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SUMMARY STATEMENT

What does this research add to existing knowledge in gerontology?

- Staff continuity and extended time with the care recipient are essential to promote adequate and safe pain assessment for care recipients with dementia
- In pain assessment of people with dementia, the need for a person-centred approach becomes evident

What are the implications of this new knowledge for nursing care with older people?

- The quality of collaboration between registered nurses and nursing assistants and the use of multiple assessment strategies provide a robust foundation for the assessment procedure

How could the findings be used to influence policy, practice, research or education?

- Home healthcare teams’ understanding of care recipients as unique individuals when assessing pain is evident and should be better acknowledged by care organisations in a move towards a person-centred perspective as highlighted in national guidelines
- Swedish home healthcare teams’ pain management should be further investigated to recognise contextual factors to optimise practice
- Systematic routines for pain assessment and training in how to use evidence-based observational behavioural pain assessment tools should be accessible to home healthcare teams and implemented in clinical practice to strengthen pain management and to meet recommendations for the use of evidence-based tools in healthcare
Introduction

Pain is often under-assessed and undertreated in people with dementia and remains a challenge in regular care, mainly due to the diminished capacity to self-report among people with dementia (Helme & Gibson, 2001; Achterberg et al., 2010; Monroe & Mion, 2012). Additional factors that contribute to under-assessment have been reported, such as the impact of dementia on the pain experience (Scherder et al., 2003; Kunz et al., 2009) and healthcare professionals’ knowledge and skills (Horgas & Dunn, 2001; Landi et al., 2001; Wall & White, 2012). Globally, research on pain and dementia has increased immensely over the last decade, and clinical practice recommendations for pain management have been developed to enhance care (Hadjistavropoulos et al., 2007; Herr et al., 2011). In Sweden, national guidelines for the care of people with dementia have been formulated to ensure quality of care. In the guidelines, the person-centred approach is central, in which the person and not the disease is the focus and the approach emerges from the person’s experience of his/her reality (Socialstyrelsen, 2010). From this perspective, person-centred care aims to understand the person from his/her perspective. The approach sees the person as an active collaborator, involves the person’s social network in the care, and creates a relationship with the person. Person-centred care puts the person in need of care at the centre of the care-planning process, respecting the wishes and needs of the individual. The use of an integral person-centred approach to dementia care is highlighted in several studies (Brooker et al., 1998; Chenoweth et al., 2009; Edvardsson et al., 2010). Pain and dementia remain a challenge in Swedish home healthcare with regard to nurses’ professional and medical skills (Furåker, 2008) as well as organisational changes and staff reductions (Hertting et al., 2004; Szebehely & Trydegård, 2012).
Demographic trends have caused home healthcare to expand in many countries and have challenged the quality of care (Feldman et al., 2006; Hasseler et al., 2006; Eloranta et al., 2008; Ryan et al., 2009; Ruder, 2010). Multi-disciplinary and collaborative teams working in home healthcare, including registered nurses (RNs) and certified nursing assistants (CNAs), have attracted attention for factors such as expertise, communication, decision-making, responsibility (Eloranta et al., 2008; Liu, 2013), and practice development (Wall & White, 2012). In Sweden, home health care is regulated by the Swedish Health- and Medical Services Act(1982) and the Social Services Act (2001) and involves 24-hour nursing care for people in need of short-term or long-term care. In the Swedish model of home healthcare, RNs and CNAs work together in teams to promote physical, psychological and social support to care recipients. Within the team, RNs hold the most responsibility and mainly perform advanced nursing care, whereas CNAs provide most of the day-to-day care but are also delegated by RNs to perform advanced nursing care (Socialstyrelsen, 1997). Generally, CNAs have daily contact with the care recipients and RNs perform check-ups and are available to the CNAs for consultation and medical assistance (Bystedt et al., 2011; Karlsson et al., 2012; Karlsson et al., 2013).

