

# The challenge of communication during home mechanical ventilation



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by

**Katja Laakso**

Institute of Neuroscience and Physiology  
at Sahlgrenska Academy  
University of Gothenburg



UNIVERSITY OF GOTHENBURG

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Division of Speech and Language Pathology, Institute of Neuroscience and Physiology  
Sahlgrenska Academy at University of Gothenburg, Sweden, 2011

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## ABSTRACT

The overall aim of this thesis was to explore and describe experience of communication during home mechanical ventilation (HMV) in adults, thereby contributing to increased knowledge and awareness of issues related to ventilator-supported communication. Mechanical ventilatory support seriously affects speaking and communication. Earlier studies have shown that many ventilator-supported patients experience difficulty and frustration with their speech and voice production.

A mixed-method research approach guided the research design of the thesis, which includes four studies. Study I was a qualitative case study exploring experience of communication of both an intensive care unit nurse and an individual receiving HMV. Participants in Studies II-IV were recruited from the National Respiratory Centre (NRC) and comprised 19 individuals receiving HMV, as well as their key communication partners (CPs). Study II included analyses of the following quantitatively measured variables; speech intelligibility, health-related quality of life and communicative participation. Studies III-IV were qualitative interview studies, exploring the experience of communication of both individuals receiving HMV and their key CPs.

One of the main findings in the first study was that ventilator-supported communication was perceived as time consuming, strenuous and requiring training. The second, larger study investigated individuals who are treated with HMV and revealed low average intelligibility scores and an impact on both HRQL and communicative participation. However, these aspects did not appear to be closely correlated. The third study concluded that individuals receiving HMV experience a long and lonely struggle to find a voice and lack support from health professionals. Six subthemes detailed different facets of their experience: *Managing changed speech conditions*, *Prioritising voice*, *A third party supporting communication*, *Using communication to get things done*, *Depending on technology* and *Facing ignorance*. The fourth and final study found that CPs encounter a number of communication limitations in the ventilator-supported individual's speech and communication, such as a weak voice and interrupted speech flow. CPs used different functional communication strategies to improve communication and assumed the role of a communication facilitator. CPs also described insecurity managing these roles, which evoked emotional reactions, but they also showed an ability to grow with experience.

In overall terms, the findings characterise aspects of communication during HMV, including the challenges facing both the individuals receiving HMC and their CPs. The findings revealed that communicative issues were a major concern for individuals receiving HMV and that CPs played an important role in communicative success. Further, it was concluded that there is a lack of knowledge about issues related to communication during HMV, from the point of view of ventilator-supported individuals, communication partners and health care professionals. It is to be hoped that the findings from the studies can be applied to raise awareness and create training programmes relating to the skills and competence needed to be an effective CP and to optimise the communication of individuals receiving HMV.

Key words: Communication, communicative partner, health-related quality of life, home mechanical ventilation, International Classification of Functioning, Disability and Health, qualitative research design.

# ORIGINAL PAPERS

This thesis is based on following papers which will be referred to in the text by their Roman numerals:

- I. Laakso K, Hartelius L & Idvall M (2009). Ventilator-supported communication – a case study of patient and staff experiences. *Journal of Medical Speech-Language Pathology*, 17(4):153-164.
- II. Laakso K, Markström A, & Hartelius L (2009). Communication and quality of life in individuals receiving home mechanical ventilation. *International Journal of Therapy and Rehabilitation*, 16(12):648-655.
- III. Laakso, K., Markström, A., Havstam, C., Idvall, M., & Hartelius, L. The communication experience of individuals treated with home mechanical ventilation. (Accepted for publication in the *International Journal of Language & Communication Disorders*).
- IV. Laakso, K., Markström, A., Havstam, C., Idvall, M., & Hartelius, L. Communicating with individuals receiving home mechanical ventilation, the experiences of key communication partners. (Submitted for publication).

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# ABBREVIATIONS

AAC	Augmentative and Alternative Communication;
BPAP	Bi-level Positive Airway Pressure;
CAQDAS	Computer-Assisted Qualitative Data Analysis Software
CP	Communication Partner;
HMV	Home Mechanical Ventilation;
HRQL	Health-Related Quality of Life;
ICF	International Classification of Functioning, Disability and Health;
ICU	Intensive Care Unit;
LwD	Living with Dysarthria;
NIV	Non-invasive ventilation;
NVivo	Software for CAQDAS
NRC	National Respiratory Centre;
PA	Personal Assistant;
PCV	Pressure-Controlled Ventilation;
PEEP	Positive End-Expiratory Pressure;
PLV	Portable volume ventilator;
PPV	Positive Pressure Ventilation;
QoL	Quality of Life;
SIP	Sickness Impact Profile;
SRI	the Severe Respiratory Insufficiency questionnaire;
SLT	Speech and Language Therapist;
VCV	Volume-Controlled Ventilation;

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# INTRODUCTION

A growing number of individuals require mechanical ventilatory support. This is related to advances in the development of mechanical ventilators, as well as the development of treatment routines. The ventilator-supported individual and the person communicating with him or her face many different challenges in both the ICU and home setting, one of which pertains to achieving functional communication.

Communicative abilities and opportunities are seriously affected in individuals receiving mechanical ventilatory support and many ventilator-supported individuals experience difficulties and frustration with their speech and voice production (Bergbom-Engberg and Haljamae, 1989, Hoit et al., 2003, Lohmeier and Hoit, 2003). Even when oral communication is achieved (e.g. by decuffing the cannula or adjusting ventilator settings), normal voicing and communication is not restored, as naturalness decreases, breathiness increases and speech loudness, vocal quality and pause length can be affected (Hoit et al., 2003).

In the following sections, issues related to ventilator-supported communication and the methodology of the thesis will be presented. Building on the existing body of knowledge on the topic, the results are then reported and discussed.

## BACKGROUND

This section is dedicated briefly to describing communication and normal speech production, as well as the way mechanical ventilation works and can affect communicative functions.

### ***Communication and normal speech production***

Communication is a basic human behaviour, fundamental to psychosocial functioning. Human communication and conversational interaction are not just a speech activity, they are both a linguistic and social activity. Communication can be seen as a two-way, jointly negotiated achievement, which is therefore reciprocal in nature. Regarding it as a dynamic process, involving interaction, also means that

it is relevant to address communicative partner skills. Moreover, viewing communication as collaborative in nature also has implications for clinical practice, moving from an impairment view, presuming that the communication problem is in the client, to a social view of communication disorders (Duchan, 2001).

In spite of this, it is still appropriate and important to address speech ability and production, as speech is the most effective and flexible means of communicating. Other means of communication, such as augmentative and alternative communication (AAC), may be useful for individuals whose speech fails to meet their needs. Speech production is essentially a motor activity, requiring the integrated function of respiratory, laryngeal and articulatory structures. Speech consists of the following three component processes: phonation, resonance and articulation. During normal speech production, the lungs supply the energy necessary for phonation during air expiration. Phonation is the generation of sound via the vibration of the vocal folds. Resonance in turn refers to the modifications that are made to the sound by the various supralaryngeal (throat) tissues and cavities, e.g. nasal and non-nasal resonance. The next phase in the speech-production process involves the adjustment of the sound by the action of the tongue, lips, teeth and palate in the oral cavity (mouth). This production and use of speech sounds, utterances, is referred to as articulation.

## ***Mechanical ventilatory support***

A ventilator moves air mechanically into and out of the lungs, to assist or control breathing in patients who are unable to maintain their ventilation spontaneously. There are various conditions that can require treatment with mechanical ventilatory support, in both adult and paediatric populations (Markstrom et al., 2008, Markstrom et al., 2010). Chronic respiratory failure can arise from underlying conditions such as pulmonary and neurological diseases and spinal cord injuries. The majority of the individuals receiving HMV only receive nocturnal mechanical ventilation (individuals with severe obesity). However, individuals with no spontaneous respiration, such as individuals with neuromuscular diseases or high spinal cord injuries, require mechanical ventilatory support > 24 hrs. The duration of mechanical ventilatory support can be short or long term, often managed at the intensive care unit (ICU) or in the form of home mechanical ventilation (HMV). The means and modes of mechanical ventilation also vary.

Mechanical ventilatory support can be achieved by tracheostomy via an endotracheal airway or by non-invasive ventilation (NIV) carried out with a nasal or face mask (Brochard, 2003). Individuals who require HMV 24 h/day often receive ventilation via a tracheostomy, but, when all the individuals requiring HMV are taken into account, those receiving NIV are in the majority, even if

practices vary between countries (Lloyd-Owen et al., 2005, Simonds, 2003). HMV is known to be a successful therapy for chronic respiratory insufficiency with regard to long-term survival and the use of HMV is expanding (Laub and Midgren, 2007, Simonds, 2003). Studies have reported good perceived health, despite severe physical limitations (Markstrom et al., 2002, Windisch and Crie, 2006).

Home mechanical ventilation (HMV) is considered to be a successful approach to improving quality of life, reducing morbidity and prolonging life (Simonds, 2003, Lloyd-Owen et al., 2005). Studies have found that individuals receiving HMV experience a relatively good QoL (Ballangrud et al., 2009, Ali and Kabir, 2007, Markstrom et al., 2002). The goal of HMV is to allow the individual to live at home, but the individual is still highly dependent on technology and health-care personnel and experiences limitations in both mobility and freedom (Brooks et al., 2004). Becoming dependent on mechanical ventilatory support is a life-changing event, involving physical, psychological, spiritual and existential changes (Brooks et al., 2004, Lindahl et al., 2005, Lewarski and Gay, 2007). To handle this adaptation process, the individual needs to have communicative capacity, e.g. to communicate needs and wishes, but he/she also has to have competent communicative partners/caregivers who understand the conveyed messages.

The Swedish HMV Register (Swedevox) (Strom and Boe, 1988, Midgren et al., 2000) is a web-based nationwide register run by the Swedish Society of Chest Medicine. It covers approximately 90% of Swedish patients starting HMV. According to the register, there were 1,800 HMV users (19/100,000) registered at the turn of the year 2009-2010 (<http://www.ucr.uu.se/swedevox/>). There are large variations in the patterns of use of HMV in Europe, in terms of prevalence, indications for treatment and the use of tracheostomies. The estimated prevalence of HMV was found to be 6.6 per 100,000 people in 2005 (Lloyd-Owen et al., 2005), but there is a steady increase in HMV users every year (Laub and Midgren, 2007, Lloyd-Owen et al., 2005).

## ***Ventilator-supported communication***

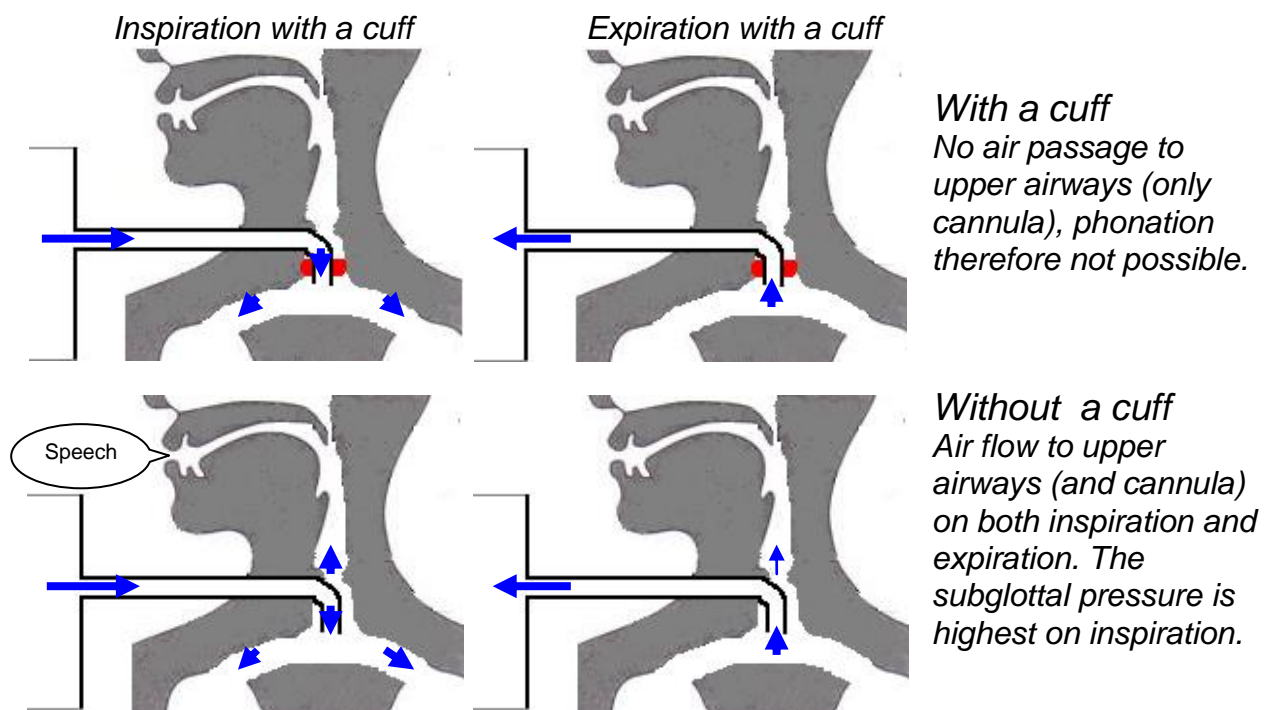
Receiving mechanical ventilatory support seriously affects speaking and communication and many ventilator-supported patients experience difficulties and frustration with their speech and voice production (Lohmeier and Hoit, 2003, Bergbom-Engberg and Haljamae, 1989). The ability/inability to communicate and be understood by others can have an impact on an individual's quality of life (QoL), overall medical care, psychological functioning and social interactions (Leder, 1990, Levine et al., 1987, Silverstein et al., 1991, Gibbons, 1996, Carroll, 2007) and attention has been paid to optimising speech production in ventilator-supported individuals (Prigent et al., 2003, Nomori, 2004, MacBean et al., 2004).

Ventilator-supported individuals often speak in short phrases and on both inspiration and expiration in order to use air flows to generate speech and voice (Hoit et al., 1994). Ventilatory adjustments, such as prolonging inspiration and adding PEEP (Positive End-Expiratory Pressure), can be made in order to shorten pause duration, increase speaking time per ventilator cycle and improve loudness and vocal quality (Hoit et al., 2003).

Many ventilator-supported individuals are periodically non-vocal, e.g. often during an intensive care period. This is the case if there is no air passage to the upper airways (due to cuffing) or if the intubation is performed with an endotracheal tube. In this procedure, the tube is inserted through the mouth down into the trachea, passing the vocal cords and thus making voicing impossible, as the vocal folds are unable to vibrate. Voicelessness can also be the result of cognitive, sensory or language deficits (Happ et al., 2004).

