

Home care communication – moving beyond the surface

Jessica Högländer



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HOME CARE COMMUNICATION

MOVING BEYOND THE SURFACE

Jessica Högländer

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School of Health, Care and Social Welfare

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Jessica Högländer

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Abstract

Communication is an essential part of care and human interaction. While communication within care entails both task-focused and socio-emotional elements, nurses are sometimes perceived as too task-focused. When in need of care, older persons want to be perceived and treated as individuals – to feel involved. However, nurses might lack the prerequisites for establishing individualised home care, which is often based on daily tasks rather than on older persons' needs and wishes. Despite the importance of communication in nurse-patient interactions, knowledge about daily communication within home care is scarce. Therefore, the overall aim of this thesis was to explore the naturally occurring communication between nursing staff and older persons during home care visits, with a focus on emotional distress and from a person-centred perspective.

This thesis is an observational, cross-sectional study of the communication in 188 audio-recorded home care visits, and is part of the international COMHOME project. In Study I, older persons' expressions of emotional distress were coded and analysed using the Verona Coding Definitions of Emotional Sequences [VR-CoDES]. The results showed that older persons often express emotional distress in the form of hints at emotional concerns, which were defined as cues. Explicit expressions of emotional distress, which were defined as concerns, were uncommon. The responses of nursing staff to older persons' cues and concerns were coded and analysed in Study II using VR-CoDES. Nursing staff often responded by providing space rather than reducing it for further disclosure of older persons' emotional distress. In Study III, the communication of emotional distress and participants' characteristics were analysed using generalised linear mixed model [GLMM]. The results revealed that most cues and concerns were expressed by older females and to female nursing staff. Furthermore, elicitations of expressions of emotional distress were influenced by native language and profession, and responses that provided space were more often given to older females and to older persons aged 65-84 years. Home care communication between registered nurses and older persons was coded and analysed in Study IV using the Roter Interaction Analysis System [RIAS]. The results revealed a high degree of person-centred communication, especially during visits lasting 8-9 minutes, and that socio-emotional communication was more frequent than task-oriented communication.

Home care communication contains important aspects of person-centred communication, with nursing staff providing space for the older person's narrative; however, there are also challenges in the form of vague and implicit expressions of emotional distress.

Keywords: communication; home care services; nursing staff; older persons; person-centred care; RIAS; VR-CoDES

He feels isolated in the midst of friends. He feels what a convenience it would be, if there were any single person to whom he could speak simply and openly, without pulling the string upon himself of this shower-bath of silly hopes and encouragements; to whom he could express his wishes and directions without that person persisting in saying, "I hope that it will please God yet to give you twenty years," or, "You have a long life of activity before you."

(Nightingale, 1860/2017, pp. 98)

*To my beloved husband and daughters, without whom
I would never have reached the end of this journey*

List of Papers

The following papers, referred to in the text by their Roman numerals, constitute this thesis:

- I Sundler, A.J., Högländer, J., Håkansson Eklund, J., Eide, H., & Holmström, I.K. (2017). 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. *Patient Education and Counselling*, 100(2), 276-282.
- II Högländer, J., Håkansson Eklund, J., Eide, H., Holmström, I.K., & Sundler, A.J. (2017). Registered nurses' and nurse assistants' responses to older persons' expressions of emotional needs in home care. *Journal of Advanced Nursing*, 73(12), 2923-2932.
- III Högländer, J., Sundler, A.J., Spreeuwenberg, P., Holmström, I.K., Eide, H., van Dulmen, S., & Håkansson Eklund, J. (2019). Emotional communication with older people: A cross-sectional study of home care. (*Accepted for publication in Nursing & Health Sciences*).
- IV Högländer, J., Håkansson Eklund, J., Spreeuwenberg, P., Eide, H., Sundler, A.J., Roter, D., & Holmström, I.K. (n.d.). A positive tone and socio-emotional talk: Exploring person-centered aspects of home care communication. (*In manuscript*).

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Abbreviations

GLMM = Generalised linear mixed model

NA = Nurse assistant

RIAS = Roter Interaction Analysis System

RN = Registered nurse

VR-CoDES = Verona Coding Definitions of Emotional Sequences

Prologue

I was standing beside the bed, and the older woman in it smiled anxiously at me. I still remember this moment quite clearly: my own communication wake-up call. She wanted to talk to me but was afraid to disturb me, because we all seemed to have so much to do; and she was right. Outside the open door everyone was rushing up and down the corridor, going somewhere they needed to be. A usual day at the ward. The older woman had pushed the alarm button, like any other patient, and here I was answering her call. Nevertheless, as I stood there waiting to hear what she needed of me, she hesitated. She apologised for taking my time: ‘You all have so many other things to do, more important things’. I told her I was there for her, that I had time for her, and still she was reluctant to talk with me. She kept apologising, something that inevitably took time, never telling me what was bothering her, the reason I was standing there, waiting. Finally, it hit me: my body language. The non-verbal words my body was telling her; what my verbal words, saying the opposite and trying to comfort her, could not silence – I was short of time. Standing next to the door, a few feet from her bed, almost as if I had not yet entered the room, I was already on my way out. I felt ashamed for telling her she wasn’t bothering me at all, that I had time for her, all the while gesturing something else. I took a chair and sat down beside her bed, looked at her and said ‘I do have time; tell me’. This example illustrates that communication is not easy. We might believe we take the time and respond in a way we intend to, and that we know what is expected of us. This is not always the case, however. Sometimes the organisation, our routines, or our resources can hinder us; sometimes, the obstacle to communication is ourselves.

1 Introduction

Many older persons wish to stay in their homes as long as possible, even when their health declines and they need home care. For some older persons, home care visits represent more than simply being cared for or receiving help. The nurses become someone they can talk to. Communication in home care often takes place on a daily and regular basis, in the context of older persons' own homes. Communication is essential, not only in terms of information exchange but also for social interaction and building relationships. However, nurses can experience challenges, such as responding to emotional or existential concerns (Ministry of Health and Social Affairs, 2017; Sundler, Eide, van Dulmen, & Holmström, 2016) or lacking prerequisites, such as time, for establishing good communication (Pejner, Ziegert, & Kihlgren, 2012). This is troublesome, since communication is regarded as central in nursing practice (Casey & Wallis, 2011) and nurses are expected to communicate and interact in a good way (Anderberg, Lepp, Berglund, & Segesten, 2007; McCabe, 2004). Failing communication has been found to make older persons feel insecure and lonely (Svanström, Johansson Sundler, Berglund, & Westin, 2013).

Home care is not to be viewed as an extension of hospital care; the two care contexts are different. The care at hospitals is described as centred on the healthcare work, and is designed accordingly. Home care is centred around the needs of the individual and their family (Roush & Cox, 2000). Based on these differences, home care communication is also likely to differ from previously more explored communication in other forms of care settings, such as hospital and primary care. At present, little is known about the communication in home care, as this is still a limited area of research. This thesis focuses on the naturally occurring communication in home care while exploring socio-emotional and person-centred aspects in the communication.

In this thesis, the term *older person* will be used when referring to persons 65 years and older. The term *patient* refers more generally to persons in need of healthcare (which also includes older persons, but not primarily in a home care context). *Nurse* or *nursing staff* is used when referring to different types of nurses. Otherwise, more specific terms such as *registered nurse* or *nurse assistant* are used. *Healthcare provider* is a broader term entailing different forms of professionals within healthcare, such as nurses and physicians. *Home care* refers to the care performed in older persons' own homes, which in this thesis consists of houses or apartments, or assisted living facilities where the

older person lives in their own apartment in the facility – in Swedish, ‘servicehus’.

The research in this thesis is part of the international research programme COMHOME (Hafskjold et al., 2015), and was conducted within the research field of Health and Welfare at Mälardalen University.

1.1 Communication as interaction and behaviour

Communication is an interaction between the nursing staff and older persons in home care. In order to describe communication as an interaction, Watzlawick et al. (1967/2014) provide a pragmatic introduction to describe the phenomenon of human communication. The communication theory entails five axioms for communication, based on behavioural and relational aspects of interpersonal communication. Interpersonal communication is described as behaviour – how people in the interaction behave and therefore communicate with each other, regardless of whether or not this is their intention. Communication as behaviour can also be viewed as feedback loops, whereby each person’s behaviour affects and is affected by others’ behaviour (Watzlawick, Bavelas, & Jackson, 1967/2014). Communication is therefore described as a reciprocal process, in which all persons involved in the communication act and react, receiving and sending messages in the communication through an interpersonal relation. Communication is therefore not merely a sender-receiver relation, but is dyadic. In a dyadic, in-person communication, the exchanged cues originate directly from verbal or non-verbal communication, or from the context in which it occurs. Therefore, all behaviour is communication (Watzlawick & Beavin, 1967).

The first axiom is behaviour, or more exactly: non-behaviour. This axiom is about how a human cannot *not* behave, i.e. communicate. All behaviour in an interaction has a message. Therefore, humans are always communicating and reacting to others’ behaviour, while the communication is not always intentional or successful; the message sent is not always equal to the message received (Watzlawick et al., 1967/2014).

The second axiom describes how all communication implies a commitment that defines the relationship. The message in communication contains both content (i.e. the information of the message) and a command (i.e. the relationship between the communicators). The command is further referred to as ‘meta-information’ and implies that the command, i.e. relationship, defines how the information, i.e. content, should be taken. Therefore, the relationship is more clearly understood in relation to the context in which the communication occurs (Watzlawick et al., 1967/2014).

The third axiom entails the interaction – how it is structured in the exchange of messages between communicators. A message contains punctuations (groups) that construct the communication sequences and organise the behaviour in the interaction. Disagreements in the punctuations can influence the relationship and cause misunderstandings in the communication (Watzlawick et al., 1967/2014).

The fourth axiom describes communication as digital and analogical, referring to verbal and non-verbal communication. The digital (i.e. verbal) and analogical (i.e. non-verbal) communication complement each other, but the analogical is described as the behaviour that defines the relationship of the interaction. Expressions of sincerity and insincerity are therefore easier to detect in the analogical than the digital communication (Watzlawick et al., 1967/2014).

The fifth axiom outlines the interaction as either symmetrical or complementary. Symmetrical entails an interaction that is equal, with the persons mirroring each other's behaviours in order to maintain equality. In the complementary interaction, the behaviours complement each other through maximised difference, with one being superior or inferior to the other. The fifth axiom does not attempt to refer to the behaviours as strong/weak or good/bad, but as set by social or cultural contexts; for example, interaction behaviour between mother and child or teacher and student (Watzlawick et al., 1967/2014).

These five axioms are intended to help in the apprehension of how nursing staff and older persons interact and behave in the communication, as a response to each other's behaviours.

1.2 Communication in healthcare

Communication is understood as dyadic, going beyond the sender-receiver message and affected by the persons involved in the interaction. In care interactions, communication is central and is regarded as a core principle for nursing practice (Casey & Wallis, 2011). The communication is often multifaceted, with different purposes for the care interactions. This entails a communication that often contains both task-focused and socio-emotional/affective elements, both considered important parts of the communication (Caris-Verhallen, Kerkstra, van der Heijden, & Bensing, 1998). However, nurses are sometimes perceived as primarily focused on their practical task (McCabe, 2004). In home care, an overly task-focused approach entails an increased risk of narrowing the home care services to practical issues and not detecting or attending to the health complaints or social needs of the older person (Karlsson, Edberg, & Hallberg, 2010). An overly task-focused communication would not fully capture the older person's needs and wishes in a home

care setting in which social communication is a central part of the interaction. Social communication helps in connecting to the older person's everyday life and what constitutes them as a person (Kristensen et al., 2017; Spiers, 2002).

Within nursing, the concept of effective communication is described as essential to nursing communication and as a way to communicate effectively to actively meet the needs of the patient (Casey & Wallis, 2011). Effective communication is further described as highly skilled communication in which nurses need to find strategies to adjust and support the communication to meet the communicational needs of the patient (Daly, 2017). Knowing how to communicate in an 'effective' way may be difficult, and it is not always obvious what type of communication a given situation requires of the nurses. But, the way nurses communicate affects the patient's experience of the communication. The feeling of involvement and mutual understanding is further described as important for the experience of satisfaction with the communication (Fossum & Arborelius, 2004). The notion that nurses understand their patient's situation and care about them as persons can be reflected through an empathic and sympathetic communication, and help patients experience that their feelings are justified. Feeling justified and understood can further alleviate anxiety and ambiguous feelings (McCabe, 2004). In order to achieve this, nurses need to show genuine behaviour in the communication. Genuineness is shown through both verbal and non-verbal communication, of which the non-verbal is the most valued for indicating genuineness (McCabe, 2004).

Communication is further described as a cornerstone in establishing a person-centred care (Kourkouta & Papathanasiou, 2014; Ministry of Health and Social Affairs, 2017), but is endangered by the influence of stereotypes. For instance, females' and males' communication can be perceived differently based on gender stereotypes (Mast & Kadji, 2018), but ageist assumptions also exist (Nemmers, 2005; Schroyen et al., 2017). These assumptions or stereotypes can lead to an objectification of the person, which hinders nurses in getting to know the person they are caring for. In the long run, this can lead to a care that is not based on or adapted to the needs of the person but is rather based on the nurses' assumptions. The risk of preconceptions and stereotypes is not a new phenomenon within nursing communication. Florence Nightingale made similar reflections in the mid-19th century, regarding the dangers when physicians or nurses in their communication ignore individual differences and fail to view their patients as unique individuals (Nightingale, 1860/2017). Nightingale called it the absurd statistical comparisons made in common conversation by the most sensible people for the benefit of the sick:

I have heard a doctor condemned whose patient did not, alas! recover, because another doctor's patient of a different sex, of a different age, recovered from a different disease, in a different place. Yes, this is really true. [...] It does not seem necessary to say that there can be no comparison between old men with dropsies and young women with consumptions. Yet the cleverest men and the

cleverest women are often heard making such comparisons, ignoring entirely sex, age, disease, place – in fact, all the conditions essential to the question. It is the merest gossip (Nightingale, 1860/2017, pp. 97-98).

Communication with a person-centred approach can help in avoiding generalisation, and can capture individual needs and contribute to health outcomes. Person-centred communication has been reported to be beneficial within different care contexts (Storlie, 2015; van Dulmen, 2011), and can help in avoiding the risk of viewing nurses or older persons as a homogenous group and instead viewing them as persons with unique needs and diversities (Daly, 2017).

