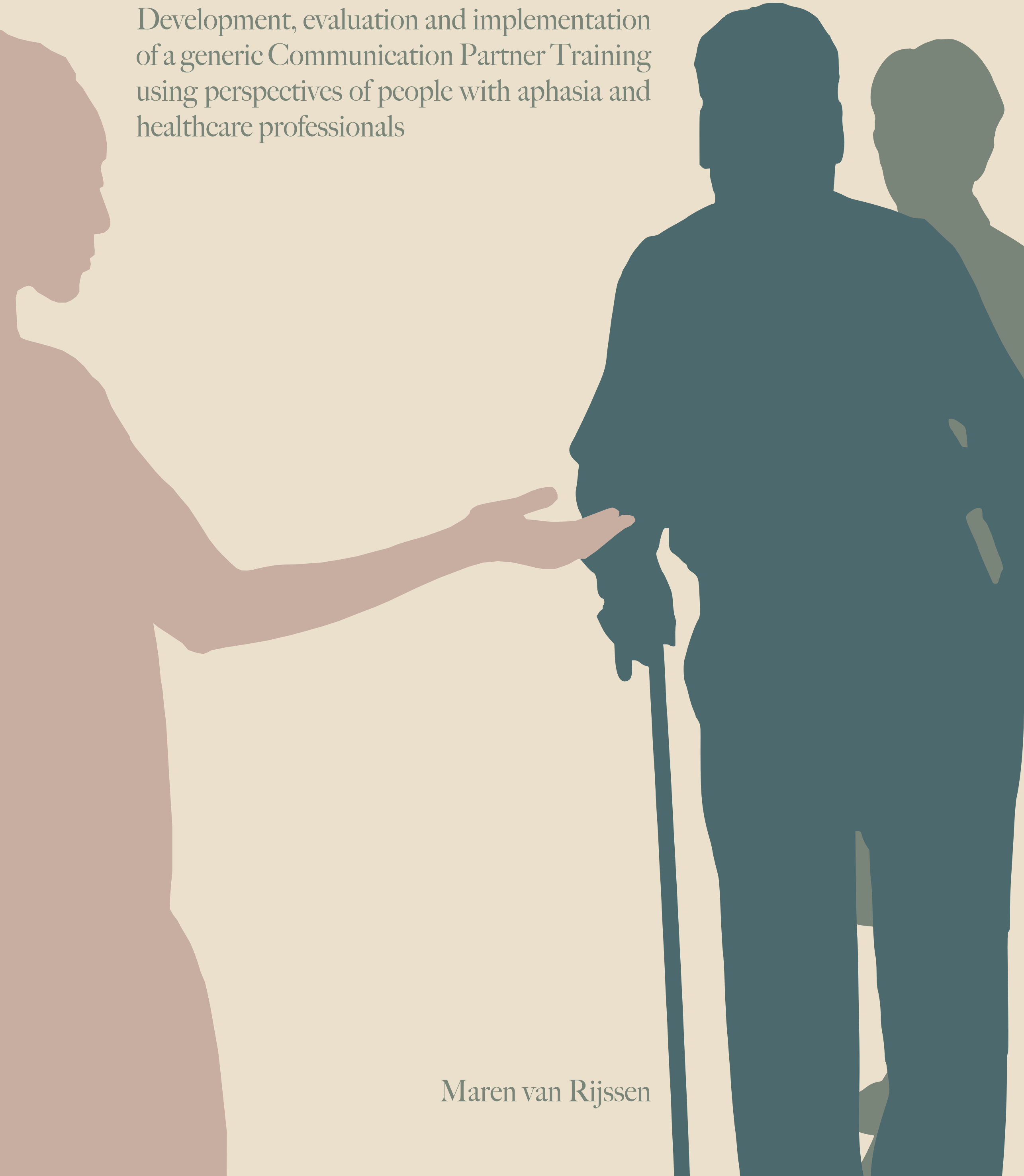
CommuniCare

Development, evaluation and implementation of a generic Communication Partner Training using perspectives of people with aphasia and healthcare professionals



Maren van Rijssen

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CommuniCare

Development, evaluation and implementation of a generic Communication Partner Training using perspectives of people with aphasia and healthcare professionals

CommuniCare: ontwikkeling, evaluatie en implementatie van een generieke Communicatie Partner Training vanuit de perspectieven van mensen met afasie en zorgprofessionals

(met een samenvatting in het Nederlands)

Proefschrift

ter verkrijging van de graad van doctor aan de Universiteit Utrecht op gezag van de rector magnificus, prof. dr. H.R.B.M. Kummeling, ingevolge het besluit van het college voor promoties in het openbaar te verdedigen op 21 december 2022 des morgens te 10.15 uur

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CHAPTER 1

1

General introduction

This thesis focuses on improving communication between people with aphasia and healthcare professionals (HCPs) working in hospitals or rehabilitation centers.

The National Institutes of Health define aphasia as "a neurological disorder caused by damage to the portions of the brain that are responsible for language production or processing". It is a language disorder without any impairments to core intelligence, which affects speaking, understanding, reading and writing. The three major causes of acquiring aphasia are stroke, traumatic brain injury and 'other causes' such as brain tumors. Because aphasia is caused by damage to regions of the brain, the language disorder often coincides with other comorbidities, such as cognitive or motoric impairments. It is estimated that each year in the Netherlands, 45.000 people suffer a stroke, 85.000 people suffer a traumatic brain injury and approximately 10.000 people suffer brain injury from other causes[1]. In 2015, more than 21% of these individuals acquired aphasia, which added up to about 30.000 people (www.afasie.nl, 2015). Aphasia is mostly caused by stroke.

The onset of aphasia is typically sudden and extremely traumatic for the person who suffers from it and for his or her family members and close relatives. The difficulties for people with aphasia can range from occasional trouble in finding words to the complete inability to speak, understand others, read and write. From one day to the next, communicating with others can become extremely challenging. All of a sudden, the person with aphasia can no longer communicate and interact as usual with loved ones, (informal) caregivers, work colleagues, and all others that are part of the person's society. Therefore, aphasia is one of the most detrimental consequences of acquired brain injury[2]. When stroke survivors are compared, people with aphasia show reduced quality of life, greater levels of anxiety and depression, reduced participation in social activities and higher mortality rates[3]. They are less likely to return to their jobs and often experience a profound sense of social isolation and loss of self-esteem[4]. It is more difficult for people with aphasia to access healthcare services[4]. People with aphasia and their families report being excluded from healthcare decisions, not being adequately informed and inappropriate discharge from hospitals[5]. People with aphasia's communication problems with HCPs increase risks for adverse events in healthcare centers, such as preventable falls and incontinence[5].

Aphasia is often a chronic condition. The prognosis of aphasia recovery depends on the underlying etiology, the severity of aphasia at onset and the age of the person with aphasia. These factors increase the likelihood of long-term deficits[6,7]. Although most people with aphasia see their ability to communicate improve to some extent, residual communication problems often persist.

People can learn to cope with the communication problems and live successfully with the residual language problems if they are given the right support. Speech and language therapists (SLTs) are the HCPs who are most qualified and have a key role in evaluating and managing language and communication difficulties. In healthcare facilities in the Netherlands, SLTs work in a multidisciplinary team that includes neurologists, physicians or geriatricians, psychologists, physiotherapists, occupational therapists, social workers and nurses. The two main approaches for aphasia treatment are cognitive- linguistic therapy, aimed at restoring language function, specifically semantics, phonology or syntax, and communicative treatment, aimed at optimizing communication by training the person with aphasia to use linguistic compensatory strategies[8]. Besides impairment-focused treatment from the SLT, other HCPs can contribute substantially by creating a communicatively accessible environment where the person with aphasia can participate.

IMPROVING COMMUNICATION BETWEEN HEALTHCARE PROFESSIONALS AND PEOPLE WITH APHASIA

After acquiring brain injury, people with aphasia generally go to healthcare facilities to receive acute- and multidisciplinary rehabilitation care. In the Netherlands, people with aphasia stay in a hospital setting for an average of 5-15 days. After that, they move to an inpatient healthcare facility for 2 to 3 months. From there, they return to society without- or with outpatient healthcare, which can last up to one year (Hersenletsel, 2022).

According to a wide variety of international and national statements, people with aphasia, like all others, have the right to (access) the highest attainable standard of healthcare services. Accessible communication and information are part of this fundamental human right. This is reflected by the Dutch Law on Medical Treatment Agreement (Wet op Geneeskundig Behandelovereenkomst (WGBO)), which states that all patients have the right to be informed and included in healthcare decisions. Collier et al. (2012, p. 207) define communication access as “having the means, supports and opportunities to communicate effectively, meaningfully, accurately and authentically in order to get equal uncompromised access to goods and services”[9]. Unfortunately, communication access in healthcare facilities has not been fully available to people with aphasia[3,5,10,11]. Many studies have shown that people with aphasia and their HCPs experience problems when communicating[3,5,10,12].HCPs control topics and flow of conversations, and often fail to represent the needs of people with aphasia[3,5]. Stroke survivors with aphasia feel they are not taken seriously, are excluded from decision-making and feel lonely and frustrated for not being able to participate in conversations and activities in healthcare settings[12]. The communication problems between people with aphasia and HCPs are a critical concern for providing and receiving good quality, patient-centered healthcare.

Patient-centered care

Over the last decades, *patient-centered care* has become center stage in discussions about quality of healthcare facilities[13]. This is for good reason: research has shown that patient-centered care leads to higher adherence to treatment[14] and improved health outcomes for patients[15]. HCPs and healthcare systems benefit from patient-centered care as well, through improved satisfaction of patients, enhanced reputations of providers, better morale and job satisfaction among healthcare staff, improved resource allocations and reduced financial costs[15]. The Institute of Medicine defines patient-centered care as "providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions."

Patient-centered care requires true partnership between the patient and his or her HCPs. Common elements are that care is collaborative, accessible and focuses on physical comfort as well as on emotional well-being, patient and family are expected members of the care team and support decisions, and information is shared fully and in a timely manner so that patients and family can make informed decisions[16]. A few decades ago, patient-centered care became the standard in the Dutch healthcare system. This meant a change in HCPs' role, attitude and competencies. Their role transformed from being a more hierarchical one, into one of equal partnership, in which collaboration with the patient is essential[17]. Good communication skills became more important than ever before.

Communication in healthcare situations can be captured as a trialogue between the patient, the relatives and his or her HCP (Figure 1). Communication takes place both verbally and non-verbally. The patient needs to be able to provide information about his or her health-related issues, understand information, make decisions, communicate his or her needs and wishes, retain the memory of information and decisions and act upon the plans that were made. The patient's relative(s) participates as a collaborator who knows the patient well and needs to be able to understand information and facilitate the patient to make decisions. The HCP participates as expert consultant and partner in the design of clinical services and interventions. HCPs need to be able to adequately comprehend and interpret the information in order to discuss and treat health issues appropriately, take account of wishes and feelings from both conversation partners, ensure that the patient and relative both understand what is being said in order to help them take preventive steps to address their health issues, and ensure that they both make their opinions known. To do this, the HCP needs to consult the patient, involve the patient, collaborate with the patient and (if the patient wishes so) empower the patient to make the final decision. These responsibilities involve treating the patient with respect, active listening, acknowledging health concerns, using lay words, making information accessible and involving the patient in health policies. The same accounts for communicating with the relative. If any of these steps are compromised, healthcare becomes ineffective, increasing the likelihood of negative patient outcomes, unsafe work environments, adverse events, transfer delays and increased costs[17].

As effective communication is a highly complex process for HCPs, relatives and patients (even without communication difficulties), it can easily become (completely) inaccessible for people with aphasia.

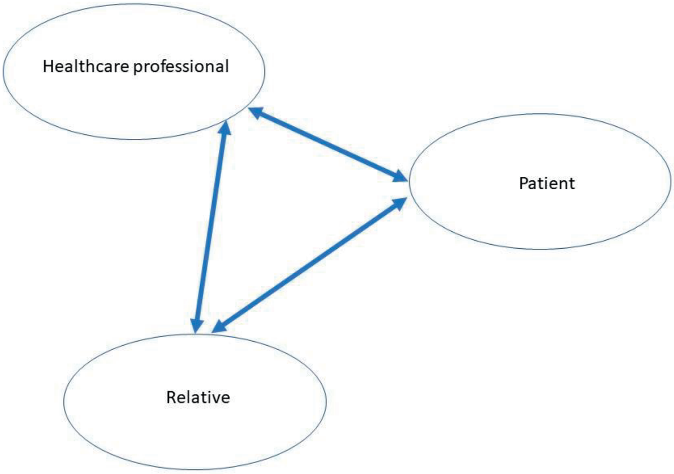

Figure 1. Communication between people with aphasia, their relatives and HCPs

THE CONSEQUENCES OF APHASIA IN HEALTHCARE

The consequences of aphasia are extensive. People with aphasia show worse rehabilitation outcomes than stroke survivors without aphasia, worse quality of life outcomes[18] and they are less likely to be discharged home[19,20]. People with aphasia even show higher mortality rates[21]. Communication failures between people with aphasia and their HCPs lead to inadequate care, such as inappropriate discharge home, as well as adverse safety incidents[20].

HCPs often reach out to SLTs for help when they experience communication difficulties with patients. Based on clinical experiences, we see that collaboration between HCPs and SLTs in healthcare facilities quite often entails SLTs taking over the conversation. HCPs often focus on general (nursing) care instead of patient interactions, as these are seen as the realm of the SLT[3]. However, SLTs cannot always be present during conversations, nor is it a desired situation that the SLT functions as a 'translator'. Effective communication is part of the role of *each* HCP. It is essential in medical and allied healthcare where the outcomes of a test must be discussed, goals must be set in collaboration with the patient, advice must be given, preferences of the patient must be discussed and exercise needs to be explained. Communication between the patient and HCP is part of almost every contact. Inadequate communication can result in wrong diagnosis, inappropriate goals and can prevent the patient's access to proper assessment necessary for receiving adequate healthcare services[22]. Collaboration between HCPs and SLTs should therefore take a different form.

IMPROVING COMMUNICATION BETWEEN PEOPLE WITH APHASIA AND HEALTHCARE PROFESSIONALS

As described above, people with aphasia are at risk of receiving low quality care that does not complement with patient-centered care approaches requisite these days. People with aphasia wish to be treated with dignity and respect, be able to communicate their basic needs, worries and opinions and be included in decision-making[20,22]. HCPs find it important to be able to respect people with aphasia's autonomy and learn how to provide information that they can understand[3]. Improving communication between HCPs and people with aphasia is therefore essential. A variety of studies have investigated ways to do this. These studies have shown that when conversation partners use supportive conversation techniques, such as drawing or using gestures, speaking slowly and asking closed-ended questions, participation by people with aphasia in those conversations improves[23,24]. HCPs' use of supportive conversation techniques has also been shown to improve people with aphasia's satisfaction about healthcare and the overall interaction between the two conversation partners[23].

Using supportive conversation techniques asks for a change in communication behavior. Communication Partner Training (CPT) can help HCPs to do this. CPT is an umbrella term that covers a range of training models aimed at learning to use supportive conversation techniques[25]. Such CPT interventions have been developed globally, for relatives as well as HCPs.

CPT interventions often include educational training, practice and psychological support. They typically include at least five stages: education, awareness raising, identification of target behaviors/strategies, practice, and sometimes implementation and post-training support[25]. Educational training often includes a theoretical part, where HCPs are explained the consequences of inaccessible communication for people with aphasia and what they can do to improve it. The identification of target behaviors and practice are often conducted in the form of face-to-face training sessions. These sessions often include roleplay, feedback and group discussion. Feedback is usually provided by SLTs or people with aphasia. Group discussions are usually participant- led. CPT interventions for HCPs are usually provided in-setting. Training sessions range in length from one hour to several days. Post-training support often includes practice, feedback and on-site problem solving. Some examples of CPT interventions that are well known include Supported Conversation for adults with Aphasia (SCA)[4], Supporting Partners of People with Aphasia in Relationships and Conversation (SPARCC)[26] and Better Conversation with Aphasia (BCA)[27]. These CPT interventions use several procedures for each of the five stages mentioned above: education about the cause of aphasia, symptoms, treatment, prognosis, deficits, and psychological aspects; raising awareness by showing instructional video clips and recordings of conversations between people with aphasia and other conversation partners; practicing supportive conversation techniques through roleplay; and coaching on the job by SLTs.

Studies evaluating the effects of CPT indicate that HCPs feel more comfortable communicating with people with aphasia, are more knowledgeable about aphasia and supportive conversation techniques, and employ more of these techniques during conversations[23]. Positive effects for people with aphasia include increased activity, participation and psychosocial wellbeing[23]. The evidence of the effects of aphasia-based CPT is strong and the provision of CPT is recommended in international best-practice statements[19].

However, the CPT interventions that are described in the literature vary widely in intervention elements (education, counselling, coaching, etc.), recipients targeted (healthcare students, HCPs, relatives, people with aphasia) and ways in which CPT was provided (individual, dyad, groups, e-learning, face-to-face)[25]. The level of detail in which these CPT interventions are described is inadequate, incomplete and insufficient to enable replication[25]. The reported goals, rationales or theories of intervention elements, materials and procedures lack detail. The ways in which the provision of CPT interventions are described (provider, mode, timing and dose) are also insufficient. The location, tailoring and modifications, adherence and fidelity are infrequently reported[25]. Although CPT results in positive effects for people with aphasia, the lack of clear intervention descriptions make it impossible to hypothesize how different intervention elements produce different outcomes- also called the mechanisms of change.

HOW DOES COMMUNICATION PARTNER TRAINING WORK?

Mechanisms of change are defined as the theory-driven reasons that change occurs[28]. The mechanisms of change enable researchers and clinicians to hypothesize which outcomes can be expected from various intervention elements in CPT. The mechanisms can also be compared between contexts, to help researchers and clinicians consider which outcomes they can expect in different healthcare settings.

When this study started in 2016, there were no Dutch generic CPT interventions available. Research in the field of CPT has shown that, to increase the likelihood of successful implementation, the intervention elements should be developed in collaboration with HCPs and people with aphasia and address their outcomes of interest[29]. This would generate an intervention that focuses on practical problems and aims to change an existing situation for the users and recipients[30]. In the past, CPT interventions were primarily developed based upon SLTs' and researchers' definition of the problem and solutions for that problem. In this thesis, we developed a Dutch CPT that was based upon the needs and wishes of people with aphasia and HCPs. In order to enable replication, each intervention element was described clearly and in detail.

Our second aim was to evaluate how the elements in our CPT produce different outcomes. In this thesis, we evaluated the mechanisms of change from HCPs' perspectives. HCP-driven evaluations are designed to provide detailed feedback and recommendations to the intervention. Their perspectives facilitate collaborative problem-solving. Understanding their reasons for changing their behavior enabled the development of implementation strategies based upon potential, real-life barriers and facilitators. These strategies were incorporated into the CPT, which is important, since contextual factors, users and recipients can vary widely among different healthcare facilities and CPT interventions should be tailored according to these differences[30].

CPT interventions are complex. Various groups and organizational levels are targeted by the intervention: HCPs from different disciplines, people with aphasia with different severities and comorbidities, and managers who need to take varying budgets, rules and regulations into account. A large number of behaviors are required by those delivering the intervention. Strict fidelity to an intervention protocol may be inappropriate because of the iterative nature of the intervention elements, such as coaching on the job. Lack of impact of CPT may reflect implementation failure rather than genuine ineffectiveness. Due to the many dimensions of complexity, we followed the recommendations of the Medical Research Council (MRC) guidelines (2008) on designing and evaluating complex interventions[31]. The MRC guidelines offer researchers a flexible yet systematic method for choosing appropriate methods for the development and evaluation of interventions. Figure 2 represents the main phases and the key functions and activities at each phase. Often these phases do not follow a linear sequence. The arrows represent the interactions between the phases. In this thesis, the 'evaluation phase' focused on understanding mechanisms that enable or limit HCPs to use supportive conversation techniques after CPT. HCPs in this thesis were defined as all staff working in a healthcare center in the Netherlands or Belgium and involved in providing healthcare services under the jurisdiction of the Ministry of Health.

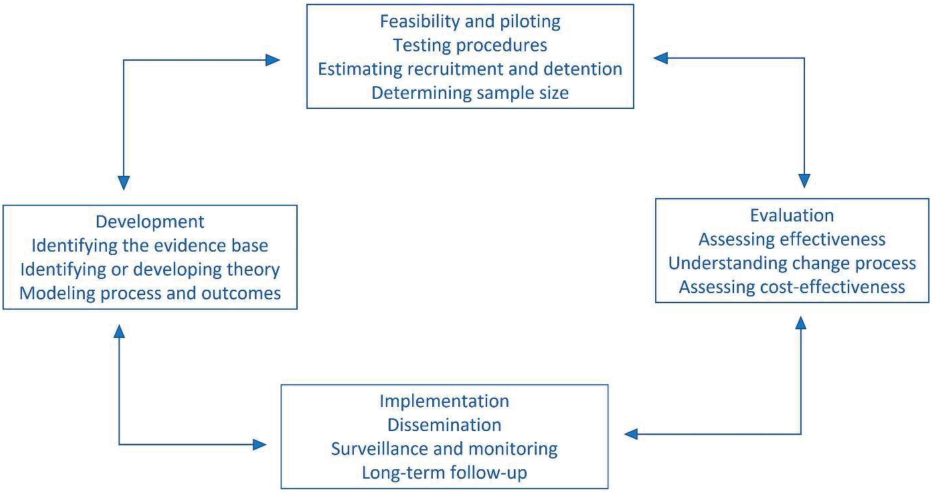

Figure 2. MRC framework for developing and evaluating complex interventions[31]

AIMS OF THIS THESIS

The general aim of this thesis was to improve the accessibility of communication in Dutch and Flemish healthcare centers for people with aphasia by developing and evaluating a Communication Partner Training (CPT) intervention for HCPs, named CommuniCare.

The specific aims of this thesis were:

1. To develop the intervention CommuniCare by an in-depth investigation of the needs and wishes of people with aphasia, HCPs and relatives regarding the accessibility of communication in healthcare centers.

2. To evaluate CommuniCare by an in-depth investigation of HCPs' self-reported mechanisms that facilitate or limit them in using supportive conversation techniques after CommuniCare.

STUDY DESIGN

The data used in this thesis were collected in the research project CommuniCare, funded by the Taskforce for Applied Research SIA under grant RAAK.PUB.04.012.

This research project had a qualitative design. All data was collected by semi-structured interviews with 20 people with aphasia, 12 relatives and 71 HCPs. The pilot version of CommuniCare was tested with 46 nurses working in a hospital in the Netherlands. The final version of CommuniCare was offered to 292 HCPs from eight Dutch or Flemish healthcare facilities, which were either hospitals, geriatric rehabilitation centres or medical rehabilitation centres. Recruitment for the interviews took place between January 2016 and February 2020. People with aphasia were included if their language comprehension was adequate enough to be able to provide informed consent (based on a Dutch language comprehension test conducted and interpreted by a SLT), aged over 18 years, had aphasia as result of stroke and were receiving- or had received care in healthcare centre(s) for an undefined period. Relatives were included if they were aged over 18 years and had contact with a person with aphasia at least once a week. People with aphasia and relatives were excluded if they had severe hearing problems, a history of psychiatric disease or no Dutch language proficiency. HCPs were included if they possessed a Certificate of Current Professional Status (CCPS), had experience with communicating with people with aphasia and communicated with people with aphasia on a regular basis at the time of the study.

ETHICAL APPROVAL

This study was approved by the Medical Ethical Committee of the University Medical Centre Utrecht (number: 18–159/C) and performed in accordance with the Helsinki Declaration and the EU General Data Protection Regulation. The researchers gave thorough written and verbal information. Aphasia-friendly informed consent forms were used for participants with moderate to severe aphasia. Informed consent was obtained from all participants involved in the study.

OUTLINE OF THIS THESIS

Chapter 2 of this thesis describes a pilot study that aimed to evaluate the first version of CommuniCare. This prototype was evaluated on the stroke unit of a peripheral hospital in the Netherlands from 2016-2018. A mixed-methods feasibility study was conducted with a pre-test post-test design in the quantitative part and two focus group discussions in the qualitative part. In the pre-test and post-test, nurses reported their barriers and facilitators for implementing CommuniCare using a questionnaire. In the focus group discussion, nurses reflected upon the intervention and their needs and wishes for further development.

Two qualitative exploratory studies in three Dutch or Flemish healthcare centers were carried out to further investigate the needs and wishes of stakeholders. **Chapter 3** aimed to investigate the needs and wishes of people with aphasia and their relatives for improving communication with their HCPs. Data was collected through qualitative semi-structured interviews with 20 people with aphasia and 12 relatives. **Chapter 4** evaluated the needs and wishes of HCPs. The data were collected through qualitative semi-structured interviews with 17 HCPs. HCPs were recruited from two geriatric rehabilitation centres in the Netherlands and one academic hospital in Belgium. The findings from chapter 2, 3 and 4 informed us how to further develop CommuniCare to the final version.

Chapter 5 describes the process of developing CommuniCare and the intervention itself, by using the Template for Intervention Description and Replication (TIDieR) checklist.

The study in **chapter 6** aimed to describe HCPs' self-reported mechanisms that led to a change in the use of supportive conversation techniques after CommuniCare. The intervention was provided to 254 HCPs from five different geriatric or medical rehabilitation centres. Two interviews were conducted with 24 HCPs directly after- and four months after receiving the training that was part of CommuniCare. HCPs' perspectives on the mechanisms of change informed us to incorporate context-specific implementation strategies in CommuniCare.

Chapter 7 presents a general discussion, where the results of the studies are integrated, the main findings are discussed, methodological considerations are presented, suggestions for future research are made and clinical implications are provided.

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CHAPTER 2

2

Feasibility of a communication program: improving communication between nurses and persons with aphasia in a peripheral hospital

Maren van Rijssen, Marloes Veldkamp, Leonore Meilof, Lizet van Ewijk

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Aphasiology. 2019;33;11:1393-1409

Abstract

Aim and objective

Difficulty in communicating (due to aphasia) can have serious consequences for patients in health care settings. Communication Partner Training is effective for improving communication between persons with aphasia and health care professionals. This study aims to evaluate the feasibility of developing and introducing a Communication Program which focuses on improving communication between nurses and persons with aphasia in a peripheral hospital setting.

Methods & procedures

A mixed-methods feasibility study was conducted with a pre-test post-test design in the quantitative part and two focus group discussions in the qualitative part. Nurses received training for communicating with persons with aphasia. In the pre-test and post-test, nurses filled in a questionnaire for barriers and facilitators and a feasibility questionnaire. Nurses' attitudes towards the Communication Program were further explored in two focus group discussions.

Outcomes & results

Forty- six nurses took part in the training sessions. Most nurses were satisfied about the Communication Program (24/30) and intended to continue using it (25/30). Almost all nurses saw positive effects for patients with aphasia (27/30), such as an increase in the ability to communicate. However, nurses reported that using the program was time consuming and that they still often experienced frustration when communicating with persons with aphasia.

Conclusions

Improving communication with persons with aphasia via the Communication Program seems feasible and valuable according to nurses. Nurses probably need more support during implementation of the Communication Program, mainly due to time barriers and the complexity of communicating with persons with aphasia. Further research should focus on revising the program, training health care professionals with different educational backgrounds, and assessing the implementation of this communication partner training in health care settings.

Keywords

Aphasia, stroke, communication, partner, training

INTRODUCTION

Difficulty in communicating can have serious consequences for patients in health care settings. Bartlett et al. (2008) found that hospital patients with communication problems are six times more likely to experience adverse events[1]. Persons with aphasia (PWA) who are restricted in their capacity to communicate their needs are at risk of receiving inappropriate or inadequate health care services [2], at risk of complications such as depression [3], have worse rehabilitation outcomes and higher mortality [4]. These data emphasize the necessity of resolving communication problems as quickly and adequately as possible and minimizing chances of miscommunication between patients and health care professionals.

Research on training health care professionals (HCP) in communicating with PWA is growing. In 2010, Simmons- Mackie et al. published a systematic review of studies investigating Communication Partner Training (CPT) in aphasia, including studies in which HCP were trained[5]. Of the 31 studies that met the inclusion criteria, 25 focussed on training communication skills of caregivers or family members. Of the remaining studies, five studies addressed training of acquiantances, volunteers, students or strangers and only one focussed on service providers alone [6]. The authors concluded that CPT is effective in improving communication between PWA and their communication partner and that CPT is recommended for communication partners of people with chronic aphasia (>4 months post onset). In 2016 the systematic review was updated, showing an increase in the number of studies focussing on CPT for HCP[7]. A total of 25 studies were added, four of which focused on HCP or health care students as communication partners [8–11]. All of the studies reported on direct communication training and showed positive outcomes for communication with people with chronic aphasia. Of the four studies that included HCP, one study used CPT based on the CONNECT partner training program [8] which includes didactic content and practical components. The remaining three studies used Supported Conversations in Aphasia (SCA)[12] as a method to train participants. SCA focuses on providing the PWA with opportunities for genuine adult conversation and interaction by training conversation partners to use communication skills in order to facilitate the PWA to participate in daily conversation. SCA-training has been shown to increase communicative skills of volunteer conversation partners and ameliorate performance of the PWA in communication [12]. Similar CPT programs have since been introduced, with similar positive effects. Heard, O'Halloran and McKinley (2017) for example found that a CPT E-learning program combined with role play sessions was just as effective as SCA in increasing the knowledge of aphasia and the confidence of health care professionals in communicating with PWA[13]. Positive effects that have been reported include less frustration for PWA, an increase in staffs' self-administered knowledge of aphasia and communication practices[9,10,14,15] and significant increase in the use of communication strategies by HCP[14]. HCP did report time constraints and that some tools to support their conversation were too complex[9].

