

OUTCOME EVALUATION IN APHASIA THERAPY

– a participants' perspective

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DANSK RESUMÈ

Evaluering af afasiundervisning er en klinisk aktivitet som på nuværende tidspunkt sandsynligvis er ved at være lige så almindelig som udredning af personen med afasi forud for interventionen er. I Danmark lægger Lov om Specialundervisning for Voksne vægt på, at enhver intervention under pågældende lovgivning skal evalueres.

Et større antal test, spørgeskemaer og andre evalueringsredskaber til både forskning og kliniske formål er identificeret i afasilitteraturen samtidig med, at der forsat efterlyses nye og bedre måder til at evaluere. Indtil nu har forskning i klinisk evaluering primært fokuseret på antallet af logopæder, der evaluerer, samt de forskellige anvendte redskaber. Der findes umiddelbart ingen forskning indeholdende grundige beskrivelser af nuværende evalueringspraksis blandt logopæder hverken i dansk eller international kontekst. I særdeles savnes et fokus på den interaktionelle proces i evalueringen, eftersom evaluering er multifacetteret og kræver mere end blot at kunne udvælge og anvende værktøjer.

Interaktion mellem logopæden og personen med afasi er umiddelbart det mest signifikante instrument i evalueringen uanset om et specifikt undersøgelsesbatteri, et evalueringsredskab, en uformel skala eller dialog anvendes. Der er således ikke tidligere forsket i interaktion som væsentlig metode eller måde hvorpå der evalueres, uanset om der er tale om formel eller uformel evaluering.

Formålet med denne afhandling har således været at undersøge hvilke selvrapporterede motiver og interaktionelle forhold der optræder i nuværende evalueringspraksis blandt danske logopæder og deres borgere med afasi. Dette formål blev understøttet af fire forskningsspørgsmål:

Hvorfor evaluerer logopæder ifølge dem selv?

Hvilken rolle spiller evaluering – og det at udføre evaluering – i afasiundervisningen?

Hvordan konstitueres evaluering i og gennem interaktionelle sekvenser med logopæder og personer med afasi?

Hvordan finder inddragelsen af personer med afasi sted i evalueringen ifølge logopæderne samt i deres handlinger?

Studiet er en etnografisk undersøgelse, som inkluderer logopæders syn på, hvorfor der evalueres og den rolle som evalueringen har i undervisningen samt en beskrivelse på mikro-niveau af evaluering

som en interaktionel aktivitet mellem logopæder og personer med afasi. Data omfatter 33 videooptagelser af evalueringssessioner mellem 12 logopæder og 28 forskellige borgere med afasi samt interviews med de samme 12 logopæder. Fundene er præsenteret i tre separate studier.

Det første studie søgte at identificere krav til at udføre evaluering så vel som den rolle evaluering spiller i afasiinterventionen i klinikken via logopædernes fortællinger derom. Seks temaer, der korresponderede med studiets forskningsformål, blev identificeret på baggrund af interviews med logopæderne. Gennem temaerne beskrives, hvordan logopæderne initialt evaluerede på grund af eksterne krav derom. Dog beskrev logopæderne også, at evaluering er en nødvendig, iboende aktivitet i undervisningen og slår fast, at de ikke vil undvære at evaluere. Evalueringen blev desuden set som en interaktiv proces mellem logopæd, borger med afasi og eventuelt pårørende. Evaluering er således ikke bare set som et redskab hvormed udbytte og/eller tilfredshed dokumenteres, men ses også som en dynamisk proces der på forskellig vis gavner borgeren, pårørende, den terapeutiske proces samt logopæderne selv. Den funktion, som evalueringen har, omfatter alt fra at fremme indsigt og accept hos borgeren og de pårørende til at planlægge det næste skridt i undervisningen eller livet med afasi efter den logopædiske intervention. Fundene påpeger et interessant forhold mellem områdets politikker og interventionspraksis, hvor logopæder har taget det initiale administrative initiativ, som evaluering var, og gjort det til en meningsfuld del i deres praksis.

Afhandlingens andet studie fokuserede på, hvordan resultatet af logopædisk afasiintervention i Danmark bliver dokumenteret i evalueringssessioner, hvor både person med afasi og logopæd deltager eventuelt også sammen med pårørende. Her forhandler deltagerne enighed omkring interventionens resultat. Hvordan denne enighed omkring undervisningens udbytte opnås interaktionelt blev undersøgt ved hjælp af principper og praksisser i metoden konversationsanalyse. Sekventielle analyser af videooptagelser af evalueringssessioner viste en tilbagevendende metode, hvormed enighed omkring fremskridt hos personen med afasi blev opnået under disse sessioner. I og gennem en speciel interaktionel baseret evalueringssekvens blev det fremsat, at personen med afasi havde bestemte kommunikative færdigheder. Sådanne påstande blev derefter systematisk substantieret eller underbygget ved at inddrage eksempler på personen med afasis udførelse af disse færdigheder enten i eller udenfor den kliniske kontekst. Substantieringen kan ses som en form for validering af påstande og danner dermed et grundlag for at opnå enighed om personen med afasis

kommunikative færdigheder, fremskridt og lignende. Studiets fund viser at, med denne type af evaluering imødekommes krav om at producere en valid redegørelse, hvori personen med afasi er blevet hørt.

Det sidste studie havde til formål at undersøge og beskrive logopædernes syn på borgerinddragelse i den beslutningstagning, der fandt sted i evalueringssessionen. Det handlede ofte om undervisningen skulle forsætte eller slutte. Desuden blev det undersøgt, hvorvidt involverende aktiviteter blev udført i interaktionen mellem logopæd, person med afasi og eventuelle pårørende. Studiets analyser blev udført i to trin, som et sekventielt mixed-methods studie med to kvalitative metoder bestående først af tematisk analyse af de samme interviews, der blev analyseret i første studie. Dernæst blev fundene derfra brugt til at guide konversationsanalysen af de videooptagede evalueringssessioner, der også optræder i studie to. Analyserne viser, at alle logopæder i studiet havde et ønske om at involvere deres borgere med afasi til trods for barrierer som sproglige vanskeligheder og andre personrelaterede faktorer der kunne være til stede hos alle deltagere. Gennem den interaktionelle organisering af de fælles beslutningstagningsprocesser tog logopæderne føringen, typisk ved at fremsætte forslag. Borgerne fik mulighed for at acceptere disse forslag eller på anden vis udtrykke deres mening indenfor en given begrænset kontekst, som i nogle tilfælde også tjente som kommunikativ støtte for personen med afasi. Praksissen med fælles beslutningstagning betød dog ikke, at logopæderne lod borgerne beslutte, hvad end de ville. I stedet viste studiet, at borgerne kunne være med til at træffe valg indenfor rammer, fastsat af logopæd eller kontekst. Det kunne i nogle tilfælde betyde, at den eneste reelle valgmulighed borgeren havde, var at acceptere forslag fremsat af logopæden. Fundene viser at genuin fælles beslutningstagning mellem ligeværdige deltagere måske ikke findes og er ikke mulige i en klinisk kontekst og er ydermere udfordret, når afasi er til stede.

Afhandlingens tre studier viser, hvordan logopæder navigerer mellem standardiseret og individualiseret intervention ved at bruge evaluering som metode til at involvere personer med afasi. Studierne bidrager således til, hvordan logopæder kan blive bedre beslutningstagere i den kliniske praksis til fordel for og sammen med borgerne med afasi. Studiernes fund er i overensstemmelse med medicinske historikers beskrivelse uddannelse og udvikling indenfor sundhedsområdet: Det 19. århundrede var en diagnosticeringsæra; det 20. århundrede den æra hvor undersøgelsesværktøjer og interventioner blev opfundet, mens de forud for dette århundrede spæde

det til at blive en beslutningstagningsæra. Udfordringen vil således blive at udvikle forskningsbaseret viden til praksis, hvormed beslutninger vedrørende udvælgelse og planlægning af interventioner kan finde sted.

ABSTRACT IN ENGLISH

Evaluating the outcomes of aphasia therapy is a clinical activity which today probably is getting as common as assessing a person with aphasia prior to the intervention. In Denmark, the Act of Special Needs Education for Adults, emphasises that any given intervention provided under this Act must be evaluated.

A great number of tests, questionnaires and other outcome evaluation tools both for research and clinical purposes are identified in the aphasia literature, but new and better ways of assessing outcomes of aphasia therapy are still sought. Until now, research into clinical outcome evaluation has focused primarily on the number of therapists who assess outcomes, and the various methods that are employed. In-depth descriptions of current practice amongst clinicians is under-researched in terms of investigating the interactional process of outcome evaluation since making outcome evaluations is multifaceted and require more than choosing and using tools. Moreover, interaction has not previously been studied as a substantial method or mean by which outcome evaluations can be made, regardless of the involvement of formal or informal outcome measures. Interaction between the professional and the person with aphasia is the most significant instrument no matter if an assessment battery, a specific outcome measure, an informal scale, or merely dialogue is used.

The aim of this thesis was therefore to investigate, which self-reported motives and interactional conditions are present in current practices of outcome evaluation amongst the researched population of Danish speech-language therapists and their clients with aphasia. It was directed by four research questions:

Why are speech-language therapists conducting outcome evaluation according to themselves?

What role does outcome evaluation – and the action of making it – play in aphasia therapy according to the speech-language therapists?

How is outcome evaluation constituted in and through interactional sequences with speech-language therapists and people living with aphasia?

How does the involvement of people living with aphasia take place in outcome evaluation according to the speech-language therapists and their actions?

The study was done by means of ethnographic exploration, and included studying speech-language therapists' views of why outcome evaluation is made and the role it plays in therapy as well as

describing, at a micro level, outcome evaluations as interactional activities between speech-language therapists and people living with aphasia. Data included 33 video recordings of outcome evaluation sessions and interviews with speech-language therapists, in total 12, participating in the videos. The findings were presented in three separate studies.

The first study sought to identify the demands for outcome evaluation as well as the role outcome evaluation plays in aphasia therapy in the clinic reported by the participating speech-language therapists in qualitative research interviews. Six themes corresponding with the aims of this study were identified, showing that the speech-language therapists initially evaluated outcomes because of external demands and interests. However, they also describe it as a necessary activity inherent to therapy and state that they would not want to be without it. Outcome evaluation is seen as an interactive process between clinicians, clients and, possibly, significant others. It is seen not only as a product in which outcome and/or client satisfaction is documented, but also as a dynamic process that benefits the clients, significant others, the therapy process and the clinicians themselves, in various ways. This role of outcome evaluation ranges from enhancement of insight and promotion of acceptance for the clients and significant others, to planning the next step in therapy or in life with aphasia after therapy. The results suggested an interesting relationship between treatment policy and treatment practice, where an initial administrative initiative is adopted by the speech-language therapists and made into a meaningful part of therapy.

The second study focuses on how outcomes of aphasia therapy in Denmark are documented in evaluation sessions in which both the person with aphasia and the speech-language therapist take part. The participants negotiate agreements on the results of therapy. How agreements on therapy outcome are reached interactionally was investigated by using the principles and practices of the research method conversation analysis. Sequential analysis of video recordings of outcome evaluation sessions demonstrated a recurrent method for reaching agreements in these sessions. In and through a special sequence of conversational assessment it is claimed that the person with aphasia has certain communicative skills. Such claims are systematically substantiated by invoking examples of the person with aphasia performing this skill either outside or inside the therapeutic setting. Substantiation can be seen as a form of validation of the claim and thereby a basis is set for agreement. The findings suggest that in this type of evaluation, the requirements of producing a valid account in which the person with aphasia has been heard, are being met.

The last study aimed to explore and describe speech-language therapists' views of involving clients in decision-making in aphasia therapy, more precisely in decisions to be taken during outcome evaluation about continuation or discharge of therapy. Furthermore, the study investigated, how such involving activities were carried out in interaction between speech-language therapists, their clients with aphasia, and possibly significant others. The analytic process was accomplished in two steps, as a sequential mixed-methods study with two qualitative methods. Firstly, thematic analysis of interviews with the 12 speech-language therapists was done which resulted in two themes. Secondly, the findings from the interviews directed applied conversation analysis of video-recorded sessions with the same 12 speech-language therapists and their clients when evaluating outcomes of aphasia rehabilitation. The findings showed that all speech-language therapists in the study had a wish to involve their clients with aphasia despite recognition of language difficulties and other person-related barriers in all interlocutors. Through the interactional organisation of shared decision making processes, the clinicians took the lead, often by proposing suggestions. The clients got an opportunity to accept these suggestions or otherwise express their opinion within a limited provided context, also serving as communicative support due to aphasia. The shared decision making practice by the participants did not let the clients decide, whatever they wanted. Instead, it let the clients have choices within a particular framework. In some cases it meant that the only real option a client had was to accept choices suggested by the speech-language therapist. This finding suggests that genuine decision making between equal parties is not present and possible within a clinical context, additionally challenged by aphasia.

The three studies in the dissertation show, how the therapists navigate between standardised and individual therapy by using outcome evaluation as a method for involving people with aphasia. The studies therefore contribute to, how speech-language therapists become better decision-makers in clinical practice for the benefit of and together with their clients with aphasia. The findings in the studies are in accordance with the field of medical historians' description of medical education and development: the nineteenth century was a diagnosis era; the twentieth century was an era of interventions where methods for assessment and intervention were generated, whereas they predict the twenty-first century to be an era of decision-making. The challenge will be to offer research based knowledge to practitioners by which decisions for selecting and sequencing treatment can be made.

1. INTRODUCTION

1.1 Background

A complex web of decisions surrounds every course of aphasia therapy.¹ Some of the questions to be answered could be: How should the individuals living with aphasia be treated, which theoretical framework, what tasks, when to start and end, how intense, individual or group therapy, and so forth. An increasing interest in aphasia research with regard to the execution of therapy has been seen in the last few decades. Studies of, for example, therapy onset, dosage, and goal setting are contributing to how clinicians best schedule and deliver therapy, and not only with regard to treatment methods (e.g. Bakheit et al., 2007; Cherney, Patterson & Raymer, 2011; Hersh, Worrall, Howe, Sherratt & Davidson, 2012). The increased emphasis on service delivery is also present in the latest update of the Cochrane review of aphasia therapy after stroke. Here the authors' conclusion points out the low to moderate evidence for high intensity and dose, and longer time of therapy delivery, at least for some people with aphasia (Brady, Kelly, Godwin, Enderby & Campbell, 2016).

Outcome evaluation, the topic of this thesis, is one aspect of aphasia therapy contributing to the structure, organisation, execution and progression of therapy among other elements such as, for example, goal setting and assessment. Decisions taken in, and because of, the outcome evaluation in the individual therapy course usually have consequences for the person with aphasia and the significant others, as well as for prospective further intervention. From a broader perspective, results of outcome evaluation can also feed back into the current knowledge regarding what works or not in order to develop new treatment methods and delivery approaches.

Evaluating the outcomes of aphasia therapy is today a clinical activity which is probably getting as common as performing assessments of a person with aphasia prior to the intervention. In Denmark, it has even been written into the Act of Special Needs Education for Adults, the

¹ "Aphasia is an acquired selective impairment of the language modalities and functions resulting from a focal brain lesion in the language-dominant hemisphere that affects the person's communicative and social functioning, quality of life, and the quality of life of his or her relatives and caregivers." (Papathanasiou & Coppens, 2013, p. XX). A stroke is the most common cause of aphasia (up to 38% according to Pedersen, Jørgensen, Nakayama, Raachou & Olsen, 1995), but other types of acquired brain injuries such as traumatic brain injuries, brain tumours and anoxia can also cause aphasia (Hedge, 2006). Rehabilitation of aphasia and other sequelae after acquired brain injuries is multidisciplinary, with the speech-language therapy centred around language impairment and its consequences (Papathanasiou, Coppens & Potagas, 2013).

legislation driving outpatient aphasia rehabilitation, when the Ministry of Education published new guidelines back in 2009 (see 1.2.3) (Ministry of Education, 2009). These guidelines emphasised that any given intervention provided under this Act must be evaluated.

Outcome evaluation after aphasia therapy can be requested by a number of stakeholders, such as policy-makers, funders, providers and the clients themselves. All of these stakeholders are likely to have different aims concerning what they want to know about therapy outcomes (Golper & Frattali, 2013; Wallace, Worrall, Rose & Le Dorze, 2014, 2016a; Wallace et al., 2016b). To date, research into clinical outcome evaluation has primarily focused on topics such as the proportion of therapists who assess outcomes and the various methods used for doing so (e.g. Hesketh & Hopcutt, 1997; Simmons-Mackie, Threats & Kagan, 2005; Verna, Davidson & Rose, 2009) (see chapter 3 for an overview of research in outcome measures of aphasia therapy). A great number of tests, questionnaires and other outcome evaluation tools are identified in the aphasia literature, for both research and clinical purposes (e.g. Brady et al., 2016). Moreover, surveys of clinical practice (e.g. Simmons-Mackie et al., 2005, Verna et al., 2009) list several tools as well as informal methods for outcome evaluation. However, new and better ways of assessing outcomes of aphasia therapy are still sought. The Cochrane review (Brady et al., 2016) expresses the need for better tools measuring functional communication in a globally accepted, valid, reliable and comprehensive manner. When lacking good comprehensive tools to measure this primary goal of aphasia therapy, less suitable methods are used, ones which measure all kinds of outcomes which are neither necessarily connected to the actual therapy nor clinically meaningful (Brady et al., 2014). Consequently, recent publications call for clinically meaningful and functionally relevant outcome measures usable for everyday therapy as well as research (Brady et al., 2014, 2016; Wallace et al., 2014).

Another important reason to pay attention to outcome evaluation, and the main point of interest in this thesis, is a further need to examine the current practice seen amongst clinicians. In-depth descriptions are sought for the complexity in outcome evaluation since making outcome evaluations is multifaceted and requires more than merely choosing and using the right tools. An example of this is the various stakeholders wanting to see outcomes reflected as different as communicative progress (person with aphasia and significant others), cost-effective services (payer) and efficient treatment methods (managers and speech-language therapists) (Hesketh & Sage, 1999). Moreover, interaction has not been studied as a substantial method or means by which outcome evaluations are made regardless of the involvement of formal or informal outcome measures. Interaction between the professional and the person with aphasia is the most significant

instrument no matter whether an assessment battery, a specific outcome measure, an informal scale or merely dialogue is used. Outcome evaluation is a social action accomplished via interaction, with each participant bringing in interactional competencies relying on experience from ordinary everyday interactions, and perhaps also experience from so-called institutional interactions, as outcome evaluation sessions (Drew & Heritage, 1992; Heritage & Atkinson, 1984).

The aim of this thesis is therefore to investigate outcome evaluation in Danish aphasia therapy. This is achieved by means of ethnographic exploration, and includes studying speech-language therapists' views of why outcome evaluation is made and the role it plays in therapy as well as describing, at a micro level, outcome evaluations as interactional activities between speech-language therapists and people living with aphasia. The findings aim to contribute to the existing knowledge regarding outcome evaluation, clinical decision making and client involvement in healthcare and other institutional practices.

1.2 Motivational background for the study

1.2.1 Interaction as a tool to evaluate outcome

From former clinical experience, I know that outcome evaluation in aphasia therapy in Denmark frequently consists of informal dialogues between clients with aphasia, speech-language therapists and possibly significant others. In Denmark, there are only a few formal tools available for assessing people with aphasia and their outcomes of therapy (Audiologopædisk Forening, 2013; Villadsen, Myhlendorph, Porskjær, Lund, Rossing & Jensen, 2007). This shortcoming of tools could be a reason for the informal and interaction-based approaches dominating. However, a significant use of informal methods and dialogue is also reported in both research studies as well as from practice surveys in other countries (Brady et al., 2016; Simmons-Mackie et al., 2005).

Since the informal dialogues in aphasia outcome evaluation are made in an institutional context, they may diverge from, yet build upon, mundane conversation between peers (Hutchby & Woofitt, 2008). However, despite the institutional context, an interaction can only be described as institutional when features in the talk-in-interaction display institutionality (Drew & Heritage, 1992). Accordingly, this thesis is interested in scrutinising informal interaction-based evaluations in institutional contexts. As the point of departure, interaction is commonly and inevitably a tool in aphasia therapy, or almost any other practice involving humans, through which we conduct the majority of our affairs with other people (Hutchby & Woofitt, 2008; Liddicoat, 2007; Roter & Hall, 1993; Sidnell, 2010; Sidnell & Stivers, 2013; Silverman, 2001). Even if formal assessments with

test batteries or questionnaires or informal assignments are involved, interaction is still the essence of the practice that is being achieved.

Despite interactions having a crucial influence upon clinical activities and decision-making processes, it is often not taken into consideration when effectiveness research or research of clinical processes is carried out (Simmons-Mackie & Damico, 2011). Interactions which, on the surface, may look unstructured and haphazard, have, in numerous studies, been shown to be very systematic (Heritage & Clayman, 2010). However, even if the institutional outcome evaluation dialogues prove to be systematic, the adequacy of interaction as an outcome evaluation tool is not yet known, but will be addressed in this study. From research in medical interaction, it is known that inadequate interaction between patients and health professionals has consequences for the health status of the patient, satisfaction, compliance, stress and anxiety (e.g. Drew, Chatwin & Collins, 2001; Lawrence & Kinn, 2012). Supposedly inadequate interactions would have similar consequences for people with aphasia, or perhaps worse due to the challenged interaction because of the disorder.

1.2.2 Changing approaches in therapy

Of inspiration to this thesis were different observed trends in aphasia therapy and the challenges they can pose for outcome evaluation. One example is the move towards a more standardised, but still individualised, service provision. Currently, best practice recommendations and clinical practice guidelines, building on research evidence and/or expert consensus, are inherent foundations of aphasia therapy delivery, or at least seek to be (Hadely, Power & O'Halloran, 2014; Shrubsole, Worrall, Power & O'Connor, 2017). However, at the same time and in some sense rather counter-intuitively, individualised therapy with high client involvement is sought (Rosewilliam, Roskell & Pandyan, 2011; Worrall et al., 2011). Perhaps falling somewhere in the middle of these trends is evidence-based practice (EBP) (Sackett, Straus, Richardson, Rosenberg & Haynes, 2000). EBP is a prominent model for clinical decision making in a large number of professions including speech-language therapy. Through EBP, research evidence, client preferences and clinical expertise is sought to be united (Dollaghan, 2007). Outcome evaluation is a central prerequisite for using the researched methods showing evidence and, at the same time, taking client preferences and clinical expertise into consideration. First, outcomes are measured during the research process of specific therapy or delivery methods, and secondly when the therapy course based on EBP needs evaluation (Dollaghan, 2007). Since evaluating standardised treatments in research has, as mentioned, been

shown to be a difficult task (Brady et al., 2016), evaluation of individualised treatments might also meet challenges in using existing methods. However, both standardised and tailored aphasia therapy need outcome measurement. Furthermore, the focus on effectiveness, efficiency and efficacy of researched methods in EBP has promoted interest in the same parameters in clinical interventions (Simmons-Mackie et al., 2005).

EBP has been shown to be a useful tool for policy-makers striving for the highest quality in healthcare for the most cost-effective expenditure despite its original goal being evidence-based healthcare (Rycroft-Malone, 2005). New Public Management², the form of governance practised in many Western countries with a large public sector such as Denmark since the 1980s, has caused demands for health services to be more efficient and effective without an increase of costs, for the benefit of the clients using the system (Brignall & Modell, 2000; Hood, 1991; Simonet, 2013). Some publications and studies within speech-language therapy from the late 1990s reflected a focus on, and in some cases fear of, financing as a ruling factor in decision-making in speech-language therapy as well as an equally increased attention towards documenting outcomes of the interventions (e.g. Frattali, 1998a; Hesketh & Sage, 1999). As a response to Hesketh and Sage's (1999) reservations regarding outcome evaluation, Worrall (1999) welcomed it as a step in the maturation process of speech-language therapy.

Another prominent trend or change is the shift in focus from predominantly impairment- or medical-based models towards services engaged with the consequences of aphasia in areas such as activity, participation and wellbeing (see 2.2.2 concerning International Classification of Functioning, Disability and Health) (Martin, Thompson & Worrall, 2008). More traditional types of outcome evaluation tools, i.e. tests or clinical judgements, are challenged with regard to the above argument of documenting functional communication as the primary outcome of therapy (Brady et al., 2016). Currently, it means it is much more common to involve the people living with aphasia in the process, ask for their opinions and so-called patient-reported outcomes have been developed, often in the format of questionnaires (e.g., Lomas, Pickard, Bester, Elbard, Finlayson & Zoghaib et al., 1989; Long, Hesketh, Paszek, Booth & Bowen, 2008).³

² In short, New Public Management is a market-oriented form of administration aiming, amongst other aspects, to increase effectiveness of the money and other resources spent in the public sector. New Public Management will not be further defined, since a thorough description is not within the scope of this thesis and nor is a critique of New Public Management. Despite critiques and writing regarding the end of New Public Management, no single form of governance has taken over. Therefore, New Public Management can still be largely ascribed as the model used in public administration (Brignall & Modell, 2000; Hood, 1991; Simonet, 2013).

³ The trends and changes likely affecting outcome evaluation are further described in chapter 2. Patient-reported outcomes are also elaborated in chapter 2.

In the foreword of a frequently cited book (Frattali, 1998a) about outcome evaluation in speech-language therapy, Lubinski writes that three words came into her mind when reading the book: *assumptions*, *value* and *change* (Lubinski, 1998). In short, the *assumptions* are tied up with the profession's own view of speech-language therapists as being the most capable to prescribe intervention, choose methods and other frames for interventions and evaluate their outcome. Lubinski's *value* term labels what can be defined as being valuable in therapy, for example, social or personal values of therapy are more important than economic ones. The last word, *change*, Lubinski connects with the shift she observed at that time, where the profession started coming under scrutiny from outside stakeholders such as funders and policy-makers. The results of this were used to make future decisions for the field of speech-language therapy. Currently, values are not solely about providing a good and valuable service for the citizens, but also in administering the funders' money sensibly (Frattali, 1998b). Lastly, the change described by Lubinski is still ongoing, only to be highlighted and perhaps amplified by the late financial crisis we are still facing here in Denmark and elsewhere. Within aphasia therapy, the speech-language therapists therefore need to demonstrate, and are likely to be held accountable for the efficiency of their services for the sake of the whole range of stakeholders, from funders and policy-makers, to consumers, and their own profession.

1.2.3 A change in local conditions

A more local motivation to study outcome evaluation in aphasia therapy has its starting point in various events. In 2007, a major structural reform of governmental administration in Denmark was conducted. Before 2007, Denmark was divided into 14 counties and again into 275 municipalities. Each county had its own clinic for adult speech-language therapy, and the county was the paying body of the treatment. As a consequence of the reform, the municipalities were made bigger, amalgamated into 98, and the counties were abolished and replaced by five big regions. The responsibility to provide adult speech-language therapy is now in the hands of the municipalities. Each municipality does not, however, have its own clinic. Instead, the old county clinics were taken over by the municipality in which it was placed or, in some cases, the region took ownership of it, albeit funded by a number of municipalities. The new municipalities without their own clinic started out by procuring speech-language therapy services in either a neighbouring municipality or the region. Today, the picture is conflicting, with many municipalities either having a clinic of their own or, together with neighbouring municipalities, offering a full service to their citizens, or in

some instances, they provide some services and supplement with services bought in other places (Mainz et al., 2011). In addition, there is some tendency towards growth in the very limited private sector (www.alf.dk).

In the years before the reform, the entire profession seemed to move towards a unity never seen before, as described by many of the experienced professionals in the field (personal conversations). The institutions were simply afraid how their new future looked and it made them work together to become better equipped for a changed system where the professionals could not conduct their daily work as before because of the new funding system. It placed a great emphasis on evaluating outcomes of current services and describing best practice and knowledge, attempting to preserve the existing expertise built up over many years, but frequently not written down (Bjerre & Petersen, 2009; Jørgensen & Aagaard, 2007; Petersen, 2007a, 2007b). In 2006, the network *Danske tale-høre-synsinstitutioner* (Danish speech-hearing-vision institutions – www.dths.dk) launched a best practice project establishing clinical guidelines for assessments of various diagnosis within the scope of the institutions (e.g. Isaksen et al., 2007; Villadsen, 2007).

Further changes took place in 2009, as mentioned, where the Ministry of Education, which grants most laws concerning speech-language therapy⁴, published new guidelines for the interpretation of the Act on Special Needs Education for Adults, for the first time in 25 years. This drew attention to evaluation of outcomes since the guidelines had specific recommendations to document the effect of any given intervention. At the same time, the economic crisis described above slowly began to impact upon budgets and funding in speech-language therapy (Mainz et al., 2012). In all probability, all of the above drew an entirely new attention to how clinical practice in areas such as aphasia therapy was arranged. Not only was outcome evaluation highly recommended in the guidelines to the current legislation, but the new structure in Denmark also put pressure on the clinics and clinicians to document therapy outcomes to their funders (Bjerre & Petersen, 2009).

1.3 Aims and research questions

Outcome evaluation in aphasia therapy in the 2010s is a relevant and timely topic to study for several reasons. Many reforms and trends make this period historically interesting with, for example, the move from medical to holistic models, evidence-based practice and increased client involvement, all of which have given outcome evaluation a more prominent place in aphasia

⁴ *Folkeskoleloven* ‘Act on Public Schools’ for children and *Lov om specialundervisning for voksne* ‘Act on Special Needs Education for Adults’ for adults as the name indicate (www.lovtidende.dk). Speech-language therapy practised outside a hospital setting is regarded as special education/teaching.

therapy. The current knowledge of outcome evaluation is being challenged by the drive towards delivering efficient services as prescribed via clinical practice guidelines and best practice statements and, at the same time, in an individualised, inclusive and person-centred manner. However, stakeholders may demand a uniform way in which different intervention trajectories are documented to be effective. This creates a tension and potentially a challenge for professionals. Furthermore, the role of interaction in formal as well as informal evaluation outcomes is under-researched.

To capture changes and new perspectives, other methods for investigating the present practices must be explored. In this thesis, an ethnographic approach is used, combining the qualitative methods of thematic content analysis and conversation analysis together with a novel methodological triangulation of those two methods.

