Person-centred care and communication disorders

Exploration and facilitation of conversational interaction involving people with acquired neurogenic communication disorders and health care providers

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Gothenburg, Sweden, 2017



Cover illustration by Christina Pettersson Back-cover photo by Walle Grünewald

Person-centred care and communication disorders – Exploration and facilitation of conversational interaction involving people with acquired neurogenic communication disorders and health care providers © 2017 Emma Forsgren emma.forsgren@neuro.gu.se

ISBN 978-91-629-0171-4 (PRINT) ISBN 978-91-629-0172-1 (PDF) http://hdl.handle.net/2077/51885

Printed in Gothenburg, Sweden 2017 Ineko AB

When life gives you lemonade, make lemons.

Life will be all like "whaaat?!"

- Phil Dunphy

Abstract

Functional communication is a prerequisite for person-centred care. However, the presence of acquired neurogenic communication disorders makes the delivery of person-centred care challenging for health care providers and they must therefore depend on using supportive communicative strategies.

Purposes: This thesis has three overall purposes: (1) To describe the experiences of communication in health care settings from the perspectives of people with acquired neurogenic communication disorders, enrolled nurses and medical students, (2) To explore the effects of two methods that are designed to facilitate communicative interaction in clinical practice, and (3) To investigate how the effects of intervention on conversational interaction may be evaluated using quantitative and qualitative methods.

Methods: The thesis entails four studies. Study I is an interview study involving 8 enrolled nurses. Study II is an implementation study with multiple-case design using goal attainment measurements, questionnaire data and interviews. This study involves 32 enrolled nurses, 10 residents and 6 unit managers. Study III is an intervention study of 69 medical students (including 33 medical students in a reference group) in which outcomes are assessed using questionnaires, and observation and quantification of communicative strategies. Study IV is a methods study that uses quantitative coding systems and a qualitative analysis to explore a conversation between an enrolled nurse and a person suffering from dementia.

Results: In study I, the enrolled nurses reported on their knowledge of several supportive communication strategies and their awareness of the importance of personal relationships with residents in facilitating interaction. However, factors in the environment were found to present barriers to communication. In study II, the success rate for implementation at each of the two nursing homes that were studied was moderate, and the motivation among staff to bring about changes differed. The enrolled nurses reported that they found communication with residents challenging while the residents felt that it worked well. In study III, the students reported that they experienced communicating with patients as challenging both before and after they had received training. However, the students' knowledge and use of supportive communication strategies had increased to a statistically significant degree after the training workshop. In study IV, it was found that only one of the two coding systems used in the analysis identified issues besides those relating directly to facilitating strategies, while the qualitative analysis yielded important results that neither of the coding systems could provide.

Conclusions: Enrolled nurses and medical students find communication with people who are suffering from communication disorders challenging, though they realise that they can play an important role in facilitating communication. However, the perspectives of enrolled nurses and medical students differed from that of the people suffering from the disorders. Interactive training of students as part of their basic education may help improve their knowledge and skills in practicing supportive communication. It was also found that factors, such as management, time allocation and staff continuity, are crucial for the successful implementation of communication routines in nursing homes. It is clear that there is a need for reliable and valid methods of assessing communicative interaction in person-centred care. Neglecting contextual factors in the analysis of interaction presents problems when used to assess person-centred communication.

Keywords: person-centred care, acquired neurogenic communication disorders, communicative interaction, enrolled nurses, medical students, quantitative methods, qualitative methods, mixed method

Sammanfattning på svenska

En person som har fått en hjärnskada på grund av en stroke eller en neurologisk sjukdom kan ha svårt att förstå vad andra säger och att uttrycka sig i tal och skrift. I sjukvården har man sett att personer med tal- och språkstörningar oftare än andra patienter råkar ut för olyckor och felbehandling. För att säkerställa att denna grupp av patienter får en fullgod personcentrerad vård, som utgår ifrån patientens unika personlighet och dennes erfarenheter, resurser och behov, behöver vårdpersonal veta hur de kan underlätta i mötet. Detta kan göras genom att vårdpersonalen till exempel använder olika stödjande samtalsstrategier i sitt arbete.

Avhandlingen har tre huvudsakliga syften. Det första syftet var att undersöka personer med tal- och språkstörningars, undersköterskors och läkarstudenters erfarenheter av samtal i vård- och omsorgssituationer. Vidare hade avhandlingen som syfte att undersöka effekten av två metoder för att underlätta samtal. Det tredje, och sista syftet var att undersöka hur man med olika metoder kan utvärdera vilken effekt träning av kommunikation har på samtal.

Avhandlingen består av fyra delstudier. I studie I intervjuades åtta undersköterskor för att undersöka deras upplevelse av samtal med boende med kommunikationssvårigheter på särskilda boenden. I studie II utvärderades en implementeringsmodell för att införa rutiner rörande kommunikation på två boenden med hjälp av målbedömning, frågeformulär, och intervjuer. Deltagarna i studie II är 32 undersköterskor, tio personer med olika kommunikationssvårigheter och sex enhetschefer. Studie III undersökte utbildning i stödjande samtalsstrategier för 69 läkarstudenter (inklusive 33 läkarstudenter i en referensgrupp). I denna studie användes frågeformulär och observation av användning av stödjande strategier i videoinspelningar. Slutligen är studie IV en metodstudie där tre olika metoder (två kvantitativa och en kvalitativ) för att undersöka kvalitén i ett samtal jämfördes.

Resultatet från studie I visade att de intervjuade undersköterskorna upplever att de har kunskap om stödjande samtalsstrategier och en medvetenhet om vikten av personliga relationer med de boende för att underlätta samtal. Trots detta upplevs faktorer i miljön såsom tidsbrist och ständiga avbrott

utgöra hinder för att bra samtal ska kunna genomföras. Utfallet i studie II tyder på lovande resultat av modellen för införandet av nya rutiner på ett av de deltagande boendena. Trots detta var den totala framgången endast måttlig. Motivation till förändring tycktes skilja sig mellan de tyå boendena och det fanns många hinder för genomförandet. I denna studie visade resultatet även att undersköterskorna uppfattade kommunikationen med de boende som relativt svår medan de boende uppgav att det fungerade bra att prata med personalen. I studie III rapporterade läkarstudenterna att de uppfattade det som ganska svårt att kommunicera med personer med tal- och språkstörningar både före och efter träning. Vidare visade resultatet att studenternas kunskap om användning av stödiande kommunikationsstrategier efter utbildning var signifikant högre endast i gruppen som fått utbildning och inte i referensgruppen. Analysen av videoinspelade samtal visade också att studenterna använde nya stödjande strategier efter workshopen. Resultaten i studie IV visade att endast en av de två kvantitativa metoder som användes vid analysen av kommunikationsstrategier kunde identifiera problem förutom användning av strategier. Den kvalitativa analysen bidrog med viktig information som inte kunde ses i användning av de kvantitativa kodningssystemen.

En slutsats som kan dras utifrån denna avhandling är att både undersköterskor och läkarstudenter upplever att det är relativt svårt att kommunicera med personer med tal- och språkstörningar. Trots detta, upplever de samtidigt att de har en betydelsefull roll i att kunna underlätta samtalen. Vidare kan sägas att det finns en diskrepans mellan hur undersköterskor och läkarstudenter uppfattar kommunikationen jämfört med hur personer med kommunikationssvårigheter uppfattar den. En annan slutsats som kan dras utifrån resultaten är att ett interaktivt träningsmoment under en grundutbildning kan öka läkarstudenters kunskap om, och förmåga att använda, strategier för att underlätta i samtal. Faktorer såsom en aktiv ledning, tid och personalkontinuitet har stor betydelse för implementering av rutiner för att underlätta i samtal på särskilda boenden. Slutligen kan sägas att det finns ett behov av reliabla och valida instrument för att kunna utvärdera samtal inom en person-centrerad vård och att ignorera kontexten i analys av person-centrerad kommunikation är problematiskt.

List of papers

This thesis is based on the following studies referred to in the text by their Roman numerals

- I. Forsgren, E., Skott, C., Hartelius, L., & Saldert C. (2016). Communicative barriers and resources in nursing homes from the enrolled nurses' perspective: A qualitative interview study. *International Journal of Nursing Studies*, 54, 112-21.
- II. Forsgren, E., & Saldert, C. (2017). Implementation of communication routines for the facilitation of person-centred care: A case study involving two nursing homes. *Submitted for publication*.
- III. Forsgren, E., Hartelius, L., & Saldert, C. (2016). Improving medical students' knowledge and skill in communicating with people with acquired communication disorders. *International Journal of Speech-Language Pathology*, Published online 31 Aug.
- IV. Forsgren, E., & Saldert, C. (2017). Exploring person-centred communication strategies: A comparison of three analysis methods. *Submitted for publication*.

Study I is reprinted with kind permission from *International Journal of Nursing Studies* © 2015 Elsevier Ltd. http://dx.doi.org/10.1016/j.ijnurstu.2015.05.006

Study III is reprinted with kind permission. It is the authors accepted manuscript of an article published as the version of record in *International Journal of Speech-Language Pathology* © 2016 The Speech Pathology Association of Australia Limited. http://dx.doi.org/10.1080/17549507.2016.1216602

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Definitions

Enrolled nurse This title refers to a person who has completed a high-

school education in nursing or a sixty-week course at post-secondary level. An enrolled nurse performs daily care tasks under the supervision of registered nurses.

Nurse's aide This title is used for staff who have no formal nursing

education but who perform the same daily care tasks as

enrolled nurses in nursing homes.

For the sake of simplicity, the term *enrolled nurse* will be used in this thesis to include both enrolled nurses and nurses' aides.

DEFINITIONS 10

Introduction

Communication in health care settings

Functional communication between patients and health care providers is described as the most important criterion that patients perceive for high quality care (Mohammed et al., 2016). In hospital settings, when patients consider the communication to be poor, this tends to increase feelings of anxiety and insecurity, while patients who experience good communication and clear information feel reassured and are more likely to participate in their own care (Russel, 1999). The power imbalance inherent the therapeutic relationship has also been described as affecting interaction since the patient's sense of vulnerability and dependence may be exacerbated or eased depending upon how the staff behave.

Long-term care institutions have been criticised for focusing primarily on physical care and failing to facilitate communicative interaction (Nussbaum, 1991). In these settings, interactions are often brief and non-verbal (Ward, Vass, Aggarwal, Garfield, & Cybyk, 2008) and it has been noted that they tend to over accommodate (or overly adapt) to stereotypes of the elderly (Ryan, Hummert, & Boich, 1995). In practice, this means that older people's competence and communicative ability tend to be overlooked and staff accordingly uses oversimplified speech (Ryan et al., 1995; Coupland, Coupland, & Giles, 1991) that can be patronizing (Ryan et al., 1995).

In addition to contextual factors, power discrepancies and entrenched communication habits among staff, language differences are becoming increasingly common and this creates additional challenges (Cioffi, 2003; Bischoff & Hudelson, 2010; Martinsson, Edberg, & Janlöv, 2013; Rosendahl, Söderman, & Mazaheri, 2016). Further, life expectancy is increasing and this means there are growing numbers of people at risk of developing acquired neurogenic communication disorders. This presents yet another challenge for communication both in hospitals (O'Halloran, Hickson, & Worrall, 2008) and in long-term care institutions (Stans, Dalemans, de Witte, & Beurskens, 2013).