Saldert, Jensen & Johansson (2018) recently proposed that two approaches can be identified in CPT: person specific communication training and generic communication training[16]. In person specific training, an individual PWA and communication partner are involved in the choice of which behaviours they want to be targetting. Tasks include the clinician providing information about aphasia and communication, video recordings of the dyad's interaction and coaching of the communication partners in the use of individually adapted conversational behaviours. The generic CPT approach is aimed at (possible) conversation partners and aims to improve communication skills of these partners by increasing knowledge of aphasia and practicing supported conversation skills. Training usually occurs in a specific context such as a Stroke Unit (SU), often in groups.

One of the difficulties in comparing research on CPT is the large variety of settings, dosage, outcome measures and severity of aphasia. Simmons-Mackie et al. (2016) reemphasize the need for the use of consistent outcome measures and the use of quality scales to guide research design[7]. Additionally, Cruice et al. (2018) highlight the importance of carefully reporting CPT to identify the essential elements and active ingredients in CPTs, and recommend the Template for Intervention Description and Replication (TIDieR) checklist as the tool of choice for the description and review of CPT[17].

In the Netherlands, CPT is not yet widely used. Wielaert et al. (2018) were the first to implement CPT in Dutch settings, in the form of PACT, which is the Dutch translation of Supporting Partners of People with Aphasia in Relationships and Conversation (SPPARC)[18]. PACT is an example of person specific training and focuses on communication in dyads. It aims to raise awareness of conversation style in PWA and the communication partner, to explore new strategies that help the PWA and their partner to become more effective and comfortable in their conversations and to enable the dyad to use their new strategies in everyday conversations.

In the current study we describe the introduction of a generic communication partner training program in the complex setting of a peripheral hospital in the Netherlands. In order to carefully capture implementation, a systematic approach to designing and conducting process evaluations is essential. We therefore use the framework for conducting and reporting process evaluation studies of complex interventions in health care[19], which is part of the Medical Research Council (MRC)- model [20].

Complex interventions are usually described as interventions that contain several interactive components[21]. They are notoriously difficult to evaluate in terms of effectiveness; outcomes of an intervention can be strongly affected by implementation failure, contextual factors or certain mechanisms of impact. Therefore, using a process evaluation to understand how an intervention works is vital in developing an evidence based intervention [19]. A key component for evaluating the process of implementation is the phase of feasibility testing. Feasibility is defined as "the quality of being useful and practical" and involves the study of practicability and applicability [22](7,14).

To provide a first step in identifying an effective method for implementing generic CPT in the Dutch health care system, and to describe how contextual factors, implementation methods and mechanisms of impact may influence outcome measures, the current study aims to evaluate the feasibility of using the Communication Program on the SU of a peripheral hospital.

The research question is: *What is the feasibility of using a Communication Program by nurses on the SU of a peripheral hospital?*

MATERIALS AND METHODS

Design

In line with the MRC-model for complex interventions, a mixed-methods feasibility study was conducted, including a pre-test post-test study in the quantitative part and two focus group discussions in the qualitative part (Figure 1).

Setting and participants

Recruitment took place on the Stroke Unit (SU) of a peripheral hospital in the Netherlands. This SU has 50 beds and provides both acute and rehabilitation care to patients with neurological disorders. Included in the study were nurses who possess a Certificate of Current Professional Status (CCPS) and gave informed consent. The hospital management allowed training sessions for nurses and focus group discussions to be conducted during working hours. All nurses were asked to participate via their manager. Demographic characteristics of nurses were collected to provide a thorough description of the sample (N=46) (Table 1). Two subgroups of 8 nurses, which is recommended as an ideal size for group dynamics [23], were selected to take part in a focus group discussion. Figure 2 shows a flow chart of participant number from admission to enrolment and analysis. The response rate in the pre-test was forty (40/46). In the post-test, the response rate was thirty (30/46).

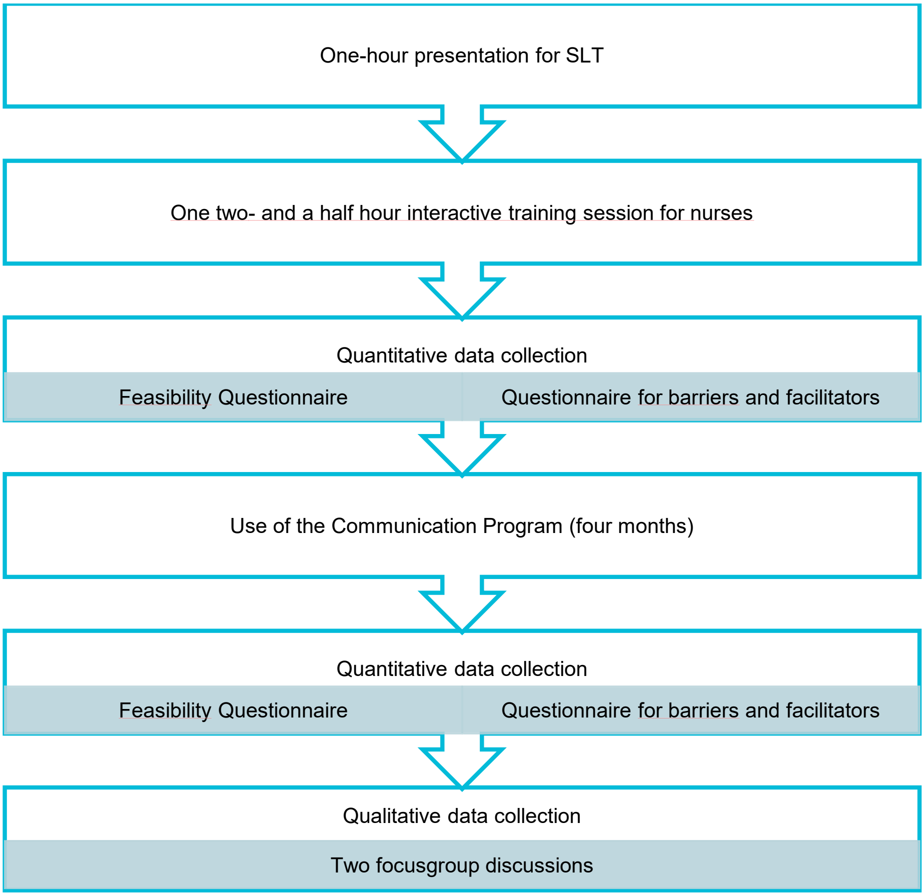


Figure 1. Flowchart of study design

Table 1. Demographic characteristics of nurses. SD= Standard Deviation, N= number

Demographic data	Total (N=40)
Mean age in years (SD)	37 (13)
Gender	
Number of males	1
Number of females	39
Mean years of experience on this ward (SD)	9,1 (7,5)
Mean years of experience on a stroke unit (SD)	9,7 (8,0)
Educational background	
Number of nurses with Associate degree (%)	23 (58)
Number of nurses with Bachelor degree (%)	17 (42)
Number of nurses with Master degree (%)	0 (0)
Mean full-time equivalent (FTE) of nurses on this ward (SD)	0,67 (0,16)

Description of the Communication Program (CP)

A blueprint of the Communication Program (CP) was developed by two speech- and language therapists (SLTs) on the participating SU based on Kagan's Supported Conversation for Aphasia (SCA)- model [12]. The content, layout and readability of the CP was then assessed by a group of experts. This group of experts included two SLTs with a Master-degree who work on the participating SU, a lecturer with years of experience in aphasia rehabilitation and a senior researcher with a PhD- degree and years of experience in clinical research. The CP was described according to the TIDieR checklist for reporting interventions [24]. The final CP consisted of a training for SLTs, an interactive training session for nurses and three checklists, which are described in detail below.

Training session for SLTs

SLTs were involved in diagnosing aphasia and providing an indication of the severity of aphasia. This was important as it provided the nurses with information on which communication skills to use: skills for extensive communication enhancement (cf. checklist 1) or less extensive communication enhancement (cf. checklist 2). In a one-hour training session for SLTs, the primary researcher presented the study procedure and CP to SLTs. The SLTs were given the opportunity to discuss the CP and ask questions.

Training session for nurses

A single training of 2.5 hours was provided by two SLTs (hospital staff) and a lecturer. The training session was split into three modules, as recommended in the literature[25], and included theory and role-play. In the first module, the importance of enhancing the communicational environment of PWA was explained and underlined. Conclusions and implications from recent literature was discussed with nurses concerning the detrimental consequences of aphasia and the risks of communication problems between HCP and PWA. The second module consisted of the introduction and explanation of generic communication skills, including two demonstration videos. After watching and discussing the videos, the group was split into smaller groups of maximum five nurses who each took part in at least one role play session. The SLT impersonated a PWA. Nurses practiced using communication skills (described in figure 2) to support their conversation with the PWA, while the others observed and gave feedback. In the third module, nurses were given the opportunity to ask additional questions and were provided with information on the study procedure for research purposes. During the training session, nurses were encouraged to think about - and afterwards develop tools to support their conversation with PWA.

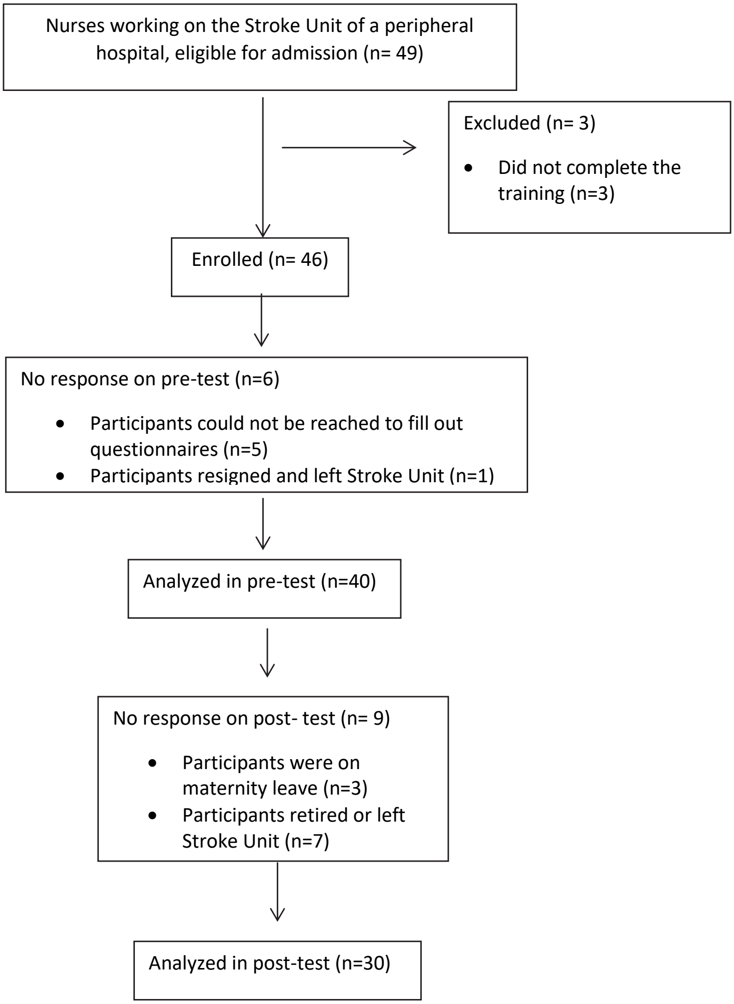


Figure 2. Flow chart of participant number from admission to enrolment and analysis.

Communication checklists

Three checklists were part of the CP (Figure 3). These checklists had the dual goal to a) help nurses remember and use communication skills and b) function as a registration checklist for how often the nurses used communication skills (for research purposes). The SLT on the SU indicated whether a PWA would benefit from checklist 1 or checklist 2, depending on the severity of aphasia. Checklist 1 describes 22 communication techniques that can be applied to patients who require extensive communication enhancement. Checklist 2 describes 17 communication techniques that can be applied to patients who require less extensive communication enhancement. Checklist 3 was used to report the number of contacts nurses had with PWA and whether this was a professional or social moment of contact. A professional moment of contact was defined as contact between a nurse and a PWA by virtue of medical/professional content, such as asking questions about pain or giving information about medication. A social moment of contact between a nurse and a PWA was defined as communication about anything else than professional content, such as conversations about the weather, about visiting relatives or about choice of music. According to Kagan, particularly social moments of contact make people feel respected and treated as equal conversation partners [25].

Data collection

Quantitative data

The communication checklists were used to register which- and how many communication skills had been used and how many moments of contact nurses had with PWA. Unfortunately, nurses did not always register their use of communication skills. Therefore we could not, as planned, provide percentages for communication skills that were used.

Feasibility of the Communication Program was investigated by evaluating attitudes of nurses towards the program. Pre-test and post-test measures (at 4 months after training) were conducted using an existing questionnaire measuring barriers and facilitators [26] and a newly developed questionnaire measuring feasibility [27,28].

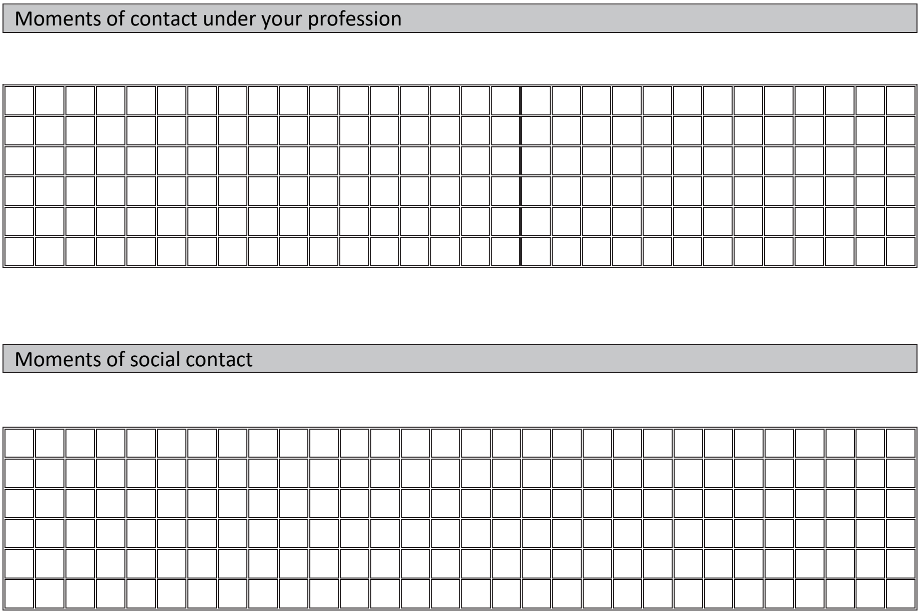
The questionnaire for barriers and facilitators[26] was adapted for this study, leaving out questions that targeted preventive care. The adapted version includes 13 questions in the pre-test and 15 questions in the post-test with a five-point Likert scale to evaluate if nurses agreed or disagreed with a statement. The feasibility questionnaire was developed based on measurements by Hafsteinsdottir et al. (2013)[28] and Bowen et al. (2012)[27]. This questionnaire includes 11 questions in the pre-test and 20 questions in the post-test with response on a dichotomous scale with 'yes' or 'no'. The feasibility questionnaire was used to evaluate nurses' views on general aspects in feasibility, such as practicality, demand and acceptability of the CP. Both questionnaires are shown in Appendix 1.

When you have a message for the PWA		**When PWA has a message for you**	
1. Stand / sit on the **unimpaired side** of the PWA.		11. Stand/ sit on the **unimpaired side** of the PWA.	
2. Reduce **incentives** as much as possible by closing the door, closing curtains, switching off radio/TV, allowing only 1 person to speak at a time.		12. Reduce **incentives** as much as possible by closing the door, closing curtains, switching off radio/TV, allowing only 1 person to speak at a time.	
3. Use **education cards VU** whenever necessary/ possible.		13. When you **don't understand PWA, point this out to the PWA.**	
		14. **Express what you do understand** and verify.	
4**. Support your message** using mimic, gestures, illustrations, drawings, written words.		15. **Support your message** using mimic, gestures, illustrations, drawings, written words.	
5. Use **short sentences.**		16. Use **short sentences.**	
6. Use a **slow rate of speech.**		17. Use a **slow rate of speech.**	
7. **Verify patient's comprehension.** (Example. Have I explained well? Fathom the non-verbal reaction of PWA).		18. Ask PWA whether message **can be found in the communication handbook.**	
8. Write important events/ conversations in the **communication handbook.**		19. Ask PWA to **point out, gesture, draw, write.**	
9.Show that you **take PWA seriously/ respect PWA** by: • Expressing this explicitly (EG: I think it's important that we understand each other). • Using a natural and mature tone of voice. • Inviting PWA to respond (turnover to next page for examples).		20. Express that you **take PWA seriously/ respect PWA** by: • encouraging to express himself • expressing that you have time to listen	
		21.Use **written conversations** to demarcate the conversation.	
		22. When you cannot trace the message of PWA, **agree to come back later and try again.**	
10. Explain that you respect PWA and take PWA seriously by creating **social moments of contact** (turnover to next page for examples).			

Figure 3A. CP checklist 1. PWA= Person With Aphasia

When you have a message for the PWA		**When PWA has a message for you**	
1. Stand/ sit on the **unimpaired side** of the PWA.		10. Stand/ sit on the **unimpaired side** of the PWA.	
2. Reduce **incentives** as much as possible by closing the door, closing curtains, switching off radio/TV, allowing only 1 person to speak at a time.		11. Reduce **incentives** as much as possible by closing the door, closing curtains, switching off radio/TV, allowing only 1 person to speak at a time.	
3. Use **education cards VU** whenever necessary/ possible.		12. Ask PWA whether message **can be found in the communication handbook.**	
4.Show that you **take PWA seriously/ respect PWA** by: • Expressing this explicitly (EG: I think it's important that we understand each other). • Using a natural and mature tone of voice. • Inviting PWA to respond (turnover to next page for examples).		13. Ask PWA to express himself **in a different way**: to describe, to use gestures, to point out, to draw, to write.	
5. Use **short sentences.**		14. Express that you **take PWA seriously/ respect PWA** by: • encouraging to express himself • expressing that you have time to listen	
6. Use a **slow rate of speech.**		15. Use **short sentences.**	
7. **Verify patient's comprehension:** summarize your message and fathom the non-verbale reaction of PWA.		16. Use a **slow rate of speech.**	
8.Write important events/ conversations in the **communication handbook.**		17**. Express what you do understand** and verify.	
9. Explain that you respect PWA and take PWA seriously by creating **social moments of contact** (turnover to next page for examples).			

Figure 3B. CP checklist 2. PWA= Person With Aphasia



Moments of contact under your profession

Moments of social contact

Figure 3C. CP checklist 3

Qualitative data

Focus groups were chosen because they provided the opportunity for nurses to share their thoughts and ideas. A semi- structured interview guide was developed based upon the research questions. The guide included introductory questions, key questions and final questions. The introductory questions were designed to make participants feel comfortable and free to discuss their experiences. Key questions considered questions the researcher wanted to explore. The final questions were used to summarize and finish the interview. Convenience sampling was conducted to collect negative, positive and neutral experiences. Two discussions with eight nurses were conducted in a quiet room in the hospital. During the discussions, the first author acted as moderator and asked in-depth questions using the interview guide. The third author acted as co-moderator and made field notes, observed group dynamics and asked questions to encourage participants to elaborate on their answers.

Data analysis

Quantitative data

Descriptive statistics, including frequencies and means, were calculated for the demographic characteristics, communication checklists and data from the questionnaires.

Qualitative data

The focus group discussions were conducted using inductive methodology [23] and audiotaped for subsequent summaries. The first author transcribed the interviews verbatim. The second author reviewed the transcripts, in order to monitor the quality of the process and get familiar with the data. Both interviews were screened for recurring topics. Single statements were identified to critically review whether these statements were one person's opinion or group opinion. Extremely positive or negative comments were expanded upon in each focus group discussion. Six topics were addressed: "implications for patients", "implications for health care professionals", "opinions on content of the CP and training sessions," "implications for quality of care" and "future expectations."

Ethical issues

This study was reviewed and approved by the Medical- Ethical Committee of Isala Hospital, Zwolle, the Netherlands and conducted according to the declaration of Helsinki. The researcher provided thorough written and verbal information to participating nurses and informed consent forms were signed.

RESULTS

Training sessions

The Communication Partner Training (CPT) was conducted on four occasions. During the training sessions nurses were encouraged to come up with potentially supporting conversation tools. Two tools were suggested, developed and then used by nurses in the course of this study: 1) information cards for PWA developed by the University Medical Centre in Amsterdam (information on stroke, aphasia, therapies, health examinations and other re-occurring activities in the hospital) and 2) cards showing pictures of health care settings in the region developed by the nurses in collaboration with SLTs.

Quantitative data

Communication checklists

Nurses' compliance with using the CP was observed using three checklists. Fifteen checklists in total were filled in by the nurses. Because nurses did not always register which communication skills were used, we were unable to provide percentages. What we do know is that nurses and PWA had more professional moments of contact than social moments of contact (ratio 4:1). Nurses seldom made use of the developed tools to support their communication. Nurses mostly used the following communication skills: standing on the unimpaired side of PWA and reducing environmental noise, supporting their conversation with non-verbal communication (mainly using facial expression and gesturing), using short sentences and using a lower speech rate.

Nurses expectations (data collected through questionnaires)

Table 2 shows what barriers and facilitators nurses expected to come across directly after the training session. The majority of nurses felt they knew enough about the program to use it (34/40). Also, most nurses felt motivated to use the program (36/40). According to the nurses, main barriers to using the CP would be changing their old routines (13/40), fitting the program into daily practice (17/40), time limitations (34/40) and lack of resources (13/40).

Table 2. Barriers to and facilitators for using the Communication Program, before- and after introduction N= number of participating nurses. Based on: Peters, MAJ, Harmsen, M, Laurant, MGH, Wensing, M. Ruimte voor verandering? Knelpunten en mogelijkheden voor verbeteringen in de patiëntenzorg. [Room for improvement? Barriers to and facilitators for improvement of patient care]. Nijmegen: Centre for Quality of Care Research (WOK), Radboud University Nijmegen Medical Centre, 2002.

	Pre-test Nurses, N=40			Post-test Nurses, N= 30		
	Agree	*Agree nor disagree*	*Agree*	*Agree*	*Agree nor disagree*	*Agree*
Attitude						
This program leaves enough room for me to make my own decisions	35	4	1	27	2	1
This program leaves enough room to weigh the wishes of the patient	35	3	2	26	3	1
Knowledge and motivation						
I thoroughly read and remember the intervention	35	4	1	21	9	0
I know enough about the program to apply it	34	6	0	28	2	0
I feel motivated to use this program	36	4	0	18	10	2
Work style						
I have no problems changing my old routines	27	9	4	20	8	2
I have no general resistance to working according to protocols	33	5	2	23	4	3
This program fits into my ways of working at my practice	23	16	1	11	14	5
Time limitations						
Working with this program is not too time consuming	6	24	10	6	15	9
Financial compensation						
Working according to this program requires no financial compensation	30	10	0	21	8	1
Resources						
I have enough resources to use this program	27	9	4	22	6	2
The program is written clearly and easy to understand	37	3	0	27	1	2
Collaboration and support						
Other professionals cooperate in applying the program	-	-	-	6	19	5
Patients cooperate when applying the program	-	-	-	11	14	5

Table 3 shows nurses' expectations towards the feasibility of the CP. All nurses (40/40) were satisfied about the CP (40/40) and intended to use it (40/40). Most nurses found that this program provided them with new insights in the care and management of patients with aphasia (31/40). Some nurses doubted whether the CP would be sustainable on their SU (9/40) and 50% of the nurses doubted whether they would have enough time to implement the CP (20/40). (Table 3 about here)

Nurses experiences (data collected through questionnaires)

The barriers to and facilitators for using the CP are shown in Table 2. The large majority of nurses felt that the CP left them enough room to make their own decisions (27/30) and to also consider the wishes of the patient (26/30). There seems to be a decline in motivation to use the CP (from 36/40 to 18/30), which was further investigated in the focus group discussions. As was expected, most nurses indeed found the CP time con-

Table 3. Feasibility of using the Communication Program. N= number of participating nurses

	Pre-test Nurses, N=40		Post-test Nurses, N= 30	
	Yes	*No*	*Yes*	*No*
Attitude				
Are you satisfied about the program?	40	0	24	6
Do you feel you successfully executed the program?	-	-	12	18
Do you intend to (continue) use of the program?	40	0	25	5
Acceptability				
Do you think the program is appropriate for patients with aphasia?	40	0	29	1
Do you think the program is important for patients with aphasia?	40	0	29	1
Does this program provide you new insights in the care, management and treatment of patients with aphasia?	31	9	23	7
Does this program correspond to your vision on care?	40	0	29	1
Do you perceive positive effects for patients?	-	-	27	3
Do you perceive negative effects for patients?	-	-	5	25
Integration in Stroke Unit				
Do you think the program is sustainable?	31	9	21	9
Do you think the program can be applied in your organization?	39	1	26	4
Do you think the program can be integrated during the care of patients with aphasia?	36	4	27	3
Do you perceive positive effects for the organization?	-	-	15	15
Do you perceive negative effects for the organization?	-	-	10	20
Practicality				
Is the program easy to use?	-	-	22	8
Are there any problems when integrating the program?	-	-	14	16
Do you find the program to be efficient?	-	-	21	9
Do you have enough time to implement the program?	20	20	10	20

suming to use (24/30). Against expectations, the majority of nurses reported that they had enough resources to implement the CP (22/30). Nurses reported that the CP was written clearly and easy to understand (27/30).

Table 3 shows nurses' experiences with feasibility of the CP. Many nurses were satisfied about the program (24/30) and intend to continue using it (25/30). However, many nurses felt they had not successfully executed the CP (18/30). The large majority reported that the CP was appropriate (29/30) and important (29/30) for PWA. Most nurses saw positive effects for patients (27/30), however some nurses saw negative effects for patients (5/30), which was further investigated in the focus group discussions.

Qualitative data

What effects did nurses observe for patients with aphasia?

In the focus group interviews, most nurses reported positive effects for PWA: mainly an increase in the ability to communicate and less frustrations. Some nurses could not relate, and had not found any positive effects. Some nurses even reported negative effects, such as feelings of pressure in PWA to mirror the communication skills of the conversation partner. *What effects did nurses observe for themselves?* All nurses reported that the program took too much time to apply. One nurse stated that she had not learned anything new during the training session, although the others could not relate to this. Most nurses still felt incapable or frustrated when communicating with PWA. The positive aspects were predominant and mostly related to knowledge and of aphasia and awareness of communication skills. Many nurses reported that they now took more time to communicate with the PWA. Nurses tried to use more supported conversation skills than before. Now knowing which communication skills they could use often gave nurses a feeling of relief.

Were nurses satisfed about the content of the CP and the training session?

All nurses were very satisfied about the training session and asked that the training session were repeated periodically. The role-play sessions in particular were evaluated as valuable. Most nurses agreed that other HCP and family members could benefit from the training session.

What effects did the CP have on quality of care?

In general, nurses agreed that the CP resulted in more knowledge and awareness towards communicating with PWA. The nurses also reflected on setting priorities; some nurses agreed that applying the CP took so much time that other equally important issues, such as mobilisation, were sometimes halted.

Nurses' future expectations for the CP.
The nurses asked for more collaboration with SLTs. Also, nurses' advice was to involve other HCP and family members in communication partner training. Nurses agreed that less registration would benefit their time to apply communication skills and therefore benefit PWA. Finally, nurses suggested online training, such as e-learning modules, for training HCP and family members.

DISCUSSION

This study aimed to evaluate the feasibility of a generic Communication Partner Training (CPT) for nurses on the SU of a peripheral hospital. Evaluating feasibility is the first phase for evaluating the implementation of this generic CPT in a complex health care environment in the Netherlands.

Although there were several barriers to implementation, most nurses were satisfied about the Communication Program (CP), and continuation of the CP on this SU appears feasible according to nurses. Training nurses in communicating with PWA appears to have had a positive impact on nurses' awareness of communication skills. Additionally, positive effects on PWA were reported by the nurses, such as an increase in patients' ability to communicate. Nurses uniformly recognized, however, that lack of time was their biggest barrier to using the CP. An important way to support nurses could be to include less registration of the use of communication techniques during the implementation of CPT. The time limitations that nurses experience would be an important issue to investigate further and discuss with supervisors or managers during the process of implementation. Effective communication with PWA with severe communication problems remained challenging, according to nurses. Also, although nurses reported that they had enough resources to support their communication with PWA, they seldom made use of the tools that were developed in the course of this study. Therefore, an important way to support nurses in the future would be to pay attention to the implementation of supported conversation tools in daily care routine.

Remarkable and seemingly also contradictory to these findings is that there was a decline in motivation for using the CP during this study. After further exploring this in the focus group interviews, nurses agreed that it was their motivation to register their actions that declined, as registration took too much time. Nurses confirmed that their motivation to attend to CPT in the future had increased.

Important implications from this feasibility study that will be used to inform future pilot testing of CPT in health care settings in the Netherlands are: a) to explore the possibility of repeating CPT periodically, which was a specific request made by the nurses on this SU, b) to extend or add interactive training sessions including role-play, c) to investigate ways in which other health care professionals (HCP) and family members can be involved in the CPT.

Our findings are in line with research showing that, after training communication partners, self-reported knowledge of aphasia increases [9,29]. Additionally, other studies have also found practitioners' self- reported positive effects for PWA, such as less frustration, and significant increases in the communication strategies that health care professionals use [9,14].

