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Older persons' worries expressed during home care and supportive communication

- analysing audio-recorded visits

A PhD dissertation in
Person-centred Health Care

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To Elias and Espen.

"If you talk to a man in a language he understands, that goes to his head. If you talk to him in his language that goes to his heart."

Nelson Mandela

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Abstract

Background: Person-centred care is advocated as the gold standard for delivering quality healthcare services for older persons in general, and for home care in particular. Person-centred care means being respectful of and viewing the person's own preferences and understanding of his/her health and emotional well-being, values and spiritual beliefs, while planning, executing and evaluating healthcare. The moments when the older person shares and discusses his/her emotional well-being with the visiting nursing staff is termed emotional communication and this term may be used as a lens to explore features of communication relevant for person-centred care. There is currently a lack of insight into how emotional communication during home care visits is carried out, and how the discussion of emotions - in particular older persons' worries - are discussed. Given that these aspects are essential to the well-being of older persons, the focus of this thesis is on exploring expressions of worries and the nursing staff's responses to these worries.

Aims: The overarching aims of this thesis are: a) to explore how older persons express their worries to nursing staff during home care visits, b) to investigate how the nurses and nurse assistants respond to the worries expressed, and c) to discuss the findings within a supportive communication framework and discuss whether current communication behaviour is likely to facilitate person-centred care delivery in home care services.

These aims are achieved in three studies which are described in this thesis comprising three papers as well as a general discussion.

Design, materials and methods: This study was part of an international research project with the acronym COMHOME, designed as a cross-sectional study. The material analysed included 195 audio-recorded home care visits in Norway collected from four units of home care during December 2013 and May 2014. The visits captured communication

between 48 older patients (≥65 years) and nursing staff (n=33), including nurse assistants (n=17) and registered nurses (n=16). The visits collected varied in length, number of tasks and complexity to be managed during the visit, time of day and day of the week. The Verona Coding Definitions of Emotional Sequences (VR-CoDES) was used to identify expressions of distress and the subsequent responses by providers. Two coders applied the system to the complete material. The inter-rater reliability, Cohen's kappa, was >0.6. Data were subsequently analysed using both a qualitative and a quantitative approach. Drawing on the qualitative analysis, a coding scheme for thematic content in patients' expressions of worries was developed.

Paper I and paper III: Statistical testing explored associations between variables. Sum-categories were computed for the specific VR-CoDES categories covering patient expressions of worries and the nursing staff's responses. VR-CoDES categories were clustered together based on the definitions provided by the system. Sum categories of patient expressions of worries included: a) verbal and non-verbal expressions referring to emotion, b) references to unpleasant states/circumstances, and c) contextual hints of emotion. The nursing staff's responses were grouped based on communicative function and divided into emotion-focused responses, content-focused responses and responses ignoring/blocking the cue/concern. Group differences were analysed using Pearson's chi-squared test or Fisher's exact test. In paper I, a logistic regression model was included to test which variables promoted responses that allowed further disclosure of emotion (emotion-focused responses). In paper III, adjusted residuals (cut-off set at ≥2/≤–2) were used to guide analysis of associations between what types of nursing staff responses were associated with specific themes and sub-themes of worries.

Paper II: The qualitative analysis included a novel two-step approach, starting by deductively identifying expressions of worry using the VR-CoDES in 38 of the visits. Then these emotional moments in the communication, through studying the transcripts of the expressed emotions combined with listening to the whole of the conversations, were inductively approached using qualitative content analysis.

Findings: *Paper I* showed that 74% of visits were identified with one or more expressions of distress as described by the VR-CoDES. Worries were usually expressed as hints to distress rather than as explicit statements in which a negative emotion was named. Nursing staff most often elicited expressions of distress (56%). Responses to distress included 48% emotion-focused responses, 32% aimed at the content of the emotional expression (content-focused responses), 20% ignored the emotional expression, and 0.2% blocked the patient (Ignoring or blocking responses). When controlling for the individual patient and nursing staff, the multivariate logistic regression model showed that nursing staff's elicitation of the emotional expression (vs spontaneously expressed by the patient) and patients' expression with a reference to an emotion (vs reference to unpleasant states or contextual hints) were both explanatory variables for emotion-focused responses. This is the pattern observed irrespective of whether the member of staff was a nurse or nurse assistant.

Paper II showed that the emotional expressions were grouped under four main categories and a series of sub-categories: 1) worries about relationships with others, 2) worries about health care-related issues, 3) worries about ageing and bodily impairment and 4) life narratives and value issues. Several unpleasant emotions were revealed through the analysis of the expressions, visualised as a layer or layers influencing how expressions of worries were expressed and shared by individual older persons.

Paper III showed that "ageing and bodily impairment" was the most frequent theme amongst worries expressed, covering 66% of all emotional expressions. "Health care-related issues" comprised 15% of the expressions, followed by "relationships with others" and "life narratives and value issues" which accounted for 9% of the expressions, respectively. Elicitation (facilitated by the nursing staff vs spontaneous expression by the patient) was associated with theme of worries. Nursing staff significantly more often elicited themes of worries which were especially prominent for "life narratives and value issues". However, worries about "ageing and bodily impairment" was elicited equally often by the older persons as by the nursing staff. Themes of worries were significantly associated with how nursing staff responded. Adjusted residuals indicated that this association was based on features of the sub-themes found under two of the main themes: "ageing and bodily impairment" (*coping with existential challenges* vs *expression of pain felt in the moment*); and "relationships with others" (*being a burden* vs *losing social ties*).

Conclusions: Emotional expressions by older persons come across mostly as hints and address several topics. Nursing staff are more likely to focus on the affective component of the worry in the instantaneous response when they elicit the emotional expression themselves and when the expressions include a reference to an emotion, a pattern unrelated to the status of being a nurse or a nurse assistant. The responses of nursing staff are associated with thematic content in general and expressions of pain in the moment are more often ignored as compared to other thematic content. The patterns characterising how nursing staff respond to worries are likely to influence level of support experienced by the older person and the type of information the nursing staff gather about an individual patient's emotional state. This may have implications for how effective nursing staff manage to implement precepts of person-centred care in a given care situation.

Implications for training: Recognition of the moments when the older person shares worries and ways nursing staff can provide support may be used as an approach to train nursing staff, students and other care providers in communication that may underpin person-centred care-delivery in home care services.

Suggestions for further research: This thesis suggests a framework describing different ways nursing staff can engage in emotional communication by using supportive response behaviours when addressing the expressions of worry by older persons to reach person-centred communication outcomes. It should be noted that this framework requires further testing to establish its validity and practical use. Moreover, there is a need for establishing older person's preferences when it comes to nursing staff's response behaviours, and a need for investigating nursing staff's perspectives on how to best engage in supportive communication when working in home care. This will help theory constructions as to which features are actually perceived as person-centred and supportive for older persons and nursing staff during emotional communication in this setting. Based on the findings presented in this thesis, further research investigating how best to address and support worries about "ageing and bodily impairment" seems especially important. Another important subject is whether nursing staff actually follow up on older person's

experiences of pain in the moment in a way that facilitates person-centred care during home care visits.

Keywords: Health services for older people; Home care services; Nursing staff; Patient care; Registered nurses; Nurse assistants; Person-centeredness; Person-centred communication; Expressed emotion; Person-centred responses; Observational study; VR-CoDES; Qualitative content analysis

List of papers omitted in the online version due to publishers restrictions

Paper I

Hafskjold L., Sundling, V., van Dulmen, S., & Eide, H. (2017).

The use of supportive communication when responding to older people's emotional distress in home care - An observational study.

BMC Nursing: doi:10.1186/s12912-017-0220-8

Paper II

Hafskjold L., Eide T., Holmstrom I.K, Sundling V., van Dulmen S., & Eide, H. (2016).

Older persons' worries expressed during home care visits: Exploring the content of cues and concerns identified by the Verona coding definitions of emotional sequences.

Patient Education and Counseling: doi:10.1016/j.pec.2016.07.015

Paper III

Hafskjold L., Sundling, V., & Eide, H. (2018).

Nursing staff's responses to thematic content of patients' expressed worries: observing communication in home care visits.

BMC Health Services Research: doi: 10.1186/s12913-018-3390-5

Main Abbreviations

ADL: Activity of Daily Living

COMHOME: Person-centred communication with older people receiving healthcare

HCSSCS: Hierarchical Coding System for Sensitivity of Comforting Strategies

USN: University of South-Eastern Norway

VR-CoDES: Verona Coding Definitions of Emotional Sequences

Initials of research members used in the thesis:

Initials	Name
HE	Hilde Eide
HR	Helene Rintalan
IKH	Inger K Holmström
LH	Linda Hafskjold
TE	Tom Eide
VS	Vibeke Sundling

Contents

List of tables, figures and picture

1 Introduction

Living a fulfilling life in old age is associated with being able to stay in one's own home as long as possible; this is described as "ageing in place" (Rostgaard et al., 2011; Tarricone & Tsouros, 2008). As a person ages, and health begins to deteriorate, that person may require assistance in daily living and healthcare which is provided by home care services to make it possible to continue living at home (Hermsen et al., 2018; Nicholson, Meyer, Flatley, & Holman, 2013; Sixsmith et al., 2014; Sudmann, 2017). When asked about ways of receiving long-term care services older persons themselves mostly prefer home care compared to nursing homes and other more regulated institutions, except when the older person needs extensive care on a continuous basis, or has a limited social network or none at all (Rostgaard et al., 2011; Sigurdardottir, Sundstrom, Malmberg, & Bravell, 2012). Thus, to facilitate ageing at home for older persons, it is important to provide home care services (Hammar, Rissanen, & Perala, 2008; Keeling, 2014).

In this thesis the term *home care* will be used to refer to healthcare services provided by trained nursing staff in the home of the person receiving the care (Hafskjold et al., 2015). It is common among European countries offering home care services for the scope of care to be complex – whether preventive, acute, rehabilitative or palliative (Genet, Wienke Boerma, Madelon Kroneman, Allen Hutchinson, & Saltman, 2012; Tarricone & Tsouros, 2008). The care provided includes a large range of activities like initiatives preventing the loss of functional abilities, assistance with daily tasks and basic needs, medication management, attending to wounds, providing psycho-social support, and other care tasks such as managing specialized, advanced medical equipment and palliative care (Johansen & Fagerstrom, 2010; Rostgaard et al., 2011; Thome, Dykes, & Hallberg, 2003). In Norway policy makers and the general public expect the provision of home care to fulfil the care needs of older persons and ensure their dignity. Moreover, it is expected that the ideal of living a good life in their own homes as long as possible is supported, while at the same time the healthcare service in question should be cost-efficient as it is funded by local governments whose resources are limited (Vabo, 2012).

In this thesis, the term *older person* is used to refer to persons who are 65 years or older (Hafskjold et al., 2015). This age limit has been chosen based on the understanding that this is the rough average retirement age in most Western countries (Gorman, 1999). In addition, this is a widely applied cut-off figure which used to define old age in research covering Western countries (Beard & Bloom, 2015; Suzman, Beard, Boerma, & Chatterji, 2015).

Evidence suggests there has been an exponential increase in age-related diseases (Heikkinen, 2003; Huang & Lin, 2002). Due to the increasing age of the population, the number of frail older persons in need of home care services has increased, introducing additional issues and complexity of care needs to be managed by nursing staff working in this setting (Algera, Francke, Kerkstra, & van der Zee, 2004; Marengoni et al., 2011; Nicholson et al., 2013; Rees & Williams, 2009; van Kempen et al., 2012). This increase in the complexity of procedures and the need for individualised care delivered by all healthcare professionals to the older population , has also been emphasized by WHO (World Health Organization, 2012, 2016).

The World Health Organization (WHO) describe how the European region of WHO enjoy some of the longest life spans in the world (World Health Organization, 2012). A greater number of people living to reach old age is a sign of success, meaning these countries' welfare states have managed to provide their citizens with life promoting living conditions. However, this may also bring challenges related to ensuring sustainability of the systems promoting health, social care and pensions due to increased strain caused by an increase in service users (Beard & Bloom, 2015).

1.1 Person-centred home care

The services provided by home care are considered to be essential to the attainment of healthy and active ageing (Genet et al., 2012). National policy in Norway has drafted strategy documents where emphasis is placed on developing healthcare services with a more holistic approach to care delivery, also emphasising the need for close cooperation with the patients and their families in service delivery (HOD, 2013, 2015, 2018). This is to be achieved at a national level, through working with several focus areas like encompassing a holistic view of people; giving greater weight to patient involvement, respect and dignity; adaption to the individual needs of the patient; respect for and care of family members; and also the provision of flexible, predictable, coordinated and integrated services (HOD, 2013). These focus areas are also specified as attributes of person-centred care (Morgan & Yoder, 2012). In addition, most recent reform implemented by the Ministry of Health and Care Services in Norway (HOD), highlights the need for care solutions that better ensure older persons have the possibility to age healthily (HOD, 2018). This reform also places emphasis on the opportunity of older persons to live satisfying lives until the end by providing care that increases the individual older person's sense of coping and mastering of his/her life as perceived by the persons themselves. This ideal is in keeping with the same ideas underpinning person-centred care for older persons, namely care services that takes the person receiving the care as the point of departure, including that person's perspective and world view, when deciding on what care to offer and how to organize the care (Cooney, Dowling, Gannon, Dempsey, & Murphy, 2014; McCormack & McCance, 2017; Ruggiano & Edvardsson, 2013).

Person-centred care is advocated as the gold standard for delivering high-quality healthcare services to older persons in general (Kogan, Wilber, & Mosqueda, 2016). Further, it is the preferred model of service delivery for home care in particular (Ruggiano & Edvardsson, 2013). For older persons to describe care delivery as being of high quality, the care has to recognise the individual older person with his/her personal history, experiences and competences (Buch, 2013; Capezuti & Hamers, 2013; Cooney et al., 2014). These elements underpin the principle of person-centred care (McCormack & McCance, 2017). Another clear feature of person-centred care is that all aspects of care delivery need~~s~~ to take the persons involved as point of departure (Cooney et al., 2014; Entwistle, Firnigl, Ryan, Francis, & Kinghorn, 2012), rather than starting with the reason for needing healthcare services, a diagnosis, or the care setting. Taking the person as a starting point may be one way of sharing control. The sense of being in control over one's own life increases for older persons when they are encouraged to take part in decision-making about their care if appropriate or to the extent the individual person desires (Davies, Laker, & Ellis, 1997; Ruggiano & Edvardsson, 2013).

Person-centred care has been defined as both a philosophy and a care model (Edvardsson et al., 2016). Person-centred care acknowledges and is inclusive, and is based upon the subjective experiences, values and preferences of the person; it promotes a care delivery that is supportive; having a holistic view of aspects which are potentially pivotal to a person's health is an integral part of this (Edvardsson et al., 2016; McCormack & McCance, 2017). The provision of care needs to acknowledge the individual person's lived experience as well as biomedical and psycho-social aspects, emotional reactions, preferences, values and spiritual beliefs, and an understanding of health and possible reasons for, and solution to, perceived health-issue(s) as necessary information needed when planning, providing and evaluating care services (McCormack & McCance, 2017; Morgan & Yoder, 2012; Slater, 2006).

Such demands can be challenging for the nursing staff in clinical practice because this requires complex and comprehensive competences (Bing-Jonsson, Bjork, Hofoss, Kirkevold, & Foss, 2015; Johansen & Fagerstrom, 2010). Nursing staff – and especially nurses – experience the need for extended professional competence due to the complexity of patients' care needs, and increasingly demanding and advanced care to be provided in the home environment (Bing-Jonsson et al., 2015; Hasson & Arnetz, 2008).

In Norway, registered nurses and nurse assistants represent the largest part of the work force providing professional home care (Johansen & Fagerstrom, 2010; Vabø & Szebehely, 2012). In this care setting nursing staff have a potentially essential role in promoting self-care and they support patients by providing necessary information, competence and a helping hand. In addition, nurses play a significant role in discussion with patients regarding aspects of their lived experiences with chronic illnesses, and nurses are sometimes preferred to general practitioners (Rees & Williams, 2009). They are well qualified and have the necessary professional competence to deal with the provision on optimal care in clinical practice; they develop personalised care plans, and are often the ones who manage the flow of information to other healthcare agencies and providers (Johansen & Fagerstrom, 2010). However, nurses often represent a limited recourse due to a shortage of nurses in community services (Tarricone & Tsouros, 2008). In general, nurse assistants and nursing staff with similar level of education are considered to be essential to the sustainability of home care because they provide most of the daily living assistance and spend the most time with the patients (Tarricone & Tsouros, 2008). However, the role of nurse assistants in relation to the provision of care for older persons has received only scant scholarly attention and research has largely been focused on the setting of nursing homes and hospitals (Medvene & Lann-Wolcott, 2010; Schirm, Albanese, Garland, Gipson, & Blackmon, 2000; van Weert, van Dulmen, Spreeuwenberg, Ribbe, & Bensing, 2005; Weitzel & Robinson, 2004). There is a need for research that includes both nurses and nurse assistants when exploring aspects of home care delivery.

Nursing staff in home care need to take into account how precisely older persons express deterioration of health and well-being (Dale, Soderhamn, & Soderhamn, 2012). The unfulfilled basic needs of older persons may result in both an increased risk of developing depression (Blazer, Sachs-Ericsson, & Hybels, 2007) and mortality (Blazer, Sachs-Ericsson, & Hybels, 2005). Increased risk of mortality is also linked to aspects of quality of life like reduced sense of control and self-realisation (Netuveli, Pikhart, Bobak, & Blane, 2012). In this thesis the concept of *quality of life* is understood as capturing descriptions of what constitutes a "good life", including both objective (environment and behavioural competences) as well as subjective aspects (life satisfaction, psychological well-being and happiness) (Netuveli & Blane, 2008). Further, studies suggest that there is a "late-life" increase in anxiety and depression starting at the age of 75, which has been explained by a decline in health and mobility, loss of partner, a reduced social network and living alone (Dykstra, van Tilburg, & de Jong Gierveld, 2005; Jylhä, 2004). It has been documented that social relationships and social support prevent cognitive ageing (Seeman, Lusignolo, Albert, & Berkman, 2001).

1.2 The role of communication in person-centred care

To meet the needs of older persons, nursing staff must communicate in a way that fosters respect and creates a trusting relationship (Caris-Verhallen, Kerkstra, van der Heijden, & Bensing, 1998; Gallagher, Li, Wainwright, Jones, & Lee, 2008; Sundler, Eide, van

Dulmen, & Holmstrom, 2016). Communication also allows nursing staff to share and receive the necessary information from the person in order to ensure optimal care (Caris-Verhallen et al., 1998; Fleischer, Berg, Zimmermann, Wüste, & Behrens, 2009; Street, Makoul, Arora, & Epstein, 2009). Thus, communication - the process of verbally and non-verbally sharing information like values, preferences and perspectives, between persons interacting in a social context - is key to the delivery of person-centred care (McCormack & McCance, 2017).

Further, we know that the way care providers communicate has a significant impact on older persons' perception of well-being and quality of life, as well as cognitive and functional abilities relevant to maintaining good health (Williams, Kemper, & Hummert, 2005). Communication also influences the experience of older persons in preserving their dignity in a care situation; in other words, this process contributes to whether older persons experience being talked to in a derogatory way or not when they are presented with actual choices in the care situation or whether they have control over their life to the degree the individual desires (Gallagher et al., 2008). Communication in itself has been closely linked to improving all aspects of service delivery (Caris-Verhallen, Kerkstra, & Bensing, 1997; de Haes & Bensing, 2009). As far as care providers are concerned, it is necessary that they are efficient in working for preserving health for the individual patient (de Haes & Bensing, 2009). There is also some evidence indicating that the fact that nurses and nurse assistants in nursing homes influences communication in different ways: nurses are associated with more comfort and enjoyment while nurse assistants are associated with more functional competence among residents (Juk Hyun, 2013).

A communication process which provides nursing staff insight into "person-specific knowledge" – namely concrete insight into a person's experiences and reaction to living with disease or illness – is a prerequisite for engaging in communication processes supportive of person-centred care practice (Zoffmann, Harder, & Kirkevold, 2008). In addition, patient–nursing staff communication includes guidance and assistance to develop self-care, and this has been highly valued especially by patients in need of advanced care at home (Sadala, Miranda, Lorençon, & de Campos Pereira, 2010). Self-care is emphasized as one of the key goals of home care services in order to meet an increasingly ageing population with complex care needs (Chatterji, Byles, Cutler, Seeman, & Verdes, 2015; Genet et al., 2012; Rostgaard et al., 2011).

The potential of patient–care provider communication which has inherent healing properties, either directly or indirectly, is linked to improved health outcomes for the patient (Street et al., 2009). Responding to the patient's emotion and managing uncertainties may reduce anxiety and worrying, having a direct, positive effect on health outcomes for the patient. Moreover, communication may indirectly affect intermediate outcomes by promoting collaboration and a reciprocal sharing of information between the care provider and the patient, allowing better care decisions with better patient compliance, increased self-management skills for the patient and an enhanced therapeutic alliance. These central aspects of communication make communication important in reaching goals of person-centred care (McCormack & McCance, 2017; Morgan & Yoder, 2012). Still, it seems to be few recent studies that explore the real-life communication that takes place during home care visits.

1.3 Emotional communication

Emotions either explicitly expressed or expressed to indicate worries indirectly *or* as hints to worries provide valuable insight into the subjective experience of an event or situation, and reveal information relevant to the individual person's care delivery (Del Piccolo et al., 2017; Zimmermann, Del Piccolo, & Finset, 2007). When a person shares his/her worries and reasons for distress, this also conveys the emotional and cognitive evaluations a person has about his/her life, allowing insight into that person's emotional well-being (Charles & Carstensen, 2010; Diener, Oishi, & Lucas, 2003). Addressing a patient's worries and distress improves patient satisfaction, better psycho-social adjustment, reduces psychological distress and need for information, as well as improves the patient–provider relationship (Bayne, Neukrug, Hays, & Britton, 2013; Lelorain, Bredart, Dolbeault, & Sultan, 2012). Unresolved distress or worry can influence quality of life, well-being, and the ability to live independently (Davies et al., 1997), which is part of the cornerstone of good health (Suzman et al., 2015). There is evidence of higher patient satisfaction scores in cancer care in the case of those nurses responding to patients' worries and distress by exploring and acknowledging patients' issues, compared to nurses who respond in a distancing and detached manner. (Uitterhoeve et al., 2009). There is also some indication that nurse assistants (or nursing staff with equivalent qualifications) use communication strategies that acknowledge the patient and in a setting of clinical communication they communicate respect to a great extent (Medvene & Lann-Wolcott, 2010). However, these findings are limited to nursing homes.

Nursing staff need to be aware of distress in order to prevent or reduce the impact on the person's health and quality of life (Davies et al., 1997; Van der Elst, Dierckx de Casterle, & Gastmans, 2012). One way of achieving this is for nursing staff to be sensitive and to respond to expressions of worries and emotional needs of a patient (Finset, 2012; Zimmermann et al., 2007). The ability of the nursing staff to engage with the person and address these issues in a person-centred way is an integral part of person-centred communication; a prerequisite for person-centred care (McCormack & McCance, 2017). Emotionally loaded utterances can reflect the patient's evaluation of a situation or a condition (Eide, Eide, Rustoen, & Finset, 2011). Emotional communication may therefore provide a window onto the person's experiences of a situation or the perceived importance of a given circumstance, and preferences and values relevant to delivering effective healthcare (Zimmermann et al., 2007). The way this is expressed in home care and the way nursing staff respond to these demands had not been the subject of research before the start of this thesis. This study represents an investigation into the under-researched question of how exactly this situation is expressed in home care and the way nursing staff respond to these demands.

Research capturing how the older person expresses worry and distress to nursing staff and how nursing staff communicate the issues raised by older persons in a home care setting could prove to be an asset in working towards the improvement of home care services (Sundler et al., 2016). However, little research is available on this topic. Thus, the overarching aim of this thesis is to narrow this gap in the knowledge base.

1.4 Communication with older people receiving home care: The COMHOME – project

The lack of communication research capturing the home care setting has long been recognised has been expressed for several years and there has, in general, been scant research into the topic (Caris-Verhallen et al., 1997; Edvardsson et al., 2016; Fleischer et al., 2009). Therefore, we know relatively little about how key functions of communication are in reality placed in clinical practice in this setting. Research related to patient–nursing staff communication has focused mainly on institutional care settings (Fleischer et al., 2009).

Home care takes place in the patient's own home and differs greatly from a general practitioner's surgery, hospital ward or nursing home (Giesbrecht, Crooks, & Stajduhar, 2014; Olsson & Ingvad, 2001; Oresland, Maatta, Norberg, Jorgensen, & Lutzen, 2008; Wiles et al., 2009). For example, the patient's personal characteristics come much more apparent when entering a person's home, as compared to a hospital ward. Social relationships and significant moments in life are visible for instance in pictures, and personal interests and spiritual beliefs may be understood through the artefacts found in the person's home, and the atmosphere of the home may reflect the person and his/her significant others. The older person's life-world becomes more visible in this setting as compared to institutional care settings. Accessing the older person's life-world may reveal key aspects of an older person's identity, personal history, experiences and competences. These are elements that convey information necessary to enable the nursing staff to provide high-quality holistic care underpinned by the principles of person- centredness (Buch, 2013; Capezuti & Hamers, 2013; Cooney et al., 2014; McCormack & McCance, 2017). In addition, the older person's home includes symbolic aspects of physical, social and emotional importance to the person, often representing a place of considerable familiarity and intimacy (Cristoforetti, Gennai, & Rodeschini, 2011; Wiles et al., 2009).

The research underpinning this thesis is part of the international study with the acronym COMHOME. The chief aim of the COMHOME project is to deepen our knowledge of clinical communication practice between different care providers and older persons who use healthcare services (≥65 years) (Hafskjold et al., 2015). The project has researched communication with older persons living at home in Norway, Sweden and the Netherlands using qualitative and quantitative methods. This thesis focuses on the communication in home care performed by nurses and nurse assistants in Norway. Table 1 shows the publications from the project from the three countries with the three papers of the current thesis highlighted in bold.

