Let’s stay in touch!

Remote communication for people with communicative and cognitive disabilities

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"I stare at my laptop. The screen has gone blank. Terror fills me…I never thought my link to the world would actually be lost, and I'd suddenly go silent. I know enough about computers to suspect this is terminal…I feel sick. If I don't have my computer, then I can't send text messages or emails…I can't laugh and joke with my friends online, tell them about my day, and ask about theirs. I can't describe to them how I'm feeling or make plans to meet up. My physical world might still be limited to the home and office, but there are parts of my life that know no boundaries as I chat to people on different continents...All I'll have to communicate with now is a battered old alphabet board that won't reach around the globe the way I need it to."

Ghost Boy by Martin Pistorius p. 144 (1)

ABSTRACT

Introduction: Being able to use remote communication through digital channels is a prerequisite for participation in contemporary society, but some people have difficulties in accessing it. **Aim**: The overall aim was to explore and describe remote communication for people with communicative and cognitive disabilities. This thesis explored remote communication in relation to self-determination and participation from users', professionals' and support persons' perspectives. **Methods**: This thesis is based on four studies: three qualitative (I, III, IV) and a mixed method (II). For study I, semi-structured interviews were used, and they were analysed by content analysis. In study II, semi-structured interviews were combined with Talking Mats, a pictorial communication tool, where qualitative data for systematic text condensation and ordinal scale data were obtained. Study III and IV's focus groups were analysed by focus group analysis. **Results**: In study I, professionals described how text messaging with both pictures and speech could increase independence and participation, and how individual assessments and user-friendly technology were important. For study II, people with communicative and cognitive disabilities described how remote communication related to self-determination. Having a choice between types of remote communication and levels of independence was important, and technological limitations forced them to find their own strategies to communicate. Support persons discussed how remote communication enabled users to have more control and feel safer while increasing self-determination and participation for study III. The results suggest communicative rights were not met, and there was a need for better provisions of technology and support. In the final study, support persons discussed what enhanced and hindered remote communication. **Conclusion**: This thesis contributes to the understanding of how people with communication difficulties need access to remote communication to have control, be self-determined and participate in society. It provides knowledge on the needed improvements for access, support and development to improve remote communication use.

Keywords: Augmentative and alternative communication, assistive technology, remote communication, digital communication, self-determination, participation, qualitative, Talking Mats, support persons, cognitive and communication disabilities

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SAMMANFATTNING PÅ SVENSKA

Vi ägnar oss alltmer åt att kommunicera med andra via telefon, sms, e-post, videosamtal, sociala medier och olika typer av meddelandetjänster, s.k. fjärrkommunikation. Att kunna använda fjärrkommunikation på något sätt är en förutsättning för delaktighet i dagens samhälle. Det används för social gemenskap och för att boka in olika slags av aktiviteter. Vi förväntas ha tillgång till internet och telefon, surfplatta eller dator för att kunna utföra viktiga aktiviteter som att kontakta hyresvärden eller kontakta support för olika tjänster. Vi behöver också kunna fjärrkommunicera för att till exempel boka hälso- och sjukvårdsbesök och ha kontakt med försäkringskassa eller arbetsförmedling.

Personer med kommunikativa och kognitiva svårigheter som har svårt att uttrycka sig i tal och skrift kan ha stora begränsningar i tillgången till fjärrkommunikation.

Denna avhandling har som syfte att utforska och beskriva fjärrkommunikation för personer med kommunikativa och kognitiva svårigheter. Avhandlingen fokuserar på fjärrkommunikation i relation till självbestämmande och delaktighet. Tre olika perspektiv har undersökts: personernas egna erfarenheter, förskrivares och stödpersoners erfarenheter.

Avhandlingen innefattar en ramberättelse och fyra delarbeten där deltagarnas erfarenheter av fjärrkommunikation beskrivs. Erfarenheterna har samlats in genom individuella intervjuer och fokusgruppsdiskussioner.

Avhandlingen beskriver hur tillgång till fungerande fjärrkommunikation är viktigt för att ha kontroll över sitt eget liv, självbestämmande och delaktighet. Den beskriver också hur det behövs ökad tillgång till fungerande teknik, kunskap och stöd för att personer med kommunikativa och kognitiva svårigheter ska kunna fjärrkommunicera som de själva önskar.

LIST OF PAPERS

This thesis is based on the following studies, referred to in the text by their Roman numerals. The published papers are reprinted with permission from Technology and Disability for study I and Disability and Rehabilitation for study II and III.

I. Buchholz M, Mattsson Müller I, Ferm U. Text messaging with pictures and speech synthesis for adolescents and adults with cognitive and communicative disabilities – professionals' views about user satisfaction and participation. *Technology and Disability* 2013; 25: 87-98.

II. Buchholz M, Ferm U, Holmgren K. "That is how I speak nowadays" – experiences of remote communication among persons with communicative and cognitive disabilities. *Disability and Rehabilitation* 2018; 40:12 1468-79.

III. Buchholz M, Ferm U, Holmgren K. Support persons' views on remote communication and social media for people with communicative and cognitive disabilities. *Disability and Rehabilitation, 2018: 1-9*.

IV. Buchholz M, Holmgren K, Ferm U. Remote Communication for People with Disabilities: Benefits, Challenges and Suggestions for Technology Development. *In manuscript*.

CONTENT

ABBREVIATIONS

AAC	Augmentative and alternative communication
ASHA	American Speech-Language-Hearing Association
AT	Assistive Technology
CMOP-E	Canadian Model of Occupational Performance
EU	European Union
ICF	International Classification of Functioning, Disability and Health
OT	Occupational therapist
SLP	Speech language pathologist
TMSS	Text messaging with picture symbols and speech synthesis
UN	United Nations
WHO	World Health Organization

PREFACE

As an occupational therapist at a regional centre for augmentative and alternative communication (AAC) and assistive technology (AT) for 25 years, I have met many people who have struggled with communication. As a part of a multidisciplinary team, my role is mainly to work with the client in order to enable access to communication and meaningful activities in everyday life. Technology has developed intensively during my years in clinical work, which has created great possibilities for people with communicative difficulties by providing advanced alternative access to digital communication aids. The development of digital communication in society has created possibilities for social interaction all around the world with remote communication, which can be an enabler for people with disabilities.

Even with the development of technology and methodology at hand, there are still many communication barriers, and we are not able to provide "perfect solutions" to all who need communication support. Enabling meaningful communication for people with communicative difficulties has been my driving force throughout the research.

This thesis has given me the opportunity to learn from people with communicative and cognitive disabilities, their support persons and professionals. I am truly grateful for this journey and hope that this thesis can contribute knowledge to promote remote communication and show its benefits to help those who struggle to communicate today.

1 INTRODUCTION

Remote communication means communication between people who are not physically in the same place. For instance, using smartphones, tablets and computers, including services for calls (e.g. WhatsApp), messaging (e.g. Messenger), video calls (e.g. Skype) and social media are common means of communication in contemporary society. Communication through digital channels is increasing as a required means of communication for interactions for daily activities, like contact with healthcare, insurance or banks and, therefore, has become a prerequisite for participation in society. Internet use throughout the world is constantly increasing but with great variation between countries (2). Approximately half of the world's population use the Internet and more than half of those people use social media (3, 4). In the Swedish context, where data for this thesis were collected, Internet access figures are high, and it is one of three countries with the highest Internet access figures in the world (2). Today, 98% of the Swedish population has access to the Internet at home, and nine out of ten own a smartphone (5).

These high Internet usage figures indicate how communication in society is carried out and how remote communication has become a prerequisite for participation within society (6). For example, the Internet is used for engaging in many daily activities. It is used in social interactions with friends and groups and finding or signing up to participate in leisure activities that are commonly advertised through social media. Remote communication is also used to book activities, like haircuts, restaurant reservations or sport club sessions. Citizens are expected to have access to the Internet and digital devices to interact and to carry out necessary tasks, such as contacting a landlord to get assistance from a janitor or helpdesks for problems with products or services. Remote communication is also necessary for taking care of one's health for booking healthcare appointments, handling medication prescriptions and having contact with healthcare insurance providers. E-health is a relatively recent healthcare practice supported by electronic communication, and it is developing rapidly (7-9). Physical, more old-fashioned means (e.g. bank tellers, reception desks), of contact are being shut down, making access to remote communication a must in order to handle essential daily life activities.

Despite this common use of the Internet and social media, several groups of people do not have Internet access or other means of remote communication at present due to older age or disability (5). Being able to use common forms of remote communication require functional speech (phone calls and video calls) and the ability to read and write (texting, e-mailing or chatting). There are

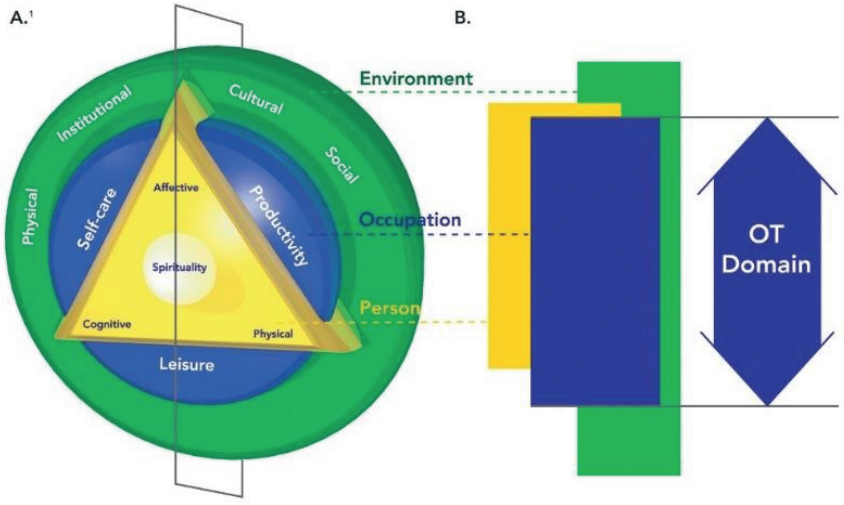
several medical conditions, such as congenital, acquired and progressive disorders that can affect communication abilities. People with a combination of communicative and cognitive disabilities may have limited speech and comprehension abilities as well as restricted reading and writing skills. This means that both their spoken and written communication are affected, limiting access to remote communication and creating a digital divide (5, 6). Internet access among people with communicative and cognitive disabilities is lower than in the general population, and, for many, Internet use can be complicated (10). To further complicate matters, figures describing their use are lacking because they are not included in the national surveys due to data collection procedures not being adapted to their communication difficulties (11).

Using remote communication has been shown to reduce isolation while enhancing social contact, independence and participation (12, 13). Those who lack access to remote communication will most likely end up on the wrong side of the digital divide and become excluded from the digitalised world of today (6, 14). The fact that people with communicative and cognitive disabilities are not included in Internet access statistics due to their communication difficulties illustrates further the need for this group to be included in the modern digital society (11).