Acquired neurogenic communication disorders

The American Speech-Language-Hearing Association's definition of a communication disorder is that it is 'an impairment in the ability to receive, send, process, and comprehend concepts or verbal, nonverbal and graphic symbol systems' (American Speech-Language-Hearing Association, 1993). A communication disorder may result from a focal brain damage (e.g. aphasia or/and dysarthria) or progressive degenerative disorders (e.g. Parkinson's disease or dementia). A speech disorder such as dysarthria may result in slow, quiet speech with indistinct articulation, while a language disorder such as aphasia can affect the ability to find and produce words and to understand others. Aphasia affects all aspects of language including the ability to read and write. A progressive disorder such as dementia may lead to changes in both speech and language and can entail problems such as word finding (Bayles, 1985) and topic management (Mentis, Briggs-Whittaker, & Gramigna, 1995).

In addition to the specific difficulties in speech and language experienced in association with brain damage, a person's overall communicative disability is also influenced by other factors. Personal characteristics, such as attitude and motivation, and contextual factors, such as communicative possibilities and the knowledge and skill of conversation partners, also affect the degree of communicative disability (World Health Organization, 2001).

Communication disorders in health care

Patients with communication disorders are perceived as challenging to diagnose and provide with information in the hospital setting (Ziviani, Lennox, Allison, Lyons, & Del Mar, 2004). They are also more likely to suffer accidents and be victims of medical misadventure than other patients (Bartlett, Blais, Tamblyn, Clermont, & MacGibbon, 2008). Nursing home residents who are suffering from dementia are often excluded from the planning of their care because they are simply assumed to be unable to participate in a meaningful way (Ward et al., 2008).

If staff are to enjoy more positive experiences of communicating with people with communication disorders, environmental factors, such as having time for communication and an interest in adapting one's behaviour according to the res-

ident's needs, are crucial (Stans et al., 2013). Also, the knowledge level and skills of health care staff with regards to communication has been reported as needing improvement (Burns, Baylor, Dudgeon, Starks, & Yorkston, 2015; Yorkston, Baylor, Burns, Morris, & McNalley, 2015; Carpiac-Claver & Levy-Storms, 2007; McGilton, Sidani, Boscart, Guruge, & Brown 2012a; Stans et al., 2013).

Person-centred care

Delivering person-centred care is considered to be tantamount to delivering high quality health care (McCormack, 2003; Edvardsson, Winblad, & Sandman, 2008; Ekman et al., 2011; Ekman, Norberg, & Swedberg, 2014). Person-centred care is one way of viewing how care should be conducted in a humanising way. with patient participation. Similar ideas include client-centred care (Rogers, 1949), shared decision making (Charles, Gafni, & Whelan, 1997), patient centeredness (Mead & Bower, 2000), person-centred nursing (McCormack & McCance, 2006) and person-directed care (White, Newton-Curtis, & Lyons, 2008). Person-centred care is based upon the premise that personhood is formed in relation to others (Kitwood, 1997). There is an emphasis on the preferences. feelings and needs of the person who is seeking care, and on collaboration between the patient and carer in creating a shared understanding of a situation (Ekman et al., 2011; Ekman et al., 2014). The patient is not considered to be a passive recipient of care and it is held that carers should not focus on the disability or on task completion. Instead, it is proposed, care should focus on the person's resources and competence. Person-centred care is thus not simply about encouraging patients' participation but about recognising the person behind their temporary role as patient.

The Swedish or Gothenburg model of implementing person-centred care builds on Paul Ricoeur's philosophical theories of personalism and ethics (Ricoeur, 1992; Kristensson Uggla, 2014; Ekman, Hedman, Swedberg, & Wallengren, 2015). Ricoeur describes first, second and third person personalism, which refer to the person, other people and the context respectively. A good life is 'the desire for an accomplished life, with and for others, in just institutions' (Ricoeur, 1992; Kristensson Uggla, 2014). In order to find out what a good life means to a particular person, their narrative - their own perception of their situation, preferences and needs - is central (Ekman et al., 2011; Ekman et al., 2014). By acknowledging the person and listening to their narrative, the carer can develop a

picture of *who* the person is. Ricoeur refers to this personhood as *ipse*, meaning an identity that persists over time (Ricoeur, 1992; Kristensson Uggla, 2014). Ricoeur also refers to another element of our identity, our *idem* or *what* we are, and this refers to characteristics that we share with others. Our total personhood thus consists of a number of elements that also define *what* we are, for example, a person with a particular diagnosis. Also, demonstrating one's personhood is always done in a context and through interaction with other people. The patient's narrative is the initial constitutive routine from which the carer and patient may then build a partnership. This process entails mutual respect between the two for the knowledge of the other party – the patient's knowledge about living with a disorder and the carer's professional knowledge about the disorder. The third routine is documentation. This means that what is agreed upon concerning care planning and management (the personal care plan) is safeguarded by being documented in the patient's medical journal.

It has been found that these three routines are used in various ways depending on the focus of care (Britten et al., 2016). However, it is clear that good communication is a prerequisite for person-centred care. In order to be able to collect personal narratives and to build a partnership, patients/residents and health care staff need to be able to understand each other. In order to facilitate interaction between people with acquired neurogenic communication disorders and health care staff, the participants' perceptions and experiences must be considered and their interactions should be observed in various contexts. Documentation (of communication ability and preferred communication strategies) is also essential to ensure both that the person suffering a communication disorder is able to participate and that others engage in partnership with them.

Studies of person-centred care in various settings (primary care centres, homes, hospitals) have shown that it has a positive effect on care costs, the length of hospital stays, patients' perceptions of care quality and their levels of anxiety, uncertainty and self-efficacy (Olsson, Jakobsson Ung, Swedberg & Ekman, 2012; Dudas et al., 2013; Pirhonen et al., 2017). In nursing homes, person-centred care has been used mainly in the care of dementia sufferers and it has reduced disruptive behaviour, agitation and the need for medication (Roth, Stevens, Burgio, & Burgio, 2002; Chenoweth et al., 2009; Cohen-Mansfield, Libin, & Marx, 2007; Fossey et al., 2006). However, its effect on longer-term outcomes for nursing home residents is still limited (Brownie & Nancarrow, 2013; Williams, Hadiistayropoulos, Ghandehari, Yao, & Lix, 2015).

Strategies to support communication

Supporting a person with a communication disorder in their interactions requires both knowledge about how different disorders affect communication and specific supportive communication strategies (Kagan, 1998; Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001; Legg, Young, & Bryer, 2005; Rautakoski, 2011; Burns, Baylor, Morris, McNalley, & Yorkston, 2012; Jensen et al., 2013; Yorkston et al., 2015; Simmons-Mackie et al., 2007; McGilton et al., 2011; Sorin-Peters, McGilton, & Rochon, 2010).

In the fields of ethnomethodology and conversation analysis, it is held that all communication builds on collaboration and that we normally assist each other in conversation (Atkinson & Heritage, 1984; Shiffrin, 1988; Schegloff, 1993). Many supporting strategies are therefore used in normal communication as well as in the presence of communication disorders. However, in conversations in which one party is suffering from a neurogenic communication disorder, the healthy partner must take greater responsibility for sustaining collaboration (Simmons-Mackie, 2008). Their level of skill will also affect how they assess the competence of the affected person (Savundranayagam, Ryan, Anas, & Orange, 2007; Kagan et al., 2001).

The healthy party may need to adapt both their verbal and non-verbal behaviour in order to support a conversation partner with a communication disorder to express themselves and understand what is said to them (Kagan, 1998; Simmons-Mackie, 2008; Rautakoski, 2011). For communicating with people suffering from aphasia, strategies such as giving them enough time to respond, putting forward just one idea at a time, asking questions, verifying responses, using gestures and low-tech aids such as pictures, writing and drawing have all been recommended. It has been noted that strategies involving verbal and non-verbal adaptations are often used more spontaneously than those involving writing and communication aids, i.e. strategies requiring additional tools (Simmons-Mackie & Damico, 1997; Morris, Clayman, Peters, Leppin, & LeBlanc, 2015; Rautakoski, 2011). Training in how to apply these strategies is also essential since their timing is so important (Kagan, 1998).

Some of the strategies that are recommended in caring for dementia sufferers are the same as those recommended for aphasia: giving the person time to respond (Sabat, 1991) and providing one direction or idea at a time (Wilson, Rochon, Mihailidis, & Leonard, 2012). Since dementia involves memory problems, using

different questions (closed ended and open ended) has also been debated. Closed ended questions are less demanding but some people with dementia may also respond well to open-ended questions. This kind of question may be appropriate in discussions about a person's personal wishes and requirements (Tappen, Williams-Burgess, Edelstein, Touhy, & Fishman, 1997). Further, questions that rely on semantic memory (general knowledge about the world) are often easier to respond to than questions that rely on episodic memory (e.g. what one has done during the day) (Small & Perry, 2005).

Training of health care staff

In addition to learning by doing in clinical practice placements, medical students and nursing students receive training in generic communication and interviewing skills, i.e. skills for communicating with patients who do not suffer from communication disorders (Schlundt, Quesenberry, Pichert, Lorenz, & Boswell, 1994; Egnew, Mauksch, Greer, & Farber, 2004; Back et al., 2007; Bowyer et al., 2010; Kiluk, Dessureault, & Quinn, 2012; Zavertnik, Huff, & Munro, 2010). Several such training programmes have been tested for health care professionals as well (Schlundt, et al., 1994; Ravasi, 1993; Booth, Maguire, Butterworth, & Hillier, 1996; Beckman & Frankel, 2003) and it has been found that training affects the skills and attitudes of students and health care staff towards patients (Kruijver, Kerkstra, Francke, Bensing, & van de Wiel, 2000).

Specific training in strategies for interacting with people who suffer from communication disorders is uncommon in health care education, but it has been tested in some studies among nursing assistant students and medical students (Welsh & Beideman Szabo, 2011; Legg et al., 2005; Burns et al., 2012; Yorkston et al., 2015; Saldert, Forsgren, & Hartelius, 2016). Programmes for increasing knowledge, training in the use of strategies and creating routines to facilitate communication with people with communication disorders have been tested in hospital settings (Simmons-Mackie et al., 2007; Jensen et al., 2015) and in nursing homes (Simmons-Mackie et al., 2007; Sorin-Peters et al., 2010; McGilton et al., 2011). Tools such as picture materials have been created (Jensen et al., 2015) and communication plans have been tried out in nursing homes (Généreux et al., 2004; McGilton et al., 2011; Sorin-Peters et al., 2010; Page, 2015). A communication plan is a summary of a person's communicative ability and preferred communication strategies that is integrated with the care plan. The use of these

plans has resulted in greater adaptation and use of strategies by care staff (McGilton et al., 2011).