Table 1. Empirical research papers of the COMHOME-project targeting the home care setting

Country	Title of the publications*
Norway	○ Characteristics of communication with older people in home care: A qualitative analysis of audio recordings of home care visits (Kristensen et al., 217) ○ ***The use of supportive communication when responding to older people's distress in home care - An observational study (Hafskjold et al., 2017)*** ○ ***Older persons' worries expressed during home care visits: Exploring the content of cues and concerns identified by the Verona coding definitions of emotional sequences (Hafskjold et al., 2016)*** ○ ***Nursing staff's responses to thematic content of patients' expressed worries: observing communication in home care visits (Hafskjold et al., 2018)***
Sweden	○ Communicative challenges in the home care of older persons - a qualitative exploration (Sundler et al., 2016) ○ Older persons' expressions of emotional cues and concerns during home care visits. Application of the Verona coding definitions of emotional sequences (VR-CoDES) in home care (Sundler et al., 2017)

	○ Registered Nurses' and nurse assistants' responses to older persons' expressions of emotional needs in home care (Hoglander et al. 2017)
The Netherlands	○ Towards enhanced emotional interactions with older persons. Findings from a nursing intervention in home health care (Veenvliet et al., 2016)

* The papers of the current thesis highlighted in bold

The development of this thesis – including the framing of the research questions and the understanding of current communication practice in home care visits – has been influenced in particular by the studies based on the Norwegian and the Swedish material.

The qualitative study, exploring the setting of Norwegian home care including nurse assistants and older persons, described the communication as being task-oriented (Kristensen et al., 2017). This means nursing staff focus on health-related problems by providing information, advice and communication related to the physical care tasks (Caris-Verhallen et al., 1998). This focus on the task may be a reason why physical needs were given more attention than existential needs (Kristensen et al., 2017). In addition, this qualitative analysis revealed that the communication was related to the person by 1) supporting the connection of older person’s to their everyday life, 2) supporting involvement in their own care, 3) giving attention to physical and existential needs, and 4) revealing the impact of continuity and predictability of care on the well-being of older persons.

The qualitative analysis of the Swedish material also focussed on nurse assistants and older persons (Sundler et al., 2016). This study found that communication challenges occurred in situations where the older person’s view of the care task and its content differed from the nurse assistant’s understanding, and when communication took an unexpected turn. The nurse assistant usually focused on the task that needed to be performed in order to reach the goals of the visit. When the older person's agenda differed from the goals in question and shifted attention to other topics – whether existential issues, that person's experience of fragility or dependence, worries about daily life, or disappointment or disagreement with care – communication challenges could result. In these situations, the nurse assistant seemed to find it difficult to respond to the older person's needs and worries.

Both of these qualitative studies indicated the need for further exploration of how older persons communicate issues of personal importance, representing challenges, worries or distressing circumstances which affect their life and health, and how nursing staff pick up on these issues and handles them during communication (Kristensen et al., 2017; Sundler et al., 2016).

Emotional communication is explored in the COMHOME-project, as well as in the present thesis which uses the observational coding system named the Verona Coding Definitions of Emotional Sequences (VR-CoDES) (Del Piccolo et al., 2011; Del Piccolo et al., 2017; Zimmermann et al., 2011). This system has been especially devised for identifying different aspects of emotional communication in patient–care provider communication taking place in a healthcare setting. The Swedish material analysed with VR-CoDES found that moments of emotional communication were present in over 50% of the home care visits. It also showed that older persons seldom expressed worries and distress explicitly (Sundler, Hoglander, Eklund, Eide, & Holmstrom, 2017). Moreover, the Swedish study concluded that further research into the responses of nursing staff to emotional expressions and how current communication practice may influence the management of the emotional needs of older persons in home care can help to underpin quality care in this setting (Hoglander, Eklund, Eide, Holmstrom, & Sundler, 2017).

1.5 Aims of the thesis

The main aims of this thesis are to explore a) how older persons express their worries to nursing staff during home care visits, b) how nurses and nurse assistants respond to the worries expressed, and c) to discuss the findings within a supportive communication framework and to discuss whether current communication behaviour is likely to facilitate person-centred care delivery in home care services.

The specific aims of the three papers were:

1. to describe how nursing staff respond to older people's expressed worries (paper I).

2. to identify conditions that encourage older people to open up for further disclosure of their emotions (paper I).

3. to identify the concerns and cues of older persons regarding unpleasant emotions expressed during home care visits (paper II).
4. to explore the cause of their worries and distress and identify the emotions expressed (paper II).
5. to explore characteristics of thematic content of older persons' worries expressed during home care visits (paper III).
6. to explore how nursing staff respond to worries with different thematic content during home care visits (paper III).

2 Empirical and theoretical framework

The current chapter presents the theoretical link between person-centred care, interpersonal communication and emotional communication underpinning this thesis.

Communication taking place in healthcare settings has been researched through the lenses of various ancillary sciences such as symbolic interactionism, interactional constructivism or communication theory like sender/receiver models or interpersonal communication (Berry, 2007; Fleischer et al., 2009). In this thesis communication is seen as a process unfolding in an interpersonal context where the persons involved attempt to understand what is important to the other person; depending on the interpretation of the other person’s, the person makes a judgment about how and what to communicate (Berger, 2005; Burleson, 1994). Status as a member of the professional nursing staff who provides represents a contextual factor that adds a professional element to the communication (Duggan & Street Jr, 2015). This influences the interpersonal setting (Oresland et al., 2008; Spiers, 2002), making it different from informal, everyday communication that takes place in private, social settings. The application of this understanding within a person-centred framework means that the person tries to adapt his/her communication to what is perceived as the informational and emotional needs of the other with the aim of achieving person-centred care outcomes (Eide, Hafskjold, Sundling, & van Dulmen, 2017; McCormack & McCance, 2017).

2.1 The concepts of person-centred care, person-centredness and patient -centredness

The boundaries between person-centred care and other concepts such as people-, patient-, client-, and family-centred care seem to be somewhat porous (Malusky, 2005; Mead & Bower, 2000; Restall, Ripat, & Stern, 2003; World Health Organization, 2016). It is not always easy to distinguish clearly between person-centred care and these closely related concepts.

The care goals of these related concepts are similar and may be said primarily to differ according to the type of care settings they refer to, and the persons included. The intention of the care delivery seems to comprise the same principles as of person-centredness, i.e. focusing on care being centred on the person receiving the care (Morgan & Yoder, 2012). A common element of patient-, client-, and family-centred care is that care delivery starts by placing it in a particular care setting. However, it may be argued that using *person* instead of a care-specific term such as patient or client, is better when advocating for a holistic approach to care delivery, which takes the person as the point of departure rather than the care setting (McCormack & McCance, 2017; Morgan & Yoder, 2012). Moreover, in the framework of providing and developing care services informed by the principles of person-centredness an equally valued aspect is to consider the care provider as a person (McCormack & McCance, 2017). This aspect seem to be given less focus in the literature describing features of the related concepts mentioned above.

In the provision of person-centred care the endeavour to approach each person in a holistic way, truly acknowledging and respecting what the individual person includes in his/her concept of self is obviously of cardinal importance (Cloninger, 2011; Entwistle et al., 2012; Finset, 2011; McCormack & McCance, 2006; Morgan & Yoder, 2012; Rogers, 1957; Ruggiano & Edvardsson, 2013). Achieving this in everyday care practice means working systematically in order actively to grasp a person's values and personal goals, as well as understanding the person more fully in his/her life context than merely as being affected by a disease or illness. The knowledge would then be used to co-create care outcomes that are underpinned by the values held by the person in question. In this way the act of delivering care is informed by what is understood as promoting good health for that person. This can also be seen as a consistent focus in the literature on person-centred care, which advocates addressing the "person as a whole" when providing healthcare rather than adopting a narrow approach to a disease, the care providers themselves, or fitting care delivery to a system (McCormack, Dulmen, Eide, Skovdahl, & Eide, 2017).

Person-centred care tailored towards older persons is described consistently as characterised by six domains including 1) holistic or whole-person care, 2) respect and value, 3) choice, 4) dignity, 5) self-determination, and 6) purposeful living (Kogan et al., 2016). This fits well with how home care services are described from the perspectives of older patients and nursing staff (Eloranta, Arve, Isoaho, & Routasalo, 2010). Moreover, it corresponds well to what is highlighted as quality care for older persons in Norwegian white papers (HOD, 2013, 2015, 2018). This is also in keeping with the standpoint adopted in this thesis regarding what is meant by the term person-centred care.

The purpose of the home care visit is based to a large extent on the specific care needs identified for the individual care recipient; these are tailored to support the person's ability to remain self-reliant for as long as possible and to live a fulfilling life in his/her own home (Eloranta et al., 2010; Rostgaard et al., 2011; Thome et al., 2003). This aspect of care delivery in home care may be characterised as being goal directed. Goal-directed care may constitute an underlying contributory factor to the task-oriented communication described as characteristic for patient – nursing staff communication as it naturally takes place in home care visits (Caris-Verhallen et al., 1998; Kristensen et al., 2017). Little is known about whether patient – nursing staff communication occurring during home care visits contributes to person-centred care delivery.

2.2 Person-centred communication

It is often claimed that communication is of pivotal importance in all nursing relationships, and the theory used to inform the understanding of this setting should reflect the characteristics of such relationships (Fleischer et al., 2009). A subsidiary aim of this thesis is to provide knowledge that describes and explores aspects relevant for the practice of principles of person-centredness in the communication in the setting of home care. The theoretically-informed reflections on ways to practice person-centred communication linked to the empirical findings provided in this thesis may help clarify just how elements of person-centredness are to be found in clinical communication as demonstrated in the setting of home care visits (Eide et al., 2017).

Attributes of *person-centred* communication are possible to derive as attributes also classed as *patient-centred* communication. A common feature these attributes is that they reflect principles of person-centredness (Epstein et al., 2005; McCormack & McCance, 2017; Street, 2017). Therefore key literature describing both person-centred and patient-centred communication is used to further inform our conceptual understanding of person-centred communication in this thesis.

The ability to engage in communication with the care recipient who allows access to what is experienced as central to that person is described as a prerequisite for the care provider in order to provide person-centred care (McCormack & McCance, 2017). There is a mass of literature which highlights *the ability to respond* to worries and distress as key functions of person-centred communication (Duggan & Street Jr, 2015; Eide & Eide, 2017; Finset, 2012; Morse, Bottorff, Anderson, O'Brien, & Solberg, 2006). The key criteria for evaluating the degree of person-centredness in the communication in relation to nursing are described as the degree to which nurses elicit information from the patient, encourage~~s~~ self-disclosure, and give empathic acknowledgement (Kasch & Dine, 1988). Relatively few studies have focused on person-centred communication with the notable exception of dementia care and institutionalised care such as is to be found in hospitals and nursing homes (Bolster & Manias, 2010; Downs & Collins, 2015; Savundranayagam, 2014; Williams et al., 2011).

Person-centredness in home- and community-based long-term care is described as being put into practice by ensuring a service that sees the patient/client *as a person*. It considers the *whole person*, takes into account *common ground*, and fosters *therapeutic alliances* (Ruggiano & Edvardsson, 2013). These are all notions which are in one way or another clearly related to clinical communication, but are not properly linked to the communication process. Literature searches performed in relation to this thesis have not provided a rating scale or other instruments capturing person-centred communication especially tailored for the setting of home care.

Thus, in this thesis the more general definition provided by Epstein and his colleagues is used to define goals of communication in accordance with person-centredness (Epstein et al., 2005; Epstein & Street, 2011). Epstein and his colleagues include four overarching goals of communication in a healthcare setting that need to be fulfilled in order to integrate principles of person-centeredness in patient–provider communication (Epstein et al., 2005):

1) *Facilitation* in eliciting and understanding of the patient perspective
2) *Promotion* of understanding of the patient within his/her unique psycho-social context
3) *Promotion* of the process of reaching a shared understanding of the problem and its treatment with the patient which is in line with the patient's values
4) *Facilitation* of the sharing of power and responsibility by involving patients in choices to the degree they wish

These four goals can be seen as partly overlapping with the goals described as person-centred care in nursing (McCormack & McCance, 2017) and they will be used as a framework in which to discuss the findings of the current thesis in relation to person-centredness. Figure 1 provides an overview of the main outcomes of person-centred communication between patients and nursing staff as conceptualised in this thesis.

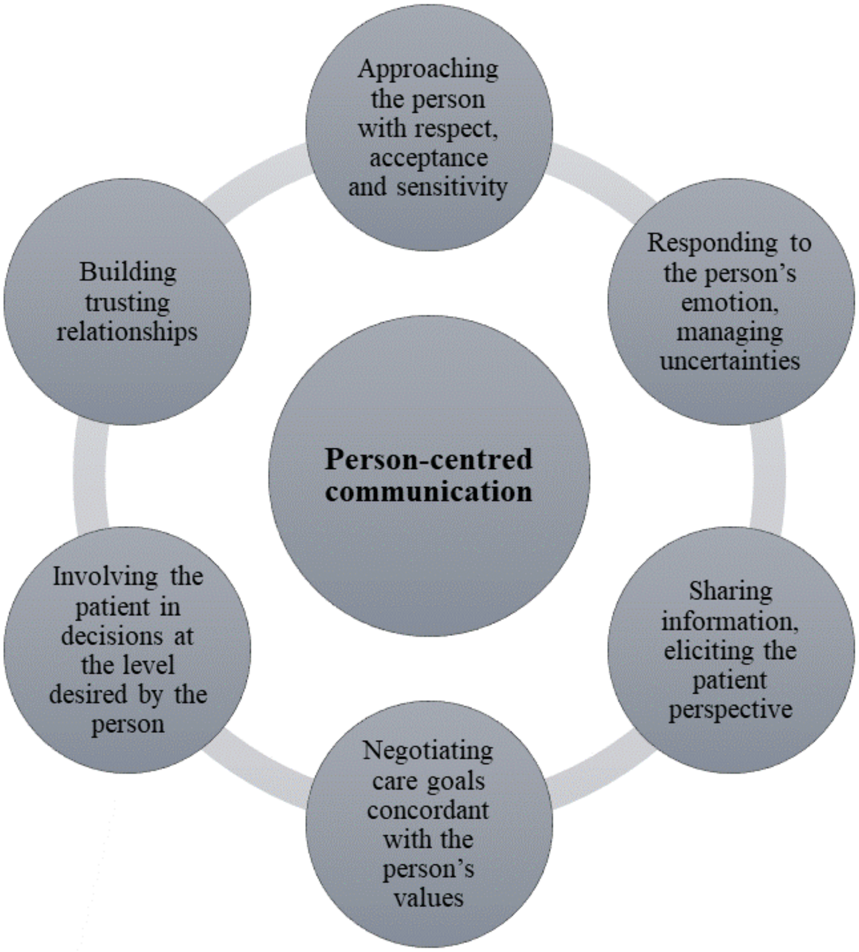


Figure 1. Outcomes of person-centred communication adapted from Epstein et al. (2005) and McCormack and McCance (2017)

2.3 Linking person-centred communication outcomes and measures of emotional communication

The need to enhance coherency and theory within the field of health communication and quality assessments have been emphasized (de Haes & Bensing, 2009; Street & Mazor, 2017). In this thesis the lens used to explore communication practice in a home-care setting regards how, and to what extent, patients express worries, and whether nursing staff pick up on these issues and addressing them in ways that may be viewed as supportive and consistent with principles of person-centredness. The chief assumption is that by describing patterns of emotional communication found in a clinical setting and linking these patterns theoretically to ways of achieving person-centred communication

(Del Piccolo, 2017), it is possible to make qualities linked to person-centred communication more explicit and relevant to home care.

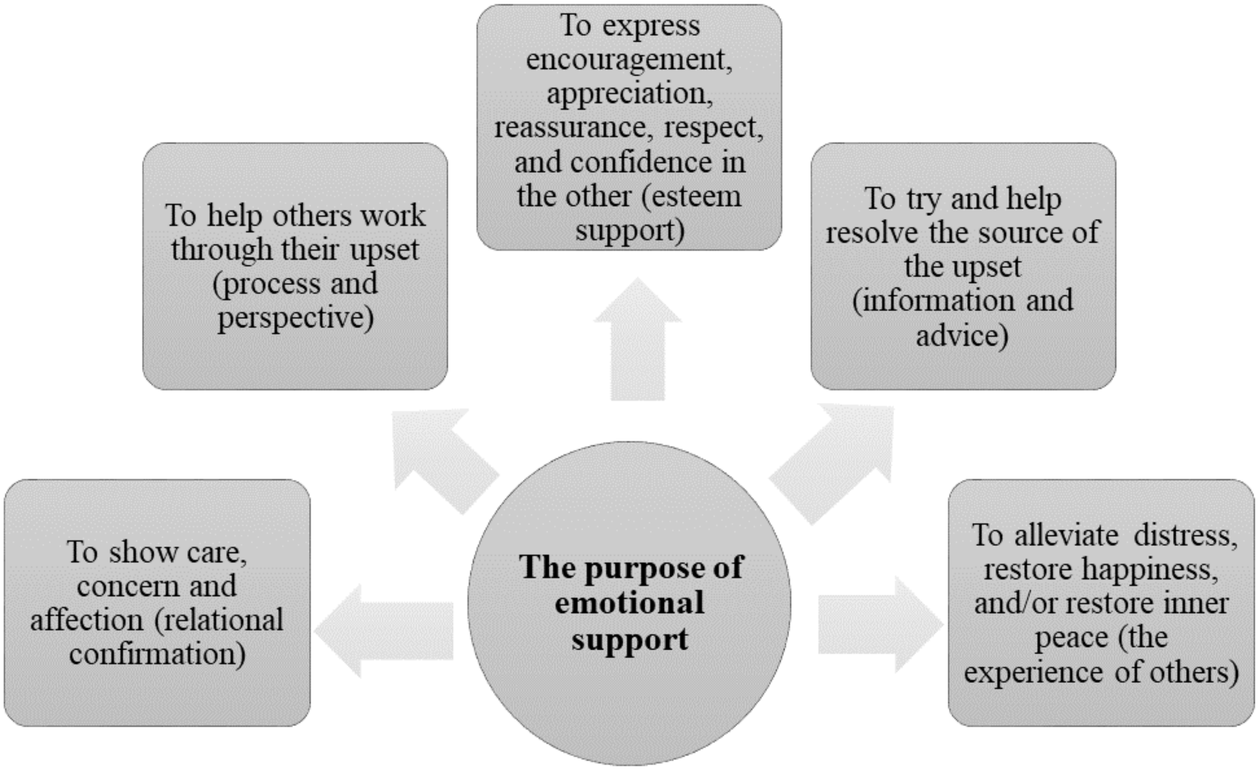
As we have seen, the VR-CoDES has been used to identify these emotional communication sequences (Del Piccolo et al., 2011; Zimmermann et al., 2011). The VR-CoDES does not provide a normative guide as to what constitutes an appropriate response to cues and concerns (Del Piccolo et al., 2011). Therefore, to be able to discuss whether observed patterns identified by the VR-CoDES are more or less likely to achieve person-centred communication outcomes in home care, the VR-CoDES terminology needs to be linked theoretically in a way that identifies relevant variables and guides interpretation of these findings.

Frameworks describing communication having a person-centred aim (also described in the medical context as patient-centred) highlight the importance of addressing the patient's emotional needs to reach the goals of person-centred care (Epstein et al., 2005; McCormack & McCance, 2017; Street et al., 2009). However, the outcomes presented are either too general or vague (see the outcomes presented in figure 1), or the characteristics of emotional communication are insufficiently defined, thereby excluding the possibility of using the descriptions of person-centred communication as a framework when interpreting data derived by the VR-CoDES alone. In this thesis the framework for supportive communication and person-centred messages developed by Burleson and colleagues (Burleson, 1994; Burleson & Macgeorge, 2014; Burleson, Sarason, & Sarason, 2009) has been used to bridge this gap. The detailed descriptions provided by Burleson and colleagues – in which different levels of person-centredness in supportive or comforting communication strategies are defined – have been successfully used in another study to evaluate nurses' responses to distress of patients as identified by the VR-CoDES in a hospital setting (Eide, Sibbern, & Johannessen, 2011).

2.3.1 Supportive person-centred communication

Successful supportive communication facilitates assistance and allows a patient to cope better and reduces distress in the person perceived as needing this aid (Bodie, Burleson, & Jones, 2012; Burleson, 1994; Burleson & Macgeorge, 2014). Such techniques are also known as "comforting communication strategies" and are directed at managing the psychological states of others (Burleson, 1994). It is Burleson's contention that communication strategies are considered as supportive when they prompt the distressed person to feel better in their immediate situation, but also when such strategies allow the person to cope better with distressing events in the future (Burleson, 1994). Although distress in this context represents reactions to circumstances linked to daily living, and excludes distress caused by a somatic condition or trauma, it should nevertheless not be dismissed as trivial or irrelevant to a person's well-being and health; such distress stems from a variety of everyday upsets, troubles and disappointments (Burleson, 1994; Burleson et al., 2009). The success of older persons to manage everyday challenges is a strong predictor of well-being and physical health (Murphy, Cooney, Shea, & Casey, 2009; Nicolaisen & Thorsen, 2012; Seeman et al., 2001).

Burleson uses the term "message" when referring to features of supportive verbal and non-verbal behaviour, the emphasis being on the verbal form and content (Burleson, 1994). When someone ponders how exactly to phrase the supportive response or message, he/she may be guided by one single purpose, but there is usually more than one purpose supporting someone's intention to comfort. Figure 2 summarises what Burleson and colleagues identifies as being possible purposes for emotional support to another person (Burleson, 2008; Burleson & Macgeorge, 2014; Greene & Burleson, 2003).



Adapted from Burleson, 2008; Burleson & Macgeorge, 2014; Green & Burleson, 2003

Figure 2. Purposes of supportive messages to aid distress in the other

Using the framework of supportive communication when exploring observations of expressions of distress by older persons and the responses of nursing staff may therefore inform us as to whether the current communication practice is more or less likely to be supportive and likely to promote person-centred communication outcomes. The term "message" used by Burleson (Burleson, 1994) and "provider response" in the VR-CoDES (Del Piccolo et al., 2011) are seen as representing the same verbal and non-verbal behaviour. However, the VR-CoDES uses the sequential nature of the communication process to restrict the provider response to be the immediate response following the expression of a cue/concern, this aspect is not well defined by Burleson's system. Here, the sequential nature is only described by the message being a reaction following the perceived distress in the other (Burleson, 1994).

2.3.2 Level of verbal person-centredness

Building on person-centred communication strategies found in educational research (Applegate, 1980), Burleson developed the Hierarchical Coding System for Sensitivity of Comforting Strategies (HCSSCS). Here, the chief aim is to distinguish between comforting strategies as characterised by their level of person-centredness (Burleson, 1994). The system comprises three main levels which can be distinguished by how effective the message legitimizes, acknowledges, elaborates on and contextualises the emotions and perspective of the other person (Burleson, 1994; Burleson et al., 2009). Based on features of the message, it is described as being a 1) low, 2) moderate or 3) highly person-centred message (Burleson, 2008). Thus messages with low verbal person-centredness are categorised under level 1 in the system. This level comprises messages which deny or play down the other person's emotions and perspective (criticizing, challenging or telling the other what to feel). Moderately verbal person-centred messages provides an implicit recognition of the other person's emotions and perspective and are categorised under level 2 (offers of sympathy and condolence, non-affective focused explanations which are appropriate to the circumstance). Last, level 3 represents highly person-centred messages including sophisticated strategies which explicitly acknowledge and legitimize~~s~~ emotions. Explicit in such messages are offers to help the other person to articulate the emotional state, an elaboration on the possible causes of the emotion in question as well as assistance in fitting the emotions into a broader context, thereby helping the other person gain new insight into the situation.

There is now a considerable body of research to support the notion that moderately and high person-centred messages have a more positive supportive effect on the recipient compared with low person-centred messages, which downplay the emotions and perspectives of the other person (Bodie et al., 2012; Burleson, 1994; Burleson, 2008; Burleson et al., 2009).

3 Detailing the Coding Definitions of Emotional Sequences (VR-CoDES)

In this chapter I shall give an account of the VR-CoDES, the observational system applied as the main approach for identifying emotional communication during home care visits. I start by providing an overview to the methodology of behavioural observation that underpins the VR-CoDES as a research method.

3.1 Behavioural observation

This thesis understands communication as behaviour, thereby making it possible to observe by using an observational method to investigate characteristics of the communication processes (Bakeman & Gottman, 1997; Bakeman & Quera, 2011), which are founded on empiricism (Bostrom & Donohew, 1992). By analysing empirical evidence and identifying patterns that may occur in particular settings and contextual circumstances, it is possible to understand communication behaviours in the light of probable behaviour or consequences (Bostrom & Donohew, 1992). The findings from such an analysis of observational data may be used in terms of describing features of communication in a given nursing setting (Eide et al., 2017). However, the validation of causal relationships identified in observational data requires randomised controlled trials (RCT) to verify the causal direction of correlations and relationships (Prasad, Jorgenson, Ioannidis, & Cifu, 2013; Ward, 2009).

Moreover, by documenting behaviour in a sequential manner (time or as successive events) it is possible to illuminate the dynamic process of social interaction (Bakeman & Gottman, 1997; Bakeman & Quera, 2011). This has proved to be valuable for communication research in general (Bakeman & Quera, 2011), and for person-centred communication research in particular (Eide et al., 2017), and as well as being a guiding principle of developing the VR-CoDES (Del Piccolo et al., 2017).

3.2 A shared approach in the classification of emotional communication

The VR-CoDES is the result of an international collaboration between health communication researchers aiming to find a shared approach to systematically observe emotional communication, classified as patients' expressions of worries or emotional needs, and the providers' subsequent response (Del Piccolo, de Haes et al. 2011, Zimmermann, Del Piccolo et al. 2011). Collaboration with this research network, "The Verona Network on sequential analysis", has been a part of my work during the research undertaken for writing this thesis. The design of the VR-CoDES allows the sequential identification of emotional communication behaviour between patients and their care providers as this is observed in a clinical setting (Del Piccolo et al., 2017).