1.1 OCCUPATION IN RELATION TO SELF-DETERMINATION AND PARTICIPATION

Occupation plays an important role in one's self and social identity (15) and, as such, enables people to interact with their environment and participate in society (16). Since the human species evolved through occupation in interaction, communication and cooperation with other people are, therefore, a vital part of our lives (17, 18). Communication and social interaction play a fundamental role in the development of a person throughout life, and they play a central part in the process of "making meaning" according to Vygotsky (19, 20). People express their personal identities through occupation, which provides meaning. Therefore, occupational limitations may have identity implications that influence the overall concept of self (21).

The Canadian Association of Occupational Therapists developed a model on enabling occupation through occupational therapy, and it focuses on occupational performance and engagement (22, 23) (see Figure 1). The model is a three-dimensional depiction of the relationship of a person. It has three performance components and three areas of occupation. The environment is represented by four elements.



A.[1] Referred to as the CMOP in *Enabling Occupation* (1997a, 2002) and CMOP-E as of this edition
B. Trans-sectional view

Polatajko, H. J., Townsend, E. A., Craik, J. (2007). *Canadian Model of Occupational Performance and Engagement* (CMOP-E). In E. A. Townsend and H. J. Polatajko, *Enabling Occupation II: Advancing an Occupational Therapy Vision of Health, Well-being, & Justice through Occupation*. p.23 Ottawa, ON: CAOT Publications ACE.

Figure 1. Canadian Model of Occupational Performance (CMOP-E). Published with permission from CAOT Publications.

As humans, we are part of a collective, and occupation is not just individuals acting independently, but it is a part of an environment interacting with others (24). The CMOP-E model describes how occupational performance is a result of a dynamic relationship between people, environment and occupation (23). The CMOP-E is an applicable model to describe the use of remote communication, as it can include all of those aspects (people, environment and occupation). CMOP-E has some relation to the International Classification of Functioning, Disability and Health (ICF), where participation (i.e. a person's involvement in different life areas) represents the social perspective of functioning (25). Classifications according to the ICF have become central in occupational therapy, but there is also criticism that there are a lack of

subjective aspects of self-determination and meaning. When aiming to gain knowledge of people's lives, researchers need to ensure to include all groups who may be impacted, so the participants are able to express their own experiences. The participants' experiences must be central to any research (26-28).

Self-determination (sometimes described as autonomy or independence) is the ability and freedom to make one's own choices, and it is essential for optimal functioning and well-being and is a prerequisite for participation (29). Wehmeyer and Schwartz (30, 31) showed that self-determination can also be correlated to overall quality of life and that students with cognitive disabilities who are able to make their own choices and decisions are more independent at work and in other aspects of their social life.

Occupational justice is a concept dealing with people's rights to have access to opportunities and resources to participate in meaningful occupations (23). Townsend and Wilcock (32) defined four occupational rights: (a) to experience occupation as meaningful and enriching; (b) to develop through participation in occupations for social inclusion and health; (c) to exert autonomy through choice of occupations and (d) to benefit from fair privileges for diverse participations in occupations. Occupational justice also relates to the power to decide over one's own occupations in daily life (23).

Freedom of speech is a fundamental human right described by the United Nations (UN) in the Universal Declaration of Human Rights (33). The right to communicate is described by the American Speech-Language-Hearing Association and in the UN-Convention on the Rights of Persons with Disabilities (34, 35). A review of the current research on occupational justice shows that occupational justice is an aspect of social justice and human rights (36). Hence, communication and occupational justice are interrelated and central to human rights, and, as such, remote communication as a mean of communication should not be overlooked (37, 38). McEwin and Santow (39) described the importance of the human right to communication as follows:

> "Humans cannot live or thrive in isolation. We are inherently social. As such, communication is essential to our humanity. It is important to our expression and self-determination as individuals, our sense of belonging within a community, our inclusion and participation within society, and in acknowledging the meaning and value of ourselves and others" (page 1) (39).

2 COMMUNICATIVE AND COGNITIVE DISABILITIES

Disability is a complex term, reflecting the interaction between a person and the surrounding society. Disability occurs in the context of both personal and environmental factors, which influence how disability and subsequently participation are experienced by the individual (25). Disability affecting the ability to communicate can affect self-determination because it decreases opportunities to initiate contact, engage in conversation and plan and participate in activities in the same way as others (40). Participation is a common goal for communication interventions and an important outcome measure in research (41-43).

People who have a restricted ability to communicate can use augmentative and alternative communication (AAC; i.e. methods to compensate for restrictions in their ability to produce and/or comprehend spoken and written communication). Complex communication needs refer to people with severe speech, language and communication impairments who need to use AAC (44, 45). An AAC system involves low and high technology that is adjusted to the individual's communication needs (46). People who have difficulties communicating may also have cognitive problems and difficulties reading and writing. For them, AAC can include graphic symbols and text-to-speech for assisted reading (35, 46, 47). Vocabulary and phrases need to be individually adapted (48). Having difficulties in reading and writing without access to assistive solutions may affect participation in daily life (49).

Intellectual disability is a complex condition which can include cognitive functions and performance limitations in learning and adapting to environmental demands (50). This thesis does not focus on the broad picture of intellectual disability but on the combination of communicative and cognitive disability affecting the ability to read and write. People who have different diagnoses and are of different ages may have the same difficulties with and needs of remote communication. Neither diagnosis nor age was in the focus of this thesis except the attempt to recruit a heterogeneous group of participants.

People with communicative and cognitive disabilities may need support in everyday activities. A support person can be anyone who supports the person in daily life, like family, friends or staff at school, an activity centre or in sheltered housing. They may also be personal assistants. In Sweden, people with communicative and cognitive disabilities may have the right to get

support from a personal assistant if their difficulties are deemed within the parameters of the Swedish Act concerning Support and Service for Persons with Certain Functional Impairment (51, 52), which aims to enable participation in daily life activities and communication.

2.1 REMOTE COMMUNICATION AND DISABILITY

For a person with disability, remote communication, including social media, may facilitate societal relationships, self-determination and participation (12-14, 43, 53-58). People who have difficulties with oral communication in combination with reading and writing problems tend to find it hard to handle mainstream communication technology, but research has shown that they may benefit from specialised software or well-designed mainstream technology (56, 59-63). Remote communication based on speech, such as phone calls or video calls, can be hard to manage. Remote communication involving writing, such as e-mail, chat, social media or texting, are also difficult (14, 46). People with complex communication needs try to bypass deficits and overcome environmental barriers to communication by utilising different strategies to maximise communication (45). However, these strategies themselves are not sufficient to achieve satisfactory communication. While digitalisation increases participation for many people in society, it may limit participation for others due to limitations in access. People with communicative and cognitive disabilities may become more excluded in a digitised world and experience a digital divide, especially when technology is not designed for them, and they may struggle to adapt to the quick technology developments (64-66).

Assistive technology means products, environmental modifications, services and processes that enable occupation and participation for people with disabilities (67). This includes mainstream, off-the shelf technology and specialised devices. Assistive technology can, to some extent, connect to and be used for remote communication. The design of service delivery processes for assistive technology are important for end-user satisfaction with the device and they differ between countries (68). In Sweden, licensed healthcare professionals, including occupational therapists and speech language pathologists, can prescribe assistive technology for communication through the national healthcare system (69).

Remote communication to a large degree depends on access to mainstream technology and services. Having access to mainstream technology and services

is, therefore, vital for communication and, as such, should be deemed a human right (6, 34). Accessibility is a concrete concept meaning of something being able to be reached, obtained or entered (70). Accessibility can also mean being easily understood, appreciated and used. However, accessibility is complex because it involves people, artefactual and natural environments and needs to be described from the perspective of the lived accessibility (71). Universal design aims for equality and non-discrimination through accessibility for everyone, and it is on the international agenda to achieve this (72). The aim of universal design for digital communication can be illustrated by the following vision of Tim Berners-Lee, W3C Director and inventor of the World Wide Web:

> "The power of the Web is in its universality. Access by everyone regardless of disability is an essential aspect" (73).

The most up-to-date research on the topic of remote communication covers specific areas, such as the use of video calls, social media or specific services like Twitter and Facebook (38, 54, 74-76). It also focuses on different devices like iPads or smartphones. In daily remote communication, most users switch between different devices, applications and services depending on whom they want to reach and how they prefer to communicate. People with disabilities may only have access to a specific device or software, limiting their choices and potentially excluding them from participating fully. Research on specific areas of remote communication is obviously important, but it is also important to get an overall, holistic picture of remote communication for people with communicative and cognitive disabilities. If a person has difficulties texting with a smartphone but can have a conversation over Messenger with assistive technology, he or she still has the possibility to participate with remote communication. The ability to use at least one mode of remote communication is vastly different compared to having no accessible devices, applications or services that he or she can use. Another reason for taking an overall perspective on remote communication is that new services and applications are constantly being developed; they change in popularity and some are discontinued. It is the overall functions of remote communication that are of crucial importance to have access to and which, therefore, warrant exploration and research.

Research on remote communication involving people with communicative and cognitive disabilities is relatively new. Issues in accessing communication technology for people with communicative and cognitive disabilities need to be highlighted and their needs must be considered. In order for research to focus on topics important for the end users, user involvement in research is mandatory (77). People with communicative and cognitive disabilities are

rarely involved in research due to limited access, but their voices and perspectives are important (78, 79). Even though this field is expanding, there remains a lack of research that needs to be addressed in order to keep up with the development of remote communication in society (12, 74, 80-84).

2.2 THE RATIONALE FOR THE THESIS

Communicative and cognitive disabilities can result in decreased interaction with other people, self-determination and participation in society. To further complicate matters, technology that could enable remote communication is often not designed for people with these disabilities. There is a need for research into what aspects of remote communication, including new technology, are important to develop. It is also important to gain knowledge on what obstacles and barriers to remote communication need to be overcome in order to meet the needs of people with cognitive and communicative disabilities. Knowing these could increase usage and access to remote communication.

In order to develop an understanding of remote communication for people with communicative and cognitive disabilities, experiences of people in the target group with varying diagnoses and ages must be taken into consideration. Understanding their views on factors that facilitate and hinder remote communication is crucial. These experiences, in combination with the perspectives of support persons and professionals, are also important to understand the broader, more complete picture of remote communication. This, in turn, may form the basis of developing remote communication for people with communicative and cognitive disabilities.

3 AIM

The overall aim of this thesis was to explore and describe remote communication for people with communicative and cognitive disabilities who have limited reading and writing abilities. This thesis explored remote communication in relation to self-determination and participation from the perspectives of the people themselves, professionals (occupational therapists and speech language pathologists) and support persons.

Study I aimed to explore the professionals' views on remote communication, including texting with picture symbols and speech synthesis, for people with communicative and cognitive disabilities after an intervention period.

Study II aimed to explore the experiences of people with communicative and cognitive disabilities using remote communication.

Study III aimed to explore support persons' views on remote communication for people with communicative and cognitive disabilities and on factors that enabled their self-determination and participation.