When I started my work on this thesis back in 2010, I saw a renewed need to address outcome evaluation. However, in this instance, it was not to provide an overview of tools or methods as has been seen in the past (Simmons-Mackie et al., 2005; Verna et al., 2009), but instead to describe outcome evaluation from an insider's perspective as the part of aphasia therapy in terms of clinical interaction and decision making. Furthermore, clinical practice may be described via structures as guidelines or methods applied, but instead the intention here has been to give clinicians an opportunity to explain outcome evaluation from their point of view and reflect upon their own practices in order to not only be able to describe what outcome evaluation tends to be, but what it actually is and what has been influencing it. At the same time, the aim is also to explore outcome evaluation as more than a procedure, but as an interactional achievement, since outcome evaluation is achieved jointly by the participants in and through interaction. In other words, what self-reported motives and interactional conditions are present in current practices of outcome evaluation amongst the researched population of Danish speech-language therapists? More specifically, the following questions are answered:

1. *Why are speech-language therapists conducting outcome evaluation according to themselves? (study 1)*
2. *What role does outcome evaluation – and the action of making it – play in aphasia therapy according to the speech-language therapists? (study 1, 3)*
3. *How is outcome evaluation constituted in and through interactional sequences with speech-language therapists and people living with aphasia? (study 2, 3)*

4. *How is the involvement of people living with aphasia taking place in outcome evaluation according to the speech-language therapists and their actions? (study 1, 2, 3)*

1.4 Terminology

1.4.1 Outcome evaluation

In Danish, the word for *evaluation* (evaluating) is used to describe anything that captures the outcome of an intervention. It could therefore characterise anything from policy-makers and administrators wanting to obtain an insight into a given service to students being evaluated through being graded for their performances. When the Danish speech-language therapists were approached for participation in this study and the term evaluation was used to describe the object of research, they already had an understanding of the concept. However, evaluation is not generally used in an international speech-language therapy context where the term *outcome measure* is more commonly used for *measuring or describing the outcome*. In the international literature, this term is often related to measuring outcome with tools, but can also comprise informal methods such as a conversation about the client's outcome (Hesketh & Hopcutt, 1997; Simmons-Mackie et al., 2005). In this thesis, *outcome evaluation* was chosen to include the Danish term, evaluation, and to depict the Danish practice of outcome evaluation, which was known to be an interaction rather than simply measures from own clinical experience as well as data collection. The World Health Organization (WHO, 2000, p. 7) defines outcome evaluation as "Outcome evaluations measure how clients and their circumstances change, and whether the treatment experience has been a factor in causing this change. In other words, outcome evaluations aim to assess treatment effectiveness." This definition is considered to be in accordance with how the term is used throughout this thesis as well as by the participating clinicians, and hence is used as the key definition of this concept. The term outcome evaluation is earlier seen used in, for example, Duchan and Black (2001) and Kagan et al. (2008) for describing outcome measures in aphasia therapy.

1.4.2 Other terms

Throughout the thesis, the terms aphasia therapy, speech-language therapist and people/person with aphasia are used interchangeably with other variations: Aphasia therapy will also be named intervention, healthcare, or just therapy, whenever appropriate or for the sake of linguistic variation. In the same way, the speech-language therapists are also named therapists, healthcare providers, professionals or clinicians. For Danish readers or readers knowledgeable with the Danish educational system within speech-language therapists, it should be noted that no distinctions

between the different educations (university degree or university college diploma) are made, since it is not the focus of the present study. However, it should be noted that the participating speech-language therapists have different educational backgrounds. The person or people with aphasia will, throughout the thesis, likewise be labelled differently. The main term used beside person with aphasia is the client or patient, since the studies explore outcome evaluation from the point of view of the therapists and, in the studies, they usually use the term client or citizen (the Danish term *borgeren*) often used by public servants in Denmark. In addition, when the term ‘people living with aphasia’ is used, it also includes significant others.

Throughout the thesis, the terms interaction, communication and conversation will be used for interactions between two or more people. Interaction and communication are here used without regard for how they are carried out (verbal, non-verbal), whereas conversation refers to verbal exchange during the thesis.

1.5 Structure of the thesis

The thesis has been organised in such a way that the first three chapters (including this one) set the foundation for answering the research questions. In this chapter, the background which motivated the project is described together with terminological considerations. Chapter 2 provides an overview of concepts and research findings of outcome evaluation in aphasia therapy.

Methodological considerations and methods of research design and analysis are presented in chapter 3. The analytical results are presented in the following three chapters, with study 1 (chapter 4) answering research questions 1, 2 and 4; study 2 (chapter 5) questions 3 and 4, and lastly questions 2, 3 and 4 in study 3 (chapter 6). The findings of the project as a whole are discussed in chapter 7, as well as implications for research and clinical relevance.

The three analytic chapters are individual articles either published (chapters 4 and 5) or ready for submission (chapter 6) in relevant scientific journals:

Study 1:

Isaksen, J.K. (2014). ‘It really makes good sense’: the role of outcome evaluation in aphasia therapy in Denmark. *International Journal of Language and Communication Disorders*, 49(1), 90-99.

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Study 2:

Isaksen, J. & Brouwer, C.E. (2015). Assessments in outcome evaluation in aphasia therapy: Substantiating the claim. *Journal of Interactional Research in Communication Disorders*, 6(1), 79-91. Included with permission from Equinox.

Study 3:

Isaksen, J.K. (unpublished). "Well, you are the one who decides": Setting the frame for decision making in aphasia therapy.

2. EVALUATING OUTCOMES IN APHASIA THERAPY

This thesis is influenced by several fields, theories and methods. These include, amongst others, aphasia therapy, including holistic therapy models and client-involving approaches, outcome evaluation, ethnography, phenomenology, interactional research as well as my own clinical experience as a speech-language therapist. Central concepts, assumptions and findings relating to outcome evaluation in aphasia therapy and adjacent fields will be described in this chapter, whereas the methodological inspirations will be covered in the ensuing chapter.

The theoretical background chapter aims to give a comprehensive overview of the existing knowledge on outcome evaluation in general with a particular emphasis on healthcare and aphasia therapy. To provide a better overview of the latter, a description will be given of some general aspects of outcome evaluation (2.1), before the following questions are attempted to be answered with regards to aphasia therapy: what is outcome evaluation (2.2); who are the participants involved in outcome evaluation (2.3); what is subject to outcome evaluation (2.4), and lastly, how is outcome evaluation accomplished (2.5).

2.1 General characteristics of outcome evaluation

As stated in the introduction, the WHO definition of outcome evaluation is in accordance with how the concept is perceived in this thesis: “Outcome evaluations measure how clients and their circumstances change, and whether the treatment experience has been a factor in causing this change. In other words, outcome evaluations aim to assess treatment effectiveness.” (WHO, 2000, p. 7). I have chosen yet another definition of the term evaluation as a framework for illustrating important aspects of what outcome evaluation is and with what it is linked. This definition is, however, one amongst many (Mark, Greene & Shaw, 2006), and has the scope of evaluating governmental interventions, but was selected due to its comprehensiveness. It describes evaluation as a “careful retrospective assessment of the merit, worth, and value of administration, output, and outcome of government interventions, which is intended to play a role in future, practical action situations” (Vedung, 1997, p. 3). The following paragraph will elaborate the elements: 1) careful and retrospective; 2) assessment; 3) merit, worth and value; 4) administration, output and outcome of (government) interventions, and 5) play a role in the future:

2.1.1 General aspects of outcome evaluation

Careful and retrospective: Many would probably be of the opinion that it is not sufficient to propose someone's point of view in an evaluation; it is the systematic methods that make it an evaluation (Dahler-Larsen, 2006). Systematicity is one of the issues Vedung addresses though using the word careful. The Danish translation of Vedung's definition the word *careful* is *systematic* (systematisk) (Dahler-Larsen, 2006). Irrespective of the wording, Vedung asserts that evaluation should be based on a rigorous collection of data resembling procedures in quantitative research (Vedung, 1997). Other definitions of evaluation include specific methods, such as Rossi, Lipsey and Freeman's (2004, p. 19), who mention "the systematic application of social research procedures" as the procedures for evaluation. Qualitative procedures can be utilised in evaluation, despite an observed trend to draw evaluation nearer to quantitative research procedures in order to ensure what Dahler-Larsen (2006) terms a methodological quality. Dahler-Larsen (2006) argues that qualitative procedures instead prioritise other criteria as being social appropriate or useful. However, methodological quality in evaluation can likely be found in both quantitative and qualitative types of evaluation as long as standards about rigorous and recurrent data collection are being met (Caracelli & Greene, 1997). An example of a qualitative and yet rigorous type of how evaluation is performed in everyday interaction is seen in Pomerantz's (1984) conversation analytic study concerning assessments taking place in everyday interaction. Assessing or evaluating by ascribing value terms to a referent, as Pomerantz (1984) defines it, is a recurrent and recognisable practise that is organised sequentially in a systematic way where an initial assessment is followed by a second assessment by the interlocutor (J: T's- tsuh beautiful day out isn't it? R: Yeh it's jus' gorgeous...) (Pomerantz, 1984, p. 61). If everyday assessment is systematic and performed recurrently, someone's point of view, as Dahler-Larsen (2006) mentioned, might not be fully adequate, but at least worthwhile to include in evaluative procedures because of the socially appropriate and yet systematic approach.

Assessment: The Vedung definition uses the word assessment to describe the activity accomplished in evaluation. In one of the studies in this thesis (chapter 5), assessment is also used, not synonymously with outcome evaluation, but rather as a constituting activity of outcome evaluation (Pomerantz, 1984). The term evaluation implies more than assessment and tries to depict a more formalised or institutionalised activity (Andersen, 2011). The creation of an evaluation culture or evaluation society is even mentioned (Dahler-Larsen, 2006, Andersen, 2011). The Danish

educational system is a good example of this trend. Assessment was certainly not unfamiliar before, as grades and other achievement levels have always been a part of the duties of schools, but today it is accompanied by a wide range of evaluating activities with aims beyond assessments of the individual student. The most commonly cited of these are perhaps the test system PISA⁵ and a recent Danish initiative of annual national test batteries (Ministry of Education, 2016). Thus, it seems that, in some contexts, the term assessment is used for one thing and evaluation for another, although they are still part of the same concept. In 1.4.1, the term in this thesis, outcome evaluation, was chosen in order to take both English (outcome measures) and Danish (evaluation) terms depicting assessment of outcomes into consideration. Furthermore, different uses of words might also mirror the breadth of the concept ranging from a more localised wish to improve the evaluated effort or assessing the impact to a more managerial, or even political, aim of controlling efforts (Dahler-Larsen, 2006; Shaw, Greene & Mark, 2006).

Merit, worth and value: To ascribe value is what separates evaluation from any other systematic investigation (Founier, 2005). Value ascription is core to evaluation and can be more or less explicit (Dahler-Larsen, 2006; chapter 5). The word evaluation originates from the word value, with the double meaning of being the worth of something and working out the value of something (Mark et al., 2006). Mark et al. (2006) describe the use of different words in various definitions as reflections of the variety of evaluation purposes. Value is used as an expression for a more numerical description (e.g. grades), whereas worth refers to a more personal judgement of something or someone (e.g. J: T's- tsuh beautiful day out isn't it?) (Pomerantz, 1984, p. 61). Merit is, to Mark et al. (2006, p. 6), similar to worth, but refers to "the intrinsic, context-free qualities" as opposed to worth as a "context-determined value". However, a major challenge seems to be the quality of the values or worth intrinsic in the evaluation as well as the quality in how to discern from where the values/worth must be derived (Dahler-Larsen, 2006). It is, for example, easy to imagine that what is valuable for a funder enquiring of evaluation is not necessarily valuable for a person in aphasia therapy. The question of if a given service is cost-effective is often present when discussing evaluation and is certainly a question of value, but also a question of what is being evaluated. As mentioned in the introduction, the blossoming interest of outcome evaluation is often ascribed to

⁵ *Programme for International Student Assessment* – an international test scheme developed by Organisation for Economic Co-operation and Development (OECD) with the aim of evaluating and comparing knowledge and skills of students in the participating countries in order to improve and standardise teaching methods amongst others – i.e. a form of benchmarking (www.oecd.org/pisa/home/).

New Public Management, where the money spent on public services needs to be worth its value (Hood, 1991; Dahler-Larsen, 2006; Andersen, 2011).

Administration, output and outcome of (government) interventions: Government interventions fall within the scope of evaluation in the definition above. I take the liberty of understanding them as any intervention of public interest or somehow related to public affairs. It means, for example, that it could be an evaluation of the death rate in private hospitals, but probably not the taste of a new brand of chocolate from a private manufacturer. Evaluation can target different parts of healthcare or interventions or beyond; termed by Vedung as administration, output and outcome. If the example was the evaluation of schools, they can be evaluated by looking at the grades of the students, parental satisfaction, the teachers' sickness absence, the condition of the buildings, the percentage of students continuing at university, the list of evaluative parameters could go on and on.

Objects of evaluation are often seen expanded beyond outcomes. A common expansion or division is seen into the concepts of structure, process and outcome (e.g. Dahler-Larsen, 2006; Frattali, 1998b; Shaw et al., 2006). This triad in outcome evaluation refers to Donabedian's (1966) model of evaluating quality of healthcare, which still serves as one of the most influential paradigms in healthcare evaluation including speech-language therapy (Frattali, 1998b; Frenk, 2000). The term structure refers to the context in which an intervention is provided (e.g., staff, equipment and facilities in general). The process is what takes place between and within the participants of the intervention or whatever is evaluated. It includes technical management as well as interpersonal aspects; in other words, the means by which the intervention is carried out, including therapy methods and interaction. Lastly, outcome refers to what is already defined through the earlier stated definition by the WHO, namely a change in a person's health status which can be attributed to the intervention. Not only are physical changes included here, but also psychological and social changes, as well as satisfaction, health-related behavioural changes and knowledge (Donabedian, 1980; Frattali, 1998b).

Play a role in the future: Evaluation can have a wide range of purposes, which are related to the specific object being evaluated. Assessment of impact, improvement or the development of an evaluated object, as a basis for decision making or for control of interventions, are some of the purposes mentioned in the literature (Dahler-Larsen, 2006; Donaldson & Lipsey, 2006; Shaw, 2006; Golper & Frattali, 2013). The purposes are also influenced by the different stakeholders (see

2.3.1). From, for example, a student's perspective, control is not a purpose; he or she would instead be interested in evaluation from an impact perspective. No matter what the exact purpose is, it points towards the future, as Vedung (1997) also wrote in his definition. Any kind of evaluation should ideally be oriented towards new actions, whether it is to continue, stop or modify, for example, an intervention. By its nature, an evaluation will always challenge the evaluated object, by assuming that nothing is obvious or untouchable, but by assuming that everything can be changed if it does not live up to its objectives (Dahler-Larsen, 2006). Outcome evaluation often leads to changes in behaviour and can be seen as a strategic or tactical move from any stakeholder. In contrast to this example, outcome evaluation can also be a more symbolic action, perhaps serving the purpose of acting a serious organisation or professional capacity (Dahler-Larsen & Larsen, 2001).

Summing up this depiction of the concept outcome evaluation based on the Vedung definition, outcome evaluation is preoccupied with outcomes of an intervention or service through a systematic and retrospective process. Outcomes are assessed via the expression of values for people and/or systems involved and with the purpose of making decisions for the future. Many aspects of outcome evaluation have been covered, but not all by far. The next paragraph aims to provide further knowledge of the area in order to further specify and relate the concept to aphasia therapy.

2.2 What is outcome evaluation in aphasia therapy?

2.2.1 Introduction to outcome evaluation in aphasia therapy

Outcome evaluation in aphasia therapy from a clinical point of view is not very well researched. Little is known from surveys of clinical practice (e.g. Simmons-Mackie et al., 2005, Verna et al., 2009), for example, with what methods clinicians accomplish outcome measures (see 2.5).

However, a recent Australian project with international collaborators has drawn attention to outcome measures in aphasia research. By using a framework from the COMET (Core Outcome Measures in Effectiveness Trial) initiative, Wallace and colleagues (Wallace et al., 2014) aim to propose a standardised set of outcome measures developed through a defined and rigorous consensus process involving different stakeholder groups such as consumers, clinicians and researchers (Williamson & Clarke, 2012). Uniform and agreed aphasia research outcome measures can likely spread into clinical aphasiology, since many of the same methods are already used for both evaluating outcomes in research and the clinic (compare, for example, Brady et al., 2016 with

Simmons-Mackie et al., 2005 and Verna et al., 2009). However, some critical points have been put forward. They argue that Wallace et al.'s (2014) own review of the current practice of outcome measures in aphasia rehabilitation research reveals challenges for a common set of measures. These are, for example, conflicting goals for therapy, different therapy approaches and philosophies and divergent understanding of the nature of aphasia amongst others (McWhinney, 2014; Hula, Fergatiosis, & Doyle, 2014). In particular, Hula, Fergatiosis, & Doyle (2014) question the idea of core outcome measures, at least before agreement is established regarding what constructs are to be measured. Agreement on how to evaluate outcomes might not necessarily be a clinical aim, but this focus on outcome measures as the primary means of evaluating aphasia therapy is very tangible and is therefore also present in guidelines and recommendations (e.g. Australian Aphasia Rehabilitation Pathway, n.d.; Royal College of Speech and Language Therapist Clinical Guidelines, 2005). However, if attention is only paid to measurement tools in clinical practice or research, there is a risk of missing out on new developments or other constructs in the field of aphasia therapy that have not yet been evaluated (Hula, Fergatiosis, & Doyle, 2014, McWhinney, 2014). The two following paragraphs will focus on how outcome evaluation in aphasia therapy is described and defined, and identify some of its many purposes, before moving on to the participants, the constructs to evaluate, and the methods and tools used in outcome evaluation.

2.2.2 Frameworks

Intervention or therapy for people with aphasia can be seen to have as many manifestations as there are therapy sessions in this world, and yet there will be many recognisable and common elements. It is influenced by a wide range of conditions and circumstances as well as by the participants. There has been a shift in philosophies behind, and approaches to, aphasia therapy, which should also be reflected in outcome evaluation. Previously, the focus was primarily on outcome evaluation in relation to linguistic skills or health, a so-called impairment focus, whereas today, therapy usually includes functionality for everyday communication, social participation, and quality of life (Lubinski, 1998, Sarno, 2004). The WHO's model, International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) is probably the most influential source in that shift and has inspired therapy as well as outcome evaluation (e.g., Kagan et al., 2008; Threats, 2008, 2009, 2012). ICF is a so-called biopsychosocial model and framework used for describing and organising information about a person with a given health condition (disease or disability) with regards to its impact on body functions and structures, activities and participation as well as the interference with

contextual factors: environment and personal factors. The ICF framework not only provides a standard language and a conceptual basis for description, but also measurement of health and disability across professions and internationally (WHO, 2001). In Denmark, the ICF not only serves as a joint framework for aphasia clinicians, but also speech-language therapists working with other communication disabilities during the therapeutic course, from assessment and goal setting to intervention and outcome evaluation (Amternes Tale-Høre Samråd, 2006). Two methods/frameworks focusing on outcome measurement have been derived from the ICF model: the method Therapy Outcome Measure (TOM) (Enderby & John, 2015) developed for assessing many kinds of intervention and the framework Living with Aphasia: Framework for Outcome Measurement (A-FROM) (Kagan et al., 2008) with a specific focus on aphasia. Both methods build on the terminology and ideas of the ICF, but are further expanded in a more psychosocial direction with concepts such as wellbeing and living with aphasia, which the authors emphasise as important to include in what is to be evaluated (see 2.5).

2.2.3 Multiple purposes

Back in 1998, Frattali noted: “There is no need for euphemism on what is driving the need for outcomes data. We all know it is cost pressures” (Frattali, 1998b, p. 21). Nonetheless, speech-language therapists have also been observed to express a desire to evaluate outcomes because of a responsibility towards their clients, a wish to develop better services or simply to be a better therapist (Enderby, 1999; Holland, 1999). Worrall (1999) notes, that making outcome measures is a step towards a more mature profession as a rather new group of professionals in healthcare. With this in mind, it seems that outcome evaluations carried out in relation to aphasia therapy can serve a number of purposes.

Outcomes evaluation related to research are not in the scope of this thesis, but nonetheless the background of why outcomes need to be documented is closely related to research. Wallace et al. (2016b, p. 2) state: “The outcome constructs measured in research must also be relevant to end users if evidence is to translate to clinical practice.” Regardless if it is the efficacy, effectiveness or efficiency of aphasia therapy being researched, it serves the same overall purpose of documenting whether therapy works and is worthwhile for clinical purposes (Robey, 2004). For example, studies of efficacy will typically have conclusions about a strict regimen of a certain administered method in a highly controlled environment with carefully selected people, whereas

studies of effectiveness and efficiency may have a higher functional validity focussing on, for example, client satisfaction and quality of life (Papathanasiou et al., 2013; Wertz & Irwin, 2001).

As stated, clinical outcome evaluation has to do with documenting if therapy works and, in that sense, it is worthwhile for the people being treated, but can certainly be much more than this. However, as opposed to other components in the aphasia intervention process, outcome evaluation is frequently not described or even mentioned in, for example, textbooks about aphasia. Elements such as goal setting, assessment and therapy are usually better described. Aside from one of the studies in this thesis (chapter 4) Simmons-Mackie et al. (2005) have also investigated what, according to speech-language therapists, outcome evaluation would be. It was found that 67% of their 93 respondents from the United States and Canada define outcome assessment in terms of measuring or evaluating changes or effects of therapy or intervention. The results of the study also pointed towards other purposes such as, for example, consumer satisfaction, documenting changes over time, and also capturing real-life improvements. Other researchers equally use a description of outcome evaluation that also accommodates broad effects of therapy as well as attitudes towards, and satisfaction with, given services (Hesketh & Sage, 1999; Verna et al., 2009).

Furthermore, purposes of clinical outcome evaluation are closely related to the present stakeholders (see further description in 2.3). Each of them, from funders and managers to clients and speech-language therapists, almost certainly aim for better language and communication skills for the clients, improving their quality of life (Simmons-Mackie et al., 2005). Additionally, the different groups of stakeholders presumably have their own purposes for, and interests in, outcome evaluations (Hesketh & Sage, 1999).

Equally, there might also be a demand for outcome evaluations on a service or population level from some of the involved parties, again depending on the intended aim (Worrall & Egan, 2001). Nonetheless, other objectives in outcome evaluation could be revealing the process and structure of therapy (Frattali, 1998b).

Outcome evaluations are often described as being either formative or summative, which also relates to the different groups of stakeholders (2.3). The outcome evaluations the speech-language therapists accomplish with their clients with aphasia often serve, as in the data for the current study, a more formative purpose. Here, the current status is uncovered and points to the client's potential in order to, for instance, set new goals. The types of outcome evaluations interesting for managers and funders usually serve more summative purposes. Here the focus is on what the final result of the therapy in a format comparable across, for example, therapists, clients or

type of disorder, would be. Summative outcome evaluations serve purposes such as selling or choosing the best, cheapest and/or most efficient service (Hesketh & Sage, 1999).

2.3 Who are the participants in outcome evaluation after aphasia therapy?

There can be many “players” in outcome evaluation. In this paragraph, both explicit and implicit participants are presented, namely the people present in outcome evaluation and the remaining stakeholders. Since participation in outcome evaluation is not well researched, involvement in aphasia therapy in general will be considered.

2.3.1 Stakeholders and their interests in outcome evaluation

There is a potentially large group of stakeholders interested in outcome evaluation in aphasia therapy, for example, policy-makers, funders, providers such as the clinic managers and the therapists, and the consumers (people with aphasia, significant others) (Hesketh & Sage, 1999; Wallace et al., 2014). Although, in some cases, the funder will be the person with aphasia, in some countries aphasia therapy is funded by private health insurance or public insurance for specific groups of people. In other countries such as Denmark, aphasia therapy is funded publically via taxes and is a part of the legislative framework governing health and social services available for citizens with special needs. Providers of aphasia therapy can be hospitals, rehabilitation clinics, outpatient clinics or community-based centres. Who the provider would be, generally depends on the stage of the aphasia. If the client is hospitalised, this is likely to be the therapy service at the hospital, later the provider might be an outpatient clinic, and at the chronic stage, it could be a community-based centre. The direct provider of aphasia therapy is likely to be a speech-language therapist. The therapist will usually be qualified from a university with additional clinical training. Some countries will also use therapy assistants or volunteers to supplement the therapy performed by the qualified therapist.

One of the main stakeholders demanding to see outcomes of therapy could be the funder of a service. Such a funder can be anyone from the client to an insurance company or, as with Denmark, the client’s municipality. However, the funder is not necessarily someone that does not know very much about the purchased service. An easy and fast understandable outcome evaluation is preferred, that can perhaps be compared to other speech-language therapy services within the same clinic or to other aphasia services in the same area (Hesketh & Sage, 1999). The funder may also be interested in evidence for the best value for money (Simmons-Mackie et al., 2005). The

latter might be a requested outcome for the clinic management as well. As provider of aphasia therapy to a funding body such as, for example, insurance companies or public authorities, the management, on the one hand, needs to keep record of clinicians' work while, on the other, needs to monitor and increase quality – preferably for less money – in order to document the given services or to benchmark the service (Hesketh & Sage, 1999; Simmons-Mackie et al., 2005). From the client's perspective, being the funder or not, he/she and the significant others can use the outcome evaluation as a way of expressing their opinion about the service, process and also result in receiving a professional evaluation based on objective methods (Hesketh & Sage, 1999). The speech-language therapists may well have overlapping interests with the clients in outcome evaluation, but they might also have an interest in assessing their interventions due to reasons such as being responsible speech-language therapists who serve the clients with the best possible methods in each given situation (Enderby, 1999; Frattali, 1998a; John, 2011). An investigation of the view of speech-language therapists when conducting outcome evaluation has shown that they find it beneficial in ways such as clarifying therapy objectives, demonstrating efficacy to funders and changes to clients (Hesketh & Hopcutt, 1997).

The abovementioned studies concerning core outcome measures from Australia with international data collection have investigated what different stakeholders, including speech-language therapists, found important in measuring outcomes and mapped the outcomes to the different ICF domains (Wallace et al., 2016a; Wallace et al. 2016b). The studies revealed that both people with aphasia (n=39), significant others (n=29) and speech-language therapists (n=265) identified that the areas important for them to measure spanned across the ICF domains, but with outcomes within the activity/participation domains being the most prominent for these stakeholder groups.

The following three paragraphs will focus on the participants directly involved in outcome evaluation: people with aphasia, significant others and speech-language therapists.

2.3.2 Involvement of people with aphasia in therapy

People with aphasia and other relevant participants are involved in aphasia therapy, including outcome evaluation, in many ways. This largely takes place via interaction with the professionals, but also through, for example, questionnaires or scales where the opinions of persons with aphasia and others can be expressed. A systematic review of 22 studies of physician-patient communication in primary care by Beck, Daughtridge & Sloane (2002) outlines both verbal and nonverbal

behaviours of general practitioners related to the favourable patient outcomes. For patients, the stated benefits of *good communication* in primary healthcare are related to client-centred or relationship-centred styles and include, amongst others, explanations, empathy, client-centred questions and other types of involvement and information-giving activities. Despite some evidence of how clinical communication interacts with patient involvement, Beck et al. (2002) conclude that, due to the lack of definitional issues, empirical studies, and conflicting findings, there is still insufficient research to draw any final conclusions or recommendations.

Speech-language therapy, including aphasia therapy, similarly lacks evidence of how people with communication disorders can be involved in their own therapy through, for example, shared decision making. The majority of clinicians will report collaboration with their clients about, and during, aphasia intervention (Bray, Ross & Todd, 2006). However, Simmons-Mackie and Damico (2011) associate a more impairment-based type of intervention with the clinician-centred approach. In such approaches, the client is commonly trained to supply correct responses to various tasks, such as naming and picture-word matching, often supplemented with corrections by the speech-language therapist until an acceptable target is reached. In contrast, interventions based on more holistic models such as ICF require the involvement of the client. For example, a discourse-based intervention will, in this light, draw upon topics and narratives introduced by the person with aphasia. Perhaps it can be seen as a continuum, the clinicians' approaches can be more or less client-involving depending on methods as well as the clinician. The type and extent of involvement requested may vary from client to client, since research shows client resistance as a barrier to involvement (Légaré, Ratté, Gravel & Graham, 2008). Additionally, the interactional style must suit the individual client to be termed client-centred. The opportunity not to get involved as a client or have different levels of involvement must equally be available to match the individual. However, there is still a gap in the knowledge about what clients prefer, since client-centred communication is often researched from the clinicians' point of view (Nordehn, Meredith, & Bye, 2006).

Within aphasia therapy, client involvement is often challenged due to communicative issues (Laakso, 2015). In research, this has been an excuse to exclude these people from studies, and also communication, because of potential problems with communicating with them. People with aphasia have been excluded from stroke studies due to their language problems, even without considering their actual communication skills or supporting their participation (Nordehn et al., 2006). Nordehn et al. (2006) have investigated barriers to participate in patient-centred communication for people with stroke-related communication disorders. Many of the comments

(74%) from this focus group study relate to more general issues, such as not being listened to or treated with respect, whereas the remaining 26% of the comments were related to the communicative impairment. For example, the participants would have liked more time to answer and a reduction in speech rate by the professionals. The study by Nordehn et al. (2006) lists a number of recommendations from their particular study as well as others to ensure or optimise involvement of communication-impaired people in healthcare. Some of the addressed issues express that the medical staff should take their portion of responsibility in such conversations by giving time, rephrasing, providing supplementary materials and equipment to enhance the involvement (Holland & Halper, 1996; Nordehn et al., 2006). Consequently, an increased awareness of the importance of providing sufficient access to healthcare for people despite aphasia or other communicative disorders is seen (e.g. Enemark & Isaksen, 2013; Jensen et al., 2015; Law, Bunning, Byng, Farrelly & Heyman, 2005; Simmons-Mackie, Kagan, O'Neill Christie, Huijbregts, McEwen, & Willems, 2007). Furthermore, methods developed to increase access for people with aphasia via conversational support are also seen to be implemented widely at, for example, hospitals, rehabilitation units and in healthcare education (Cameron, McPhail, Hudson, Fleming, Lethlean & Finch, 2015; Horton, Lane & Shiggins, 2016; Jensen et al., 2015; McGilton, Sorin-Peters, Sidani, Rochon, Boscart & Fox, 2011; Legg, Young & Bryer, 2005, Simmons-Mackie et al., 2007; Welsh & Szabo, 2011).

2.3.3 Significant others as participants in aphasia therapy

Since aphasia not only affects the person with aphasia, but also a whole family or network of extended family, friends and colleagues, significant others who might become engaged in therapy (Grawburg, Howe, Worrall & Scarinci, 2013). An interview study with 48 family members revealed different purposes of involvement such as, for example, their own needs, but also because they can take a valuable part in the recovery of the person with aphasia (Howe et al., 2012). A cross-sectional study of Swedish speech-language therapists showed a high involvement of significant others in aphasia therapy. Of the 224 respondents reporting working with people with aphasia, 192 met or worked with family members. Increasing significant others' knowledge of aphasia was the most prominent aim of making contact, as reported by 92% of the respondents. Amongst the other aims were obtaining information about the person with aphasia (62%), and improvement of the significant others' communication skills (48%), but also directly involving them in therapy such as,

for example, help with constructing assistive communication aids (23%) or assisting with home exercises (13%) (Johansson, Carlsson & Sonnander, 2011).