Observational systems, such as VR-CoDES, which are especially devised for the purpose of capturing emotional communication, are crucial for gaining a deeper understanding of these interactions (Zimmermann et al., 2011). Other observational systems are available, such as the Roter interaction analysis system (RIAS) (Roter & Larson, 2002), the Coordination and Competence System (CACS) (McNeilis, 2001) or system for analysing patient participation in health communication (Street & Millay, 2001), to mention some. All these systems aim to capture the entire communication taking place between the care provider and patient, and none of these systems are designed to capturing emotional communication at the same in-depth levels as the VR-CoDES.

The VR-CoDES considers unpleasant emotions to be a conscious experience by the patient. These emotions consist of a single basic emotion, or combinations of basic emotions, as listed by Ekman and Friesen (p.71) (only considering those with a negative connotation): sadness; anger; fear; disgust; or surprise in terms of shock, and also shame (Ekman & Friesen, 1981).

The theoretical underpinning of the VR-CoDES is based on person-centred values through capturing person-centred communication (Del Piccolo et al., 2017), i.e. communication focused on the issues of greatest importance to the patient, as reflected in his or her emotional cues and concerns (Eide, Eide, et al., 2011). The VR-CoDES assumes that identifying communication patterns where the patient feels free to express his/her worries is valuable to understand in order to find ways of increasing person-centred interactions in different clinical settings (Del Piccolo et al., 2011; Zimmermann et al., 2011).

Since the introduction the VR-CoDES, application of the system has been tested in several studies covering numerous healthcare settings including different types of care providers and adult patients indicating that the system is suitable and useful for researching emotional communication irrespective of the care setting. Studies include ***hospital consultations*** during patient admission or hospital stays and outpatient clinics and follow up care (Del Piccolo, Mazzi, Goss, Rimondini, & Zimmermann, 2012; Del Piccolo et al., 2015; Eide, Sibbern, Egeland, et al., 2011; Heyn, Ruland, & Finset, 2012; Mjaaland, Finset, Jensen, & Gulbrandsen, 2011a), ***primary care*** (Butalid, Verhaak, & Bensing, 2015; Butalid, Verhaak, van Dulmen, & Bensing, 2014; Riley et al., 2013; Zhou, Lundy, Humphris, & Mercer, 2015) and ***home care*** (Sundler et al., 2017; Veenvliet, Eide, de Lange, & van Dulmen, 2016). The evaluation of communication between medical students and simulated patients has also been tested using the system (Zhou, Collinson, Laidlaw, & Humphris, 2013).

The VR-CoDES has also been validated as a method that captures moments in communication where the patient raises important issues which he/she experienced as troubling. Further, these are issues that the patient wants the care provider to address (Eide, Eide, et al., 2011). This shows that the VR-CoDES has ecological validity as the system is able to identify moments of emotional communication of importance to the individual patient and not merely those moments which reflect the observer/researcher's perspective.

The coding system consists of three manuals: one describing the unit of analysis, one for coding patients' utterances and one for coding provider responses. For the patient utterances, a unit of analysis is determined by the applicable categories of cue or concern as defined by the coding system. Data from the two coding steps (patient's cues and concerns, and provider response) are separate and can be analysed as two sets of data or in a sequential manner. Manuals and instructions on how to use the system are available free of charge at: http://www.each.eu/research/verona-coding-system/

3.3 VR-CoDES – worries expressed as cues and concerns

VR-CoDES focuses on the level of explicitness in the patient's expression of distress that is identified without necessarily knowing what the person is worried about (Zimmermann et al., 2011). Explicitness in the patient's expression is differentiated by the coding categories, concerns and cue. Concerns are defined as clear, unambiguous expressions where emotion is current or recent and explicitly verbalized (e.g. "*I'm scared*"), whereas cues are defined as a verbal or non-verbal hints of underlying unpleasant emotion, but the expression lacks clarity (e.g. patient crying) (Del Piccolo, Finset, & Zimmerman, 2008). When a concern or a cue has been identified, the coder decides whether the patient elicited the expressions spontaneously (patient-elicited, PE) or if the care provider in some way solicited the expression (health care provider-elicited, HPE). Further, expressions coded as cues can be assigned to one of seven categories (cues a – g). Differentiation of the different cue-categories is based on linguistic properties of the expression (Del Piccolo et al., 2008) (examples of expressions found in the material analysed of this thesis):

- Vague or unspecific words describing the emotion (cue a);
- Hints to hidden concerns like using unusual descriptions or words, metaphors, exclamations, references to circumstances, etc. (cue b);
- Phrases which emphasise physiological or cognitive correlates (cue c);
- Neural expressions standing out from the narrative background (cue d);
- Patient-elicited repetition of previous neutral expression (cue e);
- Non-verbal cue (cue f);
- Clear and unambiguous expressions of unpleasant emotions which are in the past (more than one month ago) or belong to an indeterminate period of the patient's life (cue g)

3.3.1 Empirically based characteristics of cues and concerns

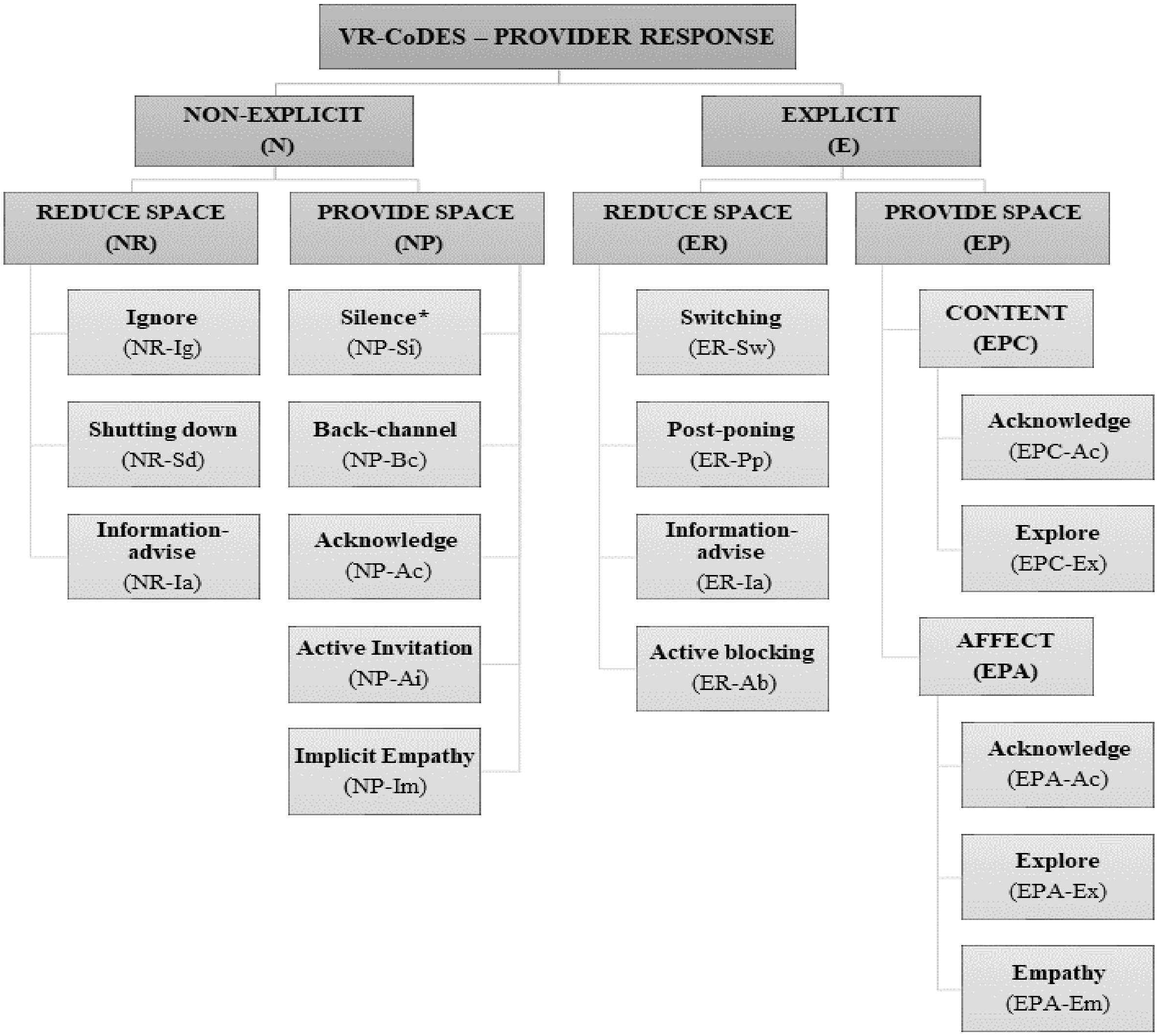
Several studies find that the cue category of hidden concerns (cue b) are the most frequent across care settings (Del Piccolo et al., 2015; Heyn et al., 2012; Sundler et al., 2017). Moreover, studies indicate that the way worries are expressed differs according to the agenda in the encounter and care setting (Eide, Sibbern, Egeland, et al., 2011; Riley et al., 2013; Schouten & Schinkel, 2015; Sundler et al., 2017). It is possible to lump together codes for patient expressions understood as having similar linguistic characteristics is possible when investigating aspects relating to how worries are disclosed, as a way of focusing on function rather than specific linguistic properties. One example is Heyn and her colleagues who computed a binary variable describing emotional explicitness categorising all cues/concerns into one of two broader categories labelled 1) descriptive cues and 2) hints to hidden emotions (Heyn, Finset, & Ruland, 2013). Another approach adopted to investigate cues and concerns includes adding information about the topical content of the distress expressed. Patients receiving primary care services are found to differentiate topical content depending on the care setting and care provider's professional status (Riley et al., 2013). It was considered appropriate to use both these analytical approaches - code distribution and topical content - in this thesis.

The question of who initiates the cues/concerns, is also of interest as this is found to vary depending on care settings. Health care provider-elicited (HPE) cues/concerns are most common compared to patient-elicited cues (PE) during home care and in hospital consultations with nurses (Eide, Sibbern, Egeland, et al., 2011; Sundler et al., 2017). In comparison, patient-elicited cues are more common in cancer care, and in consultations with neurologists and psychiatrists (Del Piccolo et al., 2012; Del Piccolo et al., 2015; Heyn et al., 2013). Another interesting finding reported in several studies concludes that cues/concerns elicited by the care provider are more likely to allow scope for further disclosure (provide space) compared to patient-elicited cues/concerns (Del Piccolo et al., 2012; Del Piccolo et al., 2015; Finset, Heyn, & Ruland, 2013; Hoglander et al., 2017).

3.4 VR-CoDES – Provider responses to expressions of unpleasant emotion

VR-CoDES – Provider Responses captures the response of nursing staff immediately following a concern or cue (Del Piccolo et al., 2009). The coding has two dimensions. First, the coder identifies whether the response refers to the concern/cue “explicitly” or “non-explicitly”. This means whether or not the member of the nursing staff maintains the wording or key elements of the concern/cue as originally uttered by the patient. This dimension points the ability to keep attention focused on the patient expression, which is assumed to hint at the nursing staff’s interest towards patient’s way of expressing him/herself (Del Piccolo, 2017). Second, the coder determines whether the response performs the function of “providing space” or “reducing space” for further disclosure of the concern/cue, thereby allowing the patient the choice whether to talk more about the distress they have expressed or not. This dimension of the response reflects the intention of the nursing staff to maintain reciprocity in the communication, changing of topical focus or changing the subject entirely (Del Piccolo et al., 2017).

One of 17 response codes can be assigned to a response. Application of the system to audio recordings does not permit the use of the code “silence, non-explicit providing space” (Del Piccolo et al., 2009). Figure 3 provides an overview of all response codes.



*Not applicable when analysing audio-recordings

Figure 3. VR-CoDES Provider Response codes

3.4.1 Empirically based characteristics of provider responses

In addition to initiation (Del Piccolo et al., 2012; Del Piccolo et al., 2015; Finset et al., 2013; Hoglander et al., 2017), the timing of the cues/concerns can influence response patterns. There is some evidence that high frequency of cues/concern and cues/concerns presented after the initial phase of the consultation are more likely to be met by reducing space responses (Del Piccolo et al., 2012; Finset et al., 2013; Zhou et al., 2013; Zhou et al., 2015).

The care provider's length of experience has also been linked to an increased cue/concern frequency in psychiatric consultations (Del Piccolo et al., 2012), indicating that professional experience may affect emotional communication. There is also some indication that female care providers and/or female patients increase the provision of providing space responses (Del Piccolo et al., 2012; Finset et al., 2013).

Many studies suggest that, overall, care providers mostly provide space and that this is usually done non-explicitly (without referring back to the affective or topical content of the cue/concern), using minimal encourages like back-channelling or unspecific acknowledgment (Butalid et al., 2014; Hoglander et al., 2017; Riley et al., 2013; Veenvliet et al., 2016; Zhou et al., 2013). On the other hand, this characteristic of provider responses is not conclusive because other studies show no significant difference between explicitly or non-explicitly providing space responses (Schouten & Schinkel, 2015), or reduce space responses are equally common as provide space responses (Del Piccolo et al., 2015).

The analytical approach adopted in this thesis has been informed as outlined above on which variables may influence provider response behaviours.

4 Research design and methodology

4.1 Research design and study population

The study had a cross-sectional, observational and exploratory design (Hafskjold et al., 2015). The study population included registered nurses and nurse assistants working in home care, and home care patients (≥65 years). Table 2 provides an overview of the samples and methods for three papers included in the thesis.

Table 2. An overview of the three papers

	Paper I	**Paper II**	**Paper III**
Sample	- 33 nursing staff - 48 older persons	- 24 patients - 13 nurse assistants	- 33 nursing staff - 48 older persons
Method	Audio-recording of home care visits	Audio-recording of home care visits	Audio-recording of home care visits
	Coding with VR-CoDES	Coding with VR-CoDES and verbatim transcripts of cues/concerns	Coding with VR-CoDES Transferring qualitatively developed concepts into a novel coding schedule
	Quantitative analysis: Associative relationships between variables	Qualitative analysis: Concept formation using qualitative content analysis Explorative deductive-inductive approach	Quantitative analysis: Associative relationships between variables

	Paper I	Paper II	Paper III
	Associative relationships between variables Identifying predictors of outcome variable		
Data for analysis	- 635 cues and concerns* - 638 nursing staff responses*	- 206 patient expressions coded as cues or concerns	- 638 cues and concerns* - 641 nursing staff responses*

*Three patient expressions were accidently omitted due to punching error for the material used in paper I, assumed to have no effect on the findings presented in this thesis.

4.2 Recruitment process

Participants were recruited from four units of home care services located in two municipalities in Norway (Ål and Drammen). Three units served dedicated areas of a city of approximately 65 000 residents, and one unit provided services in a rural municipality of approximately 5000 residents.

The planning of the recruitment process and data collection began with an invitation to management from the local health and care services of the two municipalities, and management and key staff members from the potential units of home care. After selecting the units of home care, a key contact person at each unit was chosen and local information meetings were planned. In addition, I accompanied one nurse assistant at one of the units for the duration of one day in order to gain insight into how best to plan the recruitment of participants and data collection.

A member of the research project and myself held information meetings at each of the home care units on at least two occasions. In addition, written information was provided to ensure that all eligible nursing staff received information and had the equal opportunity to participate. The study also received coverage in the local press to inform the public. All nursing staff were reminded in staff meetings held in regular intervals of the possibility to take part in the study. Eligible nursing staff volunteered to participate by signing an informed consent form which was provided by the local contact person.

One working week was dedicated to each home care unit to complete data collection. Constraints of time were introduced to ensure care 'continued' as usual, thereby minimising the effect on daily routines, and avoiding increased workloads due to additional tasks inherent in the data collection process, and to ensure that all participating nursing staff were present.

Data collection was planned and undertaken in close collaboration with the local contact person and unit management. I was present all day, for at least three days, at each unit during data collection period to assist in the case of difficulty to resolve any unforeseen problems.

To minimize the impact of the study on the routine activities of the home care services in general, the established work rounds for the units had to be taken into consideration when recruiting older people, in addition to age, gender and medical conditions. The nursing staff provided both written and oral information to eligible patients, after having received proper instructions by the research group. Emphasis was put on the importance of checking that the information was understood correctly and encouraging questions was emphasized. It was also underlined that declining to participate or withdrawing at a later date were unproblematic and of no consequence~~s~~ to the person. When nursing staff deemed it appropriate, the patient's closest relatives were included in the information process.

After a minimum of 24 hours after receiving information about the study, the patients were accepted in the study on returning signed consent forms to the participating nursing staff. To ensure that all patients were confident about their decision to participate, the local contact person talked to each one after the patient had some experience in being involved in the study. Only three patients declined to participate further. The reasons given for declining to continue to take part were: experiencing participation as tiring, deteriorating health, or being too busy. None of these three patients requested that the data which had already been collected be deleted from this study.

4.3 Sample and data collection

Older persons: The sample consisted of 48 older persons. The criteria for inclusion were that patients should be in receiving home care and able to provide informed consent. Patients diagnosed with dementia or severe cognitive decline were excluded because nursing staff expressed concerns about the patients' ability to provide informed consent. The characteristics of the patients are shown in table 3.

Nursing staff: The sample consisted of 33 nursing staff, 16 registered nurses and 17 nurse assistants. The characteristics of the nursing staff are shown in table 3. Inclusion criteria were status as a registered nurse or nurse assistant, occupying a permanent position in the home care services and being present at time of data collection. All participating staff held at least a 50% position at the given the home care unit.

Equal distribution of gender was not established as a prerequisite for inclusion, because there are more females than males in the population of nursing staff and older care recipients. Ensuring that both genders were represented in the sample was the only measure taken. Five nurses and five nurse assistants were established as the desired minimum of nursing staff to be recruited, with the aim of collecting at least five visits with the individual members of nursing staff. This number was in line with what was considered to be feasible and adequate to ensure a reliable sample. Samples of approximately 100 consultations have been successfully used in the past to analyse emotional communication taking place during consultations from different specialities (Mjaaland, Finset, Jensen, & Gulbrandsen, 2011b).

When I went through the visits collected, it became apparent that some of the nursing staff served patients who needed the care service on a continuous basis from specially designated nursing staff. This included patients living in private flats within or close to a nursing home. The staff caring for these patients were employed in the home care service, but the care setting in question was considered to be more similar to a nursing home, and at all events entirely different from the time-limited visits captured when nursing staff travelled from home to home over a larger geographical area. Consequently, visits collected in this type of care setting were excluded from this study.

Table 3. Study participants

Older Persons **(n=48)**	
Females/Males	36/12
Mean age (SD); age range	84 (±8); 65-94
Average ADL† (SD); range ADL	2,1 (±0,7); 0-3,7
Average hours of care per week (SD); range care per week	5 (±5): 0,3-21,5

Nursing Staff **(n=33)**	
Registered Nurses/Nurse Assistants (n)	16/17
Females/Males (n)	27/6
Mean age (SD); age range*	42 (±10); 23-59
Mean years of work experience (SD); range work experience**	17 (±10); 1-31

* Data missing for 2 registered nurses and 2 nurse assistants

** Data missing for 1 nurse assistant.

† Activity of Daily Living scores: the level of assistance needed to perform a range of daily tasks (0 = no assistance needed, 5 = full assistance needed) (Lawton & Brody, 1969).

The data were collected between December 2013 and May 2014. A total number of 271 visits were audio-recorded. Participating nursing staff wore a digital audio recorder (H1 Zoom Digital Field Recorder) on their upper arm (picture 1). The recorder was turned on during the entire visit. The recorder was convenient to use, and an on/off button ensured that nursing staff had the possibility to stop and start recordings quickly. This facility ensured confidentiality, as the nursing staff could stop the recording to answer the telephone thereby preventing information concerning other patients to be recorded.

Picture 1. Nursing staff with audio recorder

All nursing staff met at least three different patients, but it was also possible for them to meet the same older person in multiple visits. Likewise, the older person could encounter different nursing staff in multiple visits. Visits, which took place both during the day and evening-every day of the week except for Sunday, were included in the sample. The visits covered a range of care assignments like administering medication, helping patients with compression stockings, dressings, treating wounds, attending to personal hygiene, preparing meals, and managing necessary assistive technology. The visits also varied in complexity with regard to the number of care assignments to be completed during a single visit, varying from one to nine tasks, which ranged from simple tasks such as administering medication and changing bandages or colostomy bags, to complex or multiple tasks combining all aforementioned tasks.

A total of 195 out of the 271 visits which were audio-taped were eligible for analysis in this thesis. Among the visits collected, 68 included situations involving the patients living in private flats within or close to a nursing home and these ones were excluded. A further seven visits were excluded because they included two staff members attending to one patient; this complicated the task of identifying given statements to nursing staff. In addition, one visit had been given two ID numbers because the visit had been started and stopped twice by the nursing staff, resulting in two audio files.

4.4 Learning how to apply the VR-CoDES and the coding process

Patient–nursing staff communication was coded using VR-CoDES. A research assistant, Helene Rintalan (HR) and I coded all visits according to the VR-CoDES manuals under guidance from my main supervisor Professor Hilde Eide (HE) who is an experienced coder and one of the founders of the coding-system (Del Piccolo et al., 2011; Eide, Eide, et al., 2011). In addition, I (LH) attended two dedicated workshops organised by the Verona Network on Sequence Analysis, allowing me both to learn from, and take part in, discussions about the use of the system, benefitting from the experiences of other research groups. In addition, as I was one of the coders in another study focusing on patient–physician communication in the hospital setting, I had already gained experience with the system (Gorawara-Bhat, Hafskjold, Gulbrandsen, & Eide, 2017).

All coding was carried out by listening to the audio-recorded visits and identifying patient expressions of worries and the responses of the nursing staff as determined by the VR-CoDES. The use of VR-CoDES helped the coders to maintain focus, and heighten the sensitivity for capturing moments of potential emotional value, when listening to the communication taking place in the individual home care visits. The coding steps are shown in figure 4.

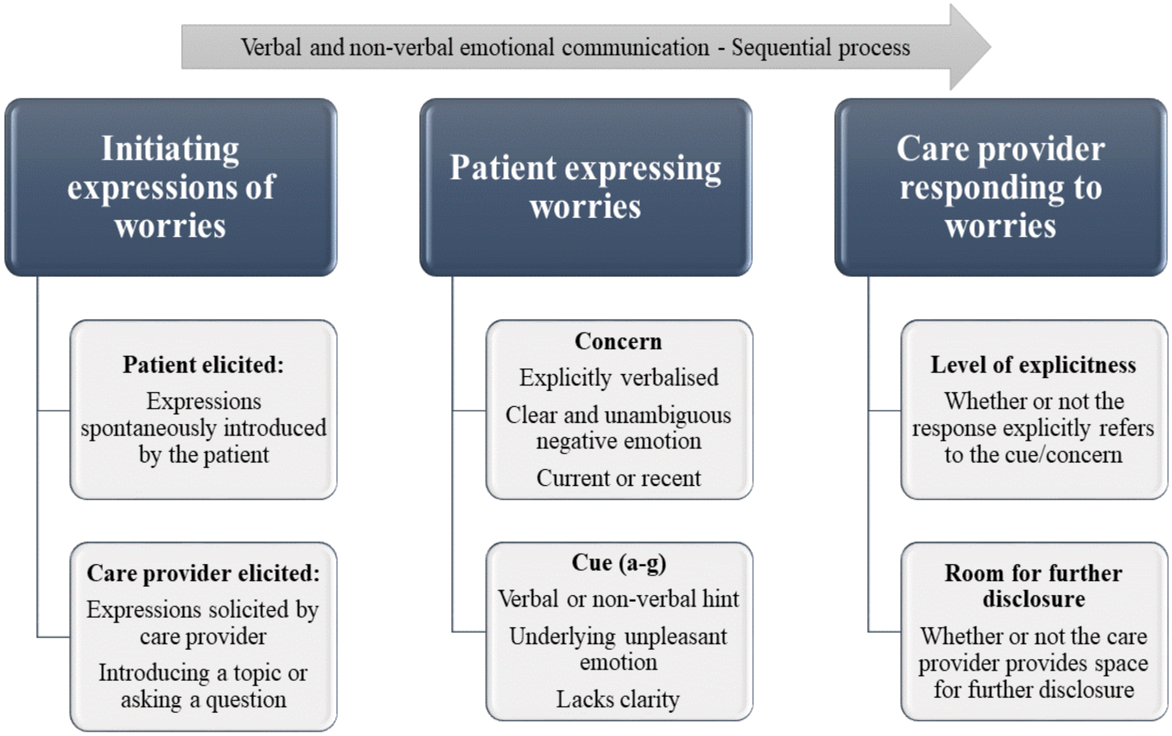


Figure 4. The coding steps of the VR-CoDES

The steps taken to ensure acceptable inter-rater reliability followed the recommendations as given in the coding manual (Del Piccolo & Mazzi, 2009). The two coders independently coded 32% of the visits to establish acceptable inter-rater reliability. An inter-rater reliability of a Cohen's kappa above 0.6 (substantial agreement) was considered sufficient for further analysis (Landis & Koch, 1977).

During the coding process it became clear that several different issues were raised in the home care visits, often combined with swift changes in topic. In addition, the coders had to adjust their understanding of the patient expressions of distress as described in the manual to the language used in the home care visits. Home care visits represented an unfamiliar setting for applying the VR-CoDES, making it necessary to establish consensus on the threshold for the patient expression to qualify as a cue and to assign proper cue-category. Reaching acceptable inter-rater reliability proved to be a lengthy process, which extended from March to September 2015.

The process of learning and coding the provider responses was experienced relatively straightforward, mostly because the moments of emotional communication were already identified from coding the cues/concerns. This made it relatively obvious to identify the subsequent provider response, leaving only the task of assigning the proper response code. The coders invested time on reaching a mutual understanding of the different types of provider response codes (Del Piccolo et al., 2009). This was achieved by using the visits already well known to the coders from identifying cues/concerns, and discussing all response codes for these visits in depth. This was done at the same time towards the end of the process of reaching inter-rater reliability of cues/concerns, ensuring that the coding process was also viewed and discussed with relation to the sequential aspect of coding.

HR coded the remaining of the visits. During this process, HR and LH met regularly to resolve issues which surfaced. When needed HE was consulted. This allowed the coding process to be controlled on an ongoing basis. The coding all of the material, both patient expressions and provider responses, was completed over a period of one year and three months.