Study IV aimed to describe support persons' views on varying aspects of and functions in technology for remote communication that enabled and stimulated independent communication, self-determination and participation for people with communicative and cognitive disabilities.

4 METHODS

4.1 DESIGN

The thesis is based on three qualitative studies (I, III and IV) and one mixed-method study with a qualitative focus (II). Qualitative research methods were chosen in order to explore an unexplored research area and find and describe the meaning of the topic (85). The qualitative approach contributes an increased understanding and in-depth knowledge that is hard to research with a quantitative approach (85, 86). The studies in this thesis included interviews and focus groups (see Table 1 for a summary of the studies).

Table 1. Overview of the studies including design, sample, data collection and data analysis.

Study	Design	Data collection	Participants	Data analysis
I	Interview study	Semi-structured interviews	Professionals working with people with communicative and cognitive disabilities N = 7	Qualitative analysis: Content analysis
II	Mixed-method study	Semi-structured interviews, including Talking Mats	People with communicative and cognitive disabilities N = 11	Qualitative and quantitative analysis: Systematic text condensation and descriptive analysis
III	Focus group study	Focus group methodology	Support persons to people with communicative and cognitive disabilities N = 21	Qualitative analysis: Focus group analysis
IV	Focus group study	Focus group methodology	Support persons to people with communicative and cognitive disabilities N = 21	Qualitative analysis: Focus group analysis

Semi-structured interviews

In study I, a study design with semi-structured interviews was chosen. The aim was to have a few open questions and seek thorough answers. In the semi-structured interviews, a topic guide was used to ensure that the same basic lines of inquiry were carried out with each participant and that the relevant topics were consistently covered (85). The interviews were partly structured, but they had open questions that allowed narrative answers and established a conversational style type interview. In study I, the topics originated from a larger project (Texting with picture symbols and speech synthesis) (87), and the topic guide was designed to correspond with the other research within that project as well.

Semi-structured interviews with Talking Mats

Study II used qualitative interviews with Talking Mats for communicative and cognitive support to enable participation of the target group—people with cognitive and communicative difficulties (88). Talking Mats is a visual framework that allows individuals with communicative and cognitive disabilities to reflect upon and express their views on different issues (89). Talking Mats has been shown to support and increase the effectiveness of communication for individuals with these disabilities, and they can be helpful for conversation partners as well (88, 90, 91). Talking Mats are used by placing a picture representing the conversational topic at the bottom of the mat, and then pictures representing an evaluation scale are placed on the top of the mat by the interviewer (88). A set of pictures, one for each question, relating to the topic are placed under the pictures of the evaluation scale by the respondent as answers to open questions (see Figure 2). Open questions are a main feature of Talking Mats to eliminate yes/no questions, which is most common with the target group due to their communicative difficulties, but yes/no questions are very limited in obtaining in-depth qualitative research (85). Nevertheless, for Talking Mats to be a reliable tool, the interviewer needs to be observant and have formal training (92, 93). The interviewer in the study was an experienced and licensed user of Talking Mats with the target group as well as an accredited trainer.

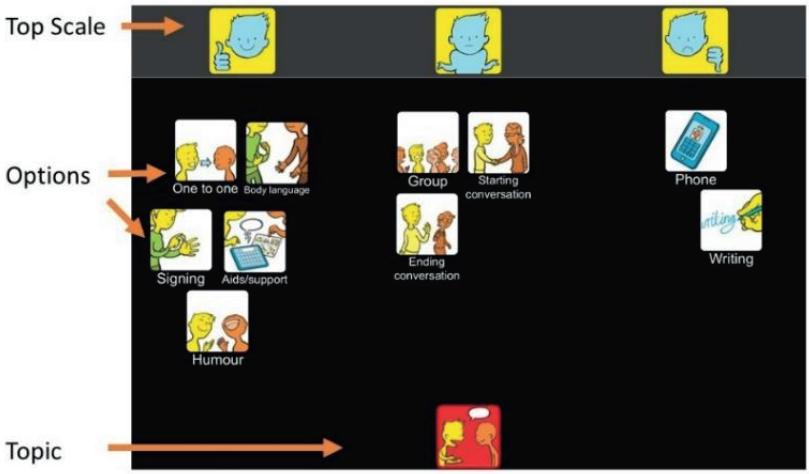


Figure 2. Talking Mats used in a discussion about opinions regarding making conversation. The upper three pictures represent the scale. The pictures below are the options (answers to questions placed under the scale steps). The picture far down represents the topic of the conversation. The symbols are designed and © to Adam Murphy and assigned to Talking Mats Ltd. in perpetuity. They may not be reproduced without permission.

Focus group method

Study III and IV used a focus group design, which is a qualitative research method with its own methodological principles and research procedures (94, 95). Focus groups share basic epistemological assumptions with social constructivism, which is a theory of knowledge where development is socially situated and knowledge is constructed through the interaction with others (94, 95). The focus group method is based on five core elements: 1) people interacting with one another; 2) connection and shared experiences; 3) a tolerant environment; 4) empowered participants and 5) awareness creation (94).

Focus groups are characterised by group discussions. Participants interact with one another in order to gather data on a certain topic (96-98). The groups should be homogeneous in relation to the participants' shared experiences of the topic to create a connection. Homogeneity enables participants to feel comfortable enough to participate in the group discussions, explain their point

of view and their reasons for those views (94, 95). The group processes can encourage participants to express ideas and experiences that might be left underdeveloped in an interview. Awareness can be created and people can explore and clarify their views (99). Groups are guided by a group leader, a so-called moderator, who nurtures the discussion and guides it to stay on topic. It is important for the moderator to be an experienced leader in order to stimulate the group process and encourage all participants to take part in the discussions (94-96, 98, 99). Kreuger and Casey recommend that a two-person team lead the group in order for one person to be able to concentrate on moderating the group while the other person could take notes and handle the recordings (96).

A series of group discussions were conducted in order to achieve a variety of perspectives and for patterns to emerge (95, 97). The participants were empowered in that they were considered the experts on the topic and were helping the researcher in creating new knowledge through the group process (95). A tolerant environment was created by careful planning. The nonthreatening atmosphere encouraged participants to share their views and ideas in the discussions.

The discussions were key in their quality of presenting different point of views, asking one another questions and sometimes changing their initial position based on others' views (96, 97, 99). Focus groups have the opportunity to obtain a diversity of perspectives, and the interactions can, therefore, enhance data quality and face validity due to that diversity (96). The method was useful in gathering views, experiences and attitudes from a certain group and created knowledge and comprehension of the researched topic (94-96, 98, 99).

4.2 TARGET GROUP AND STUDY POPULATION

There were three target groups in this thesis: (a) people with communicative and cognitive disabilities, which affected their ability to read and write and, at some level, interfered with the use of remote communication for speech and writing in daily life; (b) their professionals and (c) their support persons. The disability, rather than diagnosis, was the basis for inclusion in this thesis. The participants were recruited separately for the studies as described below, and there was no known relationship between participants between the studies.

Participants study I: professionals

The participants included in the study participated in an intervention project to test texting with graphic symbols and speech synthesis for a year. The participants included seven professionals: four occupational therapists and three speech language pathologists who had worked with seven people with communicative and cognitive disabilities in the project Texting with picture symbols and speech synthesis (87). They represented the total group of professionals in the project.

Participants study II: people with communicative and cognitive disabilities

The participants were 11 adolescents and adults with communicative and cognitive disabilities. There were several inclusion criteria: participants should have communicative and cognitive disabilities, including limited abilities in reading and writing; have an interest in sharing their experiences about remote communication; be able to participate in an interview situation; understand spoken language and pictures; be able to reflect on their communication and answer yes and no with or without AAC and be able to point at pictures with their hands, eyes or assistive technology. The intention was to obtain a varied sample of male and female participants of differing ages and with various diagnoses and communicative and cognitive problems who used different types of AAC.

Participants study III and IV: support persons

The 21 participants in studies III and IV were support persons to people with communicative and cognitive disabilities which affected ability to read and write, which, at some level, interfered with using remote communication in daily life. The participants were family members and/or staff who worked in sheltered housing, schools or as personal assistants.

Participants were selected based on their experience with the topic and were considered the experts. The formation of the focus groups was based on their shared experiences of the specific topic, but with sufficient variation to allow for contrasting opinions on the topic (95, 99). Studies III and IV were homogeneous in that all participants were support persons with shared experiences of the topic. There was a goal to include a varied sample of participants in regard to experiences assisting people with different disabilities,

client ages and types of communication support. There was also an aim for variation among the participants concerning gender, roles (family or staff) and age.

4.3 PROCEDURE

Data collection procedure: Study I

Participants were part of a project where interviews were part of the data collection process. Each interview with the professionals in the project was completed in one session, lasting between 23 and 49 minutes with an average of 35 minutes. The seven interviews were audio recorded and transcribed verbatim. The interviewer used a topic guide and the participants were continually encouraged to expand on their answers. Before the interview session was completed, the participants were given one question that they were asked to consider and answer by mail within two weeks: "What do other professionals who plan to start working with texting with graphic symbols and speech synthesis with their clients need to know?" The reason this was conducted after the interview was to give the participants time to reflect upon the interview and give them the opportunity to add information that had not come up in the interviews. All participants replied within the allotted time.

Data collection procedure: Study II

Participants were recruited through professionals working in the field of AAC in a major city and its surrounding areas in Sweden. The professionals invited participants who matched the inclusion criteria to take part in the study, and the interested participants were contacted and given thorough oral and picture based written information to be able to give proper informed consent. The procedure was thoroughly designed to enable participation despite any communicative and cognitive difficulties. One week before the interviews, the participants received a picture supported letter with a date, time and place as well as the interview's topics and a reminder to bring any communication devices they may use regularly. All participants were accompanied by a support person of their own choosing who were subsequently instructed not to take an active role in the interviews but to interpret and help the participant if required. All means of communication were encouraged as well as Talking Mats.

The 11 interviews lasted between 55 and 118 minutes with a median of 72 minutes. Each session's aim, topic and Talking Mats procedure were introduced, and the interviewer ensured that each participant understood before proceeding. Each of the three topics was introduced and explained one at a time. The participants placed the picture accompanying each question under the scale step picture (good, bad or in-between good and bad) that best represented his or her opinion (see Figure 3). The interviewer repeated the answer in order to confirm that the picture was correctly placed and asked, "How are you thinking about that?" to stimulate thorough answers orally and AAC. If a participant replied that he or she did not perform an activity or use the device asked about, the picture for that question was put aside. When a mat for a topic was completed, the interviewer repeated all the answers and asked the participant if he or she wanted to change any of the answers. Each completed mat was photographed and put aside until the final part of the interview. A new mat was used for each topic.