Practical training and constructive feedback from peers and skilled facilitators are essential if training in specific communication skills is to be effective (Parry, 2008). Various pedagogical methods, such as experiential learning (Kolb, 1984; Kolb & Kolb, 2009) and model learning (Bandura, 1986), are useful in this. Experiential learning can be described as learning through direct experience followed by critical reflection about the experience. Model learning refers to a method by which people learn not only through trial and error but also by observing themselves and others and developing a model based on this (Bandura, 1986).

Training with real patients has been used to make training feel authentic and to provide motivation. It also offers medical students a chance to interact with a variety of patients (Booken et al., 2009). Another way of making training more realistic, as well as enabling trial and error in a safe environment, is by using standardised or simulated patients. This method has been successfully included in the training of health care students (Yoo & Yoo, 2003; Legg et al., 2005; Burns et al., 2012) as well as professionals (Schlundt, et al., 1994). The term standardised patients refers to people with a particular set of symptoms who are recruited to act as patients while simulated patients are actors or students who play the part of patients (Hill, Davidson, & Theodoros, 2010). Using simulated or standardised patients makes it easier to assess how knowledge is put into practice since theoretical learning does not always lead to a change in behaviour (Bandura, 1986; Hausberg et al., 2012; Mullan & Kothe, 2010). Also, medical students who were interviewed after trying these methods reported that meeting standardised or simulated patients was helpful for preparing them to make the transition from practicing with peers to meeting patients (Booken et al., 2009). It allows students to focus on communication skills and not only diagnostic skills. The students also noted that patients may find it troubling to meet an inexperienced clinician.

Implementation of strategies & resources

Although trials with particular methods may have shown positive effects, there are barriers for implementing new routines in real clinical settings (Grimshaw, Eccles, Lavis, Hill, & Squires, 2012). Research into implementation processes

has emerged in response to this. The data available to date is based on work carried out by researchers such as Pressman and Wildavsky (1973) and Rogers (1983; 1995), who carried out studies as early as in the 1970s and 1980s. However, interest in implementation research has increased considerably since 2000 (Boersma, vanWeert, Lakerveld, & Dröes, 2015).

Successful and sustainable change depends on several factors including which implementation model is used, what is to be implemented, the people involved and the characteristics of the organisation (Greenhalgh, Robert, MacFarlane, Bate, & Kyriakidou, 2004). For example, change is more likely to occur if the intended adopters/users feel that it is necessary i.e. if there is tension for change (Gustafson et al., 2003), if the people involved can see a relative long term advantage in changing practices (Mever, Johnson, & Ethington 1997), if implementation adapts to the local context (Gustafson et al., 2003; Wensing, Van Der Weijden, & Grol, 1998) and if managers support it (Rokstad, Vatne, Engedal, & Selbæk, 2015). Engaging key individuals or champions among the staff may also be beneficial (Backer & Rogers, 1998; Markham, 1998) and giving feedback on implementation progress may increase the likelihood of long-term success (Green, 1998). The effects of the researcher's or external change agent's presence also needs to be considered (Rogers, 1995). These people should be viewed as credible by the users, they should be able to develop good relationships and be able to view things from the users' perspective. They also need to empower the users to make their own decisions about implementation.

Implementation efforts take time. It has been estimated that it takes between 2-4 years for models with appropriate design and strategies to deliver positive results but that within 3 years, approximately 80 % of the intended adaptations may be expected to have taken place (Fixen et al., 2005; Fixen, Blasé, & Van Dyke, 2011). In investigating the barriers to implementation, the *Theoretical Domains Framework* (TDF; Michie et al., 2005; Cane, O'Connor & Michie, 2012) has been used in several studies (Francis, O'Connor, & Curran, 2012). This framework consists of 14 categories or domains that are built on theories of behaviour change. It highlights the importance of factors such as individuals' motivation and goals and the social influences that operate in the setting. Implementation research in health care has focused mainly on physicians and nurses rather than on other care professionals (Wensing, 2015) though it is recognised that implementation strategies are context sensitive (Wensing et al., 1998). This means that there is as yet no standard as to which implementation strategies should be used in which care contexts (Grimshaw et al., 2012).

Exploring & evaluating communication

Various methods have been used to explore and evaluate conversational interaction between people with communication disorders and health care staff. Quantitative methods that use questionnaires, coding systems, scales and checklists (in which behaviour is assessed, scored and/or rated) have proven helpful for exploring the effects of an intervention involving large numbers of participants. However, for exploring the context and the way in which participants collaborate, qualitative methods are advantageous (Wang, Hsieh, & Wang, 2013; Müller & Guendouzi, 2005; Müller & Wilson, 2008). Performing a qualitative analysis may be more time-consuming than coding, but it increases the ecological validity of the findings (Silverman, 2010).

Carers' knowledge about and perceptions of interactions have been explored using quantitative methods such as questionnaires. Examples include the Knowledge of Aphasia Ouestionnaire (KAO: Simmons-Mackie et al., 2007), The Montreal Evaluation of Communication Questionnaire for use in Longterm Care (MECO-LTC, Le Dorze et al., 2000), Communicative Access Measures for Stroke (CAMS; Kagan, Simmons-Mackie, Victor, Sharp, Conklin, & Jokel, 2012), and the Communication Impairment Ouestionnaire (CIO; Généreux et al., 2004). Another questionnaire that investigates performance in daily communication is the La Trobe Communication Ouestionnaire (LCO; Douglas, Bracy, & Snow, 2007), though it has been used mainly for self-assessment and assessment of significant others. An example of qualitative analysis that was conducted with the same objective is content analysis. This has been used to explore the experiences of nurses who have been working with long-term care in communicating with residents who suffer from dementia (Wang et al., 2013). Another method that has been used to explore residents' views of communication is the ethnography of communication (Müller & Guendouzi, 2009). This method entails seeking communication patterns that are specific to a particular cultural group.

The Better Conversation Checklist of Facilitators and Barriers (Beeke et al., 2013) has been employed to explore interactions between people who suffer communication disorders and significant others. It uses quantitative coding systems in which behaviours are classified and their frequency is counted. There are also scales that measure the transfer of information and social interaction. These include the Measure of skill in Supported Conversation (MCS, Kagan, 1999; Kagan et al., 2001; Kagan et al., 2004) and the Measure of Interaction in Communication-Support (MIC-S, Saldert, Backman, & Hartelius, 2013; Eriksson et

al., 2014; Eriksson, Forsgren, Hartelius, & Saldert, 2016). Qualitative studies include Conversation Analysis (CA), which has been used to explore interactions in nursing homes that involve people with communication disorders (Chatwin, 2014). Conversation Analysis was developed as an analytical method in the 1960s and its background is in sociology and ethnomethodology (Atkinson & Heritage, 1984; Ten Have, 2010). The principles of CA are that: analysis is data and participant-driven, conversation is orderly, sequential context is important and there is a wariness of quantification (Wilkinson, 1999; Beeke, Maxim, & Wilkinson, 2007). CA has been used in aphasia research (Goodwin, 2003) for exploring interaction and the planning of intervention (Wilkinson, 2014). It has also been used to explore communication involving people with intellectual disabilities (Antaki, 2013) and in dementia research (Chatwin, 2014; Müller & Guendouzi, 2005).

Whether or not communication is perceived to be person-centred has been studied mainly using methods of quantification. There are many tools available for this, such as the *Emotional Tone Rating Scale* (ETRS, Williams, Boyle, Herman, Coleman, & Hummert, 2012), which measures the emotional quality of staff communication. There is also the *Global Behaviour Scale* (GBS, Grosch, Medvene, & Wolcott, 2008; Lann-Wolcott, Medvene, & Williams, 2011), which codes general behaviour, such as whether the carer prioritises the person over the task. Williams et al. (2011) have also designed a coding system for counting the number of utterances by staff and residents that are instrumental (task focused), interpersonal (person-centred, focusing on the person) and superficial (greeting, small talk that is not specifically about the person).

There are also tools for looking more specifically at strategy use in relation to person-centred care. For example, The Person Centred Behaviour Inventory (PCBI, Grosch et al., 2008; Medvene & Lann-Wolcott, 2010; Lann-Wolcott et al., 2011) codes 11 verbal and eight non-verbal behaviours. However, these studies present no clear guidelines for how to apply this coding system. Savundranaygam colleagues have developed another coding and (Sayundranaygam, 2014; Sayundranaygam & Moore-Nielsen, 2015; Sayundranaygam, Sibalija, & Scotchmer, 2016) based on Kitwood's 12 examples of interaction (positive person work) that can enhance personhood in dementia (Kitwood, 1997). Savundranayagam et al. (2014; 2015; 2016) code four categories: recognition (acknowledge the nursing home resident as a person with a life history and incorporating knowledge about the person in conversations), negotiation (consulting the person on their preferences, needs and wishes), validation (acknowledging the person's feelings and responding with empathy), and facili-

tation (assisting in a task or in communication in order for the resident to achieve what they intended). Missed opportunities for one of these types of person-centred communication to be used are also coded. Other so-called language-based strategies have been observed and analysed by the same researchers (Savundranaygam & Moore-Nielsen, 2015). These strategies arose from earlier research and are proposed to facilitate communication with dementia sufferers (see for example Sabat, 1991; Tappen et al., 1997; Watson, Chenery, & Carter, 1999; Small & Perry, 2005). When they compared these two systems, Savundranayagam and colleagues found language-based strategies that overlapped with person-centred categories, and this provided hints as to how person-centred communication could be developed. However, several limitations with these coding systems were noted, such as the fact that they ignored contextual factors.

Summary of the introduction

Communication in health care settings may be problematic because of factors such as the context and the inherent power imbalance in health care relations, negative communication styles among health care staff and language differences. Increasing longevity also means that there are greater numbers of people suffering from acquired neurogenic communication disorders and this poses additional problems for achieving good communication.

Functional communication is a prerequisite for person-centred care but people with communication disorders often do not receive the quality of care to which they are entitled because of the lack of knowledge, skills and resources among health care staff. Although studies show that training staff in strategies and routines to improve communication is fruitful in both hospital and long-term care, there are still no clear guidelines for how to sustainably implement these routines in clinical practice. Communicative interaction has been explored in various ways and each method has its strengths and weaknesses. It is mainly quantitative evaluations that have been conducted to explore behaviour and strategies that facilitate the delivery of person-centred care.

Overall purposes & specific aims

The thesis has three overall purposes: (1) To describe the experiences of communication in health care settings from the perspectives of people with acquired neurogenic communication disorders, enrolled nurses and medical students, (2) To explore the effects of two methods that are intended to facilitate communicative interaction and implementation of routines in clinical practice, and (3) To investigate how the effects of intervention on conversational interaction may be evaluated using quantitative and qualitative methods.

The specific aims of each of the four studies included in this thesis are listed below:

- I. To explore how enrolled nurses experience their everyday interactions with nursing home residents, with a particular focus on interactions with residents suffering from communication disorders.
- II. To examine a model for the implementation of routines designed to facilitate person-centred care in two nursing homes.
- III. To study the effects of an intervention designed to improve medical students' knowledge and skills in communicating with people suffering from communication disorders.
- IV. To compare the results of three methods of analysing communicative interaction: two quantitative coding systems and one qualitative analysis.