All coding of VR-CoDES was done using the Observer XT 12 (Noldus Information Technology b.v., The Netherlands). VS designed the template in collaboration with HE and LH. This ensured identical data entry and allowed data to be exported into Microsoft Office Excel 2013 for further qualitative and quantitative analysis.

4.4.1 Punching errors in the sample

As mentioned, one visit which included two audio files was inadvertently given two ID numbers. In the first paper, 196 visits were reported instead of 195. Further, three additional cues and subsequent responses were manually inserted directly in the Excel sheets with the VR-CoDES data after consensus discussion. When the data were cleaned up and prepared for the analysis of the first paper, this sequence was accidently omitted. This was discovered and corrected when the material was re-coded for the content analysis. The two punching errors are assumed to be insignificant to the reported results.

4.5 Content analysis of cues and concerns identified by VR-CoDES

The qualitative content analysis (Elo & Kyngäs, 2008) allowed for in-depth description and the exploration of the expressions of worry in a broader context than the VR-CoDES. The inductive approach (Elo & Kyngäs, 2008) was considered suitable to explore the older persons’ concerns and cues to unpleasant emotions as expressed during home care visits. The mixed-method approach (Plano Clark & Ivankova, 2016) was presented as “the two-step approach” in paper II (Hafskjold et al., 2016).

Qualitative content analysis with an inductive approach is a research method for making replicable and valid inferences from texts (Krippendorff, 2004). The texts analysed in this study were verbatim transcriptions of all cues and concerns (VR-CoDES) identified in 38 visits (19%). The analysis process was characterised by the search for patterns through discovering similarities and differences in the data (Graneheim, Lindgren, & Lundman, 2017). An effort was made to follow the steps of the qualitative content analysis with an inductive approach as described by Elo and Kyngäs: preparation phase, organising phase and reporting the analysing process and results (Elo & Kyngäs, 2008).

4.5.1 Content analysis and trustworthiness

Using VR-CoDES as a lens to identify moments of emotional talk, expressions likely to inform the research question were consistently extracted from the enormous amount of recorded communication of the home care visits. Hence, the two-step approach: 1) the deductive identification of key expressions for selecting data to be included for the 2) inductive content analysis may be seen as a way of enhancing the rigour of the analytical process (Ryan-Nicholls & Will, 2009).

The members of the research group taking part in the content analysis included experienced qualitative researchers (TE and IKH). The authors discussed the analytic steps and conclusions in regular meetings in order to avoid dwelling on specific issues resulting in premature demarcation of the analysis. Diverse background and experience, as well as variation in age and gender of the participating researchers, were considered an advantage in exploring different meanings and interpretations of the text (Graneheim & Lundman, 2004).

When necessary I returned to the original audio-recording to verify or clarify contextual factors (time and place of the utterance, activities going on at the time, atmosphere, etc.). This provided a deeper understanding for the utterances in relation to the context as well as familiarity with the material. Differences of interpretation were resolved in discussion and consensus was reached. Moreover, the findings were presented and discussed in two different research forums at the Faculty of health and social sciences, USN in order to get opinions from peer researchers on the analysis process. These matters were regarded as steps in the process of ensuring the trustworthiness of the findings of the study (Satu et al., 2014).

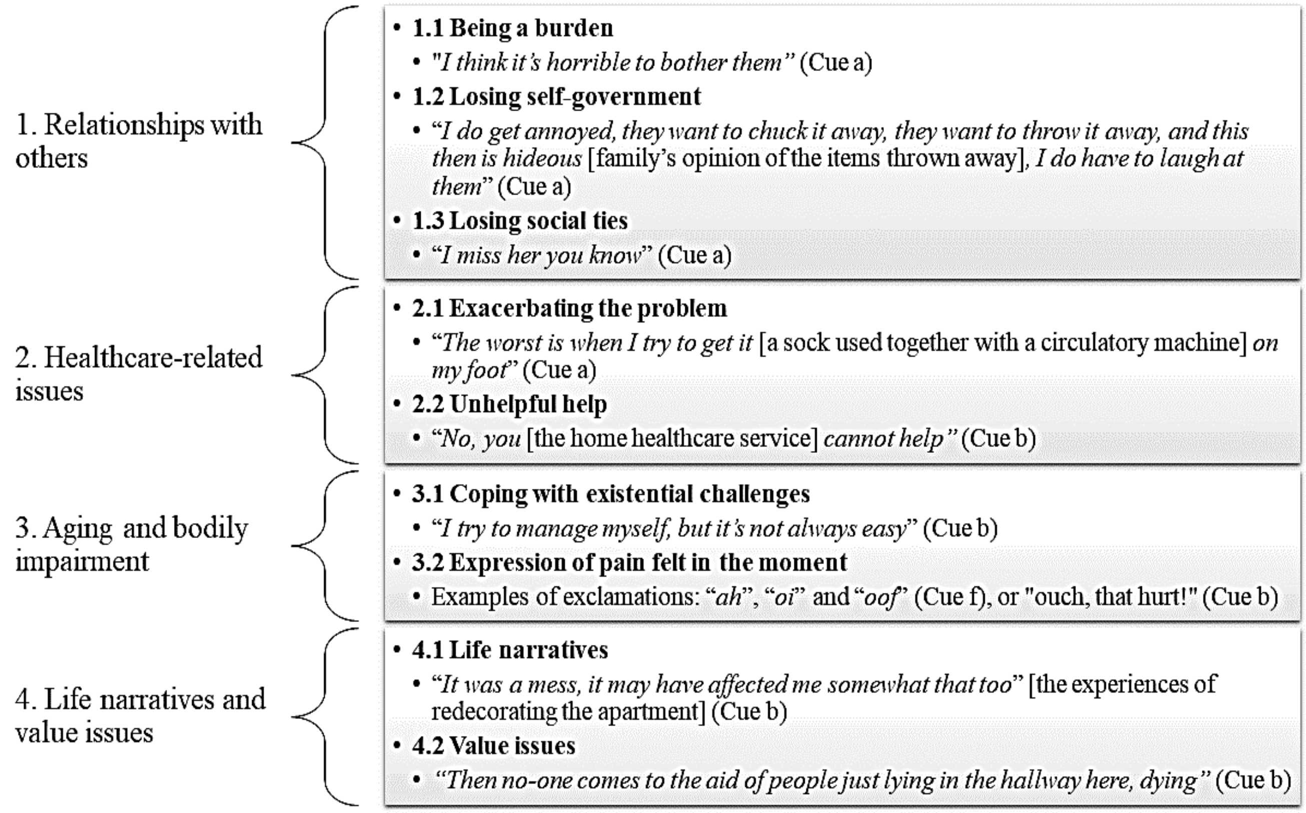
Steps taken to demonstrate trustworthiness in terms of categories and sub-categories included keeping wording and descriptions close to the text, in other words the transcribed cues and concerns (Graneheim et al., 2017). Further, sub-categories were described with genuine quotations from the material illustrating the given content of each sub-category, and demonstrating authenticity of how data were organised into categories and sub-categories. In addition, the analytical steps undertaken of the content analysis were described and visualised in a table and figure in paper II in order to provide readers with information allowing evaluation of suitability and dependability of selected data, how reflexivity was addressed, and the process of creating categories (Satu et al., 2014).

4.6 Coding scheme for thematic content: Types of worries

In order to explore whether the thematic content of worries expressed influenced emotional communication taking place during the home care visits, the data on thematic content was combined with the VR-CoDES to allow for an analysis of patterns relating to when nursing staff provide emotional focused responses as compared to when they provide information or not address the expressed worry at all.

The coding scheme was developed accordance with the model developed from the content analysis (paper II), comprising four main categories and related sub-categories: 1) worries about relationships with others, 2) worries about health care-related issues, 3) worries about ageing and bodily impairment and 4) life narratives and value issues. The use of the empirically derived model from the content analysis as a basis for developing the thematic coding scheme was considered to strengthen validity and ensure relevance with a view to analysing the setting (Plano Clark & Ivankova, 2016).

The main category "ageing and bodily impairment" originally comprised only one sub-category called *existential challenges* including expressions capturing the experience of coping with an ageing body and increased impairment (characterized by existential challenges), as well as expressions of pain caused by bodily impairment felt in the moment (paper II). After discussion, the authors concluded it was purposeful at this stage to differentiate expressions of worries descriptive of existential challenges from expressions descriptive of pain (e.g., whining, sighing, explicit statements of being in pain). This resulted in two mutually exclusive sub- themes: c*oping with existential challenges* and e*xpression of pain felt in the moment.* The coding scheme is illustrated in figure 5 together with examples of patient expressions for all sub-themes.



1. Relationships with others
- **1.1 Being a burden**
  - *"I think it's horrible to bother them"* (Cue a)
- **1.2 Losing self-government**
  - *"I do get annoyed, they want to chuck it away, they want to throw it away, and this then is hideous* [family's opinion of the items thrown away], *I do have to laugh at them"* (Cue a)
- **1.3 Losing social ties**
  - *"I miss her you know"* (Cue a)

2. Healthcare-related issues
- **2.1 Exacerbating the problem**
  - *"The worst is when I try to get it* [a sock used together with a circulatory machine] *on my foot"* (Cue a)
- **2.2 Unhelpful help**
  - *"No, you* [the home healthcare service] *cannot help"* (Cue b)

3. Aging and bodily impairment
- **3.1 Coping with existential challenges**
  - *"I try to manage myself, but it's not always easy"* (Cue b)
- **3.2 Expression of pain felt in the moment**
  - Examples of exclamations: "*ah*", "*oi*" and "*oof*" (Cue f), or "ouch, that hurt!" (Cue b)

4. Life narratives and value issues
- **4.1 Life narratives**
  - *"It was a mess, it may have affected me somewhat that too"* [the experiences of redecorating the apartment] (Cue b)
- **4.2 Value issues**
  - *"Then no-one comes to the aid of people just lying in the hallway here, dying"* (Cue b)

Figure 5. Themes and sub-themes included in the thematic coding scheme

Inter-rater reliability was calculated from a random selection of 16 previously uncoded visits, containing 78 cues/concerns. The first (LH) and second (VS) authors individually coded the transcribed cues/concerns in accordance with the coding scheme (Figure 5). For the four main themes, simple agreement between the coders was 86% and the inter-rater agreement calculated by Cohen's kappa (κ) was 0.68. For coding of sub-themes, simple agreement was 80% with $\kappa = 0.64$. After establishing inter-rater reliability, the first author (LH) coded the remaining visits. Intra-reliability for the first author was calculated based on 16 visits, including 46 cues/concerns, and showed a simple agreement of 93% and $\kappa = 0.91$.

4.7 Statistical analysis

Preparation of the data set was done in Excel 2013 (Microsoft Office Corp.). Statistical analyses were performed with IBM SPSS Statistics, version 24.0 (IBM Corp, New York, USA).

The data were checked for missing values both visually and using descriptive statistics. Percentages were rounded to whole numbers. Group differences were analysed using Pearson's chi-squared test or Fisher's exact test.

To analyse characteristics of patient expressions of distress and provider responses based on communicative function, sum-categories were computed (paper I) based on the definitions given in the manuals on linguistic characteristics to assigned to the specific codes (Del Piccolo et al., 2009; Del Piccolo et al., 2008), table 4.

Table 4. Sum-categories of VR-CoDES for patient expressions and provider responses

Patient expression of distress[1]	
Emotional references (4 VR-codes)	Cues/concerns with clear or vague words or non-verbal vocal cues related to negative emotion(s) **Example:** *"I really don't like my eyes at the moment"* - Concern, cue a, cue g, cue f
Emotional states/circumstances (2 VR-codes)	Cues about unpleasant states/circumstances, or unpleasant cognitive or physical states **Example:** *"yes, because everything is just dry"* - Cue b and cue c
Contextual hints of emotion (2 VR-codes)	Neutral expressions coded as utterances of emotion because of contextual factors or hints **Example:** *"It still resides a bit"* (third time repetition) - Cue d and cue e
Provider response[2]	
Emotion-focused *(6 VR-codes)*	Provide space for elaboration of the emotional component of the cue/concern, explicitly or non-explicitly **Example: N-E*** *"Right"*; **E*:** *"That is troubling"* - Provide space, N-E: Back-channel, acknowledgement, implicit empathy, active invitation - Provide space, E: Affective acknowledgement and active exploration
Content-focused *(5 VR-codes)*	Provide space for content, or reduce space by explicitly or non-explicitly provide information/advice, or provides a switching response of the concern/cue **Example: N-E:** *"I'll just put on this here, and wrap it round"*;

Patient expression of distress[1]	
	E: *"Oh, no, this job isn't so bad"* - Provide space, E: Content acknowledgement and exploration - Reduce space, N-E: Information-advise - Reduce space, E: Information-advise and Switching
Ignoring or blocking *(2 VR-codes)*	Ignore completely, non-explicitly diverge from or actively block the concern/cue **Example: NE:** "Well then"; **E:** *"I won't comment on that, but I don't think it's that bad"* - Reduce space, N-E: Shutting down - Reduce space, E: Active blocking

* **N-E:** Non-explicitly referring back to the cue/concern; **E:** Explicitly referring back to the cue/concern
Adapted from:
[1] Del Piccolo, et al. (2008). Consensus definition of cues and concerns expressed by patients in medical consultations - Manual for VR-CoDES.
[2] Del Piccolo, et al. (2009). Coding of Health Provider Talk Related to Cues and Concerns - Manual for VR-CoDES

In paper I, the aim of the study was to identify predictors of emotion-focused responses; that is responses facilitating or providing space for further disclosure of emotion. Based on the responses described by the VR-CoDES (Del Piccolo et al., 2009), a binary outcome variable was computed differentiating between whether the responses of nursing staff were emotion-focused, content-focused or blocked/ignored the cue/concern. Data were fitted to a logistic model starting with identifying explanatory variables using univariate logistic regression where variables reaching a significance level of ≤25% were included in the multivariate logistic regression analysis (Hosmer, Lemeshow, & Sturdivant, 2013). The significance level was set at <5%.

Paper II was a qualitative analysis and did not include any statistical analysis.

Paper III explored characteristics of the thematic content of expressed worries by older persons during home care visits, and whether nursing staff's responses differed in relation to thematic content. The sample, themes, and sum-categories of cues/concern and nursing staff responses were described using frequency and summation statistics. Group differences were tested using either Pearson's chi-squared test or Fisher's exact test. Adjusted residuals were used to guide analysis of association between categorical variables (Bakeman & Quera, 2011). The significance level was set at <5%.

4.8 Research ethical considerations

All data were handled in accordance with Norwegian legislation. The Norwegian Social Science Data Services (NSD) approved the study (project ID 36017). Research data including participant identification was kept locally at each home care unit. The research group only handled data marked with ID numbers generated specifically for the study.

The research proposal was sent to the Regional committees for Medical and Health Research Ethics in Norway and reviewed by the committee REC South East B (study protocol number 2013/1626/REK sør-øst B). They ruled that the research proposal did not fall under their jurisdiction as governed by the Health Research Act §2 (Helseforskningsloven [The Health Research Act], 2008).

Effort has been expended on conducting all steps for the carrying out of this research in compliance with the World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects (World Medical Association, 2013).

5 Main findings of the three papers

This chapter will present the main findings of the studies included in this thesis.

5.1 Findings of paper I

A total of 144 visits were identified with one or more expressions of distress as described by the VR-CoDES. The duration of the visits ranged from 1 to 72 minutes, with an average duration of 17 minutes (SD: 14).

Identified expressions of distress included 10% (n=63) concerns and 90% cues (n=572). Concerns/cues containing *emotional references* comprised 35% (n=224), 62% (n=396) captured *emotional states/circumstances* and 2% (n=15) were identified based on *contextual hints of emotion*.

The nursing staff elicited expressions of concerns/cues in 56% of the cases. Clearly verbalized emotions were more frequently expressed to nurses, whereas vague words and non-verbal vocal expressions were more frequently expressed to nurse assistants, in the case of both distress expressed by patients on their own initiative (Fisher's Exact Test: p= 0,005) and those worries elicited by nursing staff (Fisher's Exact Test: p= 0,036). In general, the relative frequency of patient initiation of disclosure and nursing staff elicitation of disclosure did not vary with the nursing staff's professional background (being a nurse or nurse assistant).

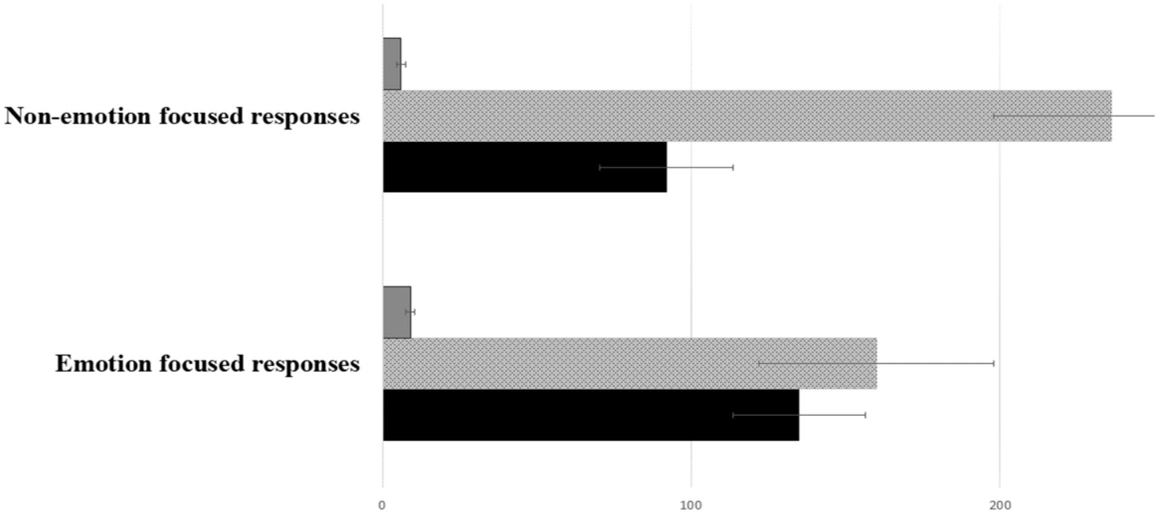
The coding process identified 638 responses due to three patient expressions being met by responses that represented two different VR response codes (i.e. there were two units of analysis within a single turn of provider talk) (Del Piccolo et al., 2009). In line with the coding manual, the code "silence, non-explicit providing space" is not applicable and note used because the coding was done on audio-recordings (Del Piccolo et al., 2009). However, to apply this code, a minimum of 3 seconds of silence needs to be observed. In the coders' experience, this very rarely happened and some verbal interaction made it more appropriate to use a different VR-CoDES response code.

In total, 48% (n=304) responses opened up space for further disclosure of the emotion, 32% (n=203) were aimed at the content of the concern/cue, 20% (n=130) ignored the emotional expression and 0.2%, representing one response, blocked the patient.

An emotion-focused response was observed more frequently when the concern/cue was elicited by the nursing staff (194 out of 359) than when the concern/cue was spontaneously expressed by the patient (110 out of 279) (Pearson Chi-Square: p<0,001). This pattern did not 2significantly 1differ between nurses and nurse assistants.

When we turned our attention to the emotional focused responses we noted that these consisted predominantly of minimal encourages such as "yes", "right", "hmm", "okay", etc. These brief interjections of encouragement belong to the VR-CoDES response code of non-explicitly provide space for further disclosure of the worry expressed (back-channel, n=107 and acknowledgement, n=100). This is described in detail in table 3 in paper I.

To further explore associative relationships between the responses of nursing staff and how patient distress were expressed, a binary variable of nursing staff responses were computed, differentiating between emotion-focused responses and non-emotion focused responses (content-focused and ignoring/blocking responses). Cues/concerns (verbally or non-verbally) with an *emotional reference* received emotion-focused responses in 60% of the cases. The patients' expressions referring to *emotional states/circumstances* and *contextual hints of emotion* were met with non-emotion-focused responses in 59% of the cases. This pattern was consistent regardless of who elicited the cue/concern. Figure 6 shows the responses of nursing staff to different types of cues/concerns.



	Emotion focused responses	Non-emotion focused responses
■ Contextual hints to emotion	9	6
▨ Emotional states/circumstances	160	236
■ Emotional references	135	92

Adapted from the VR-CoDES – Cues and concerns (Zimmermann et al., 2011):

Contextual hints to emotion: ***Cue d*** (neural expressions standing out from narrative background), ***Cue e*** (patient-elicited repetition)

Emotional states/circumstances: ***Cue b*** (hints about hidden concerns), ***Cue c*** (physiological or cognitive correlates)

Emotional references: **Concern** *(clear and unambiguous expressions describing an unpleasant current or recent emotion),* **Cue a** *(the use of vague or unspecific words describing the emotion),* **Cue f** (Non-verbal cue*),* **Cue g** *(unambiguous expressions of unpleasant emotion which is in the past)*

Figure 6. Nursing staff responses and types of cues/concerns

In a multivariate logistic regression analysis adjusted for the individual patient and nursing staff, predictors of responses that opened up space for further disclosure of the emotion (emotion-focused responses) were when the nursing staff elicited the concern/cue and when the concern/cue included a reference to an emotion, i.e. *emotional references*.

The Hosmer–Lemeshow goodness-of-fit test showed that the model prediction did not differ significantly from the observed values (p = 0.145), supporting model fit (Hosmer et al., 2013).

5.2 Findings of paper II

Through the inductive content analysis, causes described by the older persons as reasons for worrying were grouped under four main categories with several sub-categories. The four main categories were: 1) worries about relationships with others, 2) worries about health care-related issues, 3) worries about ageing and bodily impairment and 4) life narratives and value issues. The analysis of the expressions revealed several unpleasant emotions and this variety was visualised as a layer or layers influencing how expressions of worries were expressed and shared by the individual older person (figure 2, paper II).

The overarching categories and relating sub-categories were general in the sense that the different topics were found in a number of the visits analysed, and usually a given topic was raised by more than one older person. However, the way these emotional topics were raised depended on the person expressing the topic, underlining the personal meaning embedded in the expression. Emotional tone was one characteristic seen as giving emphasis to the words expressed. Noticing the emotional tone of the expression helped us to grasp how this is specific to the individual person's experience of the situation in his/her lived context. This emerged as an important feature of how to understand the content of worries expressed.

5.2.1 Worries about relationships with others

"Worries about relationships with others" included 1) *being a burden to others, 2) losing self-government, and 3) losing social ties.* A common denominator of these sub-categories were how some aspects of the older person's relationship with other people brought out some kind of worry. These worries could be fuelled by a situation or circumstance where the older persons tried to balance their own needs and wishes with the need to stay close and connected to others. This included both practical and personal issues.

5.2.2 Worries about health care-related issues

One group of worries described the health care itself as being the cause of a problem or complication. This is exemplified by descriptions of the care as exacerbating the problem that it was intended to help or assist. The treatment could also be dismissed as futile or it could be criticised. A feature of these worries seemed to be the experience of the health care services as being unhelpful, triggering negative emotions such as disappointment, frustration, sadness, irritation and aggression. "Worries about health care-related issues" were assigned to one of two sub-categories, *exacerbating the problem* or *unhelpful help*.

5.2.3 Worries about ageing and bodily impairment

Expressions of "worries about ageing and bodily impairment" was the most frequent issue raised by different older persons and in different visits. Overall, the expressions in this sub-group captured a variation of expressions characterised by descriptions of worries about the inability to cope with aspects of life as it had become, and expressions describing the older person's reflection on death and/or lack of hope for the future. Therefore, these expressions were collectively organised under the sub-category e*xistential challenges*. Within the sub-category *existential challenges* utterances could broadly be organised under two headings: inability to cope and pondering on death and the future

Inability to cope captured utterances of discomfort, distress and worry caused by bodily conditions and impairment, all of which captured bodily experience affecting the life of the person. This includes descriptions of how daily life is coloured by physical/bodily sensations and limitations. Emotions such as resignation, anxiety and anger were common. In addition, the sub-category included many cues in the form of moans, sighs and small whines particularly during care situations or when the patient moved from one position to another.

Pondering on death and the future included longing for death and end of suffering or anxiety and fear of life coming near the end. Fear of death was often expressed in connection to descriptions of severe symptoms, ill health or the further deterioration of health.

5.2.4 Life narratives and value issues

This last main category contains emotional narratives or reflections on value issues. The emotional content was often embedded in a narrative or argument which the older person had with the nurse assistant.

The narratives often provided insight into important life-events which were expressed as memories of and reminiscences on the past. Given the way these conversations about the older person's life-events evolved, it is possible to observe that the underlying unpleasant emotion captured in these situations was loneliness. Moreover, a need for attachment and fear of loss may play a central role.

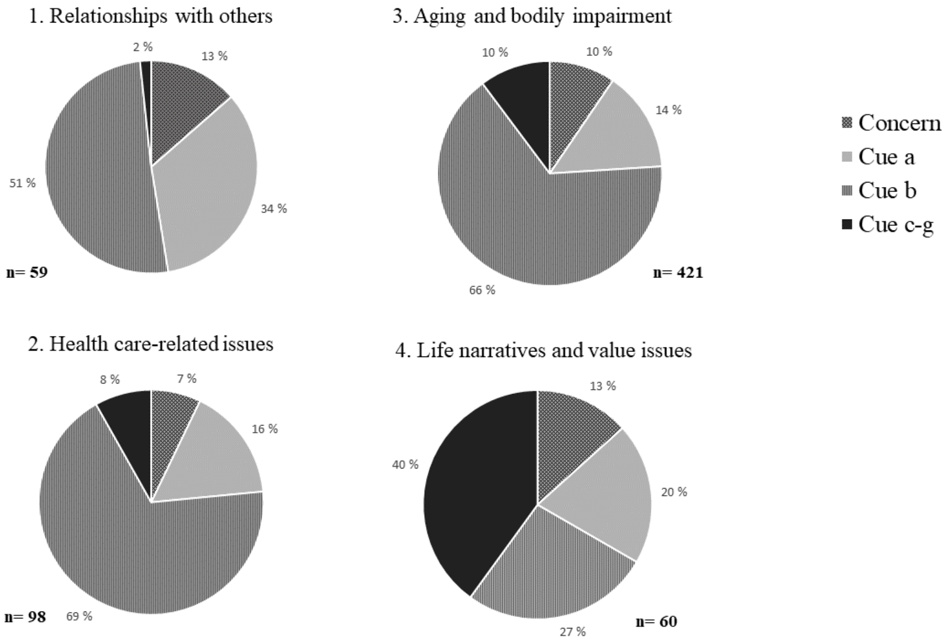
Expressions voicing value issues were often characterised by strong opinions. These expressions often contained clear and unambiguous wording, including the articulation of anger, sorrow and disquiet. Issues that triggered these concerns included the effect of local policymaking on the community and potential impact of losing local public services, or reflections on the characteristics of being a human, the moral value of compassion or the obligation to contribute to your community if needed. Even if such value statements did not necessarily relate to the patient's situation directly, such value statements may be understood in terms of political or ethical worries, as a way of confirming one's continued role as a member of the community or as vicarious expressions of emotions.