Ventilation can also be performed through a tracheostomy, a surgical procedure to create an opening in the neck into the trachea. Some strategies aimed at achieving oral communication in individuals who have been tracheotomised are described in the following presentation. One procedure aiming at oral communication is decuffing the cannula, that is removing the air from the cuff (alternatively using a cuffless and/or fenestrated cannula) (Tippett and Siebens, 1995). A cuff is a soft balloon around a cannula that can be inflated/deflated. See Figure 1 for a schematic diagram of air flows during mechanical ventilatory support when using or not using a cuff. A cuffless tracheostomy tube allows exhaled air to pass through the upper airway, enabling the individual to speak. However, normal voicing and communication are often not restored, as naturalness decreases and breathiness increases (Hoit et al., 1994), which results in a reduction in speech loudness, effects on vocal quality and longer pauses (Hoit et al., 2003). In clinical practice, the most common procedure used to achieve oral communication in ventilator-supported individuals is decuffing the cannula during the day. This allows the individual to speak during the daytime, but, after cuffing the tube, the individual has to rely on other communicative alternatives. In addition to the cuff-down technique, individuals receiving mechanical ventilation who are tracheotomised can also produce speech using a speaking valve (Kaut et al., 1996), but this requires decuffing and not all individuals are able to tolerate this. If cuffing is necessary, there is still one option to achieve oral communication, which is using a speaking/talking tracheostomy tube. This is a single-cuffed tube designed with an external air-flow line (Leder, 1990, Hess, 2005). A speaking/one-way tracheostomy valve directs air to the upper airways on expiration, thus improving voice and communicative abilities (Tippett and Siebens, 1995, Manzano et al., 1993, MacBean et al., 2004).

Even if a variety of techniques are available for achieving oral communication for individuals receiving mechanical ventilatory support, these techniques may not be suitable for all individuals, speech may still be less than satisfactory and voice and articulatory functions may not be sufficient for oral communication. The use of augmentative and alternative communication (AAC) can be warranted to meet communicative needs. Since the general motor abilities (hand and arm function) of ventilator-supported individuals are often restricted, the use of AAC can, however, be a demanding task. Some of the strategies that patients on an ICU ward use when voicing is difficult include head nods, mouthing words, gestures and writing (Happ et al., 2004). Both clinicians and family members are important communication partners when a person has communication difficulty and they need to receive training in non-vocal communication strategies, for example (Happ, 2001). Speech and language therapists (SLT) have trained tracheotomised patients in the ICU to use a unidirectional speaking valve. It helped them to talk and communicate without assistance. Patients felt better and were motivated to participate in their own care (Manzano et al., 1993).



**Figure 1** Air flows during mechanical ventilatory support achieved by a tracheostomy

## ***What remains to explore?***

There is a lack of studies examining ventilator-supported communication, especially when it comes to the communication experiences of individuals receiving HMV and their CPs. This research area needs to be developed to ensure adequate health services for this population, especially in the light of the increasing recognition of just how important it is for patients to participate in decision-making processes. The overall aim of this thesis is to contribute to increased knowledge and awareness of issues related to this topic. One of the main objectives is to focus on the insider's perspective of communication during HMV, mainly from the point of view of individuals receiving home mechanical ventilation, as well as their CPs.



# AIMS

The overall aim of the thesis was to contribute to an increased knowledge and awareness of issues related to ventilator-supported communication in an adult population.

The overall aim was investigated in four separate studies, with the following specific aims:

## Paper I

The aim was to explore both the staff's and the ventilator-supported patient's experiences of communication during ventilator care in different contexts.

## Paper II

The aim was to examine how individuals receiving HMV experience their communicative participation and their HRQL and whether there are any relationships between demographic factors, HRQL and communicative activity (specifically speech intelligibility) and participation.

## Paper III

The aim was to describe in detail the communication experience of individuals treated with HMV.

## Paper IV

The aim was to explore the communication experiences of key CPs of individuals receiving HMV. Interest focuses in particular on the opportunities, difficulties and limitations they experienced in communication, the possible support given to facilitate communication and exploring what makes a skilled communicator.



# CONCEPTUAL FRAMEWORK

## ***Combined methods***

The topic of this thesis, ventilator-supported communication, is multidimensional and the specific research questions are difficult to answer using a single approach. In contrast to a single approach, mixed methods can provide stronger inferences and the opportunity to present a greater diversity of divergent views, thereby expanding the scope of the studies. There are several types of mixed-method approach, but there is also some confusion about ways of combining qualitative and quantitative techniques (Sandelowski, 2000a). In a mixed-method research design, qualitative and quantitative approaches can be used in the types of question, research method, data collection and analysis procedure and/or inference (Teddlie and Tashakkori, 2003). Mixed methods have been used within the field of speech and language therapy, e.g. to enhance language research and intervention (Brinton and Fujiki, 2003).

Mixed methods have been defined as the mixing of quantitative and qualitative approaches within a single study, with data integrated at some stage (Creswell and Plano Clark, 2007). In this thesis, the mixed-methods approach was not used within a single study but sequentially across the included studies, thereby resembling a sequential design (Miller and Crabtree, 1994). The main reason for this approach was to allow one study to guide and inform the process of designing the ensuing studies. The first study was an introductory study with a qualitative research design and its findings guided the following studies, when it came to sampling, data collection and analysis methods, for example (see the research design overview in Table 1). The second study had a quantitative research design and provided some measured descriptions. The first two studies led to the more detailed structuring of the approach in the two final qualitative studies, regarding the focus during the analysis phase, for example. Data from all the studies were then integrated in the thesis.

## ***Qualitative research***

### **The interpretive approach**

There is increased awareness of the need for scientists to be flexible in their choices of research methods, particularly in an area as multifaceted as human

communication. In the understanding of human communication sciences and disorders, to complement quantitative research approaches, qualitative research methods have been employed and they continue to play an important role (Tetnowski and Franklin, 2003). Qualitative interpretive methods are based primarily on a social model approach, as opposed to a medical model, and, as seen above, they can be combined in a mixed-methods approach. It is, however, not an either/or dichotomy when discussing qualitative and quantitative methodologies; it would instead be more appropriate to consider them as falling on either side of a continuum. The interpretive analyst's aim is to contribute to our *understanding* of a phenomenon of interest. Qualitative research methodologies have a long history of use in the social sciences and are well suited to address the complex issues of speech, language and communication (Damico and Simmons-Mackie, 2003). Clinical speech-language pathology is moving toward the progressive use of qualitative research methodologies (Simmons-Mackie and Damico, 2003) and qualitative research is also very much needed to explore QoL when living with a communication disorder (Cruice, 2008). Qualitative methods can be used to bridge the gap between research and practice and find the best methods for therapy (Brinton and Fujiki, 2003).

Various disciplines offer descriptions and definitions of qualitative research and the following operational definition of the purposes of clinical speech-language pathology can be found in Damico and Simmons-Mackie (Damico and Simmons-Mackie, 2003); "*Qualitative research refers to a variety of analytic procedures designed to systematically collect and describe authentic, contextualized social phenomena with the goal of interpretive adequacy*" (p. 132). Interest focuses on describing and explaining the essence of the social phenomenon, as well as its meaning in the participants' lives, reflecting their views; the insiders' experience. It brings the perspective of the person with the illness to the fore (Grypdonck, 2006). Given the epistemological assumptions and the inductive approach guiding the qualitative research paradigm, the researcher interacts with what is being researched. Qualitative research interviews are therefore seen as a collaborative, interactional achievement, where knowledge is constructed jointly by the interviewer and the interviewee (Kvale, 1996). The interview text is often seen as a communication act between the researcher and the text (Graneheim & Lundman; Watzlawick et al.). The stance of the investigator is therefore relevant and explicitly acknowledged.

When wishing to understand a phenomenon such as the communication experience of individuals receiving HMV, a quantitative method would not give the entire picture. As a researcher, one is interested in examining participant meaning making. As Guba and Lincoln (1994) noted, "*Human behaviour, unlike that of physical objects, cannot be understood without reference to the meanings and purposes attached by human actors to their activities*" (p. 106) (Guba and Lincoln,

1994). The shortage of existing information on the subject of ventilator-supported communication and the rationale of the study indicated that the use of a qualitative research method (mixed with a quantitative approach) was logical and appropriate.

## **The insider's perspective**

The means for examining subjective experience require the use of a qualitative research method, since this method enables us to learn the emic or insider's perspective (Creswell, 1998). The terms "emic" and "etic" were originally coined by the linguist Kenneth Pike (1967) (Pike, 1967) and are derived from the linguistics terms "phonemic" and "phonetic". The term "emic" refers to sound differences that are consciously perceived by speakers/listeners as belonging to the language, while the term "etic" refers to physical sound differences that can be measured by a listener but are not necessarily part of the language's sound repertoire. In anthropology, the terms have been used to contrast between indigenous explications, i.e. the insider's perspective, in contrast to descriptions according to the observer's criteria, i.e. the analyst/outsider's perspective. The terms emic and etic can be applied in different ways to the studies included in this thesis. Studies III and IV in this thesis examine two different samples (ventilator-supported individuals and their CPs) that may illuminate the complexity of the issue of ventilator-supported communication. The CPs can be seen as being between emic and etic perspectives, as they observe the ventilator-supported individual in different contexts but also often act as communicative partners, thereby being both "insiders" and "outsiders". Study II can also be interpreted as having two differing perspectives, the etic perspective of the speech and language therapist (SLT) assessing aspects of communicative activity and the emic perspective of the participants (filling out the questionnaires). The main focus of this thesis has been the insider's perspective, but, as pointed out above, information is provided on both emic and etic aspects to help understand the complexity of the topic.

While striving for an insider's perspective, there was a movement towards conducting research from a social constructionist perspective. Social constructionism emphasises the idea that knowledge and action are socially constituted (Berger and Luckmann, 1966). The objective is to learn from subjects about their experiences and, in narrative form, to discover knowledge. Semi-structured qualitative interviews with individuals with experience of ventilator-supported communication are one way of obtaining an insider, or emic, perspective. This perspective requires that the subjects of research are recognised as fully engaged participants in the process and that we show respect for their dignity and autonomy as individuals, e.g. that interviews are conducted with the participants' informed consent. The insider's perspective can be a very valuable

source of data, highlighting the voices of those who are not often heard. and can help us understand the topic of this thesis, ventilator-supported communication.

## **Qualitative content analysis**

Qualitative content analysis is one of a number of qualitative research methods. Initially, it was described as “*a research technique for the objective, systematic and quantitative description of the manifest content of communication* “ (p.18) (Berelson, 1952), but, over time, it has expanded also to include interpretations of latent content. Today, the two main uses of content analysis are quantitative and qualitative, which can in turn be used in an inductive or deductive way (Elo and Kyngäs, 2008). If there is not enough former knowledge about the phenomenon or if this knowledge is fragmented, the inductive approach is preferred (Lauri & Kyngäs 2005). The underlying assumption of qualitative content analysis is communication theory (Watzlawick, Beavin Bavelas, & Jackson, 1967).

The goal of qualitative content analysis is to “*provide knowledge and understanding of the phenomenon under study*” (p.314) (Downe-Wamboldt, 1992). It can be applied to analyse different kinds of data, collected using a variety of qualitative research approaches. Hsieh and Shannon (Hsieh and Shannon, 2005) defined it as “*a research method for the subjective interpretation of text data through the systematic classification process of coding and identifying themes of patterns*” (p. 1278). In particular, qualitative content analysis emphasises similarities and differences within codes and categories (Graneheim and Lundman, 2004, Hsieh and Shannon, 2005). In comparison to phenomenology, for example, which seeks to discover the essence of a phenomenon, qualitative content analysis focuses more heavily on trying to describe variations of the phenomena under study. During the sampling process, the researcher can therefore look for participants with different experiences, as one way of achieving variation.

At all stages, the research process is creative and interactive. During the analysis process, the researcher moves from the particular (such as line-by-line codes) to more general aspects (patterns and themes within codes) and back to interview texts. The analysis usually aims to create categories that are exhaustive and mutually exclusive (Krippendorff, 2004) and to discover themes; threads of meaning that recur in domain after domain (Baxter, 1991).

## ***Health-related quality of life***

QoL and the ICF framework are two distinct yet related concepts. The latter can help us structure what the individual can and cannot do, whereas QoL helps us

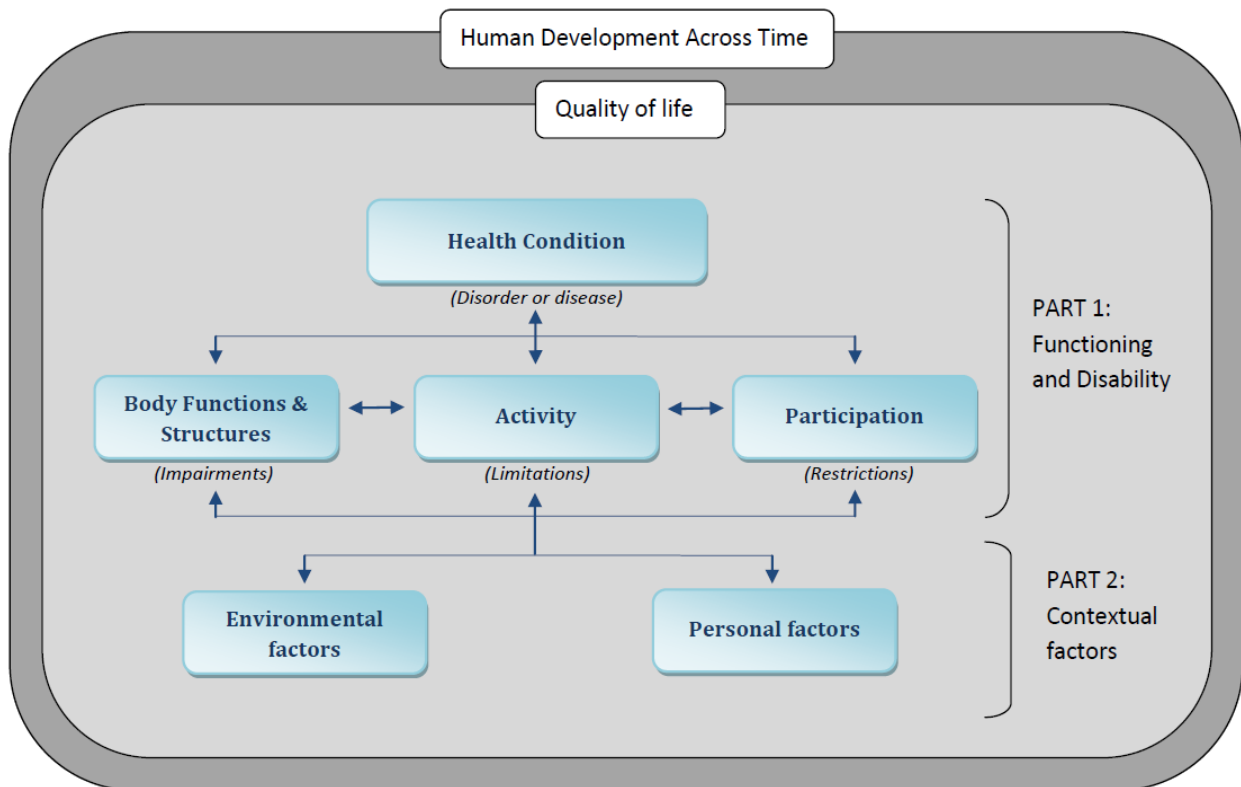
consider who the individual is, what he or she wants in life and who he or she wants to be (Cruice, 2008). QoL is closely related to the narrower concept of health-related quality of life (HRQL). The term HRQL refers to several domains of health, such as physical, psychological and social domains; these distinct areas are influenced by a person's experiences, beliefs and perceptions (Testa and Simonson, 1996, Windisch et al., 2003, Patrick et al., 1973). In overall terms, HRQL has been measured in individuals receiving HMV and has been found to differ between different diagnostic groups, with the best overall HRQL being measured in patients with kyphoscoliosis and the worst in chronic obstructive pulmonary disease (Windisch et al., 2003). Several instruments have been developed for the assessment of HRQL. Generic HRQL questionnaires include a spectrum of domains of HRQL that apply equally to various patient populations. Generic questionnaires have the advantage that the patients' scores can be compared with the scores of other patient populations and/or a healthy control population. Disease-specific questionnaires are designed to be valid for a specified condition and have the advantage of providing greater specificity and sensitivity. In this thesis, both general and disease-specific aspects of HRQL were assessed.