Methods

This thesis uses quantitative and qualitative methods as well as a mixed method design. There are a total of 121 participants consisting of 40 enrolled nurses working at nursing homes, ten residents with dementia living in nursing homes, six nursing home unit managers, and 69 medical students (see table 1).

More detailed information about the participants, procedures, materials and data analysis used in each study is given below. At the end of the methods section is a section discussing the ethical considerations pertaining to these studies.

Table 1. Overview of study design and participants in study I-IV.

Study	Design		Participants							
			Occupation/Role	Gender	Age (mean)					
I	Explorative interview study		8 enrolled nurses	8♀	29-64 (48)					
II	Multiple-case implementation study	Case 1:	19 enrolled nurses 6 residents 2 unit managers	19♀ 4♀, 2♂ 2♀	20-61 (47) 80-94 (84) 42-46 (44)					
		Case 2:	13 enrolled nurses 4 residents 4 unit managers	11♀,2♂ 2♀,2♂ 4♀	29-64 (46) 81-86 (84) 32-62 (42)					
III	Intervention study		33 medical students lecture group	20 ♀, 12♂, 1 ns.	21-32 (24)					
			36 medical students workshop group	27 ♀, 8♂, 1 ns.	22-37 (25)					
IV	Pilot methods study		1 enrolled nurse* 1 resident*	1 ♀ 1 ♂	46 86					

ns. = not specified; * also participating in study II

Study I

Communicative barriers and resources in nursing homes from the enrolled nurses' perspective: A qualitative interview study

Participants

The participants were eight enrolled nurses from six nursing homes. They were all female, between 29 and 64 (mean age 48) years of age and had worked in healthcare for 2–36 (mean 17) years. One participant did not have Swedish as her native language but had lived and worked in Sweden for several years. Participants were recruited through the unit managers and were then contacted by the researcher.

Procedures, materials and data analysis

An interview guide was constructed relating to four main areas: experiences in communicating with residents, feelings associated with interactions involving residents with communicative disabilities, meanings ascribed to interactions, and factors influencing interactions. Semi-structured interviews were then conducted individually in a private room and these lasted between 30 and 60 minutes. Each interview was video or audio recorded and was later transcribed verbatim.

The interview transcripts were analysed using conventional content analysis (Graneheim & Lundman, 2004; Hsieh & Shannon, 2005). This involved firstly reading through all the transcripts several times to get an overall sense of the participants' experiences. The text was then divided into segments (meaning units), (see figure 1 below). Segments of the text that had to do with organisational factors at the nursing home were analysed separately and the results were presented in a separate paragraph in the results section. Meaning units relating to experiences of communication were shortened or condensed (condensed meaning units) while the core meaning was maintained. The condensed meaning units were then abstracted into codes such that the content became further condensed. The codes were placed into sub-categories, the sub-categories were then grouped into three main categories and the findings were finally transformed into a theme. The analysis was not a linear process. Instead, a research group consisting of three people discussed all the analytical steps throughout the process.

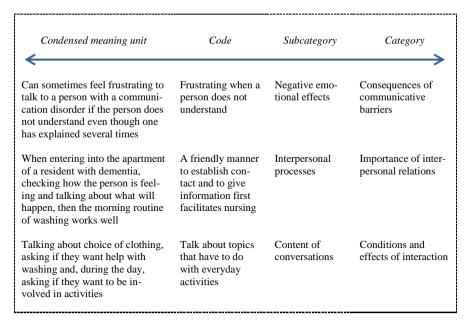


Figure 1. Examples of condensed meaning units, codes, subcategories and categories from the analytical process

Study II

Implementation of communication routines for the facilitation of person-centred care: A case study involving two nursing homes

Participants

Two nursing homes were included in this study. The first had 20 apartments and 28 enrolled nurses employed. The participants who were involved in evaluating implementation at this home were 19 enrolled nurses, all of whom were female, aged between 20 and 61 (mean 47) years, with 2-41 (mean 24) years of experience of working in health care. They had been employed at the nursing home for anywhere between a couple of months and 23 (mean 13) years. Of the six participating residents, four were female and two were male, and they were aged between 80 and 94 (mean 84) years. Three of them had been diagnosed with

Alzheimer's type dementia, one had unspecified dementia, one had severely reduced eyesight and hearing and one had had multiple strokes. They had been resident at the nursing home between 1 and 10 (mean 3) years. This nursing home had one regular unit manager who had been working at the facility for some time but since she later went on sick leave, the person responsible for planning stepped in as assistant manager (see table 1). The majority of participants had Swedish as their native language. All participants except one reported Swedish as the language they spoke best. One enrolled nurse reported that English was her best language.

The second nursing home had 43 apartments and approximately 40 enrolled nurses employed. The participants consisted of 13 enrolled nurses, 11 female and two male, aged between 29 and 64 (mean 46) years. They had 4-41 (mean 16) years of experience of working in health care, and they had been employed at the nursing home between a couple of months and 24 (mean 9) years. The four participating residents, two female and two male, were aged between 81 and 86 (mean 84) years. One had Alzheimer's type dementia, one had vascular dementia, one had mixed dementia and one had multiple illnesses. They had been at the nursing home between a couple of months and 4 (mean 2) years. There were four unit managers involved in the project (see table 1). They had been working as managers for various lengths of time. For one of them, this was her first job as manager, while one had been working as a manager for many years at different nursing homes and she took retirement during the course of the project. All participating residents had Swedish as their native language but the majority of staff had other language backgrounds. The majority still reported that their best languages were Swedish and their native language, but five enrolled nurses reported that their best language was Arabic, Persian, Amharic, English or Hungarian.

Procedures, materials and data analysis

Implementation model

The implementation model consisted of four phases, during which different implementation strategies were used.

The first phase involved a meeting with the two unit managers, at which the time plan and unit needs regarding communication were discussed. Meetings were also held with the staff to introduce the project to them. During this phase, the tension for change (Gustafson et al., 2003) was explored, managers were en-

couraged to become actively involved and the project was adapted to each nursing home.

During *the second phase*, a researcher was present at the nursing homes for 2-3 weeks, providing further information and recruiting participants. It was during this phase that key enrolled nurses or champions, i.e. people who were particularly responsible for the fulfilment of unit goals and were to function as a resource for their colleagues regarding communication issues, were recruited.

The third phase was designed to involve all available enrolled nurses in the proiect. It began with a meeting with the unit manager, 3-4 enrolled nurses and two researchers. The resources the staff had and the difficulties they experienced in communicating with residents were discussed, and preliminary goals for the two nursing homes were set. The main goal for both nursing homes was to draw up a communication plan for each resident. All the goals that were defined were intended to facilitate the delivery of person-centred care firstly by ensuring that all residents could understand and express themselves. Secondly, they were meant to ensure that all staff had general knowledge about communication disorders as well as knowledge about each resident's particular communication capacities and limitations. All the available enrolled nurses then participated in a 4-hour workshop, working in groups of 3-8. The workshop was based on previous work described in Simmons-Mackie et al. (2007), Sorin-Peters et al. (2010) and McGilton et al. (2011; 2012b) and it included the delivery of information about communication difficulties, suggestions for strategies to support interaction, watching video clips of various communication disorders, and trying out different strategies and resources through role play. The workshop was facilitated by two speech-language pathologists but required active participation by the enrolled nurses. The goals for the nursing homes were also refined during the workshops and afterwards were sent to the unit manager and all the enrolled nurses on the units. The key enrolled nurses (or champions) had two one-hour training sessions with one researcher in which they watched and discussed video recordings of themselves interacting with a resident.

In phase four, four follow-up visits were conducted at both nursing homes. One of the researchers was on site 8-15 hours a week over 1-2 weeks at each follow-up. She was available if the staff requested assistance and monitored and gave feedback on progress towards goal attainment.

Method for exploring the degree of success in implementation

A measurement of *attained unit goals* was collected on four occasions at each nursing home.

Method for exploring the effects of the implementation process on attitudes and perceptions

To explore the *attitudes of enrolled nurses* toward communication with people suffering from communication disorders, an adapted and shortened version of a questionnaire developed by Yorkston et al. (2015) was distributed on three occasions (see figure 2). Using a ten-point Likert scale on five questions, the nurses assessed the difficulty and stress they experienced as well as time-consumption and responsibility. Changes in questionnaire responses over the three occasions were analysed using the Wilcoxon signed-rank test. A Bonferroni correction was performed and the p-value was set to $p \le 0.01$.

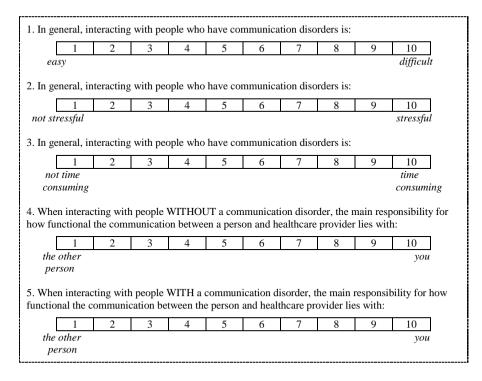


Figure 2. Questionnaire for enrolled nurses

In order to explore *residents' perception of communication* in nursing homes, structured interviews were conducted using Talking MatsTM to support the communication (Murphy et al., 1998; Murphy, Tester, Hubbard, Downs, & MacDonald, 2005). The interviews, which took 15-45 minutes, were conducted on three occasions. The questions posed were influenced by *The Assessment of Living with Aphasia* (ALA; Kagan et al., 2011), *The Montreal Evaluation of Communication Questionnaire for use in Long-Term Care* (MECQ-LTC; Le Dorze et al., 2000) as well as by the results of the interviews conducted with the enrolled nurses in study I. Twenty-one questions were posed: 13 about the residents' perception of everyday functioning in communication and eight about the use of communicative strategies in interaction with enrolled nurses.

The residents answered the questions using Talking Mats. This meant that they responded by placing a picture on a point on the mat along a scale running from things working badly (1p), moderately well (3p), to things working well (5p), or from things never taking place (1p), sometimes (3p), to often/always (5p) (see figure 3). It was also possible to place the pictures in the gaps between the three responses on each scale thus giving each scale 5 grades. The pictures used were drawn colour pictograms bv Sergio Palao for **CATEDU** (http://catedu.es/arasaac/), which publishes under Creative Common's License. Approximately 10 test questions were posed before the interview to give the participants time to get used to the method and for the researcher to assess their language comprehension. All participating residents were judged as being capable of responding to the questions. However, as the number of participants was low, no statistical comparison was made between the three occasions for data collection.