Although the inclusion of quality criteria in the past few years have increased and resulted in superior case studies, the strength of evidence for CPT remains weak. High-quality research is needed to increase the scope and strength of recommendations and to assess implementation and long- term effects of CPT. Although there is a growing interest in patient- provider communication, most communication partner research is still aimed at training familiar partners and more research should be conducted involving HCP[7].

This study has several strengths. By using a mixed- method design, we were able to formulate nurses' experiences through both quantitative data and more in- depth qualitative data. This study was conducted in a complex natural environment, which provided the ability to assess feasibility in a real- life setting. However, some study limitations need to be addressed. The focus group interviews were not conducted through an analysis process to reach saturation. This means that diversity in the study sample was difficult to acquire and we may have missed extremely positive or negative statements. Therefore we were only able to discuss the general reports and experiences of nurses. Additionally, we used only nurses' self- reported assessment to analyse feasibility of the CP.

In this study, we provided the first step in evaluating the implementation of a generic CPT for HCP in the Netherlands, using a framework widely used in medicine: the Medical Research Council (MRC) - model for developing and evaluating complex interventions. As suggested by the MRC, future steps include further feasibility studies and evaluation of the implementation of the CPT, including contextual factors, implementation factors and mechanisms of impact that may influence outcomes of the intervention.

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CHAPTER 3

3

Ways to improve communication and support in healthcare centers according to people with aphasia and their relatives: a Dutch perspective

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Abstract

Background

There is an increasing amount of research aimed at creating a better understanding of the needs and wishes of people with aphasia and their relatives with regards to improving communication with healthcare professionals (HCP). An important way to improve communication is by training HCP to use supportive conversation techniques and tools.

Objectives

This study aimed to inform the development of such a training, by adding to previous findings in the literature regarding the experiences, needs and wishes of people with aphasia and their relatives. We were interested in their experiences with communication and support from HCP and how they believed this can be improved.

Methods

An exploratory qualitative research design was chosen. Data was collected through qualitative semi-structured interviews with people with aphasia and relatives.

Results

Four themes described the data. According to people with aphasia and relatives (1) information transfer in healthcare settings and (2) the use of supported conversation techniques by HCP are inadequate, (3) there is a lack of shared decision-making in healthcare settings, and (4) support, guidance, counseling and education is mainly targeted at the person with aphasia.

Conclusions

People with aphasia and relatives reported a variety of positive and negative experiences in all themes. Even though guidelines and interventions have been developed to improve healthcare for people with aphasia and their relatives, we found that people still encounter substantial challenges in access to- and provision of information, shared decision-making, support and communication with HCP. The findings in this study provide some important recommendations for improvement.

Keywords

Aphasia, health communication, patient experiences, qualitative research

INTRODUCTION

Aphasia as a consequence of stroke is associated with even greater disability than patients after stroke without aphasia [1–3]. In a large cohort of patients living in long-term care, aphasia was reported as having the largest negative impact on quality of life among 75 different diseases and health conditions[4]. Social isolation, depression, loneliness, reduced autonomy are likely secondary impacts of aphasia [5]. Relatives of people with aphasia also report their own emotional consequences of aphasia such as irritation, stress and anxiety [6,7] and even third-party disabilities, including physical, emotional and mental health problems, limiting their own functioning [8].

Even though communication difficulties can limit communication between people with aphasia and their relatives, people with aphasia may also be faced with communication difficulties in healthcare settings. This is often due to the healthcare professionals' (HCP) lack of knowledge of aphasia and skills in communicating with people with aphasia [9]. Successful communication between people with aphasia and their HCP leads to shared understanding, increased social participation and support, positive health outcomes, patient safety and patient satisfaction [10,11]. However, HCP report barriers to successful communication and negative experiences in communicating with people with aphasia, such as time pressure, self-perceived incompetency, frustration, irritation and lack of knowledge about using supportive conversation techniques [12,13]. These struggles are corroborated by people with aphasia. A recent systematic review evaluating the perspectives of people with aphasia towards living with aphasia shows that they often experience inaccessible communication with HCP, which leaves them feeling frustrated, disappointed and irritated [14]. In addition to the detrimental effects of inaccessible communication on emotional well-being, people with aphasia are more vulnerable to adverse events in hospital and rehabilitation settings [15], they are less likely to be discharged home from inpatient settings [16] and to return to work than stroke survivors without aphasia [17].

There is an increasing amount of research aimed at creating a better understanding of the needs and wishes of people with aphasia and their relatives towards improving communication with HCP [14,18–21]. Most of these studies have analysed the views and perspectives from participants who were discharged from a healthcare setting a (long) while back. For people with aphasia, needs and wishes include the ability to communicate not only their basic needs, but also their worries and opinions [22]. People with aphasia also wish to be treated with dignity and respect and to be engaged in healthcare activities and leisure [22,23]. Relatives of people with aphasia report the need for support in taking care of the person with aphasia, emotional support for dealing with the consequences of aphasia, psychosocial and financial support [20]. The relatives also report the need for timely information about aphasia, ongoing emotional guidance, inclusion in rehabilitation, ability to cope with new responsibilities, looking after their own emotional well-being and provision of occasional respite [20,21]. Such findings were taken into consideration in the development of guidelines, such as the (revised) Dutch Guideline for Stroke [24] and The Dutch Guideline for Aphasia [25] that were developed to provide important recommendations for organizing healthcare for people with aphasia and their relatives. For example, the Dutch Guideline for Aphasia recommends that therapy for people with aphasia focuses on improving communication between people with aphasia and their conversation partners as soon as possible.

Communication between people with aphasia and HCP can be greatly improved when HCP are trained to use supportive conversation techniques, such as mimic, gestures or drawing [26]. The present study aims to inform the development of a training program for HCP, by investigating the experiences, needs and wishes of people with aphasia and relatives. The findings in this study will answer the following research question: *How do people with aphasia and their relatives experience communication with and support from HCP in healthcare settings, and how can this be improved according to them?* This study provides a broad enquiry of feedback from people with aphasia and relatives. Although we focus on adding to previous findings in the literature, by analyzing the perspectives of people with aphasia and relatives in the Netherlands, we also aim to elaborate on the previous findings. Most studies that analyze experiences with communication and support in healthcare settings have a retrospective design. They include people with aphasia and relatives who have been living in the community for a (long) period of time [14,19–21]. In contrast, we will also include people with aphasia and their relatives currently admitted to a healthcare facility. The benefits of this prospective design are that people with aphasia and relatives provide accounts of their experiences in communicating with HCP at the present moment instead of reflecting on experiences from the past.

MATERIALS AND METHODS

Context and design

This study was part of a large multicentre implementation study in the Netherlands and Belgium, in which an intervention aiming to improve communication between HCP and people with aphasia in healthcare centres was developed, implemented and evaluated. The development of the intervention was informed by identifying stakeholders' opinions about the problem, i.e. the experiences, needs and wishes of HCP (van Rijssen et al., 2021)[33], people with aphasia and relatives (the focus of this paper). An exploratory qualitative research design was chosen using semi-structured interviews.

Participants

A total of 20 people with aphasia and 12 relatives participated in this study. People with aphasia and relatives were selected by the speech- and language therapists (SLTs) working in three geriatric rehabilitation settings in the Netherlands. Selection of these settings was partly based on convenience; the management of these specific settings gave consent to participate in this study. Furthermore, they are some of the largest facilities in the region where stroke survivors receive (long-term) care. The other participants were recruited by a call for participants via social media. Ten people with aphasia and six relatives responded to this request and were recruited for this study. Participants did not necessarily have to be dyads. Inclusion criteria for people with aphasia were that their language comprehension was adequate enough to be able to provide informed consent, they were aged over 18 years, had aphasia as a result of stroke and were receiving- or had received care in healthcare centre(s) for an undefined period. Inclusion criteria for the relatives were that they were aged over 18 years and had contact with a person with aphasia at least once a week. People with aphasia and relatives were excluded if they had severe hearing problems, a history of psychiatric disease or no Dutch language proficiency. Mean age of people with aphasia was 59 years (range 46 – 93 years). Mean age of relatives was 67 years (range 39- 96 years). Twenty percent of the participants were receiving inpatient care at the time of the study. Participant details can be found in Table 1.

Data collection

Six clinician-researchers conducted the semi-structured interviews with the participants. It was a deliberate choice to have six researchers involved throughout all phases of the project. The goal was to have a group of highly experienced SLTs involved in each step of the development of the intervention. Secondly, there were practical reasons; the spread of geographical locations of the healthcare settings meant more researchers were required to conduct the interviews within the allotted time for this phase of the study. The clinician-researchers were all experienced in either qualitative research and/or had a background as SLT, meaning that they were familiar to conducting interviews and/or talking to people with aphasia. All participants were unfamiliar to the interviewers.

Table 1. Participant demographic information. PWA= person with aphasia

Participant number	PWA or relationship with PWA	Sex	Age (years)	Educational background	Time post onset stroke (year;month)	Receiving inpatient care at the time of the interview
1	PWA	Female	63	Elementary education	0;4	Yes
2	PWA	Female	56	Master degree	1;2	No
3	PWA	Female	56	Associate degree	1;0	Yes
4	PWA	Female	46	Elementary education	2;10	No
5	PWA	Male	67	Associate degree	22;0	No
6	PWA	Female	61	Elementary education	0;9	No
7	PWA	Male	57	Bachelor degree	1;3	No
8	PWA	Female	54	Associate degree	4;9	No
9	PWA	Male	59	Associate degree	6;0	No
10	PWA	Male	66	Associate degree	3;0	No
11	PWA	Male	59	Unknown	10	No
12	PWA	Female	47	Unknown	11	No
13	PWA	Male	53	Unknown	0;3	Yes
14	PWA	Female	65	Unknown	41	No
15	PWA	Female	51	Unknown	9	No
16	PWA	Male	63	Unknown	1	No
17	PWA	Male	93	Unknown	0;10	No
18	PWA	Male	51	Unknown	2;6	No
19	PWA	Female	57	Unknown	25	No
20	PWA	Female	53	Unknown	3	No
21	Husband	Male	60	Bachelor degree	1;1	Yes
22	Husband	Male	78	Elementary education	5;5	Yes
23	Wife	Female	74	Associate degree	6;0	No
24	Partner	Female	64	Master degree	1;3	No
25	Husband	Male	66	Associate degree	0;9	No
26	Wife	Female	78	Master degree	2;9	Yes
27	Wife	Female	71	Associate degree	22;0	No
28	Son	Male	39	Bachelor degree	22;0	No
29	Husband	Male	96	Bachelor degree	31;0	No
30	Wife	Female	68	Unknown	2;0	No
31	Daughter	Female	47	Associate degree	6;0	No
32	Wife	Female	65	Bachelor degree	5;0	No

The interviews took place between April and December 2018 in the participants' homes or in a healthcare setting. The participants with aphasia were given the opportunity to be supported by a relative during the interview. The interviews were conducted with open ended questions, avoiding interpretative comments. However, in order to include people with moderate to severe aphasia, the interviewer offered a choice of possible responses when needed. Interpretively rephrasing the responses of people with aphasia was sometimes needed to ensure understanding of what was said. Inspired by narrative enquiry, people with aphasia and relatives were asked to "tell their story" from the "start of the stroke". Moving on to a more phenomenological approach, further in-dept questions were guided by an interview guide that was based on the literature about the needs and wishes of people with aphasia and relatives[5,13,18,19]. The topics that were discussed can be found in table 2.

Table 2. Topics in interview guide.

Topics discussed with people with aphasia
General experiences with receiving healthcare
Experiences with communicating with HCP
Factors that may help to improve afore-mentioned negative experiences
Topics discussed with the relatives of people with aphasia
General experiences with receiving support in healthcare centres
Experiences with the frequency and nature of support from HCP
Factors that may help to improve afore-mentioned negative experiences

Data analysis

The transcripts of people with aphasia and relatives were analyzed using the six steps of Braun and Clarke for thematic analysis[27]. The qualitative data analysis software Atlas.ti 8 Windows™ (ATLAS.ti Scientific Software Development GmbH) was used to manage the data. The interviews were coded by two researchers. An iterative approach was used, where researchers checked the themes against earlier transcripts and keywords.

Rigor

Before conducting the interviews, the researchers met for one calibration session to discuss the interview guide and one calibration session to practice the interview. After the interviews, member checks were conducted with three people with aphasia and three relatives to verify data and interpretations, which included sending a summary of the interview back to the respondent to check the validity of the data. No participants requested any changes. During coding, analysis and interpretation, two researchers discussed decisions to ensure investigator triangulation. Representative quotes were translated from Dutch to English, and double checked by a translator with excellent knowledge and understanding of Dutch and English.

Ethical issues

This study was approved by the Medical Ethical Committee of the University Medical Centre Utrecht (number: 18-159/C) and performed in accordance with the Helsinki Declaration and the EU General Data Protection Regulation. The researchers provided thorough written and verbal information to participants and informed consent forms were signed. Aphasia-friendly informed consent forms were provided to participants with moderate to severe aphasia.

FINDINGS

Four themes were identified to describe the experiences of people with aphasia and relatives with communication and support in healthcare settings, and their needs and wishes for improvement.

Theme 1: Inadequate information transfer in healthcare settings

Information transfer was a prominent theme for people with aphasia and relatives. This theme highlighted the importance of providing people with aphasia and relatives with accessible information in the early stages of recovery and repeating information throughout subsequent phases. The majority of participants were dissatisfied about the way that HCP provided information. Most information was provided by written text, such as folders, presentations or through websites, and supported by spoken information. People with aphasia commented that written information was often inaccessible or too generic for their situation, as the following quote illustrates:

> *Person with aphasia; It started on my first day at the healthcare facility… Some sort of… welcome. That was strange. The woman… nurse.. she had four pages with text. There you go. But I said… I said I can't read. Then she said: the most important thing to know is that you can't smoke. We laughed… a joke… But it did leave me feeling… What am I missing? So I asked my wife to read it. It made me feel so stupid.*

Written information should be made accessible according to people with aphasia. Suggestions that they made included using more pictures, underlining words, using a bigger font size and shorter sentences, and always supporting written information with spoken information.

> *Person with aphasia*: *Make written information easier to read. Shorter sentences. Use pictures*

Opinions about the accessibility of spoken information were particularly evident in relatives' comments, which revealed that HCP used "difficult terminology", making information inaccessible to them and their family member with aphasia:

> *Relative: […] and I'm staring at this folder, with all kinds of medical terms. I told them that. Write and speak in terms that are accessible from a lay perspective.*

Relatives also commented that every piece of information, whether it was written or spoken information, should be repeated. Opinions about how often HCP should repeat information in each stage after stroke varied. The following relative commented that she wished information was repeated every three days:

> *Relative: Brochures, folder, books. All with good intentions, but please dose it more carefully, or wait. Come back after three days, and explain again page by page.*

Theme 2: Inadequate use of supportive conversation techniques by HCP

According to people with aphasia, communication with HCP improved when HCP took more time for conversations and used supportive techniques to provide structure, non-verbal support and written support. Some people with aphasia were satisfied about the supportive conversation techniques that HCP used to communicate. Others, particularly the people receiving inpatient care at the time of the interview, experienced a complete absence or insufficient use of relevant techniques by HCP. The following quotes provides an example:

> *Person with aphasia*: *I… that doctor, who, yeah, who came to visit me regularly… and that… situation I was in, OK, that was… aphasia… yes. She told me I had been lucky. Well, great. And I couldn't … I thought, let her talk. I don't understand… couldn't. She kept talking and talking. So I just let her.*

The use of supportive conversation techniques by any conversation partner made people with aphasia feel like that person was genuinely interested in their lives and their needs; a crucial component for people with aphasia to feel they could successfully live with aphasia. The following quote provides an example of suggestions made by a participant with aphasia:

> *Person with aphasia: HCP should make more effort to understand what I have to say. Try to listen between the lines. It's like when I'm reading my e-mails. I have difficulty reading because I can't see the left side properly. I really have to make an effort to read. That's what HCP should do. Make an effort to write down their words or use other ways to communicate.*

Most relatives expressed their desire that HCP acted as role models, showing them techniques that were beneficial to communicate with the person with aphasia. People with aphasia and relatives also suggested to invite experts by experience (people with aphasia and relatives in the chronic phase) to share their stories with HCP. Some relatives hypothesized that inviting experts by experience to talk about aphasia and their experiences would improve empathy from HCP. This relative had once seen a person with aphasia share her experiences during lectures:

> *Relative: She (person with aphasia) gave lectures about aphasia and how to deal with it. She gave these lectures at healthcare settings and schools. Everyone went quiet after her talk. I think it is very important that healthcare professionals know the impact of aphasia.*

Theme 3: Lack of shared decision-making in healthcare settings

For many people with aphasia, the theme of shared decision-making was mainly associated with decisions made around follow-up care. Many people with aphasia and relatives indicated that those decisions were made by the HCP and/or the relatives. One third of the people with aphasia preferred it this way, as illustrated by the following quote:

> *Person with aphasia: My husband decided which rehabilitation centre I would go to, because I had no idea. And I was happy with that.*

These participants with aphasia felt too scared or incapable to make these decisions, mainly due to their communication difficulties. They reported that they trusted HCP to make the right decisions and their loved ones to take their wishes into account. Others expressed their dismay at not being involved in decisions around follow-up care:

> *I hate it when others make the decisions for me. Or when they complete my sentences. It is my decision!*

Relatives recognized these frustrations in their family member with aphasia:

> *My daughter came back from Aruba and heard that they were planning to transfer her father to a nursing home. She rejected that decision. I do understand that health-care professionals have certain protocols they should stick to. But they could have at least discussed this with me and my husband.*

Overall, there was strong agreement that HCP should always provide people with aphasia the opportunity to make smaller decisions, such as what to eat or when to go to bed, themselves; a crucial component to feel valued and autonomous.

Theme 4: Support, guidance, counseling and education is mainly targeted at the person with aphasia

A small subgroup of relatives expressed that they were satisfied with the amount and quality of support, guidance, counseling and education in healthcare settings. Involving them in therapy especially made them feel supported in coping with the communication difficulties and educated in the consequences of aphasia. However, guidance and support for relatives was insufficiently targeted at the emotional consequences of living with a family member with aphasia. Therefore, most relatives expressed negative experiences with support, guidance, counseling and education with regards to their own needs. The following quote illustrates this:

> *Relative*: *They never asked me how I am doing and if I need any help. As long as they acknowledge that you, as a relative, may need help as well.*

One relative shared that she had missed a HCP to share her sorrows and anxiety with. Another relative expressed that she believed that if she had been guided in how to look after herself, she would have been more capable to look after her husband. One relative noted that she felt deserted by the HCP, who focused only on her husband with aphasia and not on her own psychosocial wellbeing:

> *Relative*: *I understand it's difficult, but I would have liked it if HCP had been accessible to me sometimes.*

Although some relatives asked for more emotional guidance of their own wellbeing, others expressed that the rehabilitation of the person with aphasia had priority and that they preferred to seek emotional guidance elsewhere:

> *Relative: I have experienced that these sort of problems can lead to divorce and that is not what I want. My wife was doing so well in the rehabilitation center, and I wanted her to continue improving, so I sought out help for myself elsewhere.*

Some relatives expressed that trivializing or reducing information about outcomes or expectations for the future felt disrespectful and would be counterproductive for positive relations:

> *Relative: […] not knowing what is happening and what possibilities we have. What do therapists expect for the future? Is anything changing or improving for the person with aphasia? Or not? Please be honest.*

DISCUSSION

The aim of this study was to inform the development of a training program for HCP, by analyzing the experiences, needs and wishes of people with aphasia and relatives. The findings show a large variety of positive and negative experiences within the themes. This emphasizes not only the importance of recognising and capturing people's individual realities in healthcare research, but also underlines the importance of providing personalized care.

Even though guidelines have been developed in order to improve healthcare for people with aphasia and relatives [24,25], based on the findings of our participants who shared their recent experiences, substantial challenges are still evident in this population regarding access to and provision of information, shared decision-making, support and communication with HCP. We can conclude that the organization of healthcare for people with aphasia and their relatives still requires improvement and the findings in this study provide some important areas that require attention.

According to people with aphasia and relatives, one important area of improvement is the transfer of information in healthcare settings. Spoken and written information should be made accessible to people with aphasia, by using short sentences, keywords and pictures in written information and supportive conversation techniques in spoken information. The relatives reported that they wish to be provided with "honest" information about the prognosis and expectations for the future. Providing an adequate prognosis for people with aphasia is challenging, as outcomes depend on many factors such as lesion site or aphasia severity at onset [28]. The results in this study advocate addressing this uncertainty directly in conversations with relatives instead of shying away from the topic and communicating information sensitively and repeatedly[18].

Another important area of improvement is the use of supportive conversation techniques by HCP. One way to address this, is by inviting people with chronic aphasia and their relatives to share their stories and provide recommendations to HCP. Patient involvement in healthcare education is becoming increasingly important [29], because it creates the opportunity to include the psychosocial consequences for patients and relatives and promotes patient-centred care. Inviting experts by experience during skills training provides HCP with information about health and emotional consequences from credible sources [30].

The third area that needs improvement concerns support for relatives. The finding that relatives want to be involved in the care pathway of their loved one is in line with previous findings [12,22]. In fact, better outcomes are to be expected when stroke rehabilitation is organised as family-centred care [31], which family members describe as care that focuses on preparing for discharge [32]. However, after prompting, the relatives in this study advocate providing individual support for relatives alongside a family centred approach. Suggestions they gave were screening and monitoring their (mental) health and providing them with emotional guidance. As relatives of survivors of stroke often experience third-party disabilities, such as anxiety and depression [7,31], it seems very reasonable to state that relatives should receive individual support.

In relation to study limitations, it is important to note that we aimed to include people with aphasia and relatives currently admitted to a healthcare facility. Unfortunately, we managed to recruit only six participants who met this criterion. Therefore, 20% of the findings (interviews with 3 people with aphasia and 3 relatives) are based on the experiences of communicating with HCP at that present moment. For the other participants, the findings may have been influenced by the fact that they shared experiences from the past. However, we did manage to include another six participants around 1 year post stroke, who thus shared relatively recent experiences.

Starting the interviews with a narrative approach allowed further in-depth questions to be based truly on the participants' own experiences in healthcare settings. It is important to note that we conducted qualitative research to help us inform the development of a training program for HCP. The findings in this study therefore do not represent the overall opinions of people with aphasia and relatives throughout the Netherlands and Belgium.

Conclusion

This study aimed to inform the development of a training program for HCP, by analysing the experiences of people with aphasia and relatives with communicating with HCP and their needs and wishes for improvement. People with aphasia and relatives reported both positive and negative experiences with communication and support from HCP.

The main areas that require attention in the organization of healthcare for people with aphasia include the transfer of information, individual support for the relatives, shared-decision making and communication between HCP and people with aphasia. The findings in this study provide some important recommendations in each area.

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DECLARATION OF INTEREST STATEMENT

The authors report no conflict of interest.

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CHAPTER 4

4

How do healthcare professionals experience communication with people with aphasia and what content should communication partner training entail?

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Abstract

Purpose

Aphasia after stroke has been shown to lead to communication difficulties between healthcare professionals (HCP) and people with aphasia. Clinical guidelines emphasize the importance of teaching HCP to use supportive conversative techniques through communication partner training (CPT). The aim of this study is to explore and describe the experiences of HCP in communicating with people with aphasia and their needs and wishes for the content in CPT.

Materials and methods

The data were collected through qualitative semi-structured interviews with 17 HCP. HCP were recruited from two geriatric rehabilitation centres in the Netherlands and one academic hospital in Belgium. The interviews drew upon the qualitative research methodologies ethnography and phenomenology and were thematically analysed using the six steps of Braun & Clarke.

Results

Three themes were derived from the interviews. HCP experienced that communication difficulties impede healthcare activities (theme 1) and reported the need to improve communication through organizational changes (theme 2), changing the roles of SLTs (theme 3) and increasing knowledge and skills of HCP (theme 4).

Conclusions

According to HCP, communication difficulties challenge the provision of healthcare activities and lead to negative feelings in HCP. HCP suggest that communication can be improved by providing more time in the healthcare pathway of people with aphasia, adapting healthcare information to the needs of people with aphasia, commitment of physicians and managers, changing the roles of SLTs and improving knowledge and skills of HCP.

Keywords

Aphasia, health communication, health education, qualitative research

INTRODUCTION

Successful communication between healthcare professionals (HCP) and patients is essential to engaging patients in their healthcare pathway [1] and improves patients' rehabilitation outcomes and quality of life [2,3]. As high-quality care involves successful communication, people with communication difficulties are at risk of receiving low-quality healthcare.

Aphasia, defined by the National Institute of Neurological Disorders and Stroke as "a neurological disorder caused by damage to portions of the brain that are responsible for language production or processing" [4], can cause severe communication problems between the stroke survivor and HCP. The neurological language disorder represents a life-changing experience for individuals. People with aphasia have higher risks of depression than stroke survivors without aphasia [5], show worse rehabilitation outcomes and par rates [6,7]. Clinical guidelines, such as the Dutch Guideline for Aphasia [8], emphasize the importance of improving communication skills of HCP [9] in order to improve quality of healthcare for people with aphasia.

Previous research shows that HCP describe challenges when communicating with people with aphasia [10–12]. Although HCP feel responsible for successful communication [13] and find it important to respect patient autonomy, time pressure and self-perceived incompetency in using supportive communication techniques often force HCP to take control of topics, ignore patient's responses [11,14] or communicate with family members instead of with people with aphasia themselves [13]. Two recent studies show that HCP have negative feelings when trying to communicate with people with aphasia [15,16]. HCP limit their conversations with people with aphasia and do not know how to help [16].

Communication with people with aphasia can be greatly improved when their conversation partners use relatively simple supportive communication techniques, such as mimic, gestures or drawing, and supportive conversation tools [17]. HCP report a number of reasons for not using these techniques and tools: self-perceived incompetence [11,14], unavailable resources [18], lack of confidence in using the techniques that speech-and language therapists (SLTs) suggest, lack of belief that the techniques are always effective, and lack of training [16].

SLTs and SLT researchers respond to this request for help with the development of communication partner training (CPT) interventions for HCP. CPT is an umbrella term for complex interventions that are aimed at changing behaviours of the conversation partners of people with aphasia [19]. One important and widely used element in CPT is training conversation partners to increase their knowledge and skills in using supportive conversation techniques and tools [19]. Studies have also found other elements that are important in CPT, such as leadership support after the training [20], reflection on existing practices and participation of senior staff and managers [21].

A well-known CPT is Supportive Conversation for adults with Aphasia (SCA^{TM}) [17], which aims to provide people with aphasia with genuine adult conversation by educating the conversation partner. Many CPT interventions for HCP are based on SCA [20,22,23]. Some examples are an e-learning program combined with role-play sessions [24], and an educational workshop and face-to-face training sessions provided by people with aphasia [21]. Many CPT incorporate the use of aphasia-friendly formatting, where the content and design of written health information used by HCP is made aphasia-friendly [25].

Research on the effects of CPT is increasing [21–24,26,27]. Simmons- Mackie et al. [1,28] concluded in their two systematic reviews that CPT improves the communication skills of the trained partner. Positive effects on activity, participation and psychosocial well-being of people with aphasia have been reported including increased interactions between people with aphasia and their HCP and less frustration [20]. CPT aimed at training nurses have also been shown to significantly increase staffs' self-administered knowledge of aphasia [20,22] and the use of supportive communication techniques by nurses [22].

Evidence shows that it may be difficult to use or maintain using techniques and tools after CPT without paying attention to the specific needs in a healthcare setting (21). Given that an increasing number of studies evaluate CPT and are finding positive effects of training HCP, analysing the implementation of CPT in healthcare settings has a high priority [29]. Several studies have analysed the implementation of CPT in healthcare settings [20,21]. However, to our knowledge, no studies to date have analysed HCP perspectives on the requirements of CPT. A comprehensive understanding of HCP needs and wishes on the content of CPT is essential to increase the likelihood of successful implementation of CPT interventions in healthcare settings [30]. To understand HCP needs and wishes this study explores and describes their experiences in communicating with people with aphasia in Dutch healthcare settings and their needs and wishes for CPT content.

METHODS

Design

This study was part of a multicentre implementation study in the Netherlands and Belgium that explored the development and implementation of an intervention aimed at improving communication between HCP and people with aphasia. We followed the Medical Research Council guideline for developing and evaluating complex interventions [31]. The development of the CPT intervention was informed by the experiences, needs and wishes of HCP (this paper) and people with aphasia and their relatives (van Rijssen et al. submitted). The outcomes of both studies were used to develop our CPT intervention named CommuniCare.

Participants

HCP were recruited from two geriatric rehabilitation centres in the Netherlands and one academic hospital in Belgium. Selection of these three settings was based on two thoughts. First, they are some of the largest facilities in the region where stroke survivors receive (long-term) care. Second, the management of these specific settings was able to facilitate HCP in time to participate. SLTs working in the included centres -for clarification purposes, these were not the authors- selected participants by criterion sampling [32], in which participants met the following predefined criteria: 1) participants possessed a Certificate of Current Professional Status (CCPS), 2) had experience with communicating with people with aphasia and 3) communicated with people with aphasia on a regular basis at the time of this study. We aimed to include a variety of professions. SLTs recruited HCP by sending them an e-mail with information about the study. Seventeen HCP responded and gave informed consent.

Table 1 shows participants' characteristics. Six HCP worked in an academic hospital in Belgium and provided care to people with aphasia in the acute phase after stroke. Twelve HCP worked in two different geriatric rehabilitation centres in the Netherlands and provided care to people with aphasia from one week post-onset up until the chronic phase. All participating HCP had not received CPT at the time of this study. The years of experience working as a HCP for people after stroke ranged from one year to 39 years.