The involvement of significant others in aphasia therapy is regarded as important for the success of therapy and for the wellbeing of the person with aphasia (Haley & Wangerman, 2012). However, different studies have drawn different conclusions regarding how such participation should find its place. One of the themes raised is that people with aphasia do not like ‘being spoken for’ (Gillespie, Murphy & Place, 2010; Haley & Wangerman, 2012; Purves, 2009). When a significant other participates in therapy, there is a risk of the person with aphasia being overlooked, especially if they have difficulties expressing themselves. The professional could therefore tend to orient towards the accompanying significant other, talk to them, look at them and ask questions of them instead of the person with aphasia (Nordehn et al., 2006). Simmons-Mackie, Kingston and Schultz (2004) demonstrated, in a sociolinguistic analysis of a conversation involving a person with aphasia, that there is a fine line between speaking instead of / for another and speaking on behalf of others. The fine line can easily be transgressed by the involvement of significant others in aphasia therapy if the therapist is not aware of it. Finding the balance for speaking on behalf of someone might support the person with aphasia in bringing forward their own viewpoints. If a significant other speaks instead of their relative with aphasia, the therapist might also end up with less accurate information, unsolicited contributions or corrections, and with the person with aphasia feeling demotivated or with reduced autonomy (Croteau & Le Dorze, 2006; Haley & Wangerman, 2012). Croteau, Vychytil, Larfeuil and Le Dorze (2004) state, on the contrary, in their study of six couples, where one partner had aphasia, that there is nothing wrong in speaking-for behaviour, as long as both parties understand and accept the conditions. It might even have been a pre-aphasia behaviour for some of the six couples. Thus, according to these different studies and their recommendations, the contributions from significant others are, in some constellations, regarded as silencing whereas in other cases regarded as enabling and supporting. To sum up, all participants in multi-party interactions such as outcome evaluation sessions need to be aware of their own role in the interaction as well as how it is interpreted.

2.3.4 The role of the speech language therapists

Involvement of people with aphasia in aphasia therapy means that the therapist might need to give up some professional autonomy and share, for example, decisions with their clients. In 2010, Worrall, Davidson, Hersh, Ferguson, Howe and Sherratt wrote that the majority of approaches to

aphasia to date have been focused on the perspectives of the therapists rather than the actual participant in therapy: people with aphasia and significant others. If newer trends such as client-centeredness and a holistic view on rehabilitation (for example, ICF or a social model, Simmons-Mackie, 2008) permeate, the role of the therapist will probably undergo change: The changed focus of therapy onto the person with aphasia may challenge the expert role of the clinician. Instead, the relationship between the therapist, client and possibly significant others has been proven to be of utmost importance for the success of therapy (Simmons-Mackie and Damico, 2011). This is not just a relationship where the clinician brings in professional knowledge and therapy skills, but a genuine relationship, with mutual respect for, and interest in, each other being required (Worrall et al., 2010). It requires the therapists to take risks in their relationships with their clients compared to the former concept of being professional (O'Halloran, Hersh, Laplante-Lévesque & Worrall 2010). Failing to treat clients as equals or not taking their contributions seriously can entrench a disabled identity, which is the opposite of what most clinicians aim for (Downs, 2011; Rasmussen, 2013).

With a large group of stakeholders interested in outcome evaluation of aphasia therapy as well as the different participants in the outcome evaluation, a relevant question seems to be whether these different needs can be met during the individual outcome evaluations with people with aphasia. The answer is that it is probably not possible, Hesketh and Sage (1999, p. 38) write: "Building a tool which can meet the range of needs of client, therapist, manager and purchaser is complex and, to date, incomplete".

2.4 What is subject to outcome evaluation in aphasia therapy?

Due to the complexity and nature of aphasia, aphasia therapy is complex and multifaceted. It takes its outset in, for example, primary signs and symptoms, but also the consequences of aphasia for both the person with aphasia and his/her conversation partners. This paragraph first explains the principles and practices in aphasia therapy. The last part of the chapter (2.5) outlines what is subject to outcome evaluation across and beyond domains of the ICF framework as well as interaction as a central component in the process of outcome evaluation.

2.4.1 Principles in aphasia therapy

Aphasia therapy originates from the 19th century, when neuro-pathologists began to link locations in the brain with language functions and later suggested connections between impaired language and specific brain areas. Neurological theories and findings were supplemented and, to a certain degree,

replaced with linguistic theories of aphasia well into the 20th century, where localisationism had a second revival that continues today (Tesak & Code, 2008; Isaksen, 2014). Aphasia therapy is today still practised with the concepts of aphasia subtypes in mind, and thus seems to be based on the work of Wernicke and Broca, two famous medical doctors and aphasiologists from the 19th century. However, other insights have been added to those concepts.⁶ In short, the primarily medical-linguistic approaches have been supplemented with functional/psychosocial approaches as the ones promoted by the ICF model and further expanded by the profession itself (Code, 2013; Kagan et al., 2008; Worrall, Papathanasiou & Sherratt, 2013).

Several approaches or clusters of therapy methods can be discerned. In one respect, medical/linguistic models generally focus their therapy on the impairments of the person with aphasia, which means the focus is on problem identification and the therapy aims at improving aspects of affected language components for the client to, to a certain extent, become as before the brain injury. The idea behind these approaches is that if single areas of language use, such as, for example, naming, become better, general aspects of communication and participation in social activities will be improved (Whitworth, Webster, & Howard, 2005). Functional or psychosocial approaches, in contrast, emphasise the consequences of aphasia. Such approaches often base their interventions on preserved skills in everyday communication. With a focus on the impact of aphasia in daily living, they aim to enhance, for example, the use of those preserved skills and teach communication partners in communication with people with aphasia to decrease barriers for communicative accessibility (Worrall et al., 2013). At present, a unified approach of impairment- and consequence-based therapies has not only been promoted by a number of researchers, but is likely to be the current practice amongst Danish speech-language therapists (Martin, Thompson & Worrall, 2008) (Isaksen & Larsen, 2016).

Research findings or trends in society or the field of aphasia sometimes create an interest in, or a renewal of, existing approaches, an example from clinical experience of this being the impact the Danish translation in 2005 of the test Psycholinguistic Assessments of Language Processing in Aphasia (PALPA) (Kay, Coltheart & Lesser, 1996, translated and adapted to Danish by Lønnberg & Hallas-Møller, 2005) had on moving the profession towards a more linguistic approach for a while. Today, methods such as Constraint Induced Aphasia/Language Therapy based on findings from neuroplasticity studies are observed to impact current therapy (Meinzer,

⁶ This is not an attempt to give a full description of the history of aphasiology, but merely to give some basic introduction to some of the major approaches seen today. A schematic presentation of current approaches can be seen in Worrall et al. (2013, pp. 101-102).

Rodriguez & Gonzalez Rohti, 2012) together with the German therapy method Modalitätenaktivierung in der Aphasietherapie (MODAK) (Lutz, 2009; Isaksen & Larsen, 2016). Moreover, efforts to implement principles from Supported Conversation for Adults with Aphasia (SCA) are also evident amongst both health professionals and significant others (Jensen et al., 2015; Kagan, 1998). Despite the very diverse principles lying behind these methods, they are practised in unison (Larsen, 2015). No matter what the method builds on, it is performed with the same goal: “We consider it axiomatic that the aim of all therapies with people with aphasia is to improve their functioning in the real, social world, to enable them to cope with barriers to participation and fulfilment” (Whitworth et al., 2005, p. 264). This can also be seen internationally where more comprehensive approaches are promoted and researched, for example, in various Intensive Comprehensive Aphasia Programmes (so-called ICAPs) (Rose, Cherney & Worrall, 2013). Intensive programmes generally build on the principles of neuroplasticity and are often derived from impairment-focused training such as constraint-induced aphasia therapy, while the ICAPs equally place emphasis on an intensive approach to, for example, compensative strategies and living successfully with aphasia (Kleim & Jones, 2008; Rodriguez et al., 2013).

As mentioned in the introduction, evidence-based practice is a regime influencing the principles as well as the practice of speech-language therapies, including aphasia therapy (Beeson, n.d.; Roddam & Skeat, 2010). The part of evidence-based practice concerning external evidence is, however, somewhat challenged, at least when it comes to high-level evidence such as good quality double-blinded randomised controlled trials (RCT) or even systematic reviews of RCT studies that are preferred according to evidence hierarchies (e.g. OCEBM Levels of Evidence Working Group, n.d.). As with many other areas, it can be difficult to produce such evidence in aphasia due to reasons such as the small numbers of comparable participants, difficulties in measuring outcomes of treatment on functional and social issues, and great variability in used outcome measures (Dodd, 2007; Brady et al., 2016). However, a growing number of aphasia trials and systematic reviews have been conducted. The regularly updated Cochrane review on aphasia therapy following strokes is perhaps the most accessible source for obtaining an overview of therapy outcome studies on the highest levels of evidence (Brady et al., 2016). The authors conclude regarding external evidence from RCT that, ‘there may be a benefit from speech and language therapy but there was insufficient evidence to indicate the best approach to delivering speech and language therapy’ (p. 2). The quote emphasises that finding external evidence is not easily done within aphasia therapy, which challenges the idea of striving towards evidence-based practice. However, the definition of

evidence-based practice (Sacket et al., 2000) does not exclude other types of evidence such as robust qualitative evidence. Finding evidence requires, among other elements, time, access to research articles and interpretation skills (Dodd, 2007; Nail-Chiwetalu & Ratner, 2006; Roulstone, 2011). Furthermore, the equally important components in evidence-based practice, clinical expertise and clients' perspectives, can be challenging to incorporate (Dodd, 2007). However, how to make the three components play an equal role is not well researched nor described. Consequently, studies of clinical practice, such as this thesis, are necessary for the development of both the practice of, and theories about, decision-making approaches such as evidence-based practice (Dollaghan, 2007).

As touched upon in chapter 1, the way in which aphasia therapy is carried out is affected by trends in society as well as the values, personal factors, etc. of the speech-language therapist. The following paragraph deals with these issues.

2.4.2 Practice of aphasia therapy

The actual practice of aphasia therapy will vary from one client-clinician dyad to the other. Aphasia therapy is described as, and recommended to be, individual, because of the variations of the manifestations of aphasia and its effect and consequences to the individual person and family living with aphasia and hence individual goals set for therapy (Helm-Estabrook, Albert, & Nicholas, 2014; Papathanasiou et al., 2013; Rosewilliam et al., 2011). Individualised therapy is supported by a larger qualitative interview study by Worrall et al. (2011) showing that the 50 people with aphasia interviewed have a wide range of goals for therapy across all ICF domains, as well by a qualitative review by Plowman, Hentz & Ellis (2012) describing how individual differences experienced after (in this case) stroke, such as aphasia severity, lesion site and size potentially affect recovery. Despite the practice of, and evidence for, individualised therapy aphasia intervention, there are many elements that are recognisable and general (see also 2.4.1). These include, for example, what can be considered the elements in an aphasia therapy course including some modes of service delivery, as seen below.

The routines of therapy practices, often referred to as the therapeutic cycle, are, with variations, described in many textbooks for speech-language therapy students and graduates (e.g., Helm-Estabrook et al., 2014; Worrall et al., 2013). An example of such a cycle in clinical practice is the following description of intervention steps by Worrall et al. (2013): 1) Anamnesis (sharing and gathering of information); 2) Goal-setting in collaboration; 3) Assessment; 4) Intervention, and 5) Reassessment/outcome evaluation. Despite this generic stepped model, all stages are individualised

and yet possibly influenced by the abovementioned principles (2.4.1) of having, for example, ICF as a framework as well as the condition of the client, and at what stage in the process of recovery he or she is. Based on my clinical experience, an example could be how the speech-language therapist in the goal-setting process initially involves the person with aphasia by asking about his/her personal goals. Perhaps, for instance, the long-term goal is to return to work as a secretary at City Hall. By employing the ICF framework, the therapist breaks down this goal into a few short-term goals, perhaps focusing on body level (for example, reduced phonetic paraphasias in talking and writing), activity level (reading and writing emails) and participation level (talking on the telephone). These goals are not necessarily worked on at the same time, since the person with aphasia's current status needs to be taken into consideration. Perhaps there is a need to work on goals at body level before moving to activity- and participation-based goals. Of specific relevance to this thesis is, of course, step 5, but goal-setting also plays an underlying role in study 2 of the thesis in particular (chapter 5), since outcome evaluation usually draws a clear line back to the therapy goals.

A considerable amount of research has focused on single activities in aphasia therapy. Hersh et al. (2012) reports aphasia therapy to be planned around individual goals set jointly by the therapist, the person with aphasia and, possibly, significant others. Both long- and short-term goals can be worked upon and along the way, and/or towards the end of therapy, progress is usually assessed or evaluated. Ending therapy and making outcome evaluations are, therefore, closely related, since the status of the client revealed in an outcome evaluation is often a predictor for reference to future therapy. Nevertheless, establishing the right time for discharge from therapy amongst the parties in aphasia intervention is reported to be a difficult task (Hersh, 2009). Furthermore, the decision-making process is challenged by contextual frameworks such as legislation and national guidelines. An example of such a framework in Denmark is the Act on Special Education for Adults (Ministry of Education, 201X) which dictates that, in order to continue publically funded aphasia therapy, progress must be documented. Related professional groups such as physiotherapists and occupational therapists, however, may, according to their health legislation, provide training to maintain the current physical status of their patients without such documentation (Ministry of Health, 2009). Such diversity in the rehabilitation legislation highlights clear differences in clinical decision-making processes in related professions working with stroke rehabilitation with regards to discharge of therapy.

With newer research findings, theories and approaches, such as neuroplasticity and social models of aphasia (see 2.4.1), other issues concerning discharge have emerged. Today, it is

known that people with aphasia can gain results from therapy and working on living with aphasia no matter the time in which the intervention is provided in relation to the onset of their impairments. This is opposed to earlier beliefs that people with aphasia reach a plateau of recovery and, consequently, should be discharged (Helm-Estabrooks et al., 2014; Worrall et al., 2013). Nevertheless, my clinical experience is that individual therapy is generally terminated because of client status, professional matters, management and/or economy, although people with aphasia may still participate in community-based fellowship, for example, through aphasia or stroke associations.

Bray et al. (2006) refer to therapy delivery as either direct or indirect and given individually or in a group setting. According to a description of Norwegian aphasia practice by Qvenild, Haukeland, Haaland-Johansen, Knoph and Lind (2010), direct therapy refers to face-to-face interaction in person with a client, individually or in groups, or via communications media such as the telephone or computer involving a therapist, while examples of indirect therapy could consist of counselling, including information provision and conversation partner training for family members or professional carers. Bray et al. (2006) report that commonly delivery approaches are combined; for example, individual therapy is combined with group therapy along with conversation partner training for family members. This diversity in service delivery options also matches my clinical experience as well as a recent best practice statement from Australia: “In addition to individual therapy delivered by speech pathologists aphasia rehabilitation may include: group therapy and conversation groups, computer-based treatments, telerehabilitation and trained volunteers” (The Australian Aphasia Rehabilitation Pathway, n.d.). The recommendation is supported by research studies ranging from high evidence from systematic reviews concerning trained volunteers, group therapy and computer-based treatments (Brady et al., 2016; Lanyon, Rose, & Worrall, 2013; Zhang, Lynch, & Taylor, 2016) to lower-level evidence based on a non-systematic review and a feasibility study for telerehabilitation (Cherney & van Vuuren, 2012; Dechene et al., 2011).

Time of therapy onset is also to be considered when exploring therapy delivery. Although some studies show the benefits of early therapy onset to capitalise on concurrent spontaneous recovery (e.g. Robey, 1998), others show the opposite (e.g. Bowen et al., 2012). How much and how often, questions of dosage, and intensity in aphasia therapy, are widely discussed questions with ambiguous answers, though several recent studies and meta-analyses point towards the benefits of higher doses and intensity, although perhaps not for all clients and at all phases (Bhogal, Teasell, & Speechley, 2003, Cherney, Patterson, Raymer, Frymark, & Schooling, 2008).

The latest Cochrane review also concludes that there is some indication of the benefits of high intensity and doses over a longer period, but maybe not for all those with aphasia (Brady et al., 2016).

No therapy approach has been proven to be superior to others according to Brady et al. (2016). Nonetheless, there is, as described above, research and clinical evidence on how to provide therapy. This means that what is actually subject to evaluation is not clear. The abovementioned Australian Aphasia Rehabilitation Pathway report (n.d.) recommends that “Outcome measures for people with aphasia should be suitable to the construct being measured and psychometrically robust (reliable, valid and sensitive)”. However, as mentioned in the introduction, Brady et al. (2016) problematise the issue by arguing that a globally accepted, valid, reliable and comprehensive way to measure especially functional communication is still needed. In paragraph 2.5, further consideration is offered into how working with people with aphasia and their significant others across and beyond the ICF domains holds for different types of outcome evaluation.

2.5 How is outcome evaluation accomplished in aphasia therapy?

Frattali (1998b, pp. 8-9) lists a number of outcomes that she relates to speech-language therapy: 1) clinically derived (e.g., ability to name pictures); 2) functional (use of communicative skills in everyday life); 3) administrative (e.g., number of attended sessions); 4) financial (cost-effectiveness); 5) social (e.g., ability to return to work), and 6) client-defined (e.g., quality of life, satisfaction with therapy). The different list items suggest a variety of different objectives of outcome evaluation that might be hard to meet when using only one method or tool, as the quote above from Hesketh and Sage (1999) also indicated. The following paragraphs describe how and with what tools outcome evaluations can be carried out. However, the description will not focus on every item on Frattali’s list. Instead, it will take its point of departure in interaction as a crucial tool for outcome evaluation before describing, how outcome across and beyond the ICF domains are measured.

2.5.1 Interaction as an instrument for outcome evaluation

In Roter and Hall’s 1993 book, they write that interaction is the ‘main ingredient’ in healthcare. Even the most technical-medical parts of healthcare are dependent on the ability of healthcare professionals and clients to interact. The interaction between clinician and the person with aphasia

is, as well as in other types of healthcare, a substantial, but often overlooked, part of aphasia therapy (Simmons-Mackie & Damico, 2011).

Clinical interactions are categorised by types of interactional styles. Clinical communication is often talked of as being asymmetrical, with the professional as being the most powerful, using, for example, professional jargon (Ferguson & Armstrong, 2004). Conversation analytic studies have demonstrated an interactional motivated asymmetry in the interactions referred to above by Simmons-Mackie and Damico (2011) and Silvast (1991). When the therapist dominates the interaction by choosing topics, taking the right to interpret the meaning of the client's contribution, or evaluating performance, asymmetry is a potential consequence.

Charles, Gafni, and Whelan's (1997) article on the concept of shared decision making⁷ outlines a continuum of involvement closely related to the interactional styles. At one end of the continuum, we have a situation where the clinician takes all decisions and, at the other, it is the client who takes all decisions. The authors argue in favour of an approach somewhere in the middle, a somewhat shared approach. In terms of interactional styles or therapy styles, the two most commonly mentioned are a clinician-centred and a client-centred style⁸. The clinician-centred style includes a controlling therapist who can be seen to display some of the interactional patterns mentioned above, in order to maintain control. In the client-centred style, however, each client is seen as unique and with individual needs. The client-centred style is not, as the term indicates, purely on the client's premises, but instead aims at an equal participation and shared decision making, as mentioned above. Worrall et al. (2010) introduce the term relationship-centred in aphasia intervention, which also stems from medical care. This term might embrace the meaning more precisely, as it includes significant others as well as the clinician. Common for all types of centeredness except the clinician-centred approach is that interactions in clinical settings also aim to be more evenly balanced both in respect of the individual, but also to model everyday interactions, when all participants ask questions, initiate topics and contribute to the conversation equally. The latter can, in an aphasia context, also have a therapeutic objective. The move from clinician to client-centeredness also mirrors a shift at a societal level, as touched upon in the introduction and further elaborated in the next chapters. A person with aphasia using the healthcare system is no

⁷ Shared decision making is a part of the client-centred communication/care paradigm and is one among many terms (e.g. user involvement, patient participation, patient empowerment, citizen engagement, and expert patient) describing the active involvement of clients in healthcare as opposed to a clinician-centred approach (Tritter & McCallum, 2006).

⁸ Not only are interactional styles or communications named in terms of centeredness, the same is seen with care, therapy, goal-setting etc. Client-centeredness is used as being equivalent to patient-centeredness and person-centeredness here despite a discrepancy according to, for example, Hughes, Bamford and May (2008).

longer regarded as a patient, or at least should not be regarded as such. Instead, he/she is labelled as user or even consumer. Therefore, he/she must be involved in the intervention and not just be an object to receive healthcare.

The person with aphasia's ability to produce and/or understand language is restricted, and this fact can challenge and interfere with his/her interaction with communication partners including healthcare professionals such as speech-language therapists. The challenged interaction between a person with aphasia and healthcare professionals often restricts access to the services, because it is hard to give and receive relevant information about illness and treatment decisions. Therapy can be described in terms of principles and procedures, as seen above, but as Simmons-Mackie and Damico (2011) write, therapy is more complex, precisely because it is an interactive process with improvisations and spontaneous contributions from all participants. These factors make the therapeutic process difficult to control and equally complicated to investigate, but these are nonetheless important issues, since interaction can effect therapy outcome positively as well as negatively (Drew et al., 2001; Simmons-Mackie & Damico, 2011).

Outcomes of aphasia therapy seem to go beyond whatever the goals are for the therapy because of the influences from clinical interaction. The interactions have an impact on, and consequences for, the therapeutic activities and the participants. As mentioned, it is well known from research in, predominantly, medical interactions, that beneficial consequences can be established through interactions. The most important factor of the stated advantages is higher client satisfaction. With this follows fewer referrals, a decrease in symptoms, greater comfort, less distress and greater compliance to treatment (e.g. Drew et al., 2001; Lawrence & Kinn, 2012). Poor contact with the doctor makes it more likely that the patient will complain about malpractice, poor outcomes, etc. In addition, doctors report higher satisfaction and less frustration in their daily work, when adequate communication is present (Roter, Stewart, Putnam, Lipkin, Stiles & Inui, 1997).

In relation to people with aphasia, the impact of interactions is not documented in terms of outcomes, but rather topics such as how identity is affected in interaction have been researched. Simmons-Mackie and Damico (2008) conclude from their video analysis of corrections in aphasia therapy, that this interactional phenomenon can be a somewhat delicate matter, with implications beyond the linguistic task itself into areas such as self-esteem and identity. In addition, Horton's (2007) conversation analytic study of topic generation focuses on identity, where the clinicians' choice of topics in therapy is closely related to their perception of clients as someone having communication disorders and themselves as being therapists. Furthermore, a more recent study has

looked into what people with aphasia want (Worrall et al., 2011). The respondents raised issues such as greater autonomy, dignity and respect. These are all areas that impact upon how interactions in therapy are executed.

2.5.2 Measuring outcomes across the ICF domains

Since aphasia therapy has evolved from a more dominant focus on impairment to a holistic type of therapy also containing activity, participation, environmental and personal aspects, the outcome measures must naturally address all the areas targeted in therapy. The newer approaches deriving from this holistic paradigm (see 2.4.1) address consequences of aphasia in real life, which again call for outcomes that are ecologically valid (Brady et al., 2014, 2016). Outcomes monitored in the therapeutic settings are not sufficient evidence for generalisation of the therapy into various everyday settings is crucial as well as how the person adjusts to the new life with aphasia and his/her new quality of life (Helm-Estabrooks et al., 2014).

Since ICF is an accepted framework in viewing and working with people affected by aphasia in Denmark as well as internationally, the framework will equally serve as the primary structure for this section (Simmons-Mackie & Kagan, 2007; Threats, 2013; Villadsen et al., 2007). A primary outcome for aphasia therapy, outlined by the Cochrane review, is maximising the individual's ability to communicate (Brady et al., 2016) and therefore the authors state that their primary outcome measure is to measure functional communication. The American Speech, Language and Hearing Association (ASHA) states precisely the same overarching goal, but adds the sentence "thereby improving quality of life" (ASHA, 2007, p. 7). This could speak in favour of an outcome evaluation with broad perspectives fitting into the equally wide frame for newer therapy approaches. However, it does not mean that more specific outcomes as opposed to the broader outcome 'better communication and improved quality of life' are not, and cannot, be addressed (Threats, 2013).

Impairment based training will typically focus on the four language modalities (Helm-Estabrooks et al., 2014; Martin, Thompson & Worrall, 2008). These will be within the ICF component 'Body structure/body function'. Numerous tools and tests for initial assessments are seen in this domain, and some of them are likely to be used for making reassessments (Brady et al., 2016; Villadsen et al., 2007). The 2005 survey amongst clinicians by Simmons-Mackie et al. shows this category (linguistic/cognitive) to be the most prominent, reported by 45.5% of the participants. Whether this category precisely corresponds to the ICF domain of body structure and function is,

however, unclear, but the measures reported in the category correspond to what could be expected in this domain, for example, Western Aphasia Battery (Kertesz, 1982) and Boston Diagnostic Aphasia Examination (Goodglass & Kaplan, 1983). Moreover, the research outcome measures reported in the latest aphasia therapy Cochrane review reveal a majority of linguistic/cognitive measures (Brady et al., 2016). You could also argue that scales and questionnaires about depression such as Stroke Aphasic Depression Questionnaire (Sutcliffe & Lincoln, 1998) and Aphasic Depression Rating Scale (Benaim, Cailly, Perennou & Pelissier, 2004) could be a part of evaluating the impairment since depression is one of the neuropsychiatric consequences related to aphasia (Laska et al., 2007).

Activity and participation domains of ICF call for an outcome evaluation of, for example, functional communication and in general communication for all levels of life and not only for a functional purpose, as well as for evaluation of satisfaction and quality of life, amongst others. Looking at the Simmons-Mackie et al. (2005) study, they have a category of functional measures (23.5% report evaluation in these areas), but, presumably, some measures are reported under the category of subjective/qualitative, also corresponding with the activity/participation domains. In a later Australian study (Verna et al., 2009) much higher response rates are reported within categories similar to this (97.1%). Instruments such as the Porch Index of Communicative Ability (Porch, 1967), ASHA Functional Assessment of Communication Skills (Frattali, Thompson, Holland, Wohl & Ferketic, 1995); Communicative Effectiveness Index (Lomas et al., 1989) can be used to evaluate in this domain, but certainly also other types of instruments and informal questioning that link functional and daily-life goals to an outcome (Threats, 2013).

ICF's domain environmental factors could potentially also be a part of the evaluation outcomes of an individual course of therapy. Varna et al. (2009) report a category named Family-members' rating. While not having access to what this category specifically means, it can be assumed that it is the family members' rating of communication and other parameters of the person with aphasia and not necessarily the family members' own support, environmental circumstances etc. The Communicative Effectiveness Index (Lomas et al., 1989) is a good example of a scale involving significant others in rating the communication of the person with aphasia, but not with regard to how the significant other is affected (Verna et al., 2009). On the other hand, an instrument such as Carer Communication Outcome after Stroke (Long, Hesketh & Bowen, 2009) combines communication effectiveness from the significant others' points of view with questions about the impact of aphasia on the significant other. Outcome evaluation of environmental factors can

certainly also be done by the person with aphasia him-/herself. An example could be the Communicative Access for Stroke-3 (Kagan et al., 2012), where the person with aphasia, through a questionnaire, can rate satisfaction with communicative support, level of information etc. when staying at, for example, a hospital.

The last ICF domain, personal factors, refers to the person with aphasia's inherent personal premorbid conditions and is not linked to the particular health state causing aphasia. It could be gender, age, lifestyle, educational level, social background, personality, and coping strategies, among many others. This means that the premorbid factors should be assessed in relation to how they affect the therapy outcomes (Threats, 2013). A great deal of personal or demographic information would already be known prior to the outcome evaluation as a part of the anamnesis, but whether it is linked to outcomes later is unclear. Some of the more complex personal factors such as, for example, coping, can be assessed. However, there does not seem to be any specific instruments for outcome evaluation of aphasia therapy for this domain, but the Communication-specific Coping Scale (Douglas, Knox, Di Maio, & Bridge, 2014) and Ways of Coping Questionnaire (Folkman & Lazarus, 1988) are examples of less specific measures about coping. The framework Living with Aphasia: Framework for Outcome Measurement (A-FROM) (Kagan et al., 2007), an expanded and aphasia-adapted version of ICF has expanded precisely this personal factor's domain and made it also comprise "Inherent characteristics of the person, feelings, emotions, attitudes, and identity or sense of self" (Kagan, 2011, p. 218). The A-FROM questions are examples of outcome evaluation in this domain or derived domain, together with the assessment tool Assessment of Living with Aphasia (Aphasia Institute, 2013).

A-FROM and Assessment of Living with aphasia are also examples of instruments covering more than one ICF domain. It is likely that several of the aforementioned tools along with many others do that, but like these two together, instruments such as Therapy Outcome Measures (Enderby & John, 2015) and the modified version, Australian Therapy Outcome Measures (Skeat et al., 2003) directly aim to cover all domains. Additionally, there are many other measures that are used which are either specific to aphasia or of a more generic character. They are also likely to be used together with people with aphasia, if appropriate, when evaluating the therapy outcome in relation to the ICF domains and beyond.

To sum up, there are several outcome evaluation tools that can be used regarding aphasia in all the domains of ICF. Now, we will turn to outcome evaluations outside the domains of the ICF.

2.5.3 Outcome measures beyond ICF

There also exist several outcome evaluations focusing on issues beyond domains in the ICF. An example would be wellbeing and quality of life. The abovementioned Therapy Outcome Measure (Enderby & John, 2015) includes, in addition to the ICF domains, the concept of well-being in its measures, because the ICF framework has been criticised for being too narrow and not sufficiently comprehensive (Bornbaum, Doyle, Skarakis-Doyle & Theurer, 2013). Several newer instruments cover areas such as quality of life and other areas difficult to label in accordance to the ICF domains, such as Stroke and Aphasia Quality of Life scale (Hilari, Byng, Lamping & Smith, 2003), Communication Confidence Rating Scale for Aphasia (Cherney & Babbitt, 2010) and Visual Analog Self-Esteem Scale (Brumfitt & Sheeran, 1999). However, it seems to be difficult to precisely map many of the tools to the ICF domains or other categories, because often multiple purposes in each of the readymade measures can be identified.