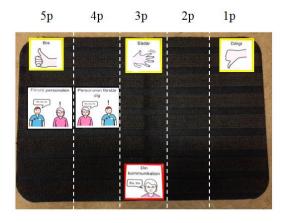


Figure 3. Talking Mat scaling

Method for exploring facilitators and barriers for implementation

Formalised interviews were conducted a year after the workshops and goal setting had been concluded to explore facilitators and barriers. At the first nursing home, one enrolled nurse and the planner (functioning as assistant manager) participated. At the second one, two enrolled nurses and a unit manager were interviewed. An interview guide was constructed using the Theoretical Domains Framework (TDF: Michie et al., 2005; Cane et al., 2012), which is based on theories relevant to behaviour change in health care. Sixteen questions were posed during the interviews, which took 25-60 minutes each. The questions revolved around issues such as how roles, social influences and the environment might affect implementation. A theory-led thematic analysis was then performed on the resulting data (Hayes, 2000). This means that the data was sorted into the following pre-defined themes; barriers and facilitators for implementation. Each item of information related to the theme was extracted and condensed into a short statement. Inter-rater reliability was calculated on 20% of the condensed items by using blinded assessments made by a second rater, and the two raters reached 100% agreement on the coding of the items as either barriers or facilitators.

Study III

Improving medical students' knowledge and skill in communicating with people with acquired communication disorders

Participants

The participants in this study were 69 medical students who were divided into two groups. The first group, the lecture group, consisted of 33 students who were aged between 21 and 32 (mean 24) years of age, and the gender distribution was 36% men, 61% women and 3% not specified. The second group, the workshop group, consisted of 36 students who were aged between 22 and 37 (mean 25) years, and the gender distribution was 22% men, 75% women and 3% not specified. No statistically significant differences in age or gender were found between groups. All students were fluent Swedish speakers and had passed the Swedish upper secondary courses Swedish A and Swedish B, since this is a requirement for enrolment in the medical programme. They had all attended a 2-hour theoretical lecture on neurogenic communication disorders during the first year of their

medical studies. They had also participated in a course on consultation skills during their third year. During the course of their studies, the students had been taught about and were given training in patient-centred consultation skills, examination techniques and medical documentation.

Procedures, materials and data analysis

Intervention

All of the 69 medical students attended a 45-minute lecture as part of their neurology course on the medical programme. This compulsory lecture focused on communication disorders following neurological disease or injury. It included information about various communication disorders, interventions for this group of patients, listening to audio clips that illustrated common symptoms, and information about supportive communication strategies. The lecture was given by an experienced speech-language pathologist.

Thirty-six of these students also participated in a 2.5-hour interactive workshop to further explore the subject of acquired neurogenic communication disorders, particularly aphasia and dysarthria. This workshop was compulsory and the students participated in groups of 8–10.

The workshop was an adapted version of the methods described in Burns et al. (2012), Yorkston et al. (2015) and Saldert et al. (2016), and training was based on theories of experiential learning (Kolb, 1984; Kolb & Kolb, 2009) and model learning (Bandura, 1986). The students received lectures on communication disorders and interaction in health care, a presentation of various supportive communication strategies and video clips of interactions, and they participated in discussions and role play. In total, some 20 strategies were described and taught during the workshop. These had been selected because they had been described in earlier research as effective (Simmons-Mackie, 2008).

Training in the use of strategies was conducted by the two speech-language pathologists who were leading the workshop. They described strategies and showed examples of their use in role play. The students also watched videorecorded interactions between health care staff and patients with aphasia or dysarthria. All the activities demanded active participation by the students and discussion with the workshop leaders. During the final hour of the workshop, the students practiced their skills in role play, both with each other and with simulat-

ed patients. The simulated patients were fourth-year speech-language pathology students who had been trained in how to act as a patient with severe aphasia and who had difficulties both expressing themselves and understanding others. Before the role play, the medical students were informed that they were about to meet a person who had suffered a stroke and had aphasia and was seeking care for pain or dizziness. The assignment was to perform a medical interview in which they should learn about the patient's problem and any environmental factors that were affecting the degree of disability. The role play was conducted in a private room where a letter board, a calendar and pen and paper were available. The speech-language pathology student gave feedback on the medical student's performance after the role play.

Methods for assessment of effects

An adapted version of *a questionnaire* developed by Yorkston et al. (2015) was used. This questionnaire was a shortened version of an adaptation that had previously been used by our research group to examine the training of medical students (Saldert et al., 2016). The questionnaire consisted of nine questions and was distributed before and again after the lecture or workshop. The questionnaire explored students' attitudes to communicating with people with communication disorders, confidence in their own knowledge about communication disorders and how to support communication, and their ability to suggest strategies to support communication.

The students assessed their attitudes and knowledge using a ten-point Likert scale on six questions. In the final three questions, which concerned the students' ability to suggest supportive communication strategies, the students wrote down all the strategies they could think of for two different patient scenarios. The scenarios described one patient with aphasia and one with dysarthria exhibiting difficulties both in using and in understanding language. Two independent raters, who did not know which answers came from which group or which came from before or after the lecture/workshop rated the responses. Intra-rater reliability, r = 0.99 (95% CI 0.985-0.993, p < 0.001), and inter-rater reliability, r = 0.95 (95% CI 0.932-0.966, p < 0.001), were calculated using the intra-class correlation coefficient (ICC) two-way mixed model, single measure and absolute agreement. They were found to be excellent according to guidelines presented by Cicchetti (1994).

The Wilcoxon signed-rank test was used to explore whether there were any changes in responses after the lecture/workshop (i.e. within groups). Following a Bonferroni correction, which was performed because there were so many comparisons, the significance level was set to $p \leq 0.006$. A comparison was also made using Mann-Whitney U between the groups regarding the final two sections of the questionnaire, and a Bonferroni correction was performed here as well, $p \leq 0.008$.

Just before and immediately after the workshop, video recordings were made of 15 volunteer medical students when they were interacting with a 'patient' who was simulating severe aphasia. Each student met the same simulated patient both before and after the workshop, but the patient's reasons for seeking health care were different on the two occasions. The video camera was set up by a member of the research team in a small private room and the students were left alone with the simulated patient during the recording. The recordings were randomised and presented in approximately 10-minute long video clips to two trained raters who performed their assessments independently of one another. The raters were experienced speech-language pathologists. They used a 22-item checklist that included one item for assessing whether they considered the conversation to be respectful and adult and 21 items describing supportive communication strategies (see figure 4). The checklist was constructed to explore the use of the strategies that had been taught during the workshop. A mean number was calculated for each strategy and each student to compare the selection and frequency of use of particular strategies.

Perception of conversation:	1	2	3	4	5	6	7	8	9	10
Adult and respectful										
Strategies:										
Slows down to give time for under- standing										
2. Allows pauses to give time for expression										
3. Keeps sentences short with simple syntax										
4. Uses common words (not unusual terms)										
5. Talks about one thing at a time										
6. Summarises what has been said										

Figure 4. A section of the checklist used for coding supportive strategies.

A Wilcoxon signed-rank test was performed to evaluate whether there was any difference in strategy use before and after the workshop. After Bonferroni correction, the significance level was set to $p \le 0.002$.

When analysed with Cohen's Kappa and using Viera and Garrett's guidelines (2005), inter-rater agreement proved to be substantial, K = 0.74 (95% CI 0.71-0.80), p < 0.001), and the intra-rater agreement, almost perfect, K = 0.86 (95% CI 0.83-0.88), p < 0.001).

Study IV

Exploring person-centred communication strategies: A comparison of three analysis methods

Participants

In this pilot study, the participants consisted of one enrolled nurse and one resident with dementia (see table 1). The enrolled nurse was female, 46 years old, and had been working in health care and at this nursing home for 15 years. Her native languages were Arabic and Persian, and she spoke Swedish fluently.

The resident was male, 86 years old, and had been diagnosed with vascular dementia. He had been living at the nursing home for one year and his native language was Swedish. Assessment using the *Dementia Severity Rating Scale* (DSRS; Clark & Ewbank, 1996) showed that he had moderately severe dementia. When his performance in daily communication was assessed using the *La Trobe Communication Questionnaire* (LCQ; Douglas, Bracy, & Snow, 2007), it showed moderate difficulty. Both of these assessments were carried out by the participating enrolled nurse.

Procedures, materials and data analysis

The data consisted of a video recording of an everyday morning routine that involved both participants. The video recording was made in the context of study II. The enrolled nurse set up the video camera on a tripod and managed the re-

cording herself. She made sure that it captured both of them during their interaction

The video was watched several times and then transcribed verbatim, with both verbal and non-verbal communication acts being noted. These acts were then coded according to two coding schemes; *language-based strategies* and *personcentred strategies*. These codings were followed by a more detailed transcription and analysis based on the principles of Conversation Analysis.

The coding system for language-based strategies

The coding system for language-based strategies was a compilation of verbal strategies that have been described by researchers as facilitating interaction with people suffering from dementia (e.g. Sabat, 1991; Tappen et al., 1997; Watson et al., 1999). The system was developed by Savundranayagam and Moore-Nielsen (2015) and it contains 21 strategies. These include: taking turns (completion and timing), clearly announcing one's intentions, confirming understanding, informing about what has been misunderstood, rephrasing, repeating, asking the other to repeat, selecting the type of question, completing sentences, matching comments, matching associations, remarking on the importance of what is said (news marks), affirming, showing politeness, greeting, right-branching sentences, using modifiers after verbs or nouns. All verbal acts were re-coded by the same rater and then by another rater, who was unfamiliar with this coding scheme. Intra-and inter-rater reliability, which was calculated as the percentage of agreement, was found to be 95% and 74% respectively.

The coding system for person-centred communication strategies

Person-centred communication strategies were coded using Savundranayagam's (2014) definitions (from Kitwood 1997). Both verbal and non-verbal acts were coded using the four categories, *recognition*, *negotiation*, *facilitation*, and *validation*, as well as *missed opportunities* for person-centred interaction. Approximately 60 % of these acts were re-coded by the same researcher and were then coded by another rater, who was unfamiliar with the coding system. Intra- and inter-rater reliability was calculated as the percentage of agreement on coded items, and found to be 100% and 82% respectively.

Qualitative analysis of strategies

In the qualitative analysis based on *Conversation Analysis* (CA, see e.g. ten Have, 2010) interaction was transcribed using a standard CA notation system (see e.g. Atkinson & Heritage, 1999). The analysis began with a detailed transcription of the verbal elements of the interaction and was then supplemented with notations on non-verbal communicative elements.

Ethical considerations

The Regional Ethics Review Board in Gothenburg approved all four studies. All participants gave informed consent for their participation. Consent procedures were adapted according to the needs of the various participants and care has been taken to protect the anonymity of all participants.

In the case of the medical students in the lecture group, their agreement to participate was assumed after they had been information about the study and asked to hand in questionnaires before and after the lecture. All of the students in the workshop group also signed a written consent form.

The unit managers were the people who had the main responsible for the project at the two nursing homes. They were initially informed about the project both verbally and in writing. They agreed to participate by maintaining regular contact with the researcher, assisting in gathering data on goal attainment and answering questions on implementation issues. All of the enrolled nurses and residents who participated also gave written consent. Great importance was awarded to ensuring that residents understood as far as possible what participation would mean. This was done in several ways and on different occasions. Initially, one of the enrolled nurses on the unit approached the resident about the study. Then, the first author asked them again, using picture support. Their significant others or relatives were also informed and, when necessary, asked to sign a written consent form on behalf of the resident. These considerations were made collaboratively between unit managers, enrolled nurses and the speechlanguage pathologist/researcher. In addition to obtaining written consent, it was ensured that the residents were asked on each visit if they were still willing to participate. Their behaviour was also monitored continuously during interviews and video recordings in order to see if there were any indications that they no longer wished to participate. If a resident was too tired, too ill or showed any

disinclination towards completing a task, data collection was paused and in some cases discontinued. However, it was noted that the positive effects for residents of being involved outweighed the negative. They generally said that they enjoyed talking about their experiences and collaborating in data collection. Their participation was also highly valued as a source of important information about their experiences of health care.