5.3 Findings of paper III

5.3.1 Themes of worries and type of expressions

"Ageing and bodily impairment" was the most frequent theme of worries expressed, covering 66% (421/638) of all cues/concerns. Of these, 69% (290/421) captured worries about c*oping with existential challenges*, such as feeling isolated when being unable to move about, worries about the future or fear of death. Whereas 31% (131/421) were e*xpression of pain felt in the moment,* including expressions of pain or enduring a painful task in the moment. The second most frequent main theme of worry was "health care-related issues", but still only comprising 15% (98/638) of the expressions. The remaining two main themes, "relationships with others" (59/638) and "life narratives and value issues" (60/638), both accounted for 9 % of the expressions.

An association was found between how older persons express worries and themes (Pearson Chi-Square, p<0,001). Figure 7 shows linguistic characteristics of worries expressed as given by the VR-CoDES found within each main theme of worries.



VR-CoDES – Cues and concerns (Del Piccolo et al., 2008)*:*
Concern: clear and unambiguous expressions describing an unpleasant current or recent emotion
Cue a: the use of vague or unspecific words describing the emotion
Cue b: hints about hidden concerns

Cue c-g: other type of hints to underlying negative emotion

Figure 7. Type of expressions and main themes

"Ageing and bodily impairment" were more frequently expressed as hints about hidden concerns (cue b) like the use of emphasis, profanities, or expressing uncertainty and hope (Adjusted Residuals, cue b: 3,4). Only two of the worries related to "relationships with others" addressed losing self-government. Adjusted residuals showed that it was more likely that worries about "relationships with others" were expressed using vague or unspecific words for the negative emotion in question (Adjusted Residuals, cue a: 3, 6). "Life narratives and value issues" were more likely expressed by using other types of hints to underlying negative emotions like crying, repetition or descriptions of unpleasant cognitive or physical states (Adjusted residuals, cue c-g: 7,1). "Health care-related issues" showed no significant pattern in terms of how worries were expressed.

5.3.2 Elicitation of themes of worries

It was found that nursing staff were more likely to elicit themes of worries (56%, 358/638) compared to the older persons (44%, 280/638) in general (Pearson Chi-Square, p<0,001). Expressions elicited by nursing staff were especially prominent when relating to "life narratives and value issues", 75% nursing staff-elicited expressions (Adjusted Residuals, 3,1) compared to 25% patient-elicited expressions (Adjusted Residuals, -3,1).

However, worries about "ageing and bodily impairment" were elicited equally often by the older persons (50%) as by the nursing staff. Further exploration of worries about "ageing and bodily impairment" indicated an association between elicitation and sub-themes (Pearson Chi-square p<0.001). The majority of worries related to the sub-theme c*oping with existential challenges* were elicited by nursing staff (61%, 177/290), whereas the majority of the sub-theme e*xpression of pain felt in the moment* were elicited by the patient (73%, 96/131).

5.3.3 Responding to themes of worries

Overall, 47% of the responses focused on the emotional component of cues/concerns, followed by responses focusing on content (32%) and responses ignoring or blocking emotional expressions (21%). There was no significant difference in the response pattern between nurse assistants and nurses.

Pearson Chi-Square showed an association between themes of worries and how nursing staff responded (p=<0,001). Adjusted residuals indicated that variation based on sub-themes was significant for the main themes “ageing and bodily impairment” and “relationships with others”. There was no significant difference between types of responses for sub-themes within “healthcare related issues” and “life narratives and value issues”.

5.3.3.1 Nursing staff responses and sub-themes

The responses of nursing staff varied within “ageing and bodily impairment” depending on whether the sub-theme was *coping with existential challenges* or *expression of pain felt in the moment* (Fisher's Exact Test, p<0,001). *Coping with existential challenges* received relatively more responses focussing on the emotion expressed (adjusted residual 3.2) than responses ignoring/blocking the expression of worry (adjusted residual -4.00). Responses to *expressions of pain felt in the moment* received relatively more ignoring/ blocking responses (adjusted residual 4.0) than responses focussing on the emotion expressed (adjusted residual -3.2).

The responses of nursing staff also varied between sub-themes within “relationships with others” Fisher's Exact Test, p=0,009). Worries about *being a burden* were relatively more often responded to with a content-focused response (adjusted residuals 2.8) than with an emotion-focused response (adjusted residuals -3.1), whereas worries about *losing social ties* were relatively more often responded to with an emotion-focused response (adjusted residuals 3.1) than with a content-focused response (adjusted residuals -3.0).

6 Discussion of the application of VR-CoDES

The VR-CoDES was applied in this thesis with the purpose of identifying and analysing real-life emotional communication taking place in a healthcare setting. This chapter will elaborate on and discuss the lessons learned from applying this system on home care visits, since it is new setting for applying the VR-CoDES.

6.1 Listening for worries in home care visits

Given that the VR-CoDES was developed for coding medical consultations (Zimmermann et al., 2011) and at time of coding the system had not been applied to the setting of home care, we could not be sure if this way of "listening for worries" would work well. When comparing the process of applying the system on patient–physician communication in a hospital setting (Gorawara-Bhat et al., 2017), it came as a surprise to learn that the challenges presented by home care visits differed considerably from those challenges we had confronted in the past.

First, one challenge was that capturing communication taking place in someone's home was very different from following the communication during a consultation or similar situations. In consultation-like settings, communication usually occurs in a specially designated room, e.g. the physician's office, thus the movements of the participants in this space are restricted. During home care visits, the participants may communicate across rooms. The older person may get dressed in the bedroom while a member of the nursing staff prepares breakfast in the kitchen and this sometimes makes it difficult to identify what the older person was saying in the other room because the recorder was attached to the nursing staff. This challenge also made it sometimes difficult to capture pauses, intonation and other hints important for identifying potential emotional moments or issues conveyed by the patient's verbal and para-verbal communication. In these situations it was very important to grasp the words spoken and the reaction the nursing staff. Discussing the possible interpretations between coders proved useful when we encountered ambiguous situations. It is probable that the use of video-recording would have allowed more sources of information to become apparent, thereby facilitating the coders’ task of interpreting the material. However, given the high mobility and different types of activities performed in this setting, it would have been almost impossible to find the most advantageous position for a camera to ensure a good view of both the nursing staff and patient at all times. Challenges relating to sound quality and participants moving about are inevitably unavoidable in this care setting. On the other hand, in relation to the current thesis where the focus is on emotional communication – moments where the older person expressed something of importance – a natural reaction of the nursing staff seemed to be to repeat the question or to approach the patient by moving into the same room as the patient. This behaviour helped to reduce some of the impact from this source of error.

Second, in the manual the code “non-explicitly providing space - silence” is not applicable when applying the VR-CoDES to audio-recordings (Del Piccolo et al., 2009). “Silence” is coded when the care provider remains silent for three seconds or more. The coder has to confirm the intention of providing space for elaboration through the interpretation of the care provider’s non-verbal communication (e.g. maintaining eye contact, leaning forward, etc.). This is obviously not really feasible when audio-recording; hence, silence during a period of over three seconds is coded as non-explicitly ignoring a cue/concern as instructed in the manual. However, the observation of complete silence lasting at least three seconds in the material is very rare based on the coders’ experiences. The likely reason is that three seconds may be experienced as a long time by the participants who are communicating. Usually, the nursing staff would finally add a word that functioned as a minimal encourager (e.g. hmm, well, yes, etc.), changing the response to a non-explicitly providing space code of either acknowledgment or back-channelling depending on the situation. Because this situation was observed relatively infrequently in this material, the impact of this on the analysis preformed in this thesis is believed to be minimal.

Third, the flow of the communication during some visits was marked by the need to handle sudden interruptions. These interruptions, together with the inherently informal nature of the communication, resulted in a swift change of topic during visits. It should be noted that this characteristic differed considerably from a hospital setting. For example, a segment in the communication might start by the older person raising an issue related to the experience of side effect of a drug, and then the topic might suddenly change to dealing with a falling glass of water, moving on to clothing, and then, equally unexpectedly, move to issues concerning a family member. It could also be challenging to stay alert through longer segments in the communication which were characterised by everyday tasks, e.g. helping the older person to get dressed. During consultations between patients and physicians it was possible to identify distinct patterns describing phases in the interaction and communication (Gorawara-Bhat et al., 2017; Mjaaland et al., 2011a). The coders were able to use the knowledge gleaned from these patterns to heighten awareness. Since the coders were only able to a limited extent to rely on hints from how the communication progressed and when emotional communication was likely to occur during the home care visits, they had to concentrate maintain their focus at all times and this made the coding process very demanding, especially for visits continuing over longer time periods, e.g. more than 20 minutes. The coders could not have resolved this by taking breaks during these protracted visits because this would have had the effect of distracting the coders from following the natural flow of the communication and sensing the atmosphere of the visit. The importance of sensing the atmosphere (e.g. gauging that "something is going on", changes in tension or ease) are an integral part of the interaction relevant for the analysis of communication, as underlined by research (Langewitz, 2007). Hence, the coders needed to commit to finishing the entire visit before taking breaks.

Last, the unpredictable topic changes also posed a challenge for the coders when trying to decide whether an utterance held negative emotional value. A segment of the communication might contain only one expression from the older person about an issue. If this expression was expressed as a hint, this sometimes meant that when deciding whether the expression actually contained a potentially negative emotion or not the coders had little info to go by. The communication was also informal and loosely organised, supported by much qualitative research indicating that both communication and relationships are influenced by attributes of the home care setting (Kristensen et al., 2017; Lindström & Heinemann, 2009; Oresland et al., 2008; Spiers, 2002; Sundler et al., 2016). It is known that the application of the VR-CoDES to a new clinical setting generates new challenges, for example when coding the emotional communication of patients and psychiatrists, coders overestimated cue frequency at the beginning of the coding process (Del Piccolo et al., 2012). However, the swift changes in topic combined with the informal nature of home care visits seemed to have had the opposite effect on coders: thus cues (hints to underlying unpleasant emotions) were easily missed. This also influenced the process of obtaining the desired inter-rater reliability. The necessary ensuing discussion of features of home care visits in general, and purposeful criteria on how to code ambiguous expressions on the borderline of the threshold of being a cue or not was time-consuming for coders.

In this respect, it was important that the coders should not miss issues likely to be of importance to the older person, but not necessarily noticed by the coders because the topic appeared initially to be unimportant or trivial (e.g. what to have for dinner, getting dressed), or the moment where topic was addressed was either unexpected or fleeting articulated. Close collaboration and time set aside on a regular basis for discussion between the members of the coding team (HE, HR and LH), allowed the threshold for identifying a patient expression as representing emotional communication in the current clinical setting to be clarified. As far as this aspect of the procedure was concerned, it was an obvious advantage that HE is a very experienced coder, and one of the founders of the VR-CoDES (Del Piccolo et al., 2011; Zimmermann et al., 2011). Cues heavily outnumber concerns (current and unambiguous expressions of a negative emotion) in both the material from the current thesis and the Swedish study (Sundler et al., 2017). The challenges of making sound judgements on how to code cues during home care visits were also discussed in the Swedish study. Here, it is underlined how frequent reference to the manual when coding the cues (hints to underlying emotions) was necessary in order to ensure reliable coding of these types of expressions (Sundler et al., 2017).

6.1.1 Systematic observations of expressions of emotions

The need to establish a threshold for when to code an utterance as an expression of worry means that some moments in the material are excluded even though these moments could arguably be close to the definition of emotional communication, and if analysed with an inductive approach, could be described as being relevant. This might include phrases expressed by the patient which are too vague to be coded as cues based on single visits, but if these phrases are viewed across visits, a topic can emerge as a source of worries. Kale and his colleagues demonstrated that when comparing a qualitative approach and the VR-CoDES on the same material, the qualitative approach included moments below the threshold set by the coders who applied the VR-CoDES (Kale, Skjeldestad, & Finset, 2013).

Paper II in this thesis combines the VR-CoDES and an inductive content analysis. This allowed the researchers to analyse larger segments of the communication, including both information from the complete flow of communication and other visits, resulting in an in-depth understanding of the causes of older persons' worries. It is not possible to gain this insight solely in accordance with the VR-CoDES. However, if the decision to assign a cue/concern were governed by the inductive interpretation of the individual coders, the results would not qualify as "systematic observations" in accordance with criteria for applying a coding system: Thus, it would lose its creditability and the possibility of statistical testing of relationships (Bakeman & Quera, 2011). One epistemological principle of using pre-defined constructs to transform social interaction into observable data appropriate for statistical testing, is the salient underpinning of the possibility of deriving knowledge from systematic observation about the social world (Carter & Little, 2007). Further, the VR-CoDES has high ecological validity in the sense that this system captures real experiences of distress confirmed by patients (Eide, Eide, et al., 2011). Thus, the use of the system is a suitable choice for exploring emotional communication in a clinical setting, even though the method may not represent an exhaustive exploration of the phenomenon of emotional communication. The insight into the limitations of the VR-CoDES and the emerging understanding of features of home care visits gained during the research process of the COMHOME-project prompted the questions guiding the qualitative analysis included in this thesis. This shows how the detailed understanding of the communication derived from the application of the VR-CoDES prompted further interesting research questions. The VR-CoDES also proved to be a valuable tool inasmuch as it identified the relevant moments to be analysed in-depth among the many hours of recorded communication.

Further, the challenge of coding expressions occurring during brief moments in the communication is unlikely to be related to the VR-CoDES in particular. Rather, it shows the limitations of applying a method which relies exclusively on an observer's view and interpretation when exploring interactions between other persons. This matter has also received attention in the recent methodological literature emphasising the limitations of using human observers (reporters) as the main approach when measuring communication, because being *a participant* involved in the interaction, or being a *third party observer*, can radically change the evaluation of the same situation (Street & Mazor, 2017). Here, the authors have emphasized need to include both participants and observers to explore features relating to communication. Participants are described as an important source of data when researching perspectives and experiences of the persons involved in the situation, for example when trying to evaluate aspects like perceived friendliness or reciprocity in the communication. On the other hand, the third party observer may use theoretically derived a priori constructs thereby allowing holistic judgements of the communication and detailed descriptions of communication behaviour not easily accessed by participants involved in the situation (Street & Mazor, 2017). When trying to understand features linked to interpersonal communication all judgements represent important knowledge. It is also worth bearing in mind that clear research aims to guide the choice of methodological measures are essential to all research projects (Plano Clark & Ivankova, 2016). Based on the aims of the research presented in this thesis, the methodological approach of applying systematic observational measures using a third party observer is considered to be justified.

6.2 Exploring communicative function based on the VR-CoDES

In the preparation of observational data for analysis it is important to consider the details on which to focus (Bakeman & Quera, 2011). In the case of the present thesis this choice was linked to whether we wanted to capture linguistic details (e.g. distribution of different types of cues and concerns) or communication behaviour. A premature focus on the latter would warrant unclear the lumping of code categories of patient expressions which were assumed to serve similar communicative functions. Literature discussing strategies for analysing observational data recommend that the coding of data needs to be on a more detailed level than that of the analysis (Bakeman & Gottman, 1997). Three main reasons are given (p.25): more detailed coding 1) promotes the collection of reliable data because of more detailed descriptions on what exactly to code; 2) enables empirical justification of lumping categories to explore a given pattern; 3) may reveal unexpected relationships or allow for exploration of further research questions (Bakeman & Gottman, 1997). The first and last points have proven valuable for the analysis process adopted in the present thesis. The detailed descriptions of different linguistic properties inherent in the expression of cues/concerns and ways of responding to these expressions specified by the VR-CoDES (Del Piccolo et al., 2009; Del Piccolo et al., 2008) allowed for deeper understanding and discussions between coders, resulting in new insight also which, in turn, prompted new research questions. On the other hand the detailed level of coding categories also presented a challenge because of the variations in frequency of individual codes in the material.

We have seen in paper I, some VR-CoDES categories are much more prominent in the material in the case of both patient expressions and nursing staff responses. For example, patient-elicited cues unambiguously stating a negative emotion of the past (cue g) were only observed twice. Similarly, in the case of nursing staff responses, the code of explicitly reducing space by active blocking the cue/concern was observed only once. Another issue resulting from the limited number of observations for each cue category was that Cohen's kappa was not calculated for the individual cue and response codes. This is to a large extent standard procedure in reporting on the use of VR-CoDES and the results in this thesis are similar to those of other studies (Del Piccolo et al., 2012; Finset et al., 2013; Heyn et al., 2013; Mjaaland et al., 2011a, 2011b). All the issues relating to code distribution challenge the possibility of exploring emotional communication on the molecular level of individual codes because of the statistical power issues caused by the rarely used codes. However, the chief aims of this thesis are to explore emotional communication in the light of the supportive communication framework presented. For this purpose, the approach adopted was to choose a level of analysis that captured communicative function of the patient expressions and the nursing staff's responses. This is detailed in paper I.

6.2.1 Creating sum-categories for patient expressions

In our analysis of patient expressions, we focused on what was understood as carrying the emotion and guiding the decision to code an expression as a cue or concern. This led to the aim of lumping categories thereby allowing us to explore how the presentation of the emotional component may affect the communication (e.g. how the cues/concerns are expressed) during these visits (sum-categories are described in table 4). This process led to three broader sum categories distinguishing between whether or not a patient expression: 1) contained a description or para-verbal expressions of negative emotion, 2) suggested an unpleasant emotional state, or 3) contained a neutral expression or phrase that was coded because of contextual factors like how it stood out from the narrative background or the use of repetition. This strategy led to three sum categories of patient expressions: concerns/cues containing *emotional references (concerns, cue a, cue f, cue g)*, cues descriptive of *emotional states/circumstances* (cue b, cue c), and cues identified from *contextual hints of emotion* (cue e, cue d).

As discussed in depth in paper I, this way of lumping the VR-CoDES of patient expressions deviates from how Heyn et al. (2013) lumped concerns/cues in their study. Heyn and colleagues see *cue f* and *cue b* as a similar way for the patients to present hints to underlying negative emotion, captured by the sum category described as "hidden emotion". *Cue b* was described as often presenting the patient's feelings of uncertainty, and *cue f* represented the patient crying. In the current thesis *cue f* also included crying. In the home care setting *cue b* includes expressions of a broad topical content but within VR-CoDES terminology, relating to some bodily state or a description of circumstances experienced by the patient (Zimmermann et al., 2011).

Heyn and colleagues explore ways of talking about feelings and worries in cancer consultations (Heyn et al., 2013). It is likely that in cancer consultations the patients' feelings of uncertainty (*cue b*) are clearly linked to the clinical situation, and this is also what causes the patients to cry. From this empirical understanding it is reasonable to link these types of cues as representing "the same" emotional state. In the current thesis, however, there was no indication that crying was related to a particular conversational topic or situation, or another cue category, based on the initial coding. Rather, the act of crying was interpreted as being a relatively clear reference to a negative emotion during home care visits. Crying had a similar communicative function as that used in the case of patients referring clearly to a negative emotion (expressing a concern). Lumping expressions that resembled concerns clearly stating an emotion was the underpinning argument of creating the sum category of cues/concerns containing emotional references. It is stated in the manual that distress expressed as concern requires the care provider to use different communication skills from those skills required when responding to cues because in the case of concerns the negative emotion is more apparent to the care provider (Del Piccolo et al., 2008). Thus, the underlying idea is that when the care provider recognizes the emotional component more easily this also has a bearing on how the care provider responds to the expression in question, thus, the cues/concerns containing emotional references represent a particular communicative function. Further, we chose to group together descriptions and expressions capturing symptoms, circumstances or bodily aspects. In the VR-CoDES manual for coding cues and concerns, both *cue c* and *cue b* are defined as cues relating to patient descriptions of states rather than expressions in which an emotion is referred to (word, phrase or para-verbal hints). Last, we wanted to identify cues that were coded predominantly based on the coders' interpretation of contextual factors, such as whether a patient mentioned issues of potential importance, repeated words or phrases, thus making it stand out of the narrative background. This was captured by *cue e* and *cue d* in the VR-CoDES (Del Piccolo et al., 2008).

6.2.2 Creating sum-categories for provider responses

When considering how to analyse provider responses, we could have chosen the strategy of using the dimensions of providing space or reducing space for further elaboration in combination with the use of explicitly or non-explicitly phrases that refer~~s~~ back to the patient expressions, as described by/in the system (Del Piccolo et al., 2011). This system was followed in the Swedish study, thereby showing that Swedish nursing staff tended most often to give non-explicit responses that provided space for further disclosure, or, put another way, the older persons could choose if, and how, they wanted to expound on a given topic (Hoglander et al., 2017). This distribution of response codes can also be seen in the Norwegian sample (table 3, paper I).

The application of these dimensions of the VR-CoDES provider responses which constitutes an indication of a care provider's approach to the patient's distress as being more or less patient-centred, is discussed in the literature (Del Piccolo, 2017). Here, the lack of empirical evidence supporting which of these dimensions is most relevant for person-centredness is stated as limiting this possibility and makes it difficult to provide clear indications for clinical practice.

However, we wanted to group together the VR-response codes to reflect levels of person-centredness as described by Burleson and colleagues (Burleson, 1994; Burleson et al., 2009) in order to discuss nursing staff responses in relation to the framework of supportive communication. Burleson developed the HCSSCS system which defines three main levels of person-centredness classed as different types of responses (Burleson, 1994; Burleson, 2008). Studies testing this system on supportive communication, also known as comforting strategies unfolding in informal, social interactions, show the most effective responses to alleviate the distress of others are achieved through moderately and highly person-centred responses (Bodie et al., 2012; Burleson, 1994; Burleson et al., 2009). Eide, Sibbern, and

Johannessen (2011) further developed this framework in combination with the VR-CoDES to suit a hospital setting.

A key feature of the moderately and highly person-centred responses is that these responses legitimize and acknowledge the other person's emotions and perspective (Burleson, 1994; Burleson et al., 2009). Further, a key feature of the highly person-centred responses are that these responses also elaborate on and contextualise the other person's emotions and perspective. Inspired by this research, we lumped the VR-CoDES response categories based on whether the response showed that the nursing staff: 1) noticed the emotion expressed and explicitly or non-explicitly allowed further elaboration, 2) noticed the expression and focused explicitly or non-explicitly on the content of the expression, or 3) ignored or blocked the patient expression of worry (Del Piccolo et al., 2009). The interpretation of when responses fulfilled a given function was carried out in accordance with the coding instructions stated in the system (Del Piccolo et al., 2011; Del Piccolo et al., 2009). This resulted in three new response variables, which are also detailed in paper I, table 3: *Emotion-focused responses* (7 VR response codes), *Content-focused responses* (5 VR response codes), and *Ignoring or blocking responses* (3 VR response codes). This gave scope to explore analytically when and how nursing staff use~~s~~ different types of supportive response behaviours in home care visits, and the level of person-centredness that can be theoretically assigned to these responses.

This thesis has not tested whether this way of lumping VR-CoDES categories for patient expressions and provider responses are in accordance with how patients or nursing staff perceive this communication. It may be a fruitful line of further research to pursue this using either a qualitative approach or vignette studies, or both.

6.3 Expressions of worries and person-centred responses

This thesis discusses findings from the VR-CoDES in a theoretical framework where being sensitive and responsive to the distress of the patient is advocated as the best way of helping the patient's healing process – when healing is possible – together with establishing a rapport and obtaining clinical relevant information (McCormack & McCance, 2017; Street et al., 2009). It is claimed that the VR-CoDES is rooted in a patient-centred and biopsychosocial model of healthcare, and the research ensuing from the application of these precepts can promote good practice in the handling of patients' emotions in healthcare encounters (Del Piccolo et al., 2017). In this thesis the principles assigned as features of patient-centredness described by the literature detailing the VR-CoDES are considered to be equivalent to principles of person-centredness. As mentioned above, in the section on cues and concerns in the manual on VR-CoDES it is clearly specified that dealing with cues or concerns requires different patient-centred communication skills from the care provider when practicing patient-centred communication (Del Piccolo et al., 2008). However, the manual and in the literature describing the VR-CoDES system also state that the response codes should not be taken to be prescriptive but should serve a descriptive purpose (Del Piccolo et al., 2011; Del Piccolo et al., 2009). Korsvold critiques this position in her thesis (p.73). She argues that the literature tends to describe the VR-CoDES indirectly, thereby pointing out that acknowledging affect is more important than providing good quality information when addressing expressions of distress in clinical communication (Korsvold, 2016). The emphasis on the affective acknowledgement as the optimum approach to the patient's expressed distress is criticised for undermining the helping role of providing information as a way of regulating the patient's worries (Salmon & Young, 2017a).

However, it is possible to argue that the focus on affective responses as being more purposeful has more in common with the theoretical framework chosen by researchers when discussing their findings based on the VR-CoDES, as opposed to being indirectly created by the system itself. Observational data cannot explain why participators behave as they do, so the findings need to be interpreted within a framework allowing this to be discussed in order to make the findings relevant for clinical practice and as a way of contributing to theory construction. This view has been investigated in various introductions and discussions of scientific papers which present studies in which the VR-CoDES has been followed (Butalid et al., 2015; Del Piccolo et al., 2015; Finset et al., 2013; Hoglander et al., 2017; Mjaaland et al., 2011b). This is also supported as a way of appraising theory-relevant strengths and weaknesses of empirical research (Hall & Schmid Mast, 2009). The value of addressing and acknowledging the emotional needs of the patient is clearly advocated in the literature that describes principles of patient-centredness in clinical care (Street, 2017; Winn, Ozanne, & Sepucha, 2015). This makes it theoretically sound that the empirical research applying the VR-CoDES also suggests that acknowledging affect may represent a patient-centred response behaviour (Butalid et al., 2015; Del Piccolo et al., 2015; Finset et al., 2013; Hoglander et al., 2017; Mjaaland et al., 2011b). The critique of the VR-CoDES as promoting affective responses may therefore overlook the fact that this may be closely related to the clinical setting in question and the purpose of the care provided. Moreover, this perceived preference may also be due to the way findings based on the application of the VR-CoDES are interpreted in a patient-centred or person-centred framework which lacks clear pathways on how this relates in practice to provider response behaviour and contextual variables, rather than the coding system itself. This highlights the need for further research in order to test the theoretical assumption currently advocated as a way of practising patient-centred communication and care (Dean & Street, 2014; Hudon, Fortin, Haggerty, Lambert, & Poitras, 2011). In addition further research into the different ways the care provider might practise the principles of person-centredness during emotional communication, without limiting this exclusively to acknowledging affect, would be highly desirable.