One may also add to the above instruments many other formal measures and many informal or self-made types of instruments or informal dialogue between the clinician and the person with aphasia. Not only does the data from this thesis show this to be a meaningful way to assess therapy outcomes, but also participants in Simmons-Mackie et al.'s (2005) study report this way of evaluating outcomes. They categorise a good part of the clinician-reported outcomes as either being subjective/qualitative (19.6%) or vague (11.3%). The partly clinician-derived or informal measures, interviews and observations, could also belong to both of these categories,

Moreover, as already described above, outcome evaluations which can be labelled as clinically or functionally derived or client-defined, can be much more than this (Frattali, 1998b). Beyond ICF domains, there are also outcomes focusing on administration and finances, but they go beyond the scope of this thesis and will therefore not be described here. Hinckley (2010) mentions yet another area of focus for evaluation in stating that evaluation also focuses on form and production of language rather than the communicative intent in the interaction.

The breadth of what can, and is, evaluated after aphasia therapy almost certainly reflects the complexity of both the evaluation process itself and, not least, also the therapy process. Straus (2006:5) writes "Just as the intervention has proved difficult to define, its evaluation has been challenging." A significant amount of speech-language therapy, including aphasia therapy, could probably be categorised as complex (behavioural) intervention (e.g., Beeke, 2015; Craig et al., 2006, 2008; Johnson, 2015). Behavioural therapies such as aphasia therapies are, in general, more

complex than, for example, pharmacological or surgical treatments when it comes to active ingredients in the treatment, as well as the range of outcomes. Furthermore, the complexities should be considered in aspects beyond the intervention itself, such as, for instance, the participants, the delivery and timing of therapy (Brady et al., 2016; Craig et al., 2006, 2008). Capturing the outcomes of aphasia therapies is therefore likely to be complicated due to the complex interventions, individual characteristics of the clients' symptoms and consequences of aphasia, the service delivery models (e.g. if the ICF framework is used or not used) and many other aspects.

2.5.4 Types of outcome evaluation instruments

The way in which outcomes of aphasia therapy can be measured is generally through a number of formal instruments as well as more informal measures, as mentioned above. The tools or instruments used for outcome evaluation can both be specifically developed for measuring outcomes such as Therapy Outcome Measures (Enderby & John, 2015) and Australian Therapy Outcome Measures (Perry, Morris, Unsworth, Duckett, Skeat & Dodd, 2004). Another type of instruments, diagnostic tools, known from initial assessments of aphasia, is, at the end of a therapy course, administered again as a re-assessment (Verna et al., 2009). Here, for example, can be seen formal standardised aphasia batteries such as the Western Aphasia Battery (Kertesz, 1982) or Boston Diagnostic Aphasia Examination (Goodglass, Kaplan & Barresi, 2000). Other outcome measure tools reported in the literature are qualitative measures such as discourse or quality of life measures and a variety of client-reported outcomes measures (Simmons-Mackie et al., 2005; Irwin, 2012). In the last category, reported outcome measures from the significant other (e.g. CETI by Lomas et al., 1989), can also be seen.

Different surveys of clinical practice in aphasia show that, in some countries, the majority of speech-language therapists use tools specifically developed for outcome evaluation (for example, Australia according to Verna et al., 2009; Singapore from Guo, Togher & Power, 2014), whereas therapists in other countries such as, for example, Finland, primarily use dialogue and observations (Klippi, Sellman, Heikkinen & Laine, 2012). This is supported by (unpublished) observations related to this thesis, where formal tools are very rarely seen used in the outcome evaluation sessions. The study of Simmons-Mackie et al. (2005) shows a large number of formal tools measuring both linguistic skills and functional communication. Both the study from Australia and from Singapore also reveal an extensive use of the same measures used in North America. The studies from different countries show a lack of consensus amongst the therapists concerning what

measures should be used in outcome evaluation. Different therapists measure different aspects of therapy outcomes (Guo et al., 2014; Klippi et al., 2012, Simmons-Mackie et al., 2005; Verna et al., 2009). The authors ascribe this variation to the different therapy approaches used by the therapists. Furthermore, there is no consensus about what constitutes the actual outcomes of the clients.

The move away from health services that are provided in a more paternalistic manner, where the professional is the expert, to a more person-centred approach, seeing the input of the client and significant others as essential, has also changed what is demanded by outcome evaluations (Worrall & Wallace, 2015). The numbers of client-reported outcome measures have increased extensively during the latter years and are increasingly used in research as well as in clinical practice (Brady et al., 2016; Irwin, 2012). Helm-Estabrooks et al. (2014, p. 224) note, “SLPs should be aware that improvements that may have occurred during treatment may not be reflected in changes on standardized testing”. With this in mind, it seems a natural advancement for the therapists to expand the use of formal tests to qualitative tools, measuring real outcome measures and tools taking the clients’ own reports into consideration.

In general, there are a large number of tools for measuring outcomes reported in aphasia research studies that supposedly are also reflected in clinical practice (Brady et al., 2016). The many different tools and informal ways to measure outcomes, together with a lack of consensus of how to measure outcomes, a large span of what to measure and the general complexity in aphasia therapy and its evaluation, makes it hard to conclude what precisely could be considered outcome evaluation in aphasia therapy. This points toward the aims of this thesis of further exploration of how outcome evaluation is carried out in interaction and what rationales are behind them.

3. METHODOLOGY

Research within speech-language therapy is based on many different traditions, since the field originates from disciplines such as medicine, neurology, linguistics and education (Enderby & Emerson, 1996; Duchan, 2006; Tesak & Code, 2008). Within some, if not most, of these disciplines, we see a tendency towards quantitative methodologies. However, an increased interest in the perspectives and practices of, for example, healthcare providers and patient is observed, which Hammell (2001) ascribes to the philosophical changes in healthcare. This change from medical to social models is also observed in speech-language therapy (see 2.2.2) and is perhaps a reason for a larger proportion of qualitative studies being observed in journals of speech-language therapy studies. Simmons-Mackie & Lynch (2013) show the increase through a systematic search for qualitative studies in aphasia. They found only six studies published in the years 1993-1997, but 45 studies in the period of 2008-2012.

Since a main purpose of qualitative research is to understand the social world as seen from a particular person's or people's perspectives by capturing their voices and experiences, qualitative methodology and methods are relevant for this thesis (Johnson & Christensen, 2014). The methodological considerations and frameworks will be covered in the first parts of this chapter (3.1-3.2), followed by a description of the design and execution of the study (3.3).

3.1 Qualitative research as a paradigm

Within the modes of qualitative inquiry, naturalistic data is collected in natural and authentic settings through, for example, direct observation and interviews. Qualitative researchers seek to get close enough to the people and/or situation being studied in order to understand what goes on in greater detail. The aim is to capture what takes place and/or what people say, i.e. the perceived facts (Lofland, Snow, Anderson & Lofland, 2006). Qualitative studies are frequently characterised by emergent design that cannot be prescriptively set out in advance. The designs often specify an initial focus and initial plans for observing and/or interviewing, but require sufficient flexibility in order that the precise conduct of the exploration unfolds and emerges as the fieldwork progresses. This is to take account of the inductive nature of the qualitative, naturalistic inquiry (Cresswell, 2013).

Through data collection such as, for example, interviews or observations, behaviours and/or accounts of people in their natural environment are obtained. Such data collection in qualitative research provides otherwise inaccessible, and is useful for conducting, research when other methods are inadequate. Data is then described in detail and interpreted in terms of

sociological theory and human meaning. Through first-hand experience, truthful reporting, and quotations of actual conversations, qualitative research aims to gain a better understanding of how the participants derive meaning from their surroundings, and how their meaning influences their behaviour, all with the purpose of generating in-depth descriptions of organisations or events (Baszanger & Dodier, 2004; Johnson & Christensen, 2014). The in-depth descriptions in qualitative research are feasible because of its focus on a small number of cases. The studied object could be a specific social setting, such as a nursing home, speech-therapy clinic or a group of people and/or their interactions. The small sample size makes the qualitative findings unsuited for generalisation, but instead provide rich information, the so-called thick description (Johnson & Christensen, 2014).

The analytic paradigm of qualitative research is underpinned by postmodern philosophy appreciating multiple realities and recognising that research is value-bound and affected by time and context (Flick, 2002). Qualitative methodologies are concerned with the detailed description and analysis of social phenomena as they occur in natural contexts. With roots in the social sciences, anthropology and sociology in particular, qualitative methodologies include phenomenology, grounded theory, conversation analysis, ethnography, narrative enquiry and case study, among others. Today, qualitative methodology is used extensively in studies by psychologists, anthropologists and sociologists, but also, as mentioned, in speech and language therapy including aphasia (Ball, Müller & Nelson, 2014; Cresswell, 2013; Silverman, 2004; Simmons-Mackie & Lynch, 2013).

Simmons-Mackie and Lynch (2013) emphasise how well qualitative research works for exploring complex phenomena such as we see in communication and communication disorders. For the purposes of this study, qualitative research methodology was chosen to: 1) get insights into the participants' perspectives on and in outcome evaluation; 2) get detailed accounts of what outcome evaluation can be; and 3) explore how outcome evaluation is used for the involvement of people with aphasia in this part of the therapeutic course. The study draws upon qualitative methodologies and methods from ethnography, phenomenology and conversation analysis. The multi-method approach or triangulation was inspired by a quote ascribed to the cultural anthropologist Margaret Mead⁹: "What people say, what people do, and what they say they do are entirely different things" since different methods are preoccupied with either what people say, do or say they do (see 3.2.4 for more about data triangulation).

⁹ The quote, however, does not come directly from Mead herself. Fitzpatrick (2011, p. 80) describes it as "a simplification of extensive writing by Mead on the fieldwork of anthropologists" without any known origin of the exact wording.

This thesis focuses on clinical practice, namely the concept or phenomenon of *outcome evaluation in aphasia therapy* and especially from the participants' view (study 1: speech-language therapists; study 2: speech-language therapists, people with aphasia; study 3: speech-language therapists, people with aphasia)¹⁰.

3.2 Methodological considerations and framework

The relatively broad research questions together with the decision to take an inductive approach to the research led to the decision of an ethnographic starting point. Later, in the process of both defining the methodologies applied in this thesis and for collecting data, phenomenology and conversation analysis were chosen as the primary analytic frameworks for parts of the data collected from a more ethnographic point of view.

3.2.1 An ethnographic umbrella

Ethnography has its origin in Western anthropology back in the nineteenth century and is today a prominent qualitative method within social research into many disciplines, as, for example, nursing, medicine and education (Cruz & Higginbottom, 2013; Goodson & Vasser, 2011; Hammersley & Atkinson, 2007, Johnson & Christensen, 2014; Savage, 2000). Ethnography is a flexible and naturalistic research paradigm useful for understanding cultures, cultural perspectives and social practices. From its outset, "classic" ethnography primarily aimed at describing ethnic cultures (macro cultures) through the system of joint values, norms, religious beliefs, rituals, artefacts and practices used by its members to understand their world (Baszanger & Dodier, 2004; Hammersley & Atkinson, 2007). Today, ethnography is similarly used for studying micro cultures (for example, people living with aphasia in a South African township; Legg, 2010) or practices (for example, compensatory strategies in aphasia; Simmons-Mackie & Damico, 1995), which can be called applied ethnography (Baszanger & Dodier, 2004; Fetterman, 2008). The term institutional ethnography is also used for types of applied ethnography studying cultures or groups of people at work places (ten Have, 2004).

Fieldwork and participant observation were, and still are, central strategies for gathering data about a culture or practice: "the ethnographer participates, overtly and covertly, in people's daily lives for an extended period of time, watching what happens, listening to what is said, asking

¹⁰ In both studies 2 and 3, significant others are present, but they are not paid as much attention in the research as they could have been.

questions, in fact collecting whatever data available to throw light on the issues with which he or she is concerned” (Hammersley & Atkinson, 1987, p. 2). The ethnographic researcher is frequently a part of the investigated culture/setting for a rather extensive period to build a relationship to the researched culture. This immersion into the setting allows the ethnographic researcher to collect sufficient data via observations or field notes of experiences and thoughts, but also other types of data, in order to describe the studied culture or group through his/her own lived experience, i.e. the personal knowledge gained by the researcher after first-hand encounters with, and involvement in, the studied culture rather than distant or theoretical explanations (Baszanger & Dodier, 2004; Fetterman, 2008; Johnson & Christensen, 2014). The immersion into the culture can be accomplished in many ways, and is often a combination of different field entries and types of data. Participant observation, research interviews, informal conversations and the collection of documents and artefacts are common procedures in studying cultures (ten Have, 2004). The different types of data, such as, for example, observations, artefacts, informal conversations, and field notes of own thoughts, individually represent a piece of the lived experience and together form the holistic description of the culture or practice. Each of the pieces of data (for example, an observation of an activity or a conversation with a person) cannot, in itself, describe the culture, but, by piecing it together, it is possible (Baszanger & Dodier, 2004; Hammersley & Atkinson, 2007; ten Have, 2004).

Ethnographic procedures share many features with other methodologies when it comes to its multiple types of data collection. The methods eventually used in this study, semi-structured qualitative interviews and video-recorded participant observations, are embedded in the types of data also seen in ethnography. What separates ethnography from the conversation analysis and phenomenology described below is the way in which the culture or phenomenon is both analysed and eventually described. Where phenomenological or conversation analytic aspects of projects such as these each contribute to a part of the whole picture, ethnography allows the researcher to tell both a narrative and integrated story about the studied object, based on observations, stories, interviews, artefacts, and so forth (Baszanger & Dodier, 2004). The researcher’s own lived experiences are central to this story (ten Have, 2004), whereas both conversation analysis and phenomenology are centred round the participants in the culture in a way better suited for the aims of this thesis (see 3.2.2; 3.2.3). Therefore, the ethnographic focus ended up serving as an umbrella term for the first stages of development of the project and data collection. Through the ethnographic procedures, substantial knowledge was pieced together from participant observations, informal

conversations, documents about institutional practices of outcome evaluation etc., making it possible to refine the research questions, create an interview guide and identify what to video record for further investigation. It means that the initial ethnographic point of origin was later left for the sake of the two other methods and the parts of the data collected initially were never used for writing an ethnography of outcome evaluation in this thesis, but instead the ethnographic data served as a thorough entry into the phenomenon of, and participants in, outcome evaluation.

3.2.2 Phenomenology

Phenomenology dates back to the beginning of the last century with German philosopher Edmund Husserl as the ascribed primary founder, but German philosopher Martin Heidegger, and French philosophers Maurice Merleau-Ponty and Jean-Paul Sartre took part in developing phenomenology as a philosophy and later research approach. Later, many of them also went on and developed other ideas and methods (Smith, 2013; Tufford & Newman, 2010). With phenomenology, Husserl and like-minded scholars wanted to create an opposition to the claim of an objective truth as was then prevalent in positivistic philosophy and research. For Husserl, the essence of phenomenology was the questioning that took place. He described it as “a way to see the world anew as it really is rather than as it is constructed” (Caelli, 2000, p. 371). Consciousness and its structures are rooted as experiences of individual people (first-person perspective should be studied for the effort of describing and deciding the nature of the phenomenon through access to the lifeworlds of people. A central structure in an experience is the intentionality being directed toward the phenomenon (Flick, 2002; Smith, 2013). The phenomena can be defined as “what appears to us — and its appearing” (Smith, 2013).

According to phenomenology, the world as it is experienced (lived experience) by the subject (the participant) is the only real world or the way of understanding the world. It means that if one wants to grasp the real nature of a phenomenon, it needs to be researched from the point of view of the subject, i.e. the reality that counts is the one seen by the individual human being. From the phenomenological point of view, the subject and world provide mutual meaning and legitimacy. The subject can only be seen as related to the world, but conversely, the world will only make sense if the phenomena in it are experienced by the subject. With this stance, phenomenology dismisses the ideas of objectivism regarding what the world is and that it must be seen in the absence of the subject (Moustakas, 1994; Zahavi, 1993). Since Husserl, phenomenology has evolved widely in different directions into being the foundation for many different schools of thought such as

existentialism, phenomenological psychology, phenomenological sociology, gestalt psychology etc. (Käufer & Chemero, 2015). What once was just named phenomenology is today typically divided into different types, each with distinct features. Smith (2013) describes seven distinct types:

- Transcendental constitutive phenomenology (studies how objects are constituted in pure or transcendental consciousness, setting aside questions of any relation to the natural world around us)
- Naturalistic constitutive phenomenology (studies how consciousness constitutes or takes things in the world of nature, assuming the natural attitude that consciousness is part of nature)
- Existential phenomenology (studies concrete human existence, including our experience of free choice or action in concrete situations)
- Generative historicist phenomenology (studies how meaning, as found in our experience, is generated in historical processes of collective experience over time)
- Genetic phenomenology (studies the genesis of meanings of things within one's own stream of experience)
- Hermeneutical phenomenology (studies interpretive structures of experience, how we understand and engage with things around us in our human world, including ourselves and others)
- Realistic phenomenology (studies the structure of consciousness and intentionality, assuming it occurs in a real world that is largely external to consciousness and not somehow brought into being by consciousness)

The approach applied in this thesis (chapters 4 and 6) is closest to hermeneutical phenomenology through its description of the speech-language therapists' experiences of why they are conducting outcome evaluation and for what purposes.

Based on the philosophical assumptions described above, phenomenology provides principles for inquiry about humans and their lifeworlds (Hinckley, 2014). According to an empirical phenomenological approach, the purpose of doing phenomenology is “to determine what an experience means for those who have had the experience and are able to provide a comprehensive description of it. From the individual descriptions, general or universal meanings are derived, in other words the essences or structures of the experience.” (Moustakas, 1994, p. 17).

Experiences of a phenomenon can be overlooked by the researcher or even by the researched participant, but in phenomenological lifeworld, the studied phenomenon comes alive as both transparent and obvious, but at the same time rich and complex (Schiermer, 2013). Hinckley (2014, p. 93) writes that phenomenology aims to “appreciate meaning in the mundane.” Phenomenology is described as a reflective enterprise, where the subjects are asked to reflect upon everyday experiences (Toombs, 2001). The phenomenological account will be “explicit assumptions” about everyday phenomena (Hinckley, 2014, p. 94), for example, in this thesis the regular occurring task at work in aphasia clinic outcome evaluation. This phenomenon might be taken for granted by the speech-language therapist, but when being enrolled in phenomenological research he/she will become conscious about the phenomenon. Precisely this narrative representation of the world has been criticised as being data constructed for the purpose of the research and not containing any “truth” useful for insights beyond the context (Miller & Glassner, 2004; Silverman 2001). However, the phenomenological researcher would regard the meaning and positions of the subject not as any truth, but instead interpretations of observed phenomena that are again interpreted by the researcher. Furthermore, it must be acknowledged by both the researcher and researcher consumer that data typically answers researcher-generated questions, meaning data is a co-constructed product (Hinckley, 2014; Holstein & Gubrium, 1995). Hinckley (2014, pp. 95-96) summarises the three key elements in phenomenology as: 1. *The first-person accounts*, i.e. in order to study consciousness of phenomena the subjects need to be asked or report themselves; 2. *The subjects’ lifeworld*, i.e. how do the participants experience the world, and 3. *Reflections*, i.e. the use of reflections to look upon past experiences in order to create meaning.

Aligning with the aims of the thesis of taking the participants’ stance in the study of outcome evaluation, phenomenology is interested in the meaning and experiences of those participating— in this case the speech-language therapists participating in outcome evaluation. Unlike, for example, conversation analysis (see 3.2.3), phenomenological research makes use of data specifically produced for the sake of the research and therefore is not necessarily naturally occurring. The primary way of collecting data in phenomenological research is through qualitative interviews (3.3.3). However, other types of data such as, for example, self-reported accounts (oral or written) could also be data useful for phenomenological research. Studies employing interviews are, however, not necessarily phenomenological studies, since interviews can be data in other types of research. In fact, a recent study of qualitative research in aphasia reveals uncertainty with regard to what analytic methods are used in 30% of qualitative aphasia studies published between 1993-

2013 (n=78), of which 96% consisted of interviews (Simmons-Mackie & Lynch, 2013). Research can be seen as phenomenological in two ways: First, its research aim is to describe a phenomenon as it is made meaningful by people experiencing it, and second, by its analytic method. Studies 1 and 3 have, in this thesis, used a type of thematic analysis as described by Braun and Clarke (2006) (see 3.3.4). In itself, this analytic framework is not declared to be phenomenological as, for example, interpretive phenomenological analysis (e.g., Smith & Osborn, 2003). However, thematic analysis ad modum Braun and Clarke *can* be used for a more phenomenological inspired analysis such as in this thesis (see chapter 4).

Related to qualitative research, but in particular phenomenological research, is the concept of bracketing. Tufford and Newman (2010) explains it as being: “a method used by some researchers to mitigate the potential deleterious effects of unacknowledged preconceptions related to the research and thereby to increase the rigor of the project” (p. 81). Bracketing, also called phenomenological reduction or epoche, are different precautions the researcher can take to ensure his/her preconceptions, feelings, biases, values, beliefs etc. are being addressed during the research process in order not to play – or at least play a visible role – in the process and results of it. Despite calling it a method, Tufford and Newman (2010) elaborate the uncertainty of what constitutes bracketing and when to do it in the research process. However, the idea for the researcher is to bracket his/her own different preconceptions by becoming aware of them. It could, for example, be via a reflexive journal, or as in the study via debriefing and discussion of different aspects of the research process with others (supervisor, fellow PhD students and other researchers at conferences, meetings, and data sessions), and all with the purpose of creating better and more rigorous research findings.

3.2.3 *Conversation analysis*

Conversation analysis is a method to study interaction. It was founded by the American sociologist Harvey Sacks back in the 1960s together with colleagues Emanuel Schegloff and Gail Jefferson (Heritage, 1984a), and was inspired by ethnomethodology and its founder and mentor of Sacks, Harold Garfinkel, Sacks’ objective was to create a research method for accessing genuine insight into human conduct (Heritage & Clayman, 2010; Hutchby & Wooffitt, 2008).

Both ethnomethodology and conversation analysis were created in opposition to more traditional branches of sociology. At this time, quantitative methods, experiments and interviews prevailed, giving an impression of, for example, a culture or social life somewhat different to the

lived experience due to such methods and the use of predefined sociological categories, whereas ethnomethodology and conversation analysis solely built their analysis on naturally occurring data (Heritage, 1984b). In many ways, the two fields of sociology, ethnomethodology and conversation analysis resemble each other. “Ethnomethodology seeks to recover social organization as an emergent achievement that results from the concerted efforts of societal members acting within local situations.” (Maynard & Clayman, 2003, p. 174). Central to ethnomethodology is the focus on the different methods that the societal members use in producing and acknowledging social activities. Conversation analysis has a focus on the “description and explication of the competences that ordinary speakers use and rely on in participating in intelligible, socially organized interaction. At its most basic, this objective is one of describing the procedures by which conversationalists produce their own behavior and understand and deal with the behavior of others.” (Atkinson & Heritage, 1984, p.1). The concept of conversation does not, however, fully cover what conversation analysts are interested in and often the concept of talk in interaction is used instead (Schegloff, 1987; ten Have, 1990). However, today conversation analysis is not only used for studying talk in interaction, but also multimodal, non-verbal and online chat interactions (e.g. Andersen, 2015; Klippi, 1996, 2015; Pilesjö & Rasmussen, 2011). Both ethnomethodology and conversation analysis are interested in social orderliness routinely produced by the participants in any given everyday life context, with conversation analysis specifically studying this order in conversations (Liddicoat, 2007). The implication of this is that only what can be studied in and through interaction is of relevance and not, for example, speculations about the inner states, cognitive abilities, emotions of the participants if they are not displayed as oriented towards by them (Sidnell, 2010).

Conversation analysis is an empirically grounded method with a purely data-driven approach to naturally occurring data collected from everyday interactions, in mundane as well as institutional settings (Hutchby & Wooffitt, 2008; ten Have, 1990). Back at the start of conversation analysis, for Sacks it was important to study mundane conversation in its many natural settings and hence confront conventional sociology, preoccupied with large-scale studies of institutions. Instead, he argued, social order can be found at all points. Sacks proved the details of conversational organisation gave an understanding of the way people do things and the different methods they use for making order in their social affairs (Sacks, 1984). However, the same detailed look has also been applied to institutional interaction and has contributed to what is known as applied conversation analysis (Antaki, 2011; Richards & Seedhouse, 2005). With the same rigorous look at data, this stream of conversation analysis also pays attention to other types of phenomena as well as

using the insights to inform and educate the interlocutors, professionals as well as clients (e.g. Beeke et al., 2015; Lock, Wilkinson & Bryan, 2001).

The data used for conversation analytic studies are typically video recordings, taking over from audiotaped recordings, the primary data source back in the 1960s in Sack's first studies. Very detailed transcripts are made of the recordings in order to have this as an additional tool for the process of analysis (Jefferson, 1984). However, the recordings are still regarded as the primary data with the transcripts functioning as a helping tool (Sacks, 1984). Some of the transcribed features are perhaps not even apparent to the naïve listener, such as, for example, micropauses. Furthermore, the transcripts are shown together with the analyses in articles using conversation analysis, which provide the readers with insight into the analysed objects (ten Have, 1990).

With the stated aims of investigating the organisation of everyday activities as they are accomplished in and through interactions, conversation analysis can be used for in-depth descriptions of actions we, as human beings, take part in all the time (Drew, 1984). In and through participants' interaction in social action, for example, greeting, assessing and agreeing is created (Hutchby & Wooffitt, 2008; Liddicoat, 2007). Sacks foregrounded the machinery of interaction when describing the reoccurring building blocks across many types of interaction (Sacks, Schegloff & Jefferson, 1974). Studying social interaction in conversation analysis is performed through uncovering the participants own methods for constructing and interpreting their interaction. The nature of turn taking between the participants is central here, i.e. how they systematically organise and orient to the resources of the turns constituting the orderliness and sequential organisation in and during the interaction. Conversation analytic findings can lead to the discovery, description and analysis of patterns and practices in interaction. These findings are either presented as collections of reoccurring patterns or phenomena in often larger collections of data (as seen in study 2, chapter 5) or via descriptions of extended sequences showing specific analytic points (as in study 3, chapter 6) (Hutchby & Wooffitt, 2008).

As mentioned, order at all points is a key assumption in conversation analysis. This order is reflected in how the interaction is carried out by the participants, where patterns are seen repeated and oriented towards during many types of different interaction (Psathas, 1995; Sacks, 1984; Schegloff & Sacks, 1973). This approach to data can be regarded as emic, i.e. the analyses are made with the perspectives of the participants (Hutchby & Wooffitt, 2008). At the same time, the orderliness in conversation demonstrated by the participants is also central for the conversation analyst, since the so-called machinery means that the researcher draws on a coherent theoretical

and analytic framework together with a growing number of detailed descriptions of interactional phenomena from many areas of interaction when looking into his/her own data. However, conversation analysis has been criticised for being too interpretive and not sufficiently analytical. Nonetheless, the arguments or proofs for the analytic point are given through the next turn proof. Here the analyst makes sure the finding is based on how the participant treats and thereby understands the previous action, and not as a result of the researcher's interpretation, despite it being acknowledged and analysed by the researcher (ten Have, 1990).

Further support of the analysis is provided through: 1) the transcript of the interactional sequences always being available, and 2) group work or so-called data sessions with peers (Sidnell, 2010; ten Have 1990, 2007). Furthermore, the conversation analyst draws on his/her membership knowledge, namely the experience of interacting in different kinds of contexts as well as being a member of society and perhaps also having knowledge about the specific setting for the studied interaction (e.g. familiarity with aphasia therapy) (Hutchby & Wooffitt, 2008). In this study, former clinical experience together with the ethnographic immersion into the participating clinics and their procedures of outcome evaluation provided membership knowledge. When looking at the data, the analyst employs her/his membership knowledge to understand what the participants are accomplishing (ten Have, 2002). Through the so-called next-turn proof procedure, the researcher studies how the interlocutors in the data display an understanding of what the prior turn was about (Hutchby & Wooffitt, 2008). In this sense, the conversation analyst is not seen to interpret, but is instead involved in so-called embodied recognition (Garfinkel, 1967, 2002). The non-interpretive approach via next-turn proof procedure can be regarded as a type of bracketing (3.2.1). The researcher attempts to see the world as it is without preconceptions. Garfinkel (1967, p. 36) wants to describe the world as it is: "the socially standardized and standardizing, 'seen but unnoticed', expected, background features of everyday scenes."

During the past decades, conversation analysis has been a prominent method to study interactions involving people with aphasia (Wilkinson, 1999a, Antaki & Wilkinson, 2012). Due to great variations in severity, symptoms, communicative skills as well as other parameters, it is rather difficult to make general assumptions about how aphasia affects interactions. In short, central issues researched in mundane everyday conversation such as sequentiality, repair, topic organisation and turn taking (Heritage, 2004) are equally seen scrutinised in interactions between people with aphasia and their partners or other interlocutors (e.g. Goodwin, 2003; Laakso & Klippi, 1999; Wilkinson, 1999b). Interaction in a setting such as aphasia therapy is called institutional or clinical

interaction (e.g. Horton, 2007; Lindsay & Wilkinson, 1999). It often differs in systematic ways from mundane conversation with, for example, peers, since it is situated in a context defined by certain structures and premises, but with the participants using resources from mundane interactions (Wilkinson, 2004). The interaction between the participants will orient itself to this specific context, but also rely on interactional practices from everyday communication (Hutchby & Woofitt, 2008). Drew and Heritage (1992) have accentuated features that often distinguish institutional interaction from mundane interaction, drawing on results from various dyads such as patient/doctor and defendant/judge: Institutional interaction involves the participants in goal-oriented behaviour relevant to the specific institutions. It means what is performed in the office of the speech-language therapist with the person with aphasia is recognised or acknowledged as speech and language therapy (assessment, therapy etc.) by the participants. Another feature is the involvement of constraints on contributions in the given context. For example, the institutional categories 'client with aphasia' and 'speech-language therapist' will invoke specific interactional actions such as the speech-language therapist taking the lead in clinical interaction, because that is what all participants expect. Lastly, in institutional interaction entailment of special inferences can take place. When it comes to aphasia therapy, it could mean remarks usually interpreted as innocent in ordinary conversation are perhaps treated as something problematic or threatening. These common features of institutional interaction are seen in the actions mentioned above (turn taking, repair etc.) as well as in lexical choice (Drew & Heritage, 1992).