This study was reviewed and approved by the Medical- Ethical Committee of University Medical Centre Utrecht, the Netherlands and conducted according to the declaration of Helsinki. The researchers provided thorough written and verbal information to participating HCP and informed consent forms were signed.

Data collection

Qualitative semi-structured interviews were used to collect the data [33]. Six researchers (five SLTs and one registered nurse) conducted one-to-one interviews according to an interview guide. The large number of researchers involved was due to two reasons. First, the spread of geographical locations of the healthcare settings meant more researchers were needed to conduct the interviews within the allotted time for this phase of the study. Second, the goal was to have a group of highly experienced SLTs and qualitative researchers involved in each step of the development of the intervention. All researchers were unfamiliar to the participants.

The interviews took place from April 2018 to December 2018 and were held during shifts at three healthcare settings in the Netherlands and Belgium. Each interview lasted approximately one hour and was audio-recorded.

The interviewers used an interview guide that was partially based on the two studies that were mentioned before, which reported on the experiences of HCP with communicating with people with aphasia [15,16]. The interviews draw upon the qualitative research methodologies ethnography and phenomenology. Ethnography involves the study of social interactions, behaviours, and perceptions that occur within teams or organisations [34]. In this study, HCP beliefs about what should be included in a CPT intervention for their organisation were analysed. Phenomenology involves the analysis of a phenomenon through the lived experiences of individuals [33]. In this study, the individual experiences of HCP in communicating with people with aphasia were explored to understand their beliefs about problems they face. The topics that were discussed are listed in Table 2.

Data analysis

The interviews were transcribed verbatim. We used an inductive approach to guide the analyses because of the explorative design. An inductive approach means that the themes that are created are strongly linked to the data. The individual experiences and beliefs of HCP were thematically analysed using the six steps of Braun & Clarke [35], which involve 1) familiarizing yourself with the data, 2) generating initial codes, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes and 6) writing the report. A theme was defined as something that has a certain level of pattern or meaning in relation to the research questions. Researchers moved back and forth between the codes and themes and decided to stop coding when no new codes generated from the transcripts. Final decisions about the themes and subthemes were made between the researchers, by discussing the content and formulation of themes in a group session. Themes were analysed within- and between HCP. Qualitative data analysis software Atlas.ti 8 Windows^{TM} (ATLAS.ti Scientific Software Development GmbH) was used to manage the data.

Rigor

Demographic data of HCP were described in detail to enable readers to draw conclusions about the transferability of our findings to their own situation. Before conducting the interviews, the researchers met for one calibration session to discuss and practice the use of the interview guide. The importance of the principles of honesty, scrupulousness, transparency, independence and responsibility as described by the code of conduct for research integrity (VSNU, 2018) were discussed in relation to possible presupposition of the researchers, who all were likely to have their own perceptions and ideas with regards to the importance of communication. After the interviews, we conducted member checks with nine participants to verify data and interpretations. Due to time limitations, we did not conduct member checks with all participants. The member checks involved sending summaries of the interviews back to the corresponding respondents to check if the summary provided a correct and complete reflection of the respondent's perspectives. The participants who conducted member checks did not require changes to the summaries. Investigator triangulation was applied by developing the interview guide with two researchers and involving all six researchers throughout the process of data analysis. In order to improve credibility, one interview was coded by six researchers and the remaining interviews were coded by one researcher and checked by a second researcher. The final version and all previous versions of Atlas.ti documents were saved and clearly labelled with a date. Representative quotes were translated from Dutch to English, and double checked by a translator with excellent knowledge and understanding of English.

RESULTS

Four themes, related to the experiences of HCP communicating with people with aphasia and their needs and wishes for CPT content, were created from the analysis. These themes were: HCP experienced that communication difficulties impeded healthcare activities (theme 1) and they reported the need to improve communication through organizational changes (theme 2), by changing the roles of SLTs (theme 3) and by increasing knowledge and skills of HCP (theme 4). Each theme is described in detail below and examples are given by including quotations. An overview of themes and subthemes can be found in table 3.

Communication difficulties impede healthcare activities

The HCP expressed that providing healthcare activities to people with aphasia is much more difficult than providing healthcare to people without communication difficulties.

In the diagnostic phase, in which HCP assess functioning, disability and health, there were two commonly expressed barriers. First, HCP experienced challenges understanding the problems that people with aphasia face, and their needs and wishes:

Table 1. Demographic data of healthcare professionals (N=17).

Name (pseudonym)	Healthcare profession	Gender	Age (years)	Educational background	Years of experience as HCP	Years of experience with people after stroke	Place of work
Ben	Physiotherapist	Male	61	Bachelor degree	35	20	GR, NL
John	Physiotherapist	Male	32	Bachelor degree	6	6	GR. NL
Ken	Psychologist	Male	33	Master degree	9	8	GR. NL
Marjorie	Activity counsellor	Female	54	Associate degree	25	25	GR. NL
Jamie	Nurse	Male	55	Associate degree	31	8	GR. NL
Vera	Nurse	Female	54	Associate degree	34	34	GR. NL
Laura	Geriatrician	Female	53	Master degree	16	15	GR. NL
Sara	Nutrition assistant	Female	58	Associate degree	12	12	GR. NL
Kim	Occupational therapist	Female	28	Bachelor degree	5	5	GR. NL
Patricia	Nurse	Female	59	Bachelor degree	39	39	GR. NL
Charlotte	Social worker	Female	29	Bachelor degree	Unknown	5	GR. NL
Fenna	Nurse	Female	51	Associate degree	Unknown	27	H, BE
Claire	Nurse	Female	55	Bachelor degree	32	32	H, BE
Kate	Nurse	Female	20	Bachelor degree	4 ½	1	H, BE
Pamela	Nurse	Female	48	Associate degree	7 ½	7 ½	H, BE
Joyce	Nurse	Female	60	Associate degree	28	8	H, BE
Ralph	Physiotherapist	Male	28	Bachelor degree	5	5	H, BE

Table 2. Topics discussed with healthcare professionals

Topics	Subtopics	Sample questions
Experiences with communicating with people with aphasia	General experiences	How do you compare providing healthcare to a person with aphasia versus to a person without aphasia?
	Causes	Why do you have those experiences with communicating with people with aphasia?
	Specific examples	Can you give examples where communication with a person with aphasia went really well and not so well?
Needs and wishes to improve communication with people with aphasia	Support from other HCP	Is there anything that works well concerning support from other HCP which you would like to see continued? Is there anything you would like to see changed in support from other HCP in order to improve communication?
	Other support	Is there anything that you would like to see continued concerning support from other professionals? Is there anything you would like to see changed in support from other professionals, such as your manager? Is there anything else that you would like to see changed in your healthcare facilitation in order to improve communication with people with aphasia?
Needs and wishes for the content of communication partner training	Need for training	Do you feel the need to receive training to improve communication with people with aphasia?
	Content for training	What content should be part of such a training, according to yourself?
	Supportive conversation tools	Do you feel the need for supportive conversation tools and what should they contain?
	Group composition during training	Would you prefer a multidisciplinary or uni-disciplinary group in that training, and why?

> *It's very difficult to judge what someone with aphasia needs. They cannot verbalize that. Some people can say or show that they're in pain, but where and what kind of pain... For someone with aphasia it's very difficult to provide a diagnosis and plan what's next.* (Kim, occupational therapist).

The second problem reported by HCP is that they find it difficult to estimate language comprehension of the person with aphasia. In consequence, HCP do not know to what extent they should adapt their communication to the specific needs of the person with aphasia.

HCP reported that the communication difficulties impede shared decision-making. In the following quote, Laura reported that she finds it almost impossible to involve people with aphasia in decisions made around their own healthcare pathway:

> *Involving people with aphasia in planning for treatment, that is so difficult. Goal setting, what would the person with aphasia like to work on? What should we focus on? With what goals shall we start? […] it's very difficult to give someone with aphasia the lead in his own treatment. It's practically impossible* (Laura, geriatrician).

In the rehabilitation phase, HCP again commonly expressed two main barriers. The first problem that HCP faced is providing instructions. A physiotherapist gave the example of trying to explain to a person with aphasia that she was allowed to walk independently with a walker:

> *[…] having aphasia makes it difficult to start practicing new things. When I said: "you may walk with the support of your walker", she didn't understand that instruction. That makes it so difficult to determine whether someone will start practicing... and to find out if someone has been practicing that day* (John, physiotherapist).

Some other physiotherapists reported that they rarely face problems when providing instructions, because they can demonstrate the intended behavior to people with aphasia. However, they elaborated that explaining *why* an exercise is necessary to perform remains difficult. The second problem that HCP commonly expressed was evaluating therapy with people with aphasia.

Besides problems in the diagnosis and treatment of people with aphasia, most HCP reported that communication problems also result in negative feelings. HCP reported that communication problems cause them feelings of discomfort, insecurity and frustration:

> *Communication problems can be very frustrating. You can't help these people […]. […] if they can't even use gestures… Then it's so difficult. I can feel helpless at times* (Pamela, nurse).

These negative feelings made it difficult for HCP to connect with people with aphasia:

> *I notice feeling foolish when asking the same thing five times in a row. And I am always determined to continue trying because I want to succeed. I think you shouldn't show the patient that you're feeling uncomfortable. That would mean showing him that you're taken aback and choosing a socially accepted path, that you're ignoring the problems and that's not something I want to do* (Ken, psychologist).

Table 3. Themes related to the experiences with communicating with people with aphasia and needs and wishes for CPT content. HCP= healthcare professionals, SLT= speech and language therapists

Main theme	Subthemes
Communication difficulties impede healthcare activities	Communication difficulties impede assessment
	Communication difficulties impede therapy
	Communication difficulties cause negative feelings in HCP
Improving communication through organizational changes	Provision of more time in the healthcare pathway of people with aphasia
	Adapting resources to make them aphasia friendly
Improving communication by changing roles of SLTs	Improved reporting in patient records
	Improved guidance
Improving communication by increasing knowledge and skills	Increasing knowledge of aphasia
	Increasing skills to engage people with aphasia in daily activities
	Ongoing training to use communication techniques and supportive conversation tools
	Increasing knowledge of accessibility of supportive conversation tools

Improving communication through organizational changes

Most HCP expressed that diagnosing and treating people with aphasia requires more time compared to people without communication problems. However, due to the funding structure in the Dutch healthcare system, people with aphasia generally do not get extra time in their care pathway. HCP suggested that healthcare centres should allocate more time for sessions with people with aphasia:

> *We have a patient at this moment who has aphasia. When she says "yes", sometimes she means "no". Last week she fell when she was in her room. One of the healthcare professionals found out that someone had forgotten to put the brakes on her bed. People thought this must have been the reason she fell. However, when I took the*

> *time to ask the patient questions about what had happened, she finally managed to tell me that the brakes on the bed were not the reason she fell. So, taking the time to communicate with this woman had helped to get her message across* (Vera, nurse).

HCP criticised the physical environment of their healthcare setting, and argued that information folders, signage and practice areas should be adapted for people with communication problems:

> *We've mainly talked about conversations with people with aphasia. But I think… I hope that we might get more help in changing our environment, making it more aphasia friendly, from the inside and out. Like folders, pictograms, things like that. I hope you can help us develop such tools. […] The building. Signage. Using more pictograms and such* (Laura, geriatrician).

Improving communication by changing the roles of SLTs

Four HCP expressed that they require more information about the communication needs of a person with aphasia in patient records. They argued that using supportive conversation techniques requires knowing the type of aphasia, knowing which modalities (language production, language recognition, reading, writing) are mainly affected and knowing which techniques might benefit conversations with the person with aphasia. HCP suggested that SLTs should report this information in electronic patient files:

> *[…] so that you can instantly see: aphasia, type of aphasia, so that you, whenever you see this patient, know that this person has trouble finding words because she no longer knows the words or no longer knows their meaning. If an SLT reported this we could efficiently approach people and not feel frustrated because we must find out what works for the person with aphasia* (Marjorie, activity counsellor).

The HCP expressed that communication would improve if they receive more guidance from SLTs. One suggestion was that SLTs should provide HCP with clinical teaching lessons:

> *We don't see SLTs very often. They work in a different way, they stay in their therapy rooms most of the time. It would be great when SLTs plan ahead and recommend the rest: how do we manage this person? What works for this person? This information should be updated on a regular basis. I think we should improve collaboration with SLTs in the future, especially to the benefit of people with aphasia* (Kim, occupational therapist).

Improving communication by increasing knowledge and skills of HCP

Some HCP expressed that increasing knowledge of aphasia would improve communication:

> *[…] but aphasia is often misunderstood. If a person cannot talk, many people believe this person doesn't understand either. […]In an ideal world, everyone who works in this healthcare centre receives education on what it means to have aphasia […]* (Kim, occupational therapist).

One HCP mentioned that especially staff who do not frequently communicate with people with aphasia lack knowledge and therefore do not have the confidence or means to use supportive conversation techniques.

One HCP expressed that it is important to understand how to engage people with aphasia in daily activities:

> *I remember when I started working as a doctor. I frequently sat down with the family alone … I stopped doing that you know […]. I find it very important to engage people with aphasia in conversations.. Sometimes you see that the person with aphasia is trying so hard to understand what we're saying, but can't… However, I think it's much better to involve people with aphasia than to not involve them at all* (Laura, geriatrician).

The HCP uniformly expressed that ongoing training in using supportive communication techniques and tools would be beneficial for the entire team. One HCP expressed that she would like to learn how to communicate with people with aphasia step by step:

> *Ideally we would receive a step-by-step plan. What should we do now? "Finish his sentence, give him more time." What can I do when someone feels frustrated? How can I deal with the family members? […]. Every situation is different, but examples of scenario's and practicing skills would benefit the entire team. […] I think it would help to boost my confidence* (Tina, occupational therapist).

HCP expressed that they often feel insufficiently competent to use techniques and tools. The HCP all reported that a mixed group of HCP during trainings would be preferred over uni-disciplinary groups.

HCP also reported that skills, or even motivation, would improve if they knew where to find and how to develop supportive conversation tools. HCP suggested that SLTs should develop these tools and a HCP or volunteer should be made responsible to adapt the tools weekly. The majority of HCP reported that there are not enough tools available. The following quote illustrates this and also shows that it is vital to develop these tools when requested and in consultation with HCP:

> *At the stroke unit? No, we don't have enough supportive conversation tools available. I mean, if a stroke unit has a demand for these tools, SLTs should explain how to developed these and inform us, and also ask us what these tools should contain* (Ralph, physiotherapist).

DISCUSSION

The aim of this study was to explore and describe the experiences of HCP in communicating with people with aphasia and their needs and wishes for the content in CPT. The findings in this study show that, from HCP perspectives, communication difficulties impede diagnosis and therapy for people with aphasia and cause negative feelings. According to HCP, communication with people with aphasia can be improved through increasing their knowledge and skills in CPT, as well as paying attention to organizational changes and changing the roles of SLTs.

Communication problems between people with aphasia and HCP have been reported as a serious concern from a medical point of view, since they are a source of error in diagnosis and therapy [36]. This study substantiates that it is probable that shared decision-making can be undermined for people with aphasia [11,13,14,16]. Also, communication problems impede the provision of instructions and the evaluation of therapy according to HCP. The impact of misunderstanding therapy instructions and not participating in evaluations is considerable. Secondary prevention depends on understanding medical recommendations and instructions, and nonadherence to instructions leads to poorer treatment outcomes [37]. Participating in healthcare evaluations is a critical target of health and rehabilitation and improves social relationships and life quality [37].

The suggestions of HCP concerning CPT content can be placed under two of the five stages Cruice et al (2018) identified in existing CPT interventions; 1) education, 2) awareness raising, 3) identification of target behaviours and strategies, 4) practice and 5) implementation and post-training support [19]. HCP in our study argue that CPT interventions should contain education in using supportive conversation techniques. This should be a combination of knowledge training and some form of hands-on practice of techniques, preferably with people with aphasia rather than an actor in role-play. HCP furthermore gave many suggestions that could be categorized as “implementation and post-training support”. Two frequently mentioned suggestions in this category were a more proactive and coaching role of the SLT, and changes at an organizational level. These two points will each be discussed below.

Concerning the role of SLTs, HCP expressed that they felt insufficiently competent to use supportive communication techniques and tools. In addition to the request for training and education they specifically addressed the need for improved guidance from SLTs after CPT. The importance of the role of SLTs was also reported by the study of Carragher et al. [16]. Our findings point towards four specific roles for SLTs to fulfil. First, SLTs have a role to provide HCP with the knowledge and skills to use supportive conversation techniques and tools. Second, SLTs have the responsibility of keeping tools up to date and easily accessible to HCP. Third, SLTs should act as visible role-models, continuously demonstrating adequate and appropriate communicative behavior with individual people with aphasia, and thus demonstrating how various techniques can be used. And fourth, SLTs should be coaching HCP on the job, supporting them to feel confident in using techniques and tools and providing them with direct feedback in their conversations with people with aphasia. These suggestions have important implications for the roles and responsibilities of SLTs. Their role will need to change, because they will need to spend more time on wards and in interprofessional collaboration with and coaching of colleagues than in current practice. It probably also means that SLTs will need to develop competencies needed to coach and support other HCP. In addition it means that funding structures in the Dutch healthcare system will need to change, as SLTs are currently funded based on the number of required hours of care for individual patients.

In addition to the changing role of the SLTs, HCP plead for more time in the care pathway of people with aphasia. The same finding was reported in the study by Carragher et al. [16]. In light of the rise of standard patient care pathways, it is even more urgent that this call for more time is taken seriously by service providers [38]. As suggested by Rodgers and Price [38], good communication and shared decision-making with patients and their families are key to high-quality stroke care. Based on our findings, we argue that for people with aphasia, high quality care can only be realized when more time is allowed in their care pathway.

HCP also identified the importance of commitment of HCP with a high level of authority and responsibility, such as physicians and managers. This means that physicians and managers should propagate the use of supportive communication techniques, feel responsible for facilitating CPT for all HCP and evaluate the use of techniques in healthcare settings. It also includes the ‘practice what you preach’ principles; all staff should be involved in the CPT intervention and learn how to adequately communicate with people with aphasia.

Our study aimed to create a comprehensive understanding of HCP experiences with communicating with people with aphasia and their needs and wishes on CPT content, as this is essential to increase the likelihood of successful implementation [30]. The results of this study formed the bases for the adaptation of the pilot version of a CPT developed in 2017 [39].

In relation to study limitations, it is important to note that HCP were recruited from only two different healthcare settings, one hospital and two geriatric rehabilitation centres. Future research would benefit from including HCP from long-term care facilities. We expect that HCP in these settings will have less experience with communicating with people with aphasia and might therefore have different needs and wishes in CPT content. Another study limitation which needs to be addressed is that the interviews were conducted and analysed by six researchers. Although we had practical and methodological reasons for this, this high number of researchers may have introduced differing practices and responses to the participants during the interview.

CONCLUSION

According to HCP, the communication difficulties with people with aphasia challenge the provision of assessments and therapy sessions and lead to negative feelings in HCP. HCP suggested that communication can be improved by increasing HCP knowledge and skills through CPT interventions, if attention is paid to making organizational changes and changing the roles of SLTs. Organizational changes include the provision of more time in the healthcare pathway and adapting healthcare information to the needs of people with aphasia. Physicians and managers should feel responsible for facilitating CPT for all HCP and evaluating the use of techniques in healthcare centres. The findings in this study point towards four specific roles that SLTs have to fulfil in order to guide HCP in using supportive conversation techniques.

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CHAPTER 5

5

The description of the intervention CommuniCare

This chapter describes CommuniCare: a Communication Partner Training (CPT) that aims to train and assist HCPs in using supportive conversation techniques during engagements with people with aphasia. The level of detail in which CPT interventions are described in the literature is inadequate, incomplete and insufficient to enable replication[1]. As a result, the intervention could be implemented incorrectly upon replication or the effects of the intervention cannot be incorporated to clinical practice. We used the Template for Intervention Description and Replication (TIDieR) checklist and guide[2] to describe the intervention that we developed and to allow for comparison, replication and potential implementation in the future. The checklist and guide were developed to improve the reporting of interventions in any evaluative study. The checklist consists of items that are considered to be the minimum elements required to describe an intervention completely and adequately. The twelve items are: 1) brief name of the intervention; 2) the rationale, theory, or goal of intervention; 3) intervention materials; 4) intervention procedures; 5) who provided the intervention; 6) delivery mode; 7) place of delivery; 8) when and how much intervention provided; 9) tailoring (i.e., personalization); 10) modifications (i.e., unforeseen modification at a study level); 11) intervention adherence and 12) intervention fidelity (planned and actual)[2]. In order to enhance comprehensibility, the TIDieR items were described in a different sequence in the subchapters below: 5.1) name of the intervention, 5.2) the rationale for developing CommuniCare, 5.3) the elements that are included in CPT interventions described in the literature, 5.4) the elements that we included in CommuniCare, 5.5) description of the background and expertise of the intervention providers, 5.6) locations where the intervention occurred, 5.7) tailoring of the intervention and 5.8) modifications to the intervention during the study. The intervention adherence and fidelity were not evaluated in this study. We therefore cannot report about TIDieR item 11 and 12.

CommuniCare was developed in collaboration with (international) researchers and Dutch stakeholders. Figure 1 shows the development process. We started with identifying and reviewing studies that evaluated people with aphasia's and HCPs' needs and wishes for communication and CPT. In two expert panel meetings, SLTs and researchers discussed which core components should be part of our CPT. They were asked to prepare for these meetings, by reading a paper describing a well-know CPT intervention, known as 'Supportive Conversations for adults with Aphasia (SCA)' by Kagan (1998)[11]. The attendants included three practicing SLTs, and one senior- and two junior researchers with backgrounds as SLTs. The prototype, CommuniCare, was developed and piloted in 2017 in a peripheral hospital for nurses working on a stroke unit. After that, two exploratory qualitative studies were conducted using the results of the pilot study.

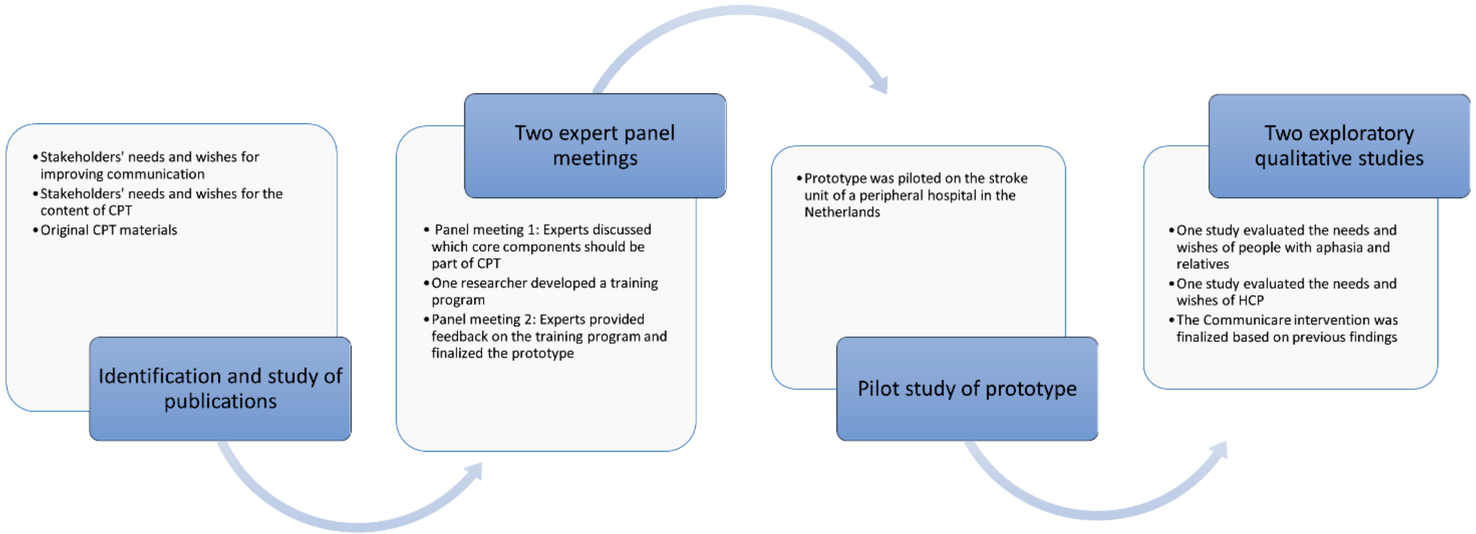


Figure 1. Development of the intervention CommuniCare

These two studies investigated the needs and wishes of people with aphasia, relatives and HCPs for improving communication and CPT content (2018-2019). CommuniCare was finalized in 2020.

1.1 NAME OF THE INTERVENTION (including TIDieR ITEM 1)

CommuniCare. This name was derived from Latin, meaning 'to impart, to share'. It also displays that the intervention aims to improve "communication" in "care".

1.2 THE RATIONALE FOR DEVELOPING COMMUNICARE (including TIDieR ITEM 2)

In 2016, various nurses and a manager from a university hospital in the Netherlands reached out to our research group, signaling significant barriers when communicating with people with aphasia. They asked for our help in enhancing HCPs skills for communicating with people with aphasia, in collaboration with the SLTs working at this site.

Several studies had been conducted worldwide to address communication problems between people with aphasia and their HCPs[3–8]. These studies showed that people with aphasia and HCPs experience a range of barriers when communicating, such as inaccessible information transfer, inadequate knowledge and use of inclusive communication styles and inadequate participation by the person with aphasia in shared decision-making. Recovery of contact and communication with their HCPs and their social environment was a top priority for people with aphasia. Based on these findings, the Dutch Guideline for Aphasia recommended that HCPs should be trained to use supportive conversation techniques as soon as possible. Not unexpectedly, training of HCPs became part of the role of SLTs, since they had a key responsibility to improve communication for people with aphasia. However, Dutch SLTs reported barriers in providing these trainings that especially included lack of time to train HCPs and lack of knowledge and clarity about suitable interventions. Indeed, there were no Dutch Communication Partner Training (CPT) interventions for HCPs available in 2016. Additionally, available international CPT interventions varied widely in target groups, dose, duration and timing, without a clear description of the core elements that should be part of CPT. For these reasons, CPT was not structurally provided in the Netherlands. The rationale for the development of CommuniCare was:

- To develop a Dutch stakeholder-informed CPT intervention that aims to raise HCPs knowledge, attitudes and skills to use supportive conversation techniques and provide them with organizational and social support to do so, in order to improve communication and participation for people with aphasia in healthcare facilities.

1.3 THE ELEMENTS IN COMMUNICATION PARTNER TRAINING INTERVENTIONS (including TIDieR ITEM 2)

To build on previous literature, we identified intervention elements that had been evaluated to be essential in CPT interventions as well as components that were often included in CPT interventions without scientific underpinning.

Although the elements in CPT interventions are rarely explicitly stated, the literature suggests that CPT interventions should include educational training, practice and psychological support. As one of very few studies that describes why these elements are essential, Johnson et al. (2017) concluded that educational training and practice resulted in increased awareness, increased use of supportive conversation techniques and increased satisfaction of people with aphasia[9]. The authors also identified that psychological support should be included in CPT interventions to change the beliefs of HCPs on the impact of the use of supportive conversation techniques and the priorities in conversations[9].

Other elements that are often included in CPT interventions had a less clear basis of the mechanisms that led to the use of supportive conversation techniques[1]. Cruice et al. (2018) investigated what elements were usually included in CPT interventions and were reported in the literature: education, roleplay, feedback and group discussion[1]. The sequence in which they are carried out seemed to be important. Often, CPT training sessions start with a formal educative element prior to active practice. The educational components often aim to raise awareness of participants' attitudes and communicative skills. This is either accomplished by review and evaluation of video-recordings of conversations, or discussions with SLTs about what HCPs usually do and how this can be improved. CPT training sessions then use role-play as a means of practicing supportive conversation techniques. Materials often include instructional videos, recordings of conversations between people with aphasia and their conversation partners, written information/hand-outs and other props. Feedback on the use of supportive conversation techniques is usually provided by SLTs and sometimes by people with aphasia. Group discussions during CPT training sessions are usually participant-led.

Some studies advocated on-site training in existing multidisciplinary teams. Most CPT interventions are entirely face-to-face and SLT-led. Involving people with aphasia during the training sessions is a recent development. The role of people with aphasia is to share their experiences and to participate during roleplay. Further investigation is needed to evaluate the benefits of this approach. There appeared to be no consensus concerning optimal dosage for training HCPs or whether HCPs working with people in the acute phase post-stroke should also be trained. Training sessions range in length from one short session (e.g., 1 hour) to a whole day. Some interventions include a staff support systems with post-training support and follow-up including on-site problem-solving[1].

1.4 THE ELEMENTS IN COMMUNICARE (including TIDiER item 2, 3, 4, 6 & 8)

To promote HCPs’ uptake of supportive conversation techniques during the delivery of care to people with aphasia, we sought to include elements in our CPT intervention that equip HCPs with the necessary knowledge, attitude, skills and social and organizational support. Based on consensus in two expert panel meetings, the elements that were identified to meet this goal are described in Figure 2. This figure illustrates the intervention elements and underlying assumptions.

The intended results of all intervention elements are that HCPs’ increase the use of supportive conversation techniques during engagements with people with aphasia. The anticipated outcomes are an increase in conversation participation by people with aphasia, and by association, beneficial outcomes with regards to shared decision-making, patient satisfaction and rehabilitation outcomes. The anticipated impacts are reductions in admission times, adverse events, costs and mortality in healthcare facilities.

The planned procedures (TIDieR item 4, 6 & 8) and materials (TIDieR item 3) for each intervention element are explained below.