METHODS 37

Results

Study I

Communicative barriers and resources in nursing homes from the enrolled nurses' perspective: A qualitative interview study

The analysis of transcripts of interviews conducted with enrolled nurses to explore their experience of everyday interactions with nursing home residents yielded 547 codes. These codes were sorted into 11 sub-categories that were grouped into three categories: importance of interpersonal relations, conditions and effects of interactions, and consequences of communicative disability. The overall theme was: the dynamic interplay between interpersonal relations, daily interactions and the managing of communicative disability (see figure 5).

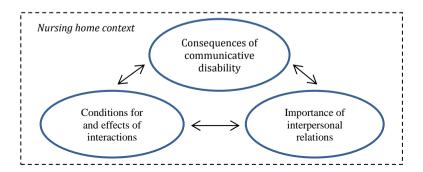


Figure 5. Visualisation of the overall theme the dynamic interplay between interpersonal relations, daily interactions and the managing of communicative disability.

The enrolled nurses explained that in the nursing home context, communicative disability may have consequences such as restricting a resident's ability to participate in interaction and this may affect both the residents and their carers emotionally. The nurses also reported using various strategies to facilitate

interactions, such as adapting their body language and manner of communication according to the particular resident's needs and in some cases using communication aids. Building good relationships with the residents was also noted as crucial in facilitating communication with them. Communicating well helped these nurses get to know the residents, and once a deeper relationship had thus been established, communication worked better. However, although the nurses recognised the importance of these factors, environmental conditions often prevented them from doing what they knew would be helpful, such as giving the residents enough time to respond.

Study II

Implementation of communication routines for the facilitation of person-centred care: A case study involving two nursing homes

Unit goal attainment

The analysis of goal attainment (which was used as a measure of implementation success) showed that the first nursing home partly reached the main goal of creating communication plans for all residents. Twelve of the 20 plans had been drawn up at the final assessment. Three of the other seven goals had also been partially met and four had been fully attained. At the second nursing home, 6 out of 43 plans had been drawn up, four of the other seven goals had been partially met and three had been fully attained.

Effects on enrolled nurses' attitudes

The enrolled nurses at both nursing homes found communicating with people who had communication disorders quite difficult, stressful and time consuming (see table 2). They also felt that they had a great responsibility to make the conversations work. At both nursing homes, the staff perceived interactions to be more time consuming at the end of the project than they had at the beginning. At follow ups, they also reported feeling a greater sense of responsibility in their interactions than they had earlier. At the second nursing home, the perception of the degree of difficulty and level of stress also increased slightly during the pro-

ject. Nevertheless, no statistically significant changes in attitude were identified at either of the nursing homes.

Table 2. Results of questions about attitude in the questionnaire at pre- and follow up 2 assessments.

	Nursing home 1			Nursing home 2		
Items:	pre (SD)	Follow -up 2 (SD)	p- value	pre (SD)	Follow -up 2 (SD)	p- value
1. In general, interacting with people who have communication disorders is: (<i>I easy - 10 difficult</i>)	5.82 (1.7)	6.00 (2.9)	0.67	6.45 (1.8)	7.14 (1.1)	0.50
2. In general, interacting with people who have communication disorders is: (1 not stressful - 10 stressful)	4.76 (2.0)	4.67 (2.1)	0.48	5.91 (1.8)	6.29 (1.0)	0.20
3. In general, interacting with people who have communication disorders is: (1 not time consuming - 10 time consuming)	5.76 (2.3)	7.67 (1.9)	0.04	7.91 (1.7)	8.14 (2.2)	0.19
4. When interacting with people WITHOUT a communication disorder, the main responsibility for how functional the communication between a person and healthcare provider lies with the: (1 the other person - 10 you)	5.94 (1.6)	5.50 (0.8)	1.00	5.00 (1.6)	5.86 (1.6)	.07
5. When interacting with people WITH a communication disorder, the main responsibility for how functional the communication between the person and healthcare provider lies with the: (1 the other person - 10 you)	8.24 (1.8)	8.50 (1.9)	0.41	7.09 (2.3)	7.57 (1.8)	0.25

Effects on residents' perception of communication

Small and inconsistent changes were reported in the assessment. In assessments from both pre and follow up the ten residents from both of the nursing homes reported that talking with and understanding the staff worked well, and they felt that the staff understood them. The most commonly reported communication strategy at both nursing homes was to use speech. The use of pictures, writing, drawing and communication aids was rarely reported.

At the first nursing home, the six residents reported no problems communicating one-to-one in a private room and they found it easy to find and understand information about planned activities. At the second nursing home, two (out of four) residents reported at pre-assessment that one-to-one communication was problematic and all four reported being largely unaware of any information about meals or other activities. Issues that they noted were problematic, such as talking to other resident (which was reported by five residents), remained largely unchanged in the follow up assessments.

Facilitators and barriers for implementation

The thematic analysis of interviews (with three enrolled nurses, one person responsible for planning and one unit manager) that explored facilitators and barriers resulted in 243 coded items from both homes. All the facilitators and barriers were grouped into four subsections; (1) Attitude, motivation and feelings, (2) Management and key ENs, (3) Follow up and reminders, and (4) Environmental resources.

Positive attitudes towards and motivations for attaining the goals seemed beneficial at both nursing homes. However, not all staff members were described by the respondents as having a positive attitude or being involved. At the second nursing home, communication problems between staff and residents because of communication disorders and language differences were noted as motivations for change. Both nursing homes suffered from insufficient management during the course of the project. Because of changes in their shifts and terminations of employment, the key enrolled nurses, who were supposed to provide a form of informal leadership, were unable to be actively involved throughout the implementation process. Further, the staff received few reminders about their goals during the period of the project and it was noted by the respondents at the first nursing home that this was a barrier. Finally, problems with time planning also represented a barrier for implementation. Although in theory the staff could spend time working on goals, and this would have been facilitating, the fact that doing so would place an extra workload on colleagues discouraged the participants from doing so.

Study III

Improving medical students' knowledge and skill in communicating with people with acquired communication disorders

Attitude, confidence in one's knowledge and the ability to suggest strategies

No statistically significant changes in the attitudes of medical students towards communicating with people suffering from communication disorders were noted in assessments made before and after training through the lecture or the workshop. However, their confidence in their knowledge about communication disorders and how to support communication increased to a statistically significant degree after training, both in the lecture group and in the workshop group. According to the experts' ratings, the students' ability to choose appropriate supportive communication strategies showed a statistically significant increase after training only in the workshop group.

Table 3. Results from the three sections in the questionnaire in assessments before and after training.

	Lecture group			Workshop group			
	pre (SD)	post (SD)	p-value	pre (SD)	post (SD)	p-value	
Self-attitude	23.5 (3.1)	22.2 (3.5)	0.015	23.3 (2.7)	23.6 (2.6)	0.481	
Self-confidence	13.0 (3.8)	18.9 (3.6)	0.001*	15.3 (3.8)	21.9 (3.0)	0.001*	
Suggested strategies	8.5 (3.4)	10.3 (3.7)	0.009	9.2 (4.1)	15.8 (4.9)	0.001*	

Use of strategies

Analysis of the video-recorded interactions of fifteen students in the workshop group revealed that there was a statistically significant increase in the use of

three *supportive communication strategies* after the workshop (see figure 6). These strategies were: encourages the patient to use gestures/pointing, uses writing/written alternatives and encourages the patient to use a calendar. These strategies were used by a greater number of medical students and for a significantly greater number of minutes of the interactions after the workshop. Eleven other strategies (such as allowing pauses to give time for expression, keeping sentences short with simple syntax, talking about one thing at a time, summarising what has been said, using objects, drawing/using pictures, encouraging the patient to draw, encouraging the patient to write, using a letter board, encouraging the patient to use a letter board and a calendar) also increased after the workshop, though not to a statistically significant degree.

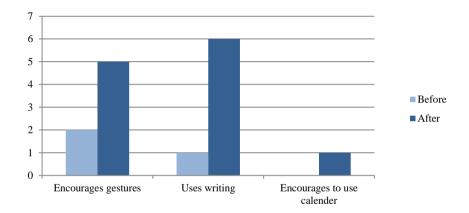


Figure 6. The three strategies that increased after the workshop. The vertical axis shows the mean frequency of strategy use in the group, i.e. the mean number of minutes for which the strategy occurs during a 10 minute recording.

Study IV

Exploring person-centred communication strategies: A comparison of three analysis methods

Coded language-based strategies

In coding using the language-based strategies that had been described as facilitating in earlier research, the analysis detected only three different verbal strategies in the interaction: yes/no-questions, verbatim repetition and affirmation.

Coded person-centred strategies

In the analysis of person-centred strategies, both verbal and non-verbal aspects of the interaction were coded. This analysis showed that the enrolled nurse negotiated with the resident by using questions. She also facilitated the activity both verbally, by saying that she could assist the resident, and non-verbally, by pointing. She recognised the resident as a person by looking directly at him and by using his name and she validated the wishes he expressed. Although this coding system captured several important aspects that were not captured by the other coding system (for language-based strategies), a degree of ambiguity was evident in the coding. A sequence that was coded as validation was also coded as a missed opportunity because the nurse validated the resident's wish at the same time as she turned her back towards him.

Conversation Analysis-based qualitative analysis

Conversation Analysis-based qualitative analysis revealed the need for repair and the prosody of speech, neither of which became apparent when either of the other two methods (person-centred and language-based strategies) were used. This analysis thus helped explain the ambiguity (noted in the person-centred coding) - the prosody used in the "validation" signalled that although the nurse seemed to be accepting the resident's wish, she did not agree to it.

Discussion

This discussion begins with a paragraph that reflects upon the three overall purposes of the thesis and compares the results of the four studies. This is followed by a paragraph discussing the methods used and the limitations of the thesis.

Overall purposes & results

The first purpose of this thesis was to describe the experiences of communicative interaction involving health care staff/students and people with communication disorders. The results showed that both enrolled nurses and medical students found this kind of communication quite difficult. Both groups felt that they had a great responsibility to make the conversations work. The enrolled nurses who were working in nursing homes and were asked about this in interviews described how they used different strategies and tried to get to know the residents in order to facilitate interactions. This result contrasts with other studies that found staff tended to lack knowledge (see e.g. Kato, Hickson, & Worall, 1996; Stans et al., 2013). However, in our study, it was noted that the nurses found certain environmental conditions, such as problems with time management, prevented them from using their communication skills. This problem has also been observed in earlier research (Hemsley, Balandin, & Worrall, 2012). These difficulties limit the possibility for nursing staff to gather the personal narratives of the residents under their care or to create a care partnership with them. These factors pose barriers for the delivery of person-centred care.