## ***The International Classification of Functioning, Disability and Health***

The World Health Organisation's conceptual framework, the International Classification of Functioning, Disability and Health (ICF, 2001), is used as a framework for this thesis, to broaden the perspective on how to work with issues associated with ventilator-supported individuals' communication. The ICF is based on its predecessor, the original 1980 International Classification of Impairments, Disabilities and Handicaps (ICIDH) (WHO, 1980). The ICF suggests an holistic approach to health conditions, as it moves from a purely medical or social model to an integrated biopsychosocial model of human functioning and disability. It provides a classification of health and health-related domains and each component can be expressed in either positive (functioning) or negative (disability) terms. The domains help us describe body structure and functions, activity and participation (Part 1: Functioning and Disability), as well as environmental and personal factors that can lead to activity limitations and participation restrictions (Part 2: Contextual factors). One of the new features of the ICF is that it provides an interactive model (see Fig. 2) and the interactions are in both directions, e.g. the presence of disability may modify the health condition.

The concept of QoL is not explicitly named or mentioned as a component of the ICF framework, but the authors of the ICF have encouraged work dedicated to establishing links between the ICF and QoL measurements (ICF, 2001). In a recent

study (McDougall et al., 2010), the ICF is expanded to include the concepts of QoL (see Figure 2). They describe a person's QoL as a composite emerging and changing phenomenon of all the aspects found in the ICF. Further, the authors depict human development across time as an overarching level. In the present thesis, QoL and its possible relationship with communicative activity and participation was explored in Study II.



**Figure 2** Interaction of the concepts in the ICF structure and their relationship to the concept of QoL

The ICF structure allows any health condition to be classified and it can subsequently also be applied to communication disorders (Threats, 2006, Threats and Worrall, 2004). Body functions are defined as physiological functions of body systems, as well as psychological functions. This includes voice and speech functions. Body structures are defined as anatomical parts of the body, such as structures involved in voice and speech. The WHO authors provided different options when it came to viewing the constructs of Activity and Participation; to consider the constructs as separate, possessing partial overlap or merged into one construct. In what follows, the constructs of activity and participation are described as separate. The activity/participation construct of the ICF contains several



chapters that relate to communication functions, e.g. “Communication”, “Interpersonal Interactions and Relationships” and “Community, Social and Civic Life”. Activity is defined as the execution of a task or action by an individual, whereas participation is defined as involvement in a life situation. Communicative activity depends to some degree on the inclusion of a listener and can be assessed, for instance, in terms of speech intelligibility and speech naturalness. Communicative participation is discussed in a section below. Environmental factors range from physical factors, such as products and technology and climate and terrain, to social attitudes, support and relationships, institutions and laws. These factors make up the physical, social and attitudinal environment in which people live and conduct their lives and they can be described as either facilitators or barriers. Personal factors are not coded within the ICF structure, but they are included to show that they can have an impact on an individual’s health and health-related states. Personal factors include age, gender, race, social status and life experiences.

The ICF framework is partly used to describe the aims of the present studies and the assessment measures used, but it is also used in the interpretation and presentation of the results. The studies elucidate how body functions and contextual functions contribute to the communicative activity and participation of ventilator-supported individuals and they also describe different barriers (activity limitations and participation restrictions) to achieving effective communication.

## **Communicative participation**

As stated above, the concept of participation can be defined as involvement in life situations (ICF, 2001) and it reflects the final common pathway for several aspects of functioning and disability (Yorkston et al., 2001). When it comes to the construct of communicative participation, it has been described as taking part in life situations where knowledge, information, ideas or feelings are exchanged (Eadie et al., 2006), taking the form of listening, speaking, reading or writing or other non-verbal methods. One fundamental feature of communicative participation is the complex interaction between the individual with the impairment or the activity limitation and the social context (Worrall, 2000). Restrictions in communicative participation need to be evaluated by the individual him/herself, e.g. by using a self-report format. Traditionally, both in clinical practice and in research, overt aspects of speech disorders (those that are identified on a structural/functional level) are assessed more frequently than covert aspects (such as the subjective consequences of living with a speech disorder). In the speech-language pathology discipline, there is a lack of self-report instruments dedicated to the construct of communicative participation. Communicative participation may be restricted as a consequence of an impairment of speech (dysarthria) or language (aphasia), for example, but it can also be restricted because of a mobility problem

that limits social contacts without a concurrent speech disorder (Eadie et al., 2006). As many individuals who receive HMV also have mobility problems, it is valuable to investigate their communicative participation, as well as speech and language functions (Cruice, 2008).

# MATERIALS AND METHODS

## *Design*

A mixed-method research approach guided the overall research design of the thesis. Study **I** was a qualitative case study. Study **II** included analyses of quantitative measured variables. Studies **III-IV** were qualitative interview studies. Table 1 describes the research design of the four studies and the details will be discussed in the following sections.

**Table 1** Research design overview

Papers	Study I	Study II	Study III	Study IV
<b>Design</b>	Explorative case study	Descriptive, correlational	Explorative, descriptive	
<b>Main data collection</b>	Research interviews	Questionnaires in conjunction with assessments by an SLT	Research interviews	
<b>Participants</b>	A nurse and an individual receiving HMV (n=2)	Individuals receiving HMV (n=19)		CPs of participants in Studies II-III (n=19)
<b>Analysis</b>	Thematic content analysis is used in conjunction with a case study approach	Statistical analysis	Qualitative content analysis	

Study **I** was seen as an introductory study, dealing with areas such as training the researcher in elements of the research process, collecting preliminary data, assessing the feasibility of a full-scale study and presenting suggestions for future research. One of the suggestions from Study **I** was to focus mainly on individuals receiving HMV, since patients in ICU settings are often sedated initially, their

autonomy is restricted and they are unable to give their informed consent. The following studies (**II-IV**) included in the thesis therefore focused on communication during HMV. Further suggestions from Study **I** included correlating the results of communicative participation with HRQL, exploring the concept of communicative participation in ventilator-supported communication in greater depth. This was done in Study **II**. In Study **I**, the role of the CP in communicative interaction in ventilator-supported communication was highlighted and the results suggested that a more active focus on the role of the listener could contribute to a deeper understanding of issues related to ventilator-supported communication. This led to the research design of the last two studies planned to be part of this thesis, qualitative interview studies with both ventilator-supported individuals, **III**, and their CPs, **IV**.

## ***Participants***

Study **I** was a case study with two participants, a nurse from an ICU setting and a ventilator-supported participant (see Table 1). The sample was based on intensity sampling, which seeks information-rich but not extreme cases. The ventilator-supported participant had suffered a high spinal cord injury.

Participants for Studies **II-III** were recruited from the National Respiratory Centre (NRC) at Danderyd Hospital in Stockholm, Sweden (Bjorling et al., 2006). The selection of participants was made strategically from the total population of individuals receiving HMV who were treated by the NRC. The inclusion criteria were HMV duration of > 1 year, full-time need for respiratory support, fluent in Swedish, adult (>18 years of age), communication skills beyond yes-no responses and the absence of severe aphasia or cognitive impairment. A total of 23 individuals were eligible to participate and four individuals declined. The drop-outs were aged between 37 and 44, with two suffering from a spinal cord injury, one from a neuromuscular disease and one from another disease; all were tracheotomised. As a result, 19 individuals participated in the studies (**II-III**).

All the 19 study participants (**II, III**) who received HMV were in need of life-long respiratory support due to severe chronic respiratory failure. Their demographics and primary aetiology are given in Table 2. The study group included five women and 14 men whose ages ranged from 26 to 76, with a mean age of 47.3 years. The average experience of HMV was 13.6 years, ranging between three and 35 years. All the participants had a stable condition and normal blood gases. Seventeen of the participants were receiving HMV via an uncuffed tracheostomy (no speaking valves), while two (participants 7 and 8) were using non-invasive ventilation (NIV). Sixteen of the participants had volume-controlled ventilation (VCV) and

three (participants 4, 11 and 12) had pressure-controlled ventilation (PCV). Most of the participants were not receiving any positive end-expiratory pressure (PEEP),

but seven of them had varying levels of cm H<sub>2</sub>O PEEP. Participants 4, 6, 11, 12, 16, 17 and 19 had PEEP levels between 4-10 cm H<sub>2</sub>O. The majority were residents in the County of Stockholm and they all lived in their own homes. To manage their daily activities, all the participants were helped by personal assistants 24 hours a day.

The 19 participants receiving HMV (**II-III**) were asked to recommend one participant each for Study **IV**, their closest CP. This meant that there were a total of 19 participants in Study **IV**. Thirteen of them chose one of their personal assistants (PAs), four someone who was both a PA and a family member and two chose family members. The CPs in Study **IV** were aged between 22 and 71 years of age, with a mean age of 36. Five were males and 14 females. Their experience of communicating with the individual receiving HMV ranged from 1 to 23 years, with a mean length of 6.5 years. The selection criteria for CPs in Study **IV** were (a) identified as a key CP by the individual receiving HMV, (b) had at least 1 year's experience communicating with the individual receiving HMV, (c) had no known speech, language, or hearing impairments and (d) fluent in Swedish.

**Table 2** Demographics of participants (communication partners [CPs]), as well as the individuals receiving home mechanical ventilation (HMV)

	Individuals receiving HMV						Communication partners				
	Gender	Age	Education level <sup>a</sup>	Primary aetiology	HMV experience (years)	Current employment	Gender	Age	Education level <sup>a</sup>	Relationship with the individual receiving HMV	Experience of communicating with the individual receiving HMV (years) <sup>b</sup>
<b>1</b>	M	69	3	Post-polio syndrome	22	None	F	53	2	PA	3
<b>2</b>	M	52	1	Spinal cord injury	35	None	F	25	2	PA	3½
<b>3</b>	M	76	2	Dystrophia myotonica	16	None	M	42	2	PA	23
<b>4</b>	M	35	2	Morquio's syndrome	8	None	F	28	2	PA	8
<b>5</b>	F	56	2	Encephalitis	12	None	F	27	2	PA and daughter	12
<b>6</b>	M	73	1	Spinal cord injury	3	None	F	71	2	Wife	3
<b>7</b>	F	36	2	Spinal muscular atrophy	10	Part time	M	30	3	Partner	6
<b>8</b>	M	26	2	Duchenne muscular dystrophy	11	Part time	F	22	2	PA and sister	11
<b>9</b>	F	30	2	Neuro-fibromatosis	30	None	F	28	2	PA	9
<b>10</b>	F	55	1	Muscular dystrophy	11	None	M	56	2	PA and husband	11
<b>11</b>	M	26	2	Duchenne muscular dystrophy	8	None	F	25	2	PA	1
<b>12</b>	M	54	3	Spinal cord injury	3	Part time	F	49	1	PA	1½
<b>13</b>	M	34	2	Congenital myopathy	12	None	M	29	2	PA	4
<b>14</b>	M	45	1	Spinal cord injury	26	None	M	24	1	PA	3½
<b>15</b>	M	32	1	Duchenne muscular dystrophy	16	None	F	25	2	PA	2
<b>16</b>	F	30	3	Spinal cord injury	11	Part time	F	43	1	PA	6
<b>17</b>	M	67	2	Spinal cord injury	13	None	F	26	2	PA	6
<b>18</b>	M	61	2	Amyotrophic lateral sclerosis	8	None	F	57	2	PA and wife	8
<b>19</b>	M	42	2	Spinal cord injury	3	None	F	24	2	PA	2

<sup>a</sup>1, Compulsory school; 2, Upper secondary school; 3, University or college. <sup>b</sup>Since family members know the individual prior to the onset of HMV, this reports their experience of communicating with the person from that point in time. F, Female; M, Male; PA, personal assistant

## **Data collection**

The data collection procedures for all four studies are outlined below. Studies **I**, **III** and **IV** included qualitative research interviews. Study **II** included questionnaires in combination with assessments by an SLT. See Table 1 for an overview of data collection procedures.

## **Settings**

The participants in Study **I** were seen at Sahlgrenska University Hospital. The participants in Studies **II-III** were seen either during a routine medical check-up at the NRC or, if they so wished, in their homes. Data collection for Studies **II-III** took place on the same occasion, but the sessions were split into two or more, allowing participants to pause when needed. The participants in Study **IV** were seen either at the NRC or in the homes of the participants in Studies **II-III**. Data collection for Studies **II-IV** covered a period of one year (June 2007 through May 2008).

## **Field observations and case study approach (I)**

In Study **I**, field observations were conducted in preparation for the semi-structured interviews, the main source of evidence. Research questions guided the development of an observation protocol used in the field observations, which were carried out in an ICU setting at the hospital to which the researcher is affiliated. Prior to field observations, staff members were informed about the study. The researcher followed a few nurses in their daily activities on several occasions over a period of two weeks. Field observations produced five sub-units of analysis. Field observations were followed by the main data collection, which consisted of interviews with the two participants following an interview guide based on the units of analysis.

## **Interviews (I, III, IV)**

The interviews in Studies **I**, **III** and **IV** were semi-structured qualitative research interviews, a type of interview that aims to understand the participant's perspectives on themes in his or her life world (Kvale, 1996). Research interviews are based on the conversations of everyday life and they are conversations with structure and purpose that are defined and controlled by the researcher. All the interviews were audio-recorded and transcribed verbatim. The interviews followed semi-structured interview guides.

The interview sessions in Studies **III-IV** lasted between 30 to 70 minutes. The interviews in Study **III** started with open questions focusing on the participants' experiences of ventilator-supported communication. All the participants had cognitive and communicative abilities that enabled them to complete interviews, all but one (using a communicative aid) using their own speech. The interviews in Study **IV** started with open questions focusing on the participants' experiences of communicating with an individual receiving HMV.

## **SLT assessments (II)**

An SLT carried out the assessments in Study **II**. Oral motor function and language abilities were assessed/screened using parts of the dysarthria and aphasia assessment tools that are standard in Sweden. Speech intelligibility was measured at sentence level by untrained raters/listeners from audio recordings. The untrained raters had a knowledge of the language but not of the speaker or the material and they were told that the passages consisted of real words. The raters listened to the audio recordings and transcribed the sentences. The percentage of correct words was then calculated. Interjudge reliability between raters in the intelligibility evaluation was found to be high ( $r=0.968$ ;  $p=0.000$ ). The degree of oral motor dysfunction was evaluated. Oral motor tasks included the oral diadochokinetic rate (repeated syllables) and the maximum duration of prolonged phonation.

## **Questionnaires (II)**

For Study **II**, three self-report questionnaires were administered and speech intelligibility was assessed. Speech intelligibility was measured using a Swedish computerised assessment procedure, the Swedish Intelligibility Test (SWINT) (Lillvik et al., 1999). The speakers were asked to read ten sentences, each from four to six words in length. To evaluate the speech difficulties as perceived by the individuals receiving HMV, the "Living with Dysarthria" (LwD) self-report questionnaire (Hartelius et al., 2008) was used. The LwD consists of 40 statements divided into three different sections; Section A comprises propositions addressing speech function, section B addresses speech activities and participation and section C comprises statements addressing environmental and personal factors.