1.3 Person-centred care and communication

There has been a power shift in healthcare: from a paternalistic and biomedical view, in which it was expected that healthcare providers' decisions and instructions were followed, to a holistic view that involves the patient in a partnership, participating as a co-producer of their own care (Taylor, 2009). One of the first to perceive the importance of placing the person at the centre of the care was the American psychologist Carl Rogers with his client-centred therapy; his book *On Becoming a Person* was published in 1961. In 1969 the concept of patient-centred medicine was introduced (Holmström & Röing, 2010), and in 1978 the Declaration of Alma-Ata declared that people should participate in planning and implementing their own care (World Health Organization, 1978). Since then the concept of patient-centredness has continued to develop, later followed by person-centred care, emphasising a need to involve patients as companions and equal experts when planning and implementing their care.

When caring for older persons, the concept of person-centred care is used to describe a care that focuses on these persons' needs and values (Kirkevold, 2010). This comprises a holistic view of a unique person (McCormack, 2003), and is described as fundamental in nursing (Manley, Hills, & Marriot, 2011). Sometimes the word person is used synonymously with words like patient, family or client, often depending on the context, and these share many similarities (Castro, Van Regenmortel, Vanhaecht, Sermeus, & Van Hecke, 2016; Coyne, Holmström, & Söderbäck, 2018; Håkansson Eklund et al., 2019; Morgan & Yoder, 2011). The two concepts of person- and patient-centredness are often used interchangeably, and share common attributes that are central to the concepts. These include empathy, respect, engagement, relationship, communication, shared decision-making, holistic focus, individualised focus, and coordinated care (Håkansson Eklund et al., 2019). Since the two concepts share many similarities and are often used interchangeably, the question is whether there really are any differences between them. A difference between

the concepts can be found on a deeper level – in the goals of the care. The goal of patient-centred care is for the patient to live a functional life, while that of person-centred care is for the patient, or person, to live a meaningful life (Håkansson Eklund et al., 2019).

In this thesis, person-centredness will be used instead of patient-centredness to emphasise the need to view the older person in a broader perspective – as a whole, with the aim that they should live a meaningful life. One argument for using person-centredness is that the concept captures the person; not focusing on them as a patient but rather on the person behind the patient (Edvardsson, Fetherstonhaugh, & Nay, 2010). The concept of person-centredness is further argued to decrease the risk of reducing the patient to merely a receiver of care or an object (Ekman et al., 2011).

Establishing a person-centred care does not merely require a person-centred approach by the healthcare providers. In order to establish a person-centred care, organisations need to change and create a person-centred culture; this would entail that person-centredness is implemented throughout the organisation. This would allow the organisation to *become* person-centred and support the healthcare providers in communicating and working together in a person-centred way. Thus, a person-centred culture is described as central in developing a care that is truly person-centred (Lindström Kjellberg & Hök, 2014; McCormack, van Dulmen, Eide, Skovdahl, & Eide, 2017).

In a person-centred care, the person's own narrative and story are essential for gaining access to their history, beliefs, knowledge, perception, and experiences (McCormack, 2003). In order to obtain the person's story, active listening is central (Motschnig & Nykl, 2014). Another important aspect is to balance the power in the relationship; to establish a companionship in which the patient is treated as someone of value, supporting their autonomy and recognising their individual needs and identities (Skea, MacLennan, Entwistle, & N'Dow, 2014), as someone who is equal. This entails acknowledging the other as a person and striving to perceive and understand the situation from their perspective – to get to know the person by establishing a relationship in which they feel accepted and begin to feel safe enough to reveal themselves – to become a person (Rogers, 1961/1995).

The nurse-patient relationship therefore needs to be built on an understanding and a recognition of the person's beliefs and values, building the relationship on mutual trust, understanding, and a sharing of collective knowledge and responsibility. Therefore, a common notion within person-centredness is to acknowledge the person as someone who is capable; someone who is able to make rational decisions and take responsibility for their decisions, with a right to self-determination. However, this also sometimes requires protecting persons from the harmful consequences of their own choices in order to preserve their wellbeing (McCormack, 2003). The importance of a person's narratives

and establishing relationships is not only central to person-centred communication, but also to a caring conversation that can help reveal and relieve suffering.

1.4 Caring conversation

Gaining access to a person's narrative and revealing their needs and worries can be difficult and take time, but can have an impact on the experience of health. In the theory of caring conversation, Fredriksson (2003) describes how important communication is for lending substance to and establishing a caring conversation that can alleviate suffering. Thus, caring conversation helps illuminate and explore how older persons reveal their suffering in terms of emotional distress. Caring conversation can also help in the apprehension of why communication about emotional distress should be considered important for older persons' experience of health.

Caring conversation theory consists of three main aspects: the narrative, the relationship, and the ethics. The narrative aspect contains the façade, and is described as a story. The patient constructs the façade in order to hide their suffering from others, but also from themselves. The façade offers protection from shame, caused by negative feelings of not being wanted or loved. The theory's relational aspect entails the presence of the nurse. This presence consists of listening, touching, and being with the patient, and inviting them to share their world with the nurse. The relationship is therefore described as a shift from contact to connection between nurse and patient, a turning point at which the façade starts to wither and the person becomes visible. The relationship is described as asymmetrical at first, and risks becoming unethical if it lacks mutuality. Mutuality entails a shared respect, articulated by the nurse's compassion and their waiting for an invitation to share in the patient's suffering. In the ethical aspect of caring conversation, the façade comes to be questioned and perceived as concealing (Fredriksson, 2003).

The patient experiences a turning point, when the façade can no longer be sustained and the suffering is unbearable, and asks for help to alleviate the suffering. At this point, it becomes imperative that the patient be taken seriously and receive support in narrating their suffering, and that the nurse show respect, compassion, and a willingness to help. Otherwise, the façade is validated and the patient continues to suffer (Fredriksson, 2003).

When the façade diminishes, the patient's life starts to become visible, together with their historical events and their desires in life and for the future. This gives a *why* question, which can create meaning in the suffering by revealing historical and future events as well as hindrances to wishes, which can cause suffering. In helping patients understand their experiences, actions or

events, meaning can be gleaned from the suffering. It can be perceived as difficult to narrate suffering. Nurses need to be sensitive, and help the patient narrate and feel capable of authority and autonomy (Fredriksson, 2003).

In the last phase of caring conversation, the façade has faded and genuine communication can become possible, whereby the meaning-of-suffering as well as the meaning-in-suffering is reflected. This process becomes possible through the relationship, built on a secure foundation and transformed from a nurse-patient relationship to being humans amongst all others. The asymmetry has now changed through the patient's restored autonomy (Fredriksson, 2003). A caring conversation can therefore be of help to older persons in relieving suffering in the form of emotional distress.

1.5 Emotions as a part of the caring interaction

Emotional distress may impact on older persons' experience of health. As people grow older, perceptions about life and their own existence are inevitable. Facing older persons' thoughts and emotions about life and death can be challenging. Sometimes, older persons are vague when expressing their concerns or existential worries, which in turn necessitates active listening and knowledge on the part of the healthcare providers in order to provide emotional support (Ministry of Health and Social Affairs, 2017).

Ekman (1992) describes six basic emotions, all of which contain variations. The basic emotions, which are considered universal, are fear, sadness, anger, happiness/enjoyment, disgust, and surprise. Emotions are often automatic and unbidden (Ekman, 1992), and occur in situations of relevance or importance for a person's goals. Emotions can be defined by how a person feels (e.g. afraid, sad, happy), what they express (e.g. smile, sigh, cry), or physiological changes in their body, for example their heart rate (Urry & Gross, 2010). It is not uncommon for older persons to experience worries, sadness, anxiety and loneliness, and the prevalence of negative emotions has been revealed to be higher in older than in younger persons (Ministry of Health and Social Affairs, 2017).

When emotions arise unbidden, they can be unwelcome or uncomfortable, which can result in the avoidance or regulation of certain emotions. Emotions can to some degree be regulated, as a person may try to think of something else, avoid situations that can trigger certain emotions, or modulate the emotional response (Urry & Gross, 2010). The ability to regulate one's emotions is important, and this ability is also connected to the experience of health (Suri & Gross, 2012). With increasing age, age-related changes can be found concerning the experience, expression, and control of emotions. Older persons have been found to exhibit lower-intensity, and fewer, expressions of emotions as well as greater emotional control (Gross et al., 1997). Further, older

persons are perceived to experience fewer negative and more positive emotions (Gross et al., 1997; Richter, Dietzel, & Kunzmann, 2011; Urry & Gross, 2010). Of course, these age-related differences are not universal for all older persons, as personal or contextual differences further affect the experience and expression of emotions (Isaacowitz, Livingstone, & Castro, 2017). An awareness of these differences regarding emotions is important; otherwise, emotional expressions may be lost in the communication.

Older persons express the wishes and needs that are important to them through their communication (Pejner, Ziegert, & Kihlgren, 2015). Being attentive to emotional expressions in the communication is central in providing emotional support. Nurses describe emotional support as essential, and as a part of their professional skills (Pejner et al., 2012). Providing emotional support is necessary when caring for older persons. With older age and/or disease and disabilities, older persons can experience difficulties managing their emotions themselves. Therefore, the possibility to talk about their emotions is considered important (Pejner et al., 2015). When older persons need emotional support they often turn to their family, but not always; sometimes they do not want to involve their social network, for example when a topic is too emotional. Instead, they turn to nurses for support and to hand over their emotions to someone (Pejner et al., 2015). With increasing age one's social network can become thinner (Nicholson, Meyer, Flatley, & Holman, 2013), which may be another reason why older persons turn to their nurses for emotional support.

It can be difficult for nurses to provide emotional support. Often, they do not know what to expect or how to respond when facing older persons' existential or emotional needs (Sundler et al., 2016). Furthermore, it can also be challenging to know how to offer support or assess when emotional support is needed. For example, the nature of emotions can be difficult to judge (Street, Makoul, Arora, & Epstein, 2009); and some emotions are harder than others to handle, such as anger (Devik, Enmarker, & Hellzen, 2013; Sheldon, Barrett, & Ellington, 2006). It can also be difficult for nurses to describe what emotional support they provide, as emotional support is sometimes offered without reflection. When the provision of emotional support becomes challenging, nurses can feel helpless, with an increased risk that they will start avoiding older persons' emotions (Pejner et al., 2012).

Reasons for the challenges involved in providing emotional support include when nurses experience insufficient preconditions – e.g. time or knowledge – for talking about emotions and providing emotional support. Nonetheless, it is perceived as important to help older persons talk about their emotions. Otherwise, unsettled emotions can risk becoming obstacles and impact on how older persons manage their everyday life (Pejner et al., 2012). Communication in home care therefore plays a central role in alleviating emotional distress and suffering, by providing emotional support for older persons.

1.6 Home care from a health and welfare perspective

The ageing population is increasing in Sweden as well as internationally. In many countries, the ageing population is expected to have doubled by 2050, and the need to respond to older persons' experiences and needs has been stressed as important in order to maintain their health (World Health Organization, 2015). What is regarded as health is not easy to define, and the concept has a number of different definitions. One is 'Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (World Health Organization, 1946, pp. 100). This definition has been criticised for only being applicable to a very few, as the conditions for experiencing health are quite high and hard to attain (Sandman & Kjellström, 2018). Another way to define health is to categorize it into either a holistic or biomedical perspective. A holistic perspective of health comprises the whole human being and their own experience of health. In the biomedical perspective the human is viewed according to their biological parts, e.g. organs (Nordenfelt, 2004), and health is often defined as the absence of disease or illness (Brülde & Tengland, 2003). To avoid limiting older persons to merely their biological or medical needs, to only what can be seen or measured, a holistic perspective of health is needed. Otherwise, a reductionist description of health risks reducing a person's whole experience of health into the 'health' of their bodily parts, rather than perceiving them as a whole – as a person.

Health is considered an important aspect of life and welfare for all people. Society invests resources in countering ill-health and its consequences through the Swedish healthcare system or welfare support, such as social insurance. Welfare can be viewed as resources that help people manage and control their living conditions (Ministry of Health and Social Affairs, 2001b). Furthermore, welfare contributes to the experience of a good life, and has the purpose of maintaining a good life throughout people's lifecycle (Cedersund & Brunberg, 2013; Hort, 2014).

Ageing in place has long influenced Swedish policies and the Swedish welfare of older persons. The aims entail older persons being able to continue living in ordinary housing with sufficient support for a longer time before moving to sheltered houses for the aged (Henning, Åhnby, & Österström, 2009). In order to be able to remain at home, the older population needs to have the possibility to participate in and influence their living conditions, and to maintain a high level of integrity and self-determination (The National Board of Health and Welfare, 2013). Therefore, social services ought to provide for older persons to live an active, meaningful, and independent life based on their prerequisites and wishes – to experience wellbeing under secure circumstances and in community with others. Furthermore, older persons should have opportunities for good housing, as well as help and support in their homes and other accessible services (Ministry of Health and Social Affairs, 2001a).

After a period of decrease, the number of older persons with home care and social services is now increasing in Sweden (The National Board of Health and Welfare, 2018). The increasing numbers of older persons in Swedish society, together with longer life expectancy, are expected to challenge the capacity of the healthcare and welfare systems to meet the needs of the growing older population. This is due to the decreasing health and functional status that comes with older age (The Public Health Agency of Sweden, 2010), which has an impact on older persons' need of health- and social care (Government Offices of Sweden, 2010).

Home care has been described in the literature since the early 20th century, but over time has changed in its moral ideals and content (Peter, 2002). Home care is part of the welfare system in Sweden, and older persons can apply for it when they begin needing help maintaining their life at home. The home care service is based on the older person's capabilities and criteria for receiving home care (Barrett, Hale, & Gauld, 2011; Olaison & Cedersund, 2006). With home care, older persons receive support in living independently and maintaining the possibility to remain in their own home despite declining health (Engelhardt & Greenhalgh-Stanley, 2010). Therefore, home care comprises a wide range of activities, from help with daily living to medical care, depending on the older person's needs (Moe, Hellzen, & Enmarker, 2013).