By contrast, residents suffering from communication disorders reported that their communication with the enrolled nurses worked well. They said they understood the nurses and they felt that the staff understood them. However, it is not entirely clear which type of communication the residents were referring to. They did not specify whether they meant everyday communication relating to care activities such washing and eating or more personal conversations. It is possible that the residents' views reflect the fact that the nurses do not have a chance to engage in the kind of interaction they would like to and this means their interactions become brief and care-focused, as has been noted in earlier research (Ward et al.,

2008; Wadensten, 2005). This may reflect the complexity of content and the duration of interactions - conversations about immediate happenings are often easier and less time-consuming to participate in than those relating personal subjects that are unrelated to an ongoing activity. Language differences also mean that nurses at nursing homes tend to facilitate communication by using simple words, clear body language and gestures (Rosendahl et al., 2016). In the implementation study (study II) it was seen that the nurses perceived communication to be more time consuming at the end of the implementation process than they had done before it. This may reflect the fact that although it was challenging, they spent more time engaging in more personal communication or made greater efforts to communicate with people who had communication disorders or residents who had different language backgrounds.

Another explanation could be that perceptions of what constitutes satisfactory and functional communication differed between the two groups. The enrolled nurses in study I reported that they wanted to build close relationships with the residents and they believed that doing so would facilitate communication. However, it has been noted in earlier research that although some residents think their relations with the staff are important, not all of them do (Berglang & Kirkevold, 2005). Some residents choose to maintain a degree of distance from the staff and expect them only to provide help with routine activities since their main social ties are with family instead.

The power inequality inherent in the care relationship may also have affected the results (Russel, 1999). In a study exploring residents' perceptions of care, including communication, (though not specifically people with communication disorders) most residents gave positive responses (Pearson, Hocking, Mott, & Riggs, 1993). These results did not correlate with observations carried out at the facility, and the authors therefore suggested this might reflect the unwillingness of residents to criticise the behaviour of the staff. This may have been a factor in the exploration of residents' perceptions in this thesis as well. The fact that the residents did not know the researcher who was interviewing them may also have made them hesitant about reporting any negative feelings towards the staff.

The second purpose of this thesis, to explore two methods for facilitating communication was undertaken using one implementation model and one intervention method in different health care contexts. In the implementation study, the participants at one of the two participating nursing homes showed promising results in drawing up communication plans to facilitate interaction. The overall success rate for both nursing homes was moderate. Communication is essential

for getting to know a person and for developing a care partnership, both of which are cornerstones of person-centred care (Ekman et al., 2011; Ekman et al., 2014).

Positive attitudes and motivation seemed beneficial for the implementation of the routines at both nursing homes, and at the second one, motivation seemed to be increased by the presence of language diversity. This meant that the second nursing home in particular had a strong tension for change (Gustafson et al., 2003). Nevertheless, barriers were noted at both nursing homes. These included inconsistent management and few reminders about implementation tasks. Since management and reminders have been identified as important for implementation (Rokstad et al., 2015; Green, 1998), these barriers presumably hindered change at the nursing homes in this study. Problems with time management were also a possible barrier for change. In the study exploring enrolled nurses' perceptions of communication (study I), environmental barriers, including time management difficulties, were described as preventing the staff from using the resources they actually had. This may be compared to the implementation study, in which barriers, such as the lack of management and reminders, hindered the development of resources and routines. It seems evident that environmental and management factors pose barriers for creating documentation routines, such as communication plans that may ensure the delivery of person-centred care.

Another barrier, which was found at both nursing homes during the implementation project and reflects the situation of many nursing homes today, was the rapid turnover of staff. This has been discussed earlier as a barrier to person-centred care, since there is poor continuity of care (Edvardsson, Fetherstonhaugh, & Nay, 2010). Thorough documentation of the needs and resources of the residents is then all the more important for helping to ensure the quality of care despite changes in staff. At both of the nursing homes studied here, the enrolled nurses found conversational interactions to be more time consuming and they felt greater responsibility for their interactions at the end of the project than they had at the beginning. At the second nursing home, they also reported experiencing greater difficulty in their interactions after the project. Although no statistical significance was found in these changes, these results may suggest that the staff had become more aware of the challenges they faced (Shewan & Cameron, 1984; Sorin-Peters & Behrmann, 1995; Rautakoski, Korpijaakko-Huuhka, & Klippi, 2008; Saldert et al., 2016).

In study III - the intervention for medical students - it was seen that the workshop increased the students' ability to suggest and employ appropriate communication strategies. This promising result is in line with previous studies of the

training of health care students (Welsh & Beideman Szabo, 2011; Legg et al., 2005; Burns et al., 2012; Yorkston et al., 2015; Saldert et al., 2016). This result suggests that it would be beneficial and effective to make this type of training available for all medical students as well as other student and professional groups. Guidelines from the USA (American Speech-Language-Hearing Association, n.d.), and from Australia (The Australian Aphasia Rehabilitation Pathway, n.d.) state that a speech-language pathologist should educate health care staff in strategies to facilitate communication. This could be done to a greater extent in Sweden as well.

The results of study III showed that the students in the lecture group (those who did not participate in the interactive workshop) reported finding communication easier after training while those who attended the workshop reported no change. However, the workshop group reported feeling a greater sense of responsibility for their interaction after attending the workshop, though this change in attitude was not statistically significant. This increase was not found in the lecture group. These differences between the results found among enrolled nurses and the two groups of medical students may reflect their different levels of experience. With increased experience, exposure and opportunities to reflect, perceptions of difficulty and responsibility may well increase (see e.g. Saldert et al., 2016).

The third and final overall purpose of this thesis was to investigate how the effects of intervention upon conversational interaction may be best evaluated. Exploring communication is challenging and the challenges were dealt with in various ways during this research. In study III, the selection and frequency of use of strategies before and after intervention were investigated using quantitative coding with a checklist. In study IV, the use of two quantitative coding systems and one qualitative analysis were conducted in order to compare the results and discuss their respective strengths and weaknesses.

The analysis of the video-recorded interactions of fifteen students in the workshop group in study III revealed a statistically significant increase in the use of three supportive communication strategies after the workshop. The strategy that increased most was the use of writing. This result echoes findings from earlier studies, and implies that training is required to enable people to use strategies that involve more than just verbal adaptation (Simmons-Mackie & Damico, 1997; Morris et al., 2015; Rautakoski, 2011). However, it should be noted that this result did not mean that the interaction was necessarily perceived to be better by the participants or that the strategies were used at the appropriate moments (Savundranayagam & Moore-Nielsen, 2015; Kagan, 1998).

In study IV, two systems were used for coding strategies. The predefined categories in one of these captured only verbal facilitating strategies. The other coding system was designed to detect non-verbal strategies and it also enabled the detection of problems in the interaction. However, the qualitative analysis gave the most complete picture of the interaction. While this was perhaps unsurprising, it highlighted the importance of choosing an analytical method that is suited to the research objectives and data. Also, in investigating the use of strategies in a particular context (not only their frequency), the paralinguistic aspects of interaction such as gaze, body positioning and prosody need to be taken into account. As Savundranayagam and Moore-Nielsen (2015) note, it is not the strategies themselves but the use of them in a successful manner that makes communication person-centred. Analysis should therefore take into account the quality or degree of success in the use of a strategy in context (Atkinson & Heritage, 1984; Gumperz, 1992; Shegloff, 1993; Allwood, Traum, & Jokinen, 2000; Ten Have, 2010). Each utterance is dependent on previous utterances (Atkinson & Heritage, 1984; Shegloff, 1993; ten Have, 2010) and they are uttered in a particular cultural context during a specific activity (Gumperz, 1992; Allwood et al., 2000). This means that what constitutes person-centred communication for one individual in a particular context may not necessarily do so for another. As noted, quantitative methods play an important role in both research and clinical management, but the significance of context should not be forgotten.

Methods & limitations

Research design

The thesis uses both quantitative and qualitative methods for analysis. In study II, a mixed method was used to explore implementation success. This meant that the topic was explored from different viewpoints i.e. the qualitative interviews were used to explain the results in terms of implementation success, the so-called *explanatory sequential* (Kettles, Creswell, & Zhang, 2011). Mixing qualitative and quantitative methods is essential for exploring such a complex phenomenon as communication involving people with communication disorders.

Participants

Although it may have been advantageous to focus on enrolled nurses even in the intervention in study III, including the perspectives of medical students enriches this thesis. It makes it possible to compare different health care contexts. However, the number of participants in the studies exploring intervention and implementation was relatively small. This may have reduced the power of the statistical analysis of degree of change and, with the Bonferroni correction, this may have led to type II errors such as a failure to detect positive effects.

In study II, we used structured interviews with Talking Mats (Murphy et al., 1998; Murphy et al., 2005) because we wanted to explore the change in residents' perceptions using statistical analysis. However, the low number of participants made it impossible to apply this.

Moreover, the participants in studies I, II and IV, and the students who were video recorded in study III were probably groups that were already very interested in facilitating communication with people suffering from communication disorders. The fact that we were not able to randomise the inclusion of participants may have affected the results. Nevertheless, the studies provided examples of barriers that may be experienced even by those who possess knowledge, skill and motivation for change, and reducing these barriers is clearly important if routines that facilitate the delivery of person-centred care are to be implemented.

Method choices studies I-IV

In study I, we chose to explore the perceptions of enrolled nurses using the qualitative method known as Content analysis (Graneheim & Lundman, 2004; Hsieh & Shannon, 2005). This choice was made since the perceptions of enrolled nurses about communicating with people under their care who suffer from communication disorders had barely been explored in earlier research. We wanted to approach the topic with as few preconceptions as possible about what we might find. In study II, by contrast, we chose a different approach. The interviews with unit managers and enrolled nurses were guided by the *Theoretical Domains Framework* (Michie et al., 2005; Cane et al., 2012) and this meant that a theoryled thematic analysis was more appropriate. We structured the interviews with a framework in mind so as to specifically explore facilitators and barriers for implementation.

In study II, case study methodology was decided upon because the two nursing homes were not randomly selected. The nursing homes were recruited from a previous study and each had different characteristics, such as size and language diversity. This made it difficult to use one nursing home as a control for the other. Instead, they provided two different examples of how nursing homes may operate.

Regarding other aspects of method choices in study II, we noted that there is sometimes confusion in the literature between intervention and implementation. Intervention studies aim to test the effects of a specific tool, resource or training programme, as we did in study III by studying the effects of a workshop. However, study II is instead an implementation study. We used previous evidence of the effects of using resources such as communication plans (Généreux et al., 2004; McGilton et al., 2011; Sorin-Peters et al., 2010; Page, 2015) and tested a model for implementing these as routines at the two nursing homes (Grimshaw et al., 2012). The model, including meetings, workshops and setting goals, was meant to be flexible and adaptable to the needs of each nursing home.

