assessment situations is needed in order to evaluate its positive outcomes in people with dementia. Further psychometric evaluation of the APS-SWE in clinical practice is needed to further strengthen validity and reliability.
Original studies

The thesis is based on the following studies, which are referred to by their Roman numerals in the text:

Study I

Study II

Study III

Study IV

The articles have been reprinted with the kind permission of the respective journals.
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Acknowledgement

During the five years of my PhD education and writing this thesis there are a number of people who have supported me in various ways, all contributing to this thesis being written. Being a doctoral student has been a pleasure throughout and I am filled with gratitude to all who have supported me. I would like to express my sincere thanks to Skövde municipal and Skövde University who financially supported my research education and, Jönköping University for being supportive throughout the education.

My special thanks go to those registered nurses and certified nursing assistants who participated in my research. Your willingness and engagement in sharing your experiences from dementia practice made this thesis possible.

Older participants, to whom this thesis really belongs, I sincerely hope that findings from the thesis will contribute to your well-being.

Managers-in-Chief, enduring correspondence and being helpful in the research process: my sincere gratitude for your collaboration.

Professor emerita Birgitta Sidenvall, you were my main supervisor during the first year. You will always be a dear friend of mine.

PhD Marie Ernsth Bravell, my co-supervisor: always supporting me with good advices. Our shared engagement in municipal elderly care motivated us.

Professor Ingrid Bergh, my main supervisor the last three years and with never-ending energy: my warmest appreciation for the sharing of wild ideas and thoughts during those three years.
PhD Kristina Ek, you entered as my co-supervisor in year three. Your wisdom and circumspectness were valuable components and encouraged me to think twice about my text. Skaraborgsinstitutet financially supported my research and contributed to academic dialogue. I offer my gratitude for your support.

Agneta Prytz and Gösta Folke Prytz Stipendiefond financially supported my third study. Thank you for the fantastic lunch and stimulating conversation.

Research colleagues, past and present, at Skövde University and Jönköping University: we had some good discussions. Thank you all for that. A special thanks to Linda Johansson for giving constructive criticism and commenting on the manuscript of study IV.

Friends and other believers: I am grateful for all your hows and whys. They’ve helped me to explain my research in everyday language and stimulated to further reflections of the research.

Leo Bjaaland, who discovered my research interest in elderly care: my warmest gratitude for your support.

Mother and father: you were so proud of my progress. This thesis is dedicated to you.

Jönköping, October 2015,
Christina Karlsson
Abbreviations

APS-SWE  Abbey Pain Scale-SWE
APS-SWEQ  Abbey Pain Scale questionnaire
CNA  Certified nursing assistant
DN  District nurse
EBP  Evidence-based practice
RN  Registered nurse

Termed used in this thesis

Certified nursing assistant  Non-registered nurse with upper secondary school including training in health care
Consultant  Integrated registered nurse role and function in municipal elderly care
Dementia  A syndrome characterised by progressive decline in cortical functions
District nurse  Registered nurse with academic graduation comprising of a three-year university programme, leading to a Bachelor's degree and one year of supplementary education as district nurse i.e. Primary Health Care - Specialist Nursing Programme
Evidence-based practice  Nursing care contributions based on conscious and systematic use of multiple knowledge sources for decision about care contributions involving best available knowledge, professional expertise and the person's situation, experience and wish of interventions
Home healthcare  Care provided in individuals’ ordinary housing, performed by registered nurses, certified nursing assistants and nursing assistants employed in the municipality
Nursing assistant  Non-registered nurse
Pain  A subjective multidimensional experience, unpleasant sensory and emotional sensation associated with actual or potential tissue damage or related to distress which may involve fear, anxiety and hallucinations that can be communicated to others when possible through reporting or through a number of pain-related signs
<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
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<tr>
<td>Person-centred care</td>
<td>A contemporary best practice perspective of care that can meet the multi-dimensional needs and preferences of people dependent on care by acknowledging, respecting and including each person’s life story, personality, capacity, and perspective of care</td>
</tr>
<tr>
<td>Registered nurse</td>
<td>Licensed nurse with academic graduation, comprising a three-year university programme leading to a Bachelor’s degree</td>
</tr>
<tr>
<td>Special housing accommodation</td>
<td>Small-scale homelike permanently accommodation for older people in need of special support</td>
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Introduction

One day a certified nurse assistant colleague of mine expressed her concern for one of the persons living in the accommodation and whom she cared for. This person had all of a sudden begun to show strange behaviour. The care staff were concerned about the person’s behaviour and reflected on whether pain was involved. The colleague tried to explain the behaviour by saying:

'We did not see any pattern in the behaviour because it differed so much. Sometimes the person was hitting in the table. Then the person switched to clapping her cheeks, and then returned to hitting the table. The first thing that strikes me when a person starts to behave like this is that the person must be bothered for some reason. We all remained puzzled and the person could not express herself verbally'.

Caring for people living with dementia can involve complex situations that may be challenging to manage by care staff. Investigating whether pain is involved when a challenging behaviour is displayed and verbally expressing is limited can be difficult. In 2010, national guidelines for care of people with dementia were developed as a framework to support care givers’ decision making and quality of care (National Board of Health and Welfare, 2011a). The guidelines take a departure from the dignity perspective in the care and preventive care contributions, analysis and diagnostics, person-centred care, multi-professional teamwork and staff training, medical treatments and behavioural psychiatric symptoms of disruption (BPSD). However, the guidelines do not specifically describe how to manage and assess complex pain assessment situations. This thesis is about detection and assessment of pain in people living with cognitive impairment and dementia, taking the perspective from experiences of registered nurses (RN) and certified nursing assistants (CNA) in municipal dementia care practice. The thesis is focused on experiences of RNs’ and CNAs’ pain assessments in order to explore how they manage pain assessment situations in regular care. In the thesis, the terms of RN and CNA are used and sometimes the term nursing staffs is used when both occupation groups are involved. The term nursing assistant (NA) is used in those cases when formal CNA training is omitted. The terms person, resident, and care recipient are used synonymously when older participants in the thesis are described.
Background

Pain

The concept of pain varies in definition. A widely used definition is ‘an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage’ (International Association for Study of Pain (IASP) (1986). A further frequent used definition is ‘pain is whatever the person say it is, and always exists when the person says it does’ (McCaffery, 1979, p. 14). The definitions are often used in clinical practice and emphasise the verbal expression of pain and guides healthcare professionals in their assessments. However, these definitions may be less applicable among people with cognitive impairment and dementia who has difficulty in verbally and adequately describing pain.

Pain can be expressed and manifested in various ways and thus has a complex connection to ill-health and suffering (Cipher, Clifford, & Roper, 2006; Husebo, Strand, Moe-Nilssen, Husebo, & Ljunggren, 2009). Each one individual who experiences pain has one’s own unique perception of pain, manifestation and coping strategy (Benyon, Muller, Hill, & Mallen, 2013; Büssing, Ostermann, Neugebauer, & Heusser, 2010). Kaasalainen (2007) have defined pain taking into account the non-verbal individual or the individual with limited ability to verbalise pain by defining pain as an uncomfortable, subjective experience that can be communicated to others when possible through report or by a number of pain-related signs. This external rating of pain symptoms is influenced by rater-specific factors, interpreted and assessed, as pain assessment (Snow, O’Malley, Cody, Kunik, Ashton, Beck, Bruera, & Novy, 2004).

Pain can be classified in several ways. A common classification of pain is based on intensity, i.e. mild, moderate and severe pain. A further classification is based on the time perspectives, i.e. acute and chronic (long-term) pain (Andersson, 2010). Acute pain emerges immediately, is temporary and disappears when the tissue damage has healed. However, untreated acute pain can develop into chronic pain. Chronic pain is a serious
condition, remaining three to six months after expected healing (a.a). Chronic pain is complex and can develop from different causes where the pain system becomes oversensitive and reacts abnormally (IASP, 1986). One suggested possible mechanism for the condition of chronic pain is a substantial and repetitive nociceptive inflow that may give a permanent effect on the nociceptive function of the spinal marrow and, that leads to chronic sensitisation of the remaining nociceptive system (Andersson, 2010).

Pain in older people

The older population has the highest rates of surgery, hospitalisation, injury and disease and are thus at an increased risk of pain (Gibson & Lussier, 2012). Studies have demonstrated that older people have a higher propensity to experience pain associated with chronic health problems, such as musculoskeletal conditions and peripheral vascular diseases (Epperson & Bonnel, 2004; Helme & Gibson, 2001). Various pain problems in older people relate to the aged body such as musculoskeletal pain while others correlate with specific diseases such as osteoporosis, arthritis, cancer and neuropathic pain as for example after a stroke or in herpes zoster (Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006; Gibson, 2006). Furthermore, post-operative pain is frequent in older people due to prolonged recovery times to restore to health after surgery (Aubrun & Marmion, 2007). Old people’s experience of pain differs from that of younger people in that pain is more frequent due to multimorbidity and often predominately chronic in nature in older people (Gibson & Lussier, 2012).

In a large-scale study on pain prevalence, it was found that pain among older people living in nursing homes ranged between 45% to 80%, depending on the patients’ specific characteristics and which measurement instruments were used (Achterberg, Gambassi, Finne-Soveri, Liperoti, Noro, Frijters et al., 2010). In this study, 44% to 60% of the total sample was diagnosed for dementia. In a four-country Nordic study it was found that high pain prevalence in long-term care facilities was similar across the countries (Finne-Soveri, Ljunggren, Schroll, Jonsson, Hjaltadottir, El K holy et al., 2000). In more than 50% of the cases pain was reported as moderate to severe. In a European study, prevalence of daily pain among older people
receiving home care ranged from 47% to 74% (Onder, Landi, Gambassi, Liperoti, Soldato, Catanatti et al., 2005).

Dementia

Dementia is a syndrome and a comprehensive term for a number of illnesses, characterised by a progressive decline in cortical functions which diminishes several functions such as memory, orientation, thinking orientation, comprehension, calculation, language and judgement (World Health Organization, 2011). In 2013, about 35 million people were estimated to be living with dementia worldwide (Alzheimer’s Disease International, 2013) with an incidence of 7.7 million new cases of early onset and of which 42% live in high-income countries (World Health Organization and Alzheimer’s Disease International, 2012). In Sweden, about 160 000 people are estimated to be living with dementia and with an incidence of about 25 000 people yearly (National Board of Health and Welfare, 2014a). Dementia is stated as a global public health challenge, with an increased demand for professional healthcare and service as well as support from relatives (World Alzheimer’s Report, 2014). International classification criteria for dementia are described in the ICD-10 Classification of Mental and Behavioural Disorders, and where the onset and progression of dementia is explained in three stages: early stage, middle stage, and late stage (World Health Organization, 2011). Dementia describes brain disorders that progressively lead to brain damage and the deterioration of an individual’s function capacity, social relations, and affecting personality as well as emotional functions (Marcusson, Blennow, Skog, & Wallin, 2011).

Across the years, definitions of dementia have varied mainly due to the complexity of diagnosing. Currently, the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) is the widely used comprehensive classification and diagnostic tool that serves as a universal authority for psychiatric diagnosis, emphasising the global disorder of intellectual functions based on minor to major neurocognitive disorder along with the individual’s ability in social relations, working and quality of life (American Psychiatric Association, 2013; 2015). A further instrument used for the measurement of cognitive status is the Mini Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975; Folstein, Folstein, &
The current Swedish version of the MMSE manual (MMSE-SR) has been developed into a more user-friendly and comprehensible protocol, including extended space for qualitative observations (Palmqvist, Terzis, Strobel, & Wallin, 2012). In Sweden, clinical examination and diagnosing of dementia is established by physicians within primary healthcare and at memory clinics. Although prevalence may be difficult to establish due to uniqueness and complexity of dementia symptoms, the most frequent subtypes of dementia are Alzheimer’s disease, vascular dementias and mixed forms of Alzheimer’s disease and vascular dementia (World Health Organization, 2011). Dementia is by far the most important contributor among chronic diseases, to disability, dependence, and, in high income countries, transition into residential and nursing home care (Alzheimer’s Disease International, 2013).

The impact of dementia on the pain expression

Compared to neurophysiological changes in normal aging, where age-associated peripheral and the central nervous system (CNS) changes already are observable, people suffering from dementia diseases demonstrates disorders or impairments of sensory functions challenging registration, interpretation and decision-making of pain as well as memory disorders affecting perception of pain (Cole, Farell, Gibson, & Egan, 2010; Gagliese & Melzack, 2005). Pain and dementia is a complex combination, taking into account the different subtypes of dementias, affecting the brain in different ways (Scherder, Herr, Pickering, Gibson, Benedetti, & Lautenbacher, 2009). Somes and Donatelli (2013) emphasises that older people with dementia are prone to infections, fractures, pressure ulcers, constipation and other painful conditions, yet they may have difficulties in adequately communicating about their pain. Although the pain experience may be intact, the individual’s interpretation of pain, along with memory impairments, makes the assessment process more difficult. It is thought that people living with dementia may perceive painful stimulus normally but the ability to remember, interpret and respond to pain is altered (Benedetti, Arduino, Vighetti, Asteggiiano, Tarenzi, & Rainero, 2004). It has been found that patients with severe dementia do not experience less pain intensity, numbers of pain diagnosis or pain locations compared to other stages of dementia (Husebo, Strand, Moe-Nilsson, Borge-Husebo, Aarsland & Ljunggren,
In other studies, dementia has been suggested to affect different pain components in different ways (Kunz, Mylius, Scharmann, Schepelmann, & Lautenbacher, 2009; Scherder, Sergeant, & Swaab, 2003; Scherder, Oosterman, Swaab, Herr, Ooms, Ribbe et al., 2005). Instead, pain and discomfort may be manifested through behavioural displays such as agitation, combativeness, verbal aggression, disruptive behaviour, wandering and social withdrawal (Closs, Cash, Barr, & Briggs, 2005). It is suggested that the impact of dementia on pain processing varies in direction and quality, depending on the type of pain, neuropathology and stage of dementia (Scherder et al., 2009). Experimental pain studies on dementia have investigated whether pain perception could be caused by altered pain processing related to neurodegenerative changes (Cole, Farrell, Duff, Barber, Egan, & Gibson, 2006). It has been demonstrating that different subtypes of dementias show specific changes along the pain pathway, affecting the different areas of the pain systems and determining the pattern of changes in pain processing (Carlino, Benedetti, Rainero, Asteggiano, Cappa, Tarenzi et al., 2010). However, evidence for alterations in pain perception and the influence of dementia on pain remains somewhat uncertain, where findings show decreasing, un-changing as well as increasing pain process (Benedetti et al., 2004; Cole et al., 2006; Kunz et al., 2009).

**Behavioural and psychological symptoms of dementia**

Dementia is frequently accompanied by distressing behavioural and psychological symptoms such as agitation, aggression, hallucinations, out-activating actions or similar challenging behaviour (Kverno, Rabins, Blass, Hicks, & Black, 2008). Such symptoms are overall defined in terms of Behavioural and Psychological Symptoms of Dementia (BPSD) (Lyketsos, 2007; Pieper, van Dalen-Kok, Francke, van der Steen, Scherder, Husebo, & Achterberg, 2013). It has been suggested that up to 90% of people with Alzheimer’s disease may present at least one BPSD during the course of the disease (Liperoti, Pedone, & Corsonello, 2008). Associations between pain and neuropsychiatric symptoms in people with dementia have been found (Ahn & Horgas, 2013; Cipher et al., 2006; Flo, Gulla & Husebo, 2014; Husebo, Ballard, Sandvik, Nilsen, Bjarte, & Aarsland, 2011; Norton, Allen, Snow, Hardin, & Burgio, 2010; Tosato, Lukas, van der Roest, Danese, Antocicco, Finne-Soveri et al., 2012). Thus, it is suggested that it is
imperative to investigate BPSD symptoms when they may be due to pain (Husebo, Ballard, & Aarsland, 2011; Ahn, Garvan, & Lyon, 2015). Research has found that a significant number of the aged care population living in nursing homes are estimated to demonstrate psychiatric symptoms (Seitz, Purandaree, & Conn, 2010). BPSD symptoms may be challenging to understand and it is suggested consideration be given to multi-factorial elements connected to setting, existence, physical illness and pharmaceutical products (Marcusson et al, 2011). BPSD symptoms are of particular concern to investigate as the failure to adequately care for people with such symptoms is associated with serious adverse outcomes including increased falls and injury (Davison, Hudgson, McCabe, & Buchanan, 2007; Eriksson, Gustafsson, & Lundin-Olsson, 2007).

**Pain assessment in people with dementia**

Pain recognition and assessment is the first step towards effective pain management (Cunningham, McClean, & Kelly, 2010; Hadjistavropoulos, Herr, Turk, Fine, Dworkin, Helme et al., 2007; Herr, Coyne, McCaffery, Manworren, & Merkel, 2011). Assessment of pain is a broad and comprehensive undertaking, which encompasses the measurement of the interplay of different factors in pain experience as affective, cognitive and intensity of pain (Lautenbacher, Kunz, Mylius, Scharmann, Hemmeter, & Schepelmann, 2007; Pasero & McCaffery, 2011). However, research has reported nurses’ uncertainty about pain in nursing home residents with dementia (Gilmore-Bykovskyi & Bowers, 2013).