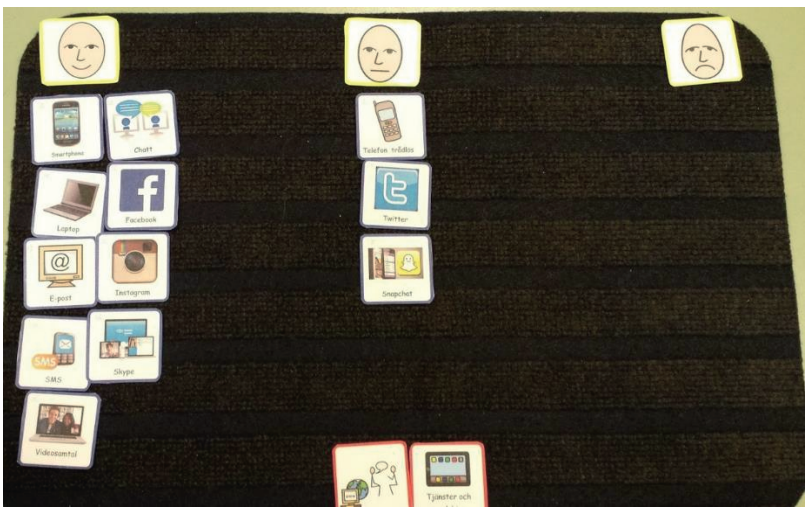


Figure 3. Example of a mat concerning services, applications and devices.

The interviewer collected all the pictures that were placed either under the scale steps bad, in-between good and bad or on the side of the mat. These pictures were then used for a final mat with a scale representing the degree of importance of the activity or device to the participant (see Figure 4). If it were of no importance at all to the participant, the picture was placed beside the mat. Here, too, the interviewer asked, "How are you thinking about that?" to stimulate more thorough answers. After this final mat, the interviewer asked if

the participant had any more thoughts about remote communication that he or she wanted to share. Two weeks after the interview, the interviewer contacted each participant by phone when they were accompanied by their support person. During this call, the participant had a chance to reflect upon, add or change anything communicated during the interview. The interviews were video recorded and transcribed verbatim. All oral communication and major body communication (e.g. nodding or shaking the head for yes and no, signing or pointing at objects) and other means of AAC were noted in the transcriptions and comprehension was facilitated by watching the films several times while the interviews were being transcribed. During the phone calls, notes were taken, and these were also added to each transcription.

Figure 4. Example of a mat concerning the importance of the different activities, services and devices.

Data collection procedure: Study III and IV

The participants were recruited online through a regional centre's website for AAC and assistive technology and through seminars and user organisations. Five focus groups were scheduled, as recommended by several researchers (95, 96, 99). Data collection continued until no new information to the research questions emerged, which was established after the fifth focus group (95, 96, 99). The original design was to have six participants per group in order to facilitate discussions while allowing all participants to have enough time to express their views (95, 96, 99). Due to cancellations and rescheduling, there

were two to six participants in each group with a total of 21 participants. Each focus group met for one session lasting between one to two hours as recommended (95, 96, 99) and continued until the discussions around the topic were completed.

A moderator led the groups and strived to enable and stimulate discussions, and an observer participated while taking notes. The same moderator and observer were used for all group discussions, helping to ensure consistency across all groups. The discussions were initiated with a recollection of the aim of the study, and the participants were encouraged to engage in discussions. Each topic was introduced with a question, and the moderator let the discussion continue and only interjected if the discussion veered off topic. A pre-established questioning route with key questions was used to gather different views, aspects and perspectives to highlight the research topic and to meet the purpose of the study (e.g. “what are your views on remote communication for people with communicative and cognitive disabilities in relation to self-determination and participation?”). At the end of each session, the focus group discussion was summarised, and the participants had the opportunity to comment and correct any misunderstandings. Directly after each session, the moderator and the observer had a reflection discussion. The focus groups and reflection discussions were audio recorded and transcribed verbatim.

4.4 DATA ANALYSIS

Qualitative analysis is the process of transforming massive amounts of research data into findings. This involves identifying significant patterns and constructing a framework for communicating the essence of what has emerged (85). Mixed methods research is characterised by the combination of at least one qualitative and one quantitative research component and takes advantage of using multiple angles to explore a research problem (100, 101).

Content analysis

The analysis was based on retrospective qualitative content theory (102, 103). Hsieh and Shannon (104) defined content analysis as “a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns” (p. 1278). Hsieh and Shannon (104) described three different approaches: conventional, directed and summative, which differ in how they are conducted. Study I used an approach that could be described as partly directed and partly conventional manifest content analysis. The researcher has to be aware of his or her own

pre-understanding and ensure there is a scientific approach throughout the process (105, 106).

The answers received by mail were added to the transcriptions for analysis. Initially, the researchers familiarised themselves with the material by listening to the recordings and reading the transcripts several times. Thereafter, the analysis began with texts being broken down into condensed phrases, sentences and meaning units. The content of the meaning units was further abstracted into codes. From there, categories were created, and the items were sorted into an inherent logical structure. Five categories and 13 subcategories were identified.

Mixed Method

Data collected in study II resulted in a large amount of material of scale-step-data from the pictures placed on the Talking Mats and rich qualitative material from the transcribed interviews. Mixed methods is a type of method in which one combines elements of both qualitative and quantitative research approaches (101). Study II was a qualitatively driven mixed-method study (100).

Descriptive analysis

The data collected by the placing of pictures with Talking Mats were analysed descriptively and resulted in ordinal scales.

Systematic text condensation

The participants' views, as expressed orally and with body communication and aids, in parallel with the placement of the pictures on the mat (88), were analysed with systematic text condensation. This analysis method, which was based on Giorgi's phenomenological analysis that was later modified by Malterud (107, 108). It has a descriptive approach fitting smaller samples that revealed the participants' own experiences, as expressed by themselves, and then condensed into meanings.

The analysis was carried out in four steps in order to: 1) establish an overall impression of the data and describe initial themes, 2) identify and organise the data into meaning units related to the phenomenon, 3) abstract and condense

the content and 4) synthesise and summarise the content into categories and subcategories representing different aspects of the participants' experiences of remote communication. Bracketing, which in summary is a process in which the researchers' suspends preconceptions, is important throughout the process (109). Analysis was carried out with consensus discussions between the researchers throughout the process.

Focus group analysis

The analysis process started with reflection discussions between the moderator and observer. Krueger's analysis guide for focus group discussions and the methodology for analysis described by Dahlin Ivanoff and Holmgren provided a frame of reference throughout the analysis process (94, 96). Analysis was carried out by the three researchers of the study, and the analysis started after the first focus group. This involved listening to the recordings and reading the transcripts several times to ensure that the inevitable loss of information and communication was reduced to a minimum. Throughout this first step of analysis, the raw data were used to understand the meaning of the whole material and to identify preliminary themes. In the second step of analysis, the raw data from all group discussions were sorted under preliminary themes. Then the data were sorted into categories under each theme. The researchers had consensus discussions to verify the themes and categories, and these discussions were held continually throughout the analysis process. In the third step of analysis, all the relevant raw material was sorted into themes and categories and descriptive summaries were created. The fourth and final step of analysis involved understanding and interpreting the material, which resulted in the development of the final themes and categories.

5 ETHICAL CONSIDERATIONS

Before data collection commenced, ethical approval was obtained. For studies I (Ref. No. 242-09) and II (Ref. No. 1024-13) approval was obtained from the regional ethical review board in Gothenburg, while, for studies III and IV (Ref. No. 2015/162-31), approval was obtained from the regional ethical review board in Linköping.

Both written and oral information about the research was given to the participants in all studies (I-IV). The information described the background and purpose of the research, how the study would be conducted, included a question if they would consent to participate in the study. The risks and advantages of the study were additionally described in detail. There was information about how confidentiality and personal data would be handled and who was responsible for the study should any questions or concerns arise. Participants were informed that their participation was voluntary and that they could withdraw from the study at any time without explanation, and withdrawing would not affect future treatment or care.

Study II involved participants with communicative and cognitive disabilities, which required extra ethical precautions. Information must be understandable, and the researcher had to ensure that participants have understood and could give truly informed consent (110). To ensure informed consent, information was adapted to make it easier to grasp. An information meeting with each participant was carried out prior to the interviews. Participants were given complementary written information in easy, plain written language with pictorial support. Oral information was given in person with thorough explanations and time for questions to be asked, adapted to each participant's preferred means of communication. The participants were accompanied by a support person that they chose that could help ensure the information was comprehended. To enable participation, ensure comprehension and gather data in a respectful way in the interviews, rigorous planning and adaptation of the interview was undertaken for study II (111). Before arriving for the interviews, participants were given comprehensive information sheets with pictorial support, describing the interview process in great detail to prepare them. Interviews also involved pictorial support, their preferred means of communication and a presence of a support person they chose. The participants chose the interview venue for them to feel as safe and relaxed as possible.

Efforts were made not to share information that could make participants recognisable in the presentation of the results. People with rare disorders could

be easily recognisable, especially in smaller countries; therefore, extra precautions regarding anonymity and confidentiality of the data were taken in all studies (I-IV). Recognisable details were removed from descriptions and citations as much as possible throughout the material. In the focus groups, participants were informed that they could choose how much they wanted to share in the discussions. They were also informed about the importance of confidentiality and that everything said in the group should be kept confidential by all participants.

6 FINDINGS

6.1 FINDINGS STUDY I

The findings from the interviews with professionals highlighted areas of importance to achieve user satisfaction with a smartphone and suggested that texting with picture symbols and speech synthesis (TMSS) could increase independence and participation in people with cognitive and communicative disabilities from the professionals' point of view.

There were three main areas of importance to achieve satisfaction with a smartphone for people with communicative and cognitive disabilities according to the professionals: *acceptance, functionality* and *usability* (see Figure 5). *Acceptance:* In order for the users to accept the smartphone, it had to live up to the user's expectations; he or she had to feel comfortable in using it in social situations and accept it as a natural part of daily life activities. *Functionality:* Technology needed to be functional for the users. It was important that the devices were easy to handle and that the speech synthesis was intelligible. *Usability:* Usability concerned how the devices were perceived to have met the needs of the user and how the devices could be part of a meaningful activity. Learning to use the device was viewed as important to be able to start using it, and this was an obstacle for some. Speech synthesis and functions for reading and writing support were indispensable features.

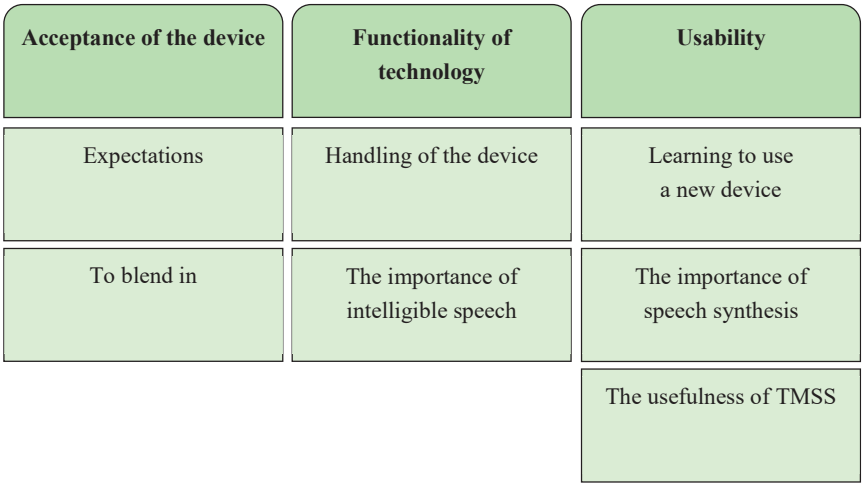


Figure 5. The professionals' views of the users' satisfaction with the devices.