Another problem relating to the interpretation of findings based on the application of the VR-CoDES, which were equally relevant in this project, concerned the "mini-sequences" the VR-CoDES capture (Del Piccolo et al., 2017). The "mini-sequence" includes the expression of worry and the elicitation of this expression, as well as provider response (as depicted if figure 4). Given that communication takes place in an interpersonal setting over time, the system tries to capture this sequential aspect through "mini sequences" captured first by coding the patient expressions and then the care provider's immediate response (Del Piccolo et al., 2017). However, the coding rules specified in the VR-CoDES limit the possibility to chart a sequence of expressions on the part of the care provider when the patient actively interacts in the dialogue. The care provider may start by providing non-specific or general information, move on to information more tailored towards the patient in question and end with an affective acknowledgment. The VR-CoDES will only capture the complete line of responses in the coding if this is said without the patient interacting or interrupting. If the patient interacts in the dialogue (that is, engages in a turn in the communication) after the non-specific information provided by the care provider, this will mark the end of one “mini sequence”. Consequently, the data will indicate that the initial cue/concern was met by non-specific information or advice, the NRIa response code (Del Piccolo et al., 2009). This sequence does not reveal how the care provider continues to elaborate on the cue/concern in the next turn of communication. This part of the care provider’s response is only included if the patient has interrupted in a way that qualifies for classification as a new cue or concern, and then this will be treated as a distinct and separate sequence of observations. The care provider’s response may be experienced as both highly person-centred and supportive by the patient because the patient is likely to focus on the communication as a continuous flow of information and not as a sequence ending because the patient is responding to the care provider. This accounts for why VR-CoDES–provider responses are only descriptive of the immediate reaction and response to cues and concerns, and do not describe how cues and concerns are handled by the care provider in the communication as a whole.

An effort to address this methodological challenge has been explored by Eide and colleagues on observational data collected from a physician-patient setting. They applied a different coding system but encountered the same problem of not being able to look for behavioural patterns occurring over time (Eide, Quera, Graugaard, & Finset, 2004). They performed a sequence analysis using Generalized Sequential Querier (Bakeman & Quera, 1995). This analysis showed that physicians used silence and minimal encouragements before patients expressed worry, and that questions from the physicians were not as efficient in eliciting the patients’ worries (Eide et al., 2004). If the research group working the development of the VR-CoDES could provide methodological guidelines on how to perform similar analysis, this could represent a significant contribution to our knowledge on how patient distress is shared and how provider responses may influence the emotional communication in extended interactions between patients and their care providers. This could help to reveal further important behavioural features characterizing emotional communication in clinical settings and prompt further theory construction.

This thesis proposes that the VR-CoDES network develops an addendum to the manuals that covers for: 1) the identification of properties defining cues/concerns as topically linked, 2) the procedure to mark complete segments of cues/concerns that are topically linked in the data material which is purposeful for statistical analysis, and 3) the sequential analysis of segments of topically linked cues/concerns and the corresponding responses. The thematic content scheme set out in this thesis may be useful in the approach in order to resolve points 1 and 2.

7 Empirical discussion of emotional communication in home care visits

Four main themes of worries were identified as underlying causes for the older person to express cues and concerns during communication with the visiting nursing staff during home care visits. The four main themes were: 1) worries about relationships with others, 2) worries about health care-related issues, 3) worries about ageing and bodily impairment, and 4) life narratives and value issues. Each overarching theme contained several sub-themes providing a more detailed understanding of what caused the older person to worry. "Ageing and bodily impairment" accounted for 66% of all worries expressed, indicating that these types of worries were common and also significant triggers of emotional communication in the visits analysed. This thesis also shows that nursing staff elicit the expressions of worries more often compared to when older persons spontaneously express worries during home care visits. When exploring the response of nursing staff more emotion-focused responses were observed in the emotional communication when nursing staff elicited the cue/concern and when the older person's expressions included a reference to an emotion. In general, the responses used by nursing staff, whether emotion-focused or content-focused responses, or ignoring/blocking communication behaviour, were also associated with the thematic content of the worries expressed.

This chapter will provide a general account of the remaining aim of this thesis, which – as mentioned earlier – means viewing the findings within a supportive communication framework and discussing whether the current communication behaviour is likely to prompt person-centred care delivery in home care visits. We start by looking at the possible reasons for a change in the responses of the nursing staff according to features of the emotional expression and topical content. We will then move on to findings describing how older persons express their worries to home care nursing staff in relation to relevant recent literature and theoretical perspectives.

7.1 Responding to worries expressed during home care visits

Providing an emotion-focused response is the most common response behaviour to be observed in the material in general, but content-focused responses and ignoring or blocking responses combined accounts for over half of the classified responses in the material. This indicates that the response behaviour of nursing staff are not inflexible but change according to thematic content and contextual factors. In this thesis contextual factors prompting emotion-focused responses comprised the older person's clarity in stating the emotional component of the worry, and whether the nursing staff elicits the worry or whether it was the patient who spontaneously raises the issue. It is hard to say whether other contextual factors such as acquaintance with the patient, the type of health condition, or other factors not investigated in this thesis, are as influential. However, it is not to be excluded that clarity of the emotional component and elicitation of worry are factors likely influencing provider response behaviour in any home care visit. These are therefore to be considered significant.

Studies in the COMHOME-project showed that disagreement on care tasks in question, unexpected turns in the conversations, the older person's worry about existential issues and the experience of being frail, represented communicative challenges which nursing staff needed to handle during home care visits (Kristensen et al., 2017; Sundler et al., 2016). Expressions about existential issues were also identified in this thesis. These were classed under the main theme "ageing and bodily impairment". This theme was further divided into worries *about coping with existential challenges* and *expressions of pain felt in the moment* by the older person. Existential challenges and coping with pain are highlighted as being essential to address and manage in order to support the older person's ability to continue living a satisfying life at home. These are important care outcomes within the responsibility of home care services (Algera et al., 2004; Eloranta, Routasalo, & Arve, 2008; Ottenvall Hammar, Dahlin-Ivanoff, Wilhelmson, & Eklund, 2016; Sorbye, Hamran, Henriksen, & Norberg, 2010; Thome et al., 2003).

7.1.1 Responding to expressions of pain

There was a marked difference in the response pattern of the two different sub-themes, *coping with existential challenges* and *expression of pain felt in the moment*, showing that 50% of worries about existential challenges were met by emotion-focused responses compared to only 34% when responding to expressions of pain. Nursing staff seem more likely to use the response strategy of ignoring/blocking an expression of pain felt in the moment.

Addressing pain and discomfort is described as important when assisting patients with chronic diseases in general (Hopman, Schellevis, & Rijken, 2016). Older patients living with comorbidities and joint pain report that unfulfilled care needs are present mostly in the psycho-social domains relating to aspects of well-being, rather than the physical domain (Hermsen et al., 2018). It may be plausible that patients living with such conditions represent patients who also communicate painful moments or experiences of pain in the care setting as found in the current thesis. Hence, nursing staff caring for patients who are living at home and coping with chronic pain need also to ensure that they are well informed about aspects of the patients' well-being. Such aspects include clinically relevant information about the experience and presence of chronic pain with a view to meeting the patients' care needs in a holistic way.

A holistic approach in this setting includes gathering information about the meaning of the symptoms to the older person, the relevance of the situation when pain is triggered and degree of suffering experienced by the older person (Spiers, 2006). Emotion- or content-focused response behaviours are likely to provide the nursing staff with more relevant information regarding the patient's well-being as compared to ignoring/blocking responses, even though ignoring/blocking the expressions of pain may be necessary at the exact time of acting.

Ignoring/blocking an expression of pain felt in the moment may be an entirely reasonable response strategy in that given moment, because the contextual situation where these expressions of pain were identified often represented moments where the nursing staff were helping the older person to change position and move from one place to another, or completing a medical or care-related task. The acknowledgment of the expression of pain – either by focusing on the potential negative emotion triggered by the pain (emotion-focused) or the practical problem or condition causing the pain (content-focused) in such a situation – may be evaluated as unhelpful or even impossible. Hence, verbally ignoring may be the best approach.

Verbally ignoring expressions of pain in the moment does not mean that the older person's struggle passes unnoticed by the nursing staff; rather, that it is inopportune to address the issue in the task-oriented setting in question. Having a task-oriented focus characterizes communication in home care across the board (Caris-Verhallen et al., 1998; Kristensen et al., 2017). Because of the limitations relating to how the VR-CoDES sequentially code the communication behaviour, it is not possible to say whether the nursing staff addressed the expressions of pain later in the visit. It is also entirely possible that expressions of pain were acknowledged non-verbally by for example touch or facial expression. This acknowledgment is not captured in this thesis since, as already mentioned, audio-recording was used for analysis.

Responding to emotion is a source of support and helps the person to experience continued self-determination (Burleson & Macgeorge, 2014). Continued self-determination is one of the domains consistently described as important when tailoring person-centred care towards older persons (Kogan et al., 2016). It may therefore be beneficial to invest further research into establishing the extent to which nursing staff follow up on older person's experience of pain during home care visits.

7.1.2 Emotion-focused responses and person-centred communication outcomes

Paper I and paper III showed that the immediate response of nursing staff to expressions of worry was to a large extent to focus on the emotional component of the expression (emotion-focused). Emotion-focused responses include the VR-CoDES responses that facilitate, acknowledge and/or explore the worry expressed, either by explicitly referring back to the emotional component or non-explicitly by facilitating behaviour allowing the older person to expound (Del Piccolo et al., 2011). It is therefore likely that the use of emotion-focused responses facilitates the process of discussing and elaborating on the event or circumstance causing the worry for the older person. This may allow the older person to share experiences, an understanding of his/her own health and physical state, beliefs and values. This is likely necessary information for the nursing staff to reach many of the person-centred communication outcomes that are described in figure 1.

Information gained from the verbal channel and non-verbal vocal cues comprises information which is essential to a correct understanding of another person's emotional state (Hall & Schmid Mast, 2007; Mast & Ickes, 2007). Moreover, the insight gained into the emotional world of the patient when using emotion-focused responses may provide the nursing staff with "person-specific knowledge"; information beneficial for practicing person-centred communication (Zoffmann et al., 2008). In addition, emotions often reflect what importance, value or consequences a person assigns to a circumstance or an event (Del Piccolo et al., 2017; Zimmermann et al., 2007). As discussed in paper I, emotion-focused responses may also indicate moments when the nursing staff express empathy with the older person and represent the process whereby the member of nursing staff is endeavouring to gain empathic insight.

Empathic insight is described as a communication process where nurses engage in patients' experiences enabling them to respond in a way that is naturally comforting and supportive to the patient (Morse, Bottorff, Anderson, O'Brien, & Solberg, 1992; Morse et al., 2006). Nursing staff who put into practice this information when trying to provide individualised care, and who work with the patient's values and beliefs, will engage in a person-centred care process (McCormack & McCance, 2017; Morgan & Yoder, 2012; van Dulmen, 2011).

As such, emotion-focused responses may foster person-centred care and constitute an important feature of practising person-centred communication (Epstein et al., 2005; McCormack & McCance, 2017). This may also be an effective response behaviour for attaining goals of person-centred communication (figure 1), including: a) communicating respect, acceptance and sensitivity; b) responding to and managing a person's emotions;

c) eliciting the patient's perspective; d) helping to make the patient's values explicit; and e) building trusting relationships (Epstein et al., 2005; McCormack & McCance, 2017).

When addressing worries about "life narratives and value issues", nursing staff responded with emotion-focused responses in 70% of the cases. This may indicate that the act of sharing a story or value issues are perceived by the nursing staff as worries that need room in the conversation. This accounts for the mass of facilitating responses associated with this particular theme. The importance of allowing older persons to share narratives during home care visits as a way of enhancing service use and of fostering robust care relationships is supported by other research (Mastel-Smith, Binder, Hersch, Davidson, & Walsh, 2011; Tetley, Grant, & Davies, 2009).

Allowing the patient scope to elaborate on worries is a response strategy also found in the home care setting in Sweden (Hoglander et al., 2017), in the hospital setting for nurses in general (Eide, Sibbern, & Johannessen, 2011; Finset et al., 2013). Such scope is also evident when physicians respond to distress expressed as cues (Mjaaland et al., 2011b). When assessed by lay people, such types of responses are shown to have a universal value as the most suitable response to patients' expressions of distress, especially when the responses explicitly refer back to the cue/concern (Mazzi et al., 2013). There is also some evidence that patients who express worries want these worries to be acknowledged and explored (Floyd, Lang, McCord, & Keener, 2005).

All the foregoing indicates that the appropriate use of emotion-focused responses may serve as an important response behaviour that can be beneficial to nursing staff in achieving person-centred communication outcomes.

7.1.3 Eliciting the patient perspective

Because emotion-focused responses constitute a communication behaviour that allows the older person to expound on the issues of concern, this also represents one means for nursing staff to elicit the patient perspective (Del Piccolo, 2017; Del Piccolo et al., 2011). Assessing patient perspective allows care providers to establish preferences and concerns. This process has proved to be beneficial across patient groups in the hospital setting (Eide, Sibbern, & Johannessen, 2011; Finset et al., 2013; Uitterhoeve et al., 2009; Weis, Zoffmann, & Egerod, 2015). For example, eliciting the expectations, preferences and worries of individual parents of children in the neonatal intensive care unit allowed more focused communication facilitating +thus better understanding of all parties involved (Weis et al., 2015). In cancer care, evidence suggests increased patient satisfaction when nurses engage with the patient’s cues of negative emotions (Uitterhoeve et al., 2009). Supportive responses are also part of providing affective communication and are shown to have positive effect on patients’ information recall in a cancer setting (van Osch, Sep, van Vliet, van Dulmen, & Bensing, 2014; van Weert, Jansen, Spreeuwenberg, van Dulmen, & Bensing, 2011).

Paper I demonstrated that when nursing staff elicited the emotional expression and when the expression of worry included concerns/cues containing emotional references, more emotion-focused responses were evident. This may be of significance to clinical practice and communication training inasmuch as it is not to be ruled out that patients whose descriptions of distress are less clear also experience less focus on the emotional content of an issue, thus, indirectly also provide nursing staff with less relevant clinical information specifically covering the emotional component. This may affect the nursing staff’s ability to provide person-centred care because their insight into the person’s preferences and values are insufficiently brought out. (McCormack & McCance, 2017). This may also indicate that achieving person-centred communication outcomes - and to some extent person-centred care delivery - does not depend exclusively on the nursing staff when it comes to care outcomes underpinned by communication, but depends to some extent also on the patient.

Table 3 in paper 1, shows that more than half of the VR-CoDES responses classed as emotion-focused responses consisted of minimal encouragements (e.g. hmm, yes, okay). This thesis only reports on minimal encouragements detected by audio-recording. The use of minimal encouragements is a way of signalling engagement in respect of what the other person is undergoing; indeed such phatic utterances are an integral part of active listening skills (van Dulmen, 2017). The use of minimal encouragers allows the older persons to explore their feelings in their own words and following their own train of thought. Our findings indicate that nursing staff in home care visits practise active listening as a common approach to the expression of worry. Other evidence confirms that minimal encouragements are found more often before patients articulate worry rather than questions or other facilitating behaviour when investigating patient–physician communication (Eide et al., 2004).

When nurses and patients manage to synchronize their responses so as to recognize the other person as an individual, they achieve communication that fosters a sense of sincerity and friendliness, thereby creating room for the patient to express sensitive issues (Spiers, 2002). It is possible that minimal encouragements function as a way of signalling that the member of nursing staff is listening. This in turn creates an atmosphere of friendliness which is essential if the older person is to share important issues. In the case of nurses this act is described as being therapeutically driven (Spiers, 2002). The act of listening whole-heartedly to the patient has been described as an essential component in clinical data gathering, also allowing the care provider to understand the other person's perspective, and an act that is highly valued by patients that enhances the care relationship (van Dulmen, 2017). A review investigating aspects of nurse–patient interaction and communication states that the main intention of communication and interaction in the health setting is to influence the patient's health or well-being (Fleischer et al., 2009). Further, this review argues that when nurses steer communication towards understanding the patient - by allowing the patient to elaborate on a story, situation or experience - it is possible to attain the goal of having therapeutic conversations.

The likelihood of the responses, or messages, as defined/used by Burleson and his colleagues, are at being perceived as supportive depends on how effectively the messages legitimize, acknowledge, elaborate on and contextualise the other person's emotions and perspective as a whole (Burleson, 1994; Burleson et al., 2009). The combination of providing information and acknowledging the affective component belongs to emotion-focused responses within the framework for response behaviours presented in paper I.

Within VR-CoDES terminology this includes: affective acknowledgement, affective exploration and empathic response that explicitly provide space (Del Piccolo et al., 2009). As we saw in Paper 1 the practice of both explicitly providing information and acknowledging the affective component is relatively rare in home care visits because emotion-focused responses are comprised mostly of minimal encourages that do not explicitly address the emotional component. Further, when the nursing staff do explicitly provide space for further disclosure of an expression of worry, this is done mainly through the explicit acknowledgement of content or through responses which explore content. These types of responses actively request the topical content and should be seen as a way to steer the conversation towards a more concrete or practical meaning of the cue/concern. This underlines the relevance of communicating in a purposeful way, in other words being conscious of what it is that one wishes to achieve by one's communication if the communication is to be effective or therapeutic.

On the other hand, the outcomes of person-centred communication relating to "sharing information, eliciting the patient perspective", "negotiating care goals concordant with the person's values", and "involving the patient in decisions at the level desired by the person" (figure 1) appear also to depend on taking practical factors into account in order to be fully reached. For example, one of the older persons included in this thesis expressed "*It's just as nasty every morning*" (2, P2, NA1, paper II) when trying to complete her morning routine. If the nursing staff only focuses on exploring the emotional component (feeling "nasty"), this may exclude relevant information as to possible practical support to relieve the impact of experiencing this activity as "nasty".

In conclusion, when trying to elicit the patient perspective through supportive responses, emotion-focused responses alone may not suffice. On the contrary, focusing on the emotional component alone may reduce the possibility of gaining more detailed information on the more practical factors relevant to the older person perceives the situation.

7.1.4 Nursing staff's response behaviours and supportive communication

In the light of a theoretical framework of supportive communication all three response behaviours outlined in this thesis can be seen as ways of engaging in supportive communication, in the sense that this is assumed to represent a type of communication behaviour which aims at managing distress in others (Burleson, 1994; Burleson & Macgeorge, 2014).

Emotion-focused responses comprised approximately 45% of all responses observed in relation to the main themes "relationships with others", "healthcare-related issues, and "ageing and bodily impairment". This shows that in more than half of the cases when the topical content revolves around these issues, nursing staff engaged in content-focused responses or ignoring/blocking the worry expressed rather than giving an emotion-focused response. This finding may be related to what the nursing staff perceive as comforting or supportive strategies in a given situation. A glance at figure 2 of this thesis which sets out the purpose of emotional support in line with supportive communication (Burleson, 2008; Burleson & Macgeorge, 2014; Greene & Burleson, 2003) suggests that the underlying motivation for providing support is assumed to influence what responses that is chosen when trying to respond to distress.

For example, in this thesis nursing staff are more likely to use content-focused responses when trying to respond to the worries of older persons about *being a burden* to others as opposed to when addressing worries about *losing social ties*. This difference in response behaviour may reflect how adding perspective and pointing to explanatory reasons in a situation (content-focused) may be perceived as more supportive by nursing staff in relation to worries about *being a burden* and that worry about *losing social ties* is supported most effectively by acknowledging the emotional component and offering relational confirmation (emotion-focused).

It seems clear that if the nursing staff perceive the main purpose of support to be to "show care, concern, and affection", a natural response would be to acknowledge the emotion, and perhaps to express empathy towards the older person, hence use an emotion-focused response. If the nursing staff's aim is to "alleviate distress" and "restore inner peace", an effective strategy may be to change the topic completely, and for example, chose to ignore the worry expressed, thus leading the nursing staff to use ignoring or blocking responses as a response behaviour. However, if the motivation stems from an "effort to resolve what is upsetting" for the older person, it could be advantageous to direct the older person's attention to contextual factors more related to the topic or content of the worry expressed, thereby eliciting information that can be used to remove obstacles or difficulties causing the upsetting circumstance. In this way the nursing staff is prompted to focus on the topical issue raised and will therefore use content-focused responses.

In the setting of cancer care, it has been argued that the provision of relevant clinical information is a more effective approach when trying to help patients to regulate worry as compared to focusing on the affective component of the patient's expression (Salmon & Young, 2017b). However, the response strategy of focusing on topical content in response to worry is also described as being perceived as only moderately supportive and most effective when combined with statements which also take into account the affective component of the person's worry (Bodie et al., 2012). Burleson and colleagues have demonstrated that the level of person-centredness in the responses is relevant in determining the extent to which comforting strategies are a source of support and comfort to others (Bodie et al., 2012; Burleson, 1994).

Burleson and his colleagues identify the most effective supportive responses as those which fulfil the requirements of *highly supportive* responses (Burleson, 1994; Burleson, 2008; Burleson & Macgeorge, 2014). These responses are characterised by explicitly recognizing and legitimizing emotions, offering help to articulate the emotional state, elaborating on possible reasons for feeling the emotions, assisting the other person to see how the emotions in question might fit in a broader context, and helping that person to gain a fresh perspective of the situation. Based on these descriptions of highly supportive responses, nursing staff need to gain insight into both the emotional component perceived by the older person, as well as the perceived practical impact of the distressing event or circumstance on the older person's hopes and goals in life (Burleson, 2008). It is likely that limiting the exploration of expressions of worries to the emotional component alone would have a negative impact on the ability of the nursing staff to implement a person-centred care process (McCormack & McCance, 2017) because of the dearth of necessary information for making a sound clinical judgement, for instance information on the patient's practical resources, physical state, etc. This matter is not investigated in this thesis, but it is suggested as a theoretical assumption which requires further exploration and testing, in order to enhance our understanding of how reach the goals of person-centred communication with a view to better provision of person-centred care.

The level of person-centredness and, by extension the assumed supportive effect perceived by the older persons is difficult to assess solely by evaluating linguistic properties of the response. It is probable that the older person's emotional state, the relevance of the response to the circumstance triggering the expression of emotion, and the contextual factors of a given situation, to mention some, are all highly relevant determinants for assessing the level of person-centredness in a response in the setting of home care visits. The material in this thesis deals only with the factors mentioned above inasmuch as this is evident in the verbal communication. Research on supportive communication has shown that *how* a person responds to the distress of others highly influences to what extent the response is believed to be supportive for that person in general, and how effective the response actually is (Bodie et al., 2012; Burleson, 1994; Burleson et al., 2009). This raises a question which has not been explored in this thesis, namely how nursing staff and/or patients [actually] evaluate [the quality of] the interactions analysed and what is perceived as a supportive response by the patients in relation to different types of worries.

The purpose of the analysis in this thesis was to explore moments of emotional communication as this takes place in home care visits. It was beyond the scope of the studies included in this thesis to trace individual cues/concerns or clusters of cues/concerns in order to identify all responses that may be considered to be responses to a given cue/concern. It is therefore impossible to say to what extent nursing staff use combinations of response behaviours when addressing a single cue/concern. Paper III of this thesis explored this based only on the thematic content of cues/concerns in general. In the future an effort should be made to shed light on how these response behaviours are observed within a temporal perspective in relation to single cues/concerns.

7.2 The expression of worries by older persons during home care visits

In this thesis, nursing staff are found to elicit most of the worries expressed in general. This is similar to what is described as a characteristic of Swedish home care visits (Sundler et al., 2017) and hospital consultations with nurses (Eide, Sibbern, Egeland, et al., 2011). In addition, nursing staff seem to use more emotion-focused responses when they elicit the cues and concerns themselves as compared to when the older persons express their worries without being facilitated by the nursing staff in advance. Studies exploring how patients in hospices and in primary care express their worries indicates that they are often selective in what issues they choose to put forward in communication with nurses, often restricting themselves to physical symptoms (Green, Jester, McKinley, & Pooler, 2013; Heaven & Maguire, 1997). This may also account in part for why the VR-CoDES code capturing descriptions of symptoms (*cue b*, (Del Piccolo et al., 2008)) is often reported as the most common way of expressing cues of distress across care settings (Del Piccolo et al., 2015; Heyn et al., 2012; Sundler et al., 2017). This is also confirmed by our findings in paper I.

The findings of this thesis show that the large variety of issues which can cause distress together with the emotional tone used when worry is expressed constitute important features of how older persons share their worries. Thus nursing staff have to be attentive in order to identify the personal meaning embedded in the expressions of worry. Picking up on this possible connection to the older person's personal world may be beneficial in the provision of support (Burleson & Macgeorge, 2014). Further, being attentive in this way may help to identify whether these expressions contain information important for how care should be provided for the individual person (Street et al., 2009).

Interestingly, over 60% of the expressions of worries were categorized under the main theme “ageing and bodily impairment”, capturing issues holding potential existential meaning for the older person (papers II and III). Functional impairment and complaints about ill health are associated with lower scores in care satisfaction and quality of life among older persons receiving home care (Karlsson, Edberg, Jakobsson, & Hallberg, 2013). This theme of worries may therefore represent a major issue in home care delivery – an issue of importance for ensuring the satisfaction in the delivery of care and preserving quality of life for the individual older person. This theme should therefore be taken into consideration when drawing up plans for optimal home care services. In addition, when caring for older persons and persons suffering from terminal illness it is highly desirable to address existential issues (Sundler et al., 2016; Tornoe, Danbolt, Kvigne, & Sorlie, 2015). It is therefore reasonable to assume that sensitivity to expressions regarding “ageing and bodily impairment” are relevant when providing home care for older persons in particular, and these aspects should be taken into account in clinical practice by nursing staff working in this sector.