Across the years, a variety of pain assessment scales have been developed to assist in pain assessment procedures. In general, pain assessment scales can be categorised into self-rating scales and observer-rated scales of behavioural pain indicators (Hadjistavropoulos et al., 2007; Lukas, Niederrecker, Günther, Mayer, & Nikolaus, 2013a). Numeric rating scales for self-reporting such as the Visual Analogical Scale (VAS) and the Numeric Rating Scale (NRS) are commonly used in healthcare settings in people who are able to understand and verbally describe their pain (Hadjistavropoulos, Dever Fitzgerald, & Marchildon, 2010; Herr et al., 2011). The construction of the VAS, a 10 cm line with the extremes no pain (0) to worst possible pain (10), and the NRS, a line marked with numbers 0-
10 at equal intervals, where 0 is no pain and 10 is worst pain imaginable, is one-dimensional, asking the person undertaking assessment of pain to mark pain intensity. However, intensity is not the only factor important in the experience of pain. Pain is conceptualised as a multidimensional sensation and is also associated with psychological and emotional effects such as fear, anxiety and depression (Gagliese & Melzack, 2005). Thus, one-dimensional instruments may be inappropriate among people who have difficulties in verbally describing the pain sensation recognisable using self-rating scales (Lukas, et al., 2013a; Lukas, Barber, Johnson, & Gibson, 2013b). Assessment procedures in older people need to be rooted in a biopsychosocial understanding of pain that takes into account that the pain experience is based on multiple dimensions (Gibson & Lussier, 2012).

Although validated pain assessment tools exist, pain assessment in older people who are unable to self-report pain is often done by interdisciplinary evaluation, which largely relies on the subjective impression of involved healthcare staff (Cohen-Mansfield & Creedon, 2002; Dobbs, Baker, Carrion, Vongxaiburana, & Hyer, 2014; Yi-Heng, Li-Chan, & Watson, 2010). Guidelines for assessment and measurement of pain in people with cognitive impairment and dementia have been developed as a support to perform structured and systematic pain assessments (Cunningham et al., 2010; Hadjistavropoulos et al., 2010; Herr, Bursch, Ersek, Miller, & Swafford, 2010; Herr et al., 2011; Shega, Emanuel, Vargish, Levine, Bursch, Herr et al, 2007). However, there is no gold standard considered as the most appropriate pain assessment tool comprehensive to the progression of cognitive impairment (Hadjistavropoulos et al., 2010; Herr et al., 2011; Lints-Martindale, Hadjistavropoulos, Lix, & Thorpe, 2012). Thus, an individual approach to assessment, whereby pain is assessed on a regular basis and fluctuation from the person’s normal pattern of scores is recorded is suggested (Herr et al., 2010; Herr et al., 2011).

Pain assessment in people with cognitive impairment and dementia is foremost discussed in relation to diminished language skills with the course of the dementia, systematic assessment, and the use of assessment tools that are psychometrically sound and clinically usable (Hadjistavropoulos et al., 2010; Helme, 2006; Herr, Bjoro, & Decker, 2006; Zwakhalen, Hamers, & Berger, 2006a; Zwakhalen, Hamers, Abu-Saad, & Berger, 2006b;
Zwakhalen, van’t Hof, & Hamers, 2012). Despite that several pain scales for this population have been developed they have to a limited extent been thoroughly clinically tested and evaluated (Herr et al., 2011; McAuliffe, Nay, O’Donnell, & Fetherstonhaugh, 2009; While & Jocelyn, 2009). It is suggested that people in the stages of mild to moderate dementia may still be able to use words to express pain intensity and to use visual descriptor scales fairly reliably (Lukas et al., 2013a). They may also be capable of pinpointing the severity of pain with pain scales (Hadjistavropoulos et al., 2010). In studies evaluating self-rating scales and their correlation with observational rating scales, it was found that self-rating scales could be used reliably in the vast majority of people with mild to moderate dementia (Pautex, Hermann, Le Lous, Fajban, Michel, & Gold, 2005; Pautex, Michon, Guedira, Emond, Le Lous, Samaras et al., 2006). Findings from these studies suggest observational scales to be reserved for only those people who lack the ability to complete self-assessment. However, a recent study among community-dwelling individuals with mild to moderate dementia expressed the criticalness of directly asking about pain as self-reporting may involve psychosocial indicators other than pain (Breland, Barrera, Snow, Sansgiry, Stanley, Wilson et al., 2014). It is described that the key task is to identify the most appropriate pain assessment tool for the individual person to make sure that no pain goes undetected, and at what point the tool serves at the best as the cognitive impairment condition progresses (Apinis, Tousignant, Arcand, & Tousignant-Lafamme, 2014; Lukas et al., 2013a).

In summary, self-report can be an adequate and reliable method for classification of pain that should be attempted in all people who are about to have pain assessed, and that may be appropriate in people with mild to moderate dementia (Hadjistavropoulos et al., 2007; Lukas et al., 2013a). When self-report is not possible, a multidimensional understanding and approach to assessment need to be considered (Herr et al., 2011).

There are fundamental clinical implications around pain management strategies that have potentials of impacting and improving patient outcomes. Shega et al. (2007) suggests that a comprehensive assessment serves for the following purposes; to identify physiological aetiology that contribute to the experience of pain, to make judgements of the severity of pain and its impact on quality of life, to develop interventions tailoring the individuals’ unique
prerequisites, and to evaluate response to treatment. Herr et al. (2011) suggest a hierarchy of pain assessment techniques to identify and assess symptoms of pain involving self-report when possible, the search for potential causes of pain, observation of behaviour, proxy-reporting by CNAs and family members, and selection of appropriate analgesics. Lukas et al. (2013a) suggest some practical recommendations for pain assessment based on a well selected toolkit or a mixture of self- and proxy report, and pain assessment tools enabling the most reliable selection of the instrument considered most appropriate for the individual person. Wall and White (2012) have presented how a training module of clinical best practice on pain assessment in dementia was developed by taking account of multidisciplinary and collaborative teamwork, open communication, person-centred care, staff information, and training. In addition, it is suggested that social withdrawal or depression symptoms are important to assess as possible indications of underlying pain (McCabe, Davison, Mellor, George, Moore, & Ski, 2006; Onder et al., 2005). There is a risk that such symptoms may be assessed inaccurately due to the course of dementia progressing rather than to an indication of pain (Kunz et al., 2009; Scherder et al., 2003; Somes & Donatelli, 2013).

Observational behaviour pain assessment scales

In recent years, research on pain assessment in people with dementia has received expanded attention in observational behaviour pain assessment scales and to their refinement (Corbett, Husebo, Malcangio, Staniland, Cohen-Mansfield, Aarsland, & Ballard, 2012; Herr et al., 2010; Herr et al., 2011; Lints-Martindale et al., 2012; Monazelli, Vasile, Odetti, & Traverso, 2013; Zwakhalen et al., 2006a; Zwakhalen et al., 2012). Observation of behaviour is suggested to be a valid approach to pain assessment (Herr et al., 2011). Observer-rated scales of behavioural pain indicators focus upon non-verbal behaviour and constitute a substitute for self-reporting (While & Jocelyn, 2009). Most observational scales comprise a multidimensional construct of physical, psychological and social aspects of pain sensory. This type of scales uses ratings of presence/absence, intensity and frequency of certain types of behaviours, and where combinations of behaviours provide a sum score that is usually interpreted as an index of likely pain (Herr et al., 2010). The design and resulting observational pain scales have been
summarised in several reviews and empirical instrument assessments (Abbey, Piller, Bellis, Esterman, Parker, Giles, & Lowcay, 2004; Herr et al., 2010; Corbett et al., 2012; Zwakhalen et al., 2006a; Zwakhalen et al., 2012). Systematic literature-based studies of existing methods for pain assessment in people with dementia have compared and reported on up to 24 observational pain scales (Aubin, Giguere, Hadjistavropoulos, & Verreault, 2007; Herr et al., 2010; Zwakhalen et al., 2006b).

Observer-rated scales are foremost critically discussed in terms of their validity, having important implications for pain therapy and decisions around pain treatment (Herr et al., 2010; Pautex et al., 2005; Sheu, Versloot, Nader, Kerr, & Craig, 2011; Yi-Heng et al., 2010; Zwakhalen et al., 2012). Validity of observational behaviour pain assessment scales has been established by correlation between the person’s self-report, if possible, and nurse raters’ scores from observational pain scales (Lukas et al., 2013a; Takai, Yamamoto-Mitani, Okamoto, Koyama, & Honda, 2010a; Takai, Yamamoto-Mitani, Ko, & Heilemann, 2014; Zwakhalen et al., 2006a), or by comparing different observational pain scales for the same measurement (Akbarzadeh & Jakobsson, 2007; Liu, Briggs, & Closs, 2010: Lukas et al., 2013b), or by adding an additional yes/no question to the nurse raters’ scoring based on their clinical judgement to assess pain (Neville & Ostini, 2014).

Among those observational pain scales that have been most frequently tested and evaluated in clinical practice with consistently positive assessments, studies have provided evidence for psychometric quality and clinical utility of Pain Assessment in Advanced Dementia (PAINAD) (Warden, Hurley, & Volicer, 2003), Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC) (Fuchs-Lacelle & Hadjistavropoulos, 2004), DOLOPLUS-2 (Wary & Doloplus, 1999), and the Abbey Pain Scale (Abbey et al., 2004). However, evaluation of observational behaviour pain assessment scales in Swedish dementia practice is sparse.

The original Abbey Pain Scale was endorsed by the Australian Pain Society and was deemed to be one of the three pain scales with the strongest support in a systematic comparison of 24 pain assessment instruments to use for elderly people with dementia (Aubin et al., 2007). The Abbey Pain Scale is a
short and easy-to-use scale for detection of pain symptoms (Abbey et al., 2004) and has been evaluated in several countries such as in Australia, Japan, Germany, the Netherlands, and Hong Kong, demonstrating satisfactory psychometric qualities and utility in clinical practice (Abbey et al., 2004; Takai et al., 2010b; Takai et al., 2014; Lukas et al., 2013b; Neville & Ostini, 2014; Zwakhalen et al., 2006a; Liu et al., 2010).

Swedish policy guidelines have been adapted to the international recommendations of using observational behavioural pain assessment scales to assess symptoms of pain in people with diminished capacity to verbally express their pain (National Board of Health and Welfare, 2011a). As a result, a Swedish version of the Abbey Pain Scale (Appendix 2) was implemented in two Swedish registries; the Palliative Registry (initiated in 2006) and the Behavioural and Mental Symptoms in Dementia (BPSD) Registry (initiated in 2010). The Palliative Registry is based on using a questionnaire to register how the deceased individual’s needs of care are followed up during the last period of life, such as pain relief. The BPSD Registry focuses on gathering information on psychological and behavioural symptoms in people with dementia, such as aggressiveness, sleep disruptions or hallucinations, with the aim to support and improve patient analyses and individual activity plans. However, this version of the Abbey Pain Scale lacks a scientific method for language translation and has not been evaluated in clinical practice.

Municipal elderly care in Sweden

In Sweden, people aged 65 and older comprise about 20% of the Swedish population (SCB, 2013). About 89,000 people (4.8%) aged 65 years and older are living permanently in nursing homes and special housing accommodation for people with dementia. About 220,000 people (12%) are receiving home care assistance and home health care interventions based on their social and medical needs (National Board of Health and Welfare, 2013a). Nursing homes, special housing accommodation, home care assistance, and home healthcare are different care forms but are all included in the Swedish municipalities’ healthcare service. The care can be organised in different ways in the municipalities (Andersson & Karlberg, 2000; National Board of Health and Welfare, 2014b; Trydegård & Thorslund, 2014).
One common feature is that every municipality is obliged to appoint a Community Chief Nurse, whose function is to assure that clinical guidelines are available to secure patient safety (SOSFS 1997:10). In the organisation of municipal elderly care in Sweden, RNs, CNAs and NAs are integrated in a joint environment, where RNs are expected to collaborate and supervise CNAs and NAs, who are the front-line staff providing the routine care and advanced nursing care on the delegation of RNs (Bystedt, Eriksson, & Wilde-Larsson, 2011; Josefsson, Sonde, Winblad, & Robins Wahlin, 2007; Norell, Ziegel, & Kihlgren, 2013; SOSFS, 1997:14).

Over the past two decades, Sweden, alongside many other countries, has seen a transition in the municipal RN role shifting into a consultative way of working in relation to CNA and NA, where the RNs’ role have shifted from providing bedside care to the direction of increased involvement in administration, documentation and coordinating duties (Boström, Nilsson Kajemo, Nordström, & Wahlin, 2008; Norell et al., 2013; Westlund & Larsson, 2002). The RN consultant function includes clinical, strategic, educational and evaluative functions (Fontaine, 2007). In Sweden, the construct of the nurse consultant role was developed from the implementation of Ädelreformen in 1992 (National Board of Health and Welfare, 1996). As an outcome of Ädelreformen, the municipal responsibility is demarcated to the care that is given within special housing accommodation in service and care and to people who participate in day activities regulated in the Social Services Act (Andersson & Karlberg, 2000; SFS, 2001). The application, however, of RN consultant role in the Swedish municipalities is somewhat varying, where the municipalities have adapted in different ways.

The consultative way of working affects RNs’ choice of interventions, in that they are dependent on the judgement of CNAs and because of organisational reasons (Juthberg & Sundin, 2010). The consultative way of working means that RNs are not regularly present, unless they have been called in by CNAs and NAs when a person is in need of RN consultation (Nilsson, Lundgren, & Furåker, 2009). Although this new organisation of RN consultant role has been implemented in several municipalities in Sweden, evaluation of its effect on the care is lacking. In the organisation of home care assistance and home healthcare, RNs, district nurses (DNs),
CNAs and NAs are supposed to work in teams (National Board of Health and Welfare, 2011a). Nevertheless, care activities conducted by RNs in Swedish municipal home care organisation yet involve the consultative character.

**Dementia care practice context**

People with dementia have special needs for care involving more personal care, more hours of care, and more supervision, all of which is associated with greater caregiver strain, and higher costs of care (Alzheimer’s Disease International, 2013). Cognitive and functional impairment often coexist with additional neuropsychiatric symptoms such as aggression, agitation and depression (Buettner, Fitzsimmons, & Dudley, 2010; van Dalen-Krok, Pieper, de Waal, Lukas, Husebo, & Achterberg, 2015). As in several other European countries, Swedish nursing homes have developed from traditional institutions into small-scale homelike accommodations i.e. special housing accommodation, with the goal of providing the care based on a person-centred philosophy (Edvardsson, Sandman, & Borell, 2014; National Board of Health and Welfare, 2011a; Verbeek, Zwakhalen, van Rossum, Ambergen, Kempen, & Hamers, 2010). In Sweden, dementia care is organised as a specialised form of care, emphasising the person-centred perspective provided on the basis of multi-professional teamwork, enabling the person in need of care to live a safe and meaningful life based on his/her own circumstances (National Board of Health and Welfare, 2011a; SOSFS, 2013). In this thesis, dementia care practice context includes special housing accommodation for permanent living, where the care is provided round-the-clock, and home healthcare settings where people live in ordinary housing i.e. their own homes, receiving care contributions by RNs, DNs, CNAs, and NA.

**Person-centred care**

Care of people living with dementia deals with confirmation of identity and integrity of the unique person, recognising seeing the person behind the disease (Kitwood, 1997). Person-centred care takes the departure from a set of values that have implications for the provision of care (Brooker, 2004). In Sweden, as in several other countries, the traditional institutional model of

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care has been replaced by one that accepts person-centred care as the guiding standard on practice (Crandall, White, Schuldheis, & Talerico, 2007; Doty, Koren, & Sturla, 2007; National Board of Health and Welfare, 2011a). Originally, the concept of client-centred care was developed by Carl Rogers (1961) in a psychotherapy setting based on acceptance, caring, empathy, sensitivity, active listening, and promoting optimal human growth. Later on, the concept of client-centred care was replaced by person-centred care, outlining a theoretical foundation comprehensive to dementia care by incorporating the concept of personhood and person-centredness (Kitwood & Bredin, 1992; Kitwood, 1995). Personhood emphasises the person’s life experiences, based on a psychosocial approach focusing on communication and relationship (Kitwood, 1997). Person-centredness emphasises the encounter between the care provider and the person in need of care, acknowledging relationship-centred care to improve the life experience and wellbeing of the person (Kitwood, 1997). Providing person-centred care to people with dementia has its meaning in close relationships with the emphasis on well-being and quality of life as defined by the individual (Brooker, 2004). Finding successful ways to communicate with the person is thus a key component in person-centred care. In order to provide person-centred interventions high-quality training for care staff is essential (Fossey, Masson, Stafford, Lawrence, Corbett, & Ballard, 2014).

In recent times, the concept of person-centred care has witnessed a renaissance, outlining a social, humanistic, and holistic perspective on how to understand and promote the care based on promoting person-centredness as a fundamental respect of subjectivity and personhood (Edvardsson, Sandman, & Borell, 2014; McCormack & McCance, 2010). Person-centred care is conceptualised as a central principle in the national guidelines for care and support in people living with dementia, i.e. encountering the person as an individual with experiences, self-esteem and rights despite impaired functions, confirming the person’s experience of the world, acknowledging person participation, and establishing a trustful relationship by collecting information of the person’s history, life pattern and preferences to better match the care (National Board of Health and Welfare, 2011a). Person-centred care is also emphasised in government policy, relating to the provision of health and social care services to people with dementia (Swedish Government, 2014). Therefore, in this thesis, pain assessment in
people living with cognitive impairment and dementia is discussed through the perspective of person-centred care.
Rationale for the thesis

Pain in people with dementia has drawn great attention in recent years and the knowledgebase of how dementia has an impact on the pain perception and pain expression has increased. Research in pain assessment and dementia has primarily focused on psychometric properties of pain assessment tools. This thesis adds an exploration of RNs’ and CNAs’ experiences of detection and assessment of pain in older people with cognitive impairment and dementia in order to better understand what their judgements are based on and what methods they use in pain assessment.

Pain assessment in people with cognitive impairment and dementia can be challenging primarily due to their reduced ability to self-reporting, which methods care professionals apply to investigate pain as well as to the knowledge-base, interpretation and understanding of pain in dementia. Without frequent pain assessments and effective interventions, under-recognition and under-treatment of pain may occur and contribute to needles suffering and diminished quality of life. Dementia affects the ability to interpret pain stimulus and the affective response to that sensation, interfering with self-report and pain behaviours. Prior research in Sweden has to a limited extent investigated RNs’ and CNAs’ management of pain assessment in municipal dementia care practice. RNs and CNAs are involved in the daily care and thus there is a need for research into their experiences of pain assessment in order to explore and strengthen the evidence base of the challenges they confront and how they deal with those challenges.