The professionals' views of the users' participation concerned two main areas: *independence* and *interaction with other people* (see Figure 6). *Independence* was perceived to be related to the users making their own decisions and taking the initiative to participate through remote communication. When using remote communication, the users managed more things on their own. The professionals experienced that the users with cognitive and communicative disabilities felt safer in their daily life situations, which increased confidence and gradually led to more independence. *Interaction with other people* was important and was enabled by TMSS giving users sufficient time to express themselves. There were issues regarding the setup of the AAC system and findings showed that using TMSS was an opportunity to practice other aspects of communication.

Independence	**Interaction with other people**
To gain confidence	Using symbols for single words and whole phrases
To manage more things on one's own	To have enough time
To feel safe in daily life	To proceed to face to face communication

Figure 6. The professionals' views of the users' participation.

6.2 FINDINGS STUDY II

Three main categories emerged from people with communicative and cognitive disabilities' experiences: *to get through in one's own way, Own strategies to enable communication* and *technology not meeting needs*. These categories each consisted of three subcategories (see Figure 7).

To get through in one's own way: Being able to make oneself understood and get through with a message was described as important but difficult. Usual means of communication did not work and participants described how they felt not being heard. Support from assistants was regarded as both wanted and unwanted depending on the situation, and the participants wished to be able to

decide which situations to get support. For instance, in communication situations where personal integrity was important to them, they did not want as much assistance to ensure they had some privacy. Decisions regarding means of communication and human support related to the concept of self-determination. *Own strategies to enable communication:* Participants described several of their own communication strategies to manage remote communication. This could, for instance, be to adapt their communication to facilitate for the communication partner or prepare for future communication. Those who were able to used writing (e.g. chat or text messaging) as an alternative to problematic spoken remote communication (e.g. phone calls). *Technology not meeting needs:* There was a lack of access to useful technology and dependence on technology, meaning they were further vulnerable to changes in technology. Participants also expressed a need for training. Technology issues could lead to the abandonment of the technology altogether.

Ordinal scale data (Talking Mats answers by placing pictures on the scale steps) were presented descriptively (see Appendix).

To get through in one's own way	**Own strategies to enable communication**	**Technology not meeting needs**
Difficulties of making oneself understood	Facilitating for the communication partner	To choose not to use technology
Self-determination through independence	Making preparations	Dependence on technology causes problems
Self-determination through assistance	Using remote communication in writing instead of speech	Lack of useful assistive technology

Figure 7. People with communicative and cognitive disabilities' experiences with remote communication.

6.3 FINDINGS STUDY III

The analysis of the focus groups with support persons resulted in three themes: *the right to communicate, increased control in life through access to remote communication* and *challenges in responsibilities of support persons*. The main themes each consisted of three to four sub-categories (see Figure 8).

The right to communicate: The support persons saw how the communicative rights of the users were not being met. Participants described a need for better access to technology and information. They wished for better competency concerning remote communication among staff for the users with cognitive and communicative disabilities and coordination in professional efforts and interventions. The users needed ongoing individual training on remote communication. *Increased control in life through access to remote communication:* The participants experienced how remote communication could enhance self-determination and participation, and how this was important for the safety and security for people with communicative and cognitive disabilities. *Challenges in responsibilities of support persons:* There were challenges in the responsibilities of the support persons. There were feelings of concern, insecurity, frustration and insufficiency. Perceived risks regarding online safety led to ethical dilemmas for the support persons.

The right to communicate	Increased control in life through access to remote communication	Challenges in responsibilities of support persons
Access to technology that works	Self-determination in daily life	Risks and possibilities
Need for increased knowledge to provide support	Participation on equal terms	Nagging and motivating
Lifelong support to users	Independence and safety	Frustration and dedication
	To be like everyone else	

Figure 8. Support persons' experiences of remote communication for people with communicative and cognitive disabilities

6.4 FINDINGS STUDY IV

The analysis resulted in three themes: *use of standard technology, use of assistive technology* and *combining standard technology and assistive technology*, each of which encompassed categories describing aspects of technology that facilitated or impeded remote communication as well as suggestions for improvements (see Figure 9).

Use of standard technology: The findings showed the support persons' views on the importance of being able to use standard technology for remote communication for people with communicative and cognitive disabilities. Some functions of standard technology could facilitate independent remote communication, like video calls and asynchronous communication. However, others could be challenging in terms of understandability, compatibility and Internet access. *Use of assistive technology:* Assistive technology was important in enabling remote communication through compensating functions, for instance, in reading and writing support, but certain issues restricted the

opportunities. The participants discussed there was a need to further develop assistive technology. *Combining standard technology and assistive technology:* The findings suggested an importance of being able to combine standard technology and assistive technology in order to have access to remote communication, but the results also highlighted that there were technical limitations and that information must be available online. They felt remote communication technology must be made more accessible and easier to use for both people with disabilities and people in their networks. The findings included a detailed list of required technology development (see Appendix).

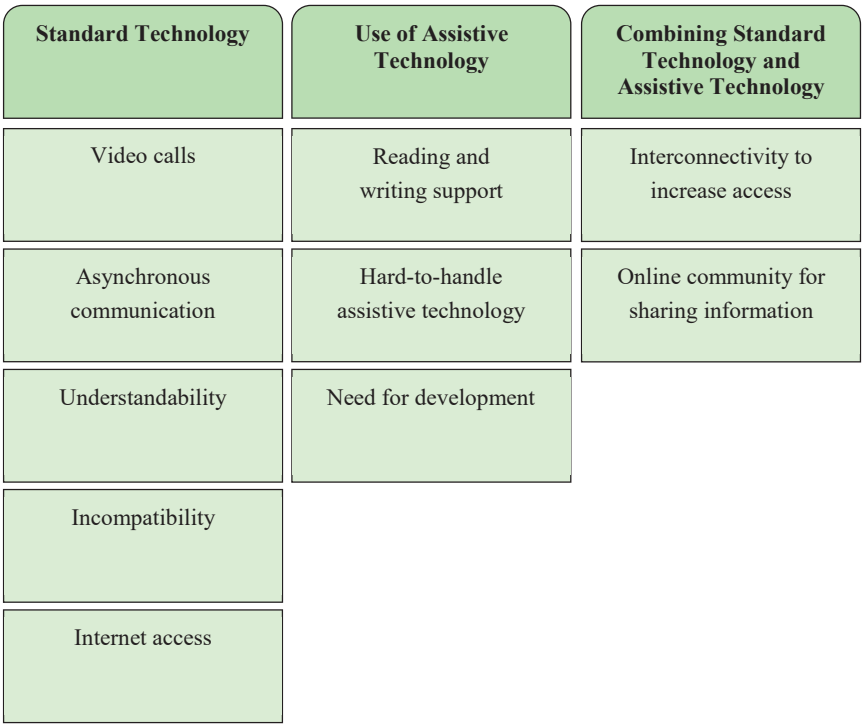


Figure 9. Support persons' views on benefits, challenges and suggestions for technology development of remote communication for people with disability.

7 DISCUSSION

The overall aim of this thesis was to explore and describe remote communication for people with communicative and cognitive disabilities with limited reading and writing abilities. The thesis explored remote communication from the perspectives of professionals, the people themselves and support persons (see Figure 10). The findings suggested how remote communication relates to self-determination and participation. The findings also highlighted needs in the areas of safety and security, access to technology and support.

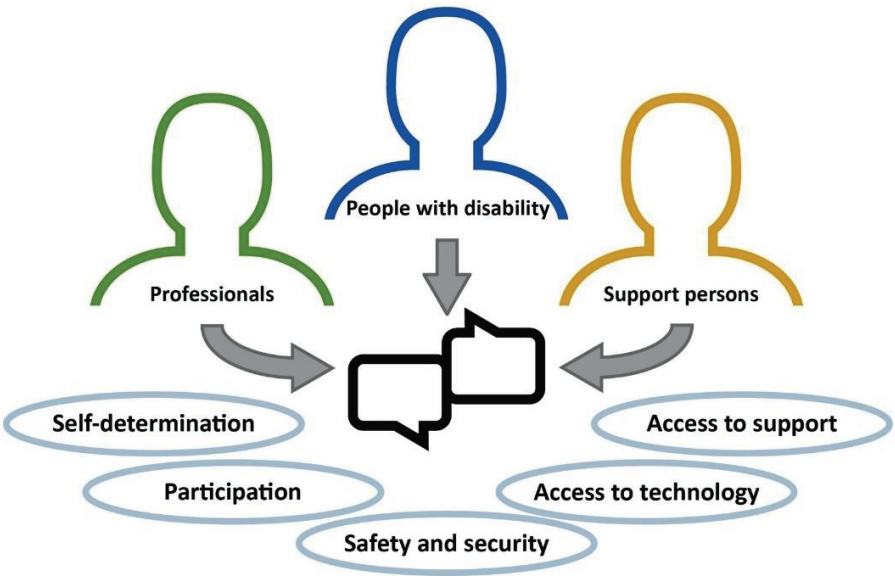


Figure 10. The figure shows the three different perspectives on remote communication for people with communicative and cognitive disabilities in this thesis.

To achieve occupational justice and communication rights, there are several prerequisites that need to be present. Digital participation, resulting in self-determination and participation, is one aspect of achieving occupational justice (112). Having safety and security, access to technology and the necessary support are important in order to be able to engage everyone in remote communication, which in turn will help and fulfil communication rights (33-35).

7.1 SELF-DETERMINATION

The findings of this thesis showed how the use of remote communication related to engagement and self-determination. Engaging in remote communication could result in increased control over one's own life because it allowed people to make their own decisions on how they interact with others and had control over their own social network. To have self-determination, as in the power to decide in occupation, is important to achieve occupational justice (23).

According to the findings of this thesis, making one's own appointments was important and could be achieved in two manners: independently by using remote communication or by having assistance. Research has shown how people with disabilities have structural barriers to healthcare due to problems in booking appointments and transportation (113, 114). According to the participants with disabilities, having control over the communication, especially in situations where personal integrity mattered, was important for self-determination. This involved the user having a choice of whether to be independent or not in remote communication and determine how assistance was received. The experienced importance of self-determination and privacy was in line with previous research (56). Having control over one's remote communication is an important step in gaining confidence towards independence (60).