In addition, two questionnaires for measurements of HRQL were administered. The Severe Respiratory Insufficiency (SRI) questionnaire (Windisch et al., 2003) provides a relatively new disease-specific measurement of HRQL in individuals receiving HMV. The SRI subscales contain social, psychological and physiological components of HRQL. The questionnaire comprises 49 questions across seven domains covering respiratory complaints, physical functioning, attendant symptoms and sleep, social relationship, anxiety, psychological wellbeing, and social functioning. The subscales are aggregated into one summary score (SRI-SS),



where high values indicate high HRQL (Windisch et al., 2003). The Sickness Impact Profile (SIP) questionnaire is a behaviour-based measurement of health-related dysfunction in an individual's daily life (Bergner et al., 1981). It measures both communication and environmental factors. It consists of 136 statements covering 12 different areas of activities: sleep and rest, eating, home management, recreation and pastimes, body care and movement, ambulation, mobility, emotional behaviour, affective behaviour, social interaction, communication, work.

### Distribution of assessment measurements according to ICF domains (I-IV)

Assessment measurements targeted different levels in the ICF hierarchy. Table 3 depicts the various domains of the ICF construct and specific factors that are investigated in the thesis are described in terms of content and the main data collection procedures. Using the ICF as a reference framework allows a researcher to see which domains are covered in a specific instrument. As seen in Figure 2 (and consequently Table 3), HRQL is not explicitly incorporated in the ICF structure.

**Table 3** Distribution of assessment measurements according to ICF domains and HRQL

ICF				HRQL		
	ICF components	Variables of interest	Assessments and instruments		Variables of interest	Assessments and instruments
			Specific	General		
PART 1: Functioning and Disability	Body function and structures	The speech function	Standard dysarthria assessments in Swedish	Interviews with individuals receiving HMV as well as their CPs	Social, psychological, and physiological components of HRQL	Questionnaires measuring HRQL (SIP and SRI)
	Activity	Speech activity: intelligibility measured as the percentage of correctly perceived utterances	The SWINT intelligibility test			
	Participation	Communicative participation	LwD questionnaire			
PART 2: Contextual factors	Environmental factors	External influences on communication, e.g. individual ventilatory modes and settings, as well as support of other people. Facilitating and hindering impact	Data gathered from medical charts	Interviews with individuals receiving HMV as well as their CPs	Social, psychological, and physiological components of HRQL	Questionnaires measuring HRQL (SIP and SRI)
	Personal factors	Internal influences on communication, e.g. age, profession and coping styles				

## **Data analysis**

The data in Study **I** were analysed using thematic content analysis in conjunction with a case study approach. In Studies **III** and **IV**, qualitative content analysis was used. Study **II** included a statistical analysis of data.

### **Thematic content analysis (I)**

Burnard describes a *thematic* content analysis adapted from both grounded theory and content analysis (Burnard, 1991, Burnard, 1995). The aim of the analysis is to produce a detailed and systematic recording of the themes and issues that are addressed in the data, assumed to be interviews. This is a 14-step approach to analysis in qualitative research. The analysis consists of the following steps; writing of notes, identification of general themes, open coding, grouping of categories under higher-order headings, merging of similar categories, independent categorisation by colleagues, re-reading of transcripts and following adjustments, using categories to code transcripts, collection of all coded sections, grouping of coded sections according to headings and subheadings, validation of findings, filing, writing up findings and finally linking findings and literature (Burnard, 1991). The analysis began with reading memos and noting general themes when transcripts were read through. Next followed the open coding of phrases that summarised passages of data. Data were coded into groups with shared characteristics and thereafter grouped together in higher-order headings in order to reduce the number of categories. A second researcher who was not involved in any other aspect of the study participated in the analysis. She is a physiotherapist familiar with the process of category generation in qualitative research. She received transcripts and made an independent analysis. To ensure validity, the categories generated by both researchers were discussed and compared and found to be similar.

### **Case study approach (I)**

Yin defines a case study as an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident (Yin, 2003). When it came to “boundaries between phenomenon and context not being clearly evident”, it was recognised that contextual elements, such as the physical environment in the hospital or in the home, sometimes appeared partly to define the phenomenon (ventilator-supported communication). In an embedded case study, attention is given to more than one unit of analysis. Units of analysis are related to the way initial research questions are defined and they delineate the specific case: *ventilator-supported communication*. A case description is an analytical strategy that relies on a framework for organising the case study and will lead to

conclusions (Yin, 2003). In Study I, field observations produced five sub-units of analysis that were used to construct an interview guide: medical and personal factors (1), external factors (2), explicit communicative barriers and strategies (3), implicit communicative interaction (4) and communicative needs (5).

### **Qualitative content analysis (III, IV)**

The data in Studies III and IV were analysed using qualitative content analysis according to Graneheim and Lundman (Graneheim and Lundman, 2004). The analysis enables meanings, contexts, consequences or intentions to describe and delimit categories (Downe-Wamboldt, 1992, Graneheim and Lundman, 2004). The overall aim of the analysis is to produce a detailed, systematic recording of the themes and issues that are addressed in the data. The focus during the analysis process can be either manifest or latent content, i.e. an interpretation of an underlying content behind the obvious surface content (Downe-Wamboldt, 1992, Graneheim and Lundman, 2004). Both levels deal with interpretation, but with varying depth and level of abstraction. The emphasis was placed on the manifest content, but the latent content has also been observed and taken into consideration, especially in the development of themes. The aim of the studies in this thesis did not go beyond examining/describing the phenomenon and qualitative content analysis therefore appeared to be more appropriate than grounded theory, for example, that aims at developing theory.

The interview texts were analysed in several steps, starting with a naïve reading of the texts and memos. The next step was a structural and detailed qualitative content analysis of the texts. The text was divided into meaning units, statements that relate to the same central meaning and to the aim of the study. The meaning units were condensed and then abstracted and labelled with codes, which were continuously compared for similarities or differences, and in this way categories were developed. No content areas (as units of analysis in Study I can be described) were developed from the start of the analysis. Instead, the categories that emerged from the data were organised into higher-order headings without first sorting categories into content areas, which enabled a more inductive analysis. The relationship between categories was further explored in the last phase of the analysis, with the aim of arriving at an interpretation of the underlying meaning and thereby the development of themes. A more comprehensive understanding evolved by joining the naïve understanding and critically analysing and comparing categories, while also taking account of the researchers' pre-understandings. The transcribed interviews were managed in the QRS NVivo<sup>®</sup> software program (NVivo 8) (Gibbs, 2002); a computerized qualitative data analysis software (CAQDAS) facilitating the management of textual data.

## **Statistical methods (II)**

All the statistical operations in Study **II** were performed using SPSS 17.0 software. Non-parametric Spearman's rank correlations were used to determine the level of correlation between the mean summary and domain scores of the three questionnaires. To assess possible correlations with demographic factors (age and years of HMV experience) and intelligibility scores, non-parametric Spearman's rank correlations were also conducted. Statistical significance was accepted at  $p \leq 0.01$ . Descriptive data were presented as the mean  $\pm$  standard deviation.

## ***Ethical considerations***

The study protocol was approved by the Regional Ethics Committee in Stockholm, Sweden, and written informed consent was obtained from all participants.

# FINDINGS

## ***Ventilator-supported communication in the ICU (I, III)***

Participants receiving HMV (III) had often experienced lengthy, frustrating non-vocal periods when first becoming ventilator dependent. Patients requiring a period of time in the ICU often have experience of being non-vocal. The findings from Study I revealed some of the characteristics of ventilator-supported communication in an ICU setting. Communicative issues were described as a major concern and the fundamental necessity of communication was stressed, as well as the specific challenges ventilator-supported communication posed for both listener and speaker. Ventilator-supported communication was described as requiring time and practice, which could lead to frustration and annoyance. The findings also indicated that, due to communication difficulty, it was more challenging to get to know ventilator-supported than non-ventilated patients. The factor that had the greatest influence on communicative success according to both participants was the listener and speaker knowing each other. The lack of caregiver continuity was therefore seen as a barrier to successful communication. To enhance communication, speaking valves were introduced to tracheotomised decuffed patients as early as possible in the ICU, with the help of instructions from the nurse. Very few, if any, patients had contact with SLTs. Information from relatives was also seen as helpful, e.g. to get to know the patient and become more familiar with his/her specific needs.

The importance of the patient making him/herself understood, to be able to express basic needs, was also addressed. Non-vocal patients used alternative means of communication, such as body and eye contact. To establish initial contact with the patient, the nurse could start by holding the patient's hand, searching for eye contact and seeing if the patient was able to respond by some means, e.g. by indicating yes and no with eye blinks or mouthing. The next step, before voicing was an option, was introducing writing and communication boards. Different situations thus required different communicative strategies.

Communicative content was also addressed; in particular, participants stressed that information about the patients' situation and condition was important. This was one way of reducing patient anxiety. The nurse focused to a considerable extent on communication as a way of establishing and maintaining contact with a patient, giving a sense of security and establishing trust. For this reason, nurses in the ICU always talked and explained medical products (procedures?) to patients as well, regardless of their consciousness/sedation levels. The nurse also indicated that she

adapted the form and content of patient information to make it more easily understood, e.g. by simplifying and repeating information. The ICU staff's skills regarding ventilator-supported communication appeared to vary, which was described as an obstacle to effective nurse-patient communication, in particular as requirements relating to patient participation in health care were being increasingly recognised.

## ***The communication experience of individuals receiving HMV (I, III)***

Study **III** looked in depth at the participants' experiences of communication during HMV. The main theme that emerged was that the participants experienced *a long and lonely struggle to find a voice*. Participants had received help and support from professionals regarding communicative issues only in exceptional cases. Six subthemes detailed different facets of the main theme: *Managing changed speech conditions, Prioritising voice, A third party supporting communication, Using communication to get things done, Depending on technology* and *Facing ignorance*. Important aspects influencing the ventilator-supported individuals' communicative performance (speech, support from others and technological solutions) were discussed. The findings from Study **I** also partly addressed the communication experience during HMV. The main findings addressed (1) the importance of communication; e.g. expressing emotions could assist recovery, (2) the frustration when communication took time and effort, (3) training aspects; learning to co-ordinate speech and ventilator cycles and planning utterances and coping with situations when communication was unsatisfactory, (4) the importance of different means of communication in different situation: the phrenic nerve pacer as an alternative to mechanical ventilation increasing mobility, access to a computer increasing participation, mouthing as an option if fatigued and using personal assistants for support and (5) the fact that knowing a person greatly facilitated communication.

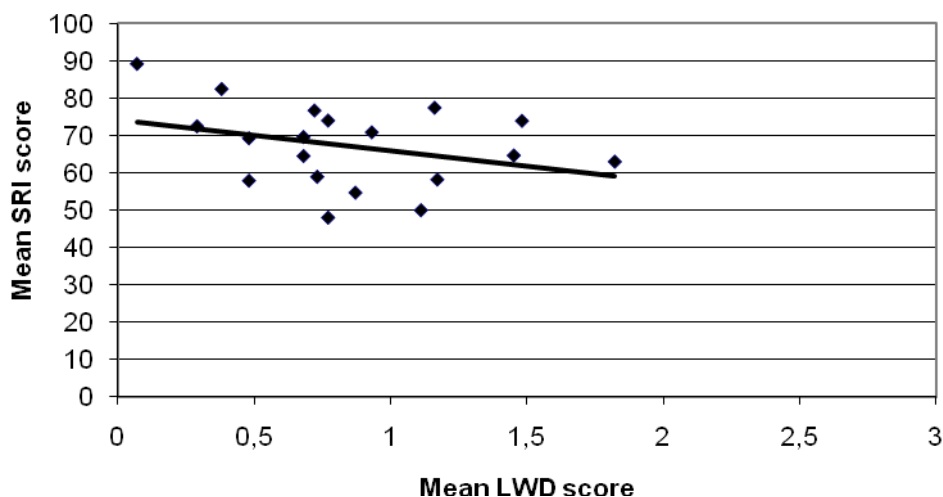
## ***Health-related quality of life during HMV (II)***

Study **II** further illustrated some of the challenges facing ventilator-supported communication during HMV, such as reduced speech intelligibility, but the study also focused on HRQL. Generic HRQL was measured with the SIP questionnaire and disease-specific HRQL was measured with the SRI questionnaire. The mean overall score on the SIP was  $30 \pm 10.2$ , indicating severe disability. The mean scores on the physical dimension and the psychosocial dimension were  $42 \pm 12.3$  and  $20 \pm 11.7$  respectively, while the highest level of dysfunction in the

psychosocial dimension was reported in the subscale of communication. The mean SRI summary score was  $67.1 \pm 10.9$ . When comparing the results on different subscales on the SRI and the SIP, the results show that the participants not surprisingly experience the greatest impact on their QoL in dimensions measuring physical functioning.

## Comparing health-related quality of life and communicative activity and participation (II)

When summary scales of the three questionnaires, the SRI, the SIP and the LwD (measuring communicative participation), were compared, a correlation was found between the summary scores of the SRI and the SIP ( $r = -0.681, p = 0.001$ ), but not between the LwD and SIP ( $r = 0.176; p = 0.472$ ) or SRI ( $r = -0.301; p = 0.210$ ). Similarly, no significant correlations were found between intelligibility scores (communicative activity) and the three questionnaires; SIP ( $r = -0.422; p = 0.072$ ), SRI ( $r = 0.422; p = 0.072$ ) or LwD ( $r = -0.280; p = 0.245$ ). No correlations were found between age, years of HMV experience and the various questionnaires (II). As stated above, there was no significant correlation between the results on the LwD and HRQL questionnaires. However, when plotting one against the other and drawing a trend line on the data, it can be seen that it has a slightly downward slope, showing a tendency towards decreasing HRQL (as indicated by lower SRI scores), with decreasing communicative participation (see Figure 3). To summarise, the results indicate that speech intelligibility, communicative participation and HRQL are not closely correlated in this group.



**Figure 3** Mean LwD scores versus mean SRI scores

## ***The communication experience of key communication partners (IV)***

Study **IV** focused on the communication experience of key communication partners (CPs) to individuals receiving HMV. CPs said that they found that individuals receiving HMV had restricted communicative abilities and that this necessitated their developing partly new reference frames for communication. CPs described different communication strategies that they used to ensure successful communication; anticipatory, attending and repair strategies. These strategies made a considerable difference when it came both to understanding the ventilator-supported individuals' speech and to interpreting meaning. In particular, they stressed the need to be highly attentive to details and nuances in the communicative interaction. Furthermore, they described different roles that they undertook as facilitators of communication; being a communication partner, an interpreter or an advocate. The challenges linked to communication and assuming different roles to support communication were, however, associated with a certain amount of role insecurity. Issues emerged regarding integrity, power and the lack of guidance. These concerns evoked emotional reactions, but they also highlighted coping strategies and their continuing ability to grow with experience. In overall terms, the participants found that communication functioned well in most situations today, now that they regarded themselves as more skilled communicators who knew the ventilator-supported individuals well.

## ***Findings in relation to the components of the ICF structure (I-IV)***

The findings touched on every area in the ICF model (see Figure 2). In what follows, the findings from the studies (**I-IV**) are related to the different components of the model, from both a positive (functioning, facilitators) and negative (disability, barriers) point of view, illustrating some of the complexities of ventilator-supported communication.

### **Body functions and structures**

The body structures and functions influencing the voice and speech of individuals receiving HMV were significantly changed. Anatomical changes to body structures included endotracheal tubes (**I**), tracheostomies or nose masks, as well as cuffing (**I-III**), which in turn had an impact on speech and voice functions, e.g. through changes in air flow and air pressure regulating voicing (**III**). Many participants



receiving HMV spoke on inspiration, as that was when sub-glottal air pressure was high enough to enable voicing (**III**).