When self-report is not possible to obtain, observational behaviour pain assessment scales are suggested as useful to assist in recognising pain. However, evaluation of observational behaviour pain assessment scales in Swedish dementia practice is missing. Hence, research into pain assessment using observational behaviour scales in this context is needed in order to evaluate whether such a scale reliably can assist in pain assessment and help RNs and CNAs to better interpret, understand and assess symptoms of pain.
Given that an observational behaviour pain assessment scale would be reliable in assisting in pain assessment procedures, it is also important to investigate the utility of the scale in its specific context where it is supposed to be used and to those care professionals who are supposed to use the scale. The Abbey Pain Scale is introduced into the Swedish BPSD Registry and the Swedish Palliative Registry. However, there have been no research studies evaluating the scale in Swedish dementia care practice. Thus, research in Swedish RNs’ and CNAs’ experiences of using the Abbey Pain Scale for pain assessment in clinical practice is needed.
Aims

The overall aim of the thesis was to explore and describe RNs’ and CNAs’ experiences of detection and assessment of pain in older people with cognitive impairment and dementia. A further aim was to evaluate the Abbey Pain Scale-SWE (APS-SWE) in dementia care practice.

The specific aims were to:

- present municipal registered nurses’ view of pain assessment in persons with dementia in relation to their municipal nursing profession as consultant advisors (Study I)

- interpret certified nursing assistants’ perception of pain in people with dementia in nursing care practice (Study II)

- explore home healthcare teams’ experiences of pain assessment among care recipients with dementia (Study III)

- test and evaluate reliability of the Abbey Pain Scale-SWE in a Swedish population of older people in special housing accommodation, and face validity for pain assessment in dementia care practice among registered nurses and certified nursing assistants (Study IV)
Methods

Design

In this thesis, a sequential exploratory design was used (Creswell, 2009). Initially, qualitative methods were applied to explore and describe RNs’ and CNAs’ experiences of pain assessment in people living with dementia (I, II, III). Subsequently, quantitative methods were applied by using observational data, instruments and, questionnaire (IV). Whereas qualitative methods using interviews enabled exploratory data to be provided by inductive reasoning, quantitative methods using instruments (APS-SWE, APS-SWE questionnaire) were used to generate data and to draw conclusions from measurement and deductive reasoning.

This thesis comprises four empirical studies (I-IV) interrelating in the main topic of RNs’ and CNAs’ pain assessments in older people with cognitive impairment and dementia. In Study I, II and III, qualitative design was employed by means of focus group interviews (I) and individual interviews (II, III). Qualitative methods are suggested to be a powerful source to generate new knowledge and to obtain in-depth understanding of phenomenon under investigation (Patton, 2002). In Study IV, a prospective, descriptive, observational, instrumental design was applied because of its appropriateness to provide measures of scale development, items, and the established validity and reliability of scores with the intent of generalisation of the findings (Streiner & Norman, 2008). In contrast to qualitative research, quantitative research involves the use of standardised measurements so that varying perspectives and experiences can fit into a limited number of predetermined response categories to which numbers are assigned (Patton, 2002). In Study IV, the research was directed towards current and available observational scales rather than to the idea of the development of a new scale. An overview of the included studies in the thesis is presented in Table 1.
Table 1. Overview of the included studies in the thesis.

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Participants</th>
<th>Method</th>
<th>Year of data collection</th>
<th>Data analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Exploratory Descriptive</td>
<td>RN (n=11)</td>
<td>Focus group interviews</td>
<td>2010</td>
<td>Qualitative content analysis</td>
</tr>
<tr>
<td>II</td>
<td>Exploratory Interpretative</td>
<td>CNA (n=12)</td>
<td>Individual interviews</td>
<td>2011</td>
<td>Philosophical hermeneutics</td>
</tr>
<tr>
<td>III</td>
<td>Exploratory Interpretative</td>
<td>RN (n=13) CNA (n=10)</td>
<td>Individual interviews</td>
<td>2012</td>
<td>Philosophical hermeneutics</td>
</tr>
<tr>
<td>IV</td>
<td>Prospective descriptive observational instrumental</td>
<td>RN (n=5) CNA (n=70) Residents (n=96)</td>
<td>Instrument translation Observation Questionnaire</td>
<td>2013/2014</td>
<td>Descriptive statistics Cronbach’s alpha Spearman’s rho Fischer-Bonett test Fischer’s transformation test</td>
</tr>
</tbody>
</table>

**Sampling and participants**

Study I was conducted in one mid-sized municipality in Western Sweden. Participants were recruited from a RN network group comprising 25 RNs working in elderly care in the municipality. The RN network group was originally developed by the dementia coordinator in the municipality with the purpose to have regular meetings for training and nursing care discussions. The participants were selected as they had broad and varied work experience from elderly care and dementia care practice, varied in age, educational background, and number of years in the RN profession. At the time for the study, each RN had nursing responsibility for 36 to 90 residents. Inclusion criteria were RN and permanent employment within municipal elderly care. All RNs were women, ranging in age from 42 to 63 years, and with RN work experience ranging from five to 40 years. Nine of the RNs were working within special housing accommodation and two RNs were working within both special housing accommodation and in home healthcare.
settings. Initially, a dialogue with the head of the RN organisation was initiated to introduce the study. Next, the RNs were informed about the study and invited to participate. Information about the study was given at one of the RN network meetings. Those RNs who had announced their interest in participating were then contacted by telephone to schedule for focus group interviews. Thirteen RNs were interested in participating. At the time of interviews two of the RNs were prevented from participating; one RN due to sick leave and one RN due to participating in a training session. In total, eleven RNs working in six different special housing accommodations within the municipality participated in the study.

Study II was conducted in the same municipality as in Study I. Two special housing accommodations were selected based on convenience sampling and of providing equivalent care. Each of the accommodations comprised ten to 12 older residents, RN in charge, CNAs and a Manager-in-Chief. The CNAs were purposefully selected based on obtaining a variety of age and work experience from dementia care practice. The inclusion criteria for participating were permanent employment in dementia practice in the municipality, formal CNA training, dementia training (training provided by the municipality and in accordance with the national fundamental values in elderly care) (National Board of Health and Welfare, 2012), and providing routine care. All CNAs were women, ranging in age from 26 to 62 years, and with work experience in dementia practice ranging from two to 35 years. Initially, Managers-in-Chief at the two special housing accommodations were contacted and informed about the study and consented to the study. The managers were then asked to provide a list of CNAs who fulfilled the inclusion criteria for the study. In total, 14 out of 15 CNAs fulfilled the criteria. Next, all the CNAs fulfilling the criteria were informed about the study and invited to participate. Twelve CNAs were interested in participating and were included in the study.

Study III was conducted in the same municipality as Study I and Study II but in home healthcare settings. In the municipality, organisation of home healthcare was divided into sub-districts. Three different sub-districts were selected for the study. The districts were selected based on convenience sampling and of providing equivalent home healthcare. Twenty-one RNs and 20 CNAs were invited to participate. Thirteen RNs (2 men and 11 women)
and ten CNAs (all women) participated in the study. From team A, four RNs and five CNAs participated, from team B, three RNs and two CNAs participated, and from team C, six RNs and three CNAs participated. At the time of this study, around 90 care recipients were receiving home healthcare in each district. In each of the sub-districts, RNs and CNAs worked together in home healthcare teams. The RNs had work experience from cardiology, surgery, infection, intensive care, medicine, and psychiatric care. Seven of the RNs had one year of supplementary education graduating to district nurse (DN) i.e. Primary Health Care - Specialist Nursing Programme. All CNAs had formal training of CNA qualification. The CNAs had work experiences from nursing homes, hospital nursing care of rehabilitation, orthopaedic, cardiology, and psychiatric care. All RNs and CNAs had received training in national basic values for elderly care in accordance with the National Board of Health and Welfare (2012). Initially, Managers-in-Chief for the RNs and for the CNAs were contacted and informed about the study. The managers were then asked to provide a list of RNs and CNAs who fulfilled the inclusion criteria. Each of the sub-districts was then contacted to schedule for an information meeting, and where the RNs and CNAs were informed and invited to participate in the study.

In Study IV, four municipalities in western Sweden were included. The municipalities were selected as to their systematic work with quality improvements in accordance with the national guidelines for care and support of people living with dementia (National Board of Health and Welfare, 2011a), the national fundamental values in elderly care (National Board of Health and Welfare, 2012), and documentation using the ICF (National Board of Health and Welfare, 2003; World Health Organisation, 2001) and the Senior Alert Registry (National Board of Health and Welfare, 2013b). In each of the municipalities, one to four special housing accommodations were selected based on providing equivalent dementia care. Each of the accommodations consisted of eight to ten single rooms, including toilet and shower room, a joint dining room and living room. Inclusion criterion for the older people to participate was permanently living at the accommodation for at least one month before the study started. In total, 96 older people participated in the study (26 men and 70 women), ranging in age from 57 to 101 years of age. Mean age was 85.4 years. The inclusion criteria for RNs and CNAs included permanent employment in the
municipality providing the care, having been working in the accommodation where the study was conducted for at least one month before data collection started, working with nursing care on daily basis, and speaking and understanding the Swedish language. In total, five RNs and 70 CNAs participated in the study. All RNs were women. Of the CNAs, three were men and 67 were women. The RNs and CNAs ranged in age from 20 to 66 years of age and their work experience in nursing care ranged from one to 39 years.

Qualitative data collection

In Study I, II and III, qualitative data collection using open-ended interviews was employed to explore RNs’ and CNAs’ experiences of pain assessment in people living with dementia. Open-ended interviews focus on a specific topic, however, without having a fixed sequence of questions formulated prior to the interview in order to ask questions in a truly open-ended fashion where people can respond in their own words (Patton, 2002). In the following sections, the data collection for each of the studies in the thesis is described.

Focus group interviews

In Study I, focus group interviewing was chosen to take advantage of group interaction when collecting data. The focus group interviews were conducted in the year 2010. Focus groups have been defined in various ways, and where one of the definitions and criteria for this form of group interviewing is defined in terms of a structured group dynamic procedure to access shared knowledge of a subject (Markova, Linell, Grossen & Salazar, 2007). Focus group interviewing is suggested to be appropriate to bring up various opinions of a topic under investigation in order to gain a rich amount of views (Markova et al., 2007; Wibeck, 2000). With respect to the participants’ availability to participate, two focus groups were organised with seven participants in the first group and four participants in the second group. The first focus group interview was conducted at the university where the author of this thesis was stationed. The second focus group took place at one of the nursing homes in the municipality where some of the participants were working. The author of this thesis was the moderator with the role of
guiding the conversation and stimulating the participants to share their experiences. In this study, no assistant to the moderator participated.

The interview sessions started off by introducing the topic to be discussed, pain assessment in people with dementia in relation to the RN consultant advisor role, and the focus group method for conversation enabling the participants to become familiar with the method. Before starting the conversation, the participants were asked whether they would allow the session to be audio recorded for further transcription and analysis. Both focus groups verbally consented to audio recording. The conversations opened with a broad enquiry of the participants’ experiences of working as RN in municipal elderly care and among people with dementia. Thereafter questions about their experiences of pain assessment in people with dementia were asked and discussed. During the conversation the participants were encouraged to narrate their RN experiences of pain assessment in people living with dementia by follow-up questions to gather as much information as possible, involving all of the group participants. In relation to what emerged from the conversation, the participants were encouraged to develop their opinions and descriptions of their role as RN, their work tasks, and how they performed pain assessment. The moderator guided the conversations with a purpose of keeping focus on the main topic and to make sure that all participants contributed. During the conversations, short notes were written down for further reflection and analysis and to enable reference to the notes during the conversation if needed. The first focus group interview lasted 120 minutes and the second interview lasted 90 minutes. Both focus group interviews were transcribed verbatim (Linell, 1994) by the author of this thesis.

**Individual interviews**

In Study II and Study III, individual interviews were employed. Interviews in Study II were conducted in the year 2011 and interviews in Study III in 2012. Interviewing using open-ended questioning is suggested as useful to encourage narration of experiences in a natural way and to obtain in-depth information of a subject (Dahlberg, Dahlberg & Nyström, 2008). In Study II, two main enquiries were posed in line with the open enquiring of the hermeneutical dialogue (Gadamer, 2004). The initial enquiry called for
experiences of pain assessment in people with dementia in regular care in order to invite the interviewees to talk openly and freely about their professional experiences. In Study III, individual interviews with RNs and CNAs working together in home healthcare teams were employed. The first enquiry asked for their experiences of assessing pain in people with dementia in home healthcare. In both studies (II, III) subsequent enquiries were asked to clarify the participants’ descriptions of pain assessment in people with dementia and to gain deeper understanding that could shed more light on their experiences and descriptions. From the dialogic way of enquiring, new questions arose from what seemed meaningful to the interviewee of pain and pain assessment and that led to obtain deeper understanding of their experiences. All interviews were conducted at the participants’ work places and scheduled with respect to their availability to participate during their ordinary work schedule. The interviews were conducted, digitally recorded and transcribed verbatim by the author of this thesis. Directly after each interview, memos were written, reflecting on experiences and the setting. The participants were interviewed once. In Study II, interviews ranged from between 40 to 55 minutes and in Study III, interviews ranged from 28 to 65 minutes.

Quantitative data collection

In Study IV, systematic observation and data registration of the older people participating in the study during rest and mobility were used to collect data. The APS-SWE was used for data registration and to score pain. The Abbey Pain Scale questionnaire (APS-SWEQ) was administered to evaluate face validity of APS-SWE on pain assessment in clinical practice among RNs and CNAs.

Instruments

Abbey Pain Scale

The original Abbey Pain Scale, modified pain scale by experts in a Delphi study (Abbey et al., 2004) where items derive from Hurley, Volicer, Hanrahan, Houde, & Volicer (1992) and Simons & Malabar (1995), is designed to assist in assessment of pain in people who are unable to clearly
articulate their pain problems. Based on observation and knowledge of the person’s usual function and medical history, the person is rated on a four-point word descriptor scale (absent=0, mild=1, moderate=2, severe=3) across six domains of pain-related behaviour (vocalisation, facial expression, change in body language, change in behaviour, physiological change and physical change). Scores are summarised to provide an overall score of pain intensity ranging from 0 to 14+ (0-2 indicates no pain, 3-7 indicates mild pain, 8-13 indicates moderate pain, and 14+ indicates severe pain). The scorer is also required to indicate the type of pain being experienced by the person - acute, chronic or acute on chronic and to repeat the assessment no more than an hour later if any pain-relieving intervention has occurred (Abbey et al., 2004) (Appendix 1).

Abbey Pain Scale-SWE

When the current Swedish version of the Abbey Pain Scale (Appendix 2) lacked a scientific method for language translation it was decided that validation of the translation was necessary before the scale could be used for data collection. The original scale developer was contacted to obtain permission to make adjustments of the scale appropriate to Swedish context. Language translation and cross-cultural adaption of health measurement scales is an important component when validating and adapting a scale for another country other than its original (Maneesriwongul & Dixon, 2004; Streiner & Norman, 2008). The language translation procedure was carried out in October to December 2013, resulting in the APS-SWE version which was used in study IV (Appendix 3). The translation was conducted in a three-step procedure suggested by Streiner and Norman (2008), following the standardised translation procedure of forward translation, backward translation and reconciliation. The translation procedure was carried out by an eight-people expert group comprising clinicians and researchers from different locations in Sweden (physician (1), RNs (2), CNAs (2), and senior researchers in nursing and psychology (3). The goal with the language translation was to achieve equivalence between the original Abbey pain scale and the current Swedish version of the Abbey Pain Scale. The three-step procedure is presented in Table 2.
Table 2. Language translation procedure of the Abbey Pain Scale.

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1 (forward translation)</td>
<td>The current Swedish version of the Abbey Pain Scale was compared to the original Abbey Pain Scale and re-translated. The scale was scrutinised for conceptual-, item-, semantic-, and operational equivalence. In this step, items were scrutinised and compared to their meaning.</td>
</tr>
<tr>
<td>Step 2 (backward translation)</td>
<td>Although the Australian nursing care context does not substantially differ from the Swedish nursing care context, the backward translation was scrutinised for cultural discrepancy to assure each item measuring pain behaviours that could match older people within the Swedish context. In this step, the items of the Swedish translated scale were compared to the original scale, back to its original concepts. A final comparison of the items of the original version, the current Swedish version and the translated version was assembled for reconciliation by comparing the original items and the translated items until a consensus was reached. Corrections were suggested and the scale was undertaken adjustment of the following: The current Swedish version of the Abbey Pain Scale uses two different dimensions for pain (item 1 and item 2 measure duration and item 3 to item 6 measures intensity). As the original Abbey Pain Scale uses intensity dimension only throughout the scale (Absent, Mild, Moderate, Severe), adjustments were made following the original scale construct. Some minor rephrasing of sub-wording of the items were conducted as well. The final translated scale was titled the Abbey Pain Scale-SWE (APS-SWE).</td>
</tr>
</tbody>
</table>

Before observation and data registration started, all RNs and CNAs included in the study received a 90-minute theoretical instructional class with the purpose of familiarising with definitions and meaning of each item on the APS-SWE, ensuring a clear understanding of behaviours associated with pain (Abbey et al., 2004). The instructional class included a theoretical description of the complexity of pain in dementia, recognition and assessment of pain as well as how to complete the APS-SWE reliably after observation. The instructional class were performed by the author of this thesis and located on-site at the special housing accommodations. The instructional classes were conducted in small groups with RNs and CNAs from each of the special housing accommodations focusing on observation
technique and how to use the APS-SWE in clinical practice, highlighting the key elements of assessing pain in people with dementia and where the participants were given the opportunity to discuss how pain assessment was managed in their care practices. Prior research has pointed to the importance of training to establish standards for the use of the Abbey Pain Scale (Abbey et al., 2004; Liu et al., 2010). The participants were carefully instructed to observe resident participants for approximately two minutes at two scheduled but different occasions (rest and mobility) by completing the APS-SWE for scoring. To safeguard reliability of observations the participants were supervised by instructions about practical problems that could show up during the study and how to manage such.