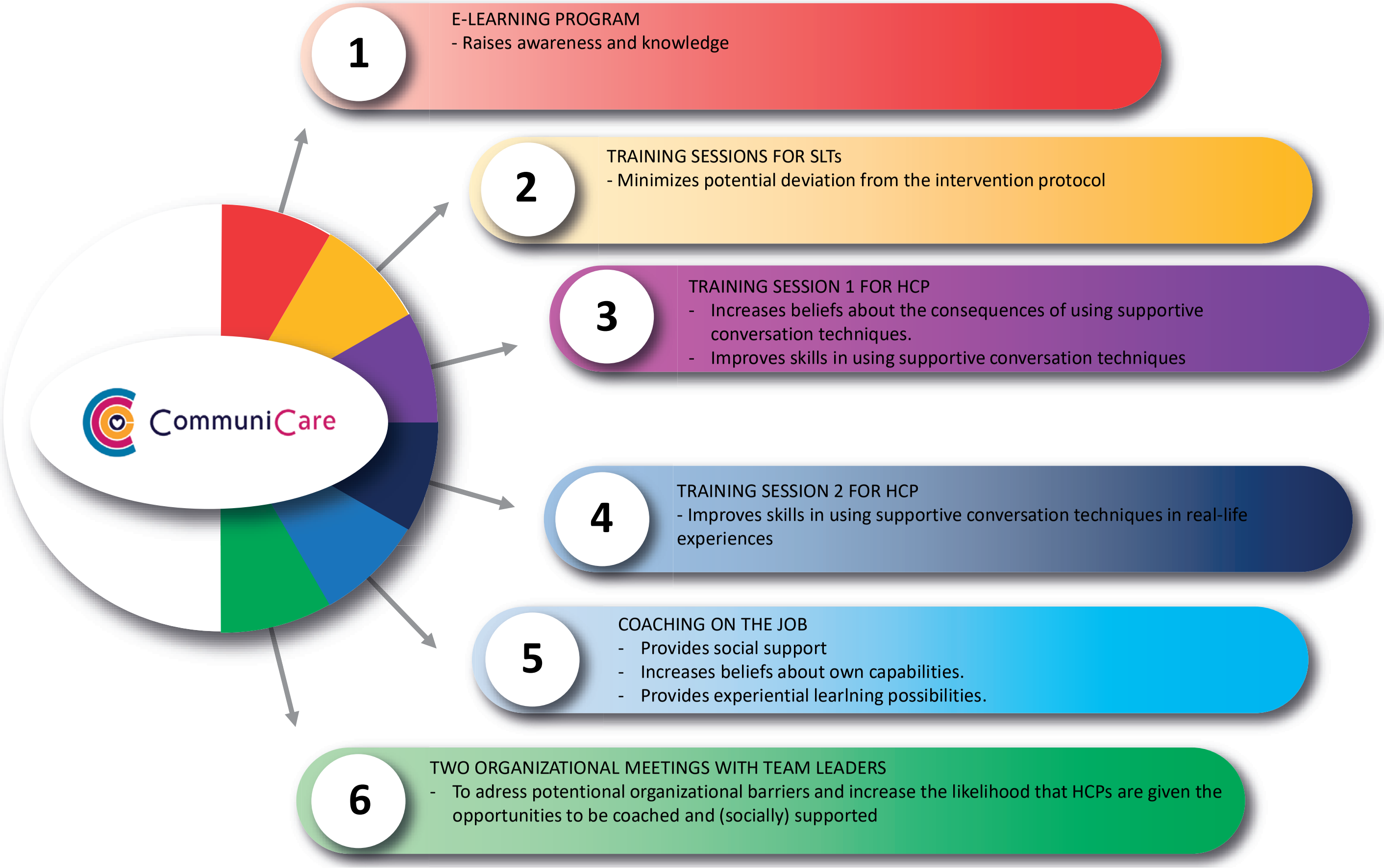
Instruction session for SLTs

The assumption was that an instruction session for SLTs, prior to the training sessions for HCPs, would minimize potential deviation from the intervention protocol. One clinician-researcher provided a two- hour face-to-face instruction session for SLTs. Six researchers, two from Belgium and four from the Netherlands, who were experienced in qualitative research and/or had a background as SLT, provided this session in the healthcare centers in their region.

In preparation, SLTs were asked to read a detailed manual of CommuniCare. The manual consisted of four chapters: 1) an introduction to the goal of CommuniCare, which is to raise HCPs knowledge, attitudes and skills to use supportive conversation techniques and provide them with organizational and social support, 2) the intervention elements and underlying assumptions as described in Figure 2, 3) the procedures and materials as described in chapter 5.4 and 4) the approach for developing supportive conversation tools, which are described in the paragraph below. The instruction session started with discussing comprehensibility of the manual, after which SLTs were provided the opportunity to ask questions to the researcher. In addition, in order to ensure comprehensibility, the researcher expanded on the outline of each intervention element. Then, the SLTs discussed the roleplay themes which would be used in the training sessions for HCPs. Finally, they practiced the development of supportive conversation tools. The approach for developing those tools throughout the intervention was: 1) HCPs request a tool for specific, recurring situations (such as conversations about wishes around CPR) 2) the SLT maps out this conversation and makes it aphasia-friendly by using the Accessible Information Guidelines of the UK Stroke Association.

E-learning program

We developed a Dutch online module that provides HCPs with information about the consequences of aphasia, the impact of communication difficulties on healthcare and the supportive conversation techniques that can improve communication, with a visual representation of these techniques (Figure 3). The underlying assumption was that the e-learning program would increase HCPs' knowledge and awareness of their communication behavior and would inform them about what they can and/or should do to improve. The online module is openly available and can be accessed through the QR-code in Appendix 1 at the end of this thesis. The first chapter of the module, 'Communicating together in healthcare', explains how every person wishes to participate in conversations and how it feels for people with aphasia when they are not able to do this. It gives a brief explanation of what aphasia is and what it means to have aphasia. This is supported by quotes from people with aphasia and their relatives. Chapter two, 'Impact of aphasia on the person with aphasia', addresses the effects of the language disorder based on literature. It illustrates real-life outcomes of aphasia based on a framework for capturing these outcomes after aphasia treatment[10]. Chapter three, 'Impact of aphasia on healthcare professionals', describes the effects of the language disorder on HCPs providing care to people with aphasia and includes quotes from a nurse and a relative. This chapter also contains a weblink with information tailored to relatives, that HCPs can point them towards. The weblink can be accessed, through the second QR-code in Appendix 1. Chapter 4, 'Supportive conversation techniques', centers around Figure 3 and provides an explanation of each technique that can help to improve communication. Chapter 5, 'How does the use of supportive conversation techniques become easier', gives a description of the strategies that can help HCPs to use these techniques: periodic



1 E-LEARNING PROGRAM
- Raises awareness and knowledge

2 TRAINING SESSIONS FOR SLTs
- Minimizes potential deviation from the intervention protocol

3 TRAINING SESSION 1 FOR HCP
- Increases beliefs about the consequences of using supportive conversation techniques.
- Improves skills in using supportive conversation techniques

4 TRAINING SESSION 2 FOR HCP
- Improves skills in using supportive conversation techniques in real-life experiences

5 COACHING ON THE JOB
- Provides social support
- Increases beliefs about own capabilities.
- Provides experiential learlning possibilities.

6 TWO ORGANIZATIONAL MEETINGS WITH TEAM LEADERS
- To adress potentional organizational barriers and increase the likelihood that HCPs are given the opportunities to be coached and (socially) supported

Figure 2: the intervention elements of CommuniCare with the underlying assumptions for each intervention element

training, practice, organizational and social support. Chapter 6, 'Video of a conversation', contains a video where a SLT uses various supportive conversation techniques during a conversation with a person with aphasia. The e-learning module ends with seven quiz-questions, which allow HCPs to assess their own understanding of the material.

HCPs were asked to complete the module within the month before the first training session. The time it took to complete the program was approximately 20 minutes.

Training session 1 for HCPs (face-to-face)

Both training session 1 and 2 were provided by SLTs working in the participating healthcare center and one researcher. They are from now on referred to as the *trainers* (see chapter 5.5 for their background). The first training session for HCPs started with exploring two short video recordings of conversations between a HCP and a person with aphasia and discussing whether this was a good or bad conversation. The underlying assumption was that discussing these video recordings would increase HCPs' beliefs about the benefits of using supportive conversation techniques. Then, the infographic (Figure 3) that was introduced in the e-learning program was discussed in groups. After that, the HCPs practiced the use of supportive conversation techniques in subgroups of five during roleplay. The underlying assumption of skills training through roleplay was that it would increase HCPs' capabilities to use supportive conversation techniques by learning through practice. Each subgroup was guided, supported and provided with feedback by one trainer.

During the training session, the trainers used a variety of materials: 1) short videos, 2) a PowerPoint presentation and 3) roleplay scripts with themes designed by the researchers. The short videos showed examples of conversations between nurses and people with aphasia, where in some cases nurses adequately used supportive conversation techniques, and in other cases did not. HCPs were asked to reflect on these cases. For privacy reasons, the short videos can only be made available with a nondisclosure agreement. The PowerPoint presentation included slides with organizational and procedural content: explaining the goals and content of CommuniCare, as well as the procedures and steps taken in the research project. The presentation also contained information on ways to adequately convey or receive a message from people with aphasia. One slide showed Figure 3 illustrating the supportive conversation techniques. The PowerPoint presentation is available upon request. The roleplay scripts were divided in two themes: 1) scripts where the HCP had something to convey to the person with aphasia, e.g., explaining medication and 2) scripts where the person with aphasia had a message or question for the HCP, e.g. asking when family would come to visit. Training session 1 lasted three hours and was provided face-to-face to a multidisciplinary team of HCPs, which included physicians, physician assistants, geriatricians, psychologists, occupational therapists, physiotherapists, dieticians, nurses and nursing assistants. The limit for the number of HCPs present was five participants per trainer. For example, if the training was provided by five trainers, the maximum number of HCPs permitted in that training session was 25.

After training session 1, HCPs were invited to make a list of frequently occurring conversation topics that they had with people with aphasia. In collaboration with the trainers, HCPs developed supportive conversation tools for those conversation topics.

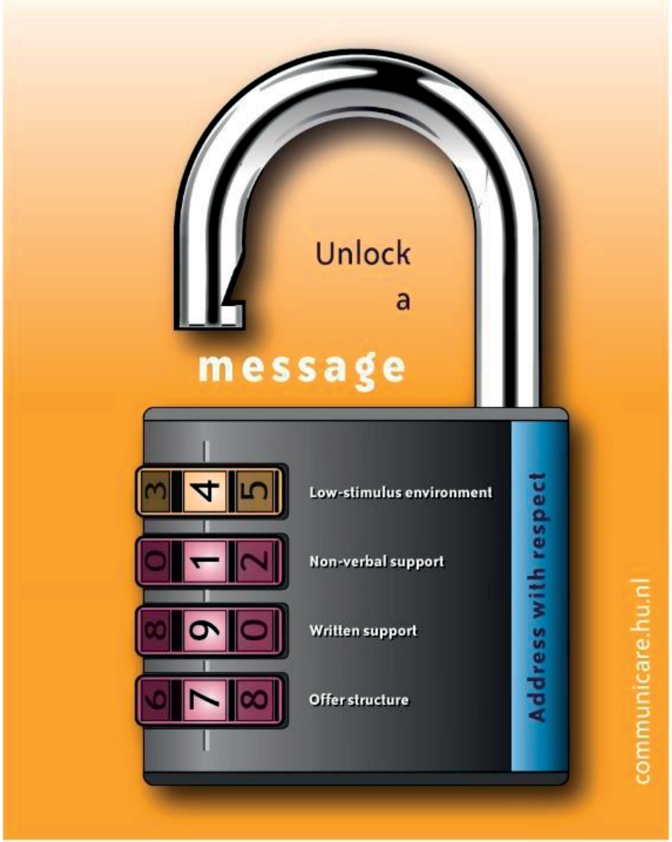
Training session 2 for HCPs (face-to-face)

Training session 2 took place approximately four weeks after the first training session, so that HCPs had the time to practice during daily activities and had session 1 still fresh in mind. At the beginning of training session 2, HCPs were asked to illustrate and reflect upon conversations that they had had with people with aphasia. These recent, real-life experiences were then practiced during roleplay, again in subgroups of five with one trainer to support them. The underlying assumption of these roleplay sessions was that they would improve HCPs' skills and self-esteem in using supportive conversation techniques in real-life situations. HCPs were given the opportunity to practice the use of the supportive conversation tools that they had developed after training session 1. The trainers used a second PowerPoint presentation, including slides showing Figure 3 once more, and slides that facilitated group discussion about HCPs' experiences and goal setting. The PowerPoint presentation is available upon request. The supportive conversation tools were devised by participants, and therefore context-specific and not available. This training session lasted two hours. Again, this session was provided face-to-face to the same multidisciplinary team and the limit for the number of participants was five per trainer.

After training session 2, HCPs were asked to formulate three personal learning goals. The achievement of these goals was evaluated after four months by use of a short questionnaire.

Coaching on the job

Between sessions 1 and 2, and until four months after session 2, the SLTs coached HCPs by answering questions, prompting HCPs to use supportive conversation techniques and tools, reminding HCPs to practice and providing feedback. The SLTs also facilitated HCPs to (further) develop supportive conversation tools for frequently occurring conversations. The underlying assumptions were that coaching on the job would provide HCPs with social support, increase their skills, increase their belief in their own capabilities and provide experiential learning possibilities. The SLTs had a total of two hours per week to deliver coaching.



HU Hogeschool Utrecht — CommuniCare — SiA

Unlock your message for the person with aphasia

3 4 5
- Position yourself at the unimpaired side of the person with aphasia
- Minimise distractions in the physical environment
- Minimise the number of healthcare staff present during the conversation

0 1 2
- Use facial expressions and gestures
- Support your message by pointing at the subject of the conversation
- Support your message by using pictures and drawings

8 9 0
- Support your message by using supported conversation tools
- Write down keywords during the conversation
- Write about important events and conversations in the communication book

6 7 8
- Use short sentences
- Talk slowly
- Verify if the person with aphasia has understood what you said
- Announce it when you're switching to another topic

- Stress that you find it important that you understand each other
- Speak and offer support in a mature and natural way
- Observe the non-verbal reactions of the person with aphasia
- Encourage the person with aphasia to respond
- Express that you have enough time to listen and talk
- Show genuine interest
- Agree to try again later if you haven't unlocked the message

Help the person with aphasia to unlock their message

0 1 2
- Encourage the person with aphasia to point at things, use gestures and make drawings
- Ask the person with aphasia whether their message can be found in the communication book

6 7 8
- Make it clear when you don't understand the message
- Repeat what you do understand and verify
- Use written conversation to structure the message of the person with aphasia

Figure 3. A visual representation of the supportive conversation techniques that help to improve communication between people with aphasia and HCPs

Two organizational meetings with manager, physicians, knowledge brokers and SLTs

Finally, as a form of organizational support, two meetings were organized with the team manager, physician, a knowledge broker from the Dutch Network of Cerebrovascular Diseases (Kennisnetwerk CVA) and the SLTs. In the first meeting, participants were informed about the content and aim of the intervention, to ensure that they had an understanding of the approach and were supportive of it. They were invited to participate in all training activities. The underlying assumption was that if managers and HCPs with a higher level of authority would propagate the use of supportive conversation techniques, HCPs' beliefs about the importance would grow and consequently result in the use of techniques. In the second meeting, the barriers and facilitators that HCPs had experienced were discussed and addressed. A plan with implementation strategies was formulated. The underlying assumption was that formulating implementation strategies and carrying out those strategies would increase the likelihood of successful implementation. The implementation plans were devised by participants and context specific. Due to its proprietary nature, the implementation plans cannot be made openly available. The first meeting took place before the first training session and the second meeting took place four months after training session 2. Both took one hour.

1.5 DESCRIPTION OF THE BACKGROUND AND EXPERTISE OF THE TRAINERS (including TIDieR ITEM 5)

The instruction session for SLTs was provided by clinician-researchers who all had a background as SLT and/ or thorough knowledge and experience with supporting conversations for people with aphasia.

The trainers were SLTs working in the participating healthcare centers and one of the clinician-researchers. They remained the same people for all training sessions in each healthcare center. The benefits of this were that the trainers built up relationships with individual HCPs and teams.

Coaching on the job was provided by SLTs working in the participating healthcare center.

1.6 LOCATIONS WHERE COMMUNICARE OCCURRED, INCLUDING ANY NECESSARY INFRASTRUCTURE OR RELEVANT FEATURES (including TIDieR ITEM 7)

CommuniCare was delivered in participating inpatient or outpatient hospital- or rehabilitation centers. The training sessions were organized during-, before- or after daytime shifts of HCPs. Participating healthcare centers included one hospital setting in Belgium and six in- and outpatient rehabilitation centers in the Netherlands. Two of these centers were medical rehabilitation centers, which provided rehabilitative therapy services for patients who experience limitations due to injuries or disease (e.g. brain injury, spinal cord injury, progressive neurological disease and amputation), or congenital disorders. Yearly, approximately 90.000 patients are admitted to medical rehabilitation centers in the Netherlands. Four centers were geriatric rehabilitation centers, which provide services focusing on the health and needs of seniors. The goal is to help them return home and participate in society as well as possible. In 2019, approximately 53.000 people received geriatric rehabilitation in the Netherlands. This number will grow rapidly due to aging of our population.

Hospital and rehabilitation care is mostly financed by healthcare insurance, and partially by government and taxes. In the Netherlands, nearly all citizens are covered by healthcare insurance and services are easily accessible. Hospital and rehabilitation care are delivered by multidisciplinary teams.

In the Netherlands, healthcare is financed by the Dutch DBC system. DBC is a Dutch abbreviation of Diagnosis Treatment Combination (Diagnose Behandeling Combinatie). In this system, healthcare facilities are paid a tariff (by health insurers) based on “paths” defined by DBCs. Each patient goes through a specifically defined pathway, from the diagnosis of a problem to the treatment of that problem, to the final discharge. Additionally, healthcare facilities have to consider pre-set budget allocations. Due to the DBC system and budget allocations, innovations usually can only take place with (external) grants.

1.7 TAILORING OF COMMUNICARE (WHAT, WHY, WHEN AND HOW) (including TIDieR ITEM 9)

The elements of CommuniCare were executed as explained in the subchapters above. The e-learning module was standardized. The training sessions were only standardized in rough outlines. However, HCPs were encouraged during the training sessions to talk about their personal experiences in communicating with people with aphasia. The trainers responded to these personal experiences by tailoring roleplay themes, discussion topics and supportive conversation tools. When implementing CommuniCare in different settings, it should be taken into account that the trainers are expected to tailor these elements to the needs of the team that is present. Coaching on the job was partly standardized. The coaches were responsible for facilitating HCPs to develop tools and use supportive conversation techniques, as explained in chapter 5.4. However, how coaching should be executed and how much coaching was needed was not standardized. Again, this intervention element is context- specific.

In chapter 6 and 7 of this thesis, we will evaluate and discuss how CommuniCare can be tailored to individual, cultural or organizational differences between healthcare settings. The adaptations required may pose challenges for trainers and implementation support practitioners, as they have to find a balance between maintaining training fidelity and maximizing the fit with characteristics of the implementation context.

1.8 MODIFICATIONS TO COMMUNICARE DURING THE STUDY (including TIDieR ITEM 10)

CommuniCare was modified using the outcomes of a feasibility study and two qualitative studies with people with aphasia, relatives and HCPs.

In the feasibility study, 46 nurses received two training sessions of two hours (Chapter 2). In their evaluation, they reported the need to lengthen the duration of the first training session in order to provide more time for roleplay. Another request was to provide the educational part of training session 1 in an e-learning program, so that HCPs could prepare for the first training session and more time would become available to practice. Both requests were included in the final version of CommuniCare.

The two qualitative studies (Chapter 3 and 4), that specifically identified the need for experiential learning, post-training and implementation support, led to an inclusion of three intervention elements: instruction sessions for SLTs, coaching on the job and two organizational meetings with managers, physicians and SLTs (described in Chapter 5.4).

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CHAPTER 6

6

Evaluating communication partner training in healthcare centers: Understanding the mechanisms of behavior change

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Background

Communication between people with aphasia and their healthcare professionals (HCPs) can be greatly improved when HCPs are trained in using supportive conversation techniques and tools. Communication Partner Training (CPT) is an umbrella term that covers a range of interventions that train the conversation partners of people with aphasia. Several CPT interventions for HCPs have been developed and used to support HCPs to interact successfully with people with aphasia.

Aims

The objective of this study was to identify the mechanisms of change as a result a Dutch CPT intervention, named CommuniCare, in order to evaluate and optimize the intervention.

Methods & procedures

254 HCPs from five different healthcare centres received CommuniCare. An explorative qualitative research design was chosen. Two interviews were conducted with 24 HCPs directly after and four months after receiving the training that was part of CommuniCare. Two conceptual frameworks were used to deductively code the interviews. HCPs' perspectives were coded into a four-part sequence following CIMO logic: the self-reported use of supportive conversation techniques or tools pre-intervention (Context), the intervention elements (Intervention) that evoked certain mechanisms (Mechanisms), resulting in the self-reported use of supportive conversation techniques and tools post intervention (Outcomes). The Capabilities Opportunities Motivation -Behaviour (COM-B) model was used to fill in the Mechanisms component.

Outcomes & results

Three themes were identified to describe the mechanisms of change that led to an increase in the use of supportive conversation techniques and tools. According to HCPs (1) information, videos, e-learning modules, role-play, feedback during training and coaching on the job increased their psychological capabilities, (2) information and role-play increased their automatic motivations and (3) information, videos and role-play increased their reflective motivations. Remaining findings show HCPs' perspectives on various barriers to use supportive conversation techniques and tools.

Conclusions & implications

HCPs in this study identified elements in our CPT intervention that positively influenced their behaviour change. Of these, role-play and coaching on the job were particularly important. HCPs suggested this last element should be better implemented. Therefore, healthcare settings wishing to enhance HCPs' communication skills should first consider enhancing HCPs' opportunities for experiential learning. Second, healthcare settings should determine which HCPs are suitable to have a role as implementation support practitioners, to support their colleagues in the use of supportive conversation techniques and tools.

WHAT THIS PAPER ADDS

- Several Communication Partner Training (CPT) interventions for healthcare professionals (HCPs) have been developed and used to support HCPs to interact successfully with people with aphasia. To date, there is limited evidence of the mechanisms of change that explain exactly what changes in HCPs' behaviour after CPT and why these changes take place.
- Evaluating our CPT intervention by identifying mechanisms of change from the perspectives of HCPs provided us with 1) a better understanding of the elements that should be included in CPT interventions in different contexts and 2) an understanding of the important remaining barriers identified by HCPs to use supportive conversation techniques, even after CPT is implemented.
- This study shows the different intervention elements in our CPT intervention that improve HCPs' capabilities, motivations or opportunities to use supportive conversation techniques and tools. Essential ingredients of CPT according to HCPs in this study were role-play and coaching on the job by an expert and were linked to an increase in HCPs' motivations or beliefs about self-competency. Healthcare settings wishing to enhance HCPs' communication skills should therefore consider appointing implementation support practitioners to coach and support HCPs, and facilitate these practitioners to fulfil this role.

INTRODUCTION

Communication difficulties are common for people with aphasia, a language disorder caused by brain damage. Successful communication between healthcare professionals (HCPs) and people with aphasia is essential for high quality care. It leads to shared understanding between professionals and patients and therefore increased patient satisfaction, increased participation of the person with aphasia in their own healthcare pathway, positive health outcomes and better patient safety [1,2]. Accordingly, reduced communication opportunities for people with aphasia have been shown to result in reduced participation in healthcare decision-making [3], adverse events in hospital – defined as unintended injuries or complications caused by the delivery of clinical care – [4] and negative impact on social participation, wellbeing, sense of identity and relationships [5].

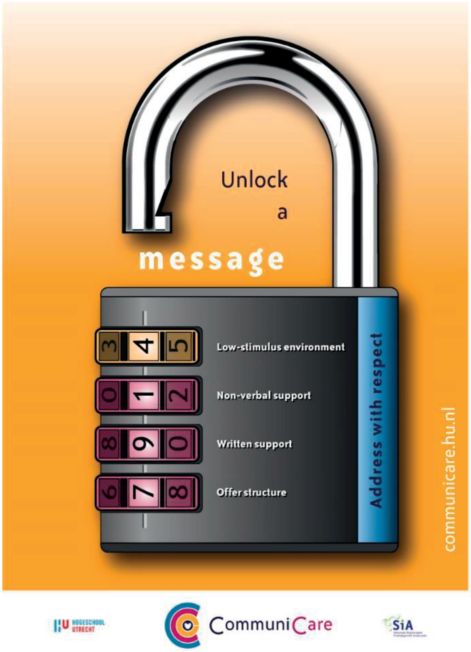
People with aphasia may face a range of barriers for communicating and participating in healthcare, often due to lack of knowledge and skills of HCPs [6]. Communication between people with aphasia and HCPs can be greatly improved when HCPs are trained to use supportive conversation techniques and tools during conversations [7,8]. Training HCPs has been shown to facilitate participation of the person with aphasia during conversations [9] and limit negative feelings often experienced by HCPs [10,11]. Communication Partner Training (CPT) is an umbrella term that covers a range of training modules developed for the conversation partners of people with aphasia. Several CPT interventions for HCPs have been developed and used to support HCPs to interact successfully with people with aphasia [9].

The behaviours targeted for change in CPT include the use of supportive conversation techniques, such as providing non-verbal support or using written text, and supportive conversation tools. However, it seems that successful implementation of the use of these techniques and tools in daily practice in healthcare settings relies on more than merely implementing CPT. It relies on organizational factors, such as the involvement of stroke unit leaders, and contextual factors, such as the speed of turnover of patients which is often high in acute care settings [12]. Different contexts and organizations therefore require contextualized adaptations of CPT to meet specific needs of settings and healthcare professions who are to receive and use it [12]. CPT interventions are complex interventions, comprised of multiple interacting elements. These target various organizational levels and are known to have complex implementation issues [12]. In their recent systematic review on the current reporting of CPT interventions, Cruice et al. recommend that CPT research should follow complex interventions guidance of the Medical Research Council (MRC) and focus on specifying how mechanisms of change produce the intended outcomes of CPT [13]. To date, there is limited evidence of the mechanisms of change that are responsible for producing behaviour change after CPT, i.e. the mechanisms that explain what has changed in conversation partner's behaviour and why this has changed.Johnson et al. (2017) found mechanisms that might be responsible for behaviour change in people with aphasia and their family member after CPT[14]. To our knowledge, this evaluation has not been done for HCPs. There is a need to evaluate the mechanisms of change as a result of CPT for HCPs as it will provide insight into reasons why HCPs do or do not start using supportive conversation techniques after CPT and to understand what elements in CPT interventions act as active ingredients to change HCPs' behaviour [15]. This study explores HCPs' experiences within a CPT intervention named CommuniCare. This introduction provides further detail on CommuniCare, a Dutch CPT intervention which was developed in accordance with the MRC guidance for complex interventions[16].

The CommuniCare intervention

CommuniCare is an intervention targeted at HCPs and aims to improve communication with people with aphasia by changing HCPs' behaviours. HCPs are trained in using generic supportive conversation techniques in conversations with people with aphasia. The target behaviour of CommuniCare is represented by an increase in the use of 25 supportive conversation techniques and tools in five domains: (1) low-stimulus environment, (2) non-verbal support, (3) written support, (4) offer structure and (5) address with respect (Figure 1).

CommuniCare consists of four intervention elements with different aims and procedures in order to facilitate HCPs to carry out the target behaviour. The aims, materials and procedures for each intervention element are represented in figure 2. These elements were selected based on current literature on existing CPT interventions and informed by HCPs, people with aphasia and their relatives. The e-learning program aims to raise awareness and increase knowledge. Receiving information about the health consequences of aphasia, what behaviours to perform, and raising awareness about the importance of changing behaviour are mechanisms that can be responsible for enabling change [17]. HCPs receive two training sessions of three hours. In training session one, HCPs receive information about and discuss the impact of aphasia and which supportive conversation techniques they can use. Literature suggests that this may persuade HCPs to use techniques and increase their beliefs about the positive consequences of doing so [17]. HCPs then practice the use of supportive conversation techniques during role-play. Providing demonstrations and feedback on behaviour are mechanisms that may be responsible for acquiring cognitive and interpersonal skills (Michie et al., 2013). In training session two, HCPs again practice the use of supportive conversation techniques and tools during role-play. The conversation tools, developed between session one and two in collaboration between the HCPs and a speech and language therapist (SLT), enable HCPs to use visual support in frequently occurring conversations. One example is conversations where patients' preferences for resuscitation are discussed. The conversation tools were developed according to guidelines for making information accessible for people with aphasia [18]. In between and after the training sessions HCPs receive coaching on the job from so called 'communication coaches'. The communication coaches are either SLTs or other HCPs working in the healthcare centre and support HCPs by monitoring their behaviour, providing feedback, practical support and prompts to use the behaviour. Literature suggests that these mechanisms may be responsible for acquiring cognitive and interpersonal skills and increasing HCPs' beliefs in their own capabilities and the positive consequences of using techniques and tools [17].