Worries embedded in “ageing and bodily impairment” may also cover issues such as the occasions when the nursing staff need to call upon other care professions like psychologists or social workers, for example if the older person’s struggle with existential issues seems to progress into symptoms of depression or anxiety. It is therefore vital to maintain a professional discussion amongst nursing staff working in home care to help to properly distinguish between the occurrences of worry relating to issues concerning coping with life in general and falling within the responsibility of home care, and the occurrences of worries which evolve into issues requiring specialised care or treatment.

7.2.1 Relational influence on themes of worries

The assessment by the home care nursing staff of a situation includes juggling competing needs among patients as a way of balancing scarce resources (Vabø, 2009). This has also been described as part of the varied work undertaken in a home care setting (Bratteteig & Eide, 2017). One strategy, which Vabø describes as being used by nursing staff who endeavour to manage these aspects of home care delivery, is known as "interactional work". This aimed at gaining understanding from the patient on the demanding working conditions in which nursing staff are working (Vabø, 2006). This is described as resulting in patients adjusting their expectations of care and trying to cope by themselves (Vabø, 2006).

We know that during communication participants heavily influence each other, and the way stories or statements are shared is shaped by communication behaviours like alignment (behaviour that supports engaging in taking turns, responding to and sharing of view points) and affiliation (the listener supports and endorses the teller's view point) (Guardiola & Bertrand, 2013; Stivers, 2008). Further, assuming that emotions are responses to how humans appraise a situation, but also that it is possible to inhibit or constrain when considered appropriate in a specific context (Del Piccolo et al., 2017; Levenson, 1999), the themes of worries raised during home care visits might be linked to what is "socially acceptable" to express as worrying for older persons. It is therefore also possible that nursing staff show more affiliation and alignment when dealing with themes they consider to be relevant, or in line with what they understand as the purpose of the visit, thereby potentially causing older persons to experience the interaction with particular nursing staff as more open to a given topical set of worries.

Home care nursing staff in Norway are expected to adjust care delivery in keeping with the patients' needs; they are also expected to exercise their own clinical judgement (Johansen & Fagerstrom, 2010), also meaning that the nursing staff have the power to offer or withdraw care in the moment (Vabø, 2006). The guiding principles for carrying out this assessment are based on the notion that nursing staff should ensure a minimum of home care focusing on maximising the coping capacity of patients or ensuring home care delivery in accordance with individualised entitlement which is informed by government policy and professional guidelines (Vabo, 2012; Vabø, 2006, 2009).

This understanding also influences how the individual member of nursing staff chooses to prioritise among patients, thus influencing care delivery for the individual patient (Vabø, 2006). The individual care provider is previously identified as a better predictor of total cues/concerns compared to provider groups in primary care (Riley et al., 2013). Older persons may recognise this power and try to justify their care needs when communicating with nursing staff who focuses on coping capacity. Issues relating to "ageing and bodily impairment" revolve around the challenges the older person experiences when trying to cope with a particular situation or circumstance. This main theme captures descriptions of how the older person struggles to handle tasks which were formerly straightforward, feeling as if the body or mind is failing, or coping with thoughts of death and lack of hope for the future (paper II). Such ruminations can be understood as reflecting the older person's coping capacity at that moment, and they may be an indirect way of asking the nursing staff for additional care or a way of justifying the need for continued care at the current level. Thus, the underlying reasons for why the majority of expressions of worries involve "ageing and bodily impairment" may represent more than the need for emotional support on a particularly relevant issue. They may also be the result of learned behaviours which help the older person to gain the sympathy or acknowledgment of the individual nursing staff in order to enable continued or adjusted care.

On the other hand, nursing staff working in home care claim that they always negotiate care with the best interests of the patient in mind (Oresland et al., 2008; Vabø, 2006). This indicates their willingness to discuss any problems patients might experience. Studies also indicate that nurses use communication as a way of supporting and adjusting their approach to care according to the patient's needs (Bottorff & Morse, 1994; Caris-Verhallen et al., 1998; McCabe, 2004; Morse et al., 2006). A qualitative analysis included in the COMHOME-project, explored communication taking place in the home care visits between patients and nurse assistants (Kristensen et al., 2017). In this case, the analysis showed that as the communication evolved, nurse assistants supported the older person's connection to everyday life, encouraging him/her to be involved in the care, while responding to that person's bodily health and well-being as well as addressing the older person's need for continuity and predictability in care. All these aspects are deemed to be important for establishing a trusting relationship between care providers and patients (Street et al., 2009; Van der Elst et al., 2012).

Thus, it is entirely possible that contextual factors like organizational policy and management play a larger part than the individual nursing staff when older persons consider what the eligible themes of worries to be raised during home care visits.

One of the foremost objectives of home care services ~~is~~ to provide tailored care and assist with daily tasks to enable the individual older person to continue living at home (Hermsen et al., 2018; Nicholson et al., 2013; Sixsmith et al., 2014). Communication taking place during the home care visits therefore needs to be focused on the recipient of care. This was also confirmed by Kristensen and her colleagues in their analysis of authentic communication between older persons and nurse assistants, also part of the COMHOME-project (Kristensen et al., 2017).

However, the afore-mentioned study also showed that there were issues of time constraints which had an impact on the older person's in-depth exposition of thoughts and concerns (Kristensen et al., 2017). The communication which took place during visits was mainly directed at the practical task at hand where the nurse assistant guided the older person to ensure the older person's participation in the task. This task-oriented focus in home care is also discussed in other studies (Caris-Verhallen et al., 1998; Lindström & Heinemann, 2009).

Studies show that care delivery which helps the older person to stay as self-reliant as possible and maintain physical functions so as to avoid unnecessary dependency is considered to be highly desirable in the provision of quality home care (Bing-Jonsson et al., 2015; Dale et al., 2012). Home care services are emphasized as vital to older persons to facilitate ageing at home through a number of services. These aim to prevent social isolation, support psychological well-being and relieve distress, together with helping to deal with illnesses, alleviate pain, and give advice on getting to sleep and resting (Hammar et al., 2008; Keeling, 2014). Enabling the patient to manage self-care is emphasized as one of the main goals of home care services in order to meet an increasingly ageing population with complex care needs (Chatterji et al., 2015; Genet et al., 2012). The capacity to cope and prevent-functional decline as a way of optimizing home care tailored towards older persons constitute overarching aims – aims which are prescribed by policy makers and management (Bing-Jonsson et al., 2015; Dale et al., 2012; World Health Organization, 2012). This may influence all aspects of home care, including communication during home care visits.

The patients' experience of prolonged dignity and of being empowered through ensuring the ability to engage in self-care has been closely linked to patient–nursing staff communication (Bastemeijer, Voogt, van Ewijk, & Hazelzet, 2017; Gallagher et al., 2008). Worries describing the older person's struggles and challenges concerning the ability to engage in everyday activities are largely captured by the main theme "ageing and bodily impairment". Expressions classed as "ageing and bodily impairment" may therefore be experienced as more intuitively relevant to care delivery and worthy of attention by all home care nursing staff as compared to expressions concerning other themes. This intuitively understanding of the relevance of this theme may influence home care nursing staff to be more responsive to worries that relate~~s~~ to the older person's ability to engage in a given task, also colouring their clinical judgment and openness to this specific theme of worries. Thus, also being a reflection of what is included in the home care services in general.

There is evidence to suggest that if the older person rates his/her subjective experience of well-being as high this may reduce physical ill-health. It is also associated with longer survival rates (Steptoe, Deaton, & Stone, 2015), underlining the importance of relieving issues concerning "ageing and bodily impairment" in home care. In addition, it is possible that nursing staff perceive themselves as being more competent in areas concerning physical and cognitive function given the clinical emphasis on these issues (Bing-Jonsson et al., 2015), and they are therefore more prepared for such issues to emerge during conversation. Thus, the finding of one main theme of worries as more prominent in emotional communication in home care visits may be the result of contextual factors captured only indirectly by the material in this thesis, and need for further research should be noted.

7.2.2 Themes of worries and theories of ageing

Another interpretation may be that worries about "ageing and bodily impairment" represent the older person's distress which is triggered by effects relating to the ageing processes. It may be that worries about "ageing and bodily impairment" reflect the older person's need for support in the struggle to maintain abilities in order to pursue desired activities such as self-reliance in handling everyday tasks (Hermsen et al., 2018; Nicholson et al., 2013; Sixsmith et al., 2014). It is therefore perhaps worthy of our attention to consider this finding in the light of theories of ageing. There are a number of theories that can be used for this purpose, for instance activity theory, disengagement theory, continuity theory, Erikson's psychodynamic theory, and the theory of gerotranscendence (Wadensten, 2003). An in-depth analysis covering all of these perspectives is beyond the scope of this discussion. Therefore, for the present purposes we will refer to just two the theories which contain different understandings of ageing: activity theory and gerotranscendence. These will serve us in our discussion of the ways different theoretical perspectives may influence the interpretation the findings of this thesis.

The view that there is a positive relationship between a person's level of activity and life satisfaction is a key understanding propounded of activity theory (Diggs, 2008). Activities represent the different ways someone can be occupied, including social and leisure activities, like being with family or gardening (Adams, Leibbrandt, & Moon, 2011). According to activity theory activity is essential to well-being and therefore any loss in activity must be replaced if a reduction in well-being is to be avoided (Diggs, 2008). The underlying assumption is therefore that the effects of ageing must be prevented and that this is best achieved through maintaining a certain level of activity (Wadensten, 2003). This understanding that health care should be focused largely on identifying problems, reducing risk and harm, and prioritise problem solving, characterizes Western health care systems in general (Reed & Clarke, 1999). The average age of the patient sample of this thesis was 84 years, making it likely that many of these older persons had entered a phase in their lives were the effects of ageing were becoming more apparent (Dale et al., 2012; Nicholson et al., 2013). Indeed, most of worries about ageing related to the experience of bodily impairment, both physical and cognitive (papers II and III). It is known that after the age of 75, many people experience more age-related diseases, including symptoms of depression (Dykstra et al., 2005; Heikkinen, 2003; Sixsmith et al., 2014). Multimorbidity is also increasingly common with increasing age, and patients having multimorbidity report high levels of needs with regard to physical illness, household issues and the prevention of falls (Hermsen et al., 2018). It was also found that patients with multimorbidity expressed distress as hints rather than as clear statements of concern (Zhou et al., 2015), indicating that multimorbidity affects how patients describe distress. This has been discussed by researchers who emphasize the way ageing has an impact on both the social and emotional life of a person (Charles & Carstensen, 2010). Here, age-related changes are pointed out as being part of a developmental process, characterised by improved self-regulation with a shift in priority towards meaningful activities on the one hand, and the decline in neurological and physical function causing stressors on the other hand. However, this does not fully account for the relatively small proportion of the other main themes. It is to be expected that a decrease in activity level caused by the effects of ageing, which hinders activities, would be extended to all aspects of a person's life, including social and leisure activities, care-related needs and the need to feel connected. Moreover, we would expect a decrease in activity to prompt worries at least captured by "relationships with others" and "health care-related issues". It is possible to argue that activity theory alone is insufficient to understand the findings presented in this thesis.

According to gerotranscendence, human development is an ongoing process that does not stop because of inability to engage in particular activities or to maintain given social roles (Schroots, 1996). Instead, gerotranscendence assumes that as a person ages and matures, he/she learns to cope better with life and transcend some barriers (Tornstam, 2011). Gerotranscendence describes human development as progressing naturally in phases; entering old age means a shift in focus away from focusing on materialistic issues and performance ideals favouring rather a more cosmic view of the world, that also includes redefining oneself and the meaning of social relationships (Tornstam, 1997). There is some evidence to show that older persons recognise themselves in these descriptions and that discussing ageing in the light of gerotranscendence is beneficial because it provides for a more positive view (Wadensten, 2005).

When considering the findings of this thesis in the light of gerotranscendence, expressions of worries in general may be seen as moments when the older person identifies something that is thwarting him/her from continuing their development. The theory of gerotranscendence suggests that identifying such issues and endeavouring to resolve these issues at a therapeutic level for the individual person, may protect against anxiety and depression, and increase life satisfaction (Tornstam, 2011).

Returning to how "ageing and bodily impairment" is the most prominent theme of worries identified in this thesis, this can indicate that this issue is particularly salient for the older person to resolve in order to continue the developmental process. The experience of the body becoming weaker, increased functional decline and symptom severity, may represent issues that the older person needs to address and come to terms with, as necessary steps to reach stages of transition associated with reaching gerotranscendence. The administration of advice on endeavouring to deflect attention away from preoccupation with the body and giving preference to enhance personal growth for older persons is also recommended as part of the guidelines set out for practical use in the care of older persons (Wadensten & Carlsson, 2003) .

This way of looking at the expressions of worries can also help to explain the large differences in proportions among the different main themes. Gerotranscendence suggests that maturing into old age allows a person to develop a more transpersonal sense of affinity with others, becoming less self-occupied, and more selective in choice of both social and other activities (Tornstam, 2011). The fact that loneliness seems to be less of a problem for many elderly people when compared to younger people may be explained by this changed understanding of affinity with others (Hawthorne, 2008; Tornstam, 2011). It has also been suggested that older people are better at regulating distress, focus more attention to and effort on processing emotional information and are better at avoiding situations involving social conflict (Sims, Hogan, & Carstensen, 2015). Elderly people who derive meaning in life from self-transcendent sources are also found to be more extrovert, open to experiences, agreeable and conscientious (Reker & Woo, 2011). Further, older persons who derive meaning from self-transcendent sources also perceive life as having greater purpose and coherence; they desire to get more out of life, are in control and feel less depressed compared to those who pursue self-serving interests (Reker & Woo, 2011). It is possible that this redefinition of the self and relationships with other people, which are described as being a part of gerotranscendence, create less conflict~~s~~ and reasons for worrying about "relationships with others". The same effects may also have a bearing on how "life narratives and value issues" are expressed.

When listening to the visits as part of the coding process, we gained the impression that the older person shared personal stories with the nursing staff even though these accounted for only 9% of the expressions of worries (paper III). This finding does not mean that storytelling is not prominent in the material as a whole, rather that it is relatively seldom expressed in terms of distress. The need to engage in reminiscing and storytelling is emphasized as important for the older persons themselves and for building strong care relationships (Mastel-Smith et al., 2011; Sixsmith et al., 2014; Williams et al., 2011). In the light of gerotranscendence, our finding may reflect how the older person is less focused on recounting distressful events, or even that the older person is appraising the actual events differently because of changes in meta-perspective (Tornstam, 1997, 2011). This would explain why these worries are less prominent in the material.

It should also be noted that older persons may attribute less negative emotional value to "healthcare-related issues" because their experience of the care delivery depends more feeling respected and having their dignity preserved, experiencing reciprocity and being able to contribute to the care (Entwistle et al., 2012; Gallagher et al., 2008). Supporting patient involvement in contributing to routine tasks of care was one of the chief characteristics of communication taking place in the home care visits identified by the qualitative analysis which was performed as part of the COMHOME project (Kristensen et al., 2017). In addition, survey-based research shows that almost 80% of older persons in Norway that have had personal experience with receiving home care, evaluate the quality of care as good in general (Førland & Folkestad, 2016). When describing good home care, older persons emphasise the preservation of autonomy and the need for a close relationship with the visiting nursing staff, and less linked to the nursing staff's performance of essential tasks (Piercy & Woolley, 1999). It is not to be excluded that this understanding of good care is linked also to a change in perspective and a decrease in self-centredness such as is experienced in old age (Tornstam, 2011), resulting in the older person to feel less inclined to criticize and disapprove with the care delivery as practised by the nursing staff.

This discussion raises many questions which, to the best of my knowledge, have not been explored. Measurements on nursing staff's theoretical assumptions on ageing may represent another hitherto neglected explanatory variable in research exploring factors having a bearing upon emotional communication. These factors also represent a missing piece that could add to our understanding of what promotes or impedes person-centred communication in a given clinical setting. The influence of the curriculum included in the education of nursing staff working in this setting, like theories of ageing, could also be an interesting area of research which could contribute to our understanding of what cultivates a person-centred care practice when interacting with older persons.

8 Strengths and limitations of design and methodology

The focus of this chapter is to discuss strengths and limitations relevant for design, methodology and study sample used in this thesis.

8.1 Study design

The COMHOME-project was designed as a cross-sectional, observational study (Hafskjold et al., 2015), and this thesis presents findings from the Norwegian part of the project. Since the main aim of the thesis was to explore worries expressed by patients and supportive communication in home care visits, the cross-sectional design was appropriate because it allows for identifying a prevalence of worries and responses, as well as multiple outcomes which are important for answering the research questions (Mann, 2003). A cross-sectional study makes it possible to identify important features of a phenomenon and relationships between variables; however it does not provide causal explanations (Mann, 2003).

The findings are founded on empiricism (Bostrom & Donohew, 1992). Rather than focusing on causality, the focus is on understanding subjects in their natural context by systematically identifying what factors increase or decrease the likelihood of given behavioural patterns to occur (Bakeman & Gottman, 1997). The applied coding system has a function equivalent to that of a microscope, enabling the phenomenon of interest to be brought into focus in an otherwise complex social setting, thus making it available for research by the researcher (Bakeman & Quera, 2011). The use of a transparent and recognised analytical approach, which ensures the possibility of reproducibility of data, ensures rigour in the conclusions drawn, as does continual critical evaluation by peers (Carter & Little, 2007).

It was important for the research group to organise the research and data collection in accordance with principles of person-centred research (McCormack et al., 2017). Researchers need to be respectful of all persons involved in the research; this included participants' understanding of their own identity, preserving the integrity of participants, and taking into account the values, preferences and concerns of potential participants: or, put another way, the researcher needs to engage actively with the participants to elicit their views, and incorporate these in the research process in a way that ensures rigour and validity of the research (McCormack et al., 2017). This was ensured through the rigorous inclusion process and the process of data collection.

8.2 Sample and representativeness

To the best of our knowledge, the COMHOME-project represents the first international research project that includes both nurse assistants and nurses in a study on patient–provider communication in home care visits. The inclusion of both of nurse assistant and nurses is important because they represent the majority of the work force providing home care (Johansen & Fagerstrom, 2010; Tarricone & Tsouros, 2008). The nurses included in this study had undergone formal nursing education equivalent to a minimum of bachelor's degree for nurses. In the case of nurse assistants, upper secondary school level had been reached. It was assumed that this training increased the competence of the participating nursing staff as compared to staff with no formal training. In addition, the nursing staff recruited had considerable work experience and were well known to their patients. As such, most of the recruited nursing staff can be described as experienced in their job setting. Previous research looking at physicians shows that familiarity with patients increases sensitivity to expressions of worries (Gulbrandsen et al., 2012; Stewart, Meredith, Brown, & Galajda, 2000). Work experience is also found to influence how physicians respond to cues and concerns (Del Piccolo et al., 2012). There is some evidence supporting the fact that knowing the patient increases nursing staff's confidence in being able to help older patients efficiently (Piercy, 2000). Moreover, patients describe a good nurse as a nurse performing tasks with confidence and signalling professional competence (Van der Elst et al., 2012). Based on characteristics of the nursing staff, a sample of unexperienced nursing staff or nursing staff unfamiliar to the patients might have provided different findings from those described in the current thesis. It is difficult to say the extent to which work experience and familiarity with patients may have a bearing on emotional communication in this setting. However, based on the literature described above it is likely to have an effect, indicating a need for further research into investigating the effect of nursing staff's work experience and familiarity with patients on characteristic of emotional communication unfolding in home care visits.

With regard to age and functional abilities the patients in this study are similar to those described in other research (Algera et al., 2004; Sigurdardottir et al., 2012). These characteristics varied in respect of factors to which weight was attributed in explaining differences in home care service usage among the older population in Norway (Førland & Folkestad, 2016). In this respect, the sample is likely to be representative of the general population of older persons.

8.3 Biases

8.3.1 Sample biases

Random sampling is considered ~~to be~~ the gold standard for obtaining generalisability, inferences to a population based on the findings from a study sample (Altman, 1991), and listwise selection (Grimes & Schulz, 2002), selecting participants from a list of eligible individuals where all individuals on the list have equal opportunity to be selected (Hultsch, MacDonald, Hunter, Maitland, & Dixon, 2002), is a method of random selection that could have been applied in this study. However, the data collection was based on two main considerations: 1) ensuring care-as-usual, and 2) ensuring voluntary consent for all nursing staff. One measure to ensure care-as-usual was to complete the data collection in the shortest possible time. Organising data collection based on randomly selected participants would have required the adaption of work lists. Therefore we decided to use a convenience sample, rather than a random sample. Variations of convenience samples are widely used in similar observational studies (Del Piccolo et al., 2012; Heyn et al., 2013; Mellblom et al., 2014) and this is a common strategy used in research focusing on psychological ageing research (Hultsch et al., 2002). However, convenience samples are often associated with participants who have greater access to resources, better education, social support or typically live in closer geographical proximity to the healthcare service centre being studied (Hedt & Pagano, 2011). This may lead to an overestimation of function and underestimation of patients' worries and needs, for example in studies of the characteristics of cognitive ageing, convenience samples are described as being younger and better functioning compared to randomly selected samples (Brodaty et al., 2014). On the other hand, evidence suggests that the difference in measures between randomly selected and convenience samples are small to moderate (Hultsch et al., 2002). In fact, the characteristics of the study sample for the thesis were similar to those described as typical of home care visits (Algera et al., 2004; Eloranta et al., 2010; Gleason & Coyle, 2015; Sorbye et al., 2010; Thome et al., 2003). Therefore, the results in this thesis are likely to represent what is currently a common way of sharing and handling emotional moments in the communication in home care, at least as far as older home care patients are concerned.

An effort was made to ensure the recruitment process encouraged nursing staff to be intrinsically motivated to participate, while also allowing them the freedom *not to* participate. Steps were taken to ensure all eligible nursing staff were informed about the study; likewise, any nursing staff who expressed interest were asked to participate. It was considered that such an approach to nursing staff was respectful of the individuals' values and preferences. This approach was considered also to demonstrate that participation was based on the person's initiative rather than being governed by power-relations (McCormack et al., 2017). Moreover, the voluntary action facilitated intent and absence of controlling influences such as management and policy makers (Nelson et al., 2011).

However, the emphasis on the voluntary nature of the recruitment process meant running the risk of recruiting nursing staff with a high interest in communication or staff with high communication self-efficacy. Moreover, practising in an academic healthcare facility and extensive experience in the setting are factors known to promote' participation (Henry et al., 2015). Caution should therefore be exercised when extrapolating the findings as these may not be representative of nursing staff with little interest in communication or more unexperienced nursing staff.

As few studies have explored emotional communication between older persons and nursing staff in home care using similar observational methods, the possibility cannot be ruled out that essential variables on socio-economic variables or particular health conditions may been inadvertently omitted from the inclusion/exclusion criteria for both the patient and nursing staff sample.

Measures taken to ensure some control over the sample and to promote generalisability included limiting the population to one county in Norway. Further, the inclusion criteria for nursing staff and patients were based on key variables relevant for the study population (Mann, 2003). This ensured variation in both participants and features of the visits, which mimic the variation found in clinical practice in home care, and therefore increased the sample representativeness and provided more accurate results (Altman, 1991). Limiting the population frame to one county and adapting a structured sampling are widely used measures for ensuring a valid study sample when situation does not allow more robust ways of randomisation (Hultsch et al., 2002). Moreover, the characteristics of care assignments, patients and nursing staff were to those described as typical of home care visits (Algera et al., 2004; Eloranta et al., 2010; Gleason & Coyle, 2015; Sorbye et al., 2010; Thome et al., 2003). The sample of home care visits is therefore assumed to be of sufficient internal validity for the aims of this thesis.

8.3.2 Validity

Audio-recordings were used to interpret emotional communication. Other researchers who have used the same approach question whether we can trust interpretation and analysis when the observation is limited to verbal communication (Del Piccolo et al., 2012; Heyn et al., 2013; Sundler et al., 2017). The use of audio-recordings as the exclusive source of information excludes observation of eye contact, touch and other non-verbal aspects which are well known to influence relationships, trust and the communication in itself (Gorawara-Bhat, Cook, & Sachs, 2007; Gorawara-Bhat, Dethmers, & Cook, 2013).

However, comparison of communication rating based on audio and video material indicates that ratings are highly correlated, and this may cast doubt on the understanding of video material being superior to audio material in this kind of observational research

(Henry, Penner, & Eggly, 2017; Williams, Herman, & Bontempo, 2013). Tone of voice, rhythm, and intonation can all provide information on the emotional state of the speaker as well as clues to the implicit meaning in the spoken message (Sbattella et al., 2014).

In an endeavour to elicit accurately information the words used is found to be most important (Hall & Schmid Mast, 2007; Ickes, 2001). Further, of secondary importance is information from non-verbal vocal cues (tone of voice, intonation, pauses, etc.), and - to a lesser extent - the non-verbal information (body posture, gestures, eye contact, etc.) (Hall & Schmid Mast, 2007; Ickes, 2001). This suggests that the internal validity of observational methods is not jeopardised by using audio material (Grimes & Schulz, 2002) and supports the methodological approach adopted in this thesis.

Moreover, audio-recordings were convenient to use for the nursing staff participating in the study. Setting up a camera would have involved a member of the research group being on site throughout the data collection in order to mount the camera and handle the videotaping. This method was used in another study and was described as time-consuming and a little intrusive for some of the patients (Lindström & Heinemann, 2009). Thus, the choice to use an audio-recorder was seen as the most efficient way of collecting a large number of visits so as to minimize the impact on nursing staff and patients. In addition, it is likely that the choice of audio-recording over video-recording minimised changes in patient–nursing staff communication due to their knowledge that they are being observed (Hawthorn effect). Audio-recordings has been confirmed by other research to have little effect on clinical communication (Henry et al., 2015).