**APS-SWEQ**

After all observations were completed, the questionnaire APS-SWEQ was administered to all RNs and CNAs who completed data registration by using the APS-SWE. The questionnaire APS-SWEQ was designed by the author to this thesis and administered to evaluate face validity of the APS-SWE on pain assessment. The APS-SWEQ consists of six items, following the item construct of the APS-SWE, and where the appropriateness of each of the items on the APS-SWE for pain assessment is rated from 0 (not at all appropriate) to 10 (very appropriate). Questions about age and work experience in dementia care were included in the questionnaire. The questionnaire also included a free text comment box, where the respondents could comment on their experiences evaluated during the eight-week period of systematic observation and data registration for pain assessment using the APS-SWE (Appendix 4).

**Systematic observation and pain assessment registration**

Systematic observation and data registration were conducted from February to June 2014. The APS-SWE was used to systematically score pain during an eight-week period, scheduled twice a week for approximately two minutes observation at rest (morning care) and mobility (walking a short distance or transferring from bed to wheelchair by lifting device) by completing the APS-SWE. For each registration, a new APS-SWE data sheet was completed. In total, each resident participant was registered on 32
assessment occasions. Of the total of 75 nursing staff participants providing observation and data registration, 68 nursing staff participants observed and assessed one resident participant each, and seven nursing staff participants observed and assessed two older residents each.

Demographics and background data of the resident participants were collected from medical journals by RNs in charge. The data included dementia diagnosis, pain-related diagnosis, prescribed pain-relieving medication and psychotropic, and episodes of depression and anxiety symptoms. Prescribed medications were registered and classified according to the anatomical therapeutic chemical (ATC) classification system (WHO, 1997). To have a comprehensive picture of health status, data was also collected from the Swedish Senior Alert Registry (initiated in 2008), which centres on regular risk assessment of developing decubitus ulcer, fall risk and, malnutrition. Risk assessment of decubitus ulcer uses the Modified Norton Scale (Ek, Unosson & Bjurulf, 1989), fall risk uses the Downton Fall risk index (Rosendahl, Lundin-Olsson, Kallin, Jensen, Gustavsson & Nyberg, 2003), and nutrition uses the Mini Nutritional Assessment instrument (MNA) (Rubenstein, Harker, Salva, Gulgoz & Vellas, 2001). The degree of independence in daily life functioning was assessed by Barthel’s Activities of Daily Living Index (ADL) (Mahoney & Barthel, 1965). This 10-point index measures the degree of self-reliance, with a total score ranging from 0 to 20. ADL scores below 5 indicate high dependency, 5 to 8 indicate medium dependency, 9 to 12 indicate low/medium dependency, and scores from 13 to 20 indicate low dependency. ADL data were collected by CNAs who had good knowledge of the person for whom the ADL data was gathered. During the data collection period, the author of this thesis regularly visited the accommodations in case there were any questions.

**Qualitative data analysis**

Qualitative data analyses were employed in Study I, II, and III. Qualitative analysis has unique steps of analysis and where the researcher uses oneself as an instrument, relying on one’s own ability to develop understanding, i.e. without using objective and standardised measurements (Creswell, 2009). This involves both curiosity and sensitivity to develop a dialogue with data while maintaining a reflective attitude throughout the analysis. Yet, qualitative data analysis can employ different philosophical assumptions.
(Patton, 2002). In the following sections, each of the qualitative analyses used in this thesis is described.

**Qualitative content analysis**

Data from the focus group interviews were analysed using qualitative manifest content analysis (Graneheim & Lundman, 2004). Using qualitative content analysis as a systematic method to analyse data takes a departure from the assumption that careful reading of the text to make sense of data and open coding to organise data is appropriate to identify patterns and to develop categories of the content of the data (a.a). Content analysis on a lower level of abstraction was used in order to stay close to the interview text and to organise and describe the visible and obvious components of the content from the focus group interviews by identifying concepts and comparing and contrasting data. To organise the amount of data, the two focus group interviews were first analysed independently and then jointly. Notes from the interviews were used for reflection in relation to the interview text.

In the first step, the interview text was carefully read to search for meaningful descriptions and patterns in the text. The analysis was conducted manually by reading the text and making notes in the margins of the transcripts. Meaningful parts in the text (meaning units) that described RNs views of pain assessment were marked. Thereafter, meaning units were extracted, condensed, and labelled with a code to their content; i.e. meaning units could be words or sentences which were condensed into close description, coded and formulated into sub-categories. Identified codes were compared and combined as to their similarities and differences, where similar codes were combined into sub-categories. Codes were then re-read and verified to make sure that all data that related to the topic were analysed. Finally, sub-categories were abstracted into categories, describing RNs views of performing pain assessment in persons with dementia as consultant advisors. The co-authors supervised in the analysis, coding and categorisation. All authors discussed the final categories. An example of meaning units, condensations, sub-categories and categories are shown in Table 3.
Table 3. Examples of meaning units, codes, sub-categories and categories in Study I.

<table>
<thead>
<tr>
<th>Categories</th>
<th>Sub-categories</th>
<th>Codes</th>
<th>Condensations</th>
<th>Meaning units</th>
</tr>
</thead>
<tbody>
<tr>
<td>Estrangement from practical nursing care</td>
<td>Feeling of remoteness from the patient</td>
<td>Relying on others</td>
<td>We work as consultant advisors, but we feel remote when we are only supposed to come when there is a problem and somebody calls for us</td>
<td>We were told to work as consultant advisors and that has destroyed a lot for us</td>
</tr>
<tr>
<td>Time consuming and unsafe pain documentation</td>
<td>Being a second-hand receiver of pain information</td>
<td>Documentation in two systems</td>
<td>Different documentation routines are used and documentation takes time</td>
<td>We feel remote</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>We are supposed to come when called on and only when there is a problem</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>We have different document routines, one for medical documentation and one for social documentation</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>It takes a lot of time to document in two places and the discussions about where to write takes time from the patients</td>
</tr>
</tbody>
</table>

**Philosophical hermeneutics**

Interviews from Study II and Study III were analysed using Dahlberg et al (2008) approach to hermeneutic interpretation of a text, based on philosophical hermeneutic of Gadamer (2004), to interpret RNs’ and CNAs’ experiences of pain assessment. This philosophical stance takes a departure from that human existence being an integral, temporal, and dynamic activity that comprises what it means to be, and that understanding is achieved only through language and openness to the perspective of other beings (Gadamer, 1977; 2004). Philosophical hermeneutic analysing aims to generate meaning and understanding of experiences, focusing on interpretation of texts with the ambition to develop a deeper level of understanding added to existing knowledge (Vandermause & Fleming, 2011).
In each of the studies, interviews were read several times to become acquainted with the text and to gain an overall understanding. The reading involved an iterative process of self-reflection and interpretation of parts of the text and the text as a whole, i.e. relating meaningful parts in the text to a comprehensive whole, recognising meaning as expandable but contextual (Dahlberg et al., 2008). Memos from the interviews were read and reflected on in relation to context and pre-understanding. Attention was directed to what the interview text described and on initial searching for meanings opened up by the text of CNAs’ perceptions of pain in people with dementia (II) and RNs’ and CNAs’ experiences of pain assessment working in home healthcare teams (III). Gadamer (2004) suggests that the process of understanding includes having a dialogue with the text in order to let new horizons and understanding emerge. The dialectic interplay between parts and the whole of the text expresses interpretation in the process of understanding, also referred to as the hermeneutic circle (Gadamer, 1977, 2004). This means to let the underlying meaning of the text emerge by moving back-and-forth in the text so as to develop new questions in order to deepen understanding i.e. what does the text say, and is this meaning or could meaning be something else. Vandermause & Fleming (2011) describe that with using philosophical hermeneutics for enquiring, the researcher becomes an involved agent of the interpretive process and cannot bracket understanding as data is gathered and analysed within the interpretive tradition. Self-reflection of one’s pre-understanding is thus an important component in hermeneutic text interpretation to allow fusion of horizons and new understanding to emerge (Gadamer, 2004). During text analysing, the author of this thesis reflected on own involvement and understanding in order to critically judge how this might impact interpretation. Reflections were also discussed with supervisors for further judgement of the impact of pre-understanding.

In Study II and Study III, analysing was based on text interpretation of the interview texts to interpret patterns in the text, and how parts in the text connected to the whole in a valid way with the purpose of describing a reasonable and acceptable interpretation (Dahlberg et al., 2008; Ödman, 2007). However, interpreting interview text using hermeneutics could involve several interpretation ideas for the same phenomenon that is to be interpreted (Dahlberg et al., 2008). Thus, hermeneutic interpretation relies on
finding the most reasonable interpretation, connected to tradition and to context. While reading the interview text, there was an effort to approach the text in an open-minded way so that interpretation did not appear too quickly. In the initial interpretation phase, analysis focused on identifying patterns of meanings in the text, relating to the participants’ descriptions of pain assessment. To attain critical reflection on interpretation and to disclose too narrow limits, ideas, thoughts and pre-understanding were reflected and discussed among the author of this thesis and supervisors. Meanings that seemed to reflect something in common were brought together and developed into tentative interpretations. Tentative interpretations were then reflected on and validly tested towards the text while critically moving between explanation and understanding. It is suggested that interpretation must be controlled against data to make sure that all moments in the interpretations are valid and that no contradictions exist between data and interpretation (Ödman, 2007). Interpretations were then formulated into themes, describing CNAs’ perceptions of pain in people with dementia (II) and RNs’ and CNAs’ experiences of pain assessment among care recipients living with dementia, working in teams (III).

**Pre-understanding**

Pre-understanding is a concept used within the hermeneutic tradition and has been described in various ways. Gadamer (2004, pp. 273) describes pre-understanding in terms of prejudices and ‘judgements that is rendered before all the elements that determine a situation have been finally examined’. Nyström & Dahlberg (2001) suggest that pre-understanding is grounded in a context recognisable to the interpreter and that may enable as well as block understanding. This would mean that only within a specific context experiences are meaningful, and thus interpretations are explained within one’s own horizon of already granted meanings and intensions. The participants in this thesis (I, II, III) were interviewed about a nursing care phenomenon experienced in their natural work environment, pain assessment in people with dementia, and that was interpreted and described based upon context and tradition.

The author’s professional pre-understanding arises from clinical work experience in municipal dementia care as a CNA. This would mean that
concepts and language from practice were recognised and that context and tradition were known. The author’s personal pre-understanding arises from experience of dementia in the personal environment, which has developed insights of how difficult it might be to interpret and understand a person who suffer from dementia. Conscious of that it may be challenging to grasp one’s pre-understanding, there was an ambition in this thesis to make pre-understanding as explicit as possible.

**Quantitative data analysis**

In Study IV, descriptive statistics were computed to describe characteristics of the sample and scored items on the APS-SWE. Cronbach’s alpha coefficient were calculated to analyse internal consistency reliability (Streiner & Norman, 2008). Differences in alpha coefficients were analysed using the Fisher-Bonett test (Kim & Feldt, 2008). Test-retest reliability was evaluated using Spearman’s Rank Order Correlation (rho). Differences in test-retest correlations were analysed using Fischer’s transformation test (Fischer, 1921). Spearman (rho) was also computed to determine the association between nursing staffs’ ratings on the APS-SWEQ and their age and work experience. To consider statistical significance, a two-tailed P value below 0.05 was established. All data were analysed using IBM Statistical software SPSS for Windows ver. 22.0.

**Ethical considerations**

Ethical considerations in the thesis were conducted in accordance with the ethical principles of research in human science as described in Helsinki declaration (World Medical Association Declaration of Helsinki, 2008), Ethical guidelines for nursing research in the Nordic countries (Northern Nurses’ Federation, 2003), and the Swedish ethical approval legislation concerning research in humans (CODEX rules and guidelines for research, 2015). The research was guided by the ethical principles of autonomy, beneficence (to do good), non-maleficence (not causing harm), and justice. Study I and Study II (Dnr 004-09), Study III (Dnr 969-11), and Study IV (Dnr 423-13) were approved by the Regional Ethical Review Board in Gothenburg, Sweden.
In this thesis, nursing staff participation was carried out during their ordinary work schedule and on a voluntary basis. No gifts or payment were distributed. Before as well as during each step in the research process, issues of identity and integrity were considered with the ambition to identify ethical aspects that could jeopardise participants’ confidentiality. All nursing staff participants received oral and written information about the study, their voluntary participation and how confidentiality was assured. Written and oral informed consent was obtained from all participants.

The research in this thesis also conformed to the ethical principles of human research of the International Association for the Study of Pain (2012), stating that people unable to provide consent should only be included in research when their involvement is essential to the goals of the research, and then by legal surrogate decision-making. In Study I, II and III, residents were not directly involved in the research, however, they were talked about and reflected on in relation to their medical pain problems. This is worthy of reflection in relation to integrity and autonomy. In Study IV, resident participants were directly involved by observation and assessment, and thus, informed consent from legal representatives was a matter of course and set as inclusion criteria. All resident participants in Study IV had written informed consent from their legal representatives, who were contacted by telephone by their contact nurse or spoken to in person when visiting their loved ones in the accommodation. The contact nurse also administered informed consent letter, including information how to contact the author of this thesis if there were any questions. Those resident participants who did not have surrogate decision-making were excluded. No observation or data collection was started until informed consent had been signed. The nursing staff participants were informed about that if a resident participant was distressed because of observation, the observation must be discontinued. If a resident participant’s condition deteriorates so much during the study that observation must be discontinued, the resident’s participation should be considered with the aim of not causing unnecessary distress. Casarett (2003) claims that studies involving people with difficulties in giving consent should consider how issues regarding recruitment and surrogate involvement affect sample size, eligibility and measurement. The sample in Study IV was considered a tailored population with direct beneficence of the research, i.e.
to have pain identified and systematically assessed. The sampling recruitment was based on an invitation of all residents living in the selected special housing accommodations, fulfilling inclusion criteria.

Interviews with RNs and CNAs (II, III) and their pain observations (IV) were intended to have direct beneficence to the resident participants, and indirect to the population of people living with cognitive impairment and dementia. In all of the included studies in the thesis, both resident and nursing staff participants were considered in terms of integrity and identity and, in relation to this, presentation and use of the findings. Data were de-identified, i.e. coded numbers were used throughout analyses of data and no names or places could be identified in the results. Questionnaires were administered by RN in charge and by the author of this thesis. Completed questionnaires were gathered at each of the accommodations and where the author of this thesis collected them. Questionnaires were anonymously completed. All data were kept safe in a locked cabinet at the University of Skövde, where only the author of this thesis had access. Code keys and data were kept separately.

Research into pain assessment in older people with cognitive impairment and dementia is of particular concern when the prevalence of both dementia and pain increases with advanced age. Hence, research is needed in order to help and improve the care for this population. However, involvement of people with dementia in research projects should be considered in light of their cognitive impairment and their inability to understand and consent to their involvement. Thus, the overall goal with research in this population must be carefully considered, and researchers should be vigilant to include multiple safeguards to protect those who participate (International Association for the Study of Pain, 2012; Monroe, Herr, Mion & Cowan, 2012). Nevertheless, including people living with dementia is important, and where the opposite of excluding those may have consequences such as greater suffering and lack of evidence to support best practice and targeted intervention strategies for those who need it the most. In this thesis, risks were considered for each of the included studies but were considered to be of no potential magnitude, harm or other negative discomfort than those ordinarily encountered in the regular care. No new or unfamiliar routines that could distress or harm the resident participants were applied. When the
studies included in this thesis were based on interviews with healthcare professionals and their observation using an observational pain assessment scale and not on experimental tests, risks were not considered to exceed the direct potential benefit of the studies. Yet, resident participants were considered to their situation of being in an exposed, vulnerable and dependent situation due to cognitive impairment.
Findings

Study I

From the focus group interviews four main categories were identified, describing RNs’ view of performing pain assessment among persons with dementia: estrangement from practical nursing care, time consuming and unsafe pain documentation, unfulfilled needs of reflection possibilities, and collaboration and coordination.

Estrangement from practical nursing care

The RNs described that pain assessment in people with dementia is a challenge primarily due to the fact that their RN role had changed and placed them further away from clinical nursing care. To work in a consultant role, the RNs have to rely on CNAs’ daily updating of information as it is CNAs who are the front-line staff. The RNs expressed their concerns with this situation in terms of inconvenience to the consultative role and feeling of remoteness from their patients.

The RNs described that both RNs’ and CNAs’ work duties in elderly care had changed from before, whereby the RNs often felt themselves being underestimated and misunderstood of their nursing competence, and where CNAs were expected to perform an extended amount of care duties when compared to previous. The changed roles of RNs and CNAs was emphasised as having a negative impact on pain assessment routines. The RNs claimed that not being present in the direct care made them feel alienated and dependent on information from other care staff performing direct care. They also strongly in-questioned this way of working in terms of feeling in a divided situation between a heavy workload of administration and at the same time responsibility for the care, and yet feeling a lack of control in care situations such as in pain assessment. To a great extent, the RNs’ found their RN tasks consisting of administrative work duties such as preparing and administrating pharmaceutical products, medical documentation,
coordination issues, and telephone contacts with relatives who were concerned about their loved ones. There was a consensus among the RNs around what it really means to be a nurse and what nurses in fact should do based on their nursing competence. Being a nurse was described in terms of visually seeing, getting to know, and being present among persons in need of care to be able to adequately assess pain. However, this was not what the RNs experienced at the present.

**Time consuming and unsafe pain documentation**

The RNs described that pain documentation routines were time consuming and unsafe due to documentation being carried out in two different systems - firstly by pen/paper day notes by CNAs and thereafter by computer-based documentation with the RNs. This procedure was considered both unsafe and complicated to manage. Receiving pain information in a second-hand manner sparked uncertainty among the RNs of how they could depend on the information they received or if there was a need for giving their own opinions on the situation, investigating and seeing for themselves by visiting the person about whom they were given information. The RNs provided somewhat different routines in how to gain information from CNAs. While some RNs had daily contact with their care units, some RNs visited their units two to three times a week only, depending on the residents’ health and CNAs’ need for RN consultation.