Possible effects on speech loudness and voice quality can be seen as one example of a functional impairment. As part of Study **II**, the participants' oral motor function, as well as language abilities, were assessed (but not reported in Study **II**) by an SLT using standard dysarthria and aphasia assessment tools. The SLTs' speech assessments revealed that the majority of the individuals receiving HMV have some degree of oral motor dysfunction. None of the 19 participants had aphasia. The degree of oral motor dysfunction was found to be mild in 9, moderate in 4 and severe in 4 cases respectively (see Table 4 for details). Two had no oral motor dysfunction. The average maximum sustained phonation was  $1.9 \pm 1.6$  seconds (range 0-8 seconds), which, for all participants, was well below normative mean reference values for Swedish speakers;  $16 \pm 6$  seconds (Claesson and Hellström, 1989). The mean oral diadochokinetic rate (syllables pa/ta/ka) was somewhat slow, 3.9, and varied between  $0-6 \pm 1.6$  syllables/second, which at group level was below the normative reference values for Swedish speakers;  $5.7 \pm 1.49$  syllables/second (Claesson and Hellström, 1989). Possible oral motor dysfunction could interfere with the ability to mouth words, which was done frequently during non-vocal periods (e.g. night time). Using facial expressions or gestures was another way of expressing emotions, conveying a message or answering yes or no to questions. Using yes/no questions was common, as it did not require verbal output. All the participants receiving HMV (**I-III**) had severely reduced mobility and their means of non-verbal communication were most often restricted to facial expressions (see Table 4).

Impairments in motility, as well as in speech and voice functions, were corroborated by the findings in Studies **III** and **IV**. The participants in Study **III** explained that speech output was controlled by the ventilator and, after becoming ventilator-dependent, they all experienced a change in speech conditions. They often experienced non-vocal periods (especially when first becoming ventilator dependent) but also strenuous speech production, loss of speech naturalness, reduced speech loudness and a monotonous voice that was difficult to vary and control, in both pitch and intensity. Speaking sometimes gave the participants (**III**) a feeling of being out of breath and trying to raise their voice could exacerbate this feeling. A few managed to stress isolated words, but this could lead to an accumulation of mucus in the lungs, in turn leading to coughing and, consequently, impaired speech and even shorter phrases. CPs (**IV**) also noticed these changes, e.g. a weak voice, interrupted speech flow, monotonous prosody or unexpected pitch variations and an overall slower pace of speech, as well as restricted non-verbal communication. They also noted that intermittent pauses in speech resulted in changes in turn-taking patterns in conversation. The prerequisites for

communication therefore differed from communication with individuals without any communication difficulty, which had an effect on communicative participation.

**Table 4** Mobility/motility and oral motor function in individuals receiving HMV

Participant	Primary aetiology	Mobility/motility	Oral motor function		
			Oral motor dysfunction	Prolonged phonation (sec)	Oral DDK
1	Post-polio syndrome	Right hand (weak)	Mild	1	6
2	Spinal cord injury	Only face	Mild	1.5	4
3	Dystrophia myotonica	Arms, legs weak	Severe	3	3
4	Morquio's syndrome	Arms and legs (weak)	Severe	1	2
5	Encephalitis	Only head/face	Mild	1	3
6	Spinal cord injury	Only face	Moderate	1.5	3
7	Spinal muscular atrophy	Only face	None	3	6
8	Duchenne muscular dystrophy	Hands (weak)	Moderate	1	6
9	Neuro-fibromatosis	Only face	Moderate	2	6
10	Muscular dystrophy	Hands (weak)	Mild	1	5
11	Duchenne muscular dystrophy	Hands (weak)	Mild	1.5	3
12	Spinal cord injury	Only face	Mild	2	5
13	Congenital myopathy	Hands (weak)	Mild	1	4
14	Spinal cord injury	Only face	Mild	1.5	4
15	Duchenne muscular dystrophy	Hands (weak)	Mild	1.5	4
16	Spinal cord injury	Only face	None	8	2
17	Spinal cord injury	Only face	Moderate	2	4
18	Amyotrophic lateral sclerosis	Only eyes/eyebrows	Severe	0	0
19	Spinal cord injury	Only face	Severe	2	4

*DDK, diadochokinetic rate*

## Activities and participation

The structural/functional impairments in the ventilator-supported individuals' speech and voice abilities made their speech more difficult to understand for listeners and also more vulnerable to a noisy environment (IV). The results from Study II pointed in the same direction, revealing that speech intelligibility was

reduced in individuals receiving HMV. Sentence intelligibility was low on average (54.7% ± 28.2). There were, however, large individual variations in speech intelligibility, with results varying between 0-87.5%.

All the individuals receiving HMV had communicative abilities that enabled them to participate in interviews (**I, III**), expressing their views, opinions and feelings. The individuals receiving HMV (**III**) and their key CPs (**IV**) also found that overall communication functioned well in everyday conversation, but, as found in those studies as well as Study **I**, this was a result of learning how to communicate effectively with time. Communication with untrained CPs could therefore be challenging, limiting communicative participation. The ventilator-supported individual and his/her communication partner not knowing each other well was seen as a barrier to communicative activity. Communicative ability, and thereby communicative activity, could also vary greatly in different contexts (**I, III, IV**). In spite of this, many were still active in society at school and work (**III**) and were able to engage in meaningful conversations with CPs (**IV**). The computer was used by the individuals receiving HMV for a multitude of activities, such as reading and writing activities, work, leisure and participating in society (**III**).

In both Study **III** and **IV**, it was found that individuals receiving HMV could have difficulty directing another person's attention to themselves, which made it difficult to interact in societal contexts, e.g. during family gatherings or encounters in health-care situations. These difficulties could also restrict them from communicative activity and participation altogether. Fatigue and stress had a profound effect on communication, making speaking more strenuous and increasing the need for pauses. This could lead to particular difficulty communicating in encounters with unfamiliar CPs, e.g. standing in queues at the supermarket or during medical check-ups (**III**). Participants receiving HMV could have difficulty expressing what they felt, their will, opinions or emotions, especially during non-vocal periods, but also since prosody and voice loudness were difficult to vary. Having a voice was described as having a way to express feelings but also to make communication more varied and lively (**III**). Furthermore, they had difficulty calling for attention due to a weak voice and difficulty speaking during meal times. Participation in social activities was restricted (**III**); not having speech (voice) could sometimes lead to social exclusion. Some preferred not talking at all or restricted themselves to uttering short phrases if they suspected problems, or avoided social gatherings altogether (**III**). Moreover, key CPs (**IV**) found that speech and communication activities were affected in individuals receiving HMV. CPs noted that restricted non-verbal abilities could lead to difficulty expressing views and opinions, rendering it difficult to decline unwanted contact (e.g. when the ventilator-supported individual was approached by a person who was intoxicated), for example.

In Study **II**, communicative participation was also measured by a self-report questionnaire (LwD) and indicated mild impact on communicative participation. The mean overall score on the LwD was 0.84 (S.D. = 0.4) (scores can vary between 0-3). There were individual differences, results varying between 0.07-1.82. The mean LwD scores on the three included subscales did not reveal any large differences. The mean result on subscale A was 1.02 (S.D. = 0.5), B was 0.68 (S.D. 0.6) and C was 0.83 (S.D. 0.61).

Many communicative activity limitations and participation restrictions were also found in ventilator-supported patients in ICU care (**I**). They could, for example, have difficulty expressing basic needs or actively participating in their care. This was often a result of being voiceless and not having adequate AAC support, but possible language or cognitive impairments could also interfere, as well as sedation levels and fatigue.

## **Contextual factors**

### *Environmental factors*

A variety of environmental factors that affected communication and facilitated participation and decision making were found in the studies (**I-IV**). (1) ACC strategies, including the use of a computer, and (2) ventilator aspects were primarily related to the category *Products and Technology* in the ICF. (1) Low-technology ACC strategies were particularly used when first becoming ventilator dependent or during non-vocal periods and (**III**) letter boards or, if possible, writing. Advanced technological communication devices such as Lightwriters or computers were also used. Accessibility features in computers, such as voice recognition software, as alternatives to screen keyboards and scanning systems, were used by many participants, as were pointers controlled by mouth or head movements, such as eye-tracking systems and sip-and-puff tubes. Voice amplifiers were used by a few participants, but one limitation was that they could amplify unwanted sounds (e.g. ventilator sounds). Some had tried voice generators, but they were particularly disappointed with the sound/voice quality. The ability to call for attention was important to participants; they often used alarms to call for attention or tongue clicking or whistling. Many of the systems for AAC were a result of the participants' own endeavours, often together with carers and family. (2) The ventilators used by participants (**I-III**) were more or less advanced and their settings (e.g. PEEP levels) and parameters (e.g. non-invasive alternatives) varied. The possible influence on speech ability of ventilators or settings of different kinds has not been explicitly examined. However, participants reported (**III**), for instance, that raising PEEP improved speech loudness, raising the rate of breaths per minute helped them to speak more cohesively and that better battery length could improve communicative participation. Tracheostomised participants

mentioned decuffing the cannula to enable voicing in the first place. Speech was found to be more susceptible to noise (e.g. ventilator and other sounds) (**I, III, IV**). Ventilator sounds, or air leakage from the stoma or the mask were reported to interfere with communication (**III**). Malfunctioning or ill-fitting technical apparatus could be a barrier to communicative participation in society or could even prove life threatening. A ventilator that was not up to standard and not custom set could influence speech negatively, by reducing speech naturalness or loudness, for example. Furthermore, due to possible voice variations and ventilator sounds, voice recognition software could be difficult to use.

The second category under Environmental factors in the ICF structure that had a substantial impact on communication was *Support and Relationships* (**III-IV**). The most important findings related to CP skills (**I, III-IV**) and attitudes, such as facing ignorance (**III**).

CP skills and support from others were found to be imperative for communicative success for the individuals receiving HMV (**III**). The findings from Study **IV** corroborate the fact that key CPs play an important role in communicative interaction. The use of anticipatory (environmental adjustments, providing medical service), attending (visual clues, physical closeness, allowing extra time) and repair strategies (preventing misunderstandings, requesting repair) were found to make a considerable difference when it came both to understanding speech and to interpreting meaning. Key CPs also supported communication by assuming three different roles as communication facilitators, as skilled CPs (1), interpreters (2) and advocates (3), in which they strove to ensure communicative success and to empower the ventilator-supported individuals. As skilled CPs (1), they acknowledged the importance of physical closeness and maintaining continuous eye contact, adapting to the changes in turn-taking patterns in conversation and accepted that the ventilator-supported individuals' speech and communication abilities could vary individually. They were also highly attentive to details and nuances in the communicative interaction and gave enough time in interaction. As interpreters (2), their role could entail explaining, or translating the ventilator-supported individuals' words to others, or guiding other CPs. The advocate role (3) included representing the ventilator-supported individual in different societal contexts, e.g. telephone conversations. It could also entail promoting and protecting their rights and interests regarding access to communication devices. The importance and functions of a responsible and competent CP also emerged in Study **III**. For example, CPs had to handle mechanical apparatus, making environmental adjustments, assisting with health-care needs or being a link between the ventilator-supported individual and his or her other CPs. This was facilitated by speaking openly with the ventilator-supported individual about his/her preferences regarding communicative styles and strategies.

When it came to attitudes, many of the individuals receiving HMV were faced with ignorance (III), in the form of preconceptions or prejudice about them, for example. The lack of understanding of their situation and people talking over their heads could lead to breakdowns in communication, alienation or mistreatment. They often also felt a lack of support from health-care professionals. People could appear to be afraid of them, avoid them, be nervous, ignorant or had prejudices. Moreover, they could be nonchalant, constantly interrupt them, stare or completely talk over their heads. In Study IV, CPs acknowledged that, if they had difficulty understanding the ventilator-supported individuals' speech, this could lead to communication apprehension and distress. Anxiety about responsibility and fear, for instance, of not understanding things about the ventilator, could influence CPs' aptitude towards taking communicative initiatives. Not understanding the ventilator-supported individuals' speech could furthermore lead to enervation and frustration and leave CPs feeling embarrassed or foolish. To avoid this, they tried to detect, avoid and repair misunderstandings. A responsible and competent CP was imperative for communication to function successfully (III); for example, they would sometimes need to help to construct and use communication devices. CPs could experience role insecurity (IV) when attempting to support communication and, in relation to this, there emerged issues relating to integrity, power and the lack of guidance.

The third and final important category was *Service, Systems and Policies*. Restricted access to adequate PA services, as well as access to qualified health care (including SLT services), was seen as an obstacle to overall functioning and participation (III). For instance, it was important for successful communication that PAs were skilled in the language the ventilator-supported individual spoke. Limited care continuity with PAs was a further source of distress. Furthermore, accessibility to proper health care could be limited (for instance, requiring ICU care instead of a regular ward), which was a problem, as the ventilator-supported individuals needed custom-fit and continuously updated devices.

### ***Personal factors***

The individuals receiving HMV (III) described issues relating to the ventilator, to AAC devices and to their speech that influenced their sense of personal identity. When it came to AAC devices, they could feel a reluctance towards having another piece of equipment (in addition to the ventilator and the power wheelchair), e.g. finding some devices not very user friendly; unattractive, bulky or time consuming to use. The participants' restricted mobility in their extremities profoundly affected their ability to use gestural language, which was experienced as a loss, making them feel not quite themselves. Changes in appearance (e.g. due to a tracheostomy or a nose mask) could also have an impact on how they viewed themselves and for some this even led to a reluctance to engage in conversation. One participant who

had started withdrawing from conversations experienced difficulties adjusting to his new voice, and said “I sound almost like a girl, wimpy” (III). A change in voice quality influenced self-esteem; for some, it could lead to uncertainty and self-chosen silence. Having speech and voice, even if they were changed or altered, was described as a way to feel noticed and confirmed. Not having speech led to feelings of alienation and ultimately a loss of power and control. Other factors also influencing their overall experiences of communication were addressed, such as underlying medical conditions and fatigue.

Issues related to coping strategies emerged from the studies. The participants in Study III said, for instance, that, when someone talked over their heads, they took charge of the situation, e.g. by being open and informing the communicative partner about their communicative problems. When dealing with communicative difficulty, they strove to maintain a positive attitude; some had a more accepting and a somewhat resigned attitude. The lack of role models was found to be challenging; most of the participants very seldom met other ventilator-supported individuals. Some participants also described how they learned not to react too emotionally to communicative problems, finding it exhausting and unproductive. When they were faced with insufficient knowledge in the health-care system, they could often take charge of their own learning and assert their communicative needs. In relation to this, education was also important; not all participants felt they had a knowledge of their rights or of how to pursue their rights in relation to PA or SLT services, for example. Privacy and integrity issues also emerged; the participants could feel controlled and experience a disintegration of boundaries between themselves and the PA. Strategies for maintaining control and privacy included choosing qualified PAs and educating/informing them, organising the care environment (having extra rooms for PAs), as well as technical solutions (e.g. internet). Furthermore, CPs addressed coping strategies (IV), such as trying to bring humour into the situation to overcome communicative misunderstandings and frustration. Letting communication take time and learning from experience were also mentioned.

The personal characteristics of CPs were also found to influence communication. A good CP was said to be attentive, concentrated, sensitive, receptive, patient, open, with an ability to concentrate and show a genuine interest in understanding (IV). The ventilator-supported individuals described a skilled CP as interested, attentive, concentrated, focused on the dialogue, not interrupting too often, being able to take initiatives and being self-confident (III).