1.7 Home care of older persons

The need of care and help in everyday life increases as people grow older, since growing older often involves adversity and constraints. With increasing age, older persons experience physical, psychological and social losses, to which they adapt to varying degrees depending on their own capacity (Barrett et al., 2011; Nicholson et al., 2013). As people age and their life changes, the feeling of familiarity becomes essential. The feeling of home is valued, and older persons describe their home as a place that gives them comfort, familiarity (Board & McCormack, 2018; Roush & Cox, 2000), and a sense of security (Borglin, Edberg, & Rahm Hallberg, 2005). This sometimes results in a wish to remain at home as long as possible (Harrefors, Sävenstedt, & Axelsson, 2009), to be able to live in a well-known and familiar environment. The possibility to stay in a familiar environment can further be connected to the experience of autonomy and quality of life for older persons (Borglin et al., 2005). With age-related constraints and adversity, it can become a challenge to maintain the ability to stay at home. Older persons' strive to remain at home often involves an adaption to ageing and declining health, negotiating what they can manage themselves and what can be handed over to others (Fänge & Ivanoff, 2009). Providing home care is therefore not only significant

in terms of need of care, but can also impact on an older person's experience of autonomy and quality of life.

1.7.1 Home care from older persons' perspectives

As previously described, the home can represent a safe place for rest and recovery, and is considered important for the experience of health (Fänge & Ivanoff, 2009). However, when receiving home care, the older person's home also becomes an arena of care. This risks diminishing older persons' opportunities to make decisions, when the private home also becomes the nurses' workplace (Öresland, Määttä, Norberg, & Lützén, 2011). Home care is also criticised for being standardised, a package, not based on individual needs (Olaison & Cedersund, 2006; Vik & Eide, 2013) but organisationally driven with a focus on the daily activities, based on older persons' physical needs and performed following routines (Turjamaa, Hartikainen, Kangasniemi, & Pietilä, 2014). An individually designed home care is emphasised for older persons' possibility to remain at home and to enhance their satisfaction with the home care they receive (Turjamaa et al., 2014).

Receiving home care that caters for the older person's needs can result in higher levels of life satisfaction and less loneliness (Kadowaki, Wister, & Chappell, 2014). Receiving home care does not merely represent being cared for or receiving help, but also includes an opportunity to have someone to talk to (Nicholson et al., 2013). Older persons, particularly those who live alone, value social interaction, especially when the nurse has a moment to sit down and talk (Holmberg, Valmari, & Lundgren, 2012).

Relationships are built through the daily interactions, and it is through the relationship with the nurses that older persons find opportunities to express personal and/or confidential information. Trust, shared decision-making, and mutual communication are emphasised as central aspects in establishing relationships in which older persons feel comfortable to share their information with the nurses (Turjamaa et al., 2014). Older persons also express the value of being respected, and a desire for a relationship in which they are recognised and treated as individuals (Holmberg et al., 2012).

Older persons want to be able to manage themselves as far as possible (Efraimsson, Höglund, & Sandman, 2008), and for the home care visits to be personal. This entails being able to discuss their daily living in a human-to-human interaction, and not merely being treated as ill (Holmberg et al., 2012). In order to establish home care visits that can be personal, continuity is needed.

Older persons describe continuity as important when receiving home care (Holmberg et al., 2012), but they also describe that there is a lack of continuity when receiving home care. They can have different nurses appointed to them, and do not always know who will visit them (Moe et al., 2013). Continuity is

central in caring for older persons, as it is through their interactions with the nurses that relationships are built, and without continuity there is a risk that older persons will experience a lack of safety and trust. Continuity in home care is also perceived as essential for obtaining knowledge about a person's history, needs, disabilities, and preferences; and furthermore, for the older person to be seen and treated as a person (Janlöv, Hallberg, & Petersson, 2006). This can further lead to older persons feeling cared for by the nurses, increasing their experience of safety, reliability, and trust (Efraimsson et al., 2008). Despite its importance, the continuity of nursing staff decreased in Swedish home care from 2007 to 2015, and has not changed during the period 2015 to 2017 (The National Board of Health and Welfare, 2018).

1.7.2 Home care from a nursing perspective

The provision of home care takes place in a home environment, with the nurses there as professionals but within the private sphere of the older person's own home. The nurses are not expected to act as guests or hosts in home care (Holmberg et al., 2012; Peter, 2002), but as professionals with respect for the older person's privacy (Holmberg et al., 2012). Being professional is also described as being able to adapt to the present situation and move between being casual and more decisive. This movement, depending on the situation, can result in nurses describing themselves as both guests and professionals (Öresland, Määttä, Norberg, Jörgensen, & Lützén, 2008). This can create a duality, which the nurses are expected to handle. This duality entails the intimacy of care and home on the one hand and the formal paid work on the other, which can create a tension regarding how to perform home care (Barrett et al., 2011).

During home care visits, nurses are also expected to encounter and handle different situations (Peter, 2002), but at the same time they experience a lack of resources or organisational prerequisites for providing care that meets the older person's needs (Breitholtz, Snellman, & Fagerberg, 2013; Choe, Kim, & Lee, 2014; Turjamaa et al., 2014). Shortage of time is a conflict during home care visits (Spiers, 2002; Öresland et al., 2011), and nurses can feel limited by their working routines. These limitations arise when the nurses often need to carry out pre-determined work tasks with little or no space to meet the needs and wishes of the older person. This constructs a conflict for the nurses, choosing between the older person's right to self-determination and the procedures and decisions of the organisation for which they work (Breitholtz et al., 2013). A home care restricted to the practical tasks at hand may place at risk the preservation of the older person's right to autonomy, independence, and social inclusion (Barrett et al., 2011). These conflicts caused by limitations can be troublesome for nurses in their attempts to provide home care that

meets older persons' needs. It is therefore important that nurses receive sufficient preconditions and support from the home care organisation. Otherwise, the home care will be insufficient and may risk challenging the experience of health for both the nurses and the older persons.

1.8 Rationale

Communication is a vital part of the home care visits, and is considered a cornerstone in all nursing. It is through communication that older persons express the wishes, worries, and needs that are important to them. Emotions are part of being human, but as they are experienced, handled and expressed in different ways they can be hard to detect or support. Emotional support is important for everyday life and the experience of wellbeing. Due to challenges in providing emotional support, nurses can experience helplessness and thus try to avoid talking about emotions with older persons, leaving the emotions unsettled. Communication becomes central in viewing the older person's unique needs and in detecting and alleviating their emotional distress. Knowledge of how older persons and nurses communicate in home care, while scarce, is important if we are to support nurses in meeting the needs of older persons.

2 Aims

The overall aim of this thesis was to explore the naturally occurring communication between nursing staff and older persons during home care visits, with a focus on emotional distress and from a person-centred perspective.

- Study I** To a) explore to what extent older persons express emotional cues and concerns during home care visits; b) describe what cues and concerns these older persons expressed, and c) explore who initiated these cues and concerns.
- Study II** To explore NAs' and RNs' responses to older persons' expressions of emotional needs during home care visits by seeking to answer the following questions: (i) To what extent do NAs and RNs respond explicitly or non-explicitly to expressions of negative emotions? (ii) To what extent do NAs and RNs provide or reduce space for further disclosure of negative emotions? (iii) Does the elicitation of emotional expressions influence NAs' and RNs' responses? And (iv) What type of responses are most frequently used?
- Study III** To explore the influence of characteristics of nurses and older people on emotional communication in home care settings. The following research question was addressed. Which characteristics of nurses and older people influence emotional communication in terms of: a) older people's expressions of emotional distress; b) elicitation of expressions of emotional distress; and c) nurses' responses in providing or reducing space for the further exploration of older people's emotional distress?
- Study IV** To explore person-centered aspects of home care communication between older persons and registered nurses. The following research questions were addressed: a) What is the relative focus of home care visit communication in terms of task-focused or socio-emotional exchange? b) What is the overall emotional tone of exchange between the RNs and the older persons in these visits? c) What is the overall degree of person-centeredness? and d) Are there older person, nurse or visit characteristics that impact the degree of person-centeredness in home care communication?

3 Methods

The studies of this thesis have an observational, cross-sectional design, and are based on audio recordings of naturally occurring communication between older persons and nursing staff in home care (Table 1). The first three studies (Studies I-III) explore emotional distress in home care. Study IV explores person-centred aspects of home care communication. In order to explore person-centredness during home care visits, an instrument for measuring patient-centredness in the communication was used. The choice to use a patient-centred instrument in a thesis on person-centredness is further discussed in *Methodological considerations*.

Table 1. Overview of methodology in Studies I-IV.

	Design	Study focus	Sample	Data collection	Analysis	Status
I	Quantitative, cross-sectional, descriptive	Older persons' expression of emotional distress	20 NA and 11 RN working in home care, together with 81 older persons	Audio-recorded communication during 188 home care visits	VR-CoDES, descriptive statistics	Published
II	Quantitative, cross-sectional, descriptive	Nursing staffs' responses to older persons' emotional distress	20 NA and 11 RN working in home care, together with 81 older persons	Audio-recorded communication during 188 home care visits	VR-CoDES, descriptive statistics	Published
III	Quantitative, cross-sectional, explorative	Explore predictors for emotional communication about emotional distress	20 NA and 11 RN working in home care, together with 81 older persons	Audio-recorded communication during 188 home care visits	Generalised linear mixed model	Accepted for publication

IV	Quantitative, cross-sectional, explorative	Explore the degree of person-centredness in the communication	11 RN working in home care and 37 older persons	Audio-recorded communication during 50 home care visits	RIAS, generalised linear mixed model	In manuscript
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3.1 Participants and setting

The setting of the data collection was the homes of the older persons receiving home care. In order to gain access to and audio record home care visits, heads of department at different home care organisations in central Sweden, 12 in total, were contacted and informed about the study. These home care departments were contacted one by one during the year-long process of data collection. After approval was received, different workplace meetings were attended in order to provide the nursing staff with both written and oral information about the project.

Collecting data and including participants in the studies of this thesis proved to be a challenging experience. It became evident that the nursing staff were interested and perceived the project as important, but they also expressed restricted time schedules and stress as reasons for being hesitant or unable to participate. Of the 12 initially contacted home care departments, eight agreed to participate in the studies. Nursing staff, both nurse assistants [NAs] and registered nurses [RNs], were recruited within these home care departments. The inclusion criteria for the nursing staff were: employment within home care and the ability to speak Swedish. The nursing staff consisted of 11 males and 20 females with an age range from 22 to 62 years. After they had given written consent to participate, the nursing staff were asked to recruit older persons. The older persons were to be 65 years or older and receiving home care, Swedish-speaking, and without speech impairment. The exclusion of older persons with speech impairment was based on the need to be able to hear the audio-recorded communication clearly. Older persons with cognitive deterioration were also excluded, based on the ethical consideration regarding informed consent to participate. The group of older persons consisted of 23 males and 58 females with an age range from 65 to 102 years. In this group, 72 lived alone and nine were cohabiting with a spouse. This distribution is not uncommon, as a majority of older persons in Sweden receiving home care live alone (Ministry of Health and Social Affairs, 2017). The older persons received oral and written information from the nursing staff about the research project, and were included in the study after giving their written consent.

An equal distribution of female and male participants was pursued, but was not achieved. This was due primarily to the distribution of females and males

both within the nursing staff teams and in the group of older persons receiving home care, in which more females than males were represented. Despite this distribution of males and females within the home care settings, the final number of males in the studies constituted almost one-third of all participants, both in the group of nursing staff and among the older persons.

3.2 Data collection

The data collection started in August 2014 and continued until November 2015. The nursing staff were instructed to begin recording when they entered the older person's home and to stop when they left. The nursing staff were instructed in how to use the recording device to ensure its utility, and to help them become acquainted with it before the visits. This was important not only for ensuring that the recording would work properly during the visit, but also for making it easier for the nursing staff, helping them feel comfortable when handling the device.

Depending on the organisation of the home care provision, the same older person could be recorded once or several times. The nursing staff were asked to perform up to ten audio recordings, which yielded an average of six audio recordings made by each nurse. The audio-recorded visits contained a variety of home care activities (Table 2). Some visits were shorter (< 5 minutes) and involved mostly medical administration or leaving or picking something up in the older person's home, such as a grocery list. There were also visits involving bodily care, housework and washing up the dishes, meals, help with getting dressed, or wound care. Socialisation and supervision were often included in the home care visits along with the other tasks to be performed. During one of the longest visits, the nursing staff baked for the older person, and during this time they talked and socialised. It became evident when listening to all these visits that the nursing staff and older persons knew each other quite well and that the communication had a highly varied content, mixing both medical and task-focused communication with more personal and social communication. No visit was identical to another, aside from similar tasks that needed to be performed, which further indicates how complex and unexpected home care visits can be.

Table 2. Descriptions of home care visits' duration, with examples of tasks and number of home care visits ($n = 188$) (Sundler, Högländer, Eklund, Eide, & Holmström, 2017).

Duration	Examples of tasks	Number of visits
1–19 minutes	Medical administration/procedure, socialising, treatment discussions/information, meals, washing up the dishes, personal hygiene, control and care of wounds, bodily care, cleaning/changing bedsheets, toileting, helping with movement.	150
20–39 minutes	Meal, helping with getting dressed, personal hygiene, changing bedsheets, medical administration/procedure, washing up the dishes, socialising/supervision, care of wounds, helping with toileting.	27
40–59 minutes	Meal, personal hygiene, socialising/supervision, helping with getting dressed, washing up the dishes, changing bedsheets, bodily care.	6
60–79 minutes	Clothing, meal, washing up the dishes, changing bedsheets, medical administration/procedure, personal hygiene, socialising/supervision.	3
> 79 minutes	Meal, washing up the dishes, baking, socialising/supervision.	2

It was recommended that the nursing staff wear the audio-recording device on their upper arm in a provided mobile case, which could be attached around the arm. The placement of the device became apparent when listening to the audio-recorded visits. Sometimes the nursing staff placed the device on a nearby surface or in their pocket when they began helping the older person. The fabric of the pocket made small, scratchy sounds, and when the device was placed somewhere static the nursing staff sounded distant as they moved around the room or walked into a nearby room. The overall sound quality of the audio-recordings was good, and disturbances in the recorded sound were uncommon. Sometimes the older person asked questions about the audio recording at the beginning or end of the visit, but they usually did not pay the recording any attention.

As previously described, this thesis is part of the COMHOME study, and the number of audio recordings was pre-determined within the international COMHOME study (Hafskjold et al., 2015). The intent was to audio record approximately 200 home care visits in Sweden. Ultimately, the data consisted of 188 audio-recorded home care visits (Table 3).