**Unfulfilled needs of reflection possibilities**

The RNs felt a need for collegial supervision where they could discuss nursing and medical patient problems with their RN colleagues to be better equipped to manage complicated pain assessment situations. As they often worked alone, i.e. without RN colleagues in their care units, they sometimes found themselves in need of support. They also reflected on the importance of having time to discuss the care together with CNAs who provided the RNs with nursing care information. However, during their daily work shifts the RNs often lacked time to come together and reflect on what had happened throughout the day due to being pre-occupied with a great amount of administrative tasks and telephone contacts emerging during the day. This was considered as an unsatisfactory RN situation.
Collaboration and coordination

Finding successful ways to collaborate and coordinate was considered as a major task for municipal RNs. There was often insufficient information from other care providers in the care chain about the person moving into the nursing homes where the RNs worked. This was seen as a problem to the RNs who were then forced to investigate and coordinate for more information about the incoming person. This was often time consuming and even more so if the person arrived during a weekend when it was much more difficult to gain information. The RNs stated that if the person arriving into the nursing home suffered from pain problems, it was important to gain the right information from those who had cared for the person before. If such information was unknown to the RNs, it was much more difficult to recognise and assess pain if the person were limited to tell about pain problems.

Study II

From the findings in Study II, three themes were interpreted with each theme on one level of abstraction, emerging in an interpretive and circular process describing CNAs’ perception of pain in people with dementia and: Being in the facing phase, Being in the reflecting phase, and Being in the acting phase. A summary of the content in each of the interpretations is described in the following section.

Being in the facing phase

Being in the facing phase means being attentive to expressions and manifestations which may indicate pain. Attentiveness takes place on an initial level in which the CNAs confront and face a variety of expressions in the daily care such as facial expressions and behavioural displays. Facial expressions is manifested by for example a wrinkled forehead, grimacing, eye expression, and mouth movements. It was described that the eyes are particularly important to look into to detect if a person is suffering from pain. This was described in terms of having sad eyes, dark eyes or even an empty look. Behavioural change such as anxiety or aggressiveness was perceived as possible indications of pain. Physical displays such as
perspiration, protection of bodily areas and stiffness were also perceived as possible pain indicators.

**Being in the reflecting phase**

Being in the reflecting phase can be understood on a second level of CNAs’ perceptions of pain, following from the initial facing phase, and where they reflect on those expressions and displays they face. The reflecting phase connects closely to familiarity with the person being cared for and about whom the CNAs have developed good knowledge which helps to identify new or estranged expressions. Based on good knowledge of the person, the CNAs are able to reflect on changes. Although the CNAs are able to perceive signs of *that* a person may suffer from pain it can be difficult to determine *where* the pain is located and the intensity of pain if the person has limited capacity to self-reporting. Nevertheless, change behaviour is perceived as an important sign that something is wrong. Based on this assumption, the CNAs start to reflect on whether or not change behaviour may be due to pain. To find out what is wrong, or if pain is involved, the CNAs reflect on their perceptions from several points of view - for one self, with colleagues, together with the RN in charge and, if needed, with occupational therapists and physiotherapists also involved in the care. The reflecting phase also involves contact with the person’s next of kin who are considered as important sources of information about their loved ones and can add history whether the person has suffered from pain in the past.

**Being in the acting phase**

Perception of pain can be understood on a third and practical level in care situations, where regular physical examination of the body’s skin takes place to look for any visible marks or changes that could cause pain. At the same time, physical examination serves as a preventive method to avoid pain occurring. Preventive care is performed by checking both sitting and lying positions to avoid pressure on fragile areas and by performing moving of the person in a careful way. An incorrect or uncomfortable position poses a risk of developing pressure sores which in turn could lead to painful complications. Perception of pain, deriving from preventive and protective care, means acting and responding to each person’s unique expressions. To
the CNAs, the acting phase also involves managing existential suffering such as depression, anxiety or delirium. To the CNAs, such symptoms are connected to a deeper expression of suffering and are thus perceived as pain expressions. However, existential suffering is considered much more difficult to deal with than that of physical pain. The CNAs try to manage this by being present, being involved and having the courage to deal with expressions of suffering.

**Study III**

Four interpretations were developed of RNs’ and CNAs’ experiences of pain assessment, working in home healthcare teams. A summary of the content in each interpretation is described in the following section.

**The need for trusting collaboration**

Pain assessment is based on a robust collaboration between RNs and CNAs. Working in teams, RNs and CNAs have put their trust in each other’s professional expertise in pain assessment procedures. CNAs have developed close relationships with the older people receiving care by their regular visits and that enables them to recognise changes. Based on this, the CNAs report ahead the information to the RN in charge. In turn, RNs rely on CNAs’ information and initial assessments. In the home healthcare teams, the collaborative climate and robust teamwork facilitates when to detect, assess and discuss pain assessment situations. By maintaining robust team collaboration, the practical implications of pain assessment become evident.

**The use of multiple assessment strategies**

Five different strategies to assess pain are used depending on how well the team succeed in communicating with the care recipient. The first strategy is based on verbal communication, if possible, to find out about pain. If it is difficult to establish verbal and intellectual communication, a second strategy is based on checking physical function or reactions to explore level of pain in mobility situations. If the person has difficulty to verbalise him/herself understandable, observation of change or decreased movement capacity or physical function is employed to check for pain-related signs. A
third strategy is used in investigating and assessing pain by being alert to changed behaviour and to consider if such may be due to pain. A fourth strategy is used to initiate dialogue with care recipients’ next of kin who are considered as valuable sources of information. Next of kin may also be able to add background history about pain in the past. A fifth strategy is based on self-rating using the visual analogical scale (VAS), however, the VAS is considered not optimal to use in people who suffer from cognitive impairment and dementia as they may have difficulties in understanding the VAS and comparing and evaluating pain from day to day. Generally, the VAS is administered by RNs only, however, the RNs consider it difficult to agree and reach a consensus about the level of pain, not only amongst RNs and the person undertaking pain assessment but also the RNs in between.

**Maintenance of staff continuity in care and assessment situations**

From the RNs’ and the CNAs’ experiences, it becomes evident that good knowledge of the person receiving care is essential in pain assessment and particularly in the care of people who find it difficult to describe their pain verbally. Good knowledge develops from continuity in the care and that is provided by the same nursing staff. Staff continuity is needed to develop a relationship with the person receiving the care and contributes to better understand the person. Staff continuity in pain assessment procedures is based on that a limited number of nursing staff is involved. If there are too many nursing staff involved, it becomes difficult to make regular comparisons and to maintain an overall picture of the pain, identify changes, and evaluate interventions.

**The need for extended time to assess pain**

When assessing pain in people living with dementia, the RNs and CNAs in the teams consider that having sufficient time is essential. However, lack of time due to a stressful work situation was often experienced by both RNs and CNAs. Providing care in a hurry was considered distressing to people suffering from dementia, and the RNs and CNAs expressed that there was a risk that pain symptoms may be overlooked if they were stressed. Sufficient time and encountering the person in a calm manner is needed along with being present in the particular situation to be able to qualitatively respond to the person’s expressions. Lack of time may jeopardise both the
communication and the situation. From the RNs’ and CNAs’ experiences, working in home healthcare is described as striking a balance between having the time to carry through all scheduled care visits on the daily list while simultaneously trying to maintain quality of care.

Study IV

Ninety-six older people participated and completed the study, 27% (n=26) men and 73% (n=70) women. According to medical journal, the most frequent pain diagnosis was musculoskeletal pain (52%). Eighty-five percent of the participants were on pain medication (including both ordinary and on-needed medication). Psychotropic medication was found in 59.3%. According to the medical chart, 54% of the participants were diagnosed with dementia, 29% were diagnosed with unspecific dementia, and 17% lacked a dementia diagnosis.

Internal consistency

Cronbach’s alpha coefficients were calculated to evaluate the APS-SWE for internal consistency. Alpha for the total scale ranged from .78 to .91 in mobility and from .93 to .95 in rest. All of the Cronbach’s alpha values were above .70. Using the Fisher-Bonett test, no significant differences between alpha scores were found.

Test-retest reliability

To evaluate test-retest reliability Spearman’s rho correlation was calculated, demonstrating adequate test-retest reliability of the total scores in both mobility and rest. The test-retest correlation coefficients calculated of each of the six items varied between \( r = .29 \) (\( p = .0012 \)) and \( r = .91 \) (\( p < .001 \)).
Distributions of scoring on the APS-SWE

Distributions of total scored pain in each of the items of the APS-SWE demonstrated that Facial expression (Item 2) was the most frequent scored item in both mobility and rest (Figure 1).

Figure 1. Distribution of scorings in each of the items of the APS-SWE (data summarised from 16 measurements of mobility (walking/transferring) and 16 measurements of rest (morning care) (1=Vocalisation, 2=Facial expression, 3=Change body language, 4=Change behaviour, 5=Physiological change, 6=Physical change).
Face validity

In total, 68 questionnaires (APS-SWEQ) were distributed, resulting in 66 responses (97%). The average rating of face validity of the items on APS-SWE (scored on a 0-10 point scale) ranged from 7.2 to 8.3 (SD ranging from 2.0 to 2.3), demonstrating that the APS-SWE was considered valid for pain assessment by the nursing staff participants (Figure 2). Mean scores were highest for Facial expression (Item 2) (mean 8.35; SD 1.97) and Vocalisation (Item 1) (mean 7.79; SD 2.24). As to the Spearman correlation test, the nursing staffs’ scoring on the APS-SWEQ was not associated with their age or work experience.

Figure 2. Nursing staffs’ (n=66) rating (face validity) on APS-SWEQ for the separate items of APS-SWE (1=Vocalisation; 2=Facial expression; 3=Change in body language; 4=Behaviour change; 5=Physiological change; 6=Physical changes).
Nursing staff participants’ comments on using the APS-SWE for pain assessment

In the free text comment box in the APS-SWEQ, the nursing staff participants were given an opportunity to comment on their experiences evaluated during the eight-week period of structured observation and pain assessment registration using the APS-SWE. In total, 18 nursing staff participants gave their comments. Overall, their responses demonstrated a positive attitude to the items in the APS-SWE for pain assessment and of using the scale in dementia care practice. The APS-SWE was considered relevant and easy to use. However, two critical comments were given of the concepts in item Physiological change and item Change in body language as being somewhat unclear and difficult to understand.
Discussion

Methodological considerations

The focus for this thesis was on RNs’ and CNAs’ pain assessments in older people with cognitive impairment and dementia; what their judgements about pain were based on, and whether any challenges were experienced in relation to pain assessment in people with cognitive impairment and dementia.

Focus group interviews were chosen to take advantage of group interaction on the topic of RNs’ view of pain assessment (I). Focus groups are often used in combination with other qualitative and quantitative methods and in the initial stage of research in order to generate ideas and to become acquainted with the field under investigation (Markova et al., 2007). The RN participants in the study constituted a homogeneous and well-defined group as to their RN work in municipal elderly care. Choosing already established groups for focus group interviews could have both advantages and limitations (Wibeck, 2000). On the one hand, enlisting people who are already known to each other may enable to not being afraid to take part in the conversation, allowing the researcher to have insights into a particular social context where ideas are shaped and decisions are made. On the other hand, focus groups are an arranged construct, comprising individuals who are told and encouraged to interact verbally in front of each other. Such an arrangement could be a limitation in the motivation of speaking openly and in an engaged manner. The participants in each of the two focus groups were known to each other although they were not working next to each other in the same unit (I).

Another limitation to consider when using established groups is that certain issues may not come up because they are taken for granted within the group and that all group members are already familiar with each other’s opinion of an issue (Wibeck, 2000). Thus, it is essential to identify how issues are negotiated and agreed or disagreed upon in order to gain rich information of the issue under exploration. In the focus groups, an obvious agreement on
what was negatively impacting pain assessment was identified as to the critic into the RN consultant role. It could also be identified how the RN participants negotiated on pain assessment in people with dementia as challenging from several aspects relating to work duties, presence or absent in the direct care, and to CNA as front-line staff (I).

A third limitation to consider when recruiting established groups for interviewing could be that existing everyday roles of the participants remain despite the interview taking place in a new environment (Markova et al., 2007). This was more difficult to grasp from the focus group conversations and when the RN everyday role at their ordinary work places was unknown to me. The overall impression from the focus groups, nevertheless, was that the conversation climate was open and friendly, where the participants listened to each other with respect and where all participants contributed (I).

The recruitment of RN participants was somewhat difficult due to the low level of interest in participating in a research study. The inclusion criteria were set with the purpose of including participants within a broad perspective related to age and work experience to obtain a variety of experiences (Patton, 2002). However, only 13 RNs showed an interest, which could be seen as a limitation (I). There are different theories about how big focus groups should be. Literature suggests somewhat various group sizes depending on the purpose of the conversation and the topic under investigation (Markova et al., 2007; Wibeck, 2000). However, if group sizes are too small there may be limitations to identify tendencies and patterns whereas in bigger groups it may be difficult to keep everybody’s attention as well as there being limitations as to how much participants can feel they have an influence and sense of belonging (Wibeck, 2000). Svedberg (2012) defines small groups comprising not more than six persons. Markova et al. (2007) points to the appropriateness of including four to 12 participants in a focus group. In this thesis, the two focus groups consisted of different numbers of participants (seven participants in the first group and four participants in the second group) due to the participants’ availability to take part during their ordinary schedule (I). A further aspect of the number of participants in a focus group relates to the physical distance between the participants and the moderator. It is suggested that it is important to the interaction that the focus group participants have a narrow distance (Wibeck,
The environment where the focus group interviewing took place was carefully and invitingly prepared in small rooms, allowing all participants and the moderator to maintain eye contact and respond to each other’s expressions (I).

A critical question that should be posed is whether a greater amount of focus groups would have generated further data. The impression from the focus groups included is that the participants were genuinely engaged in sharing their RN experiences, generating data which were meaningful to them (I). The purpose of the study, to present municipal RNs’ view of pain assessment in persons with dementia in relation to their nurse consultant role would thus have been fulfilled. However, a limitation could be that the participants seemed more concerned in discussing how their consultative RN role negatively influences pain assessment rather than discussing pain assessment specifically. Patton (2002) suggests that this can be reflected on in relation to shared experiences from a specific context, culture and tradition. There is a possibility that there would have been other experiences revealed from RNs in other municipalities or care organisations. On the other hand, the included RNs’ view of performing pain assessment were revealed in that, to them, the RN consultative role was considered having a negative impact on pain assessment quality, which is an important finding.

A third aspect of focus group interviewing concerns the moderator’s role (Wibeck, 2000). Moderator’s acting may vary depending on what type of focus group is included, nevertheless, the moderator should be familiar with the group participants’ everyday language, be able to actively listen, and maintain a neutral attitude during the conversation in order to not display any expressions that could influence the conversation in a certain direction (Markova et al., 2007). During the focus group interviews, I acted without the support from an assistant (I). On the one hand, literature suggests that assistants can be helpful with practical tasks, observation, and note-taking during the interview session. However, an assistant’s attendance in small focus groups must be considered regarding how the attendance may influence the group participants (Wibeck, 2000). The focus group size in this thesis was small and controllable which facilitated to manage interacting with the participants. During the conversation, I wrote key notes which could be useful to return to if there was such a need during the conversation (I).
There is a possibility, however, that assistant support could have added information of the participants’ interaction.

In Study II and Study III, a hermeneutic approach with inspiration of Gadamer (2004) was chosen. Gadamerian hermeneutics is widely used in nursing research to achieve deeper understanding of complex nursing phenomena and to understand experiences of others (Aasgaard, Fagerström & Landmark, 2014; Larsson & Blomqvist, 2015; Phillips, 2007). Choosing hermeneutics was based on the assumption to interpret experiences to gain a deeper understanding of how pain was perceived and managed. Applying hermeneutics was an opportunity to open up new horizons to how pain assessment was managed but also challenging in that to put one’s own established take for granted at risk. Using hermeneutics was not a linear stepwise method to apply but rather a process back-and-forth between the text and my self-awareness. Gadamerian hermeneutics is by its nature rather a philosophy than a strict method that can be applied to interpret text (Austgard, 2012; Vandermause & Fleming, 2011). Using hermeneutics to expand understanding of RNs’ and CNAs’ pain assessments in dementia care practice was a two-way process in which I was involved both perceptually and intellectually to better understand their descriptions. It was also a process to understand myself and critically inventory my interpretation ideas of the text, expressed in terms of basic patterns and key findings in the text. The critic of using hermeneutics as a methodological approach in research studies relates to the issue of pre-understanding and interpretation (Nyström & Dahlberg, 2001). In the thesis, thus, it was an effort to make my professional as well as my personal pre-understanding explicit, enabling the reader to judge my interpretation ideas.

Based on my professional work experience as a CNA in dementia care, pre-understanding of caring for people with dementia probably has had an impact on enquiries and interpretations. However, it was not an ambition to consciously put aside pre-understanding but rather to reflect on my self-awareness in order to open up for expanding understanding. Before interviewing took place, I reflected over pre-understanding and ways in which pre-understanding may have an effect on how research questions are posed. To be conscious about my pre-understanding, as far as it was possible, I wrote notes about my professional as well as my personal
experiences of caring for people with dementia before each of the studies started and also after interviewing in order to reflect on its impact, well aware of the fact that it is impossible to capture and recognise all pre-understanding as it is integrated with tradition and history (II, III). My pre-understanding would probably have affected that certain questions were asked while others were not due to that I may already understood what was described because of pre-understanding. On the other hand, pre-understanding may have helped in that I have an insider’s perspective, enabling to understand concepts and descriptions. Nevertheless, there is a possibility that other researchers would have suggested interpretation ideas other than those interpretations in this thesis. To increase the credibility during the interpretation process the aim was to stay close to the text, critically reflect on pre-understanding, and discuss interpretations with supervisors and research colleagues in order to identify alternative interpretations (Dahlberg et al., 2008).