In Sweden, approximately 250,000 people receive home healthcare, of which approximately 87 per cent are over 65 years old (Socialstyrelsen, 2008). As the risk of developing dementia increases with age, a large proportion of those who receive home healthcare are living with dementia or similar symptoms of cognitive impairment. Home healthcare teams regularly encounter complex care situations involving pain (Acello, 2001; Schwager, 2003; Teenier & Sender, 2007; Brown et al., 2011). Because inadequate treatment of pain entails an associated risk of reduced mobility and muscle weakness that seriously affects quality of life (Woolf et al., 2004; Breivik et al., 2006), healthcare providers need to pay attention to pain symptoms.
Previous research has suggested the need to be alert to facial expressions (Kunz et al., 2007; Lautenbacher et al., 2013), behavioural changes (Herr et al., 2011) and reduced activity (Breivik et al., 2006) to detect and assess pain. Research on pain and dementia has mostly used quantitative measurements. The use of exploratory qualitative research to investigate how pain is assessed has been less frequently used. Considering the complex combination of pain and dementia, an exploration of how home healthcare teams address pain assessment on a regular basis is needed.

**Aim**

The aim of this study was to explore home healthcare teams’ experiences of pain assessment among care recipients with dementia.

**Method**

**Design**

An exploratory qualitative design was used. Qualitative research has contributed to increased practical knowledge in healthcare and has been incorporated in standard hierarchies of evidence used to establish evidence-based practice (Sandelowski, 2004). The study design was framed by the principles of empirical hermeneutic caring-science research described by Dahlberg et al (2008). Gadamer’s (2004) approach to text interpretation, grounded in philosophical hermeneutics, was used to gain deeper understanding of home healthcare teams’ experiences of pain assessment. Philosophical hermeneutics is an interpretative methodology rather than a strict method and has been widely used in nursing science to gain profound understanding of the way human beings interpret their reality (Austgard, 2012). Drawing on hermeneutics may be helpful to explore the indispensable roles of dialogue and understanding when making clinical judgements.
Setting and participants

RNs and CNAs from three district units, each providing 24-hour home healthcare to approximately 90 recipients, in a medium-sized community in the west of Sweden were invited to participate in the study. The participants were selected from the staff list by the district head. A purposive sampling of RNs and CNAs was used to achieve variation in age and professional experience. The inclusion criteria were professional training and permanent employment in home healthcare for a minimum of one year. Those who met these criteria were invited to participate. The first author invited all the selected participants to informational meetings about the study, which took place at the participants’ workplaces. The RNs had professional experience in cardiology, surgery, infection, intensive care, medicine, and psychiatric care. The CNAs had experience in rehabilitation and in orthopaedic, cardiac, and psychiatric care. Twenty-one RNs and 20 CNAs were invited to participate. Thirteen RNs (two men and eleven women) and ten CNAs (all women) were interested and agreed to participate. The demographic characteristics of the participants are shown in Table 1.

Insert Table 1 about here

Ethical considerations

The study was approved by the ethics committee of the University of Gothenburg (Ref. No 969-11). Before the interviews started, all the participants in the study gave informed consent after detailed information about the study was explained by the first author. The transcribed interviews were de-identified and coded and were kept in a locker at the first authors’ University. Only the first author had access to the locker. The participants were assured confidentiality and informed about their voluntary participation and that they could withdraw at any time.
**Data collection**

*Interviews*

Individual interviews using open-ended questions were conducted by the first author in the participants’ workplaces from May to August 2012. The time and date for the interviews were organised in agreement with each of the participants. All participants were interviewed once and the interviews were conducted in privacy in a room next to the nurses’ offices. Open-ended questioning was used to encourage narration about experiences in a natural way and to allow the interviewer to reflect on what was narrated in relation to subject and context (Dahlberg et al., 2008). The broad initial question was *What are your experiences of assessing pain in people with dementia in home healthcare?* To clarify aspects of pain assessment that emerged as meaningful, subsequent questions were asked, such as *How do you perform pain assessment?* and *What are your assessments based on?* The interviews lasted from 28-65 minutes. All interviews were digitally recorded and transcribed verbatim by the first author using Word for Windows and a separate datasheet for each interview. Transcription was focused on the narrated words rather than on non-verbal information. While transcribing, hand-written notes were written in the margins reflecting what was narrated in relation to language (nursing as a sub-culture) and context (community-based home healthcare). The transcription was scrutinised by the co-authors, edited for the English language by a professional editor and then re-read by the first author to check for meaning.