The thesis' findings also showed how users actively adapted to the situation to facilitate communication and made preparations for the remote communication to work. They took a large part of the responsibility to ensure the remote communication worked largely because they had the practical knowledge about what would work. These are responsibilities that should be shared with the communication partner, but they seem to fall mostly to the people with cognitive and communicative disabilities. This should be taken into account and allow the users themselves to have an active role in assessments and choice of remote communication technology. Their experiences and strategies should be taken into consideration to facilitate them receiving better working remote communication of their own choosing (77).

According to the findings of the studies I-III, remote communication could compensate for physical, cognitive and social limitations, for instance, with virtual meetings. This finding was in line with other research (6, 115). Compensatory measures could increase occupational performance (23). Professionals who work with people with communicative and cognitive

disabilities should, therefore, include access to remote communication in assessments and interventions.

7.2 PARTICIPATION

The findings of this thesis showed how the use of remote communication was also related to participation in daily activities and in society. Well-functioning remote communication was reported to increase participation. Having access to remote communication could help people participate in social networks and engage in interests and meaningful activities. These are a means to occupational justice.

Having a broader social network than only family was important, and without this, participation in daily life and society was more limited. According to study II and III results, not being understood was a problem that limited social interactions. Caron has shown the importance of being able to use remote communication on social media to expand the amount of contact for people who use AAC (116). Not being understood in remote communication could be explained in part by the communication disabilities but also by not having access to assistive technology and not having a listening and respectful communication partner. A Talking Mats study interviewing AAC users on what communication strategies they wanted their communication partners to use showed that communication partners needed to take initiatives, repair communication breakdowns and have patience in understanding what AAC users wanted to express (117). Communication partners need to take the time and make the needed effort to enable remote communication with people with communicative and cognitive disabilities.

Using mainstream technology could help users to expand their interests, blend in and also gain status for possessing and using popular technology. Access to remote communication technology seemed to enable participation on more equal terms according to the findings from studies I-III. It was described as important to look or seem like everyone else by being able to use mainstream looking technology. The findings showed how it was important to be able to participate in online activities and choose their own online persona, including deciding whether or not to reveal their disability. This is in line with research showing that occupation played an important role in relation to the concept of self, and interacting with the environment had an impact on social identity (15, 16, 21). In order to manage using social media, it is important to be able to handle text-based communication. The findings of this thesis showed that the communication partner did not see whether the person used assistive technology (like AAC-software or writing support) or not. Communication

partners only saw the result (i.e. the final message) and not the process used to create it, and then the person with a disability could participate on his or her own terms.

Access to remote communication could enable participation in meaningful occupations, for instance, engaging in gaming or social media, according to the findings of this thesis, which aligns with previous research (118). Findings from studies I-III demonstrated that it was not necessary that the activity was carried out independently to be meaningful. This was also found by Caron that described how only watching content on social media had benefits in participation and even despite minimal interaction, it allowed connection with the world for people experiencing online barriers (116). In their study, a framework in five steps from low to high levels of engagement (119) was used to show how interactions on all levels were important for participation. It is important to be aware that even limited use of social media can be very valuable for users with disabilities, and we should not only compare their Internet use with mainstream users.

7.3 SAFETY AND SECURITY

According to the findings in the studies I-III, remote communication could affect users' security in different ways. On one hand, access to remote communication could increase safety and security by increasing the ability to contact someone when needing help or support. However, using the Internet and social media could also mean taking risks due to online safety issues.

There were several aspects of increased safety and security. In study I and III, independent remote communication was perceived to enable users to manage more things independently in society or to stay home alone. Being able to call for assistance was described as increasing and developing the users' confidence and independence. Feeling safe is a basic need. It is necessary to be adventurous, develop new skills and take part in new life areas, thereby increasing self-determination and participation (28).

Access to remote communication was necessary to be able to make emergency calls in case of danger. The findings of study II showed how people with communicative and cognitive disabilities did not think that it worked well to call for help. Even if possible, it was doubtful that emergency personnel would know how to communicate with the person calling (120). Safety was also to be able to call for assistance or advice from family and staff when necessary. There is a need for more knowledge concerning how adults with disabilities could use remote communication to better interact with healthcare

professionals (74, 113, 114). It is important that professionals acknowledge that if a person with a disability ever spends time on their own, it must be ensured that he or she can call for help independently to be safe, which is a basic human right (33).

From the support persons' perspectives, the subject of safety had both advantages and disadvantages. Support persons described how they strived for increased self-determination and participation for their users and encouraged them to use different means of remote communication, but they experienced how using the Internet and social media could cause harm. Online safety is an issue for everyone today, and people with communicative and cognitive disabilities face risks when using remote communication on their own. Sallafranque and Normand (115) have described how people with intellectual disabilities or autism spectrum disorders were insulted, mocked or threatened online, and the participants had experienced unwanted sexual solicitation. They also had agreed to meet Internet acquaintances alone in real life, potentially putting themselves at risk for assault or other forms of victimization. Sorbring, Molin and Löfgren-Mårtenson (121) have described how parents of intellectually challenged young people were worried that their children were in danger of unwelcome content and interactions on the Internet. However, research has shown that in spite of the online risks, the users gained increased self-determination and social contacts, maintained long-distance relationships and received social support through Internet use (115). Study III showed that support persons who care for users could provide safety and help the users to identify online risks. The drawback is that support persons themselves can become a barrier to Internet access, self-determination and participation for the users when trying to protect them from any potential online risks (80). There have been several studies dealing with the problem of balancing between safety and self-determination. Seale (122) and Seale and Chadwick (123) have described how the potential of positive risk-taking can be a useful conceptual framework to find the right level of support. A study by Grace et al. (124) involved five youths who had communication difficulties, physical disability and limited literacy skills in an intervention programme to learn to use the Internet to connect with others. They reported concern on the part of the parents, but their results showed that participants could learn to use the Internet for remote communication while being safe online. Seale and Chadwick (123) demonstrated how people providing support to adolescents and adults with intellectual and developmental disabilities negotiated and handled risks online. They found that normal life means to be digitally included, which involves taking risks and exercising the same human rights as others and they proposed a framework of a positive risk-taking involving support persons. These findings are important and can lead the way to

increased knowledge on how support persons can help users handle online risks without interfering with their participation and self-determination. The findings of study III highlighted the importance of more knowledge on the topic of safety and security among professionals.

7.4 ACCESS TO TECHNOLOGY

An important, and perhaps not surprising, finding from this thesis was that access to technology was perceived as crucial for being able to use remote communication, supporting other research (39, 125). According to the findings of this thesis, communicational rights of people with communicative and cognitive disabilities were not met due to limitations in service delivery, technology as well as economic reasons, resulting in occupational injustice.

Findings in study III indicated limitations in service delivery. People with communicative and cognitive disabilities needed individually assessed and adapted technology. According to the support persons, there seemed to be a lack of professionals acknowledging this and including remote communication in assessments and interventions. Another issue was how technology for remote communication was provided. In Sweden, AAC-systems can be prescribed by occupational therapists and speech language pathologists free of cost for those who need it (69). If the device is considered everyday-technology (e.g. tablets and smartphones), the user may need to buy it at his or her own cost, but regulations differ regionally. There seemed to be uncertainties around what could be provided by professionals as well as gaps between assistive- and everyday-technology that became an obstacle in accessing remote communication. It was hard for the users to find suitable devices on their own. A systematic review by Larsson Ranada and Lidström showed how satisfaction with the service delivery process as a whole was related to the satisfaction with and usability of assistive technology (68). It is of interest then to further explore how the provision systems work regarding remote communication in daily life for the users.

Findings of this thesis showed how people with communicative and cognitive disabilities needed technology that is functional, useful, reliable and up to date. In study II, a user said, when talking about smartphones and the need for alternative access to be able to use it: *"Then it will probably be like with everything else, a big damned thing that becomes difficult to bring with me, and then to hell with it!"*. This is a colourful illustration of technology not meeting the users' needs and how that can lead to abandonment of assistive technology and subsequently decreased participation. It is an occupational right to participate in occupations of one's own choosing and to have access to

the necessary technology to do so (32). Larsson Ranada and Lidström have highlighted the importance of a client centred approach achieving the desired goals of participation in everyday activities in relation to satisfaction with assistive technology (68).

This thesis demonstrated how depending on specific technology for remote communication in daily life can be problematic. An example of this was a device for adapted texting that was used in study I. Although potentially useful for people with communicative and cognitive disabilities, it disappeared from the market due to changes in technology development. Today, there is no equivalent product, and it is missed by former users. Another example of this was a participant in study II who depended on software developed in a project for remote communication, but at the end of the project, the software was no longer available. One solution to this problem could be to base software for AAC-users on open source code that was carried out in an EU project (126). Making this standard could resolve problems when a manufacturer decides to take a product out of production because someone else could take over to develop and distribute the software.

Cost can be a factor limiting access to remote communication if the user must purchase technology themselves as was shown in study III. Even with provided devices and applications, there were still costs for the Internet and mobile subscriptions. People with communicative and cognitive problems often have low or no income, which can inhibit access to remote communication for a group that already experiences obstacles in communication (127). These findings are in line with Jaegers description of a digital divide for people with disabilities (6). Consequences of not being able to afford technology or services must be taken into account in guidelines for technology delivery and assessments involving the target group. Swedish Internet statistics (5) did not include the target group of this study (11). Limitations in Internet access are documented (10), but the extent of lack of access is not known. The suggestion of free Wi-Fi in all environments where people with communicative and cognitive disabilities spend their time could, to some extent, equalize the digital divide. If the goal is equal access to communication for all, the issue of costs must be considered.

According to the findings of this thesis technology must be easy to handle, and the findings from studies II-IV showed how this was not the case. There were issues with handling touch screens and a lack of alternate access, leading to communication limitations. Technology was described as too complicated to use for both people with communicative and cognitive disabilities and support persons. When the supporters cannot help, what can the users do? Difficulties

in handling remote communication technology have been described in other research (12, 76, 84). The new standard for web accessibility can perhaps solve some of these issues (128).

The lack of interconnectivity shown in study IV complicated the use of technology. Switching between applications and specific devices in the way that is necessary in mobile technology today was difficult for people with communicative and cognitive disabilities. The importance of interconnectivity has also been shown in other research (42, 54). It is of utmost importance to enable interconnectivity between technology for AAC and remote communication to make remote communication accessible for those who use AAC-technology.

One beneficial function is speech synthesis. In study I, II and IV, it was described as a major prerequisite for constructing and reading messages that should be available in all remote communication applications in line with previous research (87). Speech synthesis has gone from expensive assistive technology to a standard function in off-the-shelf devices, on webpages and in standard software and is today aiming for a more natural and personalised voice (129). Hopefully this development can increase access to speech synthesis for those who need it.

Another beneficial function found in study IV was video calls. This was an example of easy to handle universal design that worked in favour of all users. The possibility of involving many visual means of AAC and body communication seemed to stimulate remote communication as others have found (13). Even though video calls made it possible to incorporate means of AAC, it was not always easy to include communication boards or assistive devices or applications. Solutions for using different camera angles for AAC would be useful.