An important aspect of trustworthiness in qualitative studies is whether the research question is relating to the aim of the study, and whether the findings relate to the aim (Patton, 2002). In Study I, the participants were concerned to discuss the negative outcomes of their RN consultative role. It can be discussed whether their concerns have placed pain assessment in the background in relation to the aim of the study. In Study III, the intention was to capture the team perspective of how RNs and CNAs working together managed pain assessment situations. Team-based healthcare has been described as the provision of health services to individuals, families, and/or their communities by at least two health providers who work collaboratively with patients and their caregivers to accomplish shared goals within and across settings to achieve coordinated, high quality care (Mitchell, Wynia, Golden, McNellis, Okun, Webb, & Von Kohorn, 2012). However, as it was difficult to schedule for interviews which included RNs and CNAs simultaneously, individual interviews became the alternative approach to obtain their experiences. The employment of individual interviews to explore team experiences could be a limitation, and there is a possibility that it is individual experiences rather than team experiences that are interpreted.

The open-ended enquiring probably enabled and encouraged the participants to describe their experiences in a natural way (I, II, III). It is suggested that
the qualitative approach may offer possibilities to obtain insights of a sophisticated nature by using open-ended questions, giving the respondents opportunities to develop and describe their own experiences (Patton, 2002). As to the purpose of exploring experiences, the included participants had a variety of work experience and ranged in age, which would have increased the possibility of gaining data from a broad perspective (I, II, III). The impression from the interviews is that the participants very openly described both difficulties and possibilities of pain assessment. A limitation, however, could be that as the participants mainly consisted of women, the gender perspective was limited. There is a possibility that other experiences could have been described from a male perspective. On the other hand, the sampling in the studies portraits the reality of municipal elderly care where female RNs and CNAs are in the majority.

Another challenge of using hermeneutics in research studies is to decide what is the most meaningful and acceptable interpretation (Dahlberg et al., 2008). It would be taken into account that the experiences of reality is changing over time, is bound by context and culture, and where each person interprets reality within his/her individual horizon (Gadamer, 1977). On the one hand, the fact that the participants belonged to the same organisation can be a limitation in relation to transferability (I, II, III). On the other hand, it was not an aim of the thesis to generate generalisation of experiences and, thus, the belonging would rather reflect unique experiences which was important and meaningful to this defined sample within this particular context. However, it cannot be left out that including participants from other municipalities and dementia care practices could have revealed other experiences depending on context and care organisation. Patton (2002) points to the contextual belonging and meaning in qualitative studies and the importance of describing the context when results rely on contextual aspects. Hence, findings from the studies included in this thesis are not automatically transferable to other contexts but rather they would tell the reader about experiences from the included participants and that may have the possibility to be transferable to other contexts similar to the context in this thesis on pain management in people who are limited in self-reporting pain.

Dependability is suggested as referring to the stability of data over time in relation to various conditions (Polit & Tatano Beck, 2008). All interviews in
the thesis were conducted, transcribed and analysed by the author of this thesis. The fact that I was familiar with the care context where the studies were conducted facilitated understanding of concepts and descriptions. However, the impact of my presence and enquiring in the interviews needs to be reflected. Although, the ambition was to maintain open-mindedness in a way that allowed the interviewees to speak freely and to be responsive to follow-up questioning, it cannot be left out that the participants’ descriptions may have been influenced by the interview situation (Patton, 2002). Nevertheless, interview data contained rich descriptions which would indicate that the interviewees were speaking freely on the basis of their experiences (I, II, III).

Straight after each of the interviews memos were written in order to reflect thoughts and ideas from the interview and to context (Creswell, 2009). Memos were not included in the result. Rather they were used to reflect upon in relation to pre-understanding in order to identify whether too narrow limits were drawn from the interviews.

Verbatim transcription was performed as soon as possible after each interview, often the same day or the day after the interview (Dahlberg et al., 2008). These steps taken would increase dependability.

Tentative interpretations were discussed with supervisors and in research seminars in order to minimise neglecting, identify misinterpretation, and to validate interpretations towards data (Ödman, 2007).

Member checking (Creswell, 2009) of tentative interpretations were conducted, where interpretations briefly were presented to all the participants in the study in order to have their reactions and to check for misinterpretation (II). Member checking did not consist of raw transcripts; rather it consisted of follow-up discussion with the participants, providing an opportunity to check for misinterpretation. Member checking as a means of taking preliminary findings back to participants to determine accuracy have been discussed as to whether quality and accuracy can be addressed in this way (Polit & Tatano Beck, 2008). In this thesis, the participants included reacted positively on member checking and confirmed their experiences (II).
Statistical analyses were computed to evaluate reliability and face validity on the APS-SWE (IV). With regard to the degree to which a test is repeatable and how consistent test scores are, test-retest is a widely used method (Raykov & Marcoulides, 2011). The APS-SWE demonstrated adequate test-retest reliability of the total scores both in mobility and in rest, which would suggest that the scale is consistent and reliable (IV). However, test-retest has disadvantages in that certain traits change over time, independently of the measure’s stability (Polit & Tatano Beck, 2008). It could be discussed whether pain is a phenomenon stable to the extent that it is relevant evaluating using test-retest. Although pain may be a changeable phenomenon between testing occasions, it is important to regularly evaluate by using repeated measurements when studies shows that pain prevalence in older people with dementia is high (Achterberg et al., 2010; Zwakhalen, Koopman, Geels, Berger, & Hamers, 2009). A further problem with stability estimates can be memory interference of the observer’s initial responses on the second administration, regardless of the actual values the second measure (Polit & Tatano Beck, 2008). Another critical factor contributing to the magnitude of test-retest reliability is the time interval between the tests (Streiner & Norman, 2008). In the study, observations were performed twice a week at about 8 Am and 12 Am. With regard to nursing staff participants’ work schedule, the length between each day for observation and data registration was no more than 4 days (IV). Literature suggests that there is no single answer as to what is the optimal length in order to obtain a good reliability estimate; however, the interval needs to be long enough in order to minimize memory or learning effects (Raykov & Marcoulides, 2011).

When considering quality in quantitative research studies, Kazdin (2003) suggests that validity and reliability must be addressed. There are several threats to validity that need to be taken into consideration in order to be minimised (Creswell, 2009). Internal validity refers to whether an investigation rules out or makes unlikely alternative explanations of the result, and whether factors other than the independent variable could explain the result (Kazdin, 2003). A threat to internal validity could be sampling (Creswell, 2009). The participants in the study comprised older people with a range of cognitive impairment and dementia (IV). The information of dementia type was ‘unspecific dementia’ for 29% of the resident participants. When inclusion criteria for participating were determined, it
was unknown to me that diagnosing of dementia was poorly recorded. This is because I depended on medical records for this information. However, this was identified when background data from medical journals was collected. Taking the aim of the study into consideration, it was decided to invite all of the older people living in the selected special housing accommodations as they were recorded as cognitive impaired to that extent that they had difficulties with intellectual descriptions. It may be seen as a limitation that a considerable amount of the older people participants were diagnosed with ‘unspecific dementia’. The term ‘unspecific dementia’ is widely used in clinical practice when although dementia symptoms are evident, a physician’s examination could not establish a specific dementia diagnosis (National Board of Health and Welfare, 2014a). National evaluation of dementia diagnosing shows that ‘unspecific dementia’ is the most common diagnosis and diagnosed in 47.6% of all cases. Thus, adequate diagnosing is identified as an important issue in need of improvement (National Board of Health and Welfare, 2014a). It should be noted that to be allowed to move permanently into special housing accommodation in Sweden, cognitive impairment should be that severe as to heavily affect the person’s everyday life and prevent the person from managing daily life on his/her own. However, not all who move into special housing accommodation have gone through basic investigation for dementia although dementia symptoms may be displayed. Since the original Abbey Pain Scale is developed to assist in pain assessment situations in people who are unable to clearly articulate their pain problems (Abbey et al., 2004), and evaluated in studies comprising similar samples as to those in this thesis, the sample in the study (IV) was considered representative of the target population for which the scale originally was developed.

Non-responding could be a further threat to internal validity (Creswell, 2009). In Study IV, the same nursing staff participant observed and assessed the same person throughout the study. All included nursing staff completed the study which would strengthen internal validity. However, seven of the nursing staff participants assessed two residents each, which could have influenced to become somewhat more trained in using the APS-SWE than those nursing staff participants who assessed one resident only. The reason for this was that the number of nursing staff participants included in the study was lesser than that of resident participants included. To be able to
include as many resident participants as possible, seven nursing staff participants assessed two residents each.

As to data registration on the APS-SWE, the analysis showed that there were few internal missing data, which would strengthen internal validity. The large amount of nursing staff conducting data registration, in the same setting and similar conditions throughout the study, would strengthen validity. During the data registration period, I regularly visited all special housing accommodations included in the study to follow up registrations and to be available if there were any questions about the data collection procedure, which as well would have influenced internal validity.

A further threat to validity concerns instrument development and whether the instrument used is changed during the ongoing study (Creswell, 2009). A reflection of the APS-SWE (IV) concerns translation in language other than English, which is the original language of the Abbey Pain Scale. Instrument translation and evaluation of translation is claimed to be an important component in the process of developing research instruments into the language of the culture being studied (Aubin et al., 2007; Maneesriwongul & Dixon, 2004). The language translation of the APS-SWE followed a standardised research method that helped to systematically scrutinise the language in the current Swedish version of the Abbey Pain Scale as this version had not been undertaken translation following a scientific method and was not equivalent with the original Abbey Pain Scale (Abbey et al., 2004) to its construct. The expert panel of clinicians and researchers was assembled to assess the content and semantic equivalence between the current Swedish version of the Abbey Pain Scale and the original scale, which would strengthen internal validity. The meaning of each item of the Abbey Pain Scale was compared with the original version for equivalence. This was also undertaken to assess whether the original Abbey Pain Scale, developed in Australia, was appropriate for use in Swedish cultural settings. After adjustments in accordance with the original Abbey Pain Scale, the APS-SWE was used throughout the study without any further adjustments being undertaken (IV).

The questionnaire APS-SWEQ was designed to evaluate face validity of the APS-SWE for pain assessment (IV). The construct of the APS-SWEQ was
related to the item construct and terminology of the APS-SWE, with the purpose of evaluating the appropriateness of the items for pain assessment. Face validity refers to whether the instrument looks as though it is measuring the appropriate construct (Polit & Tatano Beck, 2008). Another definition of face validity is the judgement that a scale looks reasonable and if the instrument appears to be assessing the desired qualities (Streiner & Norman, 2008). In total, 68 questionnaires were distributed, resulting in 66 responses (97%), which demonstrate a small number of drop-outs. From the responses, adequate face validity was established which would strengthen validity and indicate that the APS-SWE was considered valid among the sample included in the study (IV).

Another threat to validity concerns study instructions and the way in which information and instructions are given to participants (Kazdin, 2003). Instructions about the study and how to administer the APS-SWE for data registration was clarified in instructional classes before observation took place in order to minimise the risk of misunderstandings during observation and data registration in practice (IV). All nursing staff participants were given the same instructions. From statistic analysing, only a small amount of error was found which was likely to be due to instructional training. During the instructional class, assessment of pain in people with cognitive impairment and dementia was discussed, which probably raised the nursing staff participants’ awareness.

External validity refers to what extent the result can be generalised to others not included in the specific study (Kazdin, 2003). Threats to external validity include interaction of setting and selection (Creswell, 2009). The included special housing accommodations were equivalent to their environment and care structure. Observation and data registration was conducted based on the same conditions and at about the same time of period of the day in order to establish as equivalent conditions as possible (IV). However, it could not be left out that as I was not constantly present during the entire data collection period, there is a possibility that conditions for some reason could have changed at one or several occasions.

Judgement of reliability deals with whether an instrument used in a study accurately and consistently measures stability, internal consistency, and
equivalence (Streiner & Norman, 2008). The APS-SWE demonstrated adequate internal consistency with all alpha values above .70 (which indicates that 70% of the measurement is reliable of the variance and 30% have random errors), suggesting satisfactory homogeneity among the items and indicating that the scale measures in a reliable way (Streiner & Norman, 2008). Alphas above .70 is suggested as a rule of thumb of reliability coefficient equivalence in research evaluation of health measurement scales although at least .80, and preferably .90, would be viewed as needed to place trust in scores (Bland & Altman, 2010; Cronbach, 1990). For research on group level, alpha above .70 is suggested as minimum for reliability and above .80 as desirable (Bland & Altman, 2010). In clinical practice, and on an individual level, alpha above .90 is the preferred value for important decisions (Cronbach, 1990; Streiner & Norman, 2008). To a great extent, the older people participants were scored 0-2 (absence of pain) on the APS-SWE, which leaves fairly little variation to the statistical analysis (IV). This would probably have influenced alpha values.

Comparing reliability results is somewhat challenging when studies evaluating pain scales among people with dementia have rarely used the same methods or use equivalent sampling. Thus, comparing Cronbach’s alpha value studies in between is suggested to be made with caution as comparing alpha is relevant only in relation to studies which include similar sampling and study conditions (Raykov & Marcoulides, 2011). In study IV, it was an ambition to carefully present reliability results along with study design and sampling.

In practice, CNAs are in staff majority and, thus, the number of CNAs in the study was greater than that of RNs. Including both CNAs and RNs was based on the assumption of including those nursing staffs who worked together on daily basis in each of the special housing accommodations included in the study and that would benefit of using evidence-based pain tools for decision making about pain (IV). In this study, it was not a purpose to achieve equivalent numbers of CNAs and RNs, nor to compare scoring as to their occupation belonging. When computing the Spearman correlation test, no associations were found between the nursing staff’s scoring on the APS-SWEQ regarding age or working experience.
Discussion of the findings

The overall aim of the thesis was to explore and describe RNs’ and CNAs’ experiences of pain assessment in older people with cognitive impairment and dementia. A further aim was to evaluate the Abbey Pain Scale-SWE (APS-SWE) in dementia care practice. The main findings show that the RNs experiences of pain assessment in people with cognitive impairment and dementia are challenging primarily due to their changed RN role, where they find themselves to a greater extent working as administrative consultants rather than providing bedside care, which in turn limits the time they are able to spend providing routine daily nursing care for longer interval, negatively influencing detection and assessment of pain symptoms (I). It was also found that this situation has influenced pain assessment routines in that RNs to a greater extent than previous have to rely on CNAs’ information about pain, as it is the CNAs who are the front-line staff providing routine care and often are the first to recognise symptoms of pain (I, II, III). This experience was more clearly defined from the RNs working in special housing facilities than that of home healthcare. In turn, the CNAs describe that they recognise signs of pain by being present and attentive in the care situation, facing and readily responding to signs and expressions that could be due to pain. Good knowledge of the individual person enables recognition of behavioural and physical changes in the person’s usual pattern. Furthermore, providing care in a preventively, protectively, and supportively way enables detection of symptoms of pain and helps to avoid painful situations occurring (II). RNs and CNAs working together in home healthcare teams use an array of strategies to detect and assess pain involving verbal communication with the person undertaking the assessment, observation, checking physical reactions, dialogue with next of kin and by using the self-rating scale VAS. The close collaboration between RNs and CNAs in this settings enables to manage pain assessment situations (III). Communicating effectively within the healthcare team has been highlighted as an important contributor in pain assessment situations (MacSorley, White, Conerly, Walker, Lofton, Ragland et al., 2014). However, using the VAS with older people who are cognitively impaired to the extent that they do not understand how to score on the VAS is considered problematic by the RNs (III). Many self-report instruments such as the VAS have a unidimensional construct, in that they provide an
indicator of pain intensity alone, disregarding other pain qualities, location, and functions (Hadjistavropoulos et al., 2007). Furthermore, the VAS has demonstrated substantially high error rate among older people compared with the NRS and thus is not recommended in this population (Hadjistavropoulos et al., 2014; Wood, Nicholas, Blyth, Asgahri, & Gibson, 2010). When the observational behaviour pain assessment scale the APS-SWE was evaluated in dementia care practice, adequate internal consistency, reliability, and face validity for pain assessment was demonstrated (IV), which would suggest that the scale is a useful pain tool to RNs and CNAs in the care of people who are limited in verbally and intellectual expressing pain. In the discussion section, the main findings of detection and assessment of pain in people with cognitive impairment and dementia by RNs and CNAs are discussed in relation to person-centred care as described in literature and to implications in dementia care practice.

**Relationship-centred care as the foundation to detect and assess pain**

In this thesis, it is apparent that managing pain assessment situations among people with cognitive impairment and dementia to a great extent relies on robust collaboration between RNs and CNAs, trusting on each other’s competence to detect, assess and report pain symptoms, and where their experience-based knowledge and medical skills can complement each other in pain assessment situations (III). It has also become obvious that it is important to establish a trustful relationship with the person in need of care in order to be able to recognise changes in usual pattern that could possibly be due to pain (II, III). Collaboration quality was more specifically referred to by the RNs and CNAs in the home healthcare teams when compared to those providing care in special housing accommodation. One explanation for this could be that the different roles and responsibilities of RN and CNA may be more clearly defined in the home healthcare setting and that this is based on the situation of feeling safe and competent in the team. Prior research have shown that the importance of each team member’s functions, responsibilities, and accountability to have a clear understanding and expectation of each role improves the team’s efficiency (MacSorley et al., 2014).
In the thesis, it was described that detection and assessment of pain in people with dementia can be a prolonged process and that calls for having sufficient time to be present in care situations to be able to draw significant conclusions of individual displays or behaviour and their relation to pain (III). However, it was also experienced that the nurse consultant function have put RNs somewhat distant from routine care and rather closer to administrative duties, which prevents recognising changes and early detections of pain (I). Findings from prior research reveal that nurse consultant role achievement has organisational influences involving support systems, internal trust networks and forums as well as links with higher education institutions, and where RNs experiences ambiguity about the role, and that change nursing roles are not always easily accepted in multidisciplinary settings (Norell et al., 2010; O’Baugh, Wilkes, Vaughan & O’Donnohugh, 2007; Woodward, Webb & Prowse, 2006). The RNs in this thesis experienced that the nurse consultant role limits making adequate pain assessment and that it had a negative impact on pain assessment quality (I). Furthermore, the RNs expressed their profound dependency on CNAs, as the front-line staff, to obtain daily reports of information (I, III). Similar findings of dependency have been found in other Swedish studies (Nilsson et al., 2009; Norell et al., 2013).