Results from studies on the interaction between speech-language therapists and people with aphasia support findings from other types of institutional interaction as well as revealing interactional patterns also seen in mundane conversation. It is often observed in combination with atypical behaviour caused by the aphasia. Examples of such are the central position of repair, presumably because of the high prevalence of 'errors' such as word searches, incorrect naming and misunderstandings in aphasic talk. Usually repair is done fast, often within the same or maybe the next turn, to ensure that the conversation can continue with the least disruption (Kitzinger, 2013). When aphasia is present, repair is often lengthy and troublesome, since the source of the repair usually continues to be problematic (Antaki & Wilkinson, 2012). In this way, repair becomes a substantial part of the conversation, where the non-aphasic speaker perhaps even prolongs the repair sequences by continuing to guess or even start practising missing words (Lindsay & Wilkinson, 1999). Lindsay and Wilkinson's (1999) study revealed significant differences between therapists and significant others as interlocutors. The therapists generally tried to diminish the repair

sequences by, for example, paraphrasing the troubled topic/word intending in order to not let it disturb the rest of the conversation. However, quite the contrary was observed with the significant others, who often went into prolonged repairs by asking ‘what?’ and chasing the answer. Simmons-Mackie and Damico (2011) refer to results showing the therapists controlling topic introduction, turns and interpretation of meaning, evaluating their clients’ performance, requesting known information and often talking more than the clients. However, an older study by Silvast (1991) found that, in the interactions she studied, the people with aphasia talked the most, but the conversation was still regulated by the speech-language therapists through topic initiations, questions for clarifications and checks of understanding.

By describing mundane activities, such as outcome evaluation, in the aphasia clinic via the clinical interaction taking place during outcome evaluation, the conversation analytic parts of this study provide the participants’ perspectives of what is outcome evaluation and how clients are becoming involved in such.

3.2.4 Triangulation

As described earlier, the starting point of this thesis’ methodology was anchored in ethnography with multiple data collection methods (see 3.2). The plan from the beginning was to make more general observations with field notes in the clinics, when the opportunities were there to video record sessions of pre-planned outcome evaluations, collect documents, and subsequently interview the speech-language therapists participating in the videos. The later choice of not writing up an ethnography using the different types of data that were collected, did not rule out the opportunity of using the data, though not all, for not only membership knowledge as mentioned in 3.1.3, but also for triangulating the findings. The methodologies behind the analyses (3.1.1-3.1.3) are alike in terms of taking the participants’ perspectives. Nevertheless, they differ in characteristics such as, for example, the nature of data (interviews vs. video-recordings), focus area (meanings/emotions vs. behaviour) and aims (description of how the person experiences a phenomenon vs. description of how a phenomenon is constructed). A phenomenological type of research is often labelled as emotionalism, where the participants’ views, emotions and experiences are in focus. It is contrasted with constructionism, which conversation analysis can be characterised as being where all participants are central to the analysis via how they construct their social worlds and understandings in and through interaction (Silverman, 2001). This means that, through phenomenological studies, one type of findings will be created, i.e. reported lived experiences and opinions of the participants

(accounts of lived experiences), whereas the findings from conversation analysis will shed light on how the lived experiences are constructed by the participants 'in vivo'. In this study, the phenomenon of outcome evaluation is not only described through how the speech-language therapists see it, but also how it is constructed in interactions between the participants in the outcome evaluation.

A major reason for using the different methods is to be able to triangulate what is said about outcome evaluation in aphasia therapy with how it is carried out in and through interactions acknowledging that the 'what is said' is only represented by the speech-language therapists in the study and not the people with aphasia. Goffman (1989, p. 131) writes about triangulation as: "I don't give hardly any weight to what people say, but I try to triangulate what they are saying with events." This might be an overly harsh way of putting it, but at least the validity of a description of a phenomenon is increased by triangulation. The triangulation of methods will compensate for eventual weaknesses in one method by using one or more methods to gather data about the same topic/phenomenon.

Triangulating data can be used for validation and corroboration of findings. However, in this study, it rather serves the purpose of providing a richer and more multifaceted account of the phenomenon 'outcome evaluation in aphasia therapy' from the participants' points of view and actions. The use of more than one method will likely facilitate a deeper understanding (Denzin, 1978; Patton, 1999). In this sense, the triangulation in this thesis both concerns the internal findings from the different studies as well as the external, meaning that the sparse existing findings about outcome evaluation in aphasia therapy (e.g. Simmons-Mackie et al., 2005, Verna et al., 2009) can be triangulated with the present findings. Different types of triangulation have been described in the literature, including methods triangulation, triangulation of sources, analysts' triangulations and perspectives/theories triangulation (Denzin, 1978; Patton, 1999). Two of these methods suit the type of triangulation intended in this project, namely methods triangulation with the use of different types of method to enrich the phenomenon, and perspectives/theories triangulation covering differences between the used methodologies as well as the involved participants. Therefore, triangulation with different methods and participants has, in this project, enriched the exploration of the studied phenomenon, but has, however, also forced the researcher to expend time and energy on different types of research methodologies and methods, which perhaps means less stringency.

3.3 Design and execution of the study

Data collection started in November 2010 and continued until August 2011, a total of 10 months. In the remainder of this chapter, the process from the planning stage until data analysis is described.

3.3.1 Participants and setting: selection criteria, recruitment and overview

From the outset of the project, no criteria were set with regard to numbers of participating clinics, speech-language therapists and session of outcome evaluations. The aim was instead to reach a level of saturation for the different types of data. Since collecting data from multiple sites during a period was not feasible, contact with the different clinics was made individually. Since the vast majority of speech-language therapy clinics in Denmark are public, a decision to only involve those was taken. The composition of the clinics was considered, but without specifically calling it purposive sampling. The four clinics contacted were known to have worked consciously with outcome evaluation, though more clinics would have fallen under that criterion. All four locations agreed to participate, some immediately, while others were visited to explain the project and data collection methods for managers as well as clinicians. Two clinics are situated to the west of Denmark, and two to the east. Three clinics were operated by the local municipality, but offered their services to a broader area of surrounding municipalities, one was anchored in the region (i.e. county) and also serving several municipalities. At the time of data collection, there were, according to a confederation) of public speech-language therapy clinics (Danske Tale-, Høre-, & Synsinstitutioner, approximately 20 clinics. The individual speech-language therapists were self-selected and hence only participated if they wanted to in agreement with the clinic managers. No selection criteria were applied to them. In total, 13 therapists gave consent, but eventually only 12 provided data for the project. Of the people contacted initially, the participating therapists were generally known to me, since the population of aphasia therapists in Denmark is rather small. It should be acknowledged that potentially this would have affected recruitment and data.

The therapists themselves recruited the participants with aphasia. They were provided an information sheet about the project and an informed consent form. People with aphasia could contact me to hear more about the project, although only one did so. To what extent the therapists were gatekeeping, i.e. keeping me away from certain people with aphasia, is hard to say. However, during the process nothing indicated this, since a broad range of people with aphasia (n=28) in all ages, with different types of severities and aphasia, after different types of aphasia therapy were

recruited. In fact, one of the therapists in clinic IV in particular, planned her schedule with several outcome evaluation sessions in one day, since I had to travel a long way to get there.

In 14 of the total of 33 sessions, significant others participated, in most cases family members as partner or parent, but in one instance, it was an occupational therapist, who had a current supportive role for the person with aphasia. Despite the self-selection of therapists, eventual gate keeping and the lack of more or less conscious sampling strategies, this had no influence on the analyses made. At the time, the greatest challenge experienced was to remain in contact with the therapists in order for them not to forget to get in touch me at the point where the video recordings of scheduled outcome evaluation sessions had started in order for me to come and observe and record. I selected an individual in each clinic whom I repeatedly contacted because I trusted them the most to keep the ball rolling in their clinic. Table 1 contains an overview of the clinics and participants as well as the only personal information asked of the therapists, i.e. years of experience in aphasia therapy, mainly asked as an opening question in the interviews. The letter and number codes are used for the purpose of anonymising the participants as well as referring to them in the findings.

Table 1. Overview of participants in the study. Codes from this table are used in reference to data, e.g. IV-I-21b is referring to something said/done etc. in clinic IV with SLT I and client 21 in the second (b) evaluation.

Clinic-ID	SLT-ID	Years of experience in aphasia therapy	PWA-ID (letters indicate if seen more than once)	Duration in minutes	Other participants
I	A	25	1	50	Wife
			2a	60	Occupational therapist
			2b	25	-
			3a	55	Wife
			3b	60	Wife
	C	1	4a	70	Husband
			4b	50	-
			4c	70	Husband
II	D	6	5	50	-

			6	8	Group + other SLT
			7	9	Group + other SLT
			8	7	Group + other SLT
			9	14	Group + other SLT
			10	11	Group + other SLT
			11	7	Group + other SLT
			12	3	Group + other SLT
	E	3	13	10	-
			14	10	-
			15	7	-
F	11	16	50	-	
III	G	8	17	60	-
			18	40	-
	H	3	19	(60)	-
			20	(50)	-
IV	I	3	21a	30	Mother (stepmother?)
			21b	20	Father
	J	9	22	45	Husband
			23	45	-
			24*	50	Wife + SLT K
	K	11	24*	50	Wife + SLT J
	L	Not asked	25	50	Wife
			26	40	Mother
			27	45	Wife
			28	45	Wife

* PWA 24 is noted next to two therapists because both were interviewed. I did not see SLT K in other situations, whereas SLT J was seen with other clients. Therefore, outcome evaluation with client 24 and wife was only seen once. However, in study 2 a total of 34 sessions are reported due to this error. Many of sessions with SLT D were also made with another SLT, but she was not interviewed because she retired during the data collection period.

3.3.2 Ethics

Many decisions regarding research ethics are to be made before and during a research project. Aside from more obvious decisions about ethical approval and informed consent, many speculations and

concerns came about when entering a field for research of which I once was a part as a speech-language therapist. However, looking back, only the relationship with one therapist was challenging in that sense, despite following former colleagues and students. This therapist, whom I had not previously known, was relatively newly educated and continuously asked for advice and my assessment of her practice. This was managed either by talking to her as a peer colleague or simply by telling her that I was not able to advise and she was encouraged to seek assistance elsewhere.

After consulting the ethics department of the University of Southern Denmark, the project was not registered at the Danish Data Registry since no personal information compromising the anonymity of the participants was recorded. However, informed consent was sought and given by all participants. A written form was first presented to people with aphasia prior to the data collection and later again explained, if necessary, by the researcher, before they signed it. The consent form included information about the project, what the data would be used for and who had access to it, along with the anonymization of participants, and the right to withdraw at any time. Participating significant others and speech-language therapists gave oral consent after being presented with the same information. Throughout the process, the data was encrypted and, when not in use, stored in locked cabinets according to the university's rules.

3.3.3 Data collection

When planning the initial stages of data collection it was necessary to consider what methods would best frame research questions and give the best possible data for analysis. An inductive stance was taken and ideas of different types of data were considered. Hence, as described above, an ethnographic-inspired data collection began and was evolved over time into the use of two different methodologies; conversation analysis and phenomenology, and a combination of these (see figure 1).

Capturing data from the field study, for example, field notes and video recordings are crucial in ethnographic-inspired research in order to have “*academically adequate evidence*” (ten Have, 2004, p. 109). The data logging, however, needs to be done in ways that do not disturb or interrupt the activities or culture being studied (Emerson, Fretz & Shaw, 2011; ten Have, 2004). Traditionally, note taking has been the primary source for carrying out the field observations, but technical developments have, over the years, made it possible to also use video recordings for this purpose. A combination of traditional fieldwork and video ethnography has created a bridge to

research methodologies such as ethnomethodology, that are closely related to the conversation analysis described above (4.1) (ten Have, 2004).

Parts of the study were pilot tested in order to make corrections prior to, and better decisions in, the actual data collection. The whole period of observing in the clinics directed the choice of what was relevant to video record later in the process together with a video-recorded session of outcome evaluation with SLT B and a person with aphasia. The pilot recording could have been a part of the actual data set, but technical problems with formatting the video hindered this. After the recorded session in particular, decisions were taken about how to be able to get the best possible recordings without disturbing (i.e. via handling the camera) the sessions too much. Prior to the interviews of the participating therapists, the interview guide was tried out and discussed with a therapist colleague, and subsequently altered according to the experiences that took place.

Figure 1. Chart of order/progression in data collection.



Observations, field notes, documents and presence: As mentioned, the data collection for this study contained ethnographic data never used in the writing up of the research reports. Nonetheless, the knowledge gained during that process has partly formed the researcher's membership knowledge in accessing the rest of the data for analyses. This data consisted of: 1. *Observations with field notes* (Pure observations without video recordings, documented with field notes; observations with video-recordings (see below), also documented with field notes). The non-recorded observations were primarily relating to therapy, both with the clients above from the evaluation settings as well as other clients, whereas the majority of outcome evaluations were recorded. 2. *Artefacts in the form of documents* (Documents either requested by the researcher or referred to by the therapists). Documents such as written procedures, evaluation forms, homemade tools for evaluation etc. were gathered, but their nature differed from clinic to clinic. 3. *Presence* (The researcher being present at the clinics for whatever activities were going on including informal chats with the therapists participating and their colleagues, e.g. over lunch). This type of participation/observation gave a

great deal of insight into the clinics' culture. Inevitably, the presence created a great deal of talk about outcome evaluation amongst and with the employees.

This type of data collection was performed in the beginning of the process. At that time, the whole project was still evolving, and hence the observations, in particular, were used for deciding the further course of data collection. A notable issue present at that stage was the differences between “pure” observations (with field notes) and recorded observations. Accordingly, a major question at that time was: What would be least disturbing to the naturally occurring activities I wanted to observe and what would the participants accept regarding my presence? It was, however, impossible to answer those questions before entering the field. Already by the pilot study, I discovered both clients and therapists felt uncomfortable being filmed. Not that this was noticed in the actual situation, but it was reported after the session. Would it impact upon the accomplished activity? My guess was probably not, but I would have to ask the participants. Writing field notes could also cause a disturbance, though the researcher always has the opportunity to write notes after the actual observations. In my case, I did not consider this option, since I wanted to capture smaller details, such as exact sentences/phrases, and it would be impossible to remember those if writing notes afterwards. In addition, as Emerson, Fretz and Shaw (2011) note, the postponement of field note writing may dilute the information gathered. Another argument that would call for writing notes contemporaneously is that clients in the particular settings are used to note taking as a speech-language therapist often notes answers and observations down during therapy. Despite this, I had doubts, because the informants would feel they were under surveillance or because a cognitively impaired client may be too disturbed by note taking. The former concern would not be removed by choosing the camera, but if I had experienced the latter, I would probably have stopped taking notes. Furthermore, Emerson, Fretz and Shaw (2011) state that field notes involve inscriptions of social life and social discourse, but will always be a reduction or an account of the real world, that I had an intention to study.

Video recordings: After a period of observation, a decision to video record what the speech-language therapists had announced as being outcome evaluation was taken. Prior to the outcome evaluation session, the person with aphasia was informed either verbally or, in some clinics, they had received a written notice, generally if the significant other was also invited. This type of session could take place after any course of aphasia therapy, e.g. group therapy, individual therapy or a

course involving significant others. This could evolve as the final outcome evaluation either after one or more therapy courses or it could happen en route, e.g. between different therapy courses.

The idea behind the decision to record scheduled sessions was to secure some *core* data. After pilot testing the recordings of a session, a single camera was decided upon since the situation could require a great deal of manipulation with the camera and, in some instances, there was no ideal place to site the tripod. When possible, an external microphone was attached. Unfortunately, the choice of only one camera restricted access to important information such as all participants' faces or documents and activities going on at the table. In contrast to field notes of observations and certainly to the latter interviews, the camera catches a glimpse of the real world, but only what could be captured of it within the limitations of only one camera and a restricted camera angle. As Sacks noted about his audio tapes: "The tape-recorded materials constituted a 'good enough' record of what had happened. Other thing, to be sure, happened, but at least what was on the tape had happened." (Sacks, 1984, p. 26). As opposed to field notes and audio recordings, videos contain extra characteristics also present in interaction such as gaze, body movement, facial expression and gesture (Hutchby & Wooffitt, 2008).

As noted, the researcher was present in the room, for instance, for handling the camera, given that participants moved around the room, and in order to write field notes. The wish was to disturb and interfere as little as possible. However, the presence of both a camera and a researcher can certainly have affected the activities, although research shows participants tend to forget the presence of a camera (Mondada, 2013). The videos have several examples of the participants involving me in their conversation, reacting to a sneeze or being somehow affected by my presence. I only stopped the camera when the SLT asked me to do so, as the camera made her client so nervous that she could not participate in the therapy. However, after a while, it was possible to turn the camera on again, when the client felt more comfortable with my presence.

The video data included a total of 33 outcome evaluation sessions and around 17 hours of recordings. The sessions lasted between a few minutes and up to more than an hour. In general, the sessions evaluating group therapy were the shortest (PWA 6-14), individually scheduled sessions (often after individual therapy) tended to be longer.

Interviews: After finishing the observations and video recordings, each of the participating speech-language therapists was interviewed, in July and August 2011, with the aim of uncovering their understandings of the activity *outcome evaluation*, for example, *situations, meanings, approaches*,

and *experiences* regarding this phenomenon (Tanggaard & Brinkmann, 2010). While observing the four different groups of therapists in action, group interviews were considered. The impression was that some of the therapists supported each other very much. In one clinic, I used to eat lunch with all of them and they always had conversations about their profession, whereas the therapists in two other clinics were either located in different settings or gave the impression they did not talk very much together. Through acknowledging that the data set already consisted of a diverse collection of data, the decision was made to include only individual interviews.

As quoted in the beginning, the interviews were intended to answer some of my research questions and add other perspectives to the findings from the microanalysis, while talking either retrospectively about specific sessions, though this was only done if the therapists chose to do so, or asking about general meanings about, and experiences with, outcome evaluation.

In this study, qualitative semi-structured research interviews were conducted. All interviews were audio recorded and later transcribed (see 3.3.4). Each interview took approximately one hour. Since they were performed after following the therapists for eight months and having seen many outcome evaluations and looking through the recordings of some of them again, the interview guide was developed with these experiences in mind. The design of interview guide was inspired by Tanggaard and Brinkmann (2010) with a number of smaller research questions steering the interview questions and topics. However, due to the inductive nature of the project as a whole, the questions sought to cover a range of topics regarding outcome evaluation while also leaving it up to the interviewees to introduce what was important to them. For example, client involvement (see study 3) was not a specific topic introduced in the interviews, but something all the therapists discussed.

As mentioned in 3.2.2, the nature of the interview is to provide an option for the interviewees to reflect upon their own practices and methods rather than giving fixed answers. An example was SLT B explaining during the interview that our interaction, here and now, made her start thinking differently and directly inspired her to change the en route evaluations. Moreover, SLT C said, during the interview, that many of the questions were not anything she had thought of before. Precisely this co-creation of data can be expected and, when recruiting therapist participants for the study, I mentioned that the interview could serve as a way to reflect upon their own practice and perhaps be inspired.

3.3.4 Analytic procedures

The descriptions of the methodologies in 3.2 touch upon how the choice of specific methodologies either project a specific type of methods of data and/or analysis. For instance, conversation analysis is always based on naturally occurring conversation, however with expectation as mentioned above, whereas phenomenological analyses can be accomplished through a number of methods, albeit primarily using one type of data, the interview.

Transcription: Common to both methods used in this thesis are transcriptions. It can be discussed whether transcription of data as video- and audio-recordings fall under the categories of either data or analysis. At the least, it is something created by the researcher in order to support the originally collected data in the analysis. The experience created through this project is that the transcriptions are already in the process of making a contribution to the analysis. Since the making of the transcription is a kind of immersion into the recorded data, it is likely that the transcriber will receive analytical ideas at this point.

Two different types of transcription systems are employed for the studies here. The phenomenologically inspired analyses of the interviews required a “rougher” type of transcript as opposed to the finer transcriptions used for conversation analysis. The full 12 interviews were transcribed verbatim with no regard to pauses, overlaps and similar features. Names, places and other personal information were anonymised. This type of transcription was considered sufficient in relation to both the research aim and level of required details (Bailey, 2008). For example, the decision to write the full words, as “jeg ved det ikke” (I do not know) instead of “ja ve de ik”, which would be more how it sounded, was taken due to the readability for both researcher during the analysis process and later for the readers of the reported data. It must be acknowledged that transcription is not a neutral activity. The choices made in this simplified transcript both reduce the richness of the data as well as contain interpretations from the transcriber (Bailey, 2008), though no transcription system can be seen as capturing every detail in human interactions (Hutchby & Wooffitt, 2008). However, this said, simplification and reduction applies to all types of manipulation with data whether it is translation, transcription, coding, etc.

Transcriptions of the video data contained another level of detail, in accordance with the aim of conversation analytic research a transcription reflecting the richness in interaction with regards to more or less everything (e.g. intonation, body movements, overlaps, pauses in verbal outputs, gaze). However, the exact research aims projects for the level of detail in the individual projects. The transcriptions of videos made during this thesis were, first of all, not of the entire 17

hours, but rather performed after a closer look at the videos and choices of what should be looked at more closely. A set of transcription conventions inspired by Jefferson (1984) were used (see study 2, chapter 5).

The latter use of the transcriptions did not preclude the continued use of the original data in the analytic process. The transcriptions were made in the program Transana (www.transana.org). Here, both transcript and recordings could be used simultaneously.

Apart from “translating” the recorded data into transcripts, the translation of the original Danish data into English has been partly necessary due to the research’s dissemination in English. Both my English ability and contextual understanding might have reduced the intended meanings in the data.

Thematic analysis (phenomenological analysis): As mentioned in section 4.1.2, a phenomenological analysis can be made in different ways and the method chosen here is Braun and Clarke’s (2006) thematic analysis. Braun and Clarke write that their method is not specifically attached to a certain methodology such as, for example, interpretive phenomenological analysis (e.g., Smith & Osborn, 2003). However, if adopting an phenomenological approach, i.e. looking for meanings and experiences regarding a phenomenon in the participants’ statements, to the data, this type of thematic analysis differs only marginally to other types of thematic/content analytic procedures (Hsieh & Shannon, 2005).

Through the thematic analysis, the aim was to identify, analyse, and report themes within data contributing to, and enriching, the current knowledge concerning outcome evaluation. As covered above, the questions asked were inspired by the previous data collection, but sought to be open to the topic in order to obtain insights into what was meaningful to the interviewees according to their experiences with outcome evaluations. Therefore, the researcher tried to remain open to what was emphasised by the participants instead of perhaps their own existing experiences and prejudices.

Braun and Clarke (2006) describe six phases in the analytical procedure: The first phase was familiarisation with the data, which had already started in the beginning of the data collection and was followed by verbatim transcription of the interviews. The next phases concentrated on giving equal attention to all parts of the interviews by systematically dividing them into meaningful parts with attached keywords. At this stage, themes started to emerge, on the basis of collections of keywords or similar paragraphs. Keywords, as well as themes, were identified via the semantic

content and at a more interpretive level. The work with sorting the interviews according to keywords and themes was an iterative process. The going back and forth into the data was essential during the next phases. The next step was to review the themes. It was not until this point that the research questions for the study began to take form. Not all themes became essential for this study, and others could be regarded as sub-themes in larger units. At this point, the process of writing of the findings could start with defining and naming the final themes subject to this study.

Conversation analysis: As described above, the analyst, on the one hand, takes an emic approach, and, on the other, has some kind of membership knowledge about what is seen in the data. To avoid preconceived meanings, hypothesis and analytical bias, the data is looked upon with fresh eyes, called unmotivated looking, as we did in study 2 (chapter 5) in this thesis (Sacks, 1984). This means the analyst does not bring any categories or other preconceptions to the data. However, some might start an analysis with some kind of steering question, for example, inspired by literature, interests or, as with the cases for study 3 in this thesis, analysis of interviews with some of the participants. Psatas (1995, p. 45) writes: “Rather the first stages of research have been characterized as unmotivated looking. Data may be obtained from any available source, the only requirements being that these should be naturally occurring.” Nonetheless, the unmotivated looking is also paradoxical, since something must have motivated the process of research from the beginning (ten Have, 2007). However, ten Have states that the unmotivated looking should be understood as being open to phenomena rather than looking for predefined concepts.

In all probability, the unmotivated looking will lead to finding reoccurring interactional patterns. In this stage of the analysis, the experienced conversation analyst will likely draw upon accumulated knowledge from previous encounters with data as well as the substantial body of research reports of others’ findings, while the novel researcher may solely adhere to the described procedures when arriving at a point of interest for the deep analysis (e.g. Pomerantz & Fehr, 1997). Pomerantz and Fehr (1997, pp. 71-74) describe five tools to apply: 1. Select a sequence (from beginning to end as oriented to by the participants); 2. Describe the actions in the sequence (describe what the participants are doing turn by turn); 3. Consider what forms the participants are using to produce the actions (e.g. how is a greeting performed knowing that it can be done in numerous ways); 4. Give a detailed description of turn taking (How are certain understandings arrived at in terms of timing in turn taking?), and 5. Consider how specific roles, identities and relationships are conveyed through the interactions (e.g. speech-language therapist and person with

aphasia). Such sequential analyses could project for different outcomes of conversation analytic studies, for example, a collection of a specific conversational phenomenon, a description of a recurrent sequence organisation or single cases (Hutchby & Wooffitt, 2008).

Mixing methods: Study 3 is based on a sequential mixed-methods study (Morse & Niehaus, 2009a) using two qualitative methods: phenomenology-inspired thematic analysis of the qualitative interviews with speech-language therapists (Braun & Clarke, 2006) and conversation analysis of video recordings of outcome evaluation (Hutchby & Wooffitt, 2008). Through the process of accomplishing studies 1 and 2, it became clear that combining the two data sets and methods would contribute to different levels of analysis that could not be achieved by using the methods and data separately (Morse & Niehaus, 2009b). The combination would contribute with issues of client involvement raised by the speech-language therapists via the thematic analysis, but also underpin the issues by describing them, or their lack, via a microanalysis of sequences with presumed client-involving activities. The interview data does not provide a description of how the therapists envision that their clients should be involved, just that involvement and reaching agreement is important because people with aphasia have the right to do so and are capable of it, whereas the videos allow the analysis to be taken further and reveal how the clients are involved.

Despite no questions about involvement or shared decision making being asked in the interviews, the speech-language therapists talked a great deal about the importance and value of giving voice to their clients with aphasia, and this set the agenda for another thematic analysis focusing on all aspects of the interviews where involvement was mentioned. The next step was executing conversation analysis of parts with a not-so-unmotivated-looking, but focused on collecting a range of different examples that illuminated themes from the initial analysis rather than identifying reoccurring phenomena or sequences and building collections, as described in 3.1.3. This does not mean that the findings cannot reoccur to build a collection, but this was not the intention. Instead, the analysis was carried out as parallel case studies resembling a variety of examples showing different attempts and types of involvement and how they are handled by the participants (Heritage, 1984a; Hutchby & Wooffitt, 2008).

Research Report

'It really makes good sense': the role of outcome evaluation in aphasia therapy in Denmark

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Abstract

Background: Measuring or evaluating outcomes is a common activity for many speech–language therapists (SLTs). A major focus has been on external forces claiming outcome evaluation to optimize quality and the use of resources without integrating the viewpoints of SLTs.

Aims: To identify the purpose of outcome evaluation by letting SLTs identify not only the actual demands for outcome evaluation, but also the role of outcome evaluation in aphasia therapy in the clinic.

Methods & Procedures: Twelve SLTs participated in semi-structured interviews to identify the demands they met for outcome evaluation as well as the role the outcome evaluation had in their work with people with aphasia. The interviews were transcribed verbatim and analysed by means of qualitative thematic analysis.

Outcomes & Results: Six themes corresponding with the aims of this study were identified. These show that the SLTs initially evaluated outcomes because of external demands and interests. However, they also describe the process as a necessary activity inherent to therapy and state that they would not want to be without it. The outcome evaluation is seen as an interactive process between SLTs, clients and possibly significant others. Not only it is seen as a product in which outcome and/or client satisfaction is documented, but also it is described as a dynamic process that benefits the clients, significant others, the therapy and the SLTs themselves in various ways. This role of outcome evaluation ranges from enhancement of insight and promotion of acceptance for the clients and significant others to planning the next step in therapy or in life with aphasia after therapy. In all of which the clients play a significant role, since their active participation is sought throughout the sessions.

Conclusion & Implications: The results suggest an interesting relationship between treatment policy and treatment practice, where an initial administrative initiative to conduct outcome evaluation is adopted by the SLTs and made into a meaningful part of therapy in which the clients play a significant role.

Keywords: outcome evaluation, aphasia therapy, qualitative research.

What this paper adds?

Many SLTs make outcome evaluations after therapy. A major focus on the purpose of such evaluations has been on external demands to benchmark services including, for example, documenting the effectiveness of intervention and the amount of change effected. This study, however, describes how SLTs view their current use of outcome evaluation. Within Denmark outcome evaluation is demanded externally, but internally it has proved valuable in documenting outcomes and reflective practice with implications for both continuing therapy interventions and discharge from care.

Introduction

The term *outcome evaluation* will be used throughout this paper instead of the more common term *outcome measure*. Outcome evaluation reflects the term used

by the participants in this study (of *evaluation*) and their specific procedures that often involve less formal measurement methods like tests or scales. Instead a

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dialogic approach is usually applied, where mutual understandings of the outcome are settled between a speech–language therapist (SLT), a person/people with aphasia (PWA), and possibly a significant other by sharing stories from therapy and life outside (Isaksen and Brouwer 2013).

All stakeholders in aphasia therapy, from funders and managers to clients and SLTs, are likely to aim for better language and communication skills for the PWA in order to promote quality of life (Simmons-Mackie *et al.* 2005). Even though the goals for therapy are the same for the stakeholders, the outcome evaluations in aphasia therapy depend on a range of variables. This includes what is evaluated, how it is done, whose perspectives count and its purpose (Simmons-Mackie *et al.* 2005, John *et al.* 2005). An eclectic approach to outcome evaluation, where different methods are used and various aspects of aphasia taken into consideration, is used by almost 90% of respondents in a survey by Simmons-Mackie *et al.* (2005).

This article aims to unveil a greater understanding of the role outcome evaluation plays in aphasia therapy by investigating how clinicians handle demands for outcome evaluations in their daily work with PWA. Attention is focused on who instigates the outcome evaluation and the role of the evaluation within the clinical process.