Unlock your message for the person with aphasia

345
- Position yourself at the unimpaired side of the person with aphasia
- Minimise distractions in the physical environment
- Minimise the number of healthcare staff present during the conversation

012
- Use facial expressions and gestures
- Support your message by pointing at the subject of the conversation
- Support your message by using pictures and drawings

890
- Support your message by using supported conversation tools
- Write down keywords during the conversation
- Write about important events and conversations in the communication book

678
- Use short sentences
- Talk slowly
- Verify if the person with aphasia has understood what you said
- Announce it when you're switching to another topic

- Stress that you find it important that you understand each other
- Speak and offer support in a mature and natural way
- Observe the non-verbal reactions of the person with aphasia
- Encourage the person with aphasia to respond
- Express that you have enough time to listen and talk
- Show genuine interest
- Agree to try again later if you haven't unlocked the message

Help the person with aphasia to unlock their message

012
- Encourage the person with aphasia to point at things, use gestures and make drawings
- Ask the person with aphasia whether their message can be found in the communication book

678
- Make it clear when you don't understand the message
- Repeat what you do understand and verify
- Use written conversation to structure the message of the person with aphasia

Figure 1. The supportive conversation techniques.

This study focuses on the period after CommuniCare was developed. The objective of this study was to identify the mechanisms of change as a result of CommuniCare in order to evaluate and optimize the intervention. The research question guiding this study was: 'What are HCPs' reflections on the mechanisms of behaviour change as a result of CommuniCare?'

METHODS

This study was part of a large multicentre study consisting of two phases: the development phase and the implementation phase of CommuniCare. The primary goal of the first phase was to develop an intervention aimed at improving communication between HCPs and people with aphasia, based on the experiences, needs and wishes of the stakeholders[30,31]. The outcomes of the development phase was the intervention CommuniCare. The present study reports on interviews in the implementation phase, where the intervention CommuniCare was used in five healthcare settings throughout the Netherlands and Belgium. These included two medical rehabilitation centres and three centres for geriatric rehabilitation, a form of rehabilitation care for patients that or more vulnerable than patients admitted to medical rehabilitation centres. Medical rehabilitation involves complex rehabilitation with goals for multiple conditions that require intensive multidisciplinary treatment. Both settings are designed to help their clients regain sufficient independence to move back home.

Procedure of CommuniCare in five healthcare centres

HCPs were asked to complete the 15 minute e-learning program. After one month, all HCPs received the two 3 hour face-to-face training sessions in the healthcare centre where they worked. The training sessions, with one month in between, were delivered by one to three SLTs working in the healthcare centre and a clinician researcher. Each training session was provided to a multidisciplinary group of HCPs, varying from 20 to 65 participants. The SLTs in the healthcare centres were asked to select HCPs who could be suitable to fulfil the roles as communication coaches after the training sessions and recruited these coaches. The coaches were provided with one training session of one hour, where they learnt how to develop conversation tools together with HCPs and how to support HCPs after the training sessions. In each healthcare centre, the coaches had two hours per week during four subsequent months to develop tools and support HCPs in the use of supportive conversation techniques and tools.

In total, 254 HCPs received the intervention (neurologists, psychologists, physicians, physician assistants, geriatricians, nurses, physiotherapists, occupational therapists, social workers, dieticians and healthcare assistants). An explorative qualitative research design was chosen and semi-structured interviews on the basis of an interview guide were used to collect the data.

Participants

To evaluate the mechanisms of change, three to six HCPs from each healthcare centre were asked to participate in two interviews. HCPs were recruited based on purposive

Intervention type	Aim	Materials	Procedures
E-learning program (max. 30 min)	To increase knowledge by informing HCP about the consequences of aphasia and the supported conversation techniques that HCP can use	E-learning program developed in Articulate^{TM} software. The e-learning includes the following modules: - Communicating in healthcare - Impact of aphasia on the person with aphasia - Impact of aphasia on the HCP - Communication techniques - Two video's of conversations between a HCP and a person with aphasia - Quiz	To prepare for training session 1, participants complete an e-learning program. Participants can choose between completing the e-learning program in the healthcare centre or at home.
	To increase awareness by informing HCP about the importance of using supported conversation techniques and –tools		
Training session 1 (3 hours)	To persuade HCP to use communication techniques by exploring and discussing the detrimental consequences of aphasia	-One video showing a conversation between a speech- and language therapist and person with aphasia and three videos showing a conversation between a nurse and person with aphasia.	Training session 1 starts with looking back at the e-learning. Four videos are shown to HCP to explore the consequences of communication breakdown and the conversation techniques that can be used. HCP are provided with an infographic showing them an overview of the conversation techniques. HCP then practice the use of these techniques in roleplay with a SLT and 4 other HCP. SLTs show how they use techniques and provide feedback to HCP. HCP leave with two assignments: - First, HCP are instructed to practice the use of techniques in conversations with people with aphasia in the 4 weeks before training session 2. - Second, HCP are asked to explore frequently occurring conversations with people with aphasia and develop a supported conversation tool for these conversations in collaboration with SLTs.
	To increase beliefs about the consequences of using conversation techniques by exploring conversation techniques and -tools that can improve conversation	- An infographic* showing 25 supported conversation techniques that HCP can use, divided into five domains (low-stimulus environment, non-verbal support, written support, offer structure, address with respect) (Appendix 1).	
	To increase cognitive and interpersonal skills by practicing the use of supported conversation techniques in roleplay	- 10 roleplays: 5 roleplays where the person with aphasia has something to say, 5 roleplays where the HCP has something to say.	
Training session 2 (3 hours)	To increase cognitive and interpersonal skills by practicing the use of supported conversation techniques and -tools.	- Infographic* (see training session 1) - The developed supported conversation tools	At the beginning of training session 2, HCP are asked to reflect on the conversations that they have had with people with aphasia in the previous weeks. HCP provide each other with feedback or suggestions. HCP then practice the use of techniques and tools in roleplay with a SLTs and 4 other HCP. SLTs show how they use techniques and provide feedback to HCP.

Figure 2. The intervention CommuniCare

sampling to attain as much variety in disciplines as possible. 24 HCPs were asked to participate and all gave informed consent. Two HCPs had participated in only one of the training sessions; the other 22 HCPs had participated in both. Four HCPs did not participate in the second interview. Participants' background details and reasons for participating in only one interview can be found in Table 1.

Data collection

SLTs working in the participating healthcare centres asked HCPs to participate. The data consisted of audio-recorded interviews with HCPs about their experiences of mechanisms of change as a result of CommuniCare. Each HCP was interviewed in two phases post-training. The first phase was defined as 1-4 weeks post training (T1). In this phase, we expected HCPs to be able to reflect on things they had learnt in the training and on their first experiences with using supportive conversation techniques and tools during conversations. The second phase was defined as 4-6 months post-training (T2). In this phase, we expected that HCPs would be able to add to their first experiences, because they would have had more conversations with people with aphasia. The semi-structured interviews were carried out by the first author and five other researchers. The interview guide was designed by the first author and one of the researchers to describe self-reported outcomes concerning the target behaviour of CommuniCare and HCPs' perspectives on the mechanisms that led to these outcomes. The interview questions can be found in Appendix 1. The interviews were audio recorded and transcribed in full.

Data analysis

Interviews were analysed deductively. Two conceptual frameworks were used to deductively code HCPs' experiences on the mechanisms of behaviour change as a result of CommuniCare: CIMO logic [19] and the Capabilities, Opportunities, Motivation -Behaviour (COM-B) model [20]. CIMO-logic is a design proposition that can be used to describe causality, i.e. through which intervention types does the intervention generate mechanisms that produce the outcomes in a certain context. It is constructed as follows: in a certain Context (C), a certain Intervention-type (I) can be used to evoke certain Mechanisms (M), resulting in certain Outcomes (O). The COM-B model can be used as an aid to identify how intervention functions help to achieve behaviour change. The COM-B model is used extensively in implementation research [20]. In our study, it was used to fill in the Mechanisms component in CIMO-logic. In other words, by using the COM-B model we identified HCPs' views on the changes to HCPs' capabilities, opportunities and motivations, resulting in the use of supportive conversation techniques and tools. The definitions of the three conditions 'capability, opportunity and motivation' can be found in Table 2.

Table 1. Demographics

Healthcare centre	HCP (indicated by numbers for anonymity)	Age (years)	Healthcare profession	Years of experience as HCP (years; months)	Years of experience with people affected by stroke (years; months)	Participation in interview T1 (1- 4 weeks post-training) and/or T2 (4 -6 months post-training)	Reasons for participating in one out of two interviews
Rehabilitation centre 1	1	32	Nurse	10	1	T1, T2	
	2	29	Social worker	5	4	T1, T2	
	3	24	Occupational therapist	2	1	T1,T2	
	4	27	Psychologist	0.5	0;6	T1,T2	
	5	54	Physiotherapist	30	30	T1,T2	
	6	54	Nurse	30	29	T1	No response on e-mail and telephone calls
Rehabilitation centre 2	7	54	Occupational therapist	20	20	T1	Wished to withdraw because HCP by one's own account had no new experiences.
	8	39	Internist	13	3	T1, T2	
	9	23	Nurse	3	2;6	T1, T2	
Geriatric rehabilitation centre 1	10	55	Physiotherapist	33	33	T1, T2	
	11	57	Nursing assistant	20	0;3	T1, T2	
	12	46	Geriatrician	22	12	T1	No time for second interview due to other education and training courses
	13	24	Occupational therapist	1	0;2	T1, T2	
	14	56	Nurse	34	0;6	T1	Unknown
	15	53	Social worker	30	1	T1, T2	

Table 1. Demographics (*continued*)

Healthcare centre	**HCP (indicated by numbers for anonymity)**	**Age (years)**	**Healthcare profession**	**Years of experience as HCP (years; months)**	**Years of experience with people affected by stroke (years; months)**	**Participation in interview T1 (1- 4 weeks post-training) and/or T2 (4 -6 months post-training)**	**Reasons for participating in one out of two interviews**
Geriatric rehabilitation centre 2	16	37	Nurse intern	17	12;6	T1,T2	
	17	61	Nurse	7	7	T1,T2	
	18	48	Nurse	29	14	T1,T2	
	19	27	Psychologist	3	2	T1,T2	
	20	60	Psychologist	3	3	T1,T2	
	21	54	Nurse	35	35	T1, T2	
Rehabilitation centre 3	22	40	Physiotherapist	18	18	T1, T2	
	23	54	Geriatrician	24	24	T1, T2	
	24	23	Nurse	1;5	1;5	T1, T2	

The steps taken in the analysis can be found in Figure 3. A worked example of step 2 to 5 was given in Appendix 2. Step 1 involved listening to audio recordings and reading transcripts. Step 2 involved highlighting fragments that reflected HCPs' perspectives on the mechanisms of behaviour change as a result of CommuniCare. In step 3, the highlighted fragments were coded into a four-part sequence following CIMO logic: the self-reported use of supportive conversation techniques or tools pre-intervention (Context), the intervention elements (Intervention) that evoked certain mechanisms (Mechanisms), resulting in the self-reported use of supportive conversation techniques and tools post intervention (Outcomes). In step 4, the self-reported outcomes (O) were labelled to the five domains of the target behaviour. The intervention elements (I) were kept unchanged and therefore represented the literal words of HCPs. In step 5, the mechanisms (M) were labelled to the COM-B model. The final step, step 6, included integrating the CIMO-logic model and the COM-B model, in order to explain how intervention elements in CommuniCare led to an increase in capabilities, opportunities and motivations and ultimately in the use of supportive conversation techniques and tools. All steps were conducted in Qualitative data analysis software Atlas.ti 8 Windows™ (ATLAS.ti Scientific Software Development GmbH). The process of analysis was iterative; moving back and forth between the quotes, categories and themes, in order to develop an accurate description of the data.

Rigor

Before conducting the interviews, the researchers met for one calibration session to discuss and practice the use of the interview guide. Four researchers coded and analysed the interviews. To ensure investigator triangulation [21], two interviews were coded by all four researchers and differences and similarities were discussed until consensus was reached. The remaining interviews were coded by one researcher and checked by a second researcher. These researchers discussed decisions about coding, analysis and interpretation. Representative quotes were translated from Dutch to English, and checked by a translator.

Ethics

This study was ethically approved by the Medical Ethical Committee of [anonymous] and performed in accordance with the Helsinki Declaration and the EU General Data Protection Regulation.

Table 2. The definitions of the three different conditions in the COM-B model (definitions from Michie et al., 2011)[20]

Condition in COM-B model	**Definition**
Capability	Capability represents an individual's psychological and physical capacity to perform the behaviour. Physical capability refers to the ability or proficiency that is learned through practice. Psychological capability refers to the mental processes or skills that are required for the person to perform the behaviour.
Motivation	Motivation represents a complex set of mechanisms that activate or inhibit behaviour. Motivations can be reflective or automatic. Automatic motivation refers to people's motives (what do they want), impulses (what urges them on) and their reflex responses. Reflective motivation refers to people's intentions (conscious planning) and their evaluations (their beliefs about what is good or bad).
Opportunity	Opportunity encompasses any aspect from the external environment that enables or constrains the performance of a behaviour Social environment refers to the social influences that enable or constrain the performance of behaviour Physical environment refers to the physical influences that enable or constrain the performance of behaviour

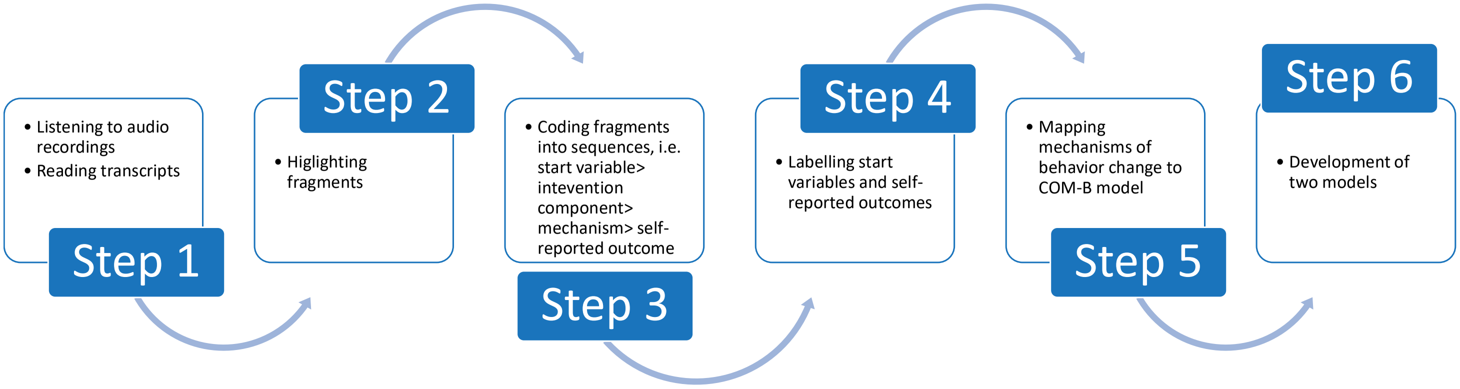


Figure 3. Six-step process in the analysis

RESULTS

The results show HCPs' perspectives on the mechanisms that have led to behaviour change after CommuniCare or have kept HCPs' behaviour unchanged.

Six different intervention elements (information, role-play, videos, e-learning, feedback during the training and coaching on the job) combined with three different conditions (psychological capabilities, automatic motivations and reflective motivations) acted as mechanisms that according to HCPs changed their use of supportive conversation techniques and tools (Figure 4). Three themes were identified to describe these combinations. Each theme represents the mechanisms of change that explained how, according to HCPs, intervention elements led to an increase in the use of supportive conversation techniques and tools in healthcare settings. The intervention elements represent the literal words of HCPs. Information and videos correspond with what was provided in the e-learning program and training sessions, and role-play and feedback during training correspond with what was provided in the training sessions.

Mechanism 1: According to HCPs, information, videos, e-learning modules, role-play, feedback during training and coaching on the job increase their psychological capabilities

The information provided in the training sessions, videos, the e-learning program, role-play and feedback during the training increased HCPs' knowledge about the supportive conversation techniques and tool that they can use. This resulted in an increase in the number of times HCPs conversed with people with aphasia in a low-stimulus environment and an increase in non-verbal support, written support, offering structure, addressing people with aphasia with respect and the use of supportive conversation tools.

> *Usually I never pointed out what I was talking about. Now I do. That's because I now have a list of things that I can do. Pointing out things makes the conversation simpler. First, we would have had a discussion lasting thirty minutes and we would end the discussion because we didn't understand each other. Now, if I don't understand the person with aphasia, I point out the toilet or other small things and it makes a difference.*

The information, e-learning and videos helped HCPs become aware of what they do and what they can change in their behaviour. This resulted in an increase in addressing people with aphasia with respect.

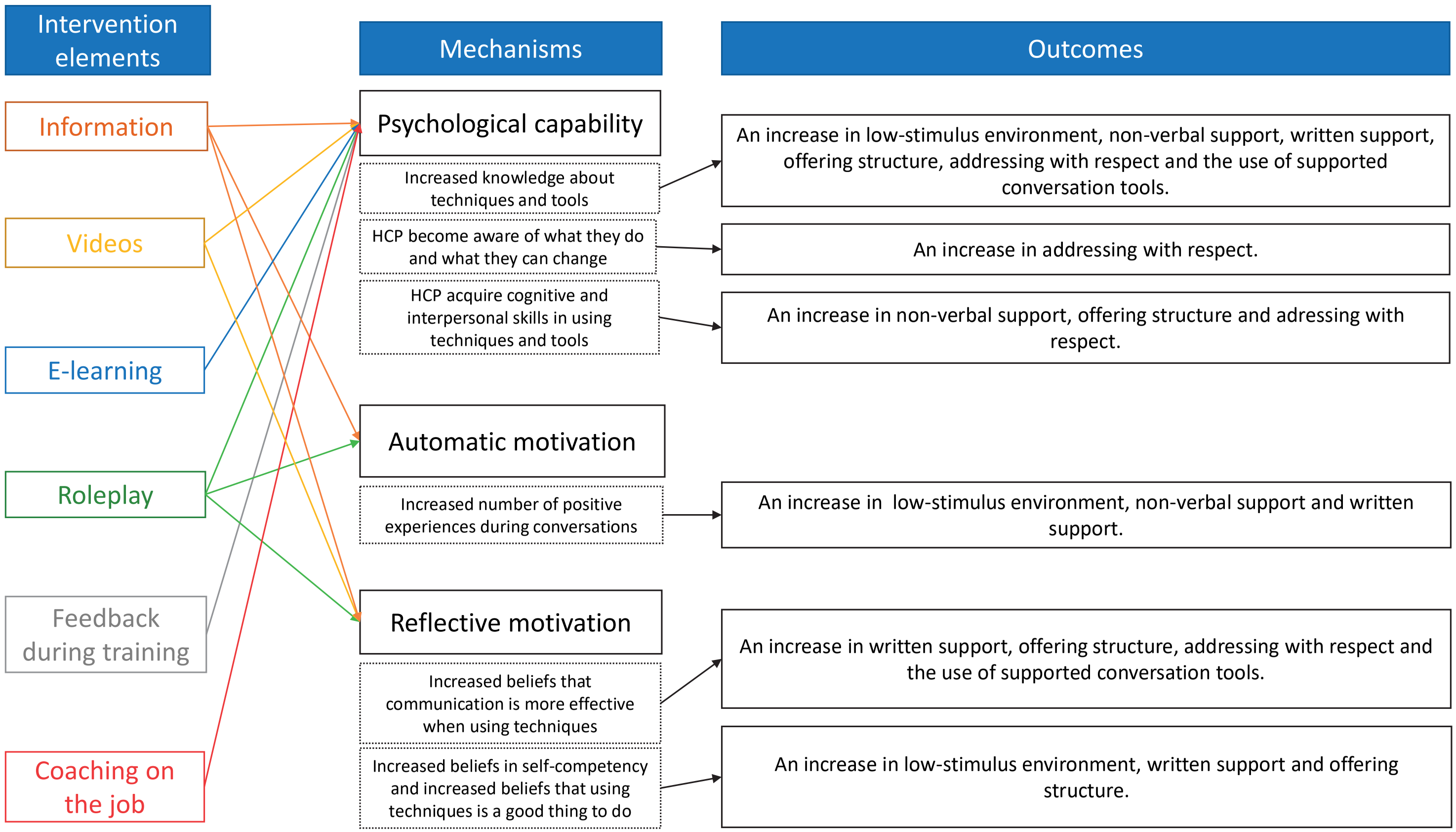


Figure 4. How does CommuniCare increase capabilities and motivations

> *I had to explain to her (person with aphasia) that she required tube feeding. And then I had to ask her if she understands. I think that I am more aware of explaining everything I do to people with aphasia. It's because I read that section in the e-learning module, about how everyone has the right to know what will happen to her.*

Coaching on the job enabled HCPs to acquire cognitive and interpersonal skills in using supportive conversation techniques and tools. This resulted in an increase in non-verbal support, offering structure and addressing people with aphasia with respect.

> *The biggest difference for me is that I try to use more supportive conversation tools than before. I also try to use different channels, such as verbal and written support. I now ask the SLT for help: how should I communicate with this person with aphasia? I think I do all this because … It's not because I've read about everything that I should do. It's because I've practiced after the training and got feedback from the SLT.*

Mechanism 2: According to HCPs, information and role-play increase their automatic motivations

According to HCPs, information provided in the training sessions and role-play increased the number of positive experiences during conversations. This resulted in an increase in the number of times HCPs conversed with people with aphasia in a low-stimulus environment and an increase in non-verbal support and written support.

> *When it comes to communicating with people with aphasia in low-stimulus environments, I now try to be better prepared by finding out if I can find a quiet room. That's something I do differently. After the training I noticed that people with aphasia understand me better when I talk to them in a quiet room.*

Mechanism 3: According to HCPs, information, videos and role-play increase their reflective motivations

Information provided in the training sessions, videos and role-play increased HCPs' beliefs that communication is more effective when using supportive conversation techniques (beliefs being a part of people's reflective motivations). This resulted in an increase in written support, offering structure, addressing people with aphasia with respect and the use of supportive conversation tools.

> *I ask questions that provide structure, such as 'is this about you, or about me?' I didn't do that before. It's because I practiced during role-play. Because of that, I believe that if I ask more focused and structured questions, we will understand each other better.*

Information and role-play increased HCPs' beliefs that using supportive conversation techniques is a good thing to do, and something that they can do. This resulted in an increase in the number of times HCPs conversed with people with aphasia in a low-stimulus environment and an increase in written support and offering structure.

> *I am more convinced that I am capable of making sure my message comes across. And more capable of understanding what people with aphasia want to say. Before, I was more inclined to fill in words. But now that I know about these techniques that I can use, I don't do that as often as before.*

Additional findings

Although HCPs reported the mechanisms that led to an increase of the use of supportive conversation techniques and tools after CommuniCare, they also spoke about barriers that prevented them from changing their behaviour (Figure 5). Four different conditions led to barriers in the use of techniques and tools. The first condition concerned HCPs' physical capabilities. Some HCPs reported that in order to use supportive conversation techniques, and in particular speaking, remembering and selecting the right words to write down during conversations, they needed to acquire more skills outside role-play. The second condition concerned HCPs' reflective motivations. One HCP reported that he lacked self-esteem when it came to writing down important keywords during the conversation; this had to do with having dyslexia. Some HCPs who shared their experiences with communicating with people with severe aphasia said that they did not believe in the positive consequences of using supportive conversation techniques or that successful communication was essential to improve recovery and psychosocial wellbeing of the person with aphasia, and therefore did not use supportive conversation techniques. The third condition concerned HCPs' automatic motivations. One HCP did not receive enough reinforcement from people with aphasia to use supportive conversation techniques or tools; in fact some people with aphasia had suggested they did not like the HCP using supportive conversation techniques.Therefore, this HCP did not get used to using the techniques and tools. The last condition concerned HCPs' physical opportunities. Some HCPs reported directly after the training that they did not have enough time to use supportive conversation techniques and tools. Four months later, this experience was no longer reported by any HCPs. Many HCPs reported that the presence and accessibility of supportive conversation tools was an important condition for the use of these tools. One HCP reported that she did not always have the possibility to converse with people with aphasia in a low-stimulus environment because of the absence of available, single, quiet rooms. Finally, many HCPs expressed that social support from a role model or credible source was an important condition to use supportive conversation techniques and tools.

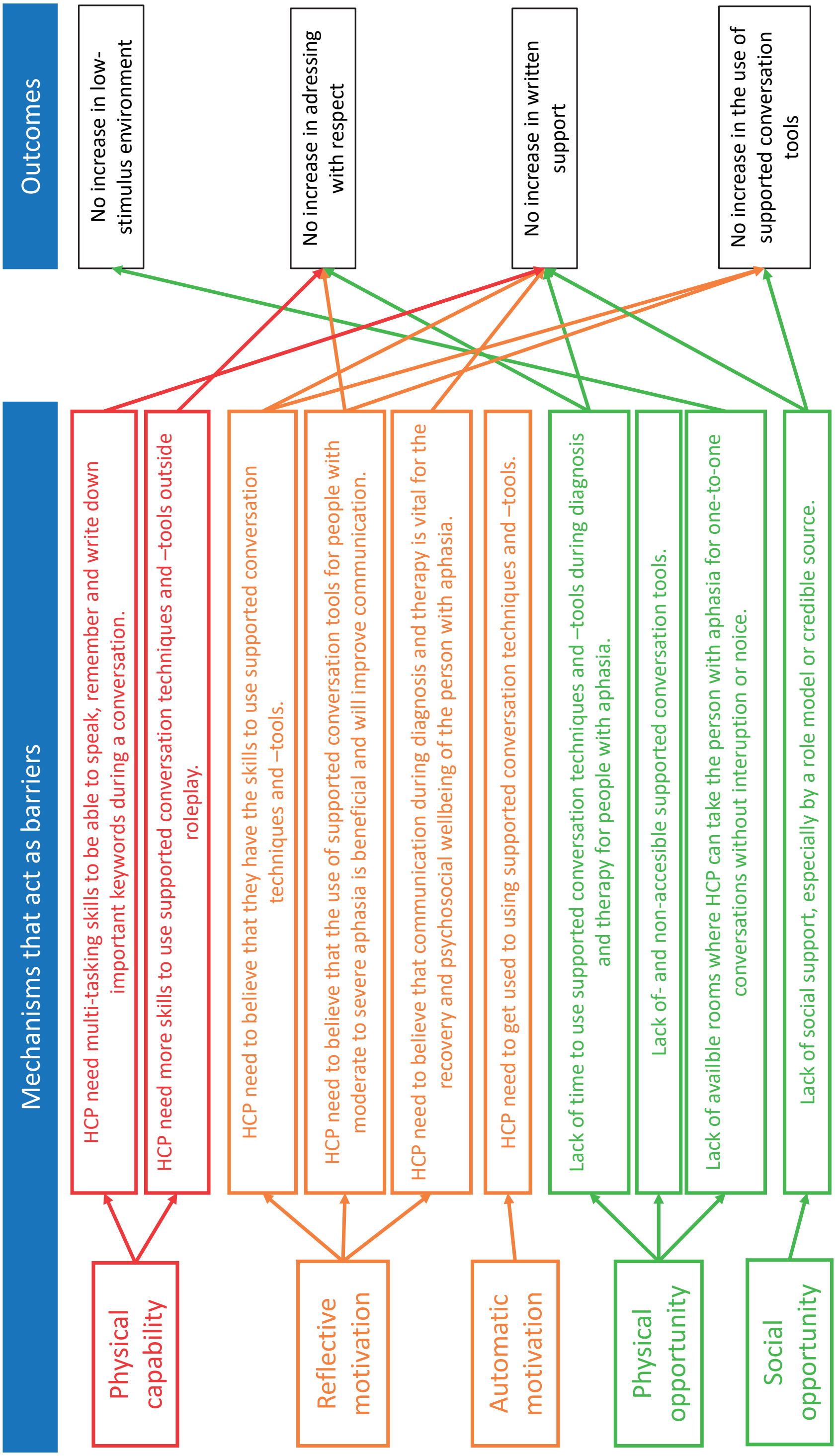


Figure 5. Mechanisms that act as barriers.

DISCUSSION

The objective of this study was to identify the mechanisms of change as a result of the CPT intervention CommuniCare from the perspectives of HCPs. Six intervention elements were mentioned by HCPs (information, videos, e-learning, role-play, feedback during training and coaching on the job), which from their perspectives all led to an increase in the use of supportive conversation techniques.

Information and videos that were provided to HCPs in an e-learning program and training sessions aimed to increase their knowledge and awareness and persuade them to use techniques and tools during conversations. HCPs confirmed that these intervention elements increased their psychological capabilities and motivations to use conversation techniques and tools. Role-play, which was part of the training sessions, aimed to increase HCPs' cognitive and interpersonal skills to use techniques and tools. HCPs confirmed that role-play increased their psychological capabilities. Moreover, HCPs also designated it as the most important intervention element for increasing their automatic and reflective motivations. Role-play is used a lot in CPT interventions [22–25] and HCPs have identified that it is a more effective element than didactic lecture-based components [24]. Role-play in CPT interventions generally involve clinicians providing instructions, discussion and feedback to help conversation partners change their behaviour. Typical behaviour change techniques that clinicians use are modelling of strategies, scaffolding, natural reinforcement and subtle prompting [26].