According to the findings of this thesis, there were also benefits in asynchronous communication in relation to the fact that producing messages using communication aids could be lengthy (58). The person with a disability does not have to be fast to be listened to and the final message did not show the real amount of time and energy spent to produce it. Due to these benefits, communication with other people can be equalized. Advantages in asynchronous communication should be considered in further development of remote communication technology and in communication assessments and interventions for people with communicative and cognitive difficulties. Research has shown the importance of participating in social media and how different platforms differ in accessibility and ease to use (74). An evaluation

of Australian e-health service showed major limitations in access for people who could not read or write (130). Therefore, support for reading and writing should be included when developing AAC-systems.

7.5 ACCESS TO SUPPORT

It is important for professionals to re-evaluate their responsibilities for support to users and their network. In study I, the professionals suggested that there should be improved teamwork between speech language pathologists and occupational therapists. Research has shown that a lack of support and insufficient training to those with cognitive and communicative difficulties led to the abandonment and/or underutilisation of assistive technology (68). In a survey with families of children with communication disabilities, wants and preferences related to mobile media technology were explored (75). The families expressed a need for more information and support from professionals. There was also a need for better coordination of services to enable remote communication for people with communicative and cognitive disabilities. The findings of this thesis demonstrated that access to support was an important factor in gaining access to remote communication and meaningful occupations.

Research has shown that training and support to people with communicative and cognitive disabilities need to be individually adapted to the users' daily activities (58). The support persons pointed out that support to people with communicative and cognitive disabilities is a lifelong process. People with communicative and cognitive disabilities may hesitate to try new, unfamiliar technology, and encouragement from their support network were important to try new technology. This was also described by Raghavendra et.al. (76) who found that digital skills in family and friends influenced the users' online communication. It is necessary to approach and support users in their use of remote communication in a systematic way (116).

The findings of study III showed how there were challenges for support persons in having the necessary technology competence, as they take a large portion of the responsibility for the users' remote communication. Support persons also need support for themselves to be able to work with independent remote communication, self-determination and participation for their users (42, 75). In an intervention study by Grace et al. (124), youths with complex communication needs received training in using social media, and the findings showed that performance and satisfaction among the participants increased in terms of Internet use for social contacts. People with disabilities as well as communication partners need intensive support and technical assistance (131).

This is in line with our support persons' call for increased competency of the support network in study III in order for them to be able to help the users.

Findings in study III also pointed to a lack of support from professionals and a non-existent coordination of services. The support persons expressed a lack of trust in support functions in society, which were described as insufficient. These findings add to the knowledge of a study among speech language pathologists in Sweden, which showed how they had very few training sessions involving the network of people with disabilities (131). The support persons in study III suggested a new professional role, an IT therapist, to take over the responsibility of the present professionals in dealing with access to remote communication.

8 METHODOLOGICAL CONSIDERATIONS

This thesis is mainly based on qualitative studies, including a mixed-method study with a qualitative focus. The purpose of using a qualitative approach was to be able to explore a mostly unexplored research area and find and describe its meaning. The qualitative approach proved to be useful to explore experiences with remote communication for people with communicative and cognitive disabilities.

Qualitative research is important for building knowledge, but the research must be trustworthy and of high quality (132, 133). To ensure trustworthiness in a study, several aspects have to be taken into account. In qualitative research, one might not want to use the regular positivistic criteria for trustworthiness (e.g. internal validity, external validity or generalisability, reliability and objectivity), but use the criteria credibility, transferability, dependability and *confirmability*. *Credibility*, in preference to internal validity, is described by Patton as depending on rigorous methods, *credibility* of the researcher and quality of the method and analyses (85). *Transferability*, in preference to external validity or generalisability, means how the results can be useful to others in similar situations. *Dependability*, in preference to reliability, deals with how the researcher handles the changing conditions in a studied phenomenon and how the design is altered accordingly. *Confirmability*, in preference to objectivity, deals with the logical interpretations and the path of analysis. In qualitative research, one cannot argue for objectivity because every analysis and interpretation will have a trace of the paradigm of the researcher (134).

8.1 TARGET GROUP AND STUDY POPULATION

When conducting research on topics involving people with disabilities, it is of the utmost importance to let the experiences of the people themselves come through. People with communicative and cognitive disabilities are often excluded from research due to their difficulties in participating in surveys, focus groups or common interviews (135, 136). In order to develop the understanding of remote communication for people with communicative and cognitive disabilities, obtaining the experiences from the target group themselves was the most crucial to obtain. To enable participation for people with communicative and cognitive difficulties, information must be understandable, and the researcher must take precautions to make sure that participants have understood and that their informed consent builds on their

understanding (110, 111). The participation of the target group themselves in study II was very valuable. However, people with communicative and cognitive disabilities may not have much experience of remote communication and can, therefore, have difficulties in discussing future needs of development. In order to get a more holistic picture of remote communication for people with communicative and cognitive disabilities, a broader group of participants was included in this thesis. Including support persons' and professionals' perspectives were important to further understand the needs of the target group and factors that could enable self-determination and participation.

Study I explored the professionals' views on TMSS. A previous study (87), not included in this thesis, described important perspectives of the users themselves (58, 83), and those findings corresponded to and strengthened the findings of study I (87). Support persons' experiences of meeting people with disabilities in daily life were also important to gather. Their perspective on remote communication for people with communicative and cognitive disabilities in study III and IV was a valuable complement to the previous studies. They assist users in communication on a daily basis and see details while at the same time, they have an outsider perspective and can reflect on remote communication on a more advanced level, which is a strength of study III and IV.

The participants were homogeneous in terms of the experiences of remote communication, but they were also recruited to represent a variation of age, gender, language and culture where possible to ensure *transferability* (studies II-IV). In the focus groups studies (III and IV), the groups were homogeneous in regard to the topic and heterogeneous to ensure discussions from a variety of perspectives were obtained (95, 96). In planning the groups, variation in regard to experiences of users in different situations as well as among the participants themselves in regard to roles, age and gender in each group was sought. In study III and IV, these were possible to achieve except for gender. The study had an overrepresentation of female participants, which was a limitation that was hard to address. The combination of the three perspectives (people with disabilities, professionals and support persons) in combination with the aims on heterogeneity expanded on previous knowledge and established *credibility* and *transferability*, which is a strength of this research.

Sample size relates to *credibility* due to its possible effect on the amount of data collected. The sample size in study I was limited, as all seven participants from the intervention project were involved in the study. The data collection generated rich material despite the limited number of participants. Sandelowski argued that there was no exemplary sample size, and that sample

size had to be evaluated in relation to the quality of the collected information, methodology and intention of the results (137).

8.2 DESIGN

Semi-structured interviews including content analysis and systematic text condensation

The studies involving semi-structured interviews (I and II) followed the recommended method throughout the studies to ensure *credibility* (85). The interviews were structured with areas and a topic guide and had open questions that enabled narrative answers to establish as much high-quality data as possible. Follow-up questions were used to ensure that all participants were able to explain what they fully meant. This strategy was used throughout all of the studies (I-IV) for *dependability*.

Using content analysis does not mean that the interviews were free from biased interpretation, as all research reflects the paradigm of the researcher, which can affect *confirmability* (85). A disadvantage can be that preconceptions inhibit supplementary questions, and the researcher has an implicit understanding, which limits the richness of the data. Additionally, the researcher's paradigm may lead him or her to interpret information in a way that is in line with their existing preconceptions. Throughout the studies, there was strict methodological adherence, and there was an attempt to bracket those preconceptions. There was a constant awareness of the pre-understanding and the need for self-reflection and self-awareness. As the co-researchers of the studies were not from the same professional discipline, this helped the bracketing in the analysis.

In study I, the researchers also led the intervention project. The researchers were aware of this limitation and, thus, tried to bridle pre-understanding and focus on self-reflection and self-awareness (138, 139). The interviewed professionals had taken an active part in the intervention themselves. On one hand, this allowed them to have detailed knowledge about the users' situations. However, it also may have biased them towards a more positive view on the effects of the intervention, meaning interpretation of the findings needs some caution.

Study II used a systematic text condensation in the analyses of the interview data (107, 108). Its descriptive approach fitted the smaller sample size of the study. To ensure *confirmability*, which deals with the logical interpretations

and the path of analysis, and *dependability*, which deals with the findings consistent with the raw data, the systematic text condensation strategy was followed carefully between the researchers (85, 107, 140). All translations by support persons had to be verified prior to their use in the analysis to ensure that they were the participants' true views that were collected. Support persons were instructed not to give their own opinions in the interviews, but, on several occasions, they started to explain the participants' answers. All other talk than that expressed by the participants was excluded from analysis, but the presence of another person in the room inevitably affected the interview as well as the participant at least to some extent. Being a qualitative study, the researchers cannot argue for objectivity because every analysis and interpretation will have a trace of the paradigm of the researcher (134). The advantage of systematic text condensation was the approach fitted the aim of this research and the data, while, at the same time, offering a more concrete and useful strategy while analysing the interview data. Malterud (107) indicated benefits, such as keeping an overview of the data, to limit the hazard of fragmentation when using systematic text condensation with a limited number of participants. This provided trustworthiness for the study.

Talking Mats

It is ethically questionable to draw conclusions about a group if efforts are not made in letting their voices be heard, but people with communicative and cognitive disabilities are often excluded from research (135, 136). When designing studies, the researchers may not have the knowledge or necessary recourses to adapt the data collection to ensure the views of everyone in the target group get collected (79, 83). Talking Mats has been shown to be an important and reliable tool in order to gather the views of people with communicative and cognitive disabilities (91, 117, 141, 142). To enable participation for people that rarely participate in interview studies due to their communication challenges, ensuring comprehension and gathering as much data as possible, rigorous planning and interview adaptation was undertaken. Using Talking Mats appeared to stimulate reasoning among participants who explained and gave practical examples when answering with the mat, which is in line with the results of previous research (90, 91). Recollecting previous answers on the final mat seemed to add to the participants' reflection. The results represented the experiences of the participants as expressed by themselves, but they do not cover the full range of potential views on remote communication.

The study also has limitations regarding the participants' comprehension. The method included asking if the person wanted to add something, but this was cognitively difficult for some to do, and, thus, individual topics might have been omitted. Interview questions were precise and created beforehand. Even though thorough work was carried out to cover a topic as much as possible, there is still a possibility that experiences might have been excluded. Using Talking Mats involves several steps and regular member checking. A practice mat was created prior to a mat on a specific issue and follow up questions were asked. At the end, the mat was summarised and the individual's placement of pictures under different symbols in the visual scale could be changed. The descriptive scale step answers varied, and there were no obvious connections between diagnosis, age or means of communication in relation to the answers. Using Talking Mats is a compromise in qualitative research because the interviews have to be structured and questions defined and illustrated with pictures. There was also a risk of misunderstanding and misinterpreting or that the presence of a support person could have influenced the participants' answers. To ensure *credibility*, procedures were rigorously designed and followed. They were described in detail to enable *transferability* and *dependability*. This study reported the views and experiences of a target group who rarely participate in qualitative research, and, in this sense, the findings are important and unique.