The nurse consultant role is not found in Sweden only. In the United Kingdom, the nurse consultant role was introduced in the year 2000 with the intention of achieving better outcomes for patients by improving quality and services (Department of Health, 2000; Fontaine, 2007). Clinical nurse consultants were also introduced in Australia as early as 1986. Despite shifting roles among RNs and CNAs, the nurse consultant contribution in the elderly care setting is not yet well evaluated (Kennedy, McDonnell, Gerrish, Howarth, Pollard, & Redman, 2012; Westlund & Larsson, 2002).

Returning to the Swedish perspective, there has been a trend of decreasing numbers of RNs in municipal care and that has resulted in RNs having decreased presence time with the people they are caring for, and to a greater extent providing nursing care at a distance as their role increasingly takes on more of a consultative focus together with an increased amount of administrative work duties (Josefsson, 2006; Szebehely & Trydegårð, 2012; Tunedal & Fagerberg, 2001). This situation is also patterned in this thesis,
where RNs also have felt a need for collegial support in complex pain assessment situations (I). For the RNs, being occupied with an increasing amount of administrative duties, reducing in-depth knowledge of the person cared for leads to uncertainties about individual pain expressions (I). Prior nurse research has shown that uncertainty about pain may include underrecognition and undertreatment of pain as well as treatment delays (Gilmore-Bykovskyy & Bowers, 2013). Swedish research shows that organisational changes in elderly care in Sweden have generally altered the RNs’ work situation from being close collaborators with physicians to today, where they consider themselves being solely responsible and lacking superiors for consultation (Josefsson et al., 2007; Tunedal & Fagerberg, 2001). In Sweden, the nurse consultative role of RNs working in municipal elderly care has been discussed with criticism regarding its development and characteristics in relation to principles of organisation, responsibility areas, delegation processes, and leadership (Bystedt et al., 2011; Heikkilä, 2006; Karlsson, Ekman & Fagerberg, 2009; Nilsson et al., 2009; SOSFS, 1997; Tunedal & Fagerberg, 2005; Westlund & Larsson, 2002). As an outcome found in this thesis, CNAs have become the RNs’ extended arm in the provision of care and in pain assessment situations (II).

From an internationally perspective, nursing assistants as front-line staff in routine care has been illuminated in prior research pointing to their importance as pain reporters to RNs (Holloway & McConigley, 2009; Horgas & Dunn, 2001; Liu, 2014; Scherder & van Manen, 2005; Yi-Heng et al., 2010). In this thesis, it was uncovered that a significant amount of the care and assessments was delegated to CNAs (II) but also that pain assessment situations was benefitting from the collaborative and relationship-centred way of working (III). In a Swedish study of RNs’ prioritized delegations in municipal elderly care settings, it was shown that the delegated nursing intervention time to non-certified staff was 62% (Norell et al., 2013). Common in Swedish elderly home care is that RNs work independently, and lead the care team without being a part of it when time pressure is perceived as high (Norell et al., 2013). According to national directions, RNs are supposed to lead CNAs in the nursing care by instructions, supervising and, delegations (SOSSF, 1997). However, the RNs in this thesis were somewhat concerned about to a great extent having become second hand receivers of pain information, which points to
suboptimal pain assessment (I). Prior studies have found similar concerns among RNs’ shifting roles in the care, with assisting nurses’ role expansion and RNs’ role as moving away from the bedside (Kennedy et al., 2012; Pearcey, 2008). This is important findings to reflect on in relation to optimal pain management. This situation is confirmed in prior research which shows that Swedish RNs working in municipal care feel striking a balance between the perceived demands and their own view of the RN role; a role which they find vague and in need of support (Furåker, 2008; Hallin & Danielsson, 2007; Josefsson et al., 2007; Skytt et al., 2008).

CNAs’ perception of pain emerges from their presence in the regular care and alertness to pain symptoms, allowing reflection on whether pain may be involved (II). This corresponds to relationship-centred care which helps to meet the needs of the person cared for (McCormack & McCance, 2010). Comparing Swedish nurse assistants with, for example Australian nurse assistants, there have been similar developments in increased responsibility for the routine care under the supervision of the RN (Nurses Board of Western Australia, 2006). Holloway and McConigley (2009) reported similar findings, describing nursing assistants’ fundamental ability in pain detection and pain assessment in older people living in nursing homes such as knowing the person, emotional attachment, extended roles and teamwork. Also Liu (2014) points to the role nursing assistants play in the process of pain management for cognitively impaired nursing home residents in terms of pain assessor, reporter and, subordinate implementing prescribed medication. Good knowledge of the person involving relationship-centredness to recognise changes is also supported from previous research in dementia settings (Mentes, Teer and Cadogan, 2004; Smebye & Kirlevold, 2013).

Previous research has supported the idea that assessment of pain in people who have limited ability to self-report rely foremost on nurses’ interpretations (Cohen-Mansfield & Creedon, 2002; Dobbs et al., 2014). The RNs’ and CNAs’ interpretations of pain in this thesis are reflected through the lens of person-centredness and the provision of person-centred care to meet multi-dimensional needs and preferences of people dependent on professional care by acknowledging, respecting and including each person’s life story, personality, and capacity (McCormack & McCance, 2010). A
clear ambition to maintain a person-centred approach in the care was revealed in the interviews (II, III). However, stress-related work conditions and lack of staff continuity were experienced as a threat to the provision of person-centred care (III). In literature, person-centred care is suggested to result in better understanding and more appropriate care (Edvardsson et al., 2014; Maslow, 2013). The theoretical and philosophical concept of person-centred care uses a variety of practice explanations within the healthcare context to improve care and outcomes for people who have various diseases, conditions, and care needs. In essence, the person-centred care approach is based on care being organised and provided around the needs and preferences of the person rather than the needs and preferences of care providers and institutions (McCormack, 2004). From the RNs’ and CNAs’ experiences of pain assessment in home health care settings, it was revealed that stressful work situations prevented them from being alert to fully responding to the person’s needs, which in turn could lead to overlooking symptoms of pain (III).

**A social and humanistic perspective on pain**

A central finding in the thesis was the importance of being present in the care situation and encountering the person based on good knowledge of him/her in order to be able to detect physical and behaviour changes that could be due to pain (I, II, III). Similar finding of behavioural change as pain indicator has been found in other studies (Kankkunen, Jänis & Vehviläinen-Julkunen, 2010). This finding corresponds to the perspective of person-centredness by being socially and accessibly involved. In Sweden, as in several other countries worldwide, the provision of person-centred care has been made mandatory in central legislation and government regulations and in professional and provider association guidelines for medical, residential, and home- and community-based care settings, including the dementia setting (Centres for Medicare and Medicaid Services, 2012; Demensförbundet, 2012; Department of Health, 2009; National Board of Health and Welfare, 2011a). Elderly care in Sweden has adapted to person-centred care as required competencies for care providers, and local as well as regional education programmes to direct care workers such as RNs and CNAs have been initiated (National Board of Health and Welfare, 2012; Svenskt Demenscentrum, 2015a, 2015b). What is urgent to reflect on is how
can person-centredness be measured and evaluated in clinical practice if the person in need of care is not capable of completing their response by verbal dialogue or by survey about pain? In other words, how do we know that we are providing person-centred care? Furthermore, is there a special track of person-centred care for people with dementia compared to that adopted with people in general with respect to decreased ability to participate in decision makings due to cognitive impairment? Literature suggests there is (Fossey et al., 2014). For example, in the UK and US, the principles of person-centred care and dementia are strongly influenced by the ideas of Tom Kitwood (1995, 1997), founded on a conceptual basis and practice-based knowledge about person-centred care for people suffering from dementia, and conceptualised in the Dementia Care Mapping (DCM) (Brooker & Surr, 2006). The DCM was originally developed as a clinical tool but has attracted interest as a potential observational measure of quality of life and well-being of long-term care residents with dementia.

As has been revealed in this thesis, pain assessment in people with dementia was critical to the fact that when verbal dialogue was difficult to achieve, it was important to have good knowledge of the person to the extent that a change in pattern could be identified (II). This would connect closely to person-centred principles in order to understand and meet humanistic and individual needs. Moreover, using multiple assessment strategies to investigate and assess the quality of pain points to the motivation of person-centredness, taking account of each individual (III). Prior research claims that the effect of person-centredness on patient outcomes has not yet been particularly well investigated although the concept of person-centred care has been implemented into policies and guidelines in several countries around the world (Brooker, 2007; Brownie & Nancarrow, 2013; Edvardsson et al., 2014). Nonetheless, it can be assumed that the principles of person-centred care would benefit pain management in vulnerable and dependent people. Interestingly, the few studies that to some extent have evaluated outcomes of person-centred care in dementia settings have found that nursing staff’s person-centred interventions are not only beneficial to the person who receives the care but also for nursing staff themselves in that they experience the provision of good care (Brownie & Nancarrow, 2013; Edvardsson et al., 2014; Sjögren, 2013; Willemse, De Jong, Smit, Visser, Depla & Pot, 2015).
Moving from the theoretical concept of person-centred care into day-to-day dementia practice, the issue of how to put theory into practice may be managed somewhat differently depending on the characteristics of the public sector. Settings included in this thesis comprised both special housing accommodation (I, II, IV) and home healthcare (III). However, even to the best of RNs’ and CNAs’ ambitions to provide person-centred care, this sometimes seemed difficult to apply as fully as possible due to heavy workloads and a stress-related environment (I, III). Literature has questioned how care providers can know the needs and preferences of a person with dementia and how can care providers ensure that the person’s needs guides decisions about the care? Furthermore, how and to what extent can care providers involve relatives in care decisions, compromising the fundamental focus on individual autonomy (Maslow, 2013). Based on the findings in this thesis, these questions can be answered in terms of the RNs’ and CNAs’ establishment of personhood with the older people being cared for, indicating a social and humanistic attitude to their care (II, III), perceptiveness and alertness to recognising new or strange displays which may be due to pain, competencies and courage to deal with challenging behaviours such as depression, anxiety or aggressiveness (II), and by obtaining background information from next of kin, who are regarded as good sources of information (I, III).

A further interesting finding was the CNAs’ personal pain experience influencing their interpretation of pain. This was interwoven with empathy for the older person’s pain experience and explained in terms of humanity (II). Similar was found in Dobbs et al (2014), showing that the personal pain experience was translated into empathy for the older vulnerable person with chronic pain. In literature, the empathy factor in pain assessment situations is explained in terms of being intertwined in the human relationship (McCaffery, 1968). Carl Rogers (1957) concluded that accurate empathy is a necessary condition for therapists in helping others in sensing the person’s private world as if it were one’s own, but without being overinvolved and overwhelmed by the person’s experience. It has been claimed that the observer’s affective responses to facing other persons’ distress may consist of responses oriented to the other as an altruistic motivation to help (Batson, 1991). Empathy also connects closely to the elements of person-centred care (Crandall et al., 2007; Smebye & Kirkevold, 2013). Thus, empathy for
vulnerable people would have a natural relationship to humanity (Sellevold, Egede-Nissen, Jakobsen & Sørlie, 2013). Findings in this thesis provide support for the use of empathy in pain assessment situations experienced by the person (II), but should be important for further reflection on whether this could bias pain interpretation and pain treatment (Monroe & Mion, 2012). Although empathy is based on humanly concerns, it may also rely on subjective values, limiting objective perspectives of pain (Benedetti et al., 2004; Carlino et al., 2010). On the one hand, empathy allows acknowledging patient expressions. On the other hand, there is a risk that empathy could bring a bias for something other than pain (Cohen-Mansfield, 2008; Dobbs et al., 2014).

It could be identified that if verbal communication is difficult to establish, several various and complementary assessment strategies are used to assess pain (III). Similar strategies have been found in prior research studies (Dobbs et al., 2014; Kovach, Muchka, Noonan & Weissman, 2000). In addition, Dobbs et al. (2014) found that the most prominent strategy was the ‘guessing game’, which became an in vivo code to address that it was a guessing game to identify where pain was located. Nevertheless, that pain was present was not that difficult to detect, by being attentive to a moaning expression or a change in behaviour. Similar experiences of judging the location of pain were found in this thesis (II). It was also found that facial responses of pain were considered as important pain indicators (II, IV). Similar findings of facial expression as a sensitive and reliable pain indicator have been found in prior research (Hadjistavropoulos et al., 2014; Kovach et al, 2000; Kunz, Scharmann, Hemmeter, Schepelmann, Lautenbacher, 2007; Lautenbacher, Niewelt & Kunz, 2013), which support the social and humanistic fundamental that being present and face-to-face in the care situation is essential to be able to recognise facial expressions that could possibly be due to pain.

Organisational aspects of care delivery and pain assessment

The home healthcare setting is, by its nature, a different arena compared to that of nursing homes. One could assume that pain assessment in people living in their own home should be somewhat more challenging than that of those living in special housing accommodation which is staffed round-the-
clock. In home healthcare, care staffs visit the person in need of care for briefer periods. Despite this, the home healthcare teams included in this thesis described their alertness on responding to symptoms that they interpreted to be due to pain (III). However, it was described that if too many care staff were involved in the pain assessment procedure, it was somewhat problematic to maintain continuity. Lacking continuity was considered negative in pain assessment situations, making it more difficult to evaluate care interventions (III). Continuity has been described as challenging to maintain in home healthcare and in need of improvement (National Board of Health and Welfare, 2014a; Szebehley & Trydegård, 2012). Furthermore, in the national evaluation involving home health care, lacking co-operation quality was found (National Board of Health and Welfare, 2014b). Nevertheless, in this thesis the co-operation quality between RNs and CNAs was evident and helped in pain assessment situations (III). However, time constraint was considered a restricting factor and that could lead to overlooking pain symptoms (III). Similar was found in Tönnessen, Nortvedt, and Förde (2011), where time constraint was suggested to lead to a confined focus, jeopardising nurses’ sensitivity and a barrier to adequately assess symptoms of pain in people with cognitive impairment. It was also found that nurses felt themselves governed by the clock rather than by care recipients’ individual needs (Tönnessen et al., 2011). Similar experiences were found in this thesis, where the CNAs and RNs considered it a difficult task to manage the daily care list whilst still maintaining the quality of care (III). Also other studies have pointed to how organisational aspects of care delivery heavily influence the choice of pain management strategies (Norell et al., 2013; Shoefield, 2013). These findings indicate a collision between the need for adequate time in pain assessment situations and organisational demands on effectiveness. The consequences of extensive workloads and staff shortages in home healthcare settings in relation to priorities and decisions have been highlighted as a threat to care quality not only in Sweden (Szebehley & Trydegård, 2012) but also in other countries (Gallagher, Alcock, Diem, Angus & Medves, 2002; Tönnesssen et al., 2011). This relates to the protection of values, standards of care, and the nurses’ role and responsibility not only in pain assessment situations but also in care in general when resources are limited (Hertting, Nilsson, Theorell, Sätterlund & Larsson, 2004). Having sufficient time to encounter and
provide care would thus be a key element to detect and assess pain in people living with dementia.

**Utility of the APS-SWE for pain assessment in dementia care practice**

When the findings from study I, II, III showed that pain assessment was experienced challenging and that method for pain assessment primarily rely on interpretation but without the support from appropriate and validated pain tools, the APS-SWE was evaluated in dementia practice. The contribution of validated standardised observational approaches in people with dementia to decrease the risk of observer bias has been highlighted in previous studies (Hadjistavropoulos et al., 2007; Herr et al., 2011; The Australian Pain, 2005; Zwakhalen et al., 2006b). The APS-SWE showed adequate reliability and face validity (IV) which correspond to previous research of the Abbey pain scale in similar settings, indicating that the APS-SWE is a useful pain scale to assist in pain assessment (Abbey et al., 2004; Liu et al., 2010; Lukas et al., 2013b; Neville & Ostini, 2014; Takai et al., 2010b; Takai et al., 2014). However, prior reliability estimation of the original Abbey Pain Scale have been evaluated in somewhat varying samples (Abbey et al., 2004; Liu et al., 2010; Lukas et al., 2013b; Neville & Ostini, 2014; Takai et al., 2010b; Zwakhalen et al., 2006a). When the APS-SWE was evaluated on test-retest reliability, an overall stability of repeated measures was supported, except for the item *Behavioural change* (IV). One explanation to this may be that the display of behaviour change is challenging to judge in relation to pain. On the other hand, association between behaviour change and pain has been found (Ahn & Horgas, 2013; Husebo et al., 2011), which would suggest that the item *Behaviour change* not automatically should be omitted from the scale in order to be more reliable. Instead, the relationship between change behaviour, like in BPSD symptoms, and pain needs to be further explored to find out how pain affects these symptoms and how the symptoms affect the pain expression. In Takai et al. (2014), it was found that item *Behaviour change* demonstrated significantly higher scores among those with lower MMSE score. However, it was also found that pain intensity tended to be overestimated in this group, which indicates that caution is required when using the scale to compare scores among older people with different cognitive capacity because of the possibility of overestimation of pain in
people with low cognitive capacity. Thus, further research is needed to investigate associations of changed behaviour and pain among people with dementia who have limited capacity to verbally express and discuss pain.