**Analysis**

All interviews were analysed in accordance with the interpretive methodological principles to search for meaning and elucidate what the text stated. Our analysis was inspired by Gadamer’s (2004) philosophical hermeneutics, in which the overall methodological principles are openness to the text and reflection on how understanding is affected by tradition (i.e.,
awareness of one’s personal history and pre-understanding when interpreting a text). Using hermeneutic text analyses, researchers must shift from their natural attitude to a reflective scientific approach to discover what is beyond individual narrow-mindedness. In the analysis, Gadamer’s philosophy was combined with the principles of hermeneutic text interpretation described by Dahlberg et al. (2008) following an explicit and reflective methodology. Dahlberg et al. (2008) suggest that text interpretation involves engaging in thinking dialogue with the message of the text to gain profound understanding. Furthermore, interpretive analysis is based on the assumption that when we understand the world, we do so in relation to implicit knowledge that is integrated within us by pre-understandings. According to von Post and Eriksson (1999), professional pre-understanding is the result of one’s professional training and experience as a nurse and is part of the nursing sub-culture. It is created from the nurse’s view on caring, medical knowledge, subjective values, and the ethics that guide nursing care. Taking pre-understanding into consideration means being aware of and questioning one’s prejudices rather than ignoring them. In this study, the first author’s professional pre-understanding due to experience as a CNA in community-based care for older people was considered and discussed. The co-authors reflected on their professional experience in nursing older people with dementia in relation to the text interpretation.

Each interview was read several times to gain an initial understanding of the text and to allow the authors to integrate the text. The first reading began as an open reading and progressed towards searching for patterns of meanings. The reading involved an iterative process of reflection and interpretation of parts of the text and the text as an entity (i.e., relating meaningful parts in the text to a comprehensive whole, paying attention to nuances and richness of meaning, and recognising meaning as contextual, expandable and emerging from the team members’ lifeworld). Hand-written notes were read and reflected on in relation to the
interview and the first authors’ pre-understanding. All the authors discussed the text, notes, tentative interpretations, and pre-understanding in an ongoing collegial dialogue throughout the analysis procedure, which proceeded in a back-and-forth movement of reading, reflecting, and interpreting. In the literature, this process is described as the hermeneutic circle (Gadamer, 2004), in which interpretation and understanding involves a continuous dialectic movement between parts and the whole towards new understanding. The authors’ initial impression was that the text was about the ability to compare care recipients being as usual or not being as usual as possible indicators of pain. To clarify meaning, further questions were asked to the text and reflected on such as How do the teams address pain assessment issues? How do they reach consensus? What is the meaning of the text? How does meaning relate to context? Lastly, all interviews were re-read as an entire text, moving from beginning to end to connect to the whole. Concluding interpretations were developed by summarising main themes, rendering the entire text consistent and coherent.

Results

Four interpretations were developed describing home healthcare teams’ experiences of assessing pain in care recipients with dementia: the need for trusting collaboration, the use of multiple assessment strategies, maintenance of staff continuity in care and assessment situations, and the need for extended time to assess pain. The interpretations are presented and illustrated by quotes throughout the text.

The need for trusting collaboration

Pain assessment is a common task in home healthcare and is considered a complex process that requires close collaboration between RNs and CNAs. Collaboration involves daily telephone contacts and meetings in which information and documentation about pain is
discussed. However, pain information that is derived from this collaboration passes through several nurses, each of whom makes their own interpretation of the information:

We often have different opinions about pain and I believe that the judgement of the CNAs could be fairer as they see the person several times a day, while I make perhaps one or two visits a week (RN1).