We used a structured method for interviewing the residents in study II, i.e. Talking Mats (Murphy et al., 1998; Murphy et al., 2005). It is possible that this method failed to capture difficulties the residents experienced in communicating with staff since our questions may have been too limited. A less structured approach may have given a deeper understanding of the residents' own perceptions. However, it can be difficult to use an open-ended approach when interviewing people who have communication disorders – if they struggle to find words, it may be demanding for them to respond to open-ended questions. We chose to use a structured method in order to capture and describe the residents' perspectives in a formalised way. However, since recruitment problems meant there was only a small number of participants, the results were difficult to interpret or draw any broader conclusions from.

It would be relevant and interesting to evaluate the use of communication plans in daily practice and the difference in use between the nursing homes (Craig et al., 2008). It would also have been interesting to perform a complete process evaluation of factors such as whether the model went according to plan, what effect particular activities had on participants and to control for contextual factors (Morley et al., 2014; Moore et al., 2015). A further limitation of this study is the fact that the final follow up was conducted only 18 months after the project was initiated, and implementation efforts usually take several years to show clear results (Fixen et al., 2005; Fixen et al., 2011).

The key enrolled nurses recruited at the two nursing homes played an important role (Backer & Rogers, 1998; Markham, 1998). They were meant to be particularly actively involved in the project and to function as motivators and resources for their colleagues. However, their recruitment was not based solely on these criteria. They were also video recorded interacting with residents and were selected because they were contacts for people with communication disorders who were willing to be videoed. The video recordings were used in individual training of the key persons. This may have affected the recruitment of these key people, narrowing selection or perhaps excluding other the staff members who may have been better suited to motivating and assisting their colleagues.

The researcher, or *external change agent* (Rogers, 1995), was available at various times to give feedback on the progress of change as this has been seen as an important factor in making implementation sustainable (Green, 1998). However, in the interviews on facilitators and barriers for implementation in the nursing homes, staff reported that there was a lack of reminders during the project and that they were only given when the researcher was there. The presence of an external agent was clearly insufficient, and the fact that managers and key enrolled nurses went on sick leave, and changed jobs and shifts meant that there was no one at these facilities who had a complete picture of the project or the ability to fully facilitate it.

In study III, we wanted to explore whether a specific type of training could affect a group of medical students' attitudes, their perceptions of their knowledge, their ability to suggest suitable communication strategies and their use of strategies. We elected to use quantitative methods. We did not attempt to explore whether the students were perceived to be good communicators by the raters. This would have required an analysis that was able to take into account all aspects of the interaction, including context. In this study, recruitment difficulties made it impossible to use a control group for video recordings of the lecture group in order to compare the use of strategies between groups. Further, the checklist used in analysis of strategies in study III was not an established instrument but was specific to this study and was designed to explore the strategies taught during the workshop. However, measures of outcomes that are closely related to the particular factors the intervention is designed to affect are generally preferable (Coster, 2013).

In study IV, two quantitative and one qualitative method were chosen. As noted earlier, quantitative analysis makes it possible to analyse large amounts of data since it is less time consuming than performing a complete qualitative analysis

of an interaction (Silverman, 2010). This begs the question of why only one short transcription was analysed in the comparison of methods in study IV. However, this study should be considered a pilot study and should not be seen as a complete exploration of this topic.

Instruments for evaluation

Unfortunately, there is a lack of valid and reliable standardised instruments in Sweden as well as internationally for evaluating communication. The established instruments that are available (see the introduction) were not found suitable for our purposes because they do not evaluate the constructs that were the outcomes of our studies (Coster, 2013). The two questionnaires in study II and III were adapted from previously used questionnaires (Yorkston et al., 2015; Saldert et al., 2016) that had been used to explore communication between health care staff and people with communication disorders. The original questionnaire was in English and Saldert et al. (2016) had previously translated it into Swedish. However, no reverse translation was done, and this is a limitation. Nevertheless, the questionnaires we used proved to have satisfactory inter- and intra-rater reliability in studies II and III, and they were sensitive enough to discriminate between the two groups that received training in study III, and this supports their validity.

In study IV, the inter- and intra-rater reliability was found to be satisfactory in the system for coding person-centred strategies. However, in the language-based system, while intra-rater reliability was judged to be satisfactory, inter-rater reliability was only 74%. This was believed to be due to the fact that some strategies were not mutually exclusive (such as "verbatim repetition" and "rephrase to add clarity"), the low number of items (n=19) and the lack of training in one of the two raters. In a previous study (Savundranayagam & Moore-Nielsen, 2015) exploring the method, all raters had received training and this gave an inter-rater reliability score of 91%.

Conclusions & implications

Based on the results of the four studies included in this thesis, it was concluded that:

- Enrolled nurses and medical students perceive communication with people suffering from communication disorders to be quite challenging and recognise that they have an important role to play in facilitating it.
- 2) There is a discrepancy between the perceptions of communication by enrolled nurses and medical students on the one hand, and by people with communication disorders on the other.

Implications: Further training of medical students and enrolled nurses and better implementation of routines for the facilitation of communication in different health care settings are important. The fact that residents report that communication with health care staff works well is difficult to interpret and this topic deserves further exploration.

- 3) Interactive training during the medical students' basic education may improve their knowledge about and skill in communicating with people with communication disorders and may better equip them with supportive strategies.
- 4) Factors such as management, time allocation and staff continuity are crucial for successful implementation of communication routines in nursing homes.

Implications: Introductory training in supportive communication strategies should be provided for medical students. In the nursing home setting, complex problems relating to staffing and time allocation need to be addressed in order for communication resources to be sustainably implemented and used.

- 5) There is a need for reliable and valid methods to assess communicative interaction in person-centred care.
- 6) Neglecting contextual factors in the analysis of interaction presents problems when used to assess person-centred communication.

Implications: The importance of context in conversational interaction need to be taken into consideration and be acknowledged in the development and use of assessment methods in the future.

Future perspectives

If sustainable routines for the delivery of person-centred care are to be implemented, despite all the barriers discussed here, communication issues must be given greater priority. In Sweden, nursing homes have teams of paraprofessionals connected to them but it is not yet standard practice to include a speech-language pathologist, although these may be consulted for supervision and support.

The Swedish Association of Local Authorities and Regions decided in 2015 to work for the implementation of person-centred care nationally. In addition, a new patient law took effect in early 2015, and it states that 'information should be tailored to the recipient's individual circumstances, such as / ... / cognitive and other disabilities' (Socialdepartementet, 2014). It also states that 'the one who gives the information should as far as possible ensure that the receiver has understood the content and significance of the information provided'. This poses new challenges in the education of health care students and professionals. They need information both on how to deliver person-centred care in general and on how to do this for patients who have communication disorders in particular.

People with communication disorders are often excluded from research because of the difficulties in obtaining informed consent and in collecting data. However, this is already a vulnerable group and excluding them from research is more problematic than trying to overcome the methodological difficulties. The benefits of exploring their perceptions and experiences of health care, if done with tact, outweigh the difficulties. More research is still required on the experiences and perceptions of people who suffer from acquired neurogenic communication disorders.

Acknowledgements

First and foremost, I would like to offer my sincere thanks to **all the partici- pants** for sharing your knowledge and experiences with me. Without you, this thesis would not have been possible.

In addition, there are many people who have been involved both directly and indirectly, and I would like to acknowledge the following:

My main supervisor **Charlotta Saldert**, who is the most knowledgeable and hard working person I know. Thank you Lotta for believing in me, answering all my questions without delay and supporting me though the stress as well as sharing in my triumphant moments.

My co-supervisor **Lena Hartelius**. Thank you for sharing your expertise with me and for always being at my side through the challenging PhD journey.

Carola Skott, who played a major role in helping my first study become a reality. Thank you for sharing your understanding of qualitative analysis and for the interesting discussions.

My funders: the **Centre for Person-Centred Care at University of Gothen-burg (GPCC)**, Sweden, which supported this work. GPCC is funded by the Swedish Government's grant for Strategic Research Areas, Care Sciences and co-funded by University of Gothenburg, Sweden.

Debbie Axlid and **Alexandra Kent** who have language edited all my manuscripts as well as the introduction. Thank you both for making my texts so much better.

My fellow (past and present) PhD students and friends:

Malin Antonsson, who started this journey with me in 2010 as we began working with communication partner training on our magister project. Thank you for

listening to all my joys and problems in life and work, and for being an awesome friend

Charlotte Johansson, who, like me, started out as an assistant researcher and then became a PhD student at almost the same time as me. I hope that we will continue to work side by side in the years to come. Thank you for being such a great colleague and trusted friend.

Emilia Carlsson, who has shared the daily ups and downs of PhD student life with me. Thank you for always taking the time to listen and giving advice as well as pep talks when needed.

Milijana Malmberg, who has literally sat by my side for five years and is the best roommate one could ever ask for. I miss you at level three.

Dr. Karin Eriksson, who has helped me with various assessments of videos and questionnaires, and has a way of calming me down with her mere presence.

Andreas Björsne, who is a trooper when it comes to organising gingerbread tastings and understands the value of a good coffee break.

Joana Kristensson, who has been involved in assessments of videos and questionnaires in the thesis. I hope that we will have more opportunities to collaborate in the future.

AnnaKarin Larsson. Thank you for all the great times in Philly and for being an excellent colleague.

Anna Rensfeltd. Thank you for interesting discussions during our PhD student meetings, which always gave me new energy.

Dr. Ann Nordberg, who shared my first years as a PhD student. I will never forget our time in Cork at ICPLA and the hilarious cookie story.

Dr. Maria Sundqvist, who was a fellow PhD student and roommate during my first years as a PhD student. Thank you for all the good times at HVB.

All my other colleagues, both past and present, at the Speech and Language Pathology Unit and Audiology Unit.

All my friends, especially:

Aldijana Talic, number 2, thank you for being the bestest of friends. You always make me feel appreciated and loved.

The Stockholm/Norrköping branch; Lena Lundgren, Elin Jakobsson and Helena Torlofson and families

Badminton4Life a.k.a. **Malin**, **Evelina Zerge**, **Maja Wennerberg** and **Cecilia**, who listen to my banter on work and life whilst playing badminton.

Walle and Jenny Grünewald, Simon Engmalm and Karin Nilsson. Thank you for all the game nights, New Year's parties, barbeque dinners, and fun times we have shared. Special thanks to Walle for the professional photoshoot.

The original Skellefteå gang; Elin Norgren, Stina Lundberg, Rebecka Söderberg and Camilla Dawkins.

Juntan a.k.a. Malin, Ina Byström, Kajsa Nilsson, Linnea Karlsson and Karin Eurenius. Having our regular dinners and watching "high quality TV-shows" have given me something to look forward to after long days at the office.

My family:

Pär Hedelund, the best person in the world. Thank you for being my biggest fan and for your endless support and love. I am looking forward to our next adventure.

My mother and father; **Karin Lundemark** and **Olle Forsgren**. You actually said that I would go down the road towards a PhD before I even knew it myself. Thank you for always believing in me.

My sister **Ida Forsgren** with family **Joël Jouannet** and **Ines Jouannet**. Thank you all three for being there for me in so many ways when I most need it. Ines: "jag ser dig".

My extended family; **Claes Hedelund**, **Christina Hedelund** and **Jan Hedelund**. Thank you for always making me feel welcome and for all the happy times with late-night card playing, "crunchy crunch" and excellent drinks.

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