This thesis found that RNs’ and CNAs’ detection and assessment of pain primarily is based on proxy rating without using pain scales (I, II, III). It is a well-known fact that proxy assessment has less validity than self-reporting and that proxy assessment, by its nature, is recognised as a challenge when to judge and assess other peoples’ subjective pain sensation (Horgas & Dunn, 2001; Jensen-Dahm, Vogel, Waldorff & Waldemar, 2012; Kovach et al., 2001). Comparing the difference in item scores of the Abbey Pain Scale to self-reporting, prior research found that the total score of the Abbey Pain Scale was significantly higher among those who reported pain compared with those reporting no pain, regardless of their cognitive levels (Takai et al., 2014). However, when scores were compared according to their cognitive level, total pain intensity was significantly higher in the lowest cognitive group. Nurses’ pain judgement has been discussed in several studies, pointing to varieties in pain reporting which indicate that pain assessment in dementia is a complicated and difficult care phenomenon (Cohen-Mansfield & Creedon, 2002; Dobbs et al., 2014; Yi-Heng et al., 2010). Nevertheless, in later stages of dementia there is a lack of optional means of assessment and where proxy rating may become the alternative.

Face validity of the APS-SWE for pain assessment was established by using the questionnaire APS-SWEQ. After completed observation and data registration by the RNs and CNAs, the APS-SWEQ was administered (IV). The high response rate and rated appropriateness of the APS-SWE supported face validity by the nursing staff participants. There are several ideas for how to establish face validity, with the main purpose of evaluating whether the items have meaning and relevance and are self-evident (Polit & Tatano Beck, 2008). Several studies have investigated the utility of observational behaviour pain scales by using qualitative information for face validity. For example, the original study of the Abbey Pain Scale used focus group interviewing (Abbey et al., 2004), while Zwakhalen et al. (2006a) used individual interviews to evaluate nursing staffs’ experiences of the PACSLAC-D scale for regular use on pain assessment. As it was considered important to obtain the nursing staff participants’ opinions of using the APS-
SWE, a free text comment box was included in the APS-SWEQ to allow qualitative comments to be given whilst using the APS-SWE. The comments given by the nursing staff participants were a valuable contribution for further research of the APS-SWE.

The result of the evaluation of the APS-SWE would be a first step to improvements in pain assessment procedures in municipal dementia care practice. RNs have a professional responsibility to implement strategies to reduce pain experienced by patients and to evaluate the efficacy of strategies they choose to implement (SOSFS, 1997:14). Implementation of the APS-SWE into Swedish dementia care practice can benefit both RNs and CNAs in pain assessment and pain evaluation in older people who have diminished capacity to verbalise pain. The APS-SWE would also have the possibility to bridging the gap of some of the barriers to pain assessment that was found in this thesis. Systematically applied, the APS-SWE could serve as an important contributor as a communication tool between RNs and CNAs when reporting and evaluating pain in those cases where pain assessment is challenging.

The fact that the Abbey Pain Scale is implemented into several national quality registries such as the Swedish Palliative registry and the Swedish registry for Behavioural and Psychiatric Symptoms in Dementia, but to this date without being scientifically evaluated in its suggested setting was a contributor to test and evaluate the scale in dementia practice. National agreements on the implementation of an evidence-based practice (EBP) (i.e. a conscious and systematic use of multiple knowledge sources for decision about care contributions) into the social services and healthcare are articulated by The Swedish Association of Local Authorities and the Federation of Swedish County Councils and the government (2015). This would include implementation of evidence-based pain tools in clinical practice as a credible complement to the experience-based knowledge of RNs and CNAs. Although EBP is a worldwide approach to improving health care, there is, however, a shortage of studies examining whether or not health care professionals are actually applying EBP in their daily work (Eccles, Grimshaw, Walker, Johnston & Pitts, 2005; Grol & Grimshaw, 2003). Research has found that RNs reported a relatively low use of research findings in daily practice, despite a positive attitude to research. It was found
that the limited use was due to lack of access to research reports at the work place and lack of support from managers and colleagues (Boström et al., 2008). A further Swedish study showed similar findings of newly graduating RNs’ (2 years post-graduation) application of EBP in clinical practice, despite EBP being an important objective in Swedish health care and educational programmes (Boström, Ehrenberg, Gustavsson & Wallin, 2009). This is important findings to consider in pain management implementation processes into municipal elderly care organisation, requiring providing RNs with a supportive organisational structure to increase their research use in practice. This would also involve training in the use of scientific information sources as well as to supportive leadership.

The RNs and CNAs who evaluated the APS-SWE were not familiar with using observational behaviour scales (IV) and so this was their very first time for using an observational behaviour pain assessment scale. Thus, instructional classes were organised to make sure that they were able to apply the APS-SWE correct and consistent (IV). The aim with the training was to learn the techniques of delivery and scoring the APS-SWE. In prior research, staff training in how to use a pain tool before testing has been reported to be an important component to minimize observer biases in pain assessment (Abbey et al., 2004; Liu et al., 2010; Torvik, Kaasa, Kirkevold, Saltvedt, Hölen, Fayers & Rustøen, 2010; Zwakhalen et al., 2012). Research has suggested that observer judgements are the product of both bottom-up input (observation of self-report and non-verbal expressions), and top-down processing, wherein observer knowledge, experience, and biases affect the judgement (Goubert, Craig, Vervoort, Morley, Sullivan, Williams et al., 2005). When preparing for a successful implementation of the APS-SWE into Swedish municipal dementia care practice, staff training would be essential. Thus, a comprehensive pain management programme, including APS-SWE and manual along with staff training, would be a contributor to the achievement of an EBP. Looking internationally, the Abbey Pain Scale is implemented in the UK assessment guidelines (Royal College of Physicians, British Geriatrics Society, British Pain Society, 2007) and in residential aged care facilities in Australia (Gouke, Scherer, Katz, Gibson, Farrel & Bradbeer, 2005).
Applying person-centred care in pain assessment situations

A major benefit of person-centred care is its strong and central focus on seeing and knowing the person, which was also found in this thesis. Taking into account that people with dementia are limited to participate in decision-making about their pain and pain treatment, it would be beneficial to add the APS-SWE into the RNs’ and CNAs’ current toolbox of person-centred pain assessment strategies to assist in pain assessment situations and to improve pain management in dementia care practice.

Clearly, the findings in this thesis correspond to the declarations of person-centred care, in that the unique person’s display and behaviour are acknowledged when investigate pain, and the effort of establishing trustful relationship with the person as well as of gathering background information of previous pain problems by involving relatives. This indicates that RNs’ and CNAs’ detection and assessment of pain follow the principles of a person-centred approach in the care. Nevertheless, yet much rely on nursing staff’s interpretations of how person-centred care can be applied in pain assessment. Based on the findings of the study (IV), adding the APS-SWE to assess and evaluate pain symptoms can contribute as an appropriate and person-centred pain tool in those cases where the VAS is problematic to use.

The CNAs described the facial expression as an important display to pay attention to when investigate pain (II), and the APS-SWEQ demonstrated that the item Facial expression in the APS-SWE was the most frequent scored item (IV). In a comparative study, the Abbey Pain Scale was found to be one out of three observational behavioural pain scales that were noted as most promising to capture relevant facial expressions (Sheu, Versloot, Nader, Kerr, & Craig, 2011). This is further promising findings for utility of the APS-SWE as a person-centred observational behavioural pain assessment tool in dementia care practice.

However, despite the availability of a number of guidelines and instruments to influence the care of people with dementia in pain, this thesis shows that putting those into practice remain although the RNs and CNAs had developed several other useful strategies to detect and assess pain. Taking into account the model of pain and dementia presented by Wall and White
(2012), several of the components in the model could be identified in this thesis as well. For example, it was revealed that a robust collaboration climate enabled to manage pain assessment (III), providing the care guided by a person-centred approach (II, III), barriers and facilitators of pain information between RNs and CNAs (I, II, III), and the need for training in using pain assessment scales (IV). Complementing evidence-based methods and instruments added to the experience-based knowledge and person-centred pain assessment strategies by the RNs and CNAs would be promising for future pain management improvements in municipal dementia care practice.

People with dementia differ in many ways which affects their functioning and care needs due to an array of decreasing cognitive and functional abilities. Dementia symptoms vary depending on the person’s underlying disease or diseases, and as dementia is progressive, dementia-related symptoms, functioning and care needs are likely to change over time which in turn complicates pain investigation. Thus, life experience and personality characteristics become vital to recognise changes in normal patterns which may be due to pain and discomfort. Findings in this thesis reveal RNs’ and CNAs’ consciousness about these aspects and efforts to achieve person-centred care in detection and assessment of pain. However, the thesis also shows that implementation of evidence-based pain scales for people with dementia remains. It is the wish of this thesis that the findings can contribute to improvements in RNs’ and CNAs’ methods for pain assessment in older people living with cognitive impairment and dementia in order to strengthen credibility of pain management quality in Swedish municipal elderly care.
Conclusions

This thesis shows that detection and assessment of pain in people living with cognitive impairment and dementia is experienced as multifaceted and complicated by RNs and CNAs working in municipal dementia care practice, involving multiple components in the assessment procedure.

- The RNs in special housing accommodation settings experiences that pain assessments in people with dementia is challenging primarily due to their changed RN role into consultant advisors, which have led to that they to a greater extent must rely on CNAs’ information about pain
- CNAs’ perception of pain in people with dementia emerges from being present and alert in the care situation, which allows changes in the person’s usual pattern to be recognised
- A robust collaborative work relationship between RNs and CNAs taking advantage of each other’s competences facilitates managing pain assessment situations
- Recognising pain involves a complex interaction of sensory, cognitive, emotional, and behavioural components and where the RNs’ and CNAs’ experience-based knowledge is used rather than appropriate and evidenced-based pain tools
- Evaluation of the APS-SWE support adequate internal consistency and test-retest reliability for pain assessment among older people with cognitive impairment and dementia, and face validity for pain assessment by the nursing staff participants
Clinical implications

- Collaboration quality between RNs and CNAs is essential to obtain comprehensive knowledge of the person in need of care, and lay the foundation for pain assessment procedures among people living with dementia.

- The use of a person-centred perspective in pain assessment situations enables a deeper and better understanding of individual displays that may be due to pain.

- Systematic routines for pain assessment in dementia care practice can benefit from using the observational behaviour pain assessment scale APS-SWE to assist in decision-making about pain.

- Training in how to use observational behavioural pain assessment scales like the APS-SWE should be accessible to RNs and CNAs working in dementia care practice in order to meet the recommendations for an evidence-based practice.

- The APS-SWE can serve as a useful communicative tool in RNs’ and CNAs’ dialogue about pain in older people who cannot verbalise their pain.

- The APS-SWE is ready for implementation in clinical practice to assist RNs and CNAs in pain assessment situations in order to be integrated as an established standard in systematic pain assessment procedures among older people who have difficulty in self-reporting their pain.
Research implications

- Evaluation of how principles of person-centred dementia care are put into practice in pain assessment interventions are needed in order to evaluate outcomes for people with dementia
- More research is needed into the relationship between pain and BPSD symptoms
- More research in home healthcare settings is needed to identify contextual factors to optimise pain assessment in people living with cognitive impairment and dementia
- Priority dilemmas on different organisation- and care professional levels are of daily concerns in municipal dementia care practice, and it is imperative for research to face these concerns for pain assessment interventions and improvements
- Further exploration need to be carried out into how organisations, RNs, and CNAs can ensure best practice for pain assessment in people living with cognitive impairment and dementia
- Further evaluation of the APS-SWE in Swedish dementia care practice is needed to strengthen validity and reliability
- Further research should also move towards implementation strategies of evaluated and validated observational behaviour pain assessment scales such as the APS-SWE into municipal dementia care practice settings

Upptäckt och bedömning av tecken på smärta hos äldre personer med demenssjukdom är en kontinuerligt pågående process i omvårdnaden och som inkluderar bedömning, rapportering, dokumentation, behandling samt uppföljning och ny bedömning för att utvärdera om insatt behandling har effekt. Forskning visar att smärtsbedömning hos personer med demenssjukdom ofta baseras på vårdprofessionellas subjektiva tolkningar snarare än med stöd av evidensbaserade observationsskalor för smärtsbedömning.

Det övergripande syftet med denna avhandling var att utforska och beskriva sjuksköterskors och undersköterskors erfarenheter av att upptäcka och bedöma smärta hos äldre personer med kognitiv svikt och demenssjukdom (Studie I, II, III). Ett ytterligare syfte var att utvärdera observations- och beteendeskalan Abbey Pain Scale-SWE (APS-SWE) i demensvårdspraktiken (Studie IV). Studie I, II och IV utfördes inom särskilt boende för personer med demenssjukdom. Studie III utfördes inom hemsjukvård.
Avhandlingen tar sin utgångspunkt från sjuksköterskors och undersköterskors perspektiv i daglig omvårdnad om äldre personer med kognitiv svikt och demenssjukdom inom kommunal vård- och omsorg. fyra empiriska studier genomfördes; tre intervjujustidier med kvalitativ ansats (I, II, III) samt en studie med kvantitativ ansats (IV). I Studie I deltog 11 sjuksköterskor, i Studie II deltog 12 undersköterskor, i Studie III deltog 10 undersköterskor och 13 sjuksköterskor. I Studie IV deltog 96 äldre personer, 70 undersköterskor och 5 sjuksköterskor. Intervjuerna analyserades med kvalitativ innehållsanalys (I) samt hermeneutisk textanalys (II, III). De huvudsakliga fynden från intervjujustidierna visar att sjuksköterskor upplever att bedömning av smärta hos personer med demenssjukdom är en utmaning främst beroende på en förändrad sjuksköterskeroll, där de i en större utsträckning än tidigare arbetar mer som rådgivande konsulter och med utökade administrativa arbetsuppgifter snarare än att delta i det dagliga kliniska omvårdnadsarbetet. Denna situation upplevs frustrerande och inte optimal för adekvat smärtbedömning. Det har också lett till att sjuksköterskor i större utsträckning än tidigare måste följa sig på undersköterskors information, då det är undersköterskor som utför de dagliga rutinerna i omvårdnaden och ofta är de första att upptäcka tecken på smärta. Undersköterskor beskriver att de varjeblir tecken på smärta genom att vara närvarande och uppmärksamme i omvårdnadssituationen om den äldre, vilket möjliggör att identifiera en mängd olika uttryck och som kan bero på smärta. God personkännedom om personen som vårdas underlättar att identifiera såväl fysiska som beteendemässiga förändringar eller mönster som avviker från det för personen normala och som kan indikera smärta.

Inom hemsjukvården arbetar sjuksköterskor och undersköterskor tillsammans i team, där de använder sig av flera kompletterande strategier för att upptäcka och bedöma tecken på smärta; verbal kommunikation med personen om möjligt, observation, kontroll av fysiska reaktioner, dialog med närstående samt användande av VAS skalan. Smärtbedömningar utförs genom ett robust samarbete mellan sjuksköterskor och undersköterskor där var och ens färddigheter och kompetens tas tillvara. Dock upplevs VAS vara problematiskt att använda hos personer med kognitiv svikt och demenssjukdom då dessa personer kan ha svårt att förstå hur VAS skattas. Intervjujustidierna visar att lämpliga smärtbedömningsskalor för personer med demenssjukdom inte används. Därför utvärderades observations- och
beteendeskalan Abbey Pain Scale-SWE bland äldre personer med demenssjukdom vid särskilda boenden (Studie IV). Då Abbey Pain Scale har implementerats i Svenska Palliativregistret samt BPSD registret, hittills dock utan att några svenska vetenskapliga forskningsstudier har utvärderat skalan, var detta en ytterligare motivering till att utvärdera skalan i klinisk demensvårdspraktik. Då den nuvarande svenska översättningen av Abbey Pain Scale saknar vetenskaplig metodik för språköversättning genomfördes en språköversättningsprocedure i tre steg utförd av en 8-personers expertgrupp bestående av kliniker (läkare, sjuksköterskor, specialistsjukskötetskor, undersköterskor) samt seniora forskare. Den version som används i studien benämns Abbey Pain Scale-SWE (APS-SWE).

Innan datainsamling startade genomfördes en teoretisk genomgång av APS-SWE för samtliga sjuksköterskor och undersköterskor som deltog i studien, där de fick möjlighet att bekanta sig med skalan och hur den skulle användas i studien. Observation, bedömning av smärta med stöd av APS-SWE samt enkät användes för datainsamling. Resultaten analyserades med beskrivande statistik och reliabilitetsanalyser. Resultaten visar att APS-SWE har adekvat intern konsistens, reliabilitet och face validitet för smärtbedömning i denna studiepopulation (Studie IV).

Sammantaget visar resultaten från denna avhandling att upptäckt och bedömning av tecken på smärta hos personer med kognitiv svikt och demenssjukdom är komplex och sker genom att vara närvarande och uppmärksam i den dagliga patientnära omvårdnaden, baseras på en förtroendefull relation till och god kännedom om personen som vårdas för att kunna upptäcka förändringar från personens normala mönster, bygger på robust samarbete mellan sjuksköterskor och undersköterskor samt personalkontinuitet för att kunna göra adekvata jämförelser och utvärderingar av insatta interventioner, användande av flera olika smärtbedömningsstrategier men avsaknad av evidensbaserade och anpassade smärtbedömningsinstrument för personer som har svårighet att rapportera smärta. En stressig arbetssituation och tidsbrist i omvårdnaden ses som hinder för bedömning av tecken på smärta och som kan orsaka att tecken på smärta förbises.
Vid utvärdering av observationsskalans APS-SWE uppvisades adekvat reliabilitet och face validitet för smärtbedömning, vilket indikerar att skalan är ett användbart verktyg som kan assistera sjuksköterskors ochundersköterskors smärtbedömningar hos personer med demenssjukdom. Fortsatt utvärdering av APS-SWE i klinisk praktik behövs för att ytterligare styrka skalans reliabilitet och validitet för smärtbedömning hos personer med kognitiv svikt och demenssjukdom.

Resultaten från studierna i denna avhandling har återförts till vårdpraktiken och diskuterats mellan författaren till avhandlingen och de vårdpraktiker som deltagit i studierna för att öppna upp för ytterligare synpunkter utifrån studieresultaten, med målet till fortsatta förbättringar av metoder för smärtbedömning i demensvårdspraktiken.
References