There has been a shift in approaches to aphasia therapy from a focus on outcome evaluation in relation to linguistic skills or health status, a so-called ‘impairment’ focus, whereas today therapy usually incorporates a wider focus that includes concepts such as functionality, social participation and quality of life (Sarno 2004). The World Health Organization’s (WHO) model International Classification of Functioning, Disability and Health (ICF) (2001) is probably one of the most influential sources in that change and it has also inspired various concepts of outcome evaluation like the method Therapy Outcome Measure (TOM) and the framework Living with Aphasia: Framework for Outcome Measurement (A-FROM) (Enderby *et al.* 2006, Kagan *et al.* 2008). Both build on the concepts of ICF and are further extended in a more psychosocial direction.

The information for outcome measures can be gathered from different respondents. There are, for example, tests where the PWA completes different tasks that contribute to forming a score (Western Aphasia Battery (WAB); Kertesz 2001), scales or questionnaires to be filled by either the SLT (e.g. ‘TOM’; Enderby *et al.* 2006), the client or significant other (e.g. Communicative Effectiveness Index (CETI); Lomas *et al.* 1989) as well as more informal measures such as observations or analysis of communication (Simmons-Mackie *et al.* 2005).

When the client or patient reported outcomes are seen flourishing in aphasia therapy it is probably also

related to the implementation of ICF or other social models, where the client is seen as the best to judge their own function and situation. For example, both TOM and CETI have a version for the PWA. Moreover, there are several scales focusing on quality of life, impact of aphasia and social participation (e.g. The Communication Disability Profile (CDP); Chue *et al.* 2010; and the Stroke and Aphasia Quality of Life Scale–39 (SAQOL–39); Hilari *et al.* 2003).

Closely related to the issue of evaluation methods are the terms *subjective* versus *objective outcome evaluation*. Kayes and McPherson (2010) criticize an observed attitude of almost anything not stemming from the client as being regarded as objective, whereas subjective contributions concern feelings and experiences reported by clients are downgraded as less informative or valuable. Many approaches to outcome evaluation in aphasia therapy seem to include self- or other- reported outcomes and often in combination with objective scores from test materials etc. (e.g. Code and Müller 1992, Enderby *et al.* 2006, Chue *et al.* 2010). Maybe objective and subjective approaches cannot stand alone, since the extent of communicative success varies with task making a subjective judgement of activity of communication a necessary supplement (Eadie *et al.* 2006, Kayes and McPherson 2010).

Better use of resources and improvement of quality have been mentioned as motivators and purposes for outcome evaluation. The various stakeholders in aphasia therapy might have different expectations to the outcome evaluations to reach those aims. Funders and managers maybe prefer a quickly understandable outcome evaluation; and possibly one comparable with other clients or to other services in the same area, known as internal and external benchmarking of a service (John *et al.* 2005, Frattali 1998). From the perspective of PWA and significant others outcome evaluations are ways to express their opinions about the service, process and result through self-reported methods, as well as to receive a professional evaluation based on, for example, objective tools or clinical observations (Hesketh and Sage 1999). SLTs are likely to have overlapping interests with the PWA in outcome evaluation, but they might also have an interest in assessing their interventions for reasons such as being responsible clinicians who continuously want to improve their services (John 2011).

A survey of SLTs conducting outcome evaluations showed that it was found beneficial in ways such as clarifying therapy objectives, demonstrating efficacy to funders and changes to clients (Hesketh and Hopcutt 1997). Worrall (1999) depicts the increase of outcome evaluation as a reflection of the profession’s maturity; others describe it as inherent to therapy (Simmons-Mackie *et al.* 2005). Skeat and Perry (2008) add additional roles to the ones mentioned above, e.g. allowing

clients to be involved in decision-making. More roles are likely to be discovered through the clinicians' use of outcome evaluations, if additional needs are identified (Skeat and Perry 2008).

The different parties' interests in outcome evaluation are often mentioned in relation to external forces demanding outcome evaluation and using it in the name of market forces (Code and Petheram 2011). As described above, there is also a focus on PWA, significant others and SLT demands, but to a much lesser extent and primarily focusing on the methods used for making outcome evaluations (Hesketh and Hopcutt 1997, Simmons-Mackie *et al.* 2005, Verna *et al.* 2009). Advantages of outcome evaluations have often been expressed in descriptions of how consumerism can be beneficial for PWA, significant others and SLTs by improvement of quality (Holland 1999), whereas this study will look into how the outcome evaluation affects the clinical practice here and now. In other words, the reflective practice of the studied group of SLTs can contribute to identifying additional scopes of outcome evaluation.

Outcome evaluations in a Danish context

Aphasia therapy in Denmark is a free and usually public delivered service given to all needy citizens under the Act on Special Education for Adults (see <https://www.lovtidende.dk>) and funded by the municipalities. In 2009 a new guideline to this law was launched emphasizing that each individual course with a client must be evaluated, including documentation of the effectiveness of the therapy. The way outcome evaluation is done in Denmark diverges from what is described in other studies (Hesketh and Hopcutt 1997, Simmons-Mackie *et al.* 2005, Verna *et al.* 2009, John 2011), since tools/formal tests, etc. are only used to a limited degree. The participants in this study do talk about testing, retesting or using other formalized measures, but first and foremost they talk about outcome evaluation as a dialogic activity involving the SLT, the PWA, and maybe significant others, where the outcome is negotiated through interactions. The dialogue can include a range of measurement strategies from Likert scales to the use of iconographic symbols such as smaller scales or 'smileys' to support the PWA. Only a few published tests, questionnaire, etc. are available in Danish (Villadsen *et al.* 2007) and at the time of this study no outcome assessment tools were available, except for a few for initial assessments. It should be added, though, that an unpublished Danish version of TOM (Rehabilitating Outcome Måling—ROM) recently has been launched and is being trialled at the moment.

The ICF model is used nationwide within aphasia therapy after a common decision between most clinics in 2007 (Association of Speech, Hearing, and Sight Clinics; see <http://www.dths.dk>).

Methods

The data used in this study are derived from a larger ethnographic data collection aiming to explore aspects of outcome evaluations made by SLTs and their clients with aphasia in Danish clinics. The dataset consists of participant observations in which SLTs make an outcome evaluation with the PWA and maybe a spouse or another significant other as well as interviews with the observed SLTs. This study is based on the interviews. Ethical approval was not required for the interview study.

Participants and settings

Twelve SLTs participated in the study. They were employed at four different clinics, which in 2012 constituted 20% of all clinics in the country (Association of Speech, Hearing, and Sight Clinics). Initially clinics were chosen with only one criterion; they should have been in a process of developing their practice and procedures of outcome evaluation. Aphasia therapy is a very small area in Denmark, so the researcher knew beforehand from talking to colleagues, etc. where to find such clinics. The clinics ended up being geographically widespread across the country.

There were two to four participants from each clinic, all working with people with aphasia in late sub-acute or chronic phases. In one clinic all SLTs working with aphasia participated. In two clinics it was approximately half the employees, whereas only a minor part of all SLTs from the last clinic participated. Some municipalities have their own service, whereas others buy the service from neighbouring municipality or from a more regionally based service. It is organized as either pay per each client or as a subscription, based on how many inhabitants the purchasing municipality has. The SLTs had 10 months to 25 years of experience, with an average of 7.5 years. The researcher was familiar with most of the participants in the study. Due to the small population of aphasia therapists in Denmark it was not possible to find only unknown participants.

Procedure

Semi-structured qualitative interviews were completed by the researcher after a period of time observing the individual SLTs' work with outcome evaluation. An interview guide was used with no fixed order of questions and wording to provide possibilities to deviate from it and follow ideas brought up by the interviewees (Tanggaard and Brinkmann 2010). All were asked the same initial question: What is your definition of evaluation? The questions evolved around the participant's perception of the main themes for the bigger outcome project: What is outcome evaluation, how is it done and why is it done? Due to the inductive nature of the project,

no exact research question for this particular part of the study was made until later in the analysis. The questions were mainly open-ended and exploratory with a broad focus on outcome evaluation, aiming at having the main focus of each interview emerging from the participant and not the interviewer. The interviews lasted between 33 and 60 min and were audio-taped.

Analysis

Qualitative thematic analysis aiming to identify, analyse and report themes within data was applied (Braun and Clarke 2006), acknowledging the view of Thorne (2000), who states that every part of data handling, from collection to writing it up, is a part of the analysis in qualitative research. Software for qualitative analysis, Transana 2.50, was used to administer the data (see <http://www.transana.org>). The first phase was familiarization with the data, which already started at the beginning of data collection and was followed by verbatim transcription of the interviews. The next phases concentrated on giving equal attention to all parts of the interviews by systematically dividing them into meaningful parts with attached keywords. At this stage themes started to emerge on the basis of collections of keywords or similar paragraphs. Keywords as well as themes were identified via the semantic content and at a more interpretive level. The work with sorting the interviews according to keywords and themes was an iterative process. The going back and forth into the data was essential during the next phases. The next step was to review the themes. Not until this point did the research questions for the study begin to take form. Not all themes became essential for this study, and others could be regarded as sub-themes in larger units. At this point the process of writing up the findings could start by defining and naming the final themes subject to this study.

The Transana programme made it possible to listen to the sound files while reading the transcripts, and this was found to be very useful, especially since some of the intentional meanings from the interviews can get lost in a verbatim transcription. As a consequence of this, the original data formed the basis throughout the whole process of analysis.

Rigour was established through a process of peer review by fellow researchers. Moreover, the final selected themes were presented to and discussed with the interviewees and their colleagues at three of the participating institutions.

Findings

The following six themes were identified to describe the purpose of making outcome evaluation according to SLTs: (1) Who is requesting outcome evaluations? and

(2) How are the results used in aphasia therapy? The results will be supported by quotations by the interviewees, named SLTs A–L. Since the quotations are translations of spoken Danish, there might be some slightly unclear passages, despite an attempt to adapt them to a more readable style.

Theme 1. External demands: 'I have to'

External demands for making outcome evaluation are expressed by all participants. The majority says something like because 'I have to' (SLT E). From the interviewees' answers it is not always obvious who exactly is demanding this of them, though it is clear that external stakeholders are making the initial claim. It is most likely the direct demands in their daily clinical work stem from the clinic management: 'There is an instruction here that we must do outcome evaluations' (SLT B) and 'I am working a clinic where you now do evaluation' (SLT H). Despite the new guideline to the law, only one SLT mentions the legal obligation: 'I am utterly satisfied that the law also demands it [outcome evaluation], so I can be sure that it is a common approach' (SLT A).

The different structures in the four clinics possibly have an impact on the claims for outcome evaluation. Clinics I and IV are owned by the municipalities in their area of location, but are funded by several surrounding municipalities that pay an annual subscription fee based on the number of citizens in their area. Clinic II also has clients from surrounding municipalities, but they are paid per client. Clinic III is funded both by subscriptions and pay per client, depending on what the purchasing municipality has chosen to do. Especially in clinic II with the pay per client has direct external demands for providing results of outcome evaluations to the municipalities of their clients:

and not least it [the outcome evaluation] is for the municipality so they can see—I do not know how much they are reading of it if we do not apply for any more [therapy], but it is clearly used if we use it as background to apply for new [therapy]. (SLT D)

Being in a clinic with so-called subscription financing does not mean that the clinics do not have any obligations regarding outcome evaluation towards external funders. It is just done with more central accounts and not on a single-case level.

The SLTs from clinic II express the strongest feelings about demands being put on their shoulders externally:

It is incredible how much time is used [to evaluate]. My experience tells me and maybe also my prejudice tells me that it is very, very seldom that the case officers [in the purchasing municipalities] know what we are doing and what we mean when we write like this. So in many

ways they cannot use very much of what I am writing. (SLT F)

At the same time, the same SLT also talks about the benefits of making outcome evaluations compared with how it was years ago, when outcome evaluation was not done:

I actually think it is nice to be forced to think of what it is one is doing and we did not do that in the same way before where we were just going on and on. [...] So we did not look that much at what we were doing and we have to do that more now and it is really good.

Theme 2. Internal demands: 'It really makes good sense'

On the one hand there are external demands put upon the SLTs to make outcome evaluations, but on the other hand all 12 participants say that they would make some kind of outcome evaluation even if there were not told to:

The main reason [for performing outcome evaluation] is that we have to, but also because it really makes good sense. If we did not make outcome evaluations, it would be easy to go ahead and therefore, not be able to keep track. (SLT I)

It is considered as a natural, inherent and necessary activity for most of the SLTs: 'I think it is just an everyday thing, it is just such an element, a part of my job. It is just a necessary thing' (SLT G). And as SLP G, others also consider the outcome evaluation a necessary part of an intervention: 'They [outcome evaluations] are totally necessary and I could not even dream of not doing it' (SLT L). The SLTs see it as their responsibility to wrap up any intervention with an outcome evaluation: 'I would think that every request or contact should responsibly demand that you respond to what you have been doing together' (SLT A).

Few complain about an enormous amount of time needed, not necessarily for the actual outcome evaluation, but to write it up for, for example, case officers in clients' municipalities. Another thinks there is too much fuss about outcome evaluation in this area as well as in other contexts, but she does and considers it as important as the other participants:

I think it has been made a little bigger than it really is. Evaluation has become really big, but in reality it is just that dialogue we have. It is just an absolutely normal dialogue we make a written report on, about how things are and how they have been. I see it as if you had done something together then we talk about, how it has been. (SLT C)

The SLTs have many reasons to do outcome evaluation, stemming from either external demands or from

themselves, whereas the PWA and their significant others are reported not to have put any demands on them regarding making outcome evaluations. According to the SLTs, some of the clients and their significant others have general knowledge about outcome evaluation, but never make the initial demands for it. It does not mean that the PWA are not central in the outcome evaluation. One SLT asserts that during the years she has been working the client's role in outcome evaluation has become more and more central: 'There has been a greater awareness over the years of outcome evaluation as not just something for me and the records, but to a greater extent for the client's learning' (SLT A). The PWA might not demand outcome evaluation, but the SLTs put demands on themselves on behalf of their clients: 'So it is also for the sake of the clients' (SLT E). A responsibility for the client's well-being and the outcome evaluation as a platform for them to speak up for themselves is also reported.

Theme 3. The role of outcome evaluations: assessment of everyday communication

As described above, improvements in language and communication for the PWA are usually the goal of therapy and therefore, essential in outcome evaluation. This was also mentioned by several of the participating SLTs. It is also clear that it is not the only thing for which to use an outcome evaluation. Perhaps the most striking thing in the SLTs' reports about 'the real outcome evaluation' is their emphasis on the ecological validity of the therapy. They all underpin the importance of giving voice to the PWA and significant others in order for them to report, how therapy has improved their daily communication:

I encourage very much to ask, how is it perceived at home, and how can you see improvements. Try to give some examples and what is your neighbour saying and ask a lot about activity, so are you picking up the phone, are you better at chatting with the neighbour, if the doorbell is ringing do you dare to go open the door and such things. (SLT J)

One clinician calls the therapy in the clinic 'the false life' and says the most important thing is that improvements can be monitored in real life, meaning outside her office, where the clients communicate with family, friends, shopkeepers, etc. Many of them emphasize not only the view of the PWA, but also the significant others:

All the time I would like that the client in question relates to whether they think anything has become easier for them. So they can evaluate, if they think, that they have become better, or if the significant others think more is happening. (SLT L)

The wish to evaluate everyday communication usually stems from the ICF-framework: 'I evaluate those, well, body, activity and participation. [...] It is not just the body functioning, but also how does everything function here' (SLT B). Furthermore, the outcome evaluations build on individual goals that have been set jointly for the therapy:

What has really been happening in therapy compared with the goal, but if there is anything more we will also include it. So I think it often will be at such a personal level: how do you think things really are now compared to when we started out? (SLT H)

The lack of tools or specific methods in Danish means that the clinicians usually use a dialogue to question the PWA and significant other, though goal attainment scaling has been attempted at some of the clinics: 'It[goal attainment scaling] simply was not qualitative enough. It became goals that one really could not use, because then he could say five words more and so what? It was not really related to anything else' (SLP D). More measures are requested by some of the participants, especially someone covering more than the impairment level.

Theme 4. The role of outcome evaluations: documentation and record keeping

Written reports seem to be as common as the evaluation session itself. SLT D explains who the receivers are: 'It is both for ourselves, for our own documentation and if the case should be brought up again, and then it is for the client, and then it is not least for the municipality.' The documenting part of outcome evaluation serves a wide range of purposes, stemming from both external and internal demands as already indicated in the quotation above. Whether the reason is record-keeping, informing the client or applying to a municipality for another period of therapy, it might require a difference in style: 'The more it is going to be presented to the outside, the more formal it will get' (SLT B) and:

Because it shall be written in a manner that both the client and the municipality understands what it is you write, so in that sense you must consider it more compared to if you were just writing it to yourself or to the records of the place. (SLT D)

In some of the other clinics where they do not have the same demands from the funders they still keep records, not only for their own sake, but also to have documentation if anyone requests to view the outcome: 'It is a requirement now that it [goals and evaluation] must be there. I sense it is there in preparation for if anyone comes and asks for access to what we get for our money' (SLT K).

In some of the clinics you cannot proceed with a client unless an outcome evaluation is written in the electronic journal system: 'I cannot end or apply for additional hours in a case, unless an outcome evaluation has been made' (SLT H). No matter who makes the decision for ending therapy or prolonging it, the written report of the outcome evaluation serves as a base for everyone involved in decision-making.

Theme 5. The role of outcome evaluations: an influential process

The SLTs' perception of the use of outcome evaluation does not stop with the more traditional and product-oriented purposes as described in themes 3 and 4, since the process of outcome evaluation seems to have a variety of other applications as well. One of the most mentioned is the structure and orderliness it brings into the therapy:

I think it is such a great working tool, of course it takes a lot of time, but it also helps me to keep the common thread, where are we actually going, but I also think it gives me a good tool in relation to the client and finds out what, where are we going together in this course. (SLT H)

I think it affects me that I know I will evaluate, but I think it is in a good sense. (SLT G)

I think that evaluation is a tool to keep me on the track, where am I and where are we going, so I would not go without the evaluation, so I think it is absolutely necessary to be able to make a continuing plan or to determine whether it is the end. (SLT B)

Moreover, the SLTs report several ways of using the outcome evaluation in the learning processes of their clients:

to force people to relate to where, to try to keep them captured, to look into oneself and see, what is important and what would be good if it was a little better, because it is really all people, families in crisis and they just want things to get better, right. (SLT L)

It is also for the sake of the client involved. Well I have actually become better at some things even if you lose heart sometimes, well yes I have actually moved a bit and so now I can do this and I was not able to do that before as a little victory. (SLT E)

Regardless of whether the outcome evaluation leads to a new referral for continued therapy or if it is the end, the process is used by the clinicians either to make a new set of goals together with the person with aphasia or to ease the ending that could potentially be problematic. Several of the participants say that the process of outcome evaluation makes it easier to let go of the PWA because they have been involved in the process. The

actual outcome evaluation activity is maybe in this case also used for preparing the client for life after therapy:

So I tell them right from the beginning that I think this is our last time and before we would have talked it over several times. So it is never a shock when it is our last time, then it is much more talk about—okay what now? We evaluate what we have been doing, but we have to very importantly have some things put in order, so they do not feel that now it is ending and what do I do then. (SLT G).

Theme 6. The role of outcome evaluations: joint decision-making

As already indicated, the PWA and their significant others play an important role or equal role in outcome evaluation. The SLTs contribute their professional knowledge and opinions, but also say that they listen equally to the contribution of the other party:

I would like that there is time and space for both the significant other and the client and myself to put into words, how things are going. I would like the client and the significant other to feel, that they have had the time to tell, what they would like to tell. (SLT I)

What you must focus on is really to share the responsibility with them as much as you can and give them a common sense that, what we are doing here must never be a coffee club even if we drink a lot of coffee. It is my philosophy that knowledge is power and one should regain the power in life again. So it must never be unclear what we are doing here. (SLT J)

At the same time, it is acknowledged that it can be hard due to the nature of aphasia. Even if all the participants agree that the joint decision-making process or user participation is good and necessary, it can be hard with persons with aphasia as well, due to other reasons:

They [persons with aphasia] are so individual and exactly because the aphasias are so different then you choose your wording very differently and the whole use of language in relation to the one sitting in front of you so sometimes it will be more, well, not commanding, but a little more leading than other times. (SLP F)

Several of the interviewees addressing their professional role in decision-making also acknowledge the possibility of misusing it:

Because they [the PWA and significant others] are of course influenced by me, people would also like to say something nice to me. (SLP G)

I know I have the power of definitions, but anyhow I think I must consider those, who have the problem. (SLP C).

Discussion

Sarno (2004) has described the concept of outcome evaluation as a substantial challenge and change in aphasia rehabilitation, as she foresaw a new area of healthcare purely driven by an economic agenda. In relation to the findings in this study, we have not quite reached that point. Maybe it is better to say that economy is a motivational factor in outcome evaluation of aphasia therapy, but it is not necessarily in contradiction to the needs of clients and clinicians, as Holland (1999) also explicated.

For the participants in this study there seemed to be numerous purposes for engaging in outcome evaluation, but economy or resource optimization was never used as a motivation despite the report of external demands. Neither was the overall framework for outcome evaluation in Denmark the new law, since only one participant mentioned it. Yet it is likely that the law is one of the ruling factors behind the requests of the management or funders. Danish managers and funders do not seem to have any other requests than a written outcome evaluation based on ICF terminology and maybe written into a specific template in the electronic client system to document the therapy and to take decisions about the future of the clients. Form and content was not described further according to the SLTs. Aims such as benchmarking of the service are not addressed either, and since each outcome evaluation is constructed individually, it can hardly be used for such a purpose (John 2011).

The only complaint by the participants is the amount of time used especially for writing up understandable reports for case officers without any professional knowledge, as well as for PWA and their significant others and still suitable for documenting the cases in the record files. The system of pay per client at clinic II and partly at clinic III has only been an option since a major structural reform in the Danish public system a few years ago. Therefore, many things could possibly change in future and one could imagine a move towards further external requests for more specific types of evaluation for, for example, benchmarking or research purposes (John 2011).

Since the interviews were conveyed in 2011 the clinics have introduced a Danish TOM core scale (ROM) (Enderby *et al.* 2006). Amongst the purposes of this introduction are continued development of quality together with the assessment of treatment efficacy (personal communication with SLTs and managers). This is the first Danish attempt to make an overall rating of a service and contrasts with the very individual approach reported by the participants, since the data from the ROM can be collated to provide an overall profile of change and typical change across dimensions.

The relatively unrestricted external demands for content and use of outcome evaluations give the SLTs

free hands to put whatever they want to into this activity. The participants use this opportunity surprisingly homogeneously, as expressed in themes 3–6. This homogeneity is likely to be caused by several factors. For example, will the outcome evaluation reflect the areas targeted in therapy intervention—change in expression and comprehension affecting communication understanding and speech affects the PWA's ability to lead their life, interact with others and how they feel.

As mentioned above, the area of aphasia therapy is relatively small in Denmark, so trends and tendencies seen in one place are likely to spread to other places relatively quickly. Moreover, all four clinics use the ICF as a framework for assessment, therapy and outcome evaluation. This might be the reason for having a uniform approach to outcome evaluation, together with factors such as the same culture and the same access to continued professional development. Access to the same tools is another common prerequisite. Some participants' report retesting with the Western Aphasia Battery (Kertesz 2001), which is one of few formal measures mentioned. It is in opposition to surveys on tools of outcome evaluations in English-speaking countries (Hesketh and Hopcutt 1997, Simmons-Mackie *et al.* 2005, Verna *et al.* 2009), where there is a greater impact on tools and where a lot of tools are actually available in their language. A Danish review of existing tools describes 10 published assessment methods, nine of which are at the impairment level (Villadsen *et al.* 2007), and none specifically developed for outcome evaluation. The use of ICF terminology together with a lack of tools at all the ICF levels and areas as quality of life could be causing the emphasis on the informal and qualitative outcome evaluation the participants describe. Though some do mention that more methods are needed, no one states lack of tools as the reason for using informal dialogues as the most prominent; instead they describe it as a good way to make outcome evaluations where the opinions of the clients can be heard (Kagan *et al.* 2008, Kayes and McPherson 2010). The same could have been obtained with formalized questionnaires, scales or interview guides (e.g. Hilari *et al.* 2003, Chue *et al.* 2010).

It seems like the use of outcome evaluation is very dynamic as opposed to a more static and retrospective approach. What appears in the outcome evaluation is not just for documenting something to put into the clients' files. Instead, the outcome evaluation is transformed into meaningful activities here and now as well as in future for the SLTs and the PWA. It resembles a description of outcome evaluation by Dinesen and De Wit (2010: 15; translated from the Danish 'Evaluation must force innovation from practice and give meaning for the practitioners in their organisational tasks. Evaluation must create development from practice and not just measure practice retrospectively or measure irrel-

evant goals.' The authors call this concept *innovative evaluation*. The widespread use of the outcome measures for pedagogical or learning purposes serve as examples (themes 5 and 6). For example, the outcome evaluations operate as bases for setting new goals, easing the often difficult ending based on agreements by the parties, or in fostering awareness of the PWA, new situations and changed life conditions. Results from the above-mentioned formal tools could maybe be used to achieve the same, but likely not the unique interactive process, where the PWA counsel is sought all the time and combined with the SLTs' professional assessment and experience.

Such a type of dialogic outcome evaluation could easily be mistaken for a 'chat' between the parties, but other studies of outcome evaluation in Denmark show an individualized activity, planned for and expanded in the exact situation, where a certain structure is seen (Isaksen and Brouwer 2013). Yet there can be different consequences of primarily basing the outcome evaluation on dialogue. One can imagine it can be sensitive to talk about and be honest with areas the parties do not agree on, in contrast to often anonymous contributions evaluated by questionnaires or a fixed test procedure. Moreover, there might be issues in never using methods that are standardized, valid and reliable in the sense of psychometric testing. This is not to say that the procedures and actions presented here cannot be all of the above. Outcome evaluations based upon informal dialogues are probably not possible to use for anything else than describing the specific cases. In contrast, formalized measures can be compared with set baselines or tests to give an idea of improvements that can be easily communicated to the clients, before you scored 8 now you scored 12. Using the same comparable methods in several cases would also give the possibility of doing comparative case studies. On the other hand, there are several benefits in the dialogic method. For example, there is the possibility of orienting the whole outcome evaluation towards functionality and participation in the daily life of the individual client. Yet another characteristic with this dialogic outcome evaluation is the high level of user involvement that is praised and recommended in aphasia therapy as well as other health services (Hersh *et al.* 2012). The PWA, language and communication problems can make it hard to have equal opportunities in this conversational activity. The primary tool in the dialogue, language and communication is also the object of what is evaluated, which may make them disadvantaged in several ways. Furthermore, the participants aim to create a joint narrative in the outcome evaluation, where opinions and views of the parties are equally taken into considerations. Such action can possibly be sensitive in a context like this, where two different people work in agreement to define results of a given intervention.

In summary the enhanced benefits of the outcome evaluations in this Danish context are (1) they fulfil the requests from demanding parties, (2) they evaluate effects of therapy in everyday communication, and (3) they are useful for pedagogical purposes like planning next steps, promoting insight and involving the PWA.

Could it be obtained with other types of outcome evaluation? In answering the question it is important to return to the often-stated purposes of outcome evaluation: improve or secure quality and use of resources (John *et al.* 2005). For such purposes formal methods are useful, whereas the purposes reported from the SLTs in this study is further expanded and maybe therefore, requires additional methods as the dialogue. Fredslund (2013) has developed a new model for evaluation, called *narrative evaluation*, that in many ways resembles the approach used in this study. Moreover, the intention of the methods further expand the purpose of evaluation into learning and development beside the more controlling purposes as quality and resource control. Therefore, the findings in this study give interesting perspectives on the expansion of empowerment, user involvement, and social participation that is promoted in many social and medical contexts including aphasia therapy (Hersh *et al.* 2012).

Methodological issues

In a study such as this one needs to take into account that meanings that were not there initially are co-constructed by interviewee and interviewer en route. An answer from SLT B indicates that: 'Well I am just thinking right now, maybe we should put more emphasis on the under-way-evaluation, really.' For this SLT, meaning was created in the situation, likely generated by the researcher's questions and her own answers and reflections. In thematic analysis there is the possibility to create categories only known to the researcher. As stated above, it was addressed by discussing the themes with most of the participants, but it does not fully eliminate the risk.

Furthermore, the in-depth exploration of themes could possibly have been targeted better if themes were selected before (a more deductive approach). On the other hand, is the chosen inductive approach beneficial since it will reflect whatever is experienced as important to the interviewees.

The quotations above were made more readable by adding punctuation, which adds to the general risk of misinterpretations, as does the translations of the quotations from spoken Danish into written English.

Conclusion

This study has shed light on SLTs' use of outcome evaluation in their clinical practice, making it clear that

there are functions attached to the process of outcome evaluation as well as the results of it. Although the outcome evaluation for these SLTs is initially requested by external stakeholders such as the funding municipality or clinic management, it is described as an activity necessary and meaningful to the SLTs. All of them report that outcome evaluation is an essential part of therapy, and they would definitely perform it even without external demands for it. The more traditional use of outcome evaluation as assessing the language and communication outcome of people with aphasia and their satisfaction with process and structure is mentioned, but the ecological validity of the intervention is prioritized. Another emphasis is on a dynamic use of the results. It includes pedagogical use of the process and results for, for example, creating structure in therapy, setting new goals for further therapy or help ending therapy on an informed basis. The outcome evaluation also serves as an important platform for user involvement and shared decision-making.

The outcome evaluations reported in this study seem to meet the needs of the claiming stakeholders, since no incongruity is reported. Whether the results would be the same in case of equal access to a range of readymade tests and tools as in, for example, English-speaking countries, we do not know. Certainly there would be benefits in using standardized or even well-explored materials, though it would open up the possibility of missing the context sensitiveness of this informal method as well as the chance of losing the empowering aspects of having each therapeutic dyad/triad to make their own decisions along the process of intervention and outcome evaluation.

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5. STUDY 2

Assessments in outcome evaluation in aphasia therapy: Substantiating the claim

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Abstract

Outcomes of aphasia therapy in Denmark are documented in evaluation sessions in which both the person with aphasia and the speech-language therapist take part. The participants negotiate agreements on the results of therapy. By means of conversation analysis, we study how such agreements on therapy outcome are reached interactionally. The sequential analysis of 34 video recordings focuses on a recurrent method for reaching agreements in these outcome evaluation sessions. In and through a special sequence of conversational assessment it is claimed that the person with aphasia has certain communicative skills. Such claims are systematically substantiated by invoking examples of the person with aphasia performing this skill either outside or inside the therapeutic setting. Substantiation can be seen as a form of validation of the claim and thereby a basis is set for agreement. The findings suggest that in this type of evaluation the requirements of producing a valid account in which the person with aphasia has been heard are being met.