To our surprise, HCPs reported that feedback during the training sessions and coaching on the job only increased their psychological capabilities. We expected that coaching on the job would also increase HCPs' beliefs in their own capabilities and beliefs in the positive consequences. Two reasons might explain why HCPs did not confirm our expectations. First, we raise the question of fidelity: we did not evaluate the quality (fidelity) and quantity (dose) of coaching on the job. We observed logbooks that the communication coaches kept during four months after the training and suspect that the coaches might have paid more attention to developing accessible conversation tools for HCPs than prompting them to use techniques, reminding them to practice and providing them with feedback. Second, this finding raises the question of the required qualities of a communication coach. At the time we recruited communication coaches, we focused on their skills and knowledge on using supportive conversation techniques and tools. We now believe that communication coaches should also have a pro-active role in supporting their colleagues to practice the use of techniques with people with aphasia, as beliefs about the consequences and capabilities are largely triggered by patient exposure and response. The coaches should also be good implementation supporters. The roles or qualities that implementation supporters should possess remain unclearly defined in research or practice [27]. Labels that are used to describe implementation support practitioners in healthcare are "knowledge broker, coach or consultant". However, these labels lack clear definitions and role descriptions due to the novel character of these roles in healthcare. A recent research paper proposes a unique mix of roles and qualities in implementation support practitioners: 1) a formal position as implementation support practitioner, 2) a background as HCP, 3) academic and local knowledge and practical experience, 4) a positive attitude towards evidence based practice, 5) a collaborative mind-set and flexibility and 6) the skills to activate attitudes, utilise resources and apply knowledge in ways conducive to achieving goals [27]. Although these roles and qualities remain underspecified in terms of what our communication coaches should do and how their role can facilitate behaviour change in HCPs, they provide some guidance to determining which HCPs may be suitable as coaches and how than can be facilitated by the healthcare setting. Important lessons could also be learned from more general literature on so-called implementation 'champions'. Miech et al. (2018) found in their integrative review that more than 80% of implementation articles that report on champions, identified champions as one of several key factors associated with implementation success [28]. They argue that champions represent a "necessary but not sufficient" condition for implementation success: champions alone were inadequate to bring about change, yet in combination with other factors proved essential to implementation success. Our findings are in line with this statement.

Evaluating our intervention through the perspectives of the users has proven to be extremely valuable. First, it has provided us with a better understanding of the elements that should be included in CPT interventions in different contexts. In healthcare settings where HCPs have adequate knowledge and extended experience with aphasia, an e-learning program, information or videos may not be necessary, whereas role-play and coaching on the job can be of vital importance to increase HCPs' motivations or beliefs about self-competency. Second, this evaluation has shown us HCPs' barriers for using supportive conversation techniques after CPT. HCPs mainly reported a lack of belief that the use of supportive conversation techniques and tools is beneficial for people with aphasia. HCPs mentioned that these experiences generate from conversations with people with severe aphasia. However, there may be other reasons that explain why HCPs do not use supportive conversation techniques or believe in their value. One reason may be that they have not had enough opportunity to practice. Patient exposure may help HCPs to experience success and gain confidence and motivation. Healthcare settings wishing to enhance HCPs' communication skills should consider enhancing experiential learning. A few examples are: 1) the implementation of a buddy or proxy system, where two or three HCPs prompt each other to practice, provide feedback and discuss cases during peer-to-peer coaching, 2) the development of a plan to ensure that HCPs are coached by communication coaches, such a plan could include monitoring the fidelity and dose of coaches' roles and activities, evaluating the outcomes, formulating an action plan and executing the action plan. The roles and qualities that communication coaches should possess were explained earlier. Although the SLTs and the clinician researcher providing the training sessions were not necessarily "part" of the intervention, some HCPs did mention the importance of the role of the trainers. Some HCPs preferred having the same trainers for both training sessions, while others preferred having different trainers during each session. In this study, we did not investigate interactions between the HCPs and trainers. Healthcare education would benefit from future studies investigating the importance of interactions between healthcare educators and HCPs and the (behaviour change) outcomes of different interactions. Additionally, management also has an important role. Some of the barriers mentioned by HCP relate to conditions in time, tools and available rooms. These conditions are highly important in order to change HCPs' behaviour and requires support from management.

Some intervention types and materials that were used in CommuniCare to increase HCPs capabilities or motivations were not reflected on by HCPs: 1) the infographic that was used as educational material to increase HCPs' beliefs about the positive consequences of using techniques and 2) the supportive conversation tools that aimed to support HCPs in using preprepared written words and pictures. Many CPT interventions incorporate the use of supportive conversation tools, where the content and design of health information used by HCPs is made aphasia-friendly (Rose, Worrall, Hickson & Hoffmann, 2011). Therefore, future research should investigate the barriers, value and outcomes of using supportive conversation tools in healthcare settings.

With this exploration of the mechanisms of change underlying behaviour change of HCPs after CPT, we hope to add to the scarce literature on (successful) implementation research in aphasia. In their recent review on implementation science in aphasia management, Shrubsole, Worrall, Power & O'Connor (2017) call for more research to better understand the application and implementation of interventions in clinical context[29]. This paper may inspire other researchers to use a similar methodology to understand the effects of complex interventions, such as CPT, through systematic exploration of the behaviour changes of the recipients.

CONCLUSIONS

From HCPs' perspectives, seven intervention elements in our CPT intervention CommuniCare led to an increase in the use of supportive conversation techniques (information, videos, e-learning, role-play, feedback during training and coaching on the job). The remaining barriers that HCPs reported mainly involved a lack of belief that the use of supportive conversation techniques and tools is beneficial for people with aphasia. There may be other explanations as to why some of these HCPs did not use techniques and tools, such as insufficient practice. An important recommendation from our results is therefore that when healthcare settings aim to enhance HCPs' communication skills (by CPT), they should consider ways to enhance HCPs' opportunities for experiential, on-the-job learning. This should be supervised and stimulated by a designated implementation support practitioner. The importance of determining the competencies this implementation support practitioner should have, should not be underestimated. Healthcare organisations should carefully determine which HCPs are suitable to have a role as implementation support practitioners and facilitate practitioners to fulfil this role, to support their colleagues in the use of supportive conversation techniques and tools.

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CHAPTER 7

7

General discussion

The general aim of this thesis was to improve the accessibility of communication for people with aphasia in healthcare centers, which was specified in two aims:

1. To develop the intervention CommuniCare by an in-depth investigation of the needs and wishes of people with aphasia, HCPs and relatives regarding the accessibility of communication in healthcare centers.
2. To evaluate CommuniCare by an in-depth investigation of HCPs' self-reported mechanisms that facilitate or limit them in using supportive conversation techniques after CommuniCare.

This chapter provides an overview of the main findings of each chapter, a discussion of the main findings, methodological considerations, implications and the final conclusions.

MAIN FINDINGS

Chapter 2 reported about the pilot study of the first version of the Communication Partner Training (CPT) intervention CommuniCare and results indicated good feasibility for organizing Communicare on the stroke unit of a peripheral hospital. Nurses reported that the pilot version raised their awareness of the need to use supportive conversation techniques and increased people with aphasia's ability to get their message across. However, a barrier for using supportive conversation techniques was a lack of time. Nurses' recommendations for further developing CommuniCare were to extend skills training by including more time for roleplay and to investigate if and how other HCPs (beside nurses) could be involved.

In order to further develop CommuniCare and ensure the intervention addressed the needs and wishes of the users and recipients, we conducted two qualitative exploratory studies with people with aphasia, relatives and HCPs. **Chapter 3** reported on the experiences with communication of people with aphasia and relatives of people with aphasia in healthcare centers. The findings comprised a large variety of positive and negative experiences regarding aphasia-friendly communication in healthcare centers. For example, some people with aphasia and relatives were satisfied about the way that they were included in decision-making, whereas others would have wished to participate more when minor and/or major decisions were made. Another example included the experiences on the way that HCPs transferred information: the majority of participants was frustrated or unhappy about the way that HCPs shared information, because it was often inaccessible for people with aphasia, while some others were satisfied about it. One finding that was particularly evident for relatives, was that they felt insufficiently supported in their own emotional process and the consequences of their family member's stroke and aphasia on their own wellbeing. The needs and wishes of people with aphasia and relatives could be summarized in three main themes: first, improvement in the transfer of information from HCPs by the use of pictures, gestures or written words. Second, involvement of people with aphasia in CPT in order to provide information and feedback to HCPs from experts by experience. Thirdly, designating one HCP to be responsible for inquiring after the emotional wellbeing of the relatives in relation to the stroke, and in case needed refer them to the right support. **Chapter 4** focused on the needs and wishes of the users, i.e., HCPs. This qualitative study showed that Dutch and Flemish HCPs experienced significant communication difficulties with people with aphasia, which impeded diagnosis and therapy with considerable implications for healthcare quality. HCPs suggested to improve communication by increasing their knowledge and skills through CPT and providing implementation- and post-training support. The findings further showed that HCPs would encourage various roles for speech- and language therapists (SLTs), including supporting HCPs to learn and practice to communicate in an aphasia-friendly manner, coaching them on the job and keeping supportive conversation tools up to date. HCPs also proposed more time should be allocated to the care pathway of people with aphasia, and reported the need for facilitation, commitment and support by HCPs with a higher level of authority and managers.

Chapter 2, 3 and 4 led to the development of the final version of CommuniCare. Based on the findings from these studies, the intervention was modified by adding an e-learning program and providing HCPs with five hours of training instead of four. Also, HCPs need for providing implementation and post-training support resulted in three further intervention strategies: 1) instructing SLTs to provide post-training support, 2) organizational facilitation of coaching HCPs on the job and 3) implementing two organizational meetings with managers and physicians to make sure they were up to date and supportive of the implementation of CommuniCare. In **chapter 5** we described the CommuniCare intervention in detail using the 12 items of the Template for Intervention Description and Replication (TIDieR) checklist.

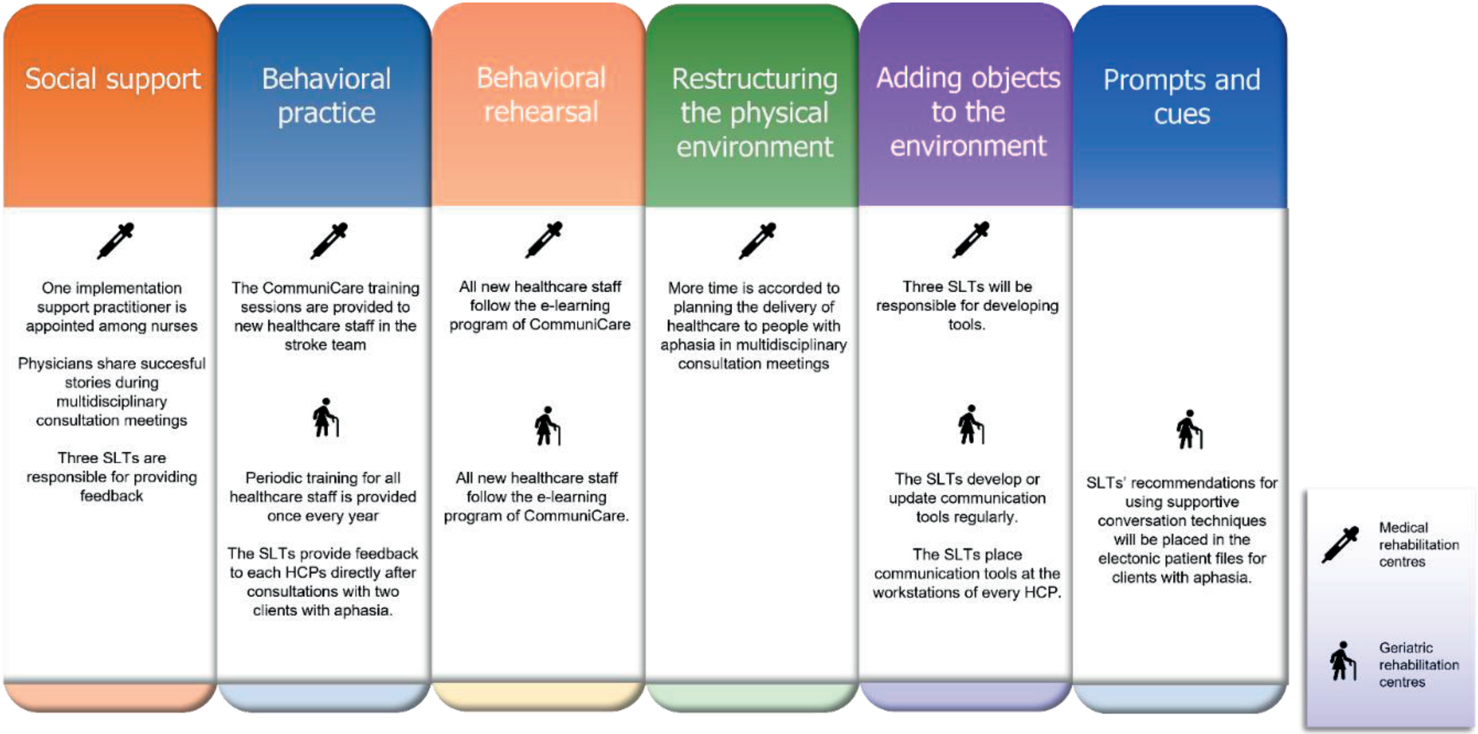
Chapter 6 explored which intervention elements in CommuniCare led to behavioral change in HCPs. This was evaluated through HCPs' perspectives by conducting interviews one month and four months after receiving CommuniCare. Six intervention elements, i.e., information about aphasia and the consequences of aphasia, video's, the e-learning module, roleplay, feedback during training and coaching on the job, led to an increase in HCPs' capabilities, motivations and opportunities to use supportive conversation techniques. Information and video's mainly increased HCPs' knowledge and awareness about aphasia-friendly communication and persuaded them to use techniques and tools during conversations. Roleplay was the most important element for increasing HCPs' self-esteem. The barriers that HCPs came across were mainly the lack of experiential learning opportunities and social support from colleagues and managers, their beliefs about the benefits for people with aphasia and their beliefs about their own capabilities. Based on the findings from this multi-center evaluation study we recommended that three intervention strategies should be included in all CPT interventions: 1) providing HCPs with experiential learning opportunities in- and outside of training sessions, 2) organizing regular team meetings with physicians, managers and SLTs to make sure they are supportive of the implementation of CPT and follow up the implementation plans, and 3) organizational and financial planning for a pro-active role of SLTs and the appointment of implementation support practitioners to encourage, coach and support HCPs in the use of supportive conversation techniques.

Based on the mechanisms of change that were found in chapter 6, the participating healthcare centers developed plans with implementation strategies to help their HCPs use supportive conversation techniques. Figure 1 shows the strategies that were chosen by the five participating healthcare centers to implement in 2021.

DISCUSSION OF THE MAIN FINDINGS

Patient-centered care has become a central point of attention in healthcare and involves effective communication between the HCP and the patient[1]. Despite various initiatives to improve communication between HCPs and people with aphasia, such as the development of CPT interventions and guidelines for making information accessible, the findings in this thesis show that people with aphasia still encounter poor communication in healthcare centers.

The direct impact of improving the inclusivity of communication for people with aphasia is difficult to capture due to a lack of outcomes for measuring successful conversations. In the first theme below, 'the impact of inclusive communication in healthcare centers' we will explain this in more detail and discuss how and why we measured outcomes in terms of behavior change. To facilitate behavior change, CPT interventions should be implemented successfully and durably, which requires more than providing a few training sessions to HCPs each year. It requires leadership-, financial and organizational support, learning opportunities and the availability of materials and appropriate spaces. We will discuss this further in the second theme 'implementing aphasia-friendly communication in healthcare centers.' Since we have found that leadership support and learning opportunities are critical components in successfully and durably implementing CPT, we advocate for laying the foundations for supportive conversation skills and leadership skills in healthcare education. This will be discussed in the third and last theme 'laying the foundations for supportive conversation skills in healthcare education'.



	Social support	Behavioral practice	Behavioral rehearsal	Restructuring the physical environment	Adding objects to the environment	Prompts and cues
Medical rehabilitation centres	One implementation support practitioner is appointed among nurses Physicians share succesful stories during multidisciplinary consultation meetings Three SLTs are responsible for providing feedback	The CommuniCare training sessions are provided to new healthcare staff in the stroke team	All new healthcare staff follow the e-learning program of CommuniCare	More time is accorded to planning the delivery of healthcare to people with aphasia in multidisciplinary consultation meetings	Three SLTs will be responsible for developing tools.	
Geriatric rehabilitation centres		Periodic training for all healthcare staff is provided once every year The SLTs provide feedback to each HCPs directly after consultations with two clients with aphasia.	All new healthcare staff follow the e-learning program of CommuniCare.		The SLTs develop or update communication tools regularly. The SLTs place communication tools at the workstations of every HCP.	SLTs' recommendations for using supportive conversation techniques will be placed in the electonic patient files for clients with aphasia.

Figure 1. The behavior change techniques chosen by healthcare centers to implement in 2021. This figure is based on the Behavior Change Taxonomy (https://digitalwellbeing.org/wp-content/uploads/2016/11/BCTTv1_PDF_version.pdf)

The impact of communication difficulties in healthcare centers

Research has shown that communication with HCPs influences how patients perceive their healthcare experience. For example, communication difficulties with HCPs impact desired autonomy and independence. Adults generally prefer to be independent and exert control on healthcare decisions[1]. Autonomy can range from making simple choices, such as what to eat or wear, to serious decisions that have a higher impact, such as whether to have surgery or what facility the patient prefers to receive care from. One of our respondents with aphasia pointed out that "*HCPs do not discuss healthcare plans with me and I feel very bad about that*". Generally, the 'solution' is that family members are asked to make the decisions or speak on behalf of the person with aphasia, even though they are not reliably accurate in predicting activity choices and desires of the person with aphasia[2]. Even though some of our respondents with aphasia were able to declare their wish that important decisions *were* made by their family members, they retained the wish to be *informed* about decisions and included in simple choices.

Other studies that have evaluated the impact of communication difficulties in healthcare for people with aphasia, show a longer length of stay in rehabilitation centers compared to stroke survivors without aphasia[3], and more adverse events in hospitals[,5]. A master student that collaborated in our research project conducted a preliminary retrospective cross-sectional study in one of the participating healthcare centers (aphasia group N=48, non-aphasia group N=50). She found that the length of stay in the rehabilitation center was on average twelve days longer in the aphasia group. Improvement scores on mobility and cognition were comparable between groups. However, people with aphasia received significantly more treatment from social workers (aphasia: 8.9 hours (SD = 9.1), non-aphasia: 4.2 hours (SD = 4.0), $p = .002$) and significantly less hours of psychological therapy (aphasia: 5.8 hours (SD = 4.6), non-aphasia: 9.0 hours (SD = 6.6), $p = .007$).

We believe that addressing the lower dose of psychological therapy is essential, as we know that the incidence of depression for people with aphasia is estimated to be 62% to 70% twelve months post-stroke and is higher than for stroke survivors who do not have aphasia [6]. Worrall et al. (2017) found that depression and anxiety were the best predictors for quality of life with aphasia in the first year after onset[6]. Depression is associated with lower functional outcomes from rehabilitation[7], poorer recovery of physical and cognitive functions[8], increased use of health services, longer hospitalizations[9], higher healthcare costs[10] and increased mortality[11]. Therefore, attention for and treatment of depression and anxiety should be high priority for people with aphasia. A language-based assessment of emotional well-being is clearly going to pose barriers. However, there are adaptive diagnostic methods for depression in individuals with aphasia. Examples include psychiatrist observations, using visual analogue scales or modifying questions to make them aphasia-friendly[12].

Up to now, little is known on whether CPT interventions improve inclusive communication in healthcare centers. The desired outcomes of CPT, i.e., improvement in communication and participation of the person with aphasia, remain difficult to capture. The outcome measures that are used in CPT research[33] are often developed for the one in need of rehabilitation, e.g., psychosocial outcomes, whereas CPT targets the quality of the conversation. Quality of conversations is a complex phenomenon that is highly dependent upon relationships, contexts, conversation topics, roles and participants' behaviors. Researchers in the field of CPT recommend developing observational and self-reported outcomes measures[14] for CPT interventions, identify the constructs to be measured and align the goals and objectives of CPT interventions with the tasks and activities used in the intervention[15].

Future research addressing the use of Patient Reported Outcome Measures (PROMs), i.e., outcomes that are relevant to the patient, may become very important in measuring the effects of CPT interventions. PROMs seem appropriate, since the findings in Chapter 3 have shown a large variety in needs and wishes of people with aphasia and emphasize the importance of personalized care. On the other hand, in order to use instruments such as PROMS reliably, effective communication is indispensable and HCPs need to be trained in order to be able to use PROMs for people with aphasia. Therefore, in this thesis, we evaluated the outcomes of CPT in terms of behavior change; how does CommuniCare change the use of supportive conversation techniques in HCPs? We used qualitative analyses to evaluate the mechanisms of change after CommuniCare. Our findings show that various intervention elements in CommuniCare can increase the capabilities, motivations and opportunities of HCPs to use techniques. This resulted in the development of context-specific implementation strategies.

Several explorative studies have been carried out or are currently being conducted to develop and investigate outcomes for people with aphasia. For example, a study that used nominal groups with people with aphasia and family members concluded that from their views, improved communication, increased life participation, changed attitudes through aphasia awareness, recovered normality, improved physical and emotional well-being and improved health services were important treatment outcomes[16]. In the UK, a large study is currently being conducted to develop outcome measures for CPT interventions (for more information, visit https://www.aphasiatrials.org/communication-partner-training-programme-grant/).

We have considered the impact of inaccessible communication on the person with aphasia, either in an emotional, social or physical sense. The effects on family members are often overlooked. Relatives of people with aphasia often experience third-party disabilities, which refer to negative functional consequences as a result of the patient's health conditions[17]. Although there has been a lot of attention for relatives in Dutch healthcare facilities in the past years, and recommendations for prevention and treatment of the consequences for family members are part of Dutch guidelines on stroke, there still is too little attention for these relatives in rehabilitation. Good communication with and attention for family members and caregivers can help them at a particularly frightening and confusing time[18–21]. Some studies have considered the best timing for providing CPT to relatives. Most family members reported that CPT would not be feasible at an early stage in (inpatient) rehabilitation. CPT would be more feasible when the person with aphasia returns home, when more natural conversations occur and the full extent of the consequences of aphasia are experienced[22]. However, HCPs' attention for the consequences experienced by relatives should start directly post onset. *"HCPs should increase their awareness of the emotional conditions of relatives at an early stage"*, as the husband of one of our respondents with aphasia expressed.

The outcomes of inclusive communication are not limited to people with aphasia and their relatives: improving the accessibility of communication in healthcare centers has the potential for very broad impact. For example, it could have an impact on people who are health illiterate (29% of Dutch adults have limited or insufficient health literacy according to Nivel, 2019): an inability to comprehend and use medical information and advice. It could also benefit people with communication difficulties resulting from cognitive impairments, language barriers and speech disorders.

Taken together, effective communication is the common thread for providing safe, high-quality and patient-centered care. To help HCPs effectively communicate with patients with aphasia, we recommend implementing strategies for aphasia-friendly communication in healthcare centers and redesign related healthcare education.

What is needed to implement aphasia-friendly communication in healthcare centers?

The implementation of CPT for HCPs is recommended in international best-practice statements and national best-practice guidelines in the Netherlands. The strategies to implement CPT should be adapted to the context and to the HCPs working in different healthcare centers[14]. However, the literature is limited in investigating which strategies are needed and effective. To our knowledge, two studies have been conducted to investigate how CPT can be implemented, one by Johnson et al. (2017)[23] and one by Chang et al. (2018)[24]. Johnson et al. (2017) focused on the implementation of CPT for dyads, i.e., the person with aphasia and his or her close relative. We will not go into more detail here, since the target group is different compared to ours. Chang et al. (2018) focused on the factors that influence the implementation of CPT interventions by SLTs, using the Theoretical Domains Framework (TDF)[25] - a theory-informed framework to identify determinants of behavior-: 1) SLTs' attitudes towards providing CPT and believing it to be part of their role, 2) work-place related factors that include behavioral regulation through monitoring systems, workplace policies to facilitate consistent provision of CPT, department culture of routinely providing CPT and encouragement from the organization and 3) resources, skills, knowledge, empowerment and beliefs of positive consequences[24]. In our evaluation study in Chapter 6, we focused on the implementation of CPT from HCPs' perspectives. We used the Behavior Change Wheel (BCW)[26] to evaluate behavior change in HCPs, which provided the basis for developing implementation plans. The process of going back and forth between HCPs' barriers and facilitators for using supportive conversation techniques, and developing implementation strategies, was reported by stakeholders to be extremely valuable. Indeed, studies have highlighted that the effectiveness of implementation strategies is dependent upon their potential to address the barriers and facilitators that influence the implementation[28.]. Understanding HCPs' experiences helped the healthcare teams to formulate context-specific implementation strategies. Taxonomies such as the Behavior Change Taxonomy or the Expert Recommendation for Implementing Change (ERIC) compilation are commonly used and valuable tools to design implementation strategies based on barriers and facilitators[27].

One year after we developed the implementation plans, three bachelor students conducted a qualitative research project to get an impression of how the implementation strategies had been carried out. 22 HCPs from four healthcare centers responded to an online questionnaire. The students concluded that, from HCPs' perspectives, the following implementation strategies had been carried out: behavioral practice (N=2 out of 3 healthcare centers), restructuring the physical environment (N=1 out of 3 healthcare centers), adding objects to the environment (N=2 out of 2 healthcare centers) and prompts and cues (N=2 out of 3 healthcare centers). The strategies for providing social support and behavioral rehearsal had not been carried out by any of the healthcare centers.

Implementation strategies are designed to help move and integrate evidence-based healthcare interventions into specific practice settings[27]. They are used "to plan, educate, finance, restructure, manage quality and attend to the policy context to facilitate implementation"[27]. Therefore, adherence to the implementation plan is essential. Clinicians and managers would benefit from future research that focuses on a process evaluation of implementation strategies for CPT: why and how are strategies carried out, and what are the outcomes.

Although healthcare centers participating in the CommuniCare research project chose their own, context-specific implementation strategies, some strategies overlapped. We believe these are transferable across healthcare settings, and we will describe them below. Most strategies are based on increasing HCPs' motivations and opportunities for using supportive conversation techniques, because the improvement of these conditions was most important from HCPs' perspectives. The strategies are nonsequential and may be carried out in any order.

- Support for the use of supportive conversation techniques should be highly visible and carried out by leaders. Leadership is known to be critical for applying complex interventions in healthcare facilities: it establishes service improvements, such as institutional support for new practices, resource obtainment and organizational partnerships[29]. Leadership can be defined as the ability to identify priorities, set visions, and mobilize actors and resources needed to achieve the visions[29]. Leaders in the field of inclusive communication must come from healthcare staff and decision makers within the system. Although little is known about how to identify leaders of change and their capacities, the research in this field is growing[30]. For example, the Implementation Support Practitioner Profile Guide describes the core competencies that practitioners need to effectively implement evidence in healthcare systems[31]. Based on these competencies, which include brokering, co-designing, assessing needs and assets, understanding the contexts and facilitating colleagues, we advocate that Dutch Knowledge Brokers from the Knowledge Broker Network of Cerebrovascular Diseases (Dutch: Kennisnetwerk CVA NL) possess these skills and can become leaders in implementing aphasia-friendly communication. They should model the use of supportive conversation techniques, promote the use as a requirement for providing safe and high-quality care, communicate their expectations and invest in support systems within the structure of the organization. The leaders should also have a role in the de-implementation of HCPs' views on their own responsibilities: HCPs must be made aware that SLTs can coach and support them, but effectively communicating with their patients is part of their own responsibility.
- Financial and organizational support is needed for annual training and coaching of HCPs in the use of supportive conversation techniques. Training is an important and widely used strategy that promotes implementation. Effective and repetitive training has the potential to increase knowledge, skills and abilities[32]. The current Diagnosis Treatment Combination (Diagnose Behandeling Combinatie (DBC)) financial system does not allow to allocate more time in the healthcare pathway of people with

aphasia. Therefore, management in healthcare centers needs to explore resourcing possibilities to fund coaching of HCPs and structural repetition of CPT.

- HCPs should be provided with learning opportunities. Two well-known adult learning theories can be used as an approach. *Experiential learning theory* focuses on shaping HCPs' experiences through reflective learning, instead of memorizing facts and figures. The four steps of Kolb's experiential learning theory include: 1) concrete experience, where the HCP actively experiences a conversation with the person with aphasia, 2) reflective observation, where the HCP consciously reflects back on that experience, 3) abstract conceptualization, where the HCP is presented with- or tries to conceptualize a model of what he or she wants to observe next time and 4) active experimentation, where the HCP tries to plan how to test that model during a forthcoming experience[33]. Another approach that could be suitable to provide HCPs with learning opportunities is the *andragogy learning theory*. The five principles of andragogy are: 1) the HCP needs to know the reason that he is being asked to use supportive conversation techniques, 2) the HCP must learn from real-life experiences, 3) the HCP needs to be responsible for learning decisions, for example by learning through online training and formulating his own goals, 4) the content of the learning should be problem oriented, rather than generic and 5) the HCP must find his individual internal motivators[34,35].
- The use of supportive conversation techniques must be integrated into treatment policies for people with aphasia. Physicians should indicate the use of techniques in the treatment plan.
- All tools and materials that are used in healthcare centers must be adapted to the needs of people with communication difficulties. Examples are signage, written information and websites. This asks for financial and organizational investment.

Laying the foundations for supportive conversation skills in healthcare education

The first stages that are required for using supportive conversation techniques are knowledge and awareness[36]. We believe that all healthcare students should possess knowledge and awareness of the importance of patient-centered care and good communication skills. We advocate that all healthcare students at the undergraduate level receive basic education in these competencies, including education on communicating with patients with communication difficulties. Based on guidance from the National Institute for Health and Care Excellence (NICE) and the Australian Commission on Safety and Quality in Health Care, the following learning goals are suggested as examples to be included in healthcare education programs: 1) the healthcare student can convey treatment plans and health education clearly, accessibly and empathetically so that patients can receive optimal care, 2) the healthcare student can share information ethically and responsibly to protect patient confidentiality, 3) the healthcare student can provide clear and honest information so that patient and provider can accurately make treatment decisions 4) the healthcare students can ask the patient about their emotional state relating to his or her health concerns 5) the healthcare student can listen attentively to patients needs and wishes and reflect back on what was said. The behaviors that healthcare education programs can teach to students to help them achieve these goals are teaching students to take time and converse with the patient at eye-level, ask open-ended questions, speak in plain language without jargon and keep information confidential.