Table 3. Characteristics of the home care visits (Sundler et al., 2017).

Characteristics of the visits	<i>n</i>
RN visits	77
NA visits	111
Duration (minutes)	1-86
Mean duration (minutes)	14

RN = registered nurse

NA = nurse assistant

3.3 Analysis

In this thesis, two methods for measuring non-transcribed communication have been used: the Verona Coding Definitions of Emotional Sequences [VR-CoDES] and the Roter Interaction Analysis System [RIAS]. These methods allowed the coding to be performed directly in the audio recordings. The VR-CoDES and RIAS helped in locating and describing communication of emotional distress, and in exploring the degree of person-centred communication. A generalised linear mixed model [GLMM] was used for analysing the coded data from the VR-CoDES and RIAS. The outcome variables in the GLMM consisted of either count or dichotomous variables. All statistical analyses in the studies were performed using SPSS statistics 24 (IBM Corp, 2016).

The analyses of the home care communication in the four studies were as follows:

- Study I** VR-CoDES were used to code older persons' expressions of negative emotions as cues or concerns in the communication. These codes were then analysed and presented using descriptive statistics. Quotes from expressions of negative emotions were presented as clarification of the codes.
- Study II** VR-CoDES were used to code the nursing staff's responses to older persons' expressions of negative emotions. These codes were then analysed and presented using descriptive statistics. Quotes from the expressions of emotional needs and the responses were presented as clarification of the codes.
- Study III** A GLMM was used for statistical analyses of the previous data with VR-CoDES from Studies I and II, together with participant characteristics such as the sex and age of the older persons, and the sex, age, language, and profession of the nursing staff. The GLMM made it possible to explore predictors that might have an influence on the communication of emotional distress. Three GLMM analyses were conducted in order to analyse the

presence of cues and concerns, elicitations of cues and concerns, and responses to cues and concerns.

Study IV The RIAS was used for distinguishing and coding socio-emotional and task-focused communication between older persons and registered nurses. RIAS-coded expressions were analysed and presented using descriptive statistics. A ratio of the RIAS codes was calculated and analysed using GLMM in order to explore the degree of person-centredness and its predictors in home care communication.

3.3.1 The Verona Coding Definitions of Emotional Sequences

For coding the emotional communication, the audio-recorded home care visits were coded with the VR-CoDES (Studies I-III). VR-CoDES are used for coding patients' expressions of emotional distress in consultations (Zimmermann et al., 2011), and have been found to be reliable in previous studies of communication in different healthcare contexts (Del Piccolo et al., 2011; Mellblom et al., 2014; Wright, Humphris, Wanyonyi, & Freeman, 2012). In VR-CoDES, three aspects are coded in a sequence containing emotional distress: the elicitation prior to the expression of emotional distress, the expression of emotional distress, and the immediate response to the emotional distress (Figure 1).

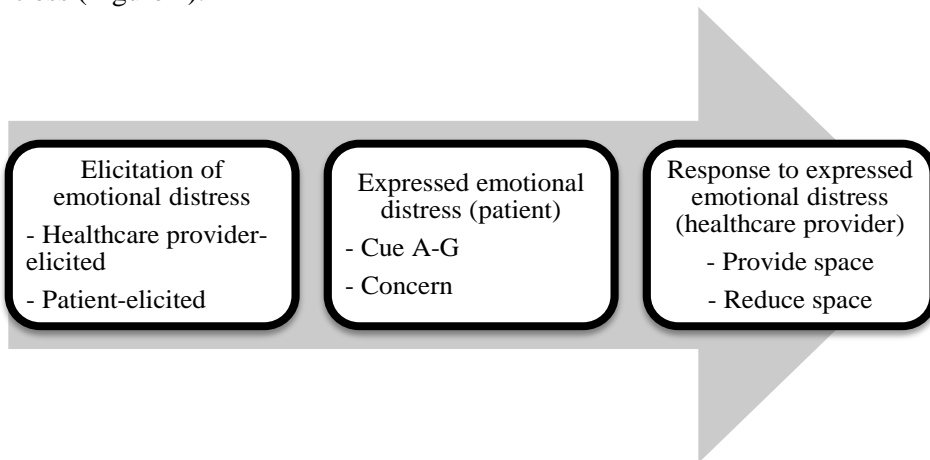


Figure 1. Sequential turn and coding steps when coding emotional communication using VR-CoDES.

Table 4. Definitions of Cues A-G and concern (Del Piccolo, Finset, & Zimmerman, 2009; Zimmermann et al., 2011).

Cue and concern	Definition
Cue	A verbal or non-verbal hint which suggests an underlying unpleasant emotion and needs clarification from the healthcare provider.
Cue A	Phrases or words in which a patient uses vague or unspecified words to describe emotions.
Cue B	Verbal hints at hidden concerns (e.g. unusual words or description of symptoms, emphasis, profanities or exclamations, ambiguous words, metaphors, expressions of uncertainty and hope).
Cue C	Phrases or words that emphasise (verbally or non-verbally) physiological or cognitive correlates of unpleasant emotional states (e.g. appetite, physical energy, sleep, excitement, concentration). Physical correlates may be described with words such as weak, dizzy, tense or restless, or with reports of crying, while cognitive correlates may be described with terms such as poor concentration or poor memory.
Cue D	Neutral expressions that mention issues of potential emotional importance which stand out from the narrative background and refer to stressful life events and conditions.
Cue E	A patient-elicited repetition of a previous neutral expression.
Cue F	Non-verbal expressions of negative or unpleasant emotions (for example, crying) or hints at hidden emotions (for example, sighing).
Cue G	A clear and unambiguous expression of an unpleasant emotion that is in the past (more than one month ago) or referring to an unclear period of life.
Concern	A clear and unambiguous expression of an unpleasant current or recent emotion, in which the emotion is explicitly verbalised. Included are patient expressions confirming healthcare provider's explicit assumption or question about an unpleasant current or recent emotion.

In the audio recordings, expressions of emotional distress were found and coded as either a cue or a concern (Table 4). Concerns are more explicit and easier to detect in the communication than cues, which are more vague emotional expressions. For example, a concern could entail the older person clearly expressing emotion, such as 'I'm so angry with him!'. An example of a cue could be 'That damn doctor!'. In this example, the older person is hinting at their emotion with a cue, B, which could be interpreted as anger. In the same sequence of turn containing emotional expressions, the healthcare provider's response is defined as either an explicit or non-explicit response (Figure 2) and is then coded into an appropriate response category (Table 5). An explicit response 'specifically mentions either the content/topic or the emotion in the cue or concern or both' (Del Piccolo, de Haes et al., 2009, pp. 5). For example, if an older person expresses to the nursing staff that they feel sad almost every day, an explicit response could mention sad or every day, or both; for instance, 'Why do you feel sad?' or 'Do you feel like that every day?' Contrarily, a non-explicit response does not explicitly refer back to the expressed cue or concern by mentioning either its content or the emotion. Non-verbal responses are also coded as non-explicit (Del Piccolo, de Haes, et al., 2009). During the coding process, the elicitation of the emotional expression is also defined. Elicitations

are coded as either ‘Patient-elicited’ or ‘Healthcare provider-elicited’ depending on who initiates the patient’s expressed cue or concern. Elicitations, emotional expressions and responses are coded according to the VR-CoDES manuals (Del Piccolo, de Haes, et al., 2009; Del Piccolo, Finset, et al., 2009).

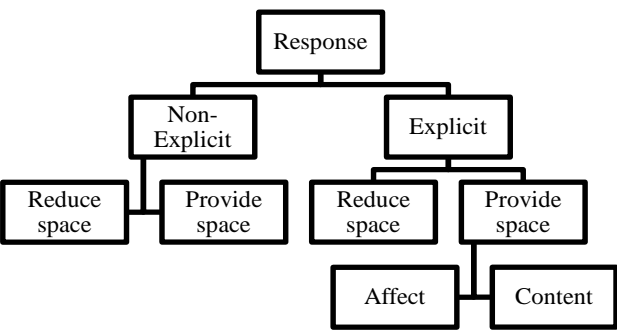


Figure 2. Different types of responses (Del Piccolo, de Haes, et al., 2009).

Table 5. Definitions of responses to cues or concerns (Del Piccolo, Finset, et al., 2009, p.6-15).

Response codes	Definition responses
Non-explicitly reducing space (NR)	<p>Non-explicitly referred to the cue/concern with the function of reducing space</p> <p>Ignore (NRIg): the cue or concern appears to be completely ignored</p> <p>Shutting down (NRSd): response actively shuts down or moves away from the cue/concern</p> <p>Information advice (NR Ia): informs, gives advice, or offers reassurance without explicitly referring to the cue/concern</p>
Non-explicitly providing space (NP)	<p>Non-explicitly referred to the cue/concern with the function of providing space</p> <p>Silence (NPSi): provides a clear space or pause (3 seconds or more) allowing the patient to say more</p> <p>Back-channel (NPBc): provides space for the patient to say more or encourages further disclosure through minimal prompt, or word</p> <p>Acknowledge (NPAc): provides space for the patient to say more by ‘non-specifically’ acknowledging what has been said</p> <p>Active invitation (NP Ai): seeks further disclosure or new information</p> <p>Implicit empathy (NP Im): provides space for further disclosure through having an empathic function</p>

Explicitly reducing space (ER)	<p>Explicitly referred to the cue/concern with the function of reducing space</p> <p>Switching (ERSw): behaviours that have the function of changing the frame of reference of the cue/concern</p> <p>Postponing (ERPp): further exploration of the cue or concern is delayed</p> <p>Information advice (ERiA): explicitly refers to the cue or concern, gives information or advice, or offers reassurance</p> <p>Active blocking (ERAb): explicit refusal on the part of the healthcare provider to talk further about the cue or concern</p>
Explicitly providing space (EP)	<p>Explicitly referred to the cue/concern with the function of providing space – may apply to affect or content, or both. When both affect and content are responded to, the affect categories should be used</p>
Explicitly providing space Affect (EPA)	<p>Explicitly referred to the cue/concern with the function of providing space – acknowledging the affect</p> <p>Acknowledgment (EPAAc): explicitly refers to the emotional aspect of the cue or concern</p> <p>Exploration (EPAEx): behaviour that explicitly picks up or refers to the affective or emotional aspect of the cue or concern</p> <p>Empathy (EPAEm): behaviour that empathises with the patient's predicament</p>
Explicitly providing space Content (EPC)	<p>Explicitly referred to the cue/concern with the function of providing space – acknowledging the content</p> <p>Acknowledgement (EPCAc): explicitly refers to the factual content or topic of the cue or concern</p> <p>Exploration (EPCEx): behaviour that refers to the factual content or topic of the cue or concern</p>

To learn how to use VR-CoDES, in 2014 I attended a learning workshop held in Amsterdam by some of the creators of VR-CoDES. Thereafter, I began training in coding. To establish the reliability of the VR-CoDES, I initially co-coded and discussed 12 recordings together with my supervisor Annelie J. Sundler in order to establish an understanding of the VR-CoDES and internal agreement. Cohen's kappa can be used for establishing the inter-rater reliability of VR-CoDES (Zimmermann et al., 2011). A total of 15 individually coded home care visits were calculated for inter-rater reliability using Cohen's kappa, providing a satisfactory kappa, $\kappa = 0.64$ ($p < .01$). The remaining audio-recorded data were thereafter coded, with continued consultations and discussions during the coding process. Discussions about VR-CoDES were also held with the Norwegian group of the COMHOME project, at meetings in both Sweden and Norway and via Skype. As VR-CoDES, initially developed for medical consultations (Zimmermann et al., 2011), have not previously been used in a home care context, their utility for the home care communication was discussed during these meetings, as was how to code and present the data.

The coding was performed using a coding scheme, developed for the computer software Noldus Observer XT (Grieco, Loijens, Krips, Zimmerman, & Spink, 2011). This program allows the coding to be performed directly in the audio file without transcribing the data. Hence, the audio-recorded home care visits were listened to and coded simultaneously. Older persons' expressions of emotional distress were identified and coded, together with the type of elicitation prior to the emotional distress and the subsequent response by the nursing staff to the expressed emotional distress. Any doubts regarding whether to code as a cue or a concern were resolved in accordance with the criteria in the VR-CoDES manual (Del Piccolo, Finset, et al., 2009).

3.3.2 The Roter Interaction Analysis System

From the audio-recorded visits with RNs and older persons, 50 visits were selected and coded with RIAS (Study IV) (Table 6). Originally, RIAS was constructed to code medical dialogue, but since then has been widely used in other areas, for example nursing (Roter & Larson, 2002). RIAS focuses on establishing different task-focused and socio-emotional elements in communication (Figure 3). The establishment of these elements is done through assigning codes to the spoken words, directly from an audio or video recording without the need of transcription. A coding scheme for the software Noldus Observer XT (Grieco et al., 2011) was used when coding RIAS. The RIAS-coded communication can furthermore be used for calculating a ratio of patient-centredness (Roter & Larson, 2001). The reliability and validity of RIAS have been demonstrated in previous studies (Roter & Larson, 2002).

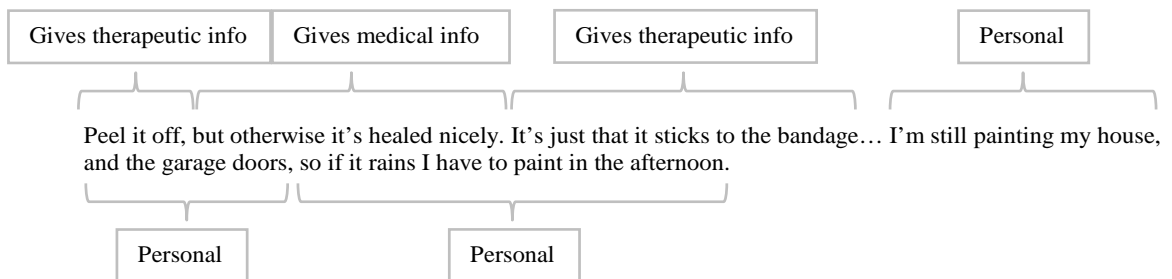


Figure 3. Coding example of RIAS, containing both task-focused and socio-emotional elements.

Table 6. Definitions of the RIAS codes (Roter, 2015).