This quote reflects differences between RNs and CNAs with regard to their professions as well as with regard to putting their trust in each other’s professional expertise. RNs rely on CNAs’ judgements because of the latters’ frequent visits. The teamwork between RNs and CNAs involves true collaboration, with CNAs as front-line staff who report to the RN in charge. The CNAs seem confident in this situation and are conscious of their importance as observers:

Our RNs say that we are their ‘eyes’ in nursing care…we see a lot when we care for the person, and we feel that we receive a response from all of them (CNA23).

The RNs have become dependent on the CNAs’ observations because the CNAs have developed a relationship with the care recipients in the regular care process and can detect signs of pain. However, the RN in the following quote explains her opinion on dependency and presents a situation that shapes the decision-making process within the team. This RN is concerned about her own role, reflecting the need for information from CNAs: We must rely on CNAs, who are well-known to the recipient. They know if something is wrong’ (RN13).

Trust collaboration in pain assessment also involves care recipients’ co-operation capabilities. In home healthcare, ethical dilemmas often occur that are associated with care recipients’ cognitive impairment. The situation can be problematic if the care recipient does
not understand the care and therefore refuses to collaborate despite the fact that he/she is troubled by pain. Such situations may be linked to the challenge of assessing pain quality when an individual’s capacity to self-report is diminished. Therefore, pain assessment often becomes an explorative task:

Sometimes you need to be like a detective, investigating what has happened in the past, previous diseases and things like that. This information is of great value when we make our assessments (RN3).

Although, self-report capacity may be diminished, the team ensures that it is important to involve the care recipient, despite dementia, by maintaining a collaborative approach and have a conversation with the person to gain information:

I always try to ask questions, even when they have dementia, and not talk over their heads. Even if I receive an answer that doesn’t make sense, I have nevertheless put the question to the person… I may well receive an adequate answer (RN9).

Two aspects of pain assessment can be interpreted based on the need for trusting collaboration. First, by seeing and acknowledging the person, the care ethics aspect of nursing care becomes visible. Second, by maintaining team collaboration the practical implications of detecting pain, information becomes apparent. The care ethics view and the practical aspect of obtaining pain information appear to be closely intertwined, guiding to judgements of pain.

The use of multiple assessment strategies

The teams describe the use of several different strategies to assess pain, depending on how they succeed in communicating with the care recipient. Their first strategy relies on the person's ability to describe pain verbally. Trusting what the person says is the basis of the
assessment. However, because they are mindful of the fact that dementia impairs memory and abstract thinking, the teams are aware that their interview technique must be based on a small number of easy questions: interview technique is important in order to obtain the right information (RN4). If there is a verbal communication barrier due to the care recipient’s cognitive impairment, the teams attempt further strategies to investigate about pain. A second strategy is to investigate movement capacity and check reactions to determine whether decreased body function could be an indicator of pain:

You must try to observe their expressed body movements… if the person is able to walk or move. Ask the person to do things, such as raise their arm or comb their hair… to see if they can move properly (RN8).

A third strategy described by the teams is to observe behavioural changes to identify any changes that could be caused by pain:

They can react to pain with aggression. It’s a rather common reaction. They could have difficulty stating where the pain is located or what is wrong, but you can see that they are anxious (CNA5).

If the care recipient shows a change in behaviour, such as anxiety, aggression or confusion, the teams reflect on possible reasons for the change: You can observe their movements… if they back off or withdraw or even shout or swear (RN4). In such situations, the teams use distraction manoeuvres to relax the person and find a good, trusting way to communicate. Using an observational attitude enables the nurses to explore changes in both behaviour and body movement and to understand whether changes may relate to pain. These observations are associated with a professional motivation to determine whether the person is suffering. One of the RNs describes an observational care situation in the following way:
Even if the person is unable to verbalise pain adequately, you can observe that the person does not appear to be in pain when sitting but may be reluctant to move (RN3).

The teams have developed deep sympathy for their care recipients when pain may be based not only on physical indications but also on existential suffering, which may affect the individual’s daily life:

They can be very depressed…in the early stages of the dementia… where they are aware that something is wrong. They know they are confused and forget things all the time. That’s the most tragic thing (CNA15).