It should be borne in mind that it is likely that communication analysed in this thesis is influenced by being placed within the cultural framework of the Norwegian society and healthcare system. The Scandinavian model for healthcare and national healthcare reforms influence organisational aspects and the service provided as part of home care (Genet et al., 2011; Rostgaard et al., 2011; Vabø, 2009). This makes it likely that the findings of this thesis are more relevant and more reliably transferable to home care services founded on healthcare models which are similar to the Norwegian or Scandinavian healthcare model in terms of universal public services (Rostgaard et al., 2011). The current findings are also likely to be specific to interactions including older persons as research indicates that the preferences of older patients differ from those of younger patients when it comes to care providers communication practice and the desired level of involvement with care decisions (Constand, MacDermid, Dal Bello-Haas, & Law, 2014; Kiesler & Auerbach, 2006), and what is considered important features of the communication when receiving care (Gallagher et al., 2008).

9 Conclusions

Nursing staff encounter a variety of topical content in moments of emotional communication with older persons during home care visits, including worries about 1) relationships with others, 2) health care-related issues, 3) ageing and bodily impairment, and 4) life narratives and value issues. We found that expressions of worries can to a large extent be classed under the main theme of “ageing and bodily impairment”. Efforts to detect and support the struggle of older persons and to deal with issues pertinent to this theme may contribute to the alleviation of a considerable amount of potential distress experienced by older persons in need of home care. However, older persons usually express their worries as cues (hints to underlying unpleasant emotion) rather than as concerns (explicitly stating unpleasant emotion). This may make it difficult for the nursing staff to notice when the older person is seeking emotional support, thereby necessitating communication skills that enable the exploration and elaboration of the issues causing the older person to worry, in order for the nursing staff to capture clinically relevant information. The response strategy allowing for both the affective component and the topical issue to be explored is captured by emotion-focused responses. These are proportionally more often observed as the immediate response to an expression of worry as compared to either content-focused responses or ignoring/blocking the worry expressed. Emotion-focused responses are promoted when nursing staff elicit the emotional expression and when the older person's expressions include a reference to an emotion. This pattern holds true irrespective of the status of the member of nursing staff. At the outset we expected to find differences in communication practice between the groups resulting from differences in competence and educational level. It is possible that these differences were levelled out based on work experience; nursing staff included in this thesis had on average 10 years of experience. Moreover, the response behaviour of nursing staff is also associated with thematic content, especially when the distress is directed at worries about “ageing and bodily impairment” or “relationships with others”. As far as *expressions of pain in the moment* are concerned, nursing staff seem to be more likely to verbally ignore or block the expressions in the moment which is expressed by the older person.

9.1 Implications for training and further research

9.1.1 Implications for communication training

The emotional tone used by the older person when expressing a worry is important to notice in order to identify the personal meaning embedded in these expressions. Thus, if nursing staff are to respond in a supportive way, it is crucial to note the tone. This will help in enabling us to establish whether these expressions convey information important for how care should be provided for the individual person. This knowledge can help nursing staff and students to become more aware of particular times during routine communication in home care visits that may be of emotional significance to the older person, and how the practice of sensitivity at these moments may be highly relevant to the provision of person-centred support and the practice of person-centred care.

This thesis suggests that the linkage described between the VR-CoDES (presented as response behaviours) and ways of providing highly supportive responses presented in this thesis, can form a sound theoretical basis for developing communication training programmes which target emotional communication in home care visits underpinned by person-centred values. The application of VR-CoDES for educational purposes is also supported by one of the studies included in the COMHOME project. There, observations were performed using the VR-CoDES which formed the basis for providing nurses with individualised feedback aimed at enhancing emotional interaction with older home care recipients (Veenvliet et al., 2016). Educational programs have been developed based on the empirical findings from this thesis, and are currently implemented in the curriculum of the nursing education at the University of South-Eastern Norway. Such training programmes may also prove helpful for nursing staff in handling moments of emotional communication during home care visits in order to ensure that the older person's emotional needs are addressed in a person-centred way - which may in turn also foster continued healthy ageing. Given the unresolved issues relating to whether an affective focus is preferred by patients, and in what circumstances emotion-focused response behaviours may contribute to more effective person-centred care delivery, further exploration may be desirable. This investigation could involve the use of research designs allowing us to examine cause and effect on outcomes like patient preferences, patient health and the care relationship.

9.1.2 Methodological development

The "two-step approach" developed through the work conducted as part of this thesis, is of methodological value in its own right in that it provides a reliable way of selecting which moments to include from the vast number of hours of recorded communication collected for this thesis. Further, the description of the purpose and significance of each step of the "two-step approach" could be used as a framework for other researchers who might encounter similar challenges to ours. This also highlights the value of a mixed-method approach in the investigation of communication.

The description of applying the VR-CoDES in an unfamiliar clinical setting contributes to the understanding of the strengths and limitations of this observational system. Further, the coding scheme for topical content of expressed worries outlined in this thesis was successfully overlaid the cues/concerns derived from the VR-CoDES. This coding scheme could be used by other researchers in a similar fashion to the way it was used in this thesis, or be further developed to allow the analysis of segments in the communication where cues/concerns and corresponding responses representing the same topical issue can be sequentially analysed.

Further, linking the VR-CoDES and the supportive communication framework allowed for the discussion of how VR-response codes reflect levels of person-centredness in a broader sense, rather than by merely focusing on the communication behaviour of acknowledging affect.

9.1.3 Implications for research

The findings of this thesis point to the need for further research into emotional communication in home care visits across the board. This thesis has suggested a theoretical approach allowing exploration of different ways for the nursing staff to practise principles of person-centredness in moments of emotional communication. However, there is a need to test this framework further. Testing older person’s preferences when it comes to nursing staff’s response behaviours will help theory constructions on what features are actually perceived as person-centred and supportive for older persons during emotional communication in this setting. Investigation into the perspectives of the nursing staff working in home care on response behaviours in relation to themes of worries can also prove fruitful. This may give us deeper insight into the driving factors influencing nursing staff’s response strategy when responding to distress. Specifically, there is a need for further research investigating how best to address and support worries about “ageing and bodily impairment”. Another important subject requiring further investigation is whether nursing staff actually follow up on older person’s experiences of pain in the moment during home care visits, either by using non-verbal behaviours, or by returning to the subject later in the visits or by applying other care measures.

This thesis does not consider the matter of whether main themes of worries are perceived as relevant for the older persons themselves, or whether the worries expressed represent issues that older persons expect to be addressed during home care at all, or how nursing staff provide support in the best way in these moments. It is impossible to say anything about how the older persons in this thesis actually appraised the different situations when the expressions of worries were identified, due to limitations of analysing observational data. However, these aspects are considered to be an eminently worthwhile subject for further investigation as a way of enhancing understanding of emotional needs among older persons receiving home care and how older persons may be supported through person-centred communication.

What does emerge is that emotional communication highlights issues relevant to older persons’ emotional well-being and health; thus emotional communication represents moments where nursing staff can offer support, which is of cardinal importance in reaching person-centred communication outcomes.

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List of papers omitted in the online version

Paper I

Hafskjold L., Sundling, V., van Dulmen, S., & Eide, H. (2017).

The use of supportive communication when responding to older people's emotional distress in home care - An observational study.

BMC Nursing: doi:10.1186/s12912-017-0220-8

Paper II

Hafskjold L., Eide T., Holmstrom I.K, Sundling V., van Dulmen S., & Eide, H. (2016).

Older persons' worries expressed during home care visits: Exploring the content of cues and concerns identified by the Verona coding definitions of emotional sequences.

Patient Education and Counseling: doi:10.1016/j.pec.2016.07.015

Paper III

Hafskjold L., Sundling, V., & Eide, H. (2018).

Nursing staff's responses to thematic content of patients' expressed worries: observing communication in home care visits.

BMC Health Services Research: doi: 10.1186/s12913-018-3390-5

Attachments

HØGSKOLEN
i Buskerud

HELSEPERSONELLINFORMASJON FOR FORSKNINGSPROSJEKTET: «KOMMUNIKASJON MED ELDRE MED BEHOV FOR HELSETJENESTER»

Verdens befolkning blir stadig eldre. I Norden er hver 8. innbygger eldre enn 80 år og andelen antas doblet innen 2040. Norsk helsepolitikk har aktiv og trygg aldring som målsetning. Et viktig aspekt i norsk helsepolitikk er personorienterte helsetjenester, med siktemål om å gjøre det mulig for den enkelte innbygger å bo hjemme så lenge som mulig. Kommunikasjon er en sentral ferdighet for å styrke kvaliteten i personorienterte helse- og omsorgstjenester. Formålet med forskningsprosjektet er å identifisere helsepersonells kompetanse i personorientert og empatisk kommunikasjon med eldre i hjemmesykepleien, ved radiografiundersøkelse (CT) og ved undersøkelse hos optiker. Vi ønsker å bruke den kunnskapen som kommer fra denne studien slik at bachelorstudenter i sykepleie, radiografi og optometri, helsefagarbeidere og sykepleiere i hjemmesykepleien, radiografer og optikere kan få undervisning om hva som er god kommunikasjon i møte med eldre brukere.

HVORFOR ER DU FORESPURT OM Å DELTA I FORSKNINGSPROSJEKTET?

Du forespørres om å delta i forskningsprosjektet fordi du er helsefagarbeider/sykepleier/optiker/radiograf og jobber med eldre i hjemmebaserte helse- og omsorgtjenester / synsundersøker eldre / CT-undersøker eldre og jobber i Drammen/Ål kommune / har pasienter som kommer fra Drammensregionen / Øvre Hallingdal.

Det er frivillig å delta i forskningsprosjektet.

HVA INNEBÆRER DELTAGELSE FOR DEG?

For å danne et bilde av kommunikasjon ønsker vi at du har på deg en lydopptager når du gjør din vanlige jobb og kommuniserer med eldre. Lydopptakeren må du ha på deg gjennom en arbeidsuke inntil minst 5 pasientmøter med eldre mennesker (>65 år) er tatt opp med lyd. Lydopptageren må være skrudd på under hele pasientmøtet. I tillegg ønsker vi at når du er ferdig med å samle inn lydopptak, svarer på et spørreskjema hvor du skal vurdere dine egne ferdigheter innen kommunikasjon. Hvis du velger å være med, men ombestemmer deg senere, vil lydopptaket og alle andre opplysninger om deg bli slettet så fort du gir oss beskjed. Datafiler som er opprettet med utgangspunkt i lydopptak og spørreskjema, men der ingen opplysninger kan føres tilbake til deg, vil ikke bli slettet. Disse filene inneholder ikke lydopptak eller opplysninger som indirekte kan knytte informasjonen til deg.

HVORDAN SKAL LYDOPPTAKET BRUKES?

Lydfilene vil bli analysert ved bruk av etablerte kodesystemer for å få et bilde av kommunikasjonsutfordringer. Prosjektet er en del av en internasjonal studie, så avidentifiserte data vil bli delt med forskere fra Sverige, Nederland og USA. Samtlige forskere har taushetsplikt. Kommunikasjonen vil også bli analysert i forhold til spesifikke pasientegenskaper som alder, kjønn, sivilstatus, pleiebehov og sykehistorie.

HVA SKJER MED DATAMATERIALET?

Du har rett til å kreve innsyn i all informasjon som handler om deg. Lydopptaket vil kun bli hørt på av forskere med taushetsplikt. Taushetsplikten tillater ikke bruk av informasjonen til noe annet formål, selv ikke om det kunne vært til din fordel (for eksempel i en rettssak). Lydopptaket blir lagret forskriftsmessig ved Høgskolen i Buskerud hvor uvedkommende ikke kan få tak i det.

Det aktuelle prosjektet varer frem til 31.12.2017, men det kan være aktuelt å bruke lydfilene til flere studier av helsepersonells kommunikasjon med eldre brukere. Vi vil derfor be om ditt samtykke til lagring til og med 31.12.2025. Dersom slike tilleggsstudier settes i gang, vil det bli søkt om tillatelse hos aktuelle kontrollorgan for forskning.

Med vennlig hilsen

Hilde Eide	Linda Hafskjold	Vibeke Sundling
Professor, prosjektleder	Stipendiat	Forsker

Kontaktinformasjon:
Hilde Eide: mob 482 43 096, Linda Hafskjold: mob: 950 54 845,
Vibeke Sundling: mob. 924 24 360

ERKLÆRING OM SAMTYKKE – HELSEFAGARBEIDER/SYKEPLEIER/OPTIKER/RADIOGRAF «KOMMUNIKASJON MED ELDRE MED BEHOV FOR HELSETJENESTER»

Jeg har lest skriftlig informasjon og fått muntlig informasjon om undersøkelsen som handler om hvordan kvaliteten på helsefagarbeideres/sykepleiers/optikeres/radiografers kommunikasjon med pasienter kan forbedres. Jeg godtar at det tas lydopptak av min kommunikasjon med pasienter ved hjemmebesøk/synsundersøkelse/CT undersøkelse som del av dette forskningsprosjektet, forutsatt at pasienten har avgitt informert samtykke.

Jeg er kjent med at jeg når som helst kan trekke tilbake mitt samtykke til oppbevaring av lydopptakene. Jeg er videre kjent med at lydopptakene kun vil bli brukt til forskning på kommunikasjon mellom helsepersonell og pasienter.

☐ Jeg gir samtykke til at lydopptakene lagres ved Høgskolen i Buskerud til bruk for forskning på kommunikasjon mellom leger og pasienter til og med 31. desember 2025. Eventuelle nye prosjekter vil bli fremlagt og vurdert av Regional komité for medisinsk forskningsetikk.

☐ Jeg gir kun samtykke til at videoopptakene lagres ved Høgskolen i Buskerud til bruk for det aktuelle prosjektet, det vil si lagring til og med 31.12.2017.

____
Sted/data

Navn: ____

Fødselsdato: ____________________________________

____
Underskrift helsepersonell

PASIENTINFORMASJON FOR FORSKNINGSPROSJEKTET:

«KOMMUNIKASJON MED ELDRE MED BEHOV FOR HELSETJENESTER»

Verdens befolkning blir stadig eldre. I Norden er hver 8. innbygger eldre enn 80 år og andelen antas doblet innen 2040. Norsk helsepolitikk har aktiv og trygg aldring som målsetning. Et viktig aspekt i norsk helsepolitikk er personorienterte helsetjenester, med siktemål om å gjøre det mulig for den enkelte innbygger å bo hjemme så lenge som mulig. Kommunikasjon er en sentral ferdighet for å styrke kvaliteten i personorienterte helse- og omsorgstjenester. Formålet med forskningsprosjektet er å identifisere helsepersonells kompetanse i personorientert og empatisk kommunikasjon med eldre i hjemmesykepleien, ved radiologisk undersøkelse (CT) og ved undersøkelse hos optiker. Vi ønsker å bruke den kunnskapen som kommer fra denne studien slik at bachelorstudenter i sykepleie, radiografi og optometri, helsefagarbeidere og sykepleiere i hjemmesykepleien, radiografer og optikere kan få undervisning om hva som er god kommunikasjon i møte med eldre brukere.

HVORFOR KAN DU BLI FORESPURT OM Å DELTA I FORSKNINGSPROSJEKTET?

Du kan bli forespurt om å delta i forskningsprosjektet fordi du er bruker av hjemmebaserte helse- og omsorgtjenester i Drammen kommune.

Det er frivillig å delta i forskningsprosjektet.

Aktuelt tidsrom hvor du kan bli forespurt er i tidsrommet etter uke 5. Hvis du blir forespurt om å delta og du velger å være med, men ombestemmer deg senere, vil lydopptaket og alle andre opplysninger om deg bli slettet så fort du gir oss beskjed. Dersom du ikke ønsker å bli spurt om å delta i studien, kan du reservere deg mot dette ved å ringe: [*navn og telefonnummer til kontaktperson ved den respektive bydel*]

HVA INNEBÆRER DELTAGELSE FOR DEG?

For å danne et bilde av kommunikasjon ønsker vi at utvalgte besøk fra hjemmesykepleien blir tatt opp med en lydopptaker. Lydopptakeren styres av aktuelle sykepleier/helsefagarbeider og står på under hele besøket. Vi vil også innhente opplysninger om deg som er registret i hjemmesykepleien; alder, om du bor alene, hva du får hjelp til, hvilke medisiner du bruker og hvordan du fungerer i daglige aktiviteter.

HVORDAN SKAL LYDOPPTAK OG INFORMASJON OM DEG BRUKES?

Lydfilene vil bli analysert av forskere som har taushetsplikt. Prosjektet er en del av en internasjonal studie, så avidentifiserte data vil bli delt med forskere fra Sverige, Nederland og USA. Disse forskerne har tilsvarende taushetsplikt. Vi vil bruke forskjellige analysemetoder som har vist seg å være gode for å få et bilde av kommunikasjonsutfordringer. Kommunikasjonen vil også bli analysert i forhold til den bakgrunnsinformasjonen vi har om deg. Lydopptaket vil kun bli hørt på av forskere med taushetsplikt. Taushetsplikten tillater ikke bruk av informasjonen til noe annet formål, selv ikke om det kunne vært til din fordel (for eksempel i en rettssak). Lydopptaket og den andre informasjonen om deg blir lagret forskriftsmessig ved Høgskolen i Buskerud og uvedkommende ikke kan få tak i det.

HVA SKJER MED DATAMATERIALET?

Du har rett til å kreve innsyn i all informasjon som handler om deg. Datafiler blir opprettet med utgangspunkt i lydopptak og opplysninger fra hjemmesykepleien. Når resultater fra studien publiseres i tidsskrifter kan ingen opplysninger føres tilbake til deg. Disse datafilene inneholder ikke lydopptak eller opplysninger som indirekte kan knytte informasjonen til deg. Det aktuelle prosjektet varer frem til 31.12.2017, men det kan være aktuelt å bruke lydfilene til flere studier av helsepersonells kommunikasjon med eldre brukere. Vi vil derfor be om ditt samtykke til lagring til og med 31.12.2025. Dersom slike tilleggs studier settes i gang, vil det bli søkt om tillatelse hos aktuelle kontrollorgan for forskning.

Med vennlig hilsen

Hilde Eide	Linda Hafskjold	Vibeke Sundling
Professor, prosjektleder	Stipendiat	Forsker

Kontaktinformasjon:
Hilde Eide: mob 482 43 096, Linda Hafskjold: mob: 950 54 845, Vibeke Sundling: mob. 924 24 360

PASIENTINFORMASJON FOR FORSKNINGSPROSJEKTET I HJEMMESYKEPLEIEN:
«KOMMUNIKASJON MED ELDRE MED BEHOV FOR HELSETJENESTER»

Vil du delta i et forskningsprosjekt?

Du blir spurt fordi du mottar hjemmesykepleie fra Konnerud omsorgsdistrikt.
Du har tidligere mottatt et mer utfyllende informasjonsskriv.
Her følger en forkortet versjon av dette:

Det er frivillig å delta.

Du får den samme undersøkelse, behandling og medisinsk oppfølging uavhengig av om du deltar i forskningsprosjektet eller ikke.

Hva innebærer deltagelse?

Utvalgte møter med hjemmesykepleien vil bli tatt opp med lydopptaker.
Forskerne får opplysninger fra hjemmesykepleien om deg.
Dette kan ikke knyttes direkte til deg gjennom navn eller personnummer.
Opplysninger som samles inn er: alder, om du bor alene, hva du får hjelp til, hvilke medisiner du bruker og hvordan du fungerer i daglige aktiviteter.

Prosjektet er en del av en internasjonal studie. Forskere som deltar er fra Norge, Nederland, Sverige og USA.

Du har rett til å kreve innsyn i all informasjon som handler om deg.

All informasjon knyttet til forskningsprosjektet vil bli oppbevart og behandlet i henhold til lover og regler. Alle forskerne har taushetsplikt.

Det aktuelle prosjektet avsluttes til 31.12.2017, men det kan være aktuelt å bruke opptaket til flere studier av kommunikasjon mellom pasienter og helsepersonell. Vi vil derfor be om ditt samtykke til lagring til og med 31. desember 2025, men du kan også velge kun å samtykke til lagring til og med 31. desember 2017.

Følgende person er ansvarlig for databehandling i prosjektet og kontaktperson:
Professor Hilde Eide, Høgskolen i Buskerud og Vestfold, mobil: 482 43 096

Navn og kontaktopplysninger på to andre kontaktpersoner:
Førsteamanuensis/optiker Vibeke Sundling, Høgskolen i Buskerud og Vestfold, mobil: 924 24 360

Stipendiat/radiograf Linda Hafskjold, Høgskolen i Buskerud og Vestfold,
mobil: 950 54 845

Erklæring om samtykke

Jeg har mottatt skriftlig og muntlig informasjon om forskningsprosjektet «Kommunikasjon med eldre med behov for helsetjenester»

☐ Jeg gir samtykke til at opplysninger om meg, inkludert lydopptak lagres ved Høgskolen i Buskerud og Vestfold til bruk i forskning på kommunikasjon mellom sykepleiere/hjelpepleiere/optikere/radiografer og pasienter til og med **31.12.2025**

☐ Jeg gir kun samtykke til at opplysninger om meg, inkludert lydopptak, lagres ved Høgskolen i Buskerud og Vestfold til bruk for dette prosjektet, det vi si til og med **31.12.2017**

____

Sted/dato

____

Navn med blokkbokstaver på pasient

____

Underskrift pasient

Jeg har gitt muntlig informasjon om forskningsprosjektet til pasienten

____

Underskrift helsefagarbeider/sykepleier

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	**Saksbehandler:**	**Telefon:**	**Vår dato:**	**Vår referanse:**
REK sør-øst	Jakob Elster	22845530	11.10.2013	2013/1626/REK sør-øst B
			Deres dato:	**Deres referanse:**
			27.08.2013	

Vår referanse må oppgis ved alle henvendelser

Til Hilde Eide

2013/1626 Kommunikasjon med eldre delstudie 2. Kommunikasjon i hjemmesykepleien

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK sør-øst) i møtet 18.09.2013. Vurderingen er gjort med hjemmel i helseforskningsloven § 10, jf. forskningsetikklovens § 4.

Forskningsansvarlig: Høgskolen i Buskerud
Prosjektleder: Hilde Eide

Prosjektomtale (revidert av REK):
Prosjektet er et delprosjekt i en studie som har som formål å utvikle, teste og implementere et online opplæringsprogram i kommunikasjon for helsepersonell som arbeider med eldre. Utdanningsprogrammet skal utarbeides på basis av tre delprosjekter. Det første skal analysere video-opptak fra konsultasjoner mellom lege og pasient på sykehus. I dette delprosjektet vil det bli satt spesifikt fokus på nonverbal kommunikasjon. Det andre delprosjektet skal analysere lydopptak fra hjemmesykepleien. Det tredje delprosjektet skal se på hvordan selve kommunikasjonsutdanningen skal tilrettelegges for de ulike målgruppene. Programmet skal kunne brukes på forskjellige utdanningsnivåer og være lett tilgjengelig for alle.

Det er det andre delprosjektet det nå søkes om godkjenning for. Målpopulasjonen for studien er hjemmeboende eldre (>65år) som har behov for helsetjenester og helsepersonell som yter helse- og omsorgtjenester til eldre. Totalt vil 20 sykepleiere, 20 helsefagarbeidere, 10 radiografer og 10 optikere bli inkludert i studien. Det vil bli samlet inn lydopptak fra 5 pasientmøter med eldre mennesker (>65 år) for det enkelte helsepersonell.Man skal dermed inkludere 200 pasienter i hjemmesykepleien, 50 som skal til CT undersøkelse og 50 som undersøkes hos optiker. Lydfilene vil bli analysert med ulike kodings- og analysesystemer. Kommunikasjonen vil også bli analysert statistisk i forhold til spesifikke pasientegenskaper som alder, kjønn, sivilstatus, pleiebehov og sykehistorie. I tillegg vil kommunikasjon i et utvalg av pasientmøter bli transkribert til tekst analysert kvalitativt ved kritisk diskursanalyse for å undersøke blant annet maktaspekter i samtalen.

Vurdering

Formålet med prosjektet er å identifisere helsepersonells kompetanse i personorientert og empatisk kommunikasjon med eldre. Videre skal man identifisere og sammenligne kommunikasjonsmønstre internasjonalt, identifisere spesielle trekk ved kommunikasjon for sykepleiere og helsefagarbeidere og sammenligne kommunikasjon med kvinnelige og mannlige eldre for å avdekke kjønnsrelaterte forskjeller i kommunikasjonsmønstre og strategier.

I lys av denne beskrivelsen av prosjektets formål, anser komiteen at dette prosjektet ikke har som formål å fremskaffe ny kunnskap om helse og sykdom. Prosjektet faller dermed utenfor helseforskningslovens virkeområde. For å gjennomføre prosjekter av denne typen, trenges det ingen særskilt godkjenning fra REK.

Vedtak

Prosjektet faller utenfor komiteens mandat, jf. helseforskningslovens § 2.

Komiteens avgjørelse var enstemmig.

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningslovens § 28 flg. Klagen sendes til REK sør-øst. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK sør-øst, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

Grete Dyb
førsteamanuensis dr. med.
leder REK sør-øst B

Jakob Elster
Seniorrådgiver

Kopi til:
Høgskolen i Buskerud ved øverste administrative ledelse
Heidi Kapstad ved HiBu

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

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Fax +47-55 58 96 50
nsd@nsd.uib.no
www.nsd.uib.no
Org.nr. 985 321 884

Linda Hafskjold
Institutt for sykepleievitenskap Høgskolen i Buskerud
PO Box 7053
3007 DRAMMEN

Vår dato: 27.11.2013 Vår ref: 36017 / 2 / AMS Deres dato: Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 23.10.2013. Meldingen gjelder prosjektet:

36017	*Kommunikasjon med eldre delstudie 2. Kommunikasjon i hjemmesykepleien*
Behandlingsansvarlig	*Høgskolen i Buskerud, ved institusjonens øverste leder*
Daglig ansvarlig	*Linda Hafskjold*

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/meldeplikt/skjema.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://pvo.nsd.no/prosjekt.

Personvernombudet vil ved prosjektets avslutning, 31.12.2017, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Vigdis Namtvedt Kvalheim

Anne-Mette Somby

Kontaktperson: Anne-Mette Somby tlf: 55 58 24 10
Vedlegg: Prosjektvurdering