Emotional aspects such as feelings were important and acknowledged in relation to communicative issues by the participants. Having a voice was linked to strong feelings (III), associated with a sense of pleasure and relief, while not having a voice created a feeling of loss. Individuals receiving HMV also said that they felt

trust and felt secure with qualified CPs. They experienced a variety of negative feelings when people talked over their heads, which they found tiresome and irritating; they felt humiliation, anger, disempowerment, as well as feeling ignored, excluded and worthless. Communicative breakdowns were found to be very frustrating. A lack of help from health-care professionals was experienced as both frightening and frustrating.



# DISCUSSION

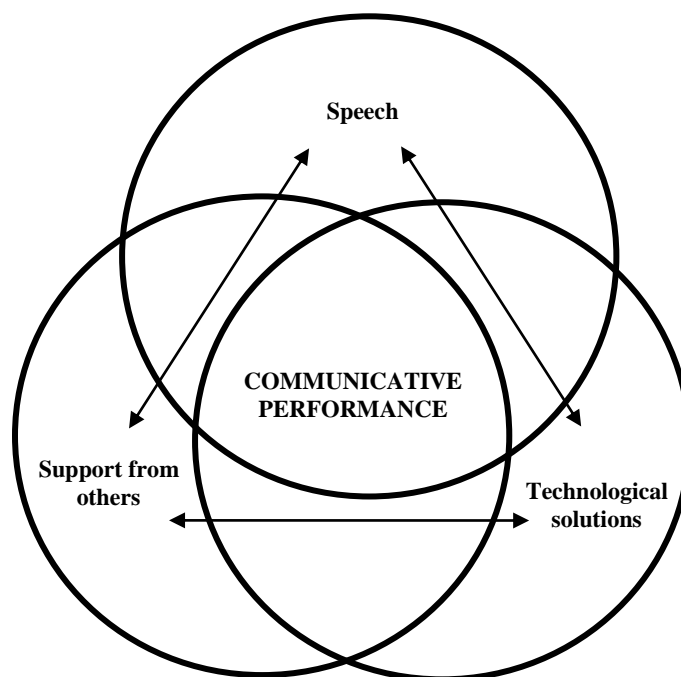
## ***General discussion of findings***

In overall terms, the findings describe aspects of communication during home mechanical ventilation (HMV). Studies **I** and **II** represented different approaches, but both indicated that communicative issues are a major concern for individuals receiving mechanical ventilatory support. One of the main findings of Study **I** was that ventilator-supported communication was perceived as time consuming, strenuous and requiring training. Study **II** revealed an impact on both HRQL and communicative participation. However, these two aspects did not appear to be closely related. Studies **III** and **IV** looked in more detail at the issues of ventilator-supported communication from the insider's point of view and from two different perspectives; the individual receiving HMV and his/her communication partners (CPs). Communication during HMV appeared as a multifaceted phenomenon involving various challenges, including both an individual and a societal context. It was also concluded that there is a lack of knowledge concerning issues related to communication during HMV, from the point of view of the ventilator-supported individuals, their CPs, as well as health care professionals. This lack of knowledge appeared for instance from findings in Study **III**, concluding that the individuals receiving HMV experienced a long and lonely struggle to find a voice and from Study **IV**, concluding that CPs experienced a lack of guidance and insecurity in assuming the role of a communication facilitator. These findings indicate an educational need and a need for more active speech and language therapist (SLT) involvement in the area of communication during HMV in order to make it easier for individuals receiving HMV to exercise their fundamental human right to communicate (ASHA, UN).

The most important factors influencing the communicative performance of the individuals receiving HMV can be summarized in three key aspects (see Figure 4). These are based mainly on findings from Study **III**. The key aspects were found to be *speech*, *support from CPs* and *technological solutions*. Speech was found have low average intelligibility (**II**) and it was also characterised as weak, monotonous and with short phrase length (**III**), which confirms and extends the findings of previous studies (Hoit et al., 1994, Hoit et al., 2003). Furthermore, the participants highlighted that having one's own voice was highly prioritised. The second aspect, technological solutions, included individual adaptation of ventilator equipment and adjustment of settings, but also alternatives to speech (e.g. communicative devices) when speech was less than optimal. Technological solutions, in particular computer technology, were described by the participants as a means of freeing themselves

from some of the constraints they experienced in their everyday lives. But they also faced difficulties in terms of accessibility to techniques and tools liable to improve communication. Many factors, such as attitude barriers, cultural differences, technological barriers and service delivery limitations, may detract from positive outcomes for individuals who use augmentative and alternative communication (Lund and Light, 2007). Support from others was the third important aspect. Findings revealed that a skilled CP was able to facilitate and support communication (III, IV). Acting as a “spokesperson” for a person with communicative difficulties has been described for instance in the aphasia literature (Simmons-Mackie et al., 2004, Kagan et al., 2001).

These three aspects are interrelated and interact with each other and contribute to optimizing the individuals’ communicative performance. But they also have different relevance for different individuals and may vary with time and context. Having an overview of the total communicative situation, including these aspects, would be a task for the SLT in collaboration with other team members. The figure is a simplified model of the complex process of communication. Other factors, such as underlying medical conditions and fatigue, could potentially influence overall communicative performance (I-IV). Using the ICF framework to further analyse the results can provide deeper insights into the different features of communication during HMV.



**Figure 4** Aspects influencing the ventilator-supported individual's communicative performance

## ***Application of the ICF framework to communication during HMV***

The ICF provided a framework for helping to decide what to study, how to study it and how to present the overall findings of the thesis. Describing the relationships between body function/body structure and activity/participation behaviours, as well as contextual factors, in relation to communication was not, however, straightforward. It is, for example, possible to ask whether speech intelligibility is a body function or a communication activity (Dykstra et al., 2007). It is also relevant to question whether communication participation constructs can be reliably measured with the available assessment methods (LwD questionnaire in Study II). The ICF structure also incorporates features that were not used in the thesis, such as qualifiers denoting the severity of a problem at numerical levels. If qualifiers had been used, it would have been possible to record the level of the impairment or restriction, but this was beyond the scope of the thesis. Furthermore, the activity/participation level could possibly have been divided into performance and capacity levels.

The applicability and usefulness of the ICF construct as a research tool has been questioned. There are those who feel that, although it is flawed and possibly theoretically weak, it has some coherence and applicability (Imrie, 2004). It can, for instance, help researchers identify aspects of health that have not previously been considered. Details of the ICF that are relevant for the profession of speech and language pathology, e.g. the differentiation of activity and participation components and their qualifiers, still remain somewhat unclear (Threats and Worrall, 2004). Furthermore, QoL is not incorporated into the ICF structure. QoL is inherently subjective, the evaluations are made by the patient him/herself (Wyller, 1997, Cruice, 2008). The ICF construct has been criticised for being underdeveloped in its subjective aspects, e.g. minimising the role of personal values and people's goals (Fuhrer, 1994). Summarising the results of all the studies using the ICF involved a certain degree of generalisation, which led to an element of vagueness or some degree of ambiguity. On an individual level, the picture could well be different.

## ***Responsibility for communication***

As part of Studies III and IV, some observations were made when interviewing the individuals receiving HMV and their CPs. One individual receiving HMV pointed out that, if CPs were more skilled and better at listening, communication would function more effectively, whereas the CP placed the responsibility on the ventilator-supported individual, wanting him/her to speak more slowly and clearly.

They therefore both placed the responsibility for functional communication on the other person, which can be interpreted as both of them perceiving themselves as taking an increased share of the communicative burden (Linebaugh et al., 1982). This can also be interpreted as a manifestation of the claim that conversation is a collaborative achievement (Schegloff, 1982), necessitating the co-operation and support of both communicative partners. The responsibility for functional communication when someone is ventilator supported should, however, also be a matter for health-care personnel, in particular SLTs. The vast majority of the participants had or had had severe difficulties with their communication, but very few had had any contact with an SLT. Both the ventilator-supported individuals and their key CPs go from being “untrained” to “trained” communicators. With time, they find ways to communicate effectively, but this process of knowledge creation could be improved with the support of skilled and experienced SLTs. For the ventilator-supported individual, it is not only a matter of becoming a trained and skilled communicator. Having a voice was found to be related to self-image (Study III). One of the participants also said that she continued to speak even during periods when she was aphonic, that she “heard her voice within her”. Prioritising voice could be interpreted as striving for normality. A few of the participants requested speech therapy in order to “sound more normal”, but some also preferred oral communication since it “felt more normal”. The importance of a voice could be attributed to feelings of an authentic self (Giddens, 1991).

### ***Does the ventilator affect speech functions or not?***

Whether or not the individuals receiving HMV who participated in the current thesis would have had communicative difficulties even if they had not been ventilator dependent is a relevant question, but answering it is not straightforward. Speech depends on the ability to control breathing, voicing and articulation and being ventilator supported implies per se that the individual has difficulty controlling breathing. Some of them would probably also have had additional articulation difficulties and they would all still have physical disabilities that made it difficult to use AAC devices or systems, as well as restricting the use of non-verbal communication. Their major physical restraints necessitate the help of personal assistance 24 h/day, which per se indicates major impairments and activity limitations. Voicing could be affected, particularly due to difficulty controlling breathing, but the use of a ventilatory device also influences speech ability, particularly voicing ability. It is thereby obvious that the ventilator, including things such as ventilator parameters and settings, is a major element with an impact on body functions and structures (and thus speech and voice functions). Taken as a whole, even if voicing was achieved satisfactorily in ventilator-supported individuals, there would still be communicative issues that would need to be further addressed by an SLT, regardless of possible underlying dysarthria.

The results of assessments of oral motor function were not reported in Paper **II**, mainly because they were seen as background data relating to the participants, without contributing to the overall purpose of the study. Assessments of oral motor function were also found to be somewhat problematic, as it was unclear what comprised the speech dysfunction per se and what was a secondary effect of the ventilator on speech function.

## ***Methodological considerations***

### **Sampling limitations**

Study **I** was a case study, involving only two participants, and it was therefore a small study from which conclusions should only be drawn with care. The study would also have been stronger if it had included only one setting, the ICU or HMV. In spite of this, the study still functioned well as an introductory study. Studies **II** and **III** would have been stronger if the study group had been more homogeneous, in terms of aetiology and mode of ventilation, for example. The study group in Study **IV** could also have been more homogeneous, by only including PAs or family members, for example. These changes would, however, also have diminished the scope of the studies substantially.

### **Limitations of the questionnaire study**

One limitation of Study **II** that needs to be addressed relates to the questionnaires that were used. With regard to the LwD questionnaire measuring communicative participation, it has been slightly revised since its use in Study **II** and has not previously been used in this population, making comparisons with previous findings more difficult. Furthermore, the LwD is constructed as an instrument mainly for assessing communicative participation, but it also incorporates items on a structural/functional, activity and contextual level, since these levels have an influence on participation. The results on the subscales were, however, very similar to those on group level. The lack of variance in LwD scores in the study sample contributed to the difficulty involved in further elucidating the relationship between communicative participation and HRQL. In overall terms, general HRQL, as rated using the generic SIP questionnaire, revealed functional disabilities in daily life for all the participants (overall score >10%). Considering that all the study participants had severe mobility restrictions, it seems plausible that these functional disabilities to some degree override concerns about communicative participation.

HRQL was assessed using two questionnaires, the disease-specific SRI questionnaire and the generic SIP questionnaire. As the SRI questionnaire is only validated for individuals receiving HMV with NIV, it might not be suitable for tracheostomised individuals (as in Study II). The SRI results obtained in the study should therefore be interpreted with care. Moreover, the SRI has not yet been validated for populations in Sweden. Nonetheless, a strong correlation was found between the summary scores of the two HRQL questionnaires (SRI and SIP), indicating that these two quality-of-life questionnaires at least measure related concepts, which may be regarded as a conditional validation of the SRI for purposes comparable to ours. Yet another limitation of the SRI is that its thresholds are not established, when it comes to what constitutes a clinically significant degree of reduction in HRQL, for example. All this renders it more difficult to interpret results when they are not used as an outcome measurement, with data gathered on multiple occasions for comparison.

QoL measurements have been criticised for measuring functioning, rather than QoL per se (Cruice, 2008). For instance, in the SIP questionnaire, many items focus on mobility and walking ability. Participants filling out the questionnaires could also sometimes find it difficult to relate to parts of the content of the questionnaires. This applies especially to the SIP questionnaire. For an individual with a permanently altered health state, many of the items do not apply directly or are irrelevant to his/her status, and the participants were therefore very hesitant about what answer to give to items such as “I don’t do housework in the usual way”. Many individuals could answer yes to this, explaining that it is normally done with assistance. The example reveals difficulties in finding a basis for comparison (pre-HMV could, for instance, be twenty years ago) and this could partly explain the variability in responses. The conclusion is that the SIP is perhaps not the best suited QoL measurement for individuals receiving HMV, but the SRI also has some limitations, as discussed earlier. An additional obvious limitation of our study is its participant selection. For our purposes, it would have been valuable to have a larger sample to enable more robust comparisons.

## **Conducting interviews with individuals on mechanical ventilation**

In-depth interviews with individuals who are ventilated are feasible but require some adaptation of the interviewing process, such as allowing enough time for the ventilated individual to respond and asking clarifying questions to avoid misunderstandings. Moreover, the transcription process is more demanding. It is helpful to have a high-quality recording and make transcription as soon as possible, with the interview still fresh in mind. It is imperative that researchers include individuals with expressive language difficulties in qualitative interviews (LLoyd et al., 2006) and it is also important to obtain an insight into their perspectives.

## **Limitations and potential of qualitative content analysis methods**

When weighing up the pros and cons of the chosen qualitative approach (qualitative content analysis) and comparing it with other qualitative approaches, it becomes apparent that content analysis offers a fairly straightforward method for analysing textual data. This does not imply that it is simplistic, rather a tool that is as easy or as complex to use as the researcher decides it is going to be (Neundorf, 2002). Its weaknesses and strengths depend on the researcher's competence, as is the case with all qualitative approaches. The theoretical underpinnings of qualitative content analysis are generally not seen as strong, although it has been related to Watzlawick's communication theory (Graneheim and Lundman, 2004, Watzlawick et al., 1967). No matter whether it is theory dependent/driven or not, it relies on many of the same theoretical assumptions as other qualitative methods (albeit to a different extent). One such assumption is life-world phenomenology, as derived from the ideas of Husserl. It can be seen as a background theory to all qualitative methodologies, including qualitative content analysis. The fact that qualitative content analysis is not overloaded with theoretical assumptions can also be seen as a merit, since it opens up more opportunities for the researcher to impose a chosen theoretical/analytical strategy on the data, thereby creating a deductive approach (Elo and Kyngas, 2008). This makes the analysis more flexible and adjustable to the data and the purposes of the study. Furthermore, the researchers' pre-understandings can be exploited and used reflexively as a source of insight during the analysis, as different from phenomenology, for example, where the researcher is instructed to "bracket", set aside, all assumptions. The different phases of the qualitative content analysis process could also be seen as pertaining to different traditions. The initial phases of the analysis process (organising text, searching for patterns) could be described as taking a structuralist approach, the phase in which interviewer and interviewee create the text together, taking the symbolic interactionism perspective, and the subsequent phases, when the findings are interpreted, are regarded as part of the hermeneutic tradition. Accordingly, there are many different orientations in qualitative content analysis.