KEYWORDS: OUTCOME EVALUATION; AGREEMENT; APHASIA THERAPY; ASSESSMENT;
CONVERSATION ANALYSIS; EPISTEMIC RIGHTS

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1. Introduction

Measures or evaluations of outcomes are commonly seen during and after aphasia therapy (Simmons-Mackie *et al.*, 2005; Verna *et al.*, 2009). Outcome measures are generally associated with formal tests or questionnaires. Simmons-Mackie *et al.* (2005) divide their findings of tools and methods for outcome measures into the categories cognitive/linguistic, functional, subjective/qualitative and vague/other. The first two are most frequently reported in studies, and make use of formal tests or specified procedures that have varying degrees of reliability and/or validity. Although this holds true for some described tools in the category subjective/qualitative too, this category as well as the category of vague/other mainly include more individualized approaches such as observations, qualitative speech analysis, and assessment of goal attainment. Natural speech and interaction is the basic element in these methods: either it is the object studied through observations or an actual tool for assessment (e.g. in the person with aphasia's (PWA) report of his/her own competencies). The evaluation sessions, which are less constrained by formal requirements, and are carried out by means of interaction, may thus pose a problem with regard to consistency: Are they at all structured, can they be compared, and, thus, can anything at all be said about their quality? The very terms denoting these methods (*subjective/qualitative*, and *vague/other*) may suggest that such sessions are unsystematic. Furthermore, an interactional approach to outcome evaluation may pose challenges to the evaluator (most often the SLT) who has to attain a PWA's true feelings about therapy while at the same time directing and guiding the conversation.

This study reports on outcome evaluations that are carried out by means of interaction. Although such sessions may vary widely with regard to what is talked about and how it is talked about, all of them contain sequences in which communicative performance by the PWA is assessed by the participants interactively. These assessment sequences have a clear interactional organization, and can be described as exemplars of outcome evaluations which are systematic and orderly.

The present study focuses on outcome evaluation as an interactional achievement by addressing the structural organization of assessment sequences. Drawing on conversation analysis (CA) (Hutchby and Woofitt, 2008; Psathas, 1995; Schegloff *et al.*, 2002; Steensig and Asmuss, 2003) the study presents in-depth analyses of how such assessment sequences are accomplished by the participants. As we will show, the interactional organization of assessment sequences in this setting resembles, but is not identical to, the organization of assessment sequences in everyday conversation as has been described by Pomerantz (1984). First of all, assessment sequences in outcome evaluation sessions are planned and prompted. Moreover, it is shown how certain traits

of the PWA's communication not only are assessed, but also how the participants work towards agreement on these assessments. One major practice in these sessions entails invoking examples of the PWA's communication performances inside or outside the clinic, either by the PWA, the speech language therapist (SLT) or a participating significant other. These examples are often presented in succession to or as a preliminary for a claim of the PWA being able to perform in such contexts. We argue that invoking such examples serves as a way of working towards agreement in the outcome evaluation session.

2. Assessments of outcomes

The literature on assessments in interaction reflects on how assessments occur in a wide range of everyday and institutional settings, and thus can be seen as a recurrent and recognizable phenomenon. Since the seminal paper by Pomerantz (1984) on assessment in conversation, a number of studies on the topic of assessment have been published, ranging from assessment in everyday conversation (Ruusuvuori and Peräkylä, 2009) to those employed in institutional settings, such as classrooms (Day and Kjærbaek, 2012; Koole, 2012; Macbeth, 2004; Mori and Koschmann, 2012), interviews (Antaki *et al.*, 2000; Simonen, 2012), parent-teacher conferences (Pillet-Shore, 2003), and commercial situations (Clark *et al.*, 2003; Mondada, 2009) as well as clinical and caregiving encounters (Brouwer, 2012; Maynard, 1991). Some articles concern interactions that involve persons with impairments of some kind (Rasmussen, 2012) and other articles focus on specific features of assessments, such as facial expressions (Ruusuvuori and Peräkylä, 2009) and phonetic aspects (Ogden, 2006).

Assessing as an interactional phenomenon is described in the abovementioned literature as a recognizable practice that is organized sequentially in a systematic way. According to Pomerantz (1984) assessments encompass ascribing *value terms* to a *referent*. Systematically, initial assessments are likely followed by second assessments, in which a second speaker shows agreement or disagreement with the initial assessment, simultaneously claiming access to the referent (J: T's- tsuh beautiful day out isn't it? R: Yeh it's jus' gorgeous ...; example from Pomerantz, 1984: 61).

The literature presents a number of useful distinctions for the purpose of this article. Lindström and Mondada (2009), following Pomerantz (1984), distinguish between assessments that are locally occasioned in the interaction, and assessments that are produced within a more global activity, such as an evaluation activity. As pointed out in Fasulo and Monzoni (2009), assessments within evaluative activities can be seen as central features of the overall activity. As we will argue, assessments in outcome evaluation following aphasia therapy are constitutive of this activity. Even though other interactional practices occur in

these sessions (complimenting, informing, joking, etc.), assessments systematically occur in all of them. In relation to assessments in everyday interactions, the assessments in our data seem more complex, since the referent for the assessment is not a single object such as a sunset or a movie, but the outcome of aphasia therapy, which may include participants' conceptions and knowledge about the intervention itself, the PWA's communicative skills in everyday encounters, and wishes or ideas about continuing or terminating the intervention.

Interaction within outcome evaluation is considered institutional and may diverge from mundane conversation between peers (Hutchby and Wooffitt, 2008). A context might be institutional, but an interaction can only be described as institutional when features in the talk-in-interaction display *institutionality*, that is how participants orient to the conversation as institutional (Drew and Heritage, 1992). The type of institutional interaction seen in our data can be regarded conversation like talks between doctor and patient. Such types of institutional interaction are more conversational in opposition to more formal settings such as news interviews or courtrooms. Traits of institutionality will be discussed in the analysis below.

Aphasia is of course a prominent factor in many interactions with PWA and thereby outcome evaluations are also likely influenced. Yet this seems to be at a formalistic language level, meaning that syntactic, morphological and lexical choice appear deviant, but not to such a degree that the actual actions of interactively assessing and agreeing on assessments are impaired. In the few cases in the data corpus where the PWA is not able to partake in such sequences, and no significant other is present to supplement, the SLT seems to organize outcome evaluations in different ways.

3. Data and methods

In the Danish context studied here, outcome evaluation in aphasia therapy has been required by law since 2009 (Undervisningsministeriet, 2009) stating that the individual persons' progress must be documented. Earlier results of outcome evaluation in Denmark show that outcome evaluation is typically carried out in talk between SLT, PWA and possibly a significant other (Isaksen, 2014), rather than by formal testing or as a substantial supplement to testing.

3.1. Data collection and analysis

The data comprises 34 video recordings of sessions of outcome evaluation. Data for this study was transcribed after conventions used in CA (Jefferson, 1984) (see appendix 1).

CA is an inductive method that deals with video- or audiotaped naturally occurring data in mundane everyday conversations as well as in organiza-

tional or institutional settings such as aphasia therapy (Hutchby and Wooffitt, 2008). CA aims through a detailed analysis of social practices, in particular the sequential development of talk-in-interaction, to describe the methods through which members of society conduct their affairs. This study is based on a collection of assessment sequences in outcome evaluation sessions in order to describe the organization of these sequences in comparison to assessments in everyday settings. Based on this analysis, we discuss central characteristics of outcome evaluation sessions.

3.2. Participants and setting

Outcome evaluation was studied in outpatient units at four public *communication centres* in Denmark. Twelve SLTs participated with clinical experience varying from 10 months to 25 years with an average of seven years. Twenty-eight different PWAs participated in the videos, in 15 instances accompanied by a significant other (partner, parent or social worker). The outcome evaluation followed a set period of therapy, either individual, group-based or interventions given to significant others. The PWAs were recruited by their SLTs with the diagnosis of aphasia as the selection criterion based upon a recent course of therapy that was to be evaluated. All outcome evaluations were instigated by the therapists, so PWAs as well as other participants were informed beforehand, that an evaluation would be conducted. In 16 recordings the evaluation completed the therapy whereas some kind of intervention continued after the remaining 18 sessions.

Researcher 1 was present at all outcome evaluations, where she took field notes and video recorded the sessions. The PWAs were informed about her presence from their therapist and had either already signed the informed consent provided or did so just prior to the session. Since this project did not gather any personal information about the PWAs and did not use any invasive medical methods, no further ethical approval was needed according to Danish legislation.

4. Findings: Sequential organization of assessment in outcome evaluation

Within the categories of subjective/qualitative and vague/other (Simmons-Mackie *et al.*, 2005) a distinction can be made between different evaluation methods. One type of evaluation consists of the SLT giving a kind of assignment to the PWA with which he or she demonstrates communicative or linguistic skills. One may see this as a method in which the participants mainly deal with what the PWA is able to do *within* the realm of the therapy. Another type, however, is based on reports about what the PWAs are able to do outside the clinic, in everyday life. This concerns issues that the SLT has no direct

access to, and where the experiences and opinions of the PWA and significant others are taken into consideration. The analysis will focus on these latter types. They are, in relation to demonstrations of skills during the outcome evaluation, to a much higher degree based on information that is exchanged between the participants through talk. A central practice in such sessions consists of assessment sequences, in which participants not only inform each other of their experiences, but also assess the PWAs' skills based on these reported experiences and work towards agreement.

We have identified a specific type of sequence across the selected consultations, and built a collection of them. By describing the features of these sequences we provide an analysis of the kind of characteristics that seem essential in these sequences that make up a central part of outcome evaluation sessions.

4.1. Assessment prompt

In the outcome evaluation sessions the SLTs typically initiate assessment sequences by posing questions towards the PWAs or significant others about the PWAs' skills and competences. These questions have different structures, for example a yes-no question tied to a value term:

(1)

01 SLT C: Er du blevet god til at være opmærksom.
have you become good at being attentive

However, more regularly, questions have the form of 'How does it go with X?' as in

(2)

01 SLT C: Hvordan lever du me:d afasien nu?
how do you live with your aphasia now

Or the same structure, but with a reference to either a goal or a problematic issue:

(3)

01 SLT B: >Så det var det< med de faste vend[inger.]
then there was the issue about the idioms
02 PWA 2: [ja]
yes
03 (0.5)
04 SLT B: Og hvordan er det så gået.
and how did that go

The similarity between these questions is that they *solicit* an assessment from the PWA, either as a (dis)confirmation of the yes-no question or with the PWA's own words. This differs from the assessments that occur in everyday conversations, in that assessments in the data we are dealing with are, demonstrably, planned and prompted. Following Pomerantz (1984), assessment sequences in everyday talk have the following traits: They occur in talk in three positions (a) when participants have direct access to a particular referent or experience, (b) within reports of past events, and (c) in paired sequences where a first assessment is followed by a second. Assessments in everyday talk, in other words, do not come out of the blue, but are occasioned by the situational context (a) or by talk about the referent (b and c). Assessments considered in our data do not come out of the blue either. As we saw in the questions above, the referent of the solicited assessment is specified in the prompt: (1) the PWA's attention, (2) living with aphasia, and (3) the use of or learning to use idioms.

The assessment prompt thus explicitly outlines the referent to be assessed. The referent of the assessment, then, is proposed by a different speaker than the speaker who is to do the assessment, which also contrasts with assessments in everyday conversation where the assessment often is done by first speaker (as in '[1]I just saw Wengreen outside [2] it w'z really horrible ...') (Pomerantz, 1984: 58). Constructions, similar to assessments in everyday interaction, do appear in the data, but they are rather infrequent as in excerpt 4:

(4)

- 01 SLT B: Det vil sige vi har øvet ord=
 that is we have been practicing words
- 02 PWA 2: =ord ja
 words yes
- 03 (0.4)
- 04 SLT B: [Hvor du kiggede på]
 where you looked at
- 05 PWA 2: [hm billederne]
 hm pictures
- 06 SLT B: billederne
 the pictures
- 07 PWA 2: Ja .hhh
 yes
- 08 (0.2)
- 09 SLT B: Og det har du faktisk ikke ret store vanskeligheder
10 med
 and you actually do not have big troubles with it

In this excerpt, the referent is outlined in line 1–6 (practising words while looking at pictures) and then assessed in lines 9–10. Thus lines 1–6 can be seen

as a prompt and assessment seems to be done by the SLT since the PWA does not provide one in lines 7–8.

Even in cases as the following, where the PWA seems to designate a referent and assesses it in the same utterance the SLT can be seen as prompting. In this case, a group of PWAs was asked to find three examples of improvement each, and thus, although a referent was not indicated by the SLT, the assessment was solicited:

(5)

01 PWA 8: Men jeg er i hvert fald bedre til at ↓læse.
but i am at least better at reading

However, these cases also appear infrequently. The assessment sequences in outcome evaluations are typically prompted in that the referent is indicated and an assessment solicited. Note that the assessment solicitations have the form of questions (excerpt 1, 2 and 3). By convention such questions imply that the speaker seeks information within the epistemic domain of the recipient rather than the speaker. In other words the speaker orients to the recipient having primary rights to the information (Heritage, 2012). In the case of outcome evaluation the SLT can be seen to orient to the PWA and/or significant other having a knowledge base on which the assessment can be grounded.

4.2. Assessment following the prompt

The prompts shown above project for the participants to tell about certain aspects of the PWAs' functioning as specified in the prompt. This is mostly done in terms of good, bad, better, worse or equal – i.e using value terms (Koole, 2012) as can be seen in the next two examples:

(6)

01 SLT I: Hvordan synes du ↑selv (0.4) at det er (.)
how do you think that it has been
02 at det er gået (0.2) i de her [tre måneder]
that it has been going in those three months
→ 03 PWA 21: [dårlig]
bad
04 (.)
→ 05 Rigtig dårlig og langsomt og alt muligt
really bad and slowly and you name it

(7)

01 PWA 26: Jeg synes (0.5) Jeg synes det går rigtig godt
i think i think it goes really well

If no explicit value term is provided it may be pursued by the SLT until such an assessment is given (see the rather lengthy example in appendix 2).

In the cases with an assessment prompt (e.g., excerpt 1), the next turn is supposed to be either a 'yes' or a 'no', because the value term is provided in the prompt by the SLT. However, we typically do not see just a yes or a no, but instead in several cases a repetition of the value term is offered together with a precision. The next excerpt is an example of this:

(8)

- 01 SLT L: Synes ↑du frank er blevet forbedret på et halvt år.
do you think frank has become better in half a year
02 (0.5)
03 WIFE: Jeg synes lige på det sidste her, (0.5) er Frank
04 blevet bedre.
i think just recently frank has become better

In this excerpt we see that in one way or the other, a value term is included in the assessment sequence. Pomerantz (1984: 58) notes that 'assessments are properly based on the speakers' knowledge of what they assess'. An initial assessment is the first speaker's claim of access to a referent, while a second assessment the second speaker's claim of access to that same referent. By means of assessments, then, participants may interactively establish their experiences as shared knowledge and thereby shared conceptions of those experiences (Goodwin and Goodwin, 1987). This is the case, of course, only if the referent of the assessment is, or has been accessible to all of the participants, (e.g., a referent which is present in the situation itself (a sunset, the weather, or food) (Lindström and Mondada, 2009)). Regularly, however, a speaker may assess a referent in a reported event, such as having seen a movie, and it may or may not be the case, that the speaker's interlocutor has access to the referent and therefore 'epistemic rights' (Stivers, 2005). By assessing a referent, a participant claims knowledge of that referent, and expresses some form of epistemic stance in relation to the referent and in relation to the interlocutor. This may be done in different ways, for example grammatically or intonationally (Heritage, 2012). In excerpt 8, the repetition of the specified referent (Frank) as well as the value term ('forbedret' – become better) in the answer to the yes-no question, may then be seen as a way in which the significant other specifically affirms such an assessment as rightfully belonging to her epistemic domain. More generally the provider of the assessment may state explicitly, that the assessment is *subjective* as is done in excerpts 7, 8 and 9. Terms like 'I think', 'I believe', and 'I feel' indicate this. Sometimes, as in excerpt 9, such terms are included in the prompt, as in excerpt 6 ('hvordan synes du selv ...' 'how do you think yourself ...'). The PWA's and significant others claim a *specific* knowledge

of the referent and explicitly mark their assessments as based on their own experiences. By doing this explicitly, it seems to be built-in to their assessment that their interlocutor may have some different assessment of the referent. The possibility of the SLT having a different opinion also seems to be oriented to by the PWAs' immediate responses to the assessment prompt. These are typically produced rather unsmoothly with several types of general characteristics with initiations filled with pauses, prolongations, restarts, 'ehms', 'jamen' (well), 'altså' (well) or combinations of these. In the excerpts 7–9 several of the ways to mitigate assessments are present. Although there are a few cases in which the assessment is delivered smoothly and without delay, the majority of the cases in our collection show an assessment that is either delayed and unsmoothly, or contains mitigating terms. By presenting the assessment in a cautious way the speaker anticipates the possibility of the SLT assessing otherwise. The speakers thus seem to orient towards the sensitivity of providing the assessment as a first, and can be heard to *propose* an assessment rather than to *assert* one.

4.3. Assessment reception

In everyday conversation, there is a strong normative expectation for assessments to be followed by second assessments. Such second assessments show agreement or disagreement with the first assessment (e.g. B: Isn't he cute A: O::h he::s a::DORable) (Pomerantz 1984: 60). Pomerantz (1984) and Buttney (1993) stated that agreement is the preferred next action after many types of initial assessment, despite a few instances of preferences for disagreement (e.g. following self-deprecations). In this study agreement seem to be the preferred, but it is not reached by making second assessments, which is the typical practice.

Second assessments are seen in our data as well, but only occasionally. Instead, the recipient of the assessment, the SLT, often reacts with a minimal response like 'yes' or 'mm'. These appear to serve as continuer or acknowledgement token (Drummond and Hopper, 1993; Schegloff, 1982):

(9)

- 01 PWA 7: Jamen det synes jeg da går meget godt.
 well i think it goes quite well
- 02 SLT D: °ja°
 yes
- 03 (0.7)
- 04 PWA 7: Jeg synes jeg kan fortælle en helt lang historie
 05 ↑ikke ↓altså.
 i think i can tell a long story right
- 06 SLT D: jo (0.4) jo
 yeah yeah

Following Pomerantz (1984) and Buttney (1993) such a minimal response can be understood as withholding, or postponing agreement. The PWA in excerpt 9 orients to a withheld agreement by producing an additional argument for her initial assessment in lines 4–7, which is reacted to minimally (line 6). In other words (this) agreement is postponed.

4.4. Substantiation of an initial assessment

By assessing something, the speaker of the assessment claims knowledge of the referent, and can be held accountable for the assessment (Pomerantz, 1984). In the light of a minimal response, which seems to withhold or postpone agreement, we see that the persons doing the assessment in our data usually substantiate the assessment by explicating the knowledge on which it is based. A ‘yes’, ‘no’ or a value term is exemplified usually with an example from either therapy, everyday life or from a specified domain or action. Just assigning a value term such as ‘good’, ‘bad’, ‘equal’, ‘worse’, ‘better’, ‘more’, ‘less’ does not seem to suffice. Examples and specifications substantiate the claim that lies in the assessment.

All participants are seen to make substantiations. Only the SLT, however, can be seen to *request* a substantiation (Buttney, 1993). This can be done implicitly, by producing a continuer, or explicitly. Excerpt 10 provides an example of a substantiation made by a PWA immediately after the assessment:

(10)

- 01 PWA 10: me men jeg tror nok jeg det er blevet bed bedre
 bu but i think i have become bet better
 02 (1.0)
 03 Fordi (0.6) til det start der kunne jeg ikke en (.)
 04 brik.
 because in the beginning i could not do anything
 05 SLT D: °Nej°
 no
 06 (0.5)
 → 07 PWA 10: Slet ikke (.)
 not at all
 08 Og nu (ved jeg at ved) jeg (.) kan huske hvad jeg
 09 hedder.
 and now i know i can remember my name
 → 10 Og hvad mine børn og sådan.
 and what my children and such

Significant others are often involved in substantiation as well:

(11)

- 01 WIFE: Jeg synes du er blevet (.)
i think you have become
02 lidt bedre til det altså hvis hvis vi
a little better at it that is if if we
03 sidder for eksempel i går aftes vi sad fire
are sitting for example yesterday evening we
were sitting four
04 der s- syntes jeg du snakkede utro:lig meget.
i thought you were talking very much

Substantiations that follow an assessment can have different forms. Often the participants refer to specific occasions from their daily lives in which they were successful or unsuccessful with the task type that is being assessed. In other cases, participants refer to recurrent occasions that form the knowledge base for the assessment or the participant may specify their assessment in terms of an account of their personal state of mind (see excerpt 12, lines 7–8, below).

In the case of outcome evaluation, participants explicate in their assessment that they assess based on their own knowledge, and thereby may assess differently from their interlocutor, and, in substantiating their assessment, they exemplify the knowledge upon which they base their assessment.

The substantiations that follow an initial assessment can be seen as a way in which the participants work towards agreement on how the referent is to be assessed. The SLT and the PWA and/or significant others do not have equal access to the referent. Since the referent-to-be-assessed in all cases are complex concepts, substantiation is a way in which some aspects of the referent are made available to the other(s), and simultaneously provide the motive for making the assessment.

4.5. Delaying (dis)agreement

Assessments can be agreed upon if the basis upon which the assessment is made is shared by the participants. As we have seen above, in the case of participants having different types of access to such knowledge, the knowledge can become shared through substantiation. This then provides a basis for (dis)agreement, which typically follows substantiation.

Agreements may be done in different ways by explicitly agreeing after the substantiation of the initial assessment:

(12)

- 01 PWA 26: Jeg synes (0.5) Jeg synes det går rigtig godt
i think i think it goes really well
- 02 SLT L: [jah↑]
yes
- 03 PWA 26: [Det synes] jeg (0.7)
i think so
- 04 Det har givet mig sådan lidt
it has given me such little
- 05 (.) kommet sådan lidt (.) (hjælpe) længere op
came such little help longer up
- 06 SLT L: Ja.
yes
- 07 CL 26: Jeg synes jeg har fået lidt mere (.)
i think i have gotten a little more
- 08 du har givet mig mere selvtillid
you have given me more self-confidence
- 09 SLT L: Og ved du hvad det var det der var meningen.
and do you know what that was what was the intention
- 10 CL 26: Ja.
yes
- 11 SLT L: d- Jeg er også så tilfreds. ((laughter))
i am also so satisfied

Or by implying an agreement, as in the next excerpt (13) where the SLT says that she has been pinpointing to the PWA that she was not able to do this type of task half a year ago:

(13)

- 01 SLT D: Det er jo også det jeg har øh (.) påpeget (.) nogle
02 gange.
that is also what i have been pinpointing a few times
- 03 PWA 7: Ja
yes
- 04 SLT D: har jeg sagt til dig det der
i have said to you that this
- 05 PWA 7: Ja
yes
- 06 SLT D: Det tror jeg ikke du kunne have gjort for (.)
this i do not think you could have done
- 07 PWA 7: næhe
- 08 SLT D: et halvt år siden ikke
half a year ago

It is the case that some of the agreements seen in the data hold features from everyday conversation like agreement by using a stronger positive term that modifies a value term and repeats the assessment (Pomerantz, 1984). For example, in excerpt 12, the PWA has expressed that it goes really well and the SLT makes the assessment stronger by adding she is 'so satisfied'. Similarly, in the next excerpt the word 'lidt' (*slightly*) is repeated by the SLT in her agreement with the PWA:

(14)

- 01 SLT B: Er det ikke gået godt Majken.
did it not go well majken
- 02 PWA 2: Lidt.
slightly
- 03 SLT B: ja↑
yes
- 04 PWA 2: ja
yes
(0.4)
- 05 SLT B: Det synes [jeg er helt rigtig.
i think it is quite right
- 06 PWA 2: [ja ja ja
yes yes yes
- 07 SLT B: Det er gået lidt godt.
it went slightly well

So far the excerpts shown exhibit agreement expressed by the SLTs. They occur most frequently when producing agreements in the data. The data only shows a few examples of PWAs stating agreement:

(15)

- 01 SLT L: Du har klaret det sindssygt godt.
you have managed incredible well
(0.7)
- 03 PWA 26: Ja det føler jeg også.
yes i also feel that

With regard to disagreements, because of the strong preference for agreement, disagreements seem to be rather uncommon in everyday conversation, and if they appear they are usually presented in a weak form (Buttney, 1993). When there is disagreement, features like pauses, pauses filled with ah's and uhm's, particles like well and extensive accounts to explain the disagreement are usually present. Disagreement is rarely seen in our data, but the few noted manifest themselves in weakened form. A few examples of preferred disagreement following self-deprecation are also seen where PWAs are asked to assess

themselves and the SLT subsequently expresses disagreement by assessing the PWAs more positively.

Conclusively we have shown through our analysis a typical pattern of assessment sequences in outcome evaluation:

SLTs: assessment prompt
PWA/significant other: assessing
PWA/significant other: substantiating
SLTs: agreement

Interestingly, this pattern emerges although no formal rules or instructions on how to assess in outcome evaluation exist. SLT's and patients seem to solve the task of assessment by contributing in relevant ways based on common sense.

5. Influence of aphasia

Since in most of the cases we are dealing with PWAs are contributing, it is notable how often these sequences appear to function in spite of aphasic speech. As we have seen in excerpts 9 and 10, the PWA, in the same way the significant other does in excerpt 11 can be heard to offer substantiation, even when speech syntactically or morphologically seems to be deviant (excerpt 10). The corpus includes many examples of aphasic speech, and thus, some of the assessment sequences in the collection likewise contain unintelligible speech produced by the PWA (e.g. excerpt 10 (line 8)). With the unintelligible speech, however, the sequence functions as a typical outcome evaluation assessment sequence. We have found instances in which the participants embark on such a sequence, but where the project is departed because of the PWAs deviant speech. Excerpts 16 and 17 provide examples:

(16)

01 SLT E: men men at du kan bruge de ord du gerne vil
 but but that you can use the words you would like to
02 PWA 13: ja ja [a::::::::::] a:::
 yes yes
03 SLT E: [og bruge dem (0.5) kommunikativt.]
 and use them communicatively
04 (0.7)
05 SLT E: Hvor meget gør du det tror du
 how much do you do that do you think
06 (1.5)
07 PWA 13: (det det somo fomå d- gide gæk mæ) ((unintelligible))
08 SLT E: Den er svær at (.)[svare på.
 it is hard to answer
09 PWA 13: [Nemlig.
 exactly

In this excerpt the SLT prompts an assessment (line 1 and 3) and pursues substantiation in line 5. The long pause in line 6 indicates trouble for the PWA, and the answer in line 7 is unintelligible. Rather than further pursuing substantiation the SLT concludes that this question was hard to answer (line 8). Note that the questions in lines 1 and 3 actually were answered with 'yes' several times. This indicates that substantiation is a significant part of the assessment sequence and without it the assessment is not complete and agreement not obtained. One could imagine that substantiation for the SLT is a way to guarantee that the assessment by PWA is intended as such. This becomes clear in the next excerpt in which a PWA participates has a stereotypical use of the word 'godt' (good) throughout the session, even when there is no assessment:

(17)

- 01 SLT E: Bruger bogen du nogensinde.
do use ever use the book
- 02 PWA 13: Ja det var (.) godt oho.
yes it was good oho
- 03 SLT E: ja
yes
- 04 PWA 13: Den er (.) godt
it is good
- 05 SLT E: ja
yes
- 06 PWA 13: den er (.) uha o (.) den er godt (godt)
it is uha o it is good good
- 07 [uh (...)]
- 08 SLT E: [den er godt slidt]
it is well worn
- 09 PWA 13: [()]
- 10 SLT E: [ja ja] jeg kan godt se den er ved at falde
yes yes i can see it is about to fall apart
- 11 [fra hinanden]
- 12 PWA 13: [nemlig godt godt (0.8) ja ja (0.7) den er godt godt
exactly good good yes yes it is good good

The first part of the sequences (lines 1–3) functions effectively as an assessment despite the aphasic speech, but since it is not followed by substantiation, the SLT chooses to make her own instead of departing the sequence as in excerpt 16.

Both excerpts show an orientation towards the substantiation of the assessment as an essential part of the sequence. If it is not provided, either the assessment is put aside as a non-answerable question or, if possible, the substantiation is offered by someone else – a significant other or the SLT.

6. Discussion

The sequential organization of assessment sequences in outcome evaluation supports a central objective of outcome evaluation as described by SLTs (Isaksen, 2014), which is to secure that the genuine opinion of the PWA and/or significant other is put forward without being influenced by the SLTs own conceptualization. The sequence of contributions resembles Sacks' (1992) description of 'going first versus going second in posing opinions'. Going first means that one party is put in a position (e.g. by a prompt for assessment as in excerpt 3) where an opinion has to be uttered without knowing what the second party will say. This is exactly what happens in our data (e.g. excerpts 7, 14). The SLT can then *go second*, but they usually do not, until substantiation is given by the PWA. In this way, the sequential organization of assessment sequences guarantees, by the PWA *going first*, that he or she has been heard not only by providing the assessment, but also by presenting it as plausible through the subsequent substantiation.

Heritage (2012) makes a distinction between epistemic stance (the moment by moment encoded *claims* of epistemic status) and epistemic status (the actual domain of information/knowledge that a person can draw upon) and asserts that while these two normally converge in a talk at turn, in some cases and for some reasons, they may diverge. It is tempting in relation to our data, to take the alleged difference in epistemic status between a SLT and a PWA and/or significant other as a point of departure in our analysis. The SLTs on the one hand can be seen as relying on professional knowledge while PWAs/spouses typically have better insight in how they function in everyday life in relation to the outcome evaluation. However, with naturally occurring clinical data we have no means that allow us to make a distinction between stance and status – we cannot *document* how a claimed epistemic status, the stance, would or would not con- or diverge from the participant's actual epistemic status. Rather, we see the orientation to different epistemic resources for the SLT on the one hand and PWA and/or significant other as a central condition for doing outcome evaluation. The SLT lets the PWA/significant other *go first* and by withholding agreement calls for a substantiation. In this way the SLT is not only provided with the PWA/significant others opinion, but also with the epistemic resources on which the opinion is made. The substantiation of a PWA's assessment can thus be seen as not only an assertion that makes the assessment acceptable for the SLT, but as providing valuable information for the SLT. In other words, through the assessment sequence including the substantiation, the participants interactively ensure that their experiences become shared knowledge. Thereby, the participants establish a basis upon which agreement can be obtained.