In this quote, the CNA places pain and the existential aspects of dementia on equal footing. From this perspective, the understanding of pain relates to human suffering, affecting both body and mind. Pain assessment from this CNA’s perspective, is based on compassion for a vulnerable human being.

A fourth strategy used by the teams is based on initiating dialogue with relatives, who are considered good sources of information about their loved ones. Relatives can add history and can explain whether the person has suffered from pain in the past. The involvement of relatives who are close to the care recipient enables the teams to broaden their understanding of pain:

If we need to know how long they have been in pain or if the pain problem has existed earlier, we always try to involve relatives, particularly if the care recipients have problems speaking for themselves. That kind of information is really important to us and can only be obtained from relatives (RN1).
A fifth strategy described by the teams is based on instrumental measurement using the visual analogue scale (VAS). Generally, the VAS is used only by RNs. However, the RNs consider the VAS to be invalid for assessing pain in people with dementia. The RNs found that their VAS scores did not agree with those of the care recipients:

Using the VAS can be difficult. The care recipients don’t understand how to use it and can’t say what the pain was like previously. They have trouble remembering and that’s why it becomes difficult to compare pain from day to day (RN9).

This quote tells us that the VAS is not considered appropriate in the care of people who have difficulty verbalising and adequately describing pain. Nevertheless, the VAS is experienced to be useful in those cases where RNs and the care recipient in fact are able to discuss pain. The RNs uses the VAS despite its limitations when they feel a need for measurement support. However, knowing that the scores from the VAS may be unreliable, the various assessment strategies, taking the person-centred approach into consideration where pain can be discussed, are used to complement and to get the whole picture of the pain situation.

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

Adequate knowledge of the care recipient is vital in pain assessment situations, particularly when caring for people who have difficulty describing their pain verbally. In-depth knowledge emerges from continuity in care when it is provided by the same staff. Staff continuity is needed to develop relationships that contribute to better understanding of whether the care recipient suffers from pain:

If you have been seeing the care recipients for some years, you get to know them, and you are able to interpret if something is wrong or if something is not quite right at that moment (CNA9).
Continuity is established when a limited number of staff is involved in pain assessment. If too many nurses are involved, regular comparison of the persons’ status becomes difficult. Involving a limited number of staff is essential for detecting changes and maintaining an overall picture of the pain situation:

Pain is a subjective experience, and that’s why continuity in the care process is important. To compare and evaluate effectively, it’s vital that it’s the same nurse who visits the care recipient (RN5).

By maintaining staff continuity among the CNAs, they are able to develop experience-based knowledge that is responsive to change. Taking advantage of this situation, the CNAs can discover nuances by which they are able to make judgements regarding the person’s day-to-day state:

You are able to see that in fact there IS a change…something has HAPPENED, and their behaviour is not their usual manner (CNA9).

When the care recipient is considered “not as usual”, this signals that something is wrong and raises awareness of when, where and how this unusualness occurs. Recognising unusualness is the first identification of a change that can guide CNAs to further investigate pain. Thus, the establishment of staff continuity enables the staff to respond to this unusualness.

The need for extended time to assess pain

Lack of time is a constant issue in home healthcare, and care is related to the number of nurses scheduled to use resources as effectively as possible. When assessing pain in people with dementia, time is a key component. However, time pressure often occurs in care situations, preventing the teams from staying with a care recipient longer than allocated in
their daily schedule. The teams state that when assessing pain in people with dementia, sufficient time is very important to explore the quality of pain. Rushing is distressing for persons with dementia due to their cognitive impairment, which diminishes understanding of what is occurring:

You must have time to listen to the care recipient so that the person really sees that you are listening. That’s the important thing…to be present in time and space (CNA8).

Encountering a person with dementia requires being in the moment in the particular situation to sufficiently respond to the care recipient. However, working in home healthcare involves striking a balance between having the time to make all the scheduled home visits and maintaining quality of care. When assessing pain, a stressful work situation is a source of frustration to the teams:

Sometimes it can be difficult when you are stressed because you have your visiting list to follow. But we are not working in a factory. It’s human beings we are caring for…anything could happen (CNA4).