Although these changes in the undergraduate education of HCPs can lay the foundations for raising their knowledge and awareness at an early stage, the changes cannot substitute for the implementation of training and learning in healthcare centers. This is because later stages of behavior change, i.e., intention, preparation, action and maintenance[36], only arise on the job when HCPs have real-life and recent experiences. Indeed, it is well-documented in the literature that teacher- centered didactic education sessions can be effective in building knowledge and shaping attitudes and beliefs, but are often insufficient to achieve practical application of interventions in real-world settings[37,38]. The transfer of knowledge and skills acquired through training to the conditions of service organizations and systems is influenced by a variety of factors, including the climate characterizing the setting and support for knowledge transfer available in the setting[32].

We advocate for post-graduate training for HCPs to become implementation support practitioners (ISPs). ISP is not a traditional role of HCPs in clinical settings. However, we believe that the formal positioning of ISPs in healthcare centers is essential to implement CPT, because research has shown that the implementation of complex interventions requires knowledge and skills in selecting and designing implementation strategies[30]. However, there are very few possibilities for training and professional development available for ISPs in healthcare centers. Only recently have courses been designed to build implementation capacity in service staff[39–41]. The implementation support skills that ISPs should possess according to the literature are quite extensive[30]. ISPs should be able to train and educate stakeholders, by identifying their support needs, supporting them, monitoring their progress and performances, identifying implementation barriers and solutions and initiating these. ISPs should develop stakeholder interrelationships, by sharing their knowledge about beneficial services and working to overcome barriers to stakeholder connectivity. ISPs should be able to adapt and tailor to the context, and support adaptions[30]. Because the skills and competencies that ISPs must possess are so extensive, we recommend that CPT interventions include implementation courses based on previous studies that were mentioned earlier. Future research would benefit from evaluating how the activities and competencies of ISPs contribute to the implementation of inclusive communication in healthcare centers.

Another change that we advocate for in healthcare education, is a clearer focus on leadership development from the earliest stages of SLTs' career. Leadership support has been found to facilitate the implementation of service organizations[42,47]. Our findings support that SLTs have a role as opinion leaders who are seen as likeable, trustworthy and influential in the field of communication. Because of their influence, they may be able to help and persuade HCPs to use supportive conversation techniques during encounters with their patients. As HCPs reported in Chapter 4, SLTs, with their field of expertise, need to take up a more pro-active role to coach HCPs in using supportive conversation techniques. Leadership can be defined as a process of social influence, occurring in a group context towards the attainment of a common goal[43]. It requires a set comprising knowledge, skills and behaviors. The core business of healthcare leaders is to bring about continuous improvement in care and health of populations[44]. Although becoming a leader is a personal journey, literature and practice provide us with knowledge and ideas about how to integrate leadership development into undergraduate health curricula. Based on recommendations from a recent research paper about medical teaching, which provides twelve tips for integrating leadership development into undergraduate medical education[44], we will provide some examples that can be helpful to integrate into the education of undergraduate SLT students. First, one strategy that has been shown to be effective is to reframe leadership as a core part of the SLTs' identity. Healthcare curricula are just as much about knowledge and skills development as about developing a professional identity. Another strategy that was shown to be effective is facilitating leadership development through team working. Learning how interprofessional teams work and what problems they come across can help students become familiar with leadership roles. Students should learn that they can lead and contribute to the collective success of teams. Third, specific leadership development modules should be available and accessible to all students. Fourth, the development of leadership competencies, knowledge, skills and behaviors amongst students must be assessed.

METHODOLOGICAL CONSIDERATIONS

The choices that we made in the multi-center development and evaluation project, were to strengthen it, but may also have posed limitations. The methodological considerations regarding the study sample, population and outcome measures will be discussed below.

Study sample and population

The CommuniCare project focused on improving aphasia-friendly communication in hospitals and rehabilitation centers. We are very pleased with the number of participating centers in this project. We aimed to include healthcare centers where people with aphasia were a relatively large target population of HCPs, and succeeded in including eight high-standard centers that provided care for people with aphasia in the Netherlands and Belgium. However, the main facilities that were included were geriatric rehabilitation centers, whereas we hoped to include (more) hospitals and medical rehabilitation centers. The reason was that, upon inclusion, relatively few hospitals and medical rehabilitation centers agreed to participate due to time limitations. Therefore, the experiences of stakeholders that were evaluated in the two qualitative studies, i.e., Chapter 3 and 4, and the barriers and facilitators for the use of supportive conversation techniques by HCPs, i.e. Chapter 6, can mainly be generalized to people who have been admitted to- or work in geriatric healthcare facilities. We might expect that in a hospital setting, where the turnover of patients is much higher and patients receive active and short-term treatment, less attention is paid to communicating effectively -this may also explain why hospitals felt time constraints to participate in the project- and the experiences of stakeholders may be quite different there. Indeed, we found differences between the interviews conducted in the one participating hospital and the rehabilitation centers. For example, HCPs in the hospital preferred shorter training sessions and provided less input to the development of supportive conversation tools. People with aphasia had fewer barriers to report, since their expectations were to stay in the hospital for a short period. Another consequence of mainly including geriatric centers was that the implementation strategies that were chosen (Figure 1) predominantly represent the strategies that physicians and SLTs considered suitable for HCPs working in those centers. The implementation of interventions can vary across different settings, since implementation is a dynamic social process that is shaped by the context in which the innovation takes place and the people that are involved in that process[45]. In medical rehabilitation centers, HCPs may have more experience in communicating with people with aphasia, resulting in a different set of relevant implementation strategies. For future research and practice, it would be beneficial to conduct participatory action research in order to evaluate the implementation of CPT and compare the outcomes across settings. Participatory action research is an approach that focuses on collaboration between stakeholders to help contextualize interventions, integrate social and cultural values, perspectives and norms into the implementation of the intervention, and strengthen the capacities of stakeholders to produce evidence-based practices that fit to the needs of staff[46].

A second point to note is that Chapter 3 and 4 do not provide a complete representation of patients', relatives' and HCPs experiences with aphasia-friendly communication in healthcare facilities in the Netherlands or Belgium. We aimed to analyze the experiences of stakeholders in order to develop the intervention CommuniCare. For that purpose, the sample size of 20 people with aphasia, 12 relatives and 71 HCPs was adequate.

The last methodological consideration regarding the study population that we would like to point out is that, in one participating geriatric rehabilitation center, relatively few people with aphasia were admitted during the study. HCPs working in this center could therefore not reflect on recent, real-life situations, because they had had very few conversations with people with aphasia during the time of the study. Instead, they reflected on earlier conversations, and hypothesized which barriers and facilitators they *expected* to experience when they would use supportive conversation techniques.

Outcome measures

All study results in this thesis were based upon qualitative outcomes or self-reported outcome measures. This may have had consequences for the objectivity of the study results. However, we believe that the benefits of collecting qualitative data outweighed this limitation. By investigating stakeholders' experiences, we were able to develop an intervention that focuses on changing existing, practical problems, and as a result increase the likelihood of successful implementation. In the evaluation study, where we evaluated the outcomes of CommuniCare based upon HCPs' perspectives, we believe this methodology has provided new insight into implementation strategies that address potential, real-life barriers, which can also increase the likelihood of successful implementation.

IMPLICATIONS FOR HEALTHCARE PROGRAMS AND CLINICAL IMPLICATIONS

The findings of the CommuniCare project emphasize the need for training early-career HCPs in good communication skills. Based on the results of this thesis, three implications for healthcare educations programs are given below. The findings also provide implications for healthcare centers wishing to enhance aphasia-friendly communication and implement the use of supportive conversation techniques.

Implications for healthcare education programs

1

Undergraduate HCPs should be educated in good communication skills and aphasia-friendly communication. Learning goals that should be included in healthcare education programs are: 1) the healthcare student can convey treatment plans and health education clearly, accessibly and empathetically so that patients can receive optimal care, 2) the healthcare student can share information ethically and responsibly to protect patient confidentiality, 3) the healthcare student can provide clear and honest information so that patient and provider can accurately make treatment decisions 4) the healthcare students can ask the patient how they are emotionally relating to their health concerns and 5) the healthcare student can listen accurately to patients needs and wishes and reflect back on what was said.

2

Implementation courses should be developed for post-graduate HCPs working in Belgium and the Netherlands. We recommend building implementation courses based upon courses that have already been designed to improve implementation capacity in service staff[33–35].

3

Undergraduate SLTs should be educated in providing leadership support. Strategies that can be undertaken include the following: 1) reframe leadership as part of the SLTs' identity, 2) teach SLTs how interprofessional teams work, what problems these teams can come across and what SLTs can do to address those problems, 3) design and implement leadership development modules, available and accessible for students wishing to develop leadership skills and 4) assess the development of leadership competencies, knowledge, and behaviors.

Clinical implications

1. Implementing the use of supportive conversation techniques will only succeed when training is repeated annually for every staff member who work with people with aphasia.
2. Managers and HCPs with a higher level of authority should develop implementation plans that include strategies that are based on the barriers and facilitators expressed by healthcare staff. Leaders should also encourage the use of supportive conversation techniques and make their support highly visible. Based on competencies of leaders and Implementation Support Practitioners from the literature, we advocate that Dutch Knowledge Brokers from the Knowledge Broker Network of Cerebrovascular Diseases (Dutch (Kennisnetwerk CVA NL) can become leaders in implementing aphasia-friendly communication.
3. HCPs should be provided by experiential learning opportunities. Implementation Support Practitioners and SLTs should support HCPs during these opportunities.
4. Tools and materials must be made aphasia-friendly and the use of supportive conversation techniques should be incorporated into treatment policies by formal leaders.

CONCLUSIONS

Patient-centered care involves effective communication between patients and healthcare professionals (HCPs) and has taken center stage in discussions about the quality of healthcare centers. Various initiatives focus on improving effective communication between people with aphasia and healthcare staff. However, the findings in this study show that people with aphasia still encounter significant barriers in communicating with their HCPs.

Communication difficulties with HCPs can have many negative consequences for people with aphasia, such as reduced participation in the recovery process and in shared decision-making, decreased satisfaction with information transfer and healthcare in general, lower quality of life, higher risks for depressions, worse rehabilitation outcomes and higher mortality rates. Communication Partner Training (CPT) interventions have been developed worldwide to improve communication between HCPs and people with aphasia. These interventions were shown to be effective in improving the participation of the person with aphasia. However, no Dutch CPT interventions were available, the interventions were insufficiently described, and little was known about the implementation of CPT in healthcare centers. Therefore, we developed a CPT intervention named CommuniCare based on the needs and wishes of people with aphasia and their HCPs, and developed implementation plans based upon HCPs' views on the mechanisms that led to change.

Based on the findings from four studies, including one pilot study, two qualitative exploratory studies and one evaluation study, we developed recommendations for implementing aphasia-friendly communication. To start, healthcare centers wishing to enhance aphasia-friendly communication should develop aphasia-friendly tools and materials. HCPs should be offered annual training and experiential learning opportunities. They should be supported by leaders, i.e., SLTs, ISPs, managers and physicians, to learn to use supportive conversation techniques. Managers and physicians should support the approach of CPT interventions and include the use of supportive conversation techniques for people with aphasia in treatment policies. Context- specific implementation plans, including goals, implementation strategies and evaluation methods, should be developed based upon the needs and wishes of people with aphasia and HCPs working in that context. Additionally, we advocate for laying the foundations of supportive conversation skills in healthcare education. Early-career HCPs should be educated in basic communication skills and in using supportive conversation techniques for patients with communication difficulties. Education for SLTs should increase the focus on leadership. Finally post-graduate education should include modules to train HCPs in the role of Implementation Support Practitioners (ISPs).

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NEDERLANDSE SAMENVATTING

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CommuniCare: ontwikkeling, evaluatie en implementatie van een generieke Communicatie Partner Training vanuit de perspectieven van mensen met afasie en zorgprofessionals

Dit proefschrift richt zich op mensen met afasie. Afasie is een taalstoornis ten gevolge van niet-aangeboren hersenletsel. De meest voorkomende oorzaken voor afasie zijn een beroerte of traumatisch hersenletsel. Afasie kan ook ontstaan na andere vormen van niet-aangeboren hersenletsel, zoals een hersentumor. De taalstoornis uit zich op verschillende manieren. Sommige mensen met afasie hebben sporadisch moeite om op woorden te komen, terwijl anderen de taalbeheersing volledig kwijtraken en niet meer kunnen spreken, begrijpen, lezen of schrijven. Mensen met afasie kunnen niet meer communiceren zoals voorheen, met familie en geliefden, mantelzorgers, collega's, zorgprofessionals, en alle anderen die onderdeel zijn van hun maatschappij. Daarom heeft afasie een grote impact op de kwaliteit van leven.

Net als iedereen in Nederland, hebben mensen met afasie recht op goede, effectieve zorg. Sinds een aantal decennia is het bieden van *persoonsgerichte zorg* **één van de belangrijkste pijlers voor de kwaliteit van zorginstellingen in Nederland. Hoge kwaliteit zorg betekent dat de zorginstelling zich focust op de ervaringen, waarden, behoeften en voorkeuren van de patiënt wanneer zorg gepland en geleverd wordt. Om dat te doen, moeten zorgprofessionals** *samenwerken* met de patiënt. Dat betekent dat de informatie die zij overdragen toegankelijk moet zijn voor de patiënt en dat de patiënt en diens naasten een centrale rol moeten spelen als er beslissingen worden genomen. Effectieve communicatie tussen de zorgprofessional en de patiënt is daarvoor essentieel.

Effectieve communicatie in de zorg is een complex proces en kan beschreven worden als een trialoog tussen de patiënt, zijn of haar naasten en zorgprofessionals. Communicatie vindt zowel verbaal als non-verbaal plaats. De patiënt neemt deel aan de trialoog als ervaringsdeskundige en moet beslissingen begrijpen, maken encommuniceren, onthouden welke beslissingen er gemaakt zijn en hier naar handelen. De naaste participeert in de trialoog als samenwerkingspartner, ervaringsdeskundige en degene die de patiënt het beste kent. De naaste moet beslissingen begrijpen en de patiënt ondersteunen in het maken van beslissingen. De zorgprofessional participeert in de trialoog als de deskundige en samenwerkingspartner in het kiezen en vormen van geschikte interventies, en moet rekening houden met de behoeften en voorkeuren van zowel de patiënt als de naaste. De zorgprofessional waarborgt dat beiden begrijpen wat er gezegd wordt en dat beiden hun wensen en voorkeuren kunnen uitspreken. Wederzijds begrip is essentieel wanneer de diagnostiek uitgelegd wordt, en wanneer doelen gesteld, adviezen gegeven en oefeningen toegelicht worden.

Aangezien effectieve communicatie een ingewikkeld proces is, kan het (volledig) ontoegankelijk worden voor mensen met afasie. Onderzoek toont aan dat de communicatie tussen zorgprofessionals en mensen met afasie moeizaam verloopt. De effecten hiervan zijn schrijnend. Mensen met afasie nemen vaak niet deel wanneer er beslissingen worden genomen in de zorg. Ze tonen slechter eindresultaat na revalidatie dan mensen met hersenletsel die daar geen afasie aan over houden. De communicatieproblemen tussen mensen met afasie en zorgprofessionals kunnen leiden tot inadequate zorg, onterecht ontslag en ongewenste bijwerkingen in zorginstellingen. Mensen met afasie vertonen slechtere uitkomsten in kwaliteit van leven en hebben zelfs een hogere kans op voortijdig overlijden.

Verschillende studies hebben onderzocht hoe de communicatie tussen mensen met afasie en zorgprofessionals verbeterd kan worden. Deze studies tonen aan dat wanneer zorgprofessionals communicatietechnieken gebruiken in gesprekken met mensen met afasie, de participatie van de persoon met afasie tijdens deze conversaties verbetert. Het gebruik van communicatietechnieken vraagt om gedragsverandering bij de zorgprofessional. Om zorgprofessionals daarbij te helpen zijn er internationaal veel verschillende Communicatie Partner Training (CPT) interventies ontwikkeld. CPT is een parapluterm voor trainingsmodules die zich richten op het aanleren van het gebruik van communicatietechnieken door de conversatiepartners van mensen met afasie en zijzelf. De evidentie voor het effect van CPT interventies is sterk. Richtlijnen, zoals de Nederlandse Richtlijn voor Diagnostiek en Behandeling van Afasie, bevelen daarom aan dat logopedisten zo snel mogelijk CPT aanbieden aan zorgprofessionals.

CPT interventies zijn complexe interventies. Ten eerste worden er veel nieuwe gedragingen gevraagd van zorgprofessionals, zoals het ondersteunen van wat er gezegd wordt met geschreven woorden, het gebruik van afbeeldingen of pictogrammen, langzamer spreken en verifiëren of de persoon met afasie hen begrepen heeft. Ten tweede zijn CPT interventies vaak gericht op veel verschillende groepen (zorgprofessionals met verschillende opleidingsniveaus, werkervaring of vakkennis) en organisaties (ziekenhuizen, revalidatiecentra, verzorgingshuizen of afasiecentra). Ook zijn de uitkomsten van CPT moeilijk te kwantitatief te bepalen en vergelijken. Het observeren van gesprekken is lastig zonder te interveniëren, en de manier waarop men een conversatie beoordeeld kan sterk verschillen. Ten slotte kunnen de effecten van CPT interventies sterk beïnvloed worden door de wijze van implementatie. Vanwege de complexiteit, zijn er veel verschillende CPT interventies ontwikkeld. Ze verschillen in trainingselementen en tijdsduur. De doelgroepen zijn verschillend; soms ontvangen studenten of zorgprofessionals de CPT, terwijl andere CPT interventies gericht zijn op de familieleden van de persoon met afasie. CPT interventies zijn vaak onvoldoende beschreven om te kunnen repliceren, en de uitkomstmaten die gebruikt worden lopen sterk uiteen waardoor de interventies niet met elkaar vergeleken kunnen worden. Ten slotte is er nog weinig onderzoek gedaan naar de implementatie van CPT interventies in zorginstellingen.

Het overkoepelend doel van dit proefschrift was om de toegankelijkheid van communicatie in Nederlandse en Vlaamse zorginstellingen te verbeteren voor mensen met afasie. Daarvoor werd een Nederlandstalige CPT interventie ontwikkelt, zodat zorgprofessionals in ziekenhuizen, revalidatiecentra en verzorgingshuizen getraind konden worden om communicatietechnieken te gebruiken. De ontwikkeling van de CPT interventie, genaamd CommuniCare, werd gebaseerd op de ervaringen, wensen en behoeften van mensen met afasie, naasten en zorgprofessionals. Op die manier werd de kans op succesvolle implementatie van CommuniCare vergroot. Na de ontwikkeling werd CommuniCare getest en geëvalueerd. De evaluatie werd gedaan door de verandermechanismen in kaart te brengen vanuit het perspectief van zorgprofessionals. De verandermechanismen geven inzicht in hoe verschillende interventie elementen in Communicare bepaalde uitkomsten teweeg brengen. Op die manier kan kennis ontwikkeld worden over het belang van verschillende interventie elementen in CPT en welke uitkomsten verwacht kunnen worden in verschillende zorginstellingen. De resultaten die in dit proefschrift werden beschreven zijn verkregen in een multicenter implementatie onderzoek: het CommuniCare project. Dit project werd uitgevoerd aan de hand van de Medical Research Council (MRC) richtlijn voor het ontwikkelen en evalueren van complexe interventies. Het CommuniCare project werd beschreven in **hoofdstuk 1**.

In **hoofdstuk 2** werden de bruikbaarheid en haalbaarheid van het prototype CommuniCare geëvalueerd in een perifeer ziekenhuis in Nederland. In deze studie ontvingen 46 verpleegkundigen de interventie. De resultaten lieten zien dat de bruikbaarheid en haalbaarheid van CommuniCare als voldoende werd beoordeeld. Verpleegkundigen concludeerden dat de trainingen hen bewust maakten van de communicatietechnieken die ze konden gebruiken. Twee aanbevelingen werden meegenomen in de verdere ontwikkeling van CommuniCare: het uitbreiden van het interactieve deel van de trainingssessies (rollenspellen) en het aanbieden van de trainingen aan multidisciplinaire teams.

Het doel van **hoofdstuk 3** was om inzicht te krijgen in de ervaringen, wensen en behoeften van mensen met afasie en hun naasten. Deze kennis werd meegenomen om CommuniCare aan te laten sluiten bij de problemen en kansen die personen met afasie en hun gezinnen tegen komen in zorginstellingen. Eerdere studies naar de ervaringen, wensen en behoeften van mensen met afasie en naasten gebruikten vaak een retrospectief design. In deze studie was het doel om mensen met afasie en naasten te includeren die nog in de zorginstelling behandeld werden. We interviewden twintig personen met afasie en twaalf naasten. De adviezen voor het verbeteren van communicatie in zorginstellingen betroffen: het overbrengen van informatie op een begrijpelijke en afasievriendelijke wijze, het gebruik van communicatietechnieken zodat de persoon met afasie kon meebeslissenen individuele ondersteuning voor de naasten.

In **hoofdstuk 4** evalueerden we de ervaringen, wensen en behoeften van zorgprofessionals met betrekking tot het verbeteren van de communicatie met personen met afasie. Deze resultaten zouden gebruikt worden om CommuniCare door te ontwikkelen tot een interventie die aansluit bij alle belanghebbenden en daardoor succesvol geïmplementeerd kan worden in een zorginstelling. Voor zover ons bekend was er nog geen studie gedaan naar waar CPT volgens zorgprofessionals aan moet voldoen. Achttien zorgprofessionals uit twee geriatrische revalidatiecentra in Nederland en een ziekenhuis in België werden geïnterviewd. De resultaten toonden aan dat zorgprofessionals het vele malen moeilijker vonden om zorg te bieden aan patiënten met afasie dan aan patiënten zonder afasie. De communicatieproblemen bemoeilijkten instructies geven, samen beslissen en diagnostiek. Ook resulteerden de communicatieproblemen in negatieve gevoelens bij zorgprofessionals, zoals frustratie of een gevoel van onmacht. De aanbevelingen die zorgprofessionals gaven voor de inhoud van CPT konden worden geplaatst in twee (van de vijf) fases die vaak toegepast worden in bestaande CPT interventies: 1) educatie en 2) post-training en implementatie ondersteuning. Zorgprofessionals gaven hun behoefte aan om meer te oefenen met het gebruik van communicatietechnieken. Ze adviseerden dat ze daarvoor een proactieve, coachende rol van de logopedist nodig hadden. De logopedist zou hen moeten stimuleren om communicatietechnieken te gebruiken, hen daarin kunnen coachen, en communicatiehulpmiddelen up-to-date moeten houden en beschikbaar stellen. Ook gaven zorgprofessionals aan meer ondersteuning nodig te hebben van het management en de artsen. Managers en leidinggevenden zouden financiële ondersteuning kunnen bieden om jaarlijks trainingen te organiseren. Artsen zouden een centrale rol spelen in het uitdragen van het belang van het gebruik van communicatietechnieken.

De voorgaande hoofdstukken leidden tot de ontwikkeling van de finale versie van CommuniCare. **Hoofdstuk 5** bevat de ontwikkeling en inhoud van CommuniCare aan de hand van de Template for Intervention Description and Replication (TIDieR) checklist. We beschrijven de zes interventie elementen in CommuniCare, inclusief de onderliggende veronderstellingen voor ieder element: een e-learning programma, een scholing voor logopedisten, twee trainingssessies voor zorgprofessionals, coaching en vergaderingen met teamleiders. Ook beschreven we de achtergrond en expertises van de interventie ontwikkelaars, de locaties waar de interventie werdgëevalueerd en de manier waarop de interventie tijdens het project werd bijgesteld.

Het doel van **hoofdstuk 6** was om de interventie CommuniCare te evalueren. Om te bepalen hoe CommuniCare tot het gebruik van communicatietechnieken leidde, ontvingen 254 zorgprofessionals in vijf verschillende zorginstellingen in Nederland en België de interventie CommuniCare. Vervolgens werden drie tot zes zorgprofessionals uit iedere zorginstelling geïnterviewd. We vonden dat, vanuit het perspectief van zorgprofessionals, de rollenspellen het meest essentiële element was. Rollenspellen vergrootten zowel hun kennis, vaardigheden en motivatie om communicatietechnieken te gebruiken. Er werden echter ook na CommuniCare barrières gevonden voor het gebruik van communicatietechnieken. Met name het vertrouwen van zorgprofessionals in hun eigen kunnen en in het effect van het gebruik van communicatietechnieken bleek een belangrijke barrière. In dit hoofdstuk werd tevens uitgebreid gereflecteerd op het belang van coaching en de competenties die een coach zou moeten hebben om zorgprofessional te ondersteunen.

Aan het einde van 2020 werd iniedere deelnemende zorginstelling een implementatieplan geschreven. Deze plannen werden gebaseerd op de barrières en faciliterende factoren van zorgprofessionals werkzaam in die instelling. Vier implementatiestrategieën lijken voor iedere zorginstelling geschikt.

- Ten eerste is leiderschap nodig. We geloven dat de Knowledge Brokers van het Kennisnetwerk CVA Nederland goede leiders kunnen zijn bij het implementeren van communicatietechnieken. De rol van de leiders is om het gebruik van communicatietechnieken te modelleren en promoten, de verwachtingen over het gebruik van communicatietechnieken te communiceren en te investeren in ondersteuning binnen de structuur van de organisatie.
- De tweede strategie om afasievriendelijke communicatie te implementeren in zorginstellingen is het bieden van financiële en organisatorische ondersteuning om een CPT jaarlijks terug te laten komen.
- Ten derde moeten zorgprofessionals de kans krijgen om te leren van oefenen en doen. De logopedist kan hier een centrale rol in spelen door mee te kijken bij gesprekken tussen zorgprofessionals en personen met afasie, samen met de zorgprofessionals doelen te stellen en te evalueren. Zij kunnen ook tijd krijgen om communicatiehulpmiddelen en materialen, zoals folders en bewegwijzering, aan te passen aan de communicatiebehoeften van mensen met afasie.
- Ten slotte moet het gebruik van communicatietechnieken geïntegreerd worden in het behandelbeleid voor mensen met afasie. Op die manier wordt het belang ervan benadrukt voor zorgprofessionals.

CURRICULUM VITAE

Curriculum Vitae
List of publications

CURRICULUM VITAE

Maren van Rijssen was born on December 20th 1989 in Utrecht, the Netherlands. In 2008, she finished secondary school at the Maartenscollege in Haren (VWO). She studied Farmacy for one year at the University of Groningen, but then decided to switch and studied Speech and Language Therapy at the Hanzehogeschool University of Applied Sciences in Groningen. At the same time, she followed the minor program Linguistics at the University of Groningen. In 2013, she finished both studies and started her Master Clinical Language, Speech and Hearing Sciences at the Utrecht University. She worked as a speech and language therapist in various hospitals, where she specialized in aphasia diagnostics and therapy. After achieving her master degree, she started as junior researcher at the research group Speech and Language Therapy of HU University of Applied Sciences. In February 2018 she officially started as a PhD-student at this research group, as part of the SIA Raak Publiek project CommuniCare. During her PhD, she followed the Course Qualitative Research at the University of Amsterdam and the Summer course Introduction to Behavior Change: Principles & Practice at the University City of London. She also gavelectures in the bachelor program Speech- and Language Therapy at HU. At present, Maren continues her work in the research group Speech and Language Therapy. In addition, she is lecturer in the bachelor program Pharmaceutical Business Administration of HU and in the master program Clinical Health Sciences of Utrecht University.

LIST OF PUBLICATIONS

Van Rijssen, M, Veldkamp, M, Meilof, L, Van Ewijk, L (2018). Feasibility of a communication program: improving communication between nurses and persons with aphasia in a peripheral hospital, Aphasiology. DOI: 10.1080/02687038.2018.1546823

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Van Rijssen, M, Isaksen, J, Vandenborre, D, Veldkamp, M, Bryon, E, Remijn, L, Visser-Meily, A, Gerrits, E, Van Ewijk, L. (2021). Ways to improve communication and support in healthcare centers according to people with aphasia and their relatives: a Dutch perspective. Aphasiology. DOI: 10.1080/02687038.2021.1988505

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APPENDICES

APPENDICES

APPENDIX 1

QR code for e-learning module for HCPs (enter password CommuniCare_2020):

QR code for information point for relatives:

DANKWOORD

DANKWOORD

Toen ik vier jaar geleden begon met mijn promotietraject, was ik dol op statistiek en wilde ik het liefst iets met cijfers doen. Wanneer u dit proefschrift leest zal u merken dat er géén statistiek in voor komt en dat de aard van alle analyses kwalitatief is. Wat ben ik blij dat ik deze uitdaging ben aangegaan. Door met mensen te praten en te luisteren heb ik meer geleerd dan ik voor mogelijkheid had gehouden. Ik ben trots op de groei die ik heb doorgemaakt als onderzoeker, coach, begeleider, interviewer, luisteraar, teamlid, docent en collega. Ik ben trots op het proefschrift dat tot stand is gekomen dankzij de samenwerking tussen (veel!) onderzoekers, docenten, zorgprofessionals en patiënten. En vooral ben ik trots op de veranderingen die we als team hebben gebracht om de zorg voor mensen met afasie te verbeteren.

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