RIAS code	Definition
Socio-emotional exchange	
Personal	Greetings/goodbyes, non-medical or social conversation
Laughs	Laughter and friendly jokes
Concern	A condition or event of concern, distress or worry, or concern for the other person present
Reassurance	Indicates optimism, reassurance or encouragement
Approval	Compliments, gratitude or appreciation towards the other person present
Compliment	Compliments, gratitude or appreciation towards the other person not present
Disapproval	Disapproval, criticism, rejection or disbelief towards the other person present
Criticism	Disapproval, criticism, rejection or disbelief towards the other person not present
Empathy	Paraphrases, interprets or recognises the emotional state of the other person present
Legitimises	Indicates that the other person's emotions, actions or thoughts are normal and understandable
Partnership*	Shows alliance with the patient, offers help and support
Self-disclosure*	Personal experience in topics of relevance for the patient, medical or emotional
Asks for reassurance	Questions with the desire or need of reassurance
Agreement	Shows agreement or understanding
Back-channel	Indicates attentive listening, sustained interest or encouragement
Task-focused Exchange	
Transition	Words that indicate a movement to another topic, train of thought or action
Orientation	Orientation about what is about to happen, what to expect, or instructions and directives
Paraphrase	Restates information to check for accuracy, confirms shared understanding or refers back to previous statement
Asks for understanding	Checks the other person's understanding of what has been said
Bid for repetition	Requests a repetition of the other person's previous statement
Asks for opinion*	Asks for the other person's opinion, view or perspective, or probes for questions or problems
Asks for permission*	Asks for permission to proceed
Asks question medical condition***	Medical history, previous treatments, symptoms, practices or allergies
Asks question therapeutic regimen***	Past, ongoing or future drug regimens, ongoing or future treatments
Asks question lifestyle information***	Lifestyle-, self-care-, family-, home- or work-related questions or insurance/cost issues
Asks question psychosocial information***	Psychosocial or emotional state, likes or dislikes

Asks question other information***	Other information regarding, for example, clinic paperwork or study procedures
Gives medical information	Information about medical condition, symptoms, diagnosis or prognosis, such as tests, treatments or hospitalisation, medical history and vital statics
Gives therapeutic information	Information about ongoing or future treatment, tests, hospitalisations or medical appointments. Information about medications taken or prescribed in the past.
Gives lifestyle information	Information about lifestyle, e.g. smoking, sleep, diet or exercise, family, home or work situations, and self-care issues
Gives psychosocial information	Information about psychosocial concerns, e.g. stress, emotions, values or beliefs
Gives other information	Information or neutral statements, e.g. paperwork or study procedures
Counsel or direct behaviour – Medical/Therapeutic*	Intent to influence the patient's behaviour, to suggest a resolution or action to be taken by the patient regarding medical condition or therapeutic regimen
Counsel or direct behaviour – Lifestyle/Psychosocial*	Intent to influence the patient's behaviour, to suggest a resolution or action to be taken by the patient regarding lifestyle or psychosocial issues
Request for service or medication**	Request for service, tests, prescriptions or referrals

* Healthcare provider category only

** Patient category only

*** Open- or closed-ended questions

In order to learn how to code RIAS, I attended a workshop held by Debra Roter in Norway 2016. At the beginning of the coding process, three audio-recorded home care visits were test-coded and discussed with supervisors to establish an understanding of and internal agreement regarding the RIAS codes. Thereafter, ten audio recordings (20%), out of the 50 home care visits, were co-coded and checked for inter-rater reliability together with main supervisor Inger K. Holmström, who has used the instrument in previous studies. The inter-rater reliability was calculated using Pearson correlation analysis, which has often been used for establishing RIAS reliability (Roter, 2015). The Pearson correlation analysis resulted in an average reliability of 0.80, demonstrating sufficient inter-rater reliability. I also discussed the RIAS coding and its preliminary results on all 50 home care visits with Debra Roter during a workshop in 2018.

3.3.3 Generalised linear mixed model

A generalised linear mixed model [GLMM] was used in Studies III and IV to account for clustered data in the home care communication. The reason for using GLMM was the risk for bias when the same nursing staff and older person occurred several times in the data. First, an intraclass correlation [ICC] was performed to check for possible correlations between the data of the home care visits. The results from the ICC revealed correlations that needed to be

considered when performing statistical analyses. With help from a statistician at the Netherlands institute for health services research [NIVEL], the choice was made to use multilevel analyses in the form of generalised linear mixed models [GLMM] in Studies III and IV. A GLMM differs from other forms of linear models in its capacity to examine unequal variances within groups and correlated data. GLMM helps account for clustered data, such as data nested within individuals through repeated measures, or from individuals clustered in groups (Heck, Thomas, & Tabata, 2012).

The independent variables in the GLMM were also checked for multi-collinearity. Multi-collinearity means that independent variables inter-correlate, which can give misleading results when predicting individual variables' effect on the outcome variable. If the multi-collinearity is high ($r > .90$) the results are affected (Pallant, 2016), but the tests for multi-collinearity in Studies III and IV showed only small or moderate correlations ($r < .70$).

The GLMM can account for data with a non-normal distribution and data that are clustered. As the data consisted of count and dichotomous values, the distribution deviated from a normal distribution. The data were clustered within groups (e.g., different older persons share the same nursing staff) and within individuals as a result of repeated observations with the same participant. Because of these clustered structures, the data share similarities that must be considered in order to make correct estimations (Heck et al., 2012). As the data were clustered, the participants cannot be assumed to be randomly sampled. The clustered data are a result of hierarchical levels in the data structure (Figure 4). With these hierarchal structures in the data, participants within sequential groups will share similarities that need to be considered if one is to estimate correct model parameters (Heck et al., 2012). In the hierarchical structures presented in Figure 4, the home care visits (Level 1) were clustered within the same older person and nursing staff, and on Level 2 the same older person was clustered within the same nursing staff (Level 3). As a result, home care visits within the same older person tend to be more similar compared to other visits. Similarly, older persons' home care visits within the same nursing staff tend to be more similar than visits with other nursing staff. With these similarities within groups and individuals, single-level models, e.g. ANOVA or regression analysis, would treat the data as individuals that are randomly sampled and not as clustered in groups, and would hence yield a stronger power and incorrect estimates (Heck et al., 2012).

In performing GLMM, three levels were implemented in the data structure of the GLMM using the ID numbers of the participants as well as those of the home care visits (Figure 4).

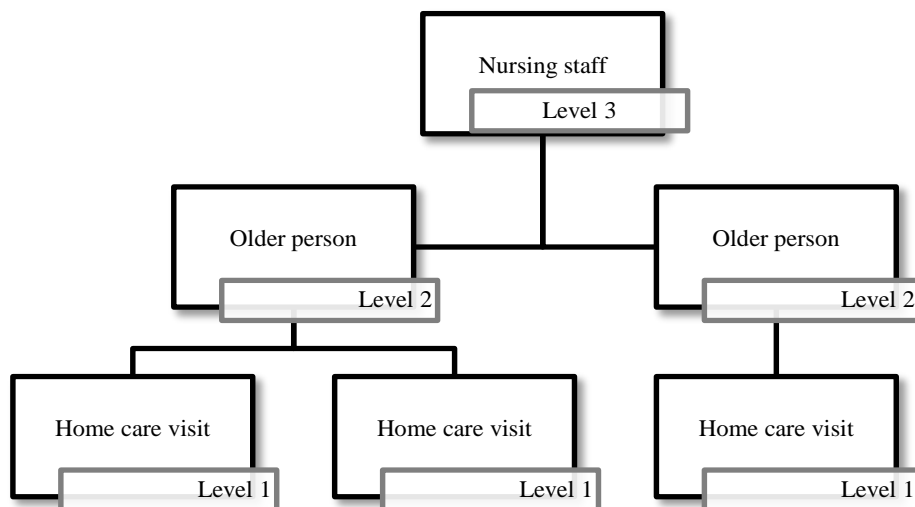


Figure 4. Example of hierarchical levels in the GLMM analyses of the audio-recorded data.

In GLMM, the term mixed indicates models with both fixed and random effects, with fixed effects assessing the influence of the predictors, i.e. independent variables, on the outcome variable. The estimates are in Studies III and IV presented with unstandardized beta coefficients together with the standard errors in parentheses. The coefficients give the degree of change in the outcome variable for every unit of change in the independent variable. The independent variables in the models are dichotomous, for example male and female or RN and NA. A positive coefficient indicates an increase in the outcome variable due to the effect of the independent variable, while a negative coefficient indicates a decrease in the outcome variable due to the effect of the independent variable. The random effects in GLMM specify the variance of the level parameters in the model (Heck et al., 2012). In Studies III and IV the random effects consist of the levels of home care visits, older persons and nursing staff. These hierarchical levels are used as random effects to account for correlations caused by the clustered data. When the random effect is close to 0, the subject variances in the level have a low effect on the outcome and the proportion of explained variance R^2 is high. R^2 can be calculated through the differences in random effects between Model 0 and successive models. The estimates of R^2 reveal the proportion of variance in the outcome variable explained by the independent variables in the model. For example, if $R^2 =$

83% then this is the proportion of the outcome that is explained by the independent variables, but 17% remains unexplained and is due to the random effect variances.

In order to learn how to use GLMM, I attended meetings and lectures at NIVEL in the Netherlands in 2017, held by co-author and statistician Peter Spreeuwenberg. I then performed the GLMM analyses, with continuous discussion and consultation with supervisor Jakob Håkansson and statistician Peter Spreeuwenberg in order to check the accuracy of the analyses and the presented models and results. GLMM was used in Studies III and IV when analysing how different characteristics may influence emotional communication (Study III) and the degree of person-centredness (Study IV).

3.4 Ethical considerations

The studies (I-IV) of this thesis have been approved by the Regional Ethical Review Board in Uppsala (Dnr 2014/018). The Declaration of Helsinki (WMA General Assembly, 1964/2013) has been considered when accommodating ethical considerations to protect the participants and uphold scientific and ethical principles. To uphold ethical research, three ethical principles have been applied to protect the participants in the studies of this thesis: the principle of respect for human dignity, the principle of beneficence, and the principle of justice (Polit & Beck, 2018).

The principle of respect for human dignity was upheld through the provision to the participants of both oral and written information about the research project, voluntary participation, and the right to withdraw at any time without consequences. They had to be able to provide written consent in order to participate. The principle of beneficence states that researchers ought to minimise harm and maximise benefit for the participants, and others, when conducting research (Polit & Beck, 2018). All participants and data were coded to ensure confidentiality. Written consent and information about the participants were stored separately and locked in a safe. The nursing staff were further instructed to remind the older person that they were audio recording and to stop if they or the older person felt uncomfortable or requested that the audio recorder be turned off. Protecting the older person by turning off the audio-recording device follows the ethical principle of doing no harm. A person's best interests are always more important to preserve than the research itself (Sandman & Kjellström, 2018), balancing the benefits and risks of participating in research (Polit & Beck, 2018). The principle of justice includes participants' rights to fair treatment and privacy. Home care visits entail caring interactions of an often intimate nature that need to be considered in relation to research ethics. One reason for not using video recordings was the desire to limit the exposure

of the older person receiving care in their home environment and in a vulnerable position. This minimises the risks of unnecessary exposure of the participants or being too intrusive (Polit & Beck, 2018) of the often intimate home. Video recordings are recommended when the same results cannot be attained through other data-collection methods (Swedish Research Council, 2017). Audio recordings can be regarded as comparable to video recordings for the analysis of emotional qualities in communication (Williams, Herman, & Bontempo, 2013). Therefore, audio recordings were considered sufficient for retrieving information about emotional communication during home care visits.

All collected data have been handled according to the Personal Data Act, SFS 1998:204 (Government Offices of Sweden, 1998), and since 2018 according to the General Data Protection Regulation [GDPR] (European Parliament & The Council of the European Union, 2018). All data have been coded in order to protect the confidentiality of the participants. Information about the participants' identities has been stored separately from the audio-recorded data to prevent identification, and will be archived according to the Archive Act, SFS 1990:782 (Government Offices of Sweden, 1990). No information that can identify the participants is stored in any other form elsewhere.

4 Results

The communication in home care was largely socio-emotional, in addition to its task-focused and biomedical content. The results provided information about older persons' expression of emotional distress, responded to through the nursing staff responses, and influenced by different characteristics of the home care visits. The communication was also mainly person-centred, approaching older persons' own needs, wishes and beliefs.

4.1 Expressions of emotional distress in home care

In the home care visits, 316 expressions of emotional distress were found, and were coded together with the same number of elicitations and responses associated with the expressed emotional distress. The results of Study I showed that expressions of emotional distress, i.e. cues and concerns, occurred in 51% of the 188 visits. This distribution did not differ much in home care visits with RNs (52%) or those with NAs (51%). Emotional distress was expressed either explicitly in the form of concerns or implicitly in the form of cues, which are hints at hidden concerns. The expressions of emotional distress were found in home care visits of different lengths. The shortest visits containing cues or concerns were two minutes long ($n = 5$); at most, one of these two-minute visits contained five cues and one concern (Study I).

Through the results of Study I, it also became clear that it was more common for older persons to express their emotional distress as cues (92%) than as explicit concerns (8%). An example of an expressed concern came from an older female who felt afraid and worried before an appointment at the hospital: 'That's what I am so terribly afraid of...that's why I'm so afraid' (87 years). In this example the older female was explicit in her concern, stating that she was afraid. These concerns make it clearer to the nursing staff what kind of emotion the older person is experiencing, and perhaps also how to respond to it. Hints, in the form of cues, may pose more challenges to the nursing staff's attentiveness than explicit concerns do when it comes to detecting them in the communication. An example of a cue can be noted in an older female telling the NA that she experiences that people are hurried when visiting her: 'You know, I think you're the only one who doesn't look at your watch: "Okay, now I must go"?...You're the only one who doesn't do that' (91 years). This

may be interpreted as a hint that she experienced the nursing staff as stressed when visiting her; she also subsequently added that everyone was so stressed. The least frequent were non-verbal hints at emotional distress, which occurred only once (0.3%) in the communication when an older woman emitted a heavy, shuddering sigh (Study I). Non-verbal communication was also explored in Study IV, in the form of affect tone of the voice. Even if expressions of emotional distress were rather common (Study I), the results of Study IV showed that the emotional tone in the visits was often positive. Older persons' and RNs' emotional tone indicating negative emotions ($m = 15.56$, $sd = 3.91$) such as anger/irritation, sadness or anxiety was lower than the more positive affect tone ($m = 39.88$, $sd = 7.65$), indicating, for example, interest and friendliness/warmth (Study IV).