When reading research articles employing varying qualitative methods, the similarities are often more apparent than the differences. In fact, the actual analytical procedures are sometimes strikingly alike, leaving the reader somewhat bewildered, when trying to make sense of the elaborate theoretical undertakings in the introductory sections. It has even been suggested (Sandelowski, 2000b) that some researchers claim to be using methods they are not in fact using, as many researchers conducting qualitative research are really "only" using qualitative descriptions. In the light of this, qualitative content analysis provides a fairly fresh method, which does not claim to be what it is not. No comprehensive and up-to-date handbook can, however, be found about how to apply the method. Numerous individual contributions have been made in the form of published papers, but, since the method can be interpreted and used in so many distinct ways, there is a risk of

blurring meaning and misuse. This makes it all the more imperative that researchers clearly present their individual approaches and procedures in their papers.

In the first study, a thematic content analysis (Burnard, 1991) was described in the methods section. Now, reconsidering the actual analysis process, it could perhaps more correctly just be called qualitative content analysis (Graneheim and Lundman, 2004) or conventional qualitative content analysis (Hsieh and Shannon, 2005). A conventional content analysis is considered appropriate when there is a desire to describe a phenomenon when existing theory or research literature on it is limited and relevant theories are addressed in the discussion section of the paper.

As a method, qualitative content analysis provides some specific norms and guidelines for data analysis. Clearly described procedures increase the transparency of the analysis method and the analyst's thought process (given that they are presented in the paper). This enhances the scientific rigour of the research. Nevertheless, the analysis can prove to be very challenging. The amount of data can be overwhelming and people's thoughts and utterances are not always easily condensed, coded or clustered. This very demanding process, like the depth of the analysis, depends heavily on the individual researcher's skills.

Graneheim and Lundman (2004) (Graneheim and Lundman, 2004) pointed out that the most suitable unit of analysis is whole interviews or observational protocols that are large enough to be considered as a whole and small enough to be kept in mind as a context for meaning units during the analysis process. With this in mind, the data for the last two publications were split in two, with two different perspectives, ventilator-supported individuals and their caregivers. Had data from the two studies been analysed together, the results might have been slightly different. Analysing them separately, however, enabled a more detailed analysis.

## **Trustworthiness**

Quality aspects of papers **I**, **III** and **IV** will be discussed in terms of the concepts of credibility, confirmability, dependability and transferability (Lincoln and Guba, 1985). These concepts were considered throughout the research process. To enhance credibility of Study **I** triangulation of data sources (field observations and interviews) was used. But field observations could have been further assessed and also performed in the home setting of long-term ventilator-supported individuals to further strengthen the study. Additional efforts were made to ensure credibility throughout the research process in studies **III** och **IV**, by strategies described as investigator responsiveness, methodological coherence and an active analytical stance (Morse et al., 2002). Investigator responsiveness, that is creativity,



sensitivity and insight regarding the analysis, was supported via ongoing discussion between co-authors. But it also included responsiveness during the interview, so that interviews were conducted in quiet surroundings and with a sufficient amount of time to allow the interviewer to grasp the context and the informant to speak at his/her own pace, and feel confident. To minimise the risk of misunderstandings in Study **III**, e.g. since informants intelligibility levels were decreased, the interviewer often repeated the informants' utterances or asked clarifying questions.

To give the reader the studies (**I**, **III** and **IV**) a chance to assess the quality and the trustworthiness of the work, an effort was made to present the method and the findings so that the reader could look for alternative interpretations (Graneheim and Lundman, 2004), for example, through quotations, thus making findings more open to confirmation or criticism. A possible risk with personal bias is, for example, that the researcher misinterprets or misunderstands information, which is a threat to confirmability. To lessen these threats several individuals participated in the analysis process of all the studies and it was seen as a strength that the research group was multidisciplinary.

Dependability deals with the degree to which data changes over time and alterations are made in the researcher's decisions during the analytic process. To strengthen dependability a semi-structured interview guide was used in all studies and the traceability of the analysis was improved by using the QRS NVivo<sup>®</sup> software program, providing an obvious audit trail (Richards, 1999). An open dialogue within the research team at all stages of the analysis facilitated the discussion of similarities and differences in content. Transferability deals with the ability to transfer findings to other environments. By providing enough information and making the analytic process clear, the reader may judge the possibility of transferring the findings of the studies to other settings. The findings of Study **III** could possibly be transferred to other persons receiving full time HMV and having personal assistance. The findings of Study **IV** will mainly be of interest to those working with individuals receiving HMV and their CPs.



# CONCLUSIONS

Individuals receiving HMV experience many challenges related to their communication. This thesis expanded the knowledge base relating to ventilator-supported communication and the specific needs of this population. The findings can be applied to raise awareness and define areas for future research, but they can also be applied to the development of intervention programmes.

This thesis illustrates some of the complexities surrounding ventilator-supported communication. To be functional and satisfactory, ventilator-supported communication imposes specific requirements on both listener and speaker. Not only does the ventilator-supported individuals' speech have an impact on communicative success, communicative partners also play an important role.

It is a fact that the topic of ventilator-supported communication is often overlooked, given the scarcity of publications in this field of research, especially when it comes to studies with a qualitative approach. The voices of the ventilated individuals themselves are not often heard. One possible reason for the communicative issues being left in the dark is that, for individuals requiring mechanical ventilatory support (both in the acute care setting and in the home setting), survival and adequate ventilation are naturally the focus of attention, making all health-care concerns of the utmost importance, possibly overshadowing other important aspects.

## **FUTURE RESEARCH**

Ventilator-supported communication remains an area for further investigation, when it comes to aspects of the different players and their interaction: the ventilator-supported individuals, the CPs and SLTs.

Communicative participation does not appear to be severely impaired in individuals receiving HMV, even if speech intelligibility is reduced. Is there a relationship between these constructs? If so, how do individuals receiving HMV with reduced speech intelligibility achieve satisfaction with communicative participation?

Studies focusing on the use of one-way speaking valves for individuals receiving ventilatory support are scarce. An intervention project aiming to examine the effects on speech and voice production after the introduction of a one-way speaking valve could provide valuable insights into this subject.

Another possible area for further investigation would be to study dyadic conversation between individuals receiving HMV and their CPs, using a communication analysis method, for example. It would be interesting to see how communication is affected by CPs with different experience, as well as individuals receiving HMV using different modes of ventilation (invasive/non-invasive), augmentative and alternative communication devices.

It is not easy to assess oral motor function in individuals receiving ventilatory support. It would, however, be interesting to develop this further in a study aimed at finding appropriate oral motor function assessment tools for individuals on ventilatory support.

Additional studies are needed to deepen our understanding of the features of ventilator-supported communication, but there is also a need to focus on aspects related to CP training, for example.

Finally, the paediatric populations should also be investigated in terms of communicative issues. Mechanical ventilatory support is also increasing in this group.

## CLINICAL IMPLICATIONS

Communication during HMV is a complex, multifactorial issue. Clinicians can be guided by the ICF structure to target relevant outcome measures, but QoL and overall well-being also need to be considered. A detailed anamnestic evaluation helps to provide information about underlying medical conditions and ventilator modes and parameters affecting communication, among other things. Communicative and voice and speech functions need to be assessed, together with communicative activity/participation and relevant contextual levels. Interventions should target the individuals receiving mechanical ventilation (e.g. to optimise speech function and offer AAC solutions) but also caregivers and family members, since environmental factors are important, in terms of communicative support, for example. The continuous education of key CPs and team members is essential for both acute and long-term conditions. Not only do communicative needs and other conditions change, the individual patterns of response (e.g. non-verbal strategies) also differ between individuals. Consequently, interventions need to be highly customised.

Experienced SLTs, skilled in the different features of ventilator-supported communication, can make a valuable contribution to the team attending to the individual receiving HMV, to ensure that speech and communication functions have been optimised according to the patient's needs. However, teams attending to individuals receiving HMV, as well as ICU clinics, differ in terms of resources and manpower and most teams in Sweden do not have adequate access to SLTs.

# SVENSK SAMMANFATTNING

## Kommunikation vid hemrespiratorbehandling, en utmaning

Avhandlingen har fokus på tal och kommunikation vid ventilatorbehandling i hemmet. När den normala andningsmekanismen är störd, behövs hjälp i form av mekanisk ventilation under kortare eller längre tid. Ventilatorn (=respiratorn) kan påverka kommunikationsförmågan negativt, t.ex. genom att fraslängd, röstkvalitet och röststyrka påverkas. Tidigare studier har visat att många ventilatorbehandlade personer upplever problem med och frustration över sin kommunikation.

I avhandlingsarbetet har fyra olika studier genomförts med det övergripande syftet att öka kunskapen och medvetenheten om olika aspekter av hemrespiratorbehandlade individers kommunikation. De specifika syftena för de olika delarbetena var: **I** att undersöka både vårdpersonalens och den ventilatorbehandlade personens upplevelser och erfarenheter av hur kommunikationen fungerar i olika kontexter. **II** Att undersöka hur personer som hemrespiratorbehandlas upplever sin kommunikativa delaktighet och sin hälsorelaterade livskvalitet, och om det finns nåt samband mellan demografiska faktorer, livskvalitet och kommunikativ aktivitet och delaktighet. **III** Att i detalj beskriva hemrespiratorbehandlade personers upplevelser och erfarenheter av hur kommunikationen fungerar. **IV** Att undersöka vilka upplevelser och erfarenheter samtalspartners till personer som hemrespiratorbehandlas har av kommunikationen.

Undersökningen har genomförts med såväl kvalitativa som kvantitativa metoder. Data har bland annat samlats in genom frågeformulär som berör hälsorelaterad livskvalitet och kommunikativ delaktighet som riktade sig till vuxna hemrespiratorbehandlade individer. Data har även samlats in genom en logopedisk bedömning av de hemrespiratorbehandlade individernas tal och genom intervjuer med hemrespiratorbehandlade individer och deras samtalspartners. Den första studien var en preliminär studie med intervjuer med två deltagare (en sjuksköterska och en hemrespiratorbehandlad person). Deltagarna i de två följande studierna bestod av 19 hemrespiratorbehandlade personer. Urvalet gjordes ur den population hemrespiratorbehandlade individer som omhändertas av Nationellt Respirationscentrum vid Danderyds sjukhus, Stockholm. Deltagarna hade framförallt höga ryggmärgsskador eller neurologiska sjukdomar. De hade alla stora funktionshinder och begränsad rörlighet och hade i medeltal vårdats i ventilator i 13.6 år. I den sista studien deltog deras samtalspartners i intervjuer. Samtalspartners var i majoriteten av fallen personliga assistenter, men några var familjemedlemmar. Dessa intervjuer analyserades med hjälp av kvalitativ innehållsanalys.

Resultaten från studie **I** karaktäriserar olika aspekter av kommunikation vid ventilatorberoende både vid intensivvård och i hemmet. Det handlade om innehållet i kommunikationen, hur kommunikationen fungerade och beskriver vidare de utmaningar som kommunikationen innebar. De fem övergripande kategorierna var: *Att kunna göra sig förstådd och att förstå är viktigt*, *Att låta kommunikationen ta tid*, *Att tala med talkanyl (ventilatorn) kräver övning*, *Att ha olika kommunikationssätt/strategier är nödvändigt vid olika situationer* och *Att känna en person underlättar kommunikationen*. Resultaten från studie **II** visade att talets förståelighet, kommunikativ delaktighet och hälsorelaterad livskvalitet var negativt påverkade, men dessa olika aspekter föreföll inte korrelerade med varandra. Resultaten från studie **III** påvisade att de hemrespiratorbehandlade individerna upplevt att det har tagit väldigt lång tid för dem att få till en fungerande röst och kommunikation och att de fått begränsad hjälp av vården med denna fråga. De betonade också vikten av en fungerande kommunikation när man har ett stort hjälpbehov. De sex subtemata som presenterades var: *Att hantera förändrade förhållanden för tal*, *Att prioritera rösten*, *Att vara beroende av andra i kommunikationen*, *Att använda kommunikationen för att få saker gjorda*, *Att vara beroende av teknik* och *Att bemöta okunnighet*. Samtalspartners visade sig fylla en viktig roll (studie **IV**), de berättade bl.a. om de kommunikativa strategier de använde för att underlätta kommunikationen och de utmaningar det innebar. De fem övergripande kategorierna var: *Att möta begränsningar i kommunikationen*, *Funktionella kommunikationsstrategier*, *Att underlätta kommunikationen*, *Rollosäkerhet* och *Känslomässiga reaktioner och coping*.

Sammanfattningsvis framkommer att kommunikativa frågor är centrala för hemrespiratorbehandlade individer, men också att både de, deras samtalspartners och vårdpersonal har begränsad kunskap om hur kommunikationen kan optimeras. Det finns alltså ett utbildningsbehov. Ytterst få av deltagarna hade haft någon logopedkontakt. Kommunikation vid ventilatorbehandling är ett område som logopederna mer aktivt skulle kunna arbeta med. Delstudierna beskriver detaljer i vad som karaktäriserar kommunikationen vid hemrespiratorbehandling. Förhoppningen är att detta aktivt skulle kunna bidra till kunskapen om vad man kan fokusera på vid intervention, men också inspirera till framtida forskning.

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## REFERENCES

- ALI, S. & KABIR, Z. 2007. Domiciliary non-invasive ventilation and the quality of life outcome of patients suffering from chronic respiratory failure. *Ir Med J*, 100, 336-8.
- ASHA. *Communication Bill of Rights* [Online]. American Speech-Language-Hearing Association (ASHA), National Joint Committee for the Communication Needs of Persons with Severe Disabilities. Available: [http://www.asha.org/NJC/bill\\_of\\_rights.htm](http://www.asha.org/NJC/bill_of_rights.htm) [Accessed 21-01-2011].
- BALLANGRUD, R., BOGSTI, W. B. & JOHANSSON, I. S. 2009. Clients' experiences of living at home with a mechanical ventilator. *J Adv Nurs*, 65, 425-34.
- BAXTER, L. 1991. Content analysis. In: MONTGOMERY, B. A. D., S (ed.) *Studying Interpersonal Interaction*. New York, London: The Guilford Press.
- BERELSON, B. 1952. *Content analysis in communication research*, Free Press.
- BERGBOM-ENGBERG, I. & HALJAMAE, H. 1989. Assessment of patients' experience of discomforts during respirator therapy. *Crit Care Med*, 17, 1068-72.
- BERGER, P. L. & LUCKMANN, T. 1966. *The Social Construction of Reality: A Treatise in the Sociology of Knowledge*, New York, Anchor Books.
- BERGNER, M., BOBBITT, R. A., CARTER, W. B. & GILSON, B. S. 1981. The Sickness Impact Profile: development and final revision of a health status measure. *Med Care*, 19, 787-805.
- BJORLING, G., JOHANSSON, U. B., ANDERSSON, G., SCHEDIN, U., MARKSTROM, A. & FROSTELL, C. 2006. A retrospective survey of outpatients with long-term tracheostomy. *Acta Anaesthesiol Scand*, 50, 399-406.
- BRINTON, B. & FUJIKI, M. 2003. Blending quantitative and qualitative methods in language research and intervention. *Am J Speech Lang Pathol*, 12, 165-71.
- BROCHARD, L. 2003. Mechanical ventilation: invasive versus noninvasive. *Eur Respir J Suppl*, 47, 31s-37s.
- BROOKS, D., KING, A., TONACK, M., SIMSON, H., GOULD, M. & GOLDSTEIN, R. 2004. User perspective on issues that influence the quality of daily life of ventilator-assisted individuals with neuromuscular disorders. *Canadian Respiratory Journal* 11, 547-554.
- BURNARD, P. 1991. A method of analysing interview transcripts in qualitative research. *Nurse Educ Today*, 11, 461-6.
- BURNARD, P. 1995. Interpreting text: an alternative to some current forms of textual analysis in qualitative research. *Social Sciences in Health*, 236-245.
- CARROLL, S. M. 2007. Silent, slow lifeworld: the communication experience of nonvocal ventilated patients. *Qual Health Res*, 17, 1165-77.