As an experienced clinician and specialist in the field including the topic of the research, there were preconceptions that need to be considered. An advantage was the experience of interacting and communicating with people with communicative and cognitive disabilities. This included understanding what support they needed in order to participate in research interviews, how to present information and questions in order for them to be understood and also interpreting their different means on communication. This was probably a prerequisite for the interviews with the target group to take place and for them to result in as much data as they did.

The Talking Mats procedure was developed based on the experiences from previous projects, but, in future studies, an advance could be to increase involvement of the target group in the design process, which was shown to be successful in recent research (141).

Mixed method

Study II involved a mixed method design due to the qualitative interview as well as scale step answers of pictures placed on the Talking Mats data that were

collected (143). Due to the study's qualitative approach, it can be defined as a qualitatively driven mixed method study (100). The ordinal scale data were analysed separately. The sample size was too small to generate advanced statistical analyses other than descriptive (144). In a study with a larger sample size, it would be interesting to use mixed method and analyse data further with triangulation (100, 101).

Focus group method and analysis

The focus group method was useful for studies III and IV, and previous research has found it to be a suitable method when conducting research involving people with disabilities and their interaction with technology (145-147). However, there are limitations of the focus group method. It can be difficult to involve all participants in the discussion, and there can be an imbalance in the discussions due to group dynamics or hesitation in fully actively participating since confidentiality cannot be completely guaranteed. To overcome these limitations, the moderator must be a skilled group leader (96, 97). Great effort was made to empower the participants and create a safe, relaxed and fruitful environment that facilitated exploration and expression of experiences and ideas. This was successful in the sense that all focus group discussions were rich and dynamic, resulting in a comprehensive body of material. Face legitimacy was ensured during the discussions in which participants confirmed and opposed each other's views, which strengthened the validity of the findings.

It is described as an advantage when the moderator and the researcher is the same person due to insight into the project and collected data (94, 95). This was a strength of study III and IV, allowing analysis to start immediately without first having to get to know and understand the material. All focus groups were immediately evaluated after each session by the first and the last author of study III to ensure legitimacy, and all sessions were run to create an in-depth discussion on the subject. All three researchers of study III and IV were involved throughout the process, and adherence to methodology was ensured throughout for *confirmability*. Analysis was also presented and discussed in a university seminar with researchers and skilled professionals. In order to achieve *transferability*, findings were presented as expressively as possible (as the research paper format allows) in themes and categories with illustrational quotes.

Due to its qualitative approach, this thesis cannot correlate certain experiences or views regarding age, diagnoses, family situation or other factors. People

with communicative and cognitive disabilities have different abilities and experiences of remote communication. Even in a seemingly homogeneous group, life situations and the amount of available support differ.

9 CONCLUSION

The overall aim of this thesis was to explore and describe remote communication for people with communicative and cognitive disabilities with limited reading and writing abilities. The thesis explored remote communication from the perspectives of the people themselves, professionals and support persons. The findings showed how remote communication related to self-determination and participation. The findings also pointed out the needs in the areas of safety and security, access and support.

Access to remote communication is crucial for participation in today's society where an increasing part of human interaction is carried out through digital channels. Using remote communication can increase independence, self-determination and participation in daily life for people with communicative and cognitive disabilities. Moreover, it can also increase safety.

Communication is a human right and must be available for all. The following points are necessary to make remote communication accessible for people with communicative and cognitive disabilities:

- Increased access to appropriate technology, including devices, applications and services.
- Improvements in technology.
- Accessible and easy to use technology. It must be reliable and possible to use without disturbances.
- More individualised adaptions and settings.
- Assistive technology possible to combine with mainstream technology for remote communication.
- Supporting people with communicative and cognitive disabilities to be able to use remote communication.
- Improving information, training and support for support persons.

10 FUTURE IMPLICATIONS

Future research should continue to involve people with communicative and cognitive disabilities and focus on how technology can be more easily accessed by those who could highly benefit from it yet currently struggle with it. New statistics on access to remote communication in society must also include people with communicative and cognitive disabilities, and there is a need for future studies involving this target group. There are other people with conditions, such as psychiatric disorders, who may also experience limitations with remote communication, and the current research could be used as a springboard for research on enabling remote communication for them.

There is a need to develop general standards to ensure remote communication can be successful even when different kinds of technology are being used. Mainstream technology developers should consider how to create devices and applications that are easy to learn without an overload of functions to navigate through while still providing enough options for individualised use. To ensure technology suits the needs of people with communicative and cognitive disabilities, people from this target group should be involved in research and development. There is a need for further detailed studies on how to increase smartphone and tablet accessibility through universal design. Well-functioning technology applications, for instance, applications for video calls, could be used as examples of good universal design supporting independent communication. These could serve as an inspiration in the development of other remote communication applications.

Assistive technology needs to keep up with mainstream technology development and should focus on interconnectivity, the possibility to combine supportive functions and developing applications to facilitate use. One interesting area would be to develop and evaluate software for AAC with speech synthesis connected to video calls. This is something that is not available today, but it could provide smoother combinations of writing in text and symbols, speech synthesis and video calls. According to the findings of this thesis, combining features of technology is complicated so this could be an important enhancement of remote communication for people with communicative and cognitive disabilities.

A health-related and low researched topic is how it works to call for help in emergency situations for people with communicative and cognitive disabilities. What options are there, how are they used and are there needs for development of technology and services? Another, also health-related, topic is

how society can make sure that every citizen has access to the fast-developing e-health services that are projected to be a large part of the future health services. The findings of this thesis suggest people with disabilities may encounter difficulties in accessing these services. Research working with this target group is very sparse, and studies are necessary to make sure that health services are available for everyone.

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APPENDIX

Study II. Ordinal scale data from Talking Mats answers by placing pictures on the scale steps

Table 1. Communicative functions and situations

				N11		*N**
How does it work to … when using remote communication?	Good	In-between	Bad	Do not use	Answers important	
Speak	5	3	3	0	5	6
Start a conversation	5	2	4	0	4	6
End a conversation	8	1	2	0	2	3
Talk one to one	9	2	0	0	2	2
Talk in a group	2	0	1	8	3	9
Participate in meetings	1	0	0	10	3	10
Find out what to say	6	3	2	0	5	5
Articulate words	1	1	7	2	7	10
Spell	6	2	2	1	2	5
Write on a computer	5	4	1	1	3	6
Read on a computer	6	3	2	0	3	5
Use a communication book	3	0	1	7	4	8

Note. *N refers to how many that were asked about how important the activity was = those who did not answer “good”.

Table 2. Reasons for remote communication

				N11		*N**
How does it work to use remote communication to…?	Good	In-between	Bad	Do not use	Answers important	
Ask something	6	2	1	2	5	5
Urge someone	5	2	1	3	5	6
Make plans	8	2	0	1	3	3
Solve problems	7	1	2	1	3	4
Make decisions	6	2	1	2	2	5
Arrange appointments	8	2	1	0	2	3
Smalltalk	7	2	1	1	2	4
Tell something	7	3	1	0	4	4
Contact someone	9	1	0	1	2	2
Book appointments	5	0	2	4	3	6
Buy something	3	0	1	7	1	6**
Ask for help	3	4	0	4	6	8
Help someone else	8	1	1	1	1	3
Keep in touch	9	1	1	0	2	2
Get information	9	1	1	0	2	2
Play games	2	0	1	8	3	9
Share pictures	5	0	1	5	4	6

Note. *N refers to how many that were asked about how important the activity was = those who did not answer "good". ** 2 persons were under-aged and were not asked this question.

Table 3. Services, applications and devices

				N11		*N**
How does it work to use … for remote communication?	Good	In-between	Bad	Do not use	Answers important	
A phone with a landline	3	0	1	7	1	8
A cordless phone	3	2	1	5	2	8
A cellphone with buttons	3	0	0	8	0	8
A smartphone	4	1	2	4	3	7
A tablet	6	0	0	5	1	5
A desktop computer	5	0	0	6	0	6
A laptop	2	2	0	7	3	9
E-mail	9	1	0	1	2	2
Text messaging	4	4	1	2	3	7
Video call	2	0	2	7	2	9
Chat	6	0	0	5	0	5
Facebook	7	0	1	3	0	4
Twitter[4]	1	1	0	9	0	10
Instagram[5]	3	0	0	8	2	8

Note. *N refers to how many that were asked about how important the activity was = those who did not answer “good”.

Study IV. List of required technology development

Table 4. Support persons' suggestions for the development of remote communication technology meeting the needs of people with communicative and cognitive difficulties.

Standard Technology	
General aspects	All-in-one devices so there is less technology to handle
	More opportunities for individualization
	Internet of Things to reduce the need for human support
	General standard so that all platforms can communicate
	Better reliability of technology
	Free Wi-Fi everywhere
Access to standard-technology devices	Tablets and smartphones that are more accessible for people with cognitive problems and limited literacy
	Availability of simpler phones with only basic, necessary functions
	Better sound quality in phones during calls
	Easier access to smartphones, tablets, and websites
	Easy-to-navigate systems: more intelligible organization of choices on the screen with a good overview
	Easy-to-understand organization of applications in devices
	Texting available for symbol users
Access to websites, services, and applications	Better accessibility for those with cognitive problems and limited literacy
	Availability of more limited, easy-to-use interfaces
	Fewer pop-ups and notifications
	Easier to choose and use symbols and emojis
	Availability of information about the meaning of an emoji
	Better designed, uncluttered interfaces (objects, colors, order)
	Smooth reading with text-to-speech in all environments
	Fewer dialog boxes
	Easier to get back to where you started in all environments
	Symbol databases in standard devices (along with emojis and other graphic symbols)
Alternative access	Standard devices such as tablets and smartphones should be possible to combine with devices for alternative access
	Websites must be made accessible for assistive technology
	Several camera angles in video calls to involve low-tech AAC
	Touchscreens that can be operated with a laser pointer

Assistive Technology	
General aspects	Better bridges between assistive technology and standard technology
	Assistive technology must enable Internet use
	Inclusion of common standard-technology features, such as buttons for sharing to social media, email, or messaging
	Assistive technology to build on open-source code
	AAC software available on standard platforms
	Easy-to-handle AAC software
AAC and remote communication	Easier inclusion of AAC and symbols in remote communication
	Seamless switching between using text and symbols
	"Premade vocabulary" for remote communication
	Faster production of messages
	Symbols and text-to-speech in texting, messaging, and Internet chatting
	Message history in texting, messaging, and Internet chatting
	Video calls using AAC software with text-to-speech
Alternative access	Technology capable of interpreting all user signals in communication in the same way as close family members do
	Settings that can easily be adapted to suit changes in day-to-day circumstances (i.e., whether the person is having a "good day", a "bad day," or something in between)