The GLMM analyses of Study III further showed that it was more common for older females to express cues or concerns during the home care visits compared to older males ($p < .05$). Female nursing staff also received more cues and concerns during the home care visits compared to their male colleagues ($p < .05$). Furthermore, the results showed that being an older female also had a slightly larger influence (0.775) on the frequency of cues and concerns than being a female nursing staff member (0.579) (Study III).

A cue or concern is always preceded by an elicitation. An elicitation, i.e. initiation, to a cue or a concern can be made by either the older persons themselves or their nursing staff. Most often, it was the nursing staff who elicited a cue or concern in the home care visits (63%) rather than being elicited by the older persons themselves. Examples of nursing staff elicitations could be when the nursing staff asked the older person questions about how they felt or about their experiences or thoughts during the visits (Study I). The GLMM analyses of Study III showed that the nursing staff elicitations were influenced by their native language and type of profession ($p < .05$). When the nursing staff had Swedish as their native language, more elicitations were made by the nursing staff than by the older persons. But if the nursing staff had a native language other than Swedish, i.e. were non-native Swedish-speaking, the elicitations between nursing staff and older persons were more equally distributed. Even if native language was significantly associated with the type of elicitation, the type of profession was revealed to have twice as strong an influence on the elicitations (-1.452) than native language had (0.777). The results concerning the type of profession showed that RNs elicited older persons' expressions of cues and concerns more often than NAs did (Study III).

4.2 Responding to emotional distress in home care

As expressions of emotional distress are common during home care visits, nursing staff encounter these expressions on almost a regular basis. Study II

showed that the nursing staff often responded by providing space for further disclosure of the expressed emotional distress. These responses were often in the form of non-explicit responses (67.7%). One example of a non-explicit response that provided space in the form of back-channel responses can be found in a visit with an older female (94 years), who was tired of being dependent on others:

Older person: This life, it's not a life worth living.

RN: No...

Older person: When you're dependent on others all the time, it's sad.

RN: Yes...

Older person: But what to do?

RN: Yes...

Older person: One just has to...

RN: Yes... Do you feel safe?

The RN provided space for further disclosure of the older female's expression of emotional distress. The older female was able to elaborate further, and finally the RN asked a question in order to learn more, probing as to whether the older female felt safe when being cared for. Providing space was also the most common if the nursing staff elicited the older persons' expressed emotional need (69.2%), compared to when it was elicited by the older persons themselves (Study II).

It was less common for the nursing staff to provide a response that reduced the space for older persons' cues or concerns. A response that reduced space could involve the nursing staff shutting down or changing the topic of conversation; for example, starting to talk about something other than what the older person intended. One example of switching the topic occurred when an older female (92 years), after a period of silence, expressed that her legs hurt:

Older person: I have so much pain in my legs.

NA: Do you have pain in your legs? Now I'll take your quilt.

Thereafter, the NA continued to make the bed. After a while, as the NA noticed that the older person was in pain, she started asking more about the pain in her legs (Study II).

The GLMM analyses of Study III showed that responses that provided or reduced space for further disclosure were influenced by the older person's sex and age. Being an older female had a significant association with responses that provided space ($p < .05$), revealing that older males received less space for their emotional distress during the home care visits. Age also showed a significant association with the type of response. Older persons (65-84 years) received more space ($p < .05$) for their emotional distress than persons older

than 85 years, who received less space for their emotional distress. These age differences reveal an increased risk of persons aged 85 years and older receiving fewer opportunities to talk about their emotional distress. Being a female older person was revealed to have a greater influence on the type of response (1.237) than the older person's age did (-1.117) (Study III).

4.3 Attending to socio-emotional and task-focused communication in the home care visits

The home care communication between RNs and older persons contained both socio-emotional and task-focused talk. Both socio-emotional and task-focused talk are central in establishing a holistic, person-centred perspective of the older person, supporting their needs, beliefs and wishes.

In Study IV, a total of 10,028 utterances were RIAS-coded. The results revealed that socio-emotional talk (65%) was more common than task-focused talk (35%) in the home care visits. Common expressions of socio-emotional talk were back-channels (23%), followed by positive talk (20%) and personal/social talk (14%). The more common expressions in the task-focused talk were medical information (17%) and psychosocial information (6%). Common examples of back-channels were short expressions of 'Mmm' or 'Yeah' that encouraged the other person to continue talking. Positive talk consisted of laughter, agreement, approval and complimenting; for example, 'Yes' (agreement), 'You're good at that' (approval), or 'She's so positive and knows what she's doing' (complimenting). Personal or social talk were the everyday talk, greetings and goodbyes, plans for the day, friends and family events, what was on television or in the newspaper, crossword puzzles and so forth. Medical information entailed medical and therapeutic information regarding tests, doctors' appointments, medical condition or medications. Psychosocial information involved psychosocial and lifestyle topics such as emotions, exercise, walks or eating habits, like the following example: 'Food is difficult, and I have to make sure I don't eat anything spicy. Otherwise I don't follow any diet' (Female, 83 years). Procedural talk entailed transition words or orientation/instructions. An example of orientation from an RN was 'It's good if you sit up so I can take them at once (blood tests)' (Female, 45 years) (Study IV).

The content of the home care communication revealed important aspects associated with person-centred care. In Study II, the nursing staff responded to older persons' expressions of emotional distress by providing space for further disclosure in the home care communication. In Study IV, the results further showed that the RN did not dominate the communication space during the home care visits. A nearly similar distribution of RIAS-coded utterances was found between the RNs (54%) and older persons (46%). These combined

results of Studies II and IV indicate that the older persons have openings to narrate in the home care communication. The nursing staff provide opportunities for them to talk more about their worries and concerns (Study II), but also for an everyday social talk (Study IV). Providing space for the older persons in the communication is an opportunity for the nursing staff to listen and to learn more about the older person (Studies II & IV).

For further exploration of the presence of person-centredness in home care communication, a ratio was calculated based on different RIAS codes. The result of the ratio (1.53) showed that the communication was more person-centred than focused on the nurses' agenda for the visit. A ratio of 1 would have indicated a balance between person-centred and a more task-focused/biomedical communication.

Further exploration of the degree of person-centredness, using a GLMM, showed that the degree of person-centredness was significantly influenced by the length of the home care visits. Time was significant for establishing a person-centred communication. However, the degree of person-centredness showed no gradual increase with longer home care visits. The degree of person-centredness peaked in visits that were eight to nine minutes long. In visits longer than five minutes the overall degree of person-centredness was higher than in shorter visits, but fluctuated and sometimes held a degree of person-centredness similar to that of the shorter visits (≤ 5 minutes) (Study IV).

With the notion in research and literature of home care as mainly task-oriented, the presence of task-focused and socio-emotional elements was explored further, based on the focus of the visit. Home care visits were therefore divided into visits with and without an intended medical procedure. Through the GLMM analysis it became evident that the focus of the visit did not significantly influence the degree of person-centredness. These results were also perceptible in the descriptive results, which showed small differences in the diversity of socio-emotional and task-focused utterances based on the focus of the visit (Study IV).

5 Discussion

The results of this thesis reveal that older persons have opportunities to express and talk about their emotional distress with nursing staff, as part of the socio-emotional communication during home care visits. The results further showed that the home care visits contained person-centred communication. Socio-emotional aspects in communication are important to explore if one is to capture what constitutes viewing someone as a person, moving beyond a conception of older persons as merely receivers of care or as being old, revealing them as a person. It is through the socio-emotional communication that nursing staff can connect to the older persons' everyday life and reveal issues of importance for their wellbeing and experience of health.

The results of the four studies are discussed in relation to theories and previous research under the three headings: *Older persons' socio-emotional communication during home care visits*, *Nursing staff's attentiveness to socio-emotional communication in home care*, and *Person-centred aspects in home care communication*. The discussion ends with *Methodological considerations* and *Ethical discussion*.

5.1 Older persons' socio-emotional communication during home care visits

It was apparent that it was common to talk about socio-emotional topics during the home care visits. Older persons have a need not only to talk about their emotional distress, expressed as cues or concerns, but also for an everyday, social talk in the home care communication. The communication therefore contained a variety of topics and may be described as multifaceted, ranging from the older persons' perceived health to social talk about the weather, family and friends, childhood memories, or the latest episode of *Little House on the Prairie* (Studies I & IV).

In the home care communication, older persons expressed their emotional distress. Expressions of emotional distress were common, but were often expressed vaguely as cues, with few explicit concerns (Study I). It may be difficult to pinpoint why the cues were the most common, but this might be related to age-related differences such as greater emotional control (Gross et al., 1997), or entail attempts to maintain a façade (Fredriksson, 2003).

Helping the older person narrate is central for capturing the person's own story, but the narrative can also help hide the person, not revealing their true self but rather maintaining a façade (Fredriksson, 2003). Vague cues during home care visits (Study I) might be a result of older persons hiding their suffering behind a façade, not being explicit about their emotional distress. The relationship between persons in an encounter influences on how they interact in the communication and how they narrate (Fredriksson, 2003; Watzlawick et al., 1967/2014), and affects the emotional communication. Insights into the interaction and relationship between nursing staff and older persons were provided by exploring the affect tone in Study IV. The results revealed an overall positive affect tone, with signs of friendliness and warmth, interest, responsiveness and respectfulness, which can indicate a good foundation for emotional communication. Through active listening, the nursing staff can help the older person narrate their emotional distress and reveal themselves. In doing so, the nursing staff may also help older persons understand more about their experiences, explore the cause of their suffering, and become more explicit in their expressions of emotional distress (Street et al., 2009).

The affect tone in the home care communication also involved emotions such as anger, anxiety, or sadness (Study IV). The affect tone can be of help to nursing staff in detecting cues of emotional distress. According to the fourth axiom by Watzlawick et al. (1967/2014), non-verbal communication can be a complement to verbal communication. In the home care visits, the affect tone provided the clearest picture of the non-verbal communication.

Expressions of emotional distress were elicited more often by the nursing staff (Study II), especially the RNs (Study III), than by the older persons themselves. Elicitations to emotional distress could be questions regarding how the older person was feeling, their experience of health or about their plans for the day. It is not uncommon for nursing staff to choose the topic of the communication, or that RNs, in comparison with NAs, often focus on topics related to older persons' experience of health and sickness in the communication (Wadensten, 2005). The overall expressions of emotional distress were further influenced by the sexes of both the nursing staff and the older persons (Study III). These results are not consistent with previous studies in other healthcare settings using VR-CoDES, which did not find significant gender differences regarding the frequency of cues or concerns (Eide, Sibbern, et al., 2011; Mellblom et al., 2014; Mjaaland, Finset, Jensen, & Gulbrandsen, 2011). One possible reason for this might be the different contexts between hospital or clinical care and home care. A previous study in home care, not using VR-CoDES, found that older females more often expressed concerns and complaints (Hellström & Hallberg, 2001), which is more similar to the results regarding cues and concerns in Study III. This may also be discussed as a possible result of gender stereotypes (Mast & Kadji, 2018), affecting the content and presence of emotional communication. Emotional talk may sometimes be

regarded as a less masculine feature, which can affect how males express or receive expressions of emotional distress in the home care visits. Possible influences of stereotypes risk making the home care unequal, and generalisations about persons are a threat to a person-centred care and communication.

Despite expressions of emotional distress, the socio-emotional communication also contained a great deal of social and positive talk. Positive talk could include expressions of laughter and jokes, friendliness, interest, or approval (Study IV). These results confirm that receiving home care can mean more to the older persons than simply receiving help and care in their homes, as it often entails the possibility to have someone to talk to (Nicholson et al., 2013).

5.2 Nursing staff's attentiveness to socio-emotional communication in home care

The content of Studies II and IV revealed that socio-emotional communication, such as expressions of emotional distress and social talk, was common. It is therefore essential that nursing staff interact in a way that responds not only to older persons' physical needs but also their socio-emotional needs.

The emotional communication became implicit in the home care visits due to a frequency of implicit cues, which can challenge nursing staff's attentiveness (Studies I & II) and impact on their behaviour in the communication. All behaviour is a form of communication, as persons react and respond according to the behaviour of others (Watzlawick et al., 1967/2014). Cues may therefore challenge the nursing staff to behave and respond in accordance with the older person's intention with their cue. According to the first axiom of communication theory (Watzlawick et al., 1967/2014), communication is not always intentional or successful, which can result in the message received not always being equal to the message sent. There is thus a risk that not being able to respond to implicit cues in the intended way will cause misunderstandings. According to the third axiom by Watzlawick et al. (1967/2014), misunderstandings can also be caused by how the communication is structured, organising the behaviour in the interaction. The structure of the home care communication, regarding implicit expressions of cues, would therefore challenge the emotional communication and the behaviour of the nursing staff in their ability to respond and provide emotional support.

Older persons' expressions of emotional distress occurred during home care visits regardless of the length of the visit (Study I), which indicates that emotional matters arise whether or not there is time to talk about them. Previous studies have described the ability to attend to and handle emotional distress as difficult (Sheldon et al., 2006; Street et al., 2009; Sundler et al., 2016) but important (Pejner et al., 2015). In order to attend to emotional distress and

provide emotional support, active listening is essential. In person-centred care and communication, the narrative and the ability to listen are described as central if one is to gain knowledge about the person as well as their needs and experience of the situation (Edvardsson et al., 2010; McCormack, 2003; Motschnig & Nykl, 2014), to understand the situation from their perspective (Rogers, 1961/1995). Listening and being attentive to the older person's story thus becomes crucial if one is to reveal them as a person. When the nursing staff responded to older persons' emotional distress by providing space, they also provided space for the older persons' own story (Study II). This creates the possibility to reveal the underlying reasons for their emotional distress and help them put their emotions into words. It is therefore positive that the nursing staff respond in a facilitating way in order to explore emotional distress.

To establish a communication in which the older person feels safe expressing themselves is essential, not only for offering emotional support but also for getting to know them as a person. This is in accordance with both a person-centred and a caring conversation whereby the genuine communication, based on mutuality and respect, becomes possible when the person feels safe revealing themselves (Fredriksson, 2003; Rogers, 1961/1995). The response by the nursing staff can therefore be crucial for how the older person chooses to proceed and reveal more about themselves and their feelings, if this is their wish. Providing space in the conversation can result in older persons experiencing being listened to and being taken seriously, and that the nursing staff care about them as persons.