Time is crucial for communication between the teams and the care recipients because caring for people with dementia requires a slow tempo to build a relationship that allows for sufficient exploration. Lack of time may jeopardise communication, leading the nurse to overlook signs of pain. One of the CNAs describes the importance of time as follows:

Sometimes it’s difficult to get through to them. They can be upset about the pain. and it could take time to establish a successful dialogue. It's important to develop a relationship (CNA2).

Establishing successful dialogue when assessing pain in people living with dementia involves creating a relationship rather than constructing the care situation as a casual acquaintance.
From the perspective of the CNA in the above quote, successful dialogues are based on familiarity and encountering the care recipient on his or her terms rather than being governed by work schedules.

**Discussion**

Home healthcare teams are responsible for providing nursing care and support to people living in their own homes. Focusing on the community-based perspective to promote better aging at home has highlighted the importance of inter-professional collaboration and coordination to maximise successful outcomes in the care of older people (Capezuti & Hamers, 2013). By recognising the care recipient, healthcare professionals can provide care that preserves personhood by acknowledging the person-centred approach in care situations (Kitwood, 1995; Touhy, 2004; McCormack & McCance’s, 2010). If the care recipient is limited in his/her ability to provide adequate information about pain, healthcare professionals should initiate consultation with colleagues and relatives to obtain information to gain a better understanding of the person’s individual needs (Socialstyrelsen, 2010). This study indicates that to investigate about pain, collaboration occur at a high level within the teams and with relatives by using each other’s competences and well-established communication. In the words of one of the CNAs, *Our RNs say that we are their ‘eyes’ in nursing care…we see a lot when we care for the recipient and we feel that we receive a response from our RN.* The collaborative view was confirmed by RNs, as stated by one of them: *We must rely on CNAs, who are well-known to the care recipients. They know if something is wrong.* Liu (2013) has highlighted the importance of nursing assistants as effective pain assessors and reporters due to their frequent contact with residents and sensitivity to subtle behavioural changes. Eloranta et al. (2008) claim that multi-professional collaboration includes communication, decision-making, and responsibility to promote the physical, psychological, and social support of home
care clients. Consistent to that, Allen et al. (2012) suggest that well-developed communication within teams provides better service and quality of care for older people. The findings from our study indicated the importance of person-centred awareness in pain assessment situations and the high priority of person-centred ambitions for care and pain assessment. However, contextual factors such as tight timetables and lack of staff continuity were experienced as barriers to person-centred care. Based on prior practice development research, several studies have demonstrated important principles in improving best practices (Mc Cormack et al., 2002; Wall & White, 2012). Due to the lack of research in pain assessment in community-based home healthcare, the findings from our study are difficult to compare with other studies. Nevertheless, the findings are important because they can be scrutinised and evaluated in relation to national guidelines, international position statements, and other care settings involving older people living with cognitive impairment. Encountering the care recipient with respect and meeting the needs of trust, meaningfulness, and decision-making must be considered (Edvardsson et al., 2008). The present study demonstrated occurrence of these aspects.

The use of multiple assessment strategies enabled the teams to view pain from more than one dimension. However, this study demonstrates that pain detection is still a significant challenge and that regular use of other evidence-based pain tools than the VAS is lacking. Current position statements and practical guidelines for adequate assessments and optimal pain control in people with cognitive impairment and dementia have been developed for use in practice (Herr et al., 2010; Herr et al., 2011). Furthermore, Wall and White (2012) have developed an interesting training module on pain and dementia that could be useful to home healthcare nurses. Considering healthcare organisations’ responsibility to provide evidence-based care, it is essential to have an integrated plan for pain management, involving guidelines for pain
assessment. In the present study, the implementation of applicable pain assessment guidelines and training to use more appropriate pain tools than the VAS such as observational behaviour pain assessment scales would seem urgently needed. Using their well-developed sensitive approach combined with observational assessment tools, would optimize detection of pain.