- CLAESSON, K. & HELLSTRÖM, C. 1989. *Utprövning av dysartritestet på en normalgrupp*. Unpublished Master's Thesis, University of Gothenburg.
- CRESWELL, J. & PLANO CLARK, V. 2007. *Designing and conducting mixed methods research*, Thousand Oaks, CA: Sage Publications.
- CRESWELL, J. W. 1998. *Qualitative inquiry and research design: choosing among five traditions*, London, SAGE.
- CRUICE, M. 2008. The contribution and impact of the International Classification of Functioning, Disability and Health on quality of life in communication disorders. *International Journal of Speech-Language Pathology*, 10, 38-49.
- DAMICO, J. S. & SIMMONS-MACKIE, N. N. 2003. Qualitative research and speech-language pathology: a tutorial for the clinical realm. *Am J Speech Lang Pathol*, 12, 131-43.
- DOWNE-WAMBOLDT, B. 1992. Content analysis: method, applications, and issues. *Health Care Women Int*, 13, 313-21.
- DUCHAN, J. F. 2001. Impairment and Social Views of Speech-Language Pathology: Clinical Practices Re-Examined. *Advances in Speech-Language Pathology*, 3, 37-45.
- DYKSTRA, A. D., HAKEL, M. E. & ADAMS, S. G. 2007. Application of the ICF in reduced speech intelligibility in dysarthria. *Semin Speech Lang*, 28, 301-11.
- EADIE, T. L., YORKSTON, K. M., KLASNER, E. R., DUDGEON, B. J., DEITZ, J. C., BAYLOR, C. R., MILLER, R. M. & AMTMANN, D. 2006. Measuring communicative participation: a review of self-report instruments in speech-language pathology. *Am J Speech Lang Pathol*, 15, 307-20.
- ELO, S. & KYNGAS, H. 2008. The qualitative content analysis process. *J Adv Nurs*, 62, 107-15.
- FUHRER, M. J. 1994. Subjective well-being: implications for medical rehabilitation outcomes and models of disablement. *Am J Phys Med Rehabil*, 73, 358-64.
- GIBBONS, M. 1996. Communication strategies help alleviate isolation of vent patients. *Advance*, 6.
- GIBBS, G. 2002. *Qualitative Data Analysis: Explorations with NVivo*, Philadelphia, Open University Press.
- GIDDENS, A. (ed.) 1991. *Modernity and self-identity: self and society in the late modern age*, Stanford, California: Stanford University Press.
- GRANEHEIM, U. H. & LUNDMAN, B. 2004. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*, 24, 105-12.
- GRYPDONCK, M. H. 2006. Qualitative health research in the era of evidence-based practice. *Qual Health Res*, 16, 1371-85.
- GUBA, E. G. & LINCOLN, Y. S. 1994. Competing paradigms in qualitative research. In: LINCOLN, N. K. D. Y. S. (ed.) *Handbook of qualitative research.*: Thousand Oaks, CA: Sage.

- HAPP, M. B. 2001. Communicating with mechanically ventilated patients: state of the science. *AACN Clin Issues*, 12, 247-58.
- HAPP, M. B., TUIITE, P., DOBBIN, K., DIVIRGILIO-THOMAS, D. & KITUTU, J. 2004. Communication ability, method, and content among nonspeaking nonsurviving patients treated with mechanical ventilation in the intensive care unit. *Am J Crit Care*, 13, 210-8; quiz 219-20.
- HARTELIUS, L., ELMBERG, M., HOLM, R., LOVBERG, A. S. & NIKOLAIDIS, S. 2008. Living with dysarthria: evaluation of a self-report questionnaire. *Folia Phoniatr Logop*, 60, 11-9.
- HESS, D. R. 2005. Facilitating speech in the patient with a tracheostomy. *Respir Care*, 50, 519-25.
- HOIT, J. D., LOHMEIER, H. L., HIXON, T. J., BANZETT, R. B. & BROWN, R. 2003. Clinical Ventilator Adjustments That Improve Speech. *Chest*, 124, 1512-1521.
- HOIT, J. D., SHEA, S. A. & BANZETT, R. B. 1994. Speech production during mechanical ventilation in tracheostomized individuals. *J Speech Hear Res*, 37, 53-63.
- HSIEH, H. F. & SHANNON, S. E. 2005. Three approaches to qualitative content analysis. *Qual Health Res*, 15, 1277-88.
- ICF 2001. 2001 International classification of function, disability and health. Retrieved December 10, 2001 from <http://www3.who.int/icf/icftemplate.cfm>.
- IMRIE, R. 2004. Demystifying disability: a review of the International Classification of Functioning, Disability and Health. *Sociol Health Illn*, 26, 287-305.
- KAGAN, A., BLACK, S. E., DUCHAN, J. F., SIMMONS-MACKIE, N. & SQUARE, P. 2001. Training volunteers as conversation partners using "Supported Conversation for Adults with Aphasia" (SCA): A controlled trial. *Journal of Speech Language and Hearing Research*, 44, 624-638.
- KAUT, K., TURCOTT, J. C. & LAVERY, M. 1996. Passy-Muir speaking valve. *Dimens Crit Care Nurs*, 15, 298-306.
- KRIPPENDORFF, K. 2004. *Content analysis : an introduction to its methodology*, Thousand Oaks, Calif., Sage.
- KVALE, S. 1996. *Interviews : an introduction to qualitative research interviewing*, Thousand Oaks, SAGE.
- LAUB, M. & MIDGREN, B. 2007. Survival of patients on home mechanical ventilation: a nationwide prospective study. *Respir Med*, 101, 1074-8.
- LEDER, S. B. 1990. Importance of verbal communication for the ventilator-dependent patient. *Chest*, 98, 792-3.
- LEWARSKI, J. S. & GAY, P. C. 2007. Current issues in home mechanical ventilation. *Chest*, 132, 671-6.
- LEVINE, S. P., KOESTER, D. J. & KETT, R. L. 1987. Independently activated talking tracheostomy systems for quadriplegic patients. *Arch Phys Med Rehabil*, 68, 571-3.

- LILLVIK, M., ALLEMARK, E., KARLSTRÖM, P. & HARTELIUS, L. 1999. Intelligibility of dysarthric speech in words and sentences: development of a computerised assessment procedure in Swedish. *Logopedics Phoniatrics Vocology*, 24, 107-119.
- LINCOLN, Y. S. & GUBA, E. G. 1985. *Naturalistic inquiry*, Beverly Hills, Calif., Sage.
- LINDAHL, B., SANDMANN, P. & RASMUSSEN, B. 2005. On becoming dependent on home mechanical ventilation. *Journal of Advanced Nursing* 49, 33-42.
- LINEBAUGH, C. W., KRYZER, K. M., ODEN, S. E. & MYERS, P. S. 1982. Reapportionment of communicative burden in aphasia. In: BROOKSHIRE, R. H. (ed.) *Clinical aphasiology*. Minneapolis: BRK Publishers.
- LLOYD-OWEN, S. J., DONALDSON, G. C., AMBROSINO, N., ESCARABILL, J., FARRE, R., FAUROUX, B., ROBERT, D., SCHOENHOFER, B., SIMONDS, A. K. & WEDZICHA, J. A. 2005. Patterns of home mechanical ventilation use in Europe: results from the Eurovent survey. *Eur Respir J*, 25, 1025-31.
- LLOYD, V., GATHERER, A. & KALSY, S. 2006. Conducting Qualitative Interview Research With People With Expressive Language Difficulties. *Qualitative Health Research*, 16, 1386-1404.
- LOHMEIER, H. L. & HOIT, J. D. 2003. Ventilator-supported communication: A survey of ventilator users *Journal of Medical Speech-Language Pathology* 11, 61-72.
- LUND, S. K. & LIGHT, J. 2007. Long-term outcomes for individuals who use augmentative and alternative communication: Part III--contributing factors. *Augment Altern Commun*, 23, 323-35.
- MACBEAN, N., WARD, E. & MURDOCH, B. Year. Optimising communication in the ventilator-dependent individual following cervical spinal injury. An examination of two cases. In: *Postgraduate Research in the School of Health and Rehabilitation Sciences*, 2004 Brisbane, Australia.
- MANZANO, J. L., LUBILLO, S., HENRIQUEZ, D., MARTIN, J. C., PEREZ, M. C. & WILSON, D. J. 1993. Verbal communication of ventilator-dependent patients. *Crit Care Med*, 21, 512-7.
- MARKSTROM, A., COHEN, G. & KATZ-SALAMON, M. 2010. The effect of long term ventilatory support on hemodynamics in children with spinal muscle atrophy (SMA) type II. *Sleep Med*, 11, 201-4.
- MARKSTROM, A., SUNDELL, K., LYSDAHL, M., ANDERSSON, G., SCHEDIN, U. & KLANG, B. 2002. Quality-of-life evaluation of patients with neuromuscular and skeletal diseases treated with noninvasive and invasive home mechanical ventilation. *Chest*, 122, 1695-700.
- MARKSTROM, A., SUNDELL, K., STENBERG, N. & KATZ-SALAMON, M. 2008. Long-term non-invasive positive airway pressure ventilation in infants. *Acta Paediatr*, 97, 1658-62.

- MCDOUGALL, J., WRIGHT, V. & ROSENBAUM, P. 2010. The ICF model of functioning and disability: incorporating quality of life and human development. *Dev Neurorehabil*, 13, 204-11.
- MIDGREN, B., OLOFSON, J., HARLID, R., DELLBORG, C., JACOBSEN, E. & NORREGAARD, O. 2000. Home mechanical ventilation in Sweden, with reference to Danish experiences. Swedish Society of Chest Medicine. *Respir Med*, 94, 135-8.
- MILLER, W. & CRABTREE, B. 1994. Clinical Research. In: DENZIN, N. & LINCOLN, Y. (eds.) *Handbook of Qualitative Research*. CA: Thousand oaks, Sage Publications.
- MORSE, J. M., BARRETT, M., MAYAN, M., OLSON, K. & SPIERS, J. 2002. Verification strategies for establishing reliability and validity in qualitative research *International Journal of Qualitative Methods*, 1, 1-19.
- NEUNDORF, K. 2002. *The Content Analysis Guidebook*, Sage Publications, Inc., Thousand Oaks, CA.
- NOMORI, H. 2004. Tracheostomy tube enabling speech during mechanical ventilation. *Chest*, 125, 1046-51.
- PATRICK, D. L., BUSH, J. W. & CHEN, M. M. 1973. Toward an operational definition of health. *J Health Soc Behav*, 14, 6-23.
- PIKE, K. 1967. *Language in Relation to a Unified Theory of the Structure of Human Nature*, The Hague & Paris: Mouton & Co.
- PRIGENT, H., SAMUEL, C., LOUIS, B., ABINUN, M. F., ZERAH-LANCNER, F., LEJAILLE, M., RAPHAEL, J. C. & LOFASO, F. 2003. Comparative effects of two ventilatory modes on speech in tracheostomized patients with neuromuscular disease. *Am J Respir Crit Care Med*, 167, 114-9.
- RICHARDS, L. 1999. *Using NVivo in qualitative research*, Thousand Oaks, Calif. ; London, SAGE.
- SANDELOWSKI, M. 2000a. Combining qualitative and quantitative sampling, data collection, and analysis techniques in mixed-method studies. *Research in Nursing & Health*, 23, 246-55.
- SANDELOWSKI, M. 2000b. Whatever happened to qualitative description? *Res Nurs Health*, 23, 334-40.
- SCHEGLOFF, E. A. 1982. Discourse as an interactional achievement: Some uses of 'uh huh' and other things that come between sentences. In: TANNEN, D. (ed.) *Georgetown University Roundtable on Languages and Linguistics*. Washington DC: Georgetown University Press.
- SILVERSTEIN, M. D., STOCKING, C. B., ANTEL, J. P., BECKWITH, J., ROOS, R. P. & SIEGLER, M. 1991. Amyotrophic lateral sclerosis and life-sustaining therapy: patients' desires for information, participation in decision making, and life-sustaining therapy. *Mayo Clin Proc*, 66, 906-13.
- SIMMONS-MACKIE, N., KINGSTON, D. & SCHULTZ, M. 2004. "Speaking for another": the management of participant frames in aphasia. *Am J Speech Lang Pathol*, 13, 114-27.

- SIMMONS-MACKIE, N. N. & DAMICO, J. S. 2003. Contributions of qualitative research to the knowledge base of normal communication. *Am J Speech Lang Pathol*, 12, 144-54.
- SIMONDS, A. K. 2003. Home ventilation. *European Respiratory Journal* 47, 38s-46s.
- STROM, K. & BOE, J. 1988. A national register for long-term oxygen therapy in chronic hypoxia: preliminary results. *Eur Respir J*, 1, 952-8.
- TEDDLIE, C. & TASHAKKORI, A. 2003. *Handbook of mixed methods in social and behavioral research*, Thousand Oaks, CA: Sage Publications.
- TESTA, M. A. & SIMONSON, D. C. 1996. Assessment of quality-of-life outcomes. *N Engl J Med*, 334, 835-40.
- TETNOWSKI, J. A. & FRANKLIN, T. C. 2003. Qualitative research: implications for description and assessment. *Am J Speech Lang Pathol*, 12, 155-64.
- THREATS, T. T. 2006. Towards an international framework for communication disorders: use of the ICF. *J Commun Disord*, 39, 251-65.
- THREATS, T. T. & WORRALL, L. 2004. Classifying communication disability using the ICF. *Advances in Speech–Language Pathology*, 6, 53 – 62.
- TIPPETT, D. C. & SIEBENS, A. A. 1995. Preserving Oral Communication in Individuals With Tracheostomy and Ventilator Dependency. *American Journal of Speech-Language Pathology*, 4, 55.
- UN. *Convention on the Rights of Persons with Disabilities* [Online]. United Nations (UN). Rights and Dignity of Persons with Disabilities. Available: <http://www.un.org/disabilities/default.asp?navid=13&pid=150> [Accessed 21-01-2011].
- WATZLAWICK, P., BEAVIN BAVELAS, J. & JACKSON, D., D 1967. *Pragmatics of human communication. A study of interactional patterns, Pathologies and Paradoxes.*, New York, London, W.W. Norton & Company.
- WINDISCH, W. & CRIEE, C. P. 2006. [Quality of life in patients with home mechanical ventilation]. *Pneumologie*, 60, 539-46.
- WINDISCH, W., FREIDEL, K., SCHUCHER, B., BAUMANN, H., WIEBEL, M., MATTHYS, H. & PETERMANN, F. 2003. The Severe Respiratory Insufficiency (SRI) Questionnaire: a specific measure of health-related quality of life in patients receiving home mechanical ventilation. *J Clin Epidemiol*, 56, 752-9.
- WORRALL, L. E. 2000. *Neurogenic communication disorders : a functional approach*, New York ; Stuttgart, Thieme.
- WYLLER, T. B. 1997. Disability models in geriatrics: comprehensive rather than competing models should be promoted. *Disabil Rehabil*, 19, 480-3.
- YIN, R. K. 2003. *Case study research: design and methods*, Thousand Oaks, Calif., Sage Publications.



YORKSTON, K. M., KLASNER, E. R. & SWANSON, K. M. 2001.  
Communication in context: A qualitative study of the experiences of  
individuals with multiple sclerosis. *American Journal of Speech-Language  
Pathology*, 10, 126-137.