The nursing staff did not always give responses that provided space. Responses that reduced space also occurred in the home care communication, for example when the nursing staff postponed, shut down, or changed the subject (Study II). Responses that reduce space may be discussed as less person-centred, as they limit the older person's narrative, which is central in person-centred care (McCormack, 2003). Responses may also be affected by the relationship between those who are present and their previous experiences; thus, the nursing staff respond accordingly. According to the second axiom by Watzlawick et al. (1967/2014), the relationship helps to define the communication. Hence, the relationship can influence when and how the nursing staff reduce space for the older person's emotional distress. Responses that reduce space may further be due to a lack of prerequisites when performing home care (Breitholtz et al., 2013): the nursing staff might have experienced limitations in time or the ability to provide space for the older person's emotional distress. Finally, responses that reduce space may also be a result of the nursing staff lacking attentiveness to cues, which risk being missed in the overall communication due to their implicit nature.

Responses that reduce space also occurred more often if the older person was male or 85 years or older, revealing a risk that older persons' opportunity to receive space for their emotional distress is influenced by their age and sex

(Study III). This may be discussed as a possible result of age-related changes, but also as a result of norms and stereotypes in society (Plant, Hyde, Keltner, & Devine, 2000; Shields, 2013). One example of this is ageism, which is a generalisation and objectification of what it means to be old (McGuire, Klein, & Chen, 2008). It is important for nursing staff to be aware of the possible influences of norms and stereotypes when encountering and responding to older persons' emotional distress. Otherwise, the emotional comfort they provide risks being unequal and inconsistent, with emotions possibly going unattended, with possible effects on the older person's experience of health.

5.3 Person-centred aspects in home care communication

The communication during home care visits with RNs revealed a high degree of person-centredness (Study IV). The degree of person-centredness indicated that the communication often focused on the older person and their own wishes and needs rather than on the nurses' own agenda for the home care visit. This may be perceived as positive, since a focus on older persons' individual needs and experiences is emphasised as central for their experience of satisfaction and health (McCabe, 2004; Turjamaa et al., 2014; World Health Organization, 2015). A person-centred communication may be viewed as a shift from a complementary communication to a symmetrical communication, according to the fifth axiom of communication theory (Watzlawick et al., 1967/2014). Complementary communication occurs in home care interaction, with the nursing staff and older person complementing each other through their differences. Complementary behaviour may result in a more asymmetric interaction, for example when giving instructions for medical treatment, which also is an important part of home care.

With the frequency of socio-emotional and personal talk in the communication, it became clear that the nursing staff were often involved in topics that were beyond the biomedical or task-focused reasons for the visit (Studies II & IV). These results were confirmed when different home care visits were explored, i.e. with or without a medical procedure, which showed no significant association with the degree of person-centredness. Nor did the intent of the visit show any great differences regarding the averages of task-focused or socio-emotional elements in the communication (Study IV). These results may be discussed in the light of the second axiom by Watzlawick et al. (1967/2014): how communication implies the relationship. Reflecting upon the second axiom, the intent of the visit would be secondary to the context and the RNs and older persons would communicate as they usually do, based on their previous relationship and shared context. The results further display how the nursing staff show interest in the older persons' social and emotional

needs, not focusing on them merely as receivers of help or care but as persons. This should be considered essential, because when RNs show understanding they can help justify a person's feelings and alleviate anxiety and ambiguous feelings (McCabe, 2004) and help the person restore and regain autonomy (Fredriksson, 2003).

In contrast to previous RIAS studies' significant results regarding gender differences (Roter & Hall, 2004; Roter, Hall, & Aoki, 2002), only time was shown to have a significant association with the degree of person-centredness in the home care visits (Study IV). The degree of person-centredness was significantly associated with the length of the visits, indicating that visits longer than five minutes can provide more opportunities for establishing communication that can be described as person-centred. The degree of person-centredness varied in the longer visits, and peaked in those lasting around eight to nine minutes, revealing that an increase in length does not give a similar increase in person-centredness. This might not be new knowledge, as previous research reports that time is a crucial, but lacking, prerequisite for attending individual needs (Breitholtz et al., 2013; Choe et al., 2014; Turjamaa et al., 2014). Time can often be restricted by the home care routines, which gives nurses little space for attending to older persons' individual needs or wishes (Breitholtz et al., 2013). With the opportunity and time to talk with the older persons, the communication can be more attentive to individual needs, beliefs and wishes, enhancing the possibilities for a more person-centred communication and home care.

At present in Sweden, there are few guidelines for how to establish person-centredness when caring for older persons. There are national guidelines for caring for people with dementia (The National Board of Health and Welfare, 2017), however, which state that persons with dementia should receive person-centred care. While there are currently no similar national guidelines for Swedish elderly care, a directive for a national quality plan was published in 2017, emphasising the importance of and need for person-centred care for older persons (Ministry of Health and Social Affairs, 2017). The process of implementing person-centred care for older persons in Sweden appears to be proceeding slowly. Despite the slow progress, however, the results of this thesis show that there are aspects in home care communication that can be discussed in relation to person-centred values. If a truly person-centred home care is to be established, the conception of person-centredness needs to be rooted and maintained throughout the whole organisation (McCormack et al., 2017). Sufficient support and preconditions are important for nursing staff when carrying out person-centred care, but also for upholding the continuity of person-centred care and communication for older persons.

5.4 Methodological considerations

5.4.1 Study design

All four studies had a quantitative design. Quantitative methods were used for analysing the qualitative content of the communication in audio-recorded home care visits. Through the extensive qualitative content in the audio-recorded home care visits, it was possible to implement qualitative elements in Studies I and II.

As part of an international research project, COMHOME (Hafskjold et al., 2015), the studies were partly predefined by the project. The COMHOME project is a collaboration between the countries of Sweden, Norway and the Netherlands. A mix of both quantitative and qualitative methods may have been desirable from a learning perspective, as this thesis is the result of doctoral studies. A qualitative content analysis was planned for Study III in order to be able to describe the content of the home care communication (Graneheim, Lindgren, & Lundman, 2017; Graneheim & Lundman, 2004). Based on the results of Studies I and II, it became apparent that more knowledge was needed concerning the VR-CoDES in home care communication, and statistical analyses were used in order to explore possible effects on VR-CoDES (Study III). Since the COMHOME project also had a person-centred approach, it became evident that there was a need to explore the degree of person-centredness in home care communication in the Study IV.

The analyses were able to both capture the communication of emotional distress as well as establish the degree of person-centredness in the communication. Ekman (1992) defines six basic emotions, all of which are represented through the four studies of this thesis.

5.4.2 Sample

The sample of participants was a combination of a purposeful and a convenience sample. The intent was to include a variety of participants, for example of different sexes, ages, professions, living conditions, and home care visits with different care or help activities, of different lengths and times of the day. Efforts were made to include both males and females, resulting in approximately one-third male participants, although the majority were females. Very few of the older persons were cohabiting with someone; the majority lived alone (Study I). In Sweden, one-third of the population aged 65 years or older live alone, and a longitudinal study of older persons in central Sweden revealed that 80% of older persons who received some form of care, either home or residential care, lived alone and that the majority were females (Ministry of Health and Social Affairs, 2017). It was regarded as important to involve both RNs and NAs in the sample as they represent two large groups of employees

in home care (Ministry of Health and Social Affairs, 2017; World Health Organization, 2008).

Due to difficulty recruiting nursing staff, often due to heavy workload and feelings of stress, nursing staff experiencing the most stress may be underrepresented or missing in the sample. Furthermore, all audio recordings were from home care visits in a county in central Sweden, providing data from a specific region and care context, i.e. home care. This may impact on the studies' generalisability to other care contexts as well as internationally. However, the collected data consist of a vast number of hours of audio-recorded home care visits. These visits have shown to contain great variety regarding the content as well as the communication in the different visits. These data contribute information on a limited area of research, the naturally occurring communication in home care.

5.4.3 Data collection and analysis

The audio recordings proved to be an effective way of gathering the naturally occurring communication during the home care visits. The recording equipment was small and fairly easy to use, which allowed the nursing staff to manage it independently. This allowed for the home care visits to be as natural as possible, with no extra person present to handle the equipment. Meanwhile, the audio recordings are limited to the verbal or para-verbal communication (Boon & Stewart, 1998) whereas any visual indicators, such as body language, have been lost. Audio recordings have been shown to be as good as video recordings in terms of capturing affective communication (Williams et al., 2013). It was also an ethical concern whether or not to use video recordings or to have additional persons, i.e. a researcher, present to record and observe the home care visits. Video recordings are more revealing, for better or worse, of the often intimate and private contexts of home care visits. The present studies aimed to observe the emotional and person-centred communication and to use code instruments appropriate for analysing audio-recorded data. A need of video- compared to audio-recorded home care visits was therefore difficult to justify, considering the risks of unnecessary exposure of the participants and intrusion into their homes and received care. The audio recordings seem to have sufficiently captured the socio-emotional and affective communication during the home care visits. Despite the audio recordings' important contribution to the results, it would have been interesting to view the posture or body language of the participants as a complement to the verbal and affective tone.

There is always a risk for bias when audio-recorded communication is used, as the awareness of being audio recorded may affect how nursing staff and older persons communicate. It may also affect whom the nursing staff choose to audio record their visit with. However, there are examples in the audio-

recorded data of less desirable features in the communication, such as expressions of anger, irritation, dissatisfaction and disagreement, from both the nursing staff as well as the older persons. This may indicate that it would have been difficult to avoid interactions with less socially desirable features in the communication. Another point worth mentioning is that the participants did not know what I was looking for in the communication, which may have made it difficult for the participants to know how to modify the communication.

How the data were collected posed challenges regarding the analyses. With repeated recordings of the same participants and the aim to record the naturally occurring communication, the content of the data was unpredictable regarding the presence of cues and concerns, but the data were also clustered. It took some time before the solution of using GLMM was chosen and help was obtained in understanding and performing the analyses. GLMM was beneficial for handling bias caused by the clustered data, for decreasing the risk of type 1 errors, but also for handling a non-normal distribution. GLMM can handle targets that are non-normally distributed, and is therefore useful for count and dichotomous outcomes. One cannot assume a normal distribution with count and dichotomous results, as count often contains many zeros in the distribution and dichotomous takes the values of 0 or 1 (Heck et al., 2012).

Another challenge when using audio-recorded data, when coding with both VR-CoDES and RIAS, was disturbances in the environment of the home care setting. Background noises, clothes rasping, phones ringing, water flushing, and persons moving around or into other rooms, are examples of conditions that impacted on the audio quality. These audio disturbances also demanded a re-listening of communication sequences in order to capture the affect or content. However, when capturing naturally occurring communication these challenges may be difficult to counteract without risking too much manipulation of the visit or the communication.

5.4.3.1 VR-CoDES and RIAS

This thesis has a person-centred approach based on the starting point of viewing older persons in home care as *persons* rather than patients. Home care is different to hospital or primary care, with older persons receiving daily help and care on a regular basis in their own homes rather than being patients seeking healthcare. However, the concept of patient-centred has been used for a longer time and is still often used in health communication and medical dialogues. Even if person-centredness is gaining ground, there are few analysis methods for person-centredness. Methods for measuring person-centred care often focus on measuring how either patients or healthcare providers rate the degree of perceived person-centred care (Edvardsson & Innes, 2010), or on outcomes of different interventions for person-centred care (Coleman & Medvene, 2013). One observational tool for coding and analysing person-cen-

tred actions in naturally occurring interaction, using the Person-Centered Behavioural Inventory [PCBI] and the Task-Centered Behavioural Inventory [TCBI] (Coleman & Medvene, 2013; Lann-Wolcott, Medvene, & Williams, 2011), has been found through literature searches. However, this tool is used for video observations, containing categories in need of this type of observation in order to be coded. Due to this current lack of observational tools for person-centred communication, the choice was to instead use RIAS, a well-used, reliable and validated instrument for measuring patient-centredness in communication (Roter & Larson, 2002). RIAS makes it possible to measure the degree of person-centred communication in naturally occurring communication in human interaction in either video or audio recordings. Therefore, RIAS allowed our audio recordings to explore whether the communication in home care could be considered to include the key aspects of person-centredness, focusing on the person rather than illness and biomedical tasks.

Both VR-CoDES and RIAS entail a quantification of qualitative data. There is a risk that, by coding the communication, other relevant aspects of the communication may be missed due to the rules of coding schemes. Furthermore, no conclusions can be drawn as to whether the communication was *experienced as* or merely *intended to be* person-centred by the participants since the collected data consist only of the audio-recorded home care visits. However, both RIAS and VR-CoDES were originally constructed for medical consultations but have been used, validated and reported in previous studies within different contexts (Eide, Eide, Rustøen, & Finset, 2011; Hafskjold et al., 2016; Roter & Larson, 2002; Zhou et al., 2014). In the audio-recorded data from home care, RIAS and VR-CoDES successfully established measurements of both emotional distress and socio-emotional and task-oriented communication. The validity of the instruments for the present studies was checked through comparisons and discussions with previous studies and within the COMHOME research project. The inter-rater reliability was tested for both VR-CoDES and RIAS. Furthermore, continuous consultations and discussions have been held within and between the different international research groups in COMHOME regarding the code instruments. I have also attended workshops in order to establish an understanding of the instruments. This has secured the reliability of using the coding schemes and analyses. The use of coding schemes and the practice of listening to the communication demanded accuracy and concentration in order to locate and assess the coding of the communication sequences. Therefore, co-coding was important and useful for learning how to code before the inter-rater reliability tests were conducted.

The VR-CoDES are described as non-normative, and do not label responses as good or bad (Del Piccolo, 2017). However, positive outcomes from responses that provided space for the further disclosure of an expression of emotional distress can be discussed. Supporting someone in narrating about

emotional distress and being able to listen and provide emotional support have been emphasised as important, both throughout this thesis and in previous research. This way of responding can further be connected to a person-centred communication in which the ability to listen to narrative is central to retrieving knowledge about the other person's situation, needs, and wishes. Handling the VR-CoDES as an instrument that does not label responses as good or bad has been difficult and, in today's emphasis on person-centred care, perhaps even unsuccessful. VR-CoDES were developed for medical consultations (Zimmermann et al., 2011), but have also proven to be a useful instrument for identifying and coding emotional communication in home care settings. This has resulted in insight into how nursing staff handle and respond to emotional distress during home care visits.