An important finding in this study was the implicit ethical quality in the care and assessment situation. Standards for dementia care practice in Sweden state that all care should be based on the formulated ethical foundation of value, in which care recipients should be cared for by maintaining respect and integrity and without discrimination due to sex, ethnicity, age, or diagnosis (Social Services Act, 2001). In the literature, the ethical nursing perspective becomes particularly visible in Watson’s (1979) theory of caring, in which care is described from the perspective of existential philosophy as an ontological expression of love and compassion, and caring is viewed as the moral ideal of nursing. The teams in this study expressed ethical concerns about pain assessment, revealing a high degree of responsibility and commitment to care. This was particularly evident when they spoke about the tragedy of dementia and the existential dimension of suffering. One explanation for this concern could be that the teams associated pain and suffering with social components rather than with physical and medical symptoms only.

Organisational demands on the teams were not in harmony with the provision of person-centred care but rather with effectiveness, and there was resentment about this situation. The main concern about these demands appeared to relate to the lack of time in care situations. Time is essential when caring for people living with dementia, and a lack of time leads to stress. Negative outcomes from streamlining home healthcare have been discussed by Szebehely and Trydegård (2012), with the focus on organisational change and quality of care.
Jones (2006) have highlighted organisational climate in home healthcare delivery, and Feldman et al. (2006) have discussed organisational change and evidence-based practice in relation to patient safety and quality of care. Care recipients with dementia who live in their own homes need supportive care that emphasizes sensitive and professional knowledge of the way that sensory impairments may alter mood or behaviour (Kunz et al., 2009) and that considers ethical challenges in the nurse-patient relationship (Tönnessen et al., 2011). Providing person-centred care rather than diagnosis-oriented care requires home healthcare nurses to attend to and safeguard a broad array of values and needs when assessing pain. Considering the current models of pain management and the perspective of person-centred care, the models attempt to encourage more personal care and to understand behavioural and psychological symptoms from the care recipient’s perspective. This study reveals that organisational contextual factors negatively impact the pain assessment procedure.

**Study limitations**

The participants in this study belonged to three different teams within one municipality. However, the fact that the participants belonged to the same organisation may limit the ability of this study to gain a broader view of home healthcare. The participants included mainly women, which may be seen as a limitation from a gender perspective. Nevertheless, our data were collected from team members with a wide range of experiences, providing a clear view of how care was constructed and how pain was assessed. The findings cannot be completely and objectively validated due to their qualitative nature. Nevertheless, qualitative findings are valuable to obtain a deeper understanding of complex nursing phenomena (Dahlberg et al., 2008). Despite the limitations, the findings could be applied to other dementia care contexts in which nursing care is provided by teams.
Conclusions

This study indicates that the home healthcare teams recognise assessment of pain in people with dementia as involving a complex interaction of sensory, cognitive, emotional and behavioural components in which efforts to acquire understanding of behavioural changes mainly guides their assessments. Nevertheless, the team coherence between RNs and CNAs aided the assessment procedure. To explore and assess pain, the team used multiple experience-based methods that complemented one another. However, pain assessment in people with dementia remains a challenge, and no systematic routines or appropriate evidence-based pain tools are used. Additionally, a stressful work situation jeopardises to adequately assess pain. The teams were motivated to assess pain due to ethical and responsible concerns for older people in need of professional care. This is an important finding and highlights the need for pain and dementia to be considered from a person-centred view based on familiarity with the care recipient.

Implications for practice

In this study, home healthcare teams’ concern for the care recipients when assessing pain was evident. This concern needs to be acknowledged by the organisation, which is responsible for the quality of care. Future studies should focus on further exploration of nurses’ experiences with pain and dementia in home healthcare settings. Studies should address what nurses identify and how they address their findings in pain assessment. It is imperative to investigate how organisations and nurses can ensure best practice and how the implementation of evidence-based routines for assessing pain and the use of appropriate tools may aid in pain assessment situations.
References


Table 1. Demographic characteristic for the participants in the study.

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<th>CNAs n=10</th>
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