Other challenges when using VR-CoDES are evident in the nature of home care visits. Home care is performed in the older persons' homes, their familiar arena, which the nursing staff often visit on a daily basis. The communication was often a mixture of social talk and more medical or task-focused talk. The content of the communication was often unpredictable and could quickly change, both regarding the affect and content of the communication. It became challenging to stay attentive and identify expressions of emotional distress in the communication, which could easily be concealed by the everyday talk. Therefore, repeated listening to some parts of the communication was conducted in order to check for missed expressions of emotional distress. The affective tone of voice was a helpful indicator for going back and listening to the communication again. Ambiguous sequences were discussed and solved, either by listening further to the subsequent communication or discussing this with supervisors.

5.5 Ethical discussion

There is always a need for ethical considerations when involving persons in research (Polit & Beck, 2018; WMA General Assembly, 1964/2013), and in this thesis the data consisted of communication from home care, provided in older persons' private homes. It was essential to protect both the nursing staff and the older persons who participated. One ethical aspect concerned unnecessary exposure of the participants and the often intimate content of home care visits. The nursing staff were informed that they could stop the audio recording at any time if needed, or if requested by the older person. This is a way to protect the participants from harm and discomfort, and to be sensitive to them (Polit & Beck, 2018). While the audio recordings may not be regarded as posing any major ethical risks to the participants, they could be experienced as sensitive or intrusive.

Older persons are dependent on the home care they receive, which can make them vulnerable when agreeing or declining to participate. Therefore, it is crucial to provide information concerning the voluntary nature of their participation, their right to withdraw, and confidentiality. While I have no information on how many older persons chose not to participate, I do know that some did decline participation. The same ethical considerations and rights were applied to the nursing staff.

With the home care visits being audio recorded, the nursing staff might feel controlled or judged in their way of communicating or providing home care. They were informed that their participation was voluntary, and were assured confidentiality. Confidentiality was upheld by providing each participant with a unique code, and the codes were stored separately from the audio recordings. However, audio recordings can include the exposure of how the nursing staff and older persons communicate, and can contain private and intimate information about the older persons, but also sometimes about the nursing staff, during the home care visits. What is said during the audio recording cannot be unsaid, and the researchers must treat any confidential information with respect in order to prevent the unnecessary exposure of those receiving or providing home care. Only information that was relevant to the results has been analysed and reported, and the quotes were carefully selected to be informative while not violating the confidentiality between the nursing staff and the older persons.

Another ethical consideration is the power balance between the nursing staff and the older persons. The older persons are dependent on the care and help provided by the nursing staff, and the nursing staff were the ones who asked the older persons if they would be willing to participate. There is therefore a possible risk that the older persons felt obliged to participate based on the asymmetric power relation between them and the nursing staff. Another possible ethical consideration is that the nursing staff and older persons have a close relationship whereby they interact on a friendly basis, a relationship that has evolved through their daily interactions. The older persons might have agreed to participate as a way to be nice and accommodate a friendly request, or out of fear that they might otherwise risk this relationship or negatively affect their care (Sandman & Kjellström, 2018).

6 Conclusions and practical implications

Home care communication was multifaceted in the four studies, but was foremost socio-emotional rather than task-focused or biomedical. The results show that older persons need both social interaction as well as emotional support and comfort when receiving home care.

Through an exploration of the socio-emotional and task-focused communication in the home care visits, person-centred aspects were revealed. However, even if the communication can be discussed in the light of person-centred values, it is not possible to draw any conclusions as to whether the communication was intended to be person-centred. As previously noted, person-centredness needs to be implemented and coordinated throughout the organisation if it is to function accordingly. That the communication is actually person-centred would be an overly facile conclusion to draw. The following conclusions can be drawn based on the results from the studies:

- The communication during home care visits was often person-centred, with the nurses providing space for the older person's narrative, focusing on their emotional and social needs in addition to the task-focused and biomedical content.
- Emotional distress was often implicit and expressed vaguely, which may challenge nursing staff's attentiveness in the communication and the provision of emotional support.
- Characteristics of the home care visits, such as sex, age and time, further influenced the emotional and person-centred communication. Sex was the characteristic that frequently influenced the communication of emotional distress: older females expressed more emotional distress and received more space in the communication, and female nursing staff received more emotional distress in the home care visits. The respective influence of different characteristics needs to be acknowledged in order to uphold an equal home care and maintain older persons' experience of health and wellbeing.

6.1 Practical implications

Knowledge drawn from these studies can help create an awareness of what to be attentive to in the communication, in order to more directly communicate regarding older persons' needs towards a person-centred communication. The results provide insight into the daily communication of home care visits regarding communication behaviour in practice, and reveal what older persons need to talk about, how they express emotional distress, and how nursing staff respond in the communication. The results further provide important awareness about influencers, such as sex or age, on socio-emotional communication in home care, which risk making the home care communication less equal and less person-centred. The results illuminate a multifaceted communication, indicating that it fills socio-emotional needs of the older persons that should not be forgotten or ignored when organising and providing home care.

Knowledge drawn from the studies of this thesis can further be used for educational purposes, for both nursing students as well as professionals, for training in detecting and responding to emotional distress and providing emotional support. This can be done, for example, through communication training with simulated situations.

At present, the results of this thesis are used in an upcoming doctoral thesis at the University of Borås, where an educational training intervention for person-centred communication has been developed and is currently being tested.

7 Future research

Studies involving the naturally occurring communication in home care are scarce in Sweden as well as internationally. More research regarding the content of home care visits would help provide a more comprehensive picture of a rather unexplored area of communication research. There is also a need of international comparisons of home care communication in order to draw conclusions regarding home care in different countries and contexts. The present results can further be used in intervention studies, in order to help implement person-centred communication and provide emotional support in home care.

The studies of this thesis do not reveal any knowledge as to whether or not the communication is perceived by the participants as person-centred or supportive of emotional distress, due to a lack of the participants' own experiences about the communication. However, the results of the studies provide knowledge about how nursing staff and older persons interact in the home care visits, revealing person-centred aspects and socio-emotional needs in the communication. Future research exploring older persons' and nursing staff's own experiences of home care communication in relation to emotional distress and person-centred values would help complement the present results.

Communication in home care can further be affected by differences in language and ethnic backgrounds; in Sweden, for instance, approximately 19% of the population was born outside Sweden (Migrationsinfo, 2019; Statistics Sweden, 2017). In Study III, native language was a predictor for exploring emotional distress, but more research, as well as a larger sample, is needed in order to explore future needs in home care for a growing ageing population with different ethnic backgrounds. Excluded in these studies were older persons with speech impairments; this group and their nursing staff encounter different forms of communicative challenges, and their interactions are another important area to explore in future research.

8 Svensk sammanfattning

Kommunikation är en central del av vård och omsorg. Inom vård och omsorg betonas vikten av att skapa delaktighet och en kommunikation där vårdpersonalen är lyhörd, genuin och involverad, vilket inte alltid varit självklart. Under de senaste årtionedena har det skett en förändring, från en paternalistiskt styrd vård där ordinationer och direktiv strikt skulle efterföljas, till en vård som involverar vårdtagarna som medskapare av den egna vården. Redan under 1950-talet började den amerikanske psykologen Carl Rogers förespråka vikten av att sätta personen i centrum, att lära känna och få kunskap om hans/hennes preferenser, önskemål och behov.

Personcentrering och patientcentrering är begrepp som ibland används synonymt och har många likheter, såsom empati, respekt, engagemang, relationer, kommunikation, delat beslutsfattande, holistiskt och individuellt fokus. Skillnader som framhållits är att personcentrerad vård har målet att människan ska leva ett meningsfullt liv medan patientcentrerad vård har målet ett funktionellt liv. Det har även diskuterats att personcentrerad vård har fokus på personen, som ibland är patient, men att patientcentrerad vård fokuserar på rollen som patient. Äldre personer med vård och omsorg i hemmet är inte främst patienter i behov av sjukvård. Därför används begreppet personcentrering i denna avhandling för att beskriva ett fokus på den äldre personen med målet att leva ett meningsfullt liv. Att äldre personer med vård och omsorg i hemmet ska ha rätten att leva ett meningsfullt liv beskrivs även i Socialtjänstlagen, vilken utgör grunden för svensk äldreomsorg.

Antalet äldre i befolkningen ökar såväl i Sverige som internationellt. Möjligheten att bo kvar hemma finns reglerad i svensk lagstiftning och många äldre önskar bo kvar hemma trots en sviktande hälsa, då det innebär en trygg och familjär miljö. För att möta den äldre befolkningens behov och upprätthålla möjligheten att bo kvar hemma förespråkas en individanpassad vård och omsorg. Den vård och omsorg som sker i äldre personers hem planeras och beslutas ofta utifrån fysiska behov. Behoven kan bestå av hjälp att handla och städa, personlig hygien eller medicinska behov. För äldre personer innebär hembesöken även en social kontakt, framförallt för dem som lever ensamma. Därför fyller vårdpersonalen även ett socialt behov. Vårdpersonalen är medveten om detta men kan känna sig begränsade av sina arbetsrutiner och uppgifter, med litet utrymme för att möta de äldre personernas individuella behov eller önskemål. För vårdpersonalen kan det skapas en konflikt mellan att värna

om äldre personers självbestämmande och de uppgifter som de är ålagda att utföra.

I denna avhandling har kommunikationen mellan vårdpersonal och äldre personer studerats med hjälp av ljudupptagningar av 188 besök av vård och omsorg i äldre personers hem. Ljudupptagningarna inkluderar hembesök med 20 undersköterskor och 11 sjuksköterskor hos 81 personer äldre än 65 år, som mottog någon form av hjälp- eller vårdinsats.

Resultaten i Studie I visar hur äldre personer gav uttryck för emotionell oro i ungefär hälften av de observerade besöken. Majoriteten av dessa uttryck var i form av hintar om en underliggande negativ emotion. Det var sällan de äldre personerna tydligt uttryckte sina emotioner explicit, exempelvis berättade att de var ledsna eller arga. De vaga uttrycken av emotionell oro kan skapa utmaningar hos vårdpersonalen att vara lyhörda och uppfatta dessa hintar i kommunikationen. Det är dock betydelsefullt att hjälpa de äldre att få sätta ord på sina upplevelser för att lättare förstå och hjälpa dem hantera sin emotionella oro.

Därför undersöktes i Studie II hur vårdpersonalen svarade an på de äldre personernas uttryck av emotionell oro. Det framkom att vårdpersonalen ofta på olika sätt uppmuntrade och gav utrymme för de äldre personerna att berätta mer om hur de kände. Genom att ge de äldre personerna utrymme och hjälpa dem sätta ord på sina upplevelser får vårdpersonalen en möjlighet att lära känna och förstå vad det är den äldre personen vill och önskar. Att lyssna in och låta de äldre personerna få berätta kan kopplas till ett personcentrerat förhållningssätt. I ett personcentrerat förhållningssätt är aktivt lyssnande, berättelsen och empati viktiga delar för att skapa en relation där personen vågar framträda och känner sig accepterad och bekräftad.

I Studie III undersöktes vad som kan påverka den emotionella kommunikationen. Det framkom att de äldre kvinnorna uttryckte mer emotionell oro än de äldre männen, och att den kvinnliga vårdpersonalen mottog fler uttryck av emotionell oro än de manliga kollegorna. Vidare framkom att vårdpersonalen som var sjuksköterskor eller hade svenska som förstaspråk var de som oftast initierade de äldre personernas uttryck av emotionell oro. Detta kunde ske i form av frågor om hur den äldre personen mådde, vad de hade för upplevelser eller tankar under besöket. Slutligen framkom det även att äldre kvinnor eller äldre personer yngre än 85 år var de som främst fick utrymme att få berätta om och utveckla sin upplevda emotionella oro. De fynd som framkom kan diskuteras i förhållande till föreställningar och normer, samt deras eventuella betydelse för kommunikationen med äldre personer. Det är riskabelt att generalisera människor eftersom de då slutar att framstå som personer. Detta medför att hur vi agerar i möten med andra människor styrs av en stereotyp förväntan vilken inte behöver stämma överens med verkligheten. Då skapas även en risk för att vård och omsorg inte sker på lika villkor där kvinnor och män, eller yngre och äldre, inte får samma förutsättningar.

I Studie IV framkom att graden av personcentrering var hög i den kommunikation som studerats. Detta antyder att vårdpersonalen fokuserar på de äldres egna behov och önskemål i mötet, och inte främst på den egna agendan för besöket. Graden av personcentrerad kommunikation blev även högre om besöken var något längre, och var som högst i besök som var 8-9 minuter långa. När uppgiftsfokuserade och socio-emotionella uttryck sammanställdes i besöken framkom att innehållet i kommunikationen främst var socio-emotionell. Vården i hemmet av äldre har kritiserats för att främst vara utformad utifrån äldre personers fysiska behov, styrd av rutinbaserade uppgifter. I denna avhandling framkom snarare att den uppgiftsfokuserade eller medicinska kommunikationen inte dominerade. Tonfallet i samtalen var övervägande positiv där både äldre personer och vårdpersonal uttryckte vänskaplighet, värme och intresse för varandra. Likväl förekom även mindre positiva tonfall i besöken vilken ändå tyder på att kommunikationen är mångfacetterad såväl angående dess samtalsämnen som tonfall.

Det som främst framkom genom de fyra delstudierna var att kommunikationen vid vård i eget hem främst var personcentrerad. Vårdpersonalen gav ofta utrymme för de äldre i kommunikationen. Vårdpersonalen fokuserade på de äldre personernas socio-emotionella behov, likväl som på deras behov av omsorg och medicinska insatser. Emotionell oro förekom i kommunikationen och var främst implicit, vilket kan utmana vårdpersonalen i att fånga upp uttrycken och ge emotionellt stöd. Kön, ålder och tid är exempel på karakteristika som påverkade den emotionella och person-centrerade kommunikationen. Hur olika karakteristika kan påverka kommunikationen behöver uppmärksammas för att upprätthålla en jämlik vård och bibehålla upplevelsen av hälsa och välbefinnande hos äldre personer.

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