7. Conclusions and clinical implications

In this study, we have identified how participants in outcome evaluations assess PWAs conduct, and work towards agreement. Such sequences of assessment, which can be seen as central to outcome evaluation as an activity, contrast with assessment sequences in everyday conversation in several ways. First, the assessments are prompted by the SLT. After the assessment is done, in which a value term is assigned to the referent outlined in the prompt, agreement is withheld, which is heard as a call for substantiation. After such substantiation is given, the SLT provides a form of agreement. In cases where the substantiation is not given by the PWA or significant other, the SLT either withdraws the assessment, pursues a substantiation, or provides, if possible, one herself. The sequential organization of these sequences points towards issues of epistemics: the initial assessment seems to have the status of a claim, and is presented as subjective. The substantiation provides a form of validation of the claim, and explicates the personal knowledge, upon which the claim is based.

The orientation to different epistemic resources for the SLT and PWA and/or significant other is a central condition for doing outcome evaluation. By letting the PWA/significant other *go first*, the unconditioned opinion of him or her can be warranted. In other words, the PWA has been heard. An interactional approach to outcome evaluation may initially be regarded as less stringent than approaches which utilize (standardized) measures. However, as we have shown, interactional outcome evaluation is not unsystematic. The systematics, however, are founded on interactional logic. In and through sequential organization, the participants deal with the central issues for evaluation which concern epistemics and aphasia as a specific condition. The features of the assessment sequences in our data relate directly to notions of doing outcome evaluation in a Danish context: Hearing the PWA and producing evaluations which are valid. The findings implicate that in this type of evaluation, the requirements of producing a valid account in which the PWA has been heard are being met. Furthermore, although the task of having to evaluate interactively with PWA's can be regarded as a challenge for an SLT, our findings show that SLTs as well as PWAs, without having been instructed in how to accomplish this task, do so in a strikingly similar way across different contexts. We argue, that interactional logic is the driving force in the emergence of this pattern. Apart from basing future practice on the pattern we have described, it may help SLTs to be reminded that an important resource for carrying out these evaluations is their interactional competence as ordinary members of society.

Having said this, practising outcome evaluation like this requires communicative abilities from the PWA. We expect that SLTs make distinctions between PWAs that possibly are or are not able to provide substantiations. We

have shown that in some cases a PWA does not provide substantiation and this may result in the assessment being waived, or the SLT making substantiation instead of the PWA. Also, we have shown that *going first* seems to be sensitive for the PWA and/or significant other, since they have to provide an assessment towards a professional that may have an entirely different opinion. As long as the SLT is aware of this, however, this does not seem to pose a problem for doing outcome evaluation in this way.

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Appendix 1

Transcription conventions

Transcription mainly follows the system developed by Gail Jefferson (cf. Jefferson 1983), with some minor adjustments. Only conventions actually used in the transcript are explained here.

This is a [word]	<i>left-hand brackets</i> mark the onset of
[Oh ye]ah	simultaneous talk by the second speaker
.	<i>right-hand brackets</i> mark where simultaneous talk stops
,	final intonation
	continuing intonation
(0.5)	length of a silence in tenths of seconds
(.)	a silence less than 0.2 seconds
↑	the syllable following the <i>arrow</i> is relatively high-pitched
↓	the syllable following the <i>arrow</i> is relatively low-pitched
°word°	the words or syllables between <i>degree signs</i> are relatively less loud
<u>words</u>	the <i>underlined</i> syllable or sound is stressed
wo::rd	<i>colons</i> indicate stretching of sounds
wo-	a <i>hyphen</i> marks that the speaker 'cuts off' his/her speech
.h	a <i>period followed by 'h'</i> indicates a hearable inbreath
h.	' <i>h</i> ' followed by a <i>period</i> indicates a hearable outbreath
>word<	marks that speech is produced relatively fast
((comment))	double parenthesis for comments
(we say)	transcriber is unsure about the wording

Appendix 2

A value term (assessment) is requested by the SLT, but not added by the PWA.
The SLT continues to pursue it, until it is reached:

- 01 SLT D: du skulle blive bedre til at tale om mere
you should become better at talking about more
- 02 komplicerede(.) og abstrakte Jemner.
complicated and abstract issues
- 03 (0.5)
- 04 PWA 7: jah.
yes
- 05 SLT D: ja
yes
- 06 SLT D: Hvordan synes du det går med det
how is that going do you think
- 07 CL 7: jamen æh (.) øhm det øver jeg mig stadigvæk meget på
well uh ahm i am still practicing a lot
- 08 SLT D: ja
yes
(1.5)
- 09 CL 7: for eksempel så øh (.) så har jeg øh på de der
for example then eh then i have eh at those
- 10 generalforsamlinger som jeg har (.) gået og hygget
AGMs that i have been having a nice time
- 11 mig med haha (.) eh forsøgt at stille spørgsmål
with haha eh tried to ask questions
- 12 SLT D: °ja°
yes
- 13 CL 7: og det synes jeg da i sig selv er en udfordring.
and i think that is in itself a challenge
- 14 SLT D: °ja°
yes
- 15 (.)
- 16 SLT D: Er det gået (.) godt [nok
has that been good enough
- 17 CL 7: [ahj det altså øhm (.) nogle gange
ahj it well ahm sometimes
- 18 als altså så kunne jeg ligesom ikke sige det
we well then i could not really it
- 19 helt helt sammenhængende
fully fully coherently
- 20 (.) men eh jeg tror nok at meningen den kom frem
but i think that the intention came through
- 21 SLT D: ja
yes
- 22 (1.1)

- 23 SLT D: °ja°
yes
- 24 (1.1)
- 25 PWA 7: tøjhø
(0.7)
- 26 SLT D: Hvad når du for eksempel her på holdet har skulle
what when you for example in the group here should
27 fortælle noget (.) med det her med mere kompliceret
tell something with this more complicated
28 og abstrakt der tænker jeg noget der ikke lige har
and abstract here i think at something that does not
exactly has
29 noget med din nære=
something with your present
- 30 PWA 7: =ja=
yes
- 31 SLT D: =hverdag [at gøre
everyday life to do
- 32 CL 7: [ja
yes
- 33 SLT D: men nogle (.) lidt mere sådan lidt bredere emner,
but with a bit more well a little broader issues
- 34 CL 7: Ja (.) Jamen det synes jeg da går meget godt.
yes well i think it goes rather well

6. STUDY 3

“Well, You Are the One Who Decides”: Setting the frame for decision making in aphasia therapy

Abstract

Background: People with aphasia want to be involved in decisions about their health and rehabilitation. Also speech-language therapists express views of willingness to involve their clients with aphasia in therapeutic decisions. Studies of stroke and aphasia rehabilitation have pointed at communication as a hindrance for involvement.

Yet not much is known about, how shared decision making and other involving activities in interactions are conducted between therapist and client with aphasia.

Aim: The aim of the study was to explore and describe speech-language therapists' views of involving clients in decision making in aphasia therapy, more precisely in decisions to be taken during outcome evaluation about continuation or discharge of therapy. Furthermore was investigated, how such involving activities were carried out in interaction between speech-language therapists, their clients with aphasia and possibly significant others.

Methods and Procedures: Data for this study was collected for a broader explorative study about outcome evaluation. Hence the analyses made in this study were secondary analysis inspired by earlier findings in the same dataset. The analytic process was accomplished in two steps as a sequential mixed-methods study with two qualitative methods: Firstly thematic analysis of interviews with 12 speech-language therapists resulting in two themes. Secondly these findings from the interviews

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directed applied conversation analysis of video-recorded sessions with the same 12 speech-language therapists and their clients evaluating outcomes of aphasia rehabilitation.

Outcomes and Results: All speech-language therapists in the study had a wish to involve their clients with aphasia despite recognition of language difficulties and other person-related barriers in all interlocutors. Through the interactional organisation of shared decision making processes, in which the clinicians took the lead often by proposing suggestions, the clients with aphasia got an opportunity to accept these suggestions or otherwise express their opinion within a limited provided context also serving as communicative support due to aphasia.

Conclusions: The shared decision making practiced by the participants was not letting their clients with aphasia decide, whatever they wanted. Instead it was letting the clients have choices within a particular framework. In some cases it meant that the only real option a client had was to accept choices suggested by the speech-language therapist. This suggests that genuine decision making between equal parties is not present and possible within a clinical context additionally challenged by aphasia.

Keywords: aphasic conversation, aphasia therapy interaction, client involvement, shared decision making, thematic analysis, conversation analysis

Background

People with aphasia want to be involved in decisions about their health and rehabilitation after stroke, such as goal setting prior to speech-language therapy (Berg, Rise, Balandin, Armstrong & Askim, 2016; Hersh, Worrall, Howe, Sherratt & Davidson, 2012; Nordehn, Nordehn, Meredith & Bye, 2006; Worrall et al., 2010). Also speech-language therapists express views of willingness to involve their clients with aphasia (Berg et al., 2016; Isaksen, 2014). Nonetheless not much is known about the specifics of shared decision making and other involving activities in interactions between clinicians and clients (see, for example, however Angell & Bolden, 2015; Reuber, Toerien, Shaw & Duncan, 2015; Stivers, 2005, 2006). Nor do we know how people with aphasia manage discussing and making decisions about their therapy. Studies in aphasia and stroke rehabilitation have not surprisingly pointed at communication as a substantial hindrance for involvement, but without looking into the actual communication and what causes the communicative challenges (e.g. Berg et al., 2016; Leach, Cornwell, Fleming & Haines, 2010; Nordehn et al., 2006; Sugavanam, Mead, Bulley, Donaghy & van Wijck, 2013).

To involve clients in decision making a number of approaches have been developed (Barry, 2002; Elwyn et al., 2004; O'Connor, Llewellyn-Thomas & Flood, 2004). These include videos to provide clients with carefully selected information and decision-aiding tools, such as decision boards, to ensure that participants consider various aspects in their decision making. Strategies supporting involvement of people with aphasia are also used in aphasia therapy, for example, visual materials like writing, drawings and pictures (Haley, Womack, Helm-Estabrooks, Lovette & Goff, 2013; Kagan, 1998; Murphy & Cameron, 2006). Furthermore there is also evidence for training health care staff in communicating with people with aphasia to support and enhance involvement (e.g. Burns, Baylor, Morris, McNalley & Yorkston, 2012; Jensen et al., 2015; Simmons-Mackie et al., 2007; Simmons-Mackie, Raymer, Armstrong, Holland & Cherney, 2010; Sorin-Peters,

McGilton & Rochon, 2010). Still the primary medium for client involvement and shared decision making is face-to-face interactions between clinician and client involving verbal language, as well as nonverbal communication. Interaction is therefore the means by which client involvement is done, but how client involvement is interactively achieved is under-researched (Dieppe, Rafferty & Kitson, 2002; Nordehn et al., 2006).

Micro level studies of institutional interaction have shown interdependence between, how doctors design their turns and the nature of the participation of their patients (Drew, Chatwin & Collins, 2001). A study by Stivers (2006) demonstrates how doctors display that they rely on acknowledgement or acceptance in and through the interactional structure, despite the fact that they do not actively invite patients or significant others to share decisions about treatment. In cases of active resistance from patients, decisions made by the doctor possibly changed, even if this change was not beneficial for the patients from the doctors' point of view (Stivers, 2005). Stivers (2006) also showed, how resistance from patients was treated as problem behaviour by the doctor, underpinning a general notion from conversation analytic studies that agreement between interlocutors is preferred in clinical interactions (see also Isaksen & Brouwer, 2015), as it is in mundane interaction (Pomerantz 1984, Sacks, 1987).

Shared decision making can also be compromised by other challenges than the person with aphasia's communicative difficulties or the interaction between him/her and the professional, for example, because of the nature of relationship between the interlocutors. The speech-language therapist and the person with aphasia fulfil different roles: one is a professional expert on the subject the other is seeking help for. The client may not agree with the suggestions made by the professional, and for the professional, the client initiatives might not sound plausible (Charles, Gafni & Whelan, 1999; Robinson, 2001). Institutional interaction as aphasia therapy is often described as a goal-directed behaviour where the participants know their roles and where the

professional usually takes the lead in, for example, controlling initiatives, topics, and questions (Drew & Heritage, 1992). Robinson (2001) describes how negotiation between doctor and patient is accomplished through adjacency-pair sequences, where the doctors lead and the clients follow. The organisation of institutional communication can provide an obstacle for genuine involvement, if the parties do not know or acknowledge their roles and the framework they operate in or if the context changes, as it might do with the newer client involvement approaches.

This study aimed to gain better insight in decision making processes towards the end of aphasia therapy, where decisions about further treatment or termination of treatment needed to be taken. The first step was to investigate speech-language therapists' perception of client involvement and secondly to examine, whether and how it was achieved in actual sessions in which speech-language therapists and clients were scheduled to discuss future plans for intervention.

Methods

The study was inspired by two different qualitative paradigms *ethnography* describing a culture or lifeworld of a number of interviewed people and their observed actions (Geertz, 1973) and *ethnomethodology* aiming through the analysis of naturally occurring interactions to document how people negotiate everyday situations (Garfinkel, 1974). However both paradigms are occupied with presenting the participants' perspectives either through their reported experiences or via their interactional actions.

Setting

The objects of investigation were joint outcome evaluation sessions during or after outpatient aphasia therapy. Speech-language therapist, person with aphasia, and possibly his or her significant others were attending. Regardless of when the outcome evaluation took place, making arrangements

for the future were part of the sessions. This sometimes involved setting new goals, shifting to another type of therapy, or addressing the question of whether therapy should stop or what community activities to enter. It meant that outcome evaluation not necessarily ended the therapy course, since an outcome of the session could be further and maybe with new goals. So in some of the cases outcome evaluation have been recorded more than once for the same person with aphasia. The sessions of outcome evaluation lasted between more than an hour, usually when the person with aphasia was accompanied by a significant other, *and* a few minutes, where the outcomes of group therapy were evaluated around the table with all members of this group participating.

Outpatient aphasia therapy in Denmark, where data is collected, is free of charge and provided by the citizen's municipality under the Act on Special Education for Adults (Ministry of Education, 2015). Some municipalities have their own speech-language therapy service, whereas others buy the services from a neighbouring municipality or a regional clinic, or very seldom from a private clinic. In some places, extended therapy must be granted by an authority whereas in other municipalities, it is clinic managers or speech-language therapists who grant extended therapy.

Participants and data collection

The data set for this study consisted of 33 videos of outcome evaluation sessions in four public outpatient clinics in Denmark, a total of 17 hours recorded over a period of ten months. The participants included 12 speech-language therapists and 28 people with aphasia, which means some of them participated in more than one outcome evaluation session because of long therapy courses; significant others, usually partners or parents, participated in 15 of 33 cases. After the video recordings the 12 speech-language therapists were revisited for qualitative semi-structured interviews. All interviews were transcribed verbatim, whereas only parts of the video recordings

were described though in greater detail using the Jeffersonian transcription conventions (Jefferson, 1984). Both types of transcriptions were made by the researcher.

The participating people with aphasia were all recruited through their own speech-language therapist and with no regard to aphasia type, severity, onset, and so on. The study was explained prior to any observation or video-recordings to all participants before they signed informed consents. Additional ethical clearance was not necessary according to Danish legislation since no personal information was obtained or recorded.

Analysis

A sequential mixed-method study (Morse & Niehaus, 2009a, 2009b), using two qualitative methods, was carried out: thematic content analysis of the qualitative interviews with speech-language therapists (Braun & Clarke, 2006) and applied conversation analysis of the video recorded outcome evaluations (Heritage, 1984; Hutchby & Woofitt, 2008).

Both interviews and video data had been analysed prior to this study, but with different aims (Isaksen, 2014; Isaksen & Brouwer, 2015). During data collection client involvement and shared decision making was not a priori interest of examination, but the prominence of the topic became clear during the first round of analysis especially of the interviews (Isaksen, 2014), though it was not thoroughly investigated until this present study. So a secondary analysis was employed starting with thematic analysis focusing on all aspects of the interviews where involvement was addressed. A thorough process in six phases as described in Braun and Clarke (2006) was followed: 1) familiarising with the interviews including transcription; 2) generation of initial codes/keywords; 3) initial search for potential themes based on the keywords, one theme often covers several keywords; 4) reviewing themes; 5) defining and naming the final themes; and 6) writing up the final findings of the analysis. Especially the phases 2-4 are an iterative process, where the data is revisited with

provision of new keywords or merging overlapping keywords, sorting the keyword over again into themes that best reflects the reported experiences of the participants. The analysis can be based on both a more semantic or latent/interpretive process, however, often a combined approach is used as is the case for this study.

Driven by the results from the thematic analysis instances of involvement initiations and responses were collected in order to do an analysis following conversation analytic procedures. By way of applied conversation analysis and its central principle of next-turn proof procedure where *“speakers display in their sequentially ‘next’ turns an understanding of what the ‘prior’ turn was about”* (Hutchby & Wooffitt, 2008:13) it became possible to not only see, what speech-language therapists did to involve their clients, but also analyse the function of the applied strategies due to the responses of their interlocutors.

The major reason for using mixing methods was to be able to triangulate, what was said about outcome evaluation in aphasia therapy with how it was carried out in and through interactions acknowledging that the “what was said” is only represented by the speech-language therapists in the study and not the people with aphasia. Goffman writes about triangulation (1989, p. 131): *“I don’t give hardly any weight to what people say, but I try to triangulate what they are saying with events.”* It might be a too harsh way to put it, but at least the validity of a description of a phenomenon is increased by triangulation. The triangulation of methods will compensate for eventual weaknesses in one method by using one or more methods to gather data about the same topic/phenomenon.

Triangulation of data can be furthermore be used for validation and corroboration of findings. However in this study it rather serves the purpose of providing a richer and more faceted account of the phenomenon *involvement in decision-making in aphasia therapy* from the participants’ point of views and actions. The use of more than one method will likely facilitate a

deeper understanding (Denzin, 1978; Patton, 1999). Instead the findings were sought validated during data sessions and discussions with peer researchers, as well as the participating clinicians and their colleagues when the clinics were revisited for presentation of the findings.

Extracts of videos and interviews are glossed from the original language, Danish. The original version together with the English gloss is shown in the parts presenting the conversation analysis, whereas original versions of the quotations from the interviews are not presented here because of limited space. All participants are anonymous. Quotations from or references to the speech-language therapists are labelled with the abbreviation SLT followed by capital letters from A to L (not all present in this article). Those from the people with aphasia are labelled PWA and a number 1–28 (not all present in this article), and those from the significant others WIFE, MOM, and so forth.

Findings

From the interviews it became clear that involvement of clients was of significant importance to all 12 speech-language therapists. Moreover, they identified a number of issues related to involvement that they regarded as either facilitators or barriers for involving their clients in decision making. This is described in two themes below. Both topics are further illustrated and expanded by findings from the video data.

Facilitating involvement in shared decision making

The participating speech-language therapists all had a wish to involve their clients in outcome evaluation when decisions of future course or termination of therapy were to be taken. They talked about listening to experiences and opinions as well as agreeing with clients and significant others which points towards different levels of engagement. SLT I said *“I would like there to be time and space for both the significant other and the client and myself to put into words how things are going. I would like the client and the*

significant other to feel that they have had time to say what they would like to say." This indicates that involvement is for all parties to have a say on whatever they want.

The reasons for engaging clients and significant others in decisions seem to be centered around inherent skills and rights; for example, clients are adults that know what is best for themselves: *"It is I, of course, that has the professional knowledge, but the client usually knows him/herself best: 'How does this work for me?' 'What therapy style do I like?' 'Do I want more home exercises, do I want fewer?' 'What can I handle?'"* (SLT I). In accordance with some of the benefits shown in earlier research (Drew et al., 2001; Hersh et al., 2012; Lawrence & Kinn, 2012; Pulvirenti, McMillan & Lawn, 2014), the clinicians spoke of involvement also as a mean of empowering clients and making them active in their own treatment: *"You will make your client active and responsible"* (SLT J).

During the interviews the speech-language therapists emphasised a number of factors they saw as supporting or promoting joint decision making. Several of them described how well they often got to know their clients. Throughout intervention they have monitored changes in their clients' state, and they have matched clients' expectations with their own during the therapy course. Some of the clinicians considered joint decision making as unproblematic because of such close relationship and familiarity, and the continuous discussions of outcomes during therapy: *"Well, I have an idea that the person with aphasia often thinks the same as me, because you have the ongoing contact where you talk about what you think (...). So often you have talked about therapy ending soon (...). You somehow know your client"* (SLT E).

According to the therapists information or explanations given by them throughout the process make their clients feel involved also in the end, when the outcome evaluation takes place: *"I have really tried to explain a lot along the way (...) really explain why we should stop now. That is why it is really important to talk about, what our goals were, what has happened (...) and also say, 'I cannot offer you anything more'"* (SLT G).

Finding the right tools or ways to involve people with aphasia were also seen as being important for successful decision making. Various aphasia-friendly initiatives supporting the interaction, like smiley scales and other graphic illustrations, were used during outcome evaluation to ease accessibility despite aphasia. One clinic for example has started using Talking Mats, a simple system of both custom- and readymade pictures that are moved around on a mat to, for example, indicate subjects or prioritise goals (Murphy & Cameron, 2006): “*I have also started using the method called Talking Mats for evaluation. And it is in fact very, very good because they [the clients] have the opportunity to enter the scene*” (SLT F).

The clinicians’ views of client involvement are reflected in the video-recordings. First of all there is an established procedure of inviting clients and in some cases significant others into these sessions to discuss outcomes of therapy. In most cases some decisions needed to be taken on, for example, continuation or termination of therapy.

The most prominent way of initiating involvement in issues regarding the future is for the speech-language therapists to propose suggestions or own opinion and either implicit or explicit prompt a response from the person with aphasia:

Extract 1

- 1 SLT C: jeg synes jo xx (.) du skal have 10 ekstra timer
well I think [name] you should have an extra 10 hours
- 2 (0.3) 10 ekstra gange
10 times extra
- 3 PWA 4: ja det vil jeg også meget gerne
yes I would also very much like that

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In extract 1 SLT C poses a suggestion of more therapy (line 1-2) which is reacted upon with her client's agreement with that suggestion (line 3). This initiation or first pair part in line 1-2 (Schegloff & Sacks, 1973) could project various reactions from PWA 4. She could have rejected or questioned the idea of more therapy. Yet the acceptance aligns with Stivers' (2006) study, showing that suggestions made by professionals in a clinical context are not necessarily up for discussion, despite taking the form of a proposal or question that potentially could be rejected. Later extracts support this, for example, extract 5 where a therapist suggests a pause and extract 4 about ending therapy are both equally accepted.

The therapists also invite their clients into participation in decision making by asking open questions or request opinions without eliciting own opinions or providing suggestions beforehand:

Extract 2a

- 1 SLT I: men hvad tænker du så er fremtidsplanen (...)
but what do you think is the future plan
- 2 hvad skal vi så nu
what are we supposed to do now

However it is not seen very often or when it is seen it is often questions asked within a closed context set for example by clinical or financial structures:

Extract 3a

- 1 SLT D: vi har aftalt xx at vi skulle snakke lidt om (.)
we have agreed xx that we should chat about about

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- 2 om øh det her forløb det skal være slut nu
 eh if this course should end now
- 3 PWA 5: ja
 yes
- 4 SLT D: eller om vi skal søge kommunen om nogle flere timer
 or whether we should apply for more hours in the
 municipality
- 5 PWA 5: (xxx)
- 6 SLT D: ja (0.6) nu prøver jeg lige at skrive her
 yes now I will just try to write here
- 7 PS: (5.6) ((SLT D writes at piece of paper))
- 8 SLT D: hvis vi nu lige først tager stilling til det
 if we just now first make up our minds about it
 ((SLT D turns the paper toward PWA 5))
- 9 PS: (0.9)
- 10 SLT D: hvad synes du
 what do you think

Extract 2a is an open-ended question (line 1–2) from the therapist to a man with aphasia and it prompts a dialogue between them where he prioritises goals of continued therapy (see extract 2b).

Extract 3a is also an example of a question (line 10), but not as open as in extract 2a. Here the therapist's question follows an explanation of the choices available: stop therapy (line 2) or apply to the municipality for continued therapy (line 4).

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In the videos many of the decisions made about the future seem to be settled without much resistance or disagreement. The findings below reflect facilitating factors in involvement mentioned by the therapists in the interviews, *familiarity with the clients, support from, for example, visual materials and explanations from the therapists*, but also other enabling means of joint decision making.

The following extract (follows extract 2a above) is showing, how the interlocutors are familiar with what can be regarded as a common frame for talking about the future. The client starts prioritising former therapy goals in a new order for continued therapy and seems very capable of this task he initiates after being asked about the future plans:

Extract 2b

- 3 PWA 21: °øhm° (1.7) det samme men ehh mål nummer tre skal
ehm the same but ehh goal number three must
- 4 (2.1)blive eh (.)op op hahh opdateret (2.4)
get eh up up hahh updated
- 5 så det er hoved (på armen)
so it is the head (at the arm)
- 6 SLT I: ah okay
- 7 PWA 21: tror jeg
I believe
- 8 SLT I: ja
yes
- 9 MUM: °opprioriteret°
greater priority
- 10 PWA 21: ja ja

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yes yes

11 SLT I: ja (0.5) så vi forsætter med at

yes so we continue with

12 SLT I: [få helt styr

gaining full control

13 PWA 21: [men eh øh nu mål nummer to skal også være eh

but eh eh now goal number two must also be eh

14 SLT I: ja den bliver vi lige som nødt til at have helt styr på

yes that we must really take control of

15 PWA 21: ja nemlig ja

yes exactly yes

16 SLT I: ja så forsætter med mål nummer to

yes so continuing with goal number two

17 PWA 21: °ja°

yes

18 SLT I: og mål nummer tre

and goal number three

19 PWA 21: °ja°

yes

20 SLT I: ja

yes

21 PWA 21: og så eh (.) mål nummer et skubber eh vi lidt væk

and then eh goal number one we push eh away a little

22 SLT I: ja

yes

23 PS: (0.4)
 24 SLT I: det gemmer vi til senere
we save that for later

PWA I's answer is prompted by the open question in extract 2a following a conversation about the client's former goals for the last therapy course. The goals were listed on a piece of paper in front of the participants. PWA 21 wanted to work with the same goals, but differently prioritised for the next course of therapy (lines 3-5, 13-14, and 21). The clinician fed into his sentences by formulating his suggestions (lines 11-12, 14, 16, 18, 24). In that sense the clinician's input is a display of understanding, but also of agreement, which is exceptional compared to most of the data, in which the clinicians either proposed suggestions or provided options in a given context. This extract could also be regarded as an example of a clinician initiated involvement within a closed context, namely goalsetting with the same goals as last therapy course. Nothing, however, in the open question (extract 2a, line 1-2) points towards that, but it projected an answer from PWA 21 that he understood it like that and also the therapist treats it as expected when she makes the summation.

The use of visual materials to support the challenged communication of some of the clients is seen several times. Both readymade materials and the use of strategies as writing and drawing are seen. Back in extract 3a the speech-language therapist supports her verbal expressions with written keywords. She initiates the decision making process by outlining the possibilities of either ending therapy or applying for more hours (line 1-2; 4). When the person with aphasia produces an unintelligible response in line 7 the clinicians supplement with written keywords for PWA 5 to point at. Similar to extract 2a an open question is asked in line 10. Here the clinician wants an opinion from the client, who is presented with limited options, serving as a kind of candidate answers, now written down for answering the question. By using a written supplement to verbal

communication the clinician promotes involvement in the form of the person with aphasia being enabled to point at his pick, but also elicit a verbal answer he did or could not do initially:

Extract 3b

11 PWA 5: m- mere ((points at the paper))

m- more

12 SLT D: du peger på mere

you are pointing at more

13 PWA 5: ja ja

yes yes

Since the clinician makes the two choices of response, this support does not necessarily lead to the same type of involvement as if the person with aphasia could make his own response either verbal or written. Nonetheless several studies show that supported communication with people with aphasia promotes involvement (e.g. Klippi, 1996; Simmons-Mackie et al., 2007).

Providing the options or candidate answers as SLT D does are also described in mundane conversation as well as in other studies of challenged interlocutors as bilinguals (Svennevig, 2012) and institutional contexts (Drew & Heritage, 1992). Here candidate answers, for example, serve as a support for people with limited skills either on a linguistic level (non-native speakers) or a contextual level (institutional communication). For PWA 5 it could be hard to answer the apparently open question “what do you think” (extract 3a, line 10) without being supported by the candidate options, here both in a verbal and written format. He like needs the support not only because of his aphasia, but also since he likely did not have the same knowledge of the possible options in the given context as the therapist had. So visual and probably other support will

inevitably limit the options, but at the same time provide a context that is necessarily to have in order to make decisions about future therapy courses.

The last facilitating factor mentioned in the interviews was explanations from the therapists during the therapy course leading to a joint decision making without disagreement or trouble. In this next extract the person with aphasia knows that therapy needs to end now

Extract 4

1 SLT L: hvad så nu

then what now

2 PS: (5.3)

3 SLT L: fordi faktisk så (0.5) dit forløb har været

because actually your course has been

4 meget meget længere end der var aftalt

much much longer than agreed

5 PWA 26: °ja jeg fik jo omkring tyve°

yes I got around twenty

6 SLT L: ja

yes

7 PS: (1.8)

8 SLT L: det det har været fordi at det har der været behov for

it it has been because it was needed

9 PS: (0.8)

10 SLT L: så det er helt okay

so that is quite okay

11 PS: (4.7)

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- 12 SLT L: du vel- du ved ved næsten godt
you vel- you know know almost
- 13 hvad jeg vil sige nu gør du ikke
what I am about to say now don't you
- 14 PWA 26: ja at jeg skal stoppe ((smiling))
yes that I must stop
- 15 SLT L: jah ((laughing))
yeah
- 16 PWA 26: ja jeg ved det godt (.) ja
yes I know yes
- 17 SLT L: det har du være indstillet på
you have been prepared for that
- 18 PWA 26: °jeg ved det godt° ((looking down))
I know

In extract 4 the speech-language therapist explains why the therapy has to end (line 3-4) and the client knows beforehand (line 14, 16 and 18). However, the long pause in line 2 together with the therapist's use of qualifiers in the argumentation ("actually" and "much much" in line 3-4) could indicate, for example, discomfort with the fact that additional therapy is not being offered or an attempt to increase the argumentation for stopping therapy (Pomerantz, 1984). PWA 26 is given many opportunities to respond in the long pauses in lines 2, 7, 9 and 11. In lines 12-13 SLT L asks PWA 26 for the decision she is about to give. It is provided by PWA 26 in line 14. Despite PWA 26 not being surprised by the fact that she must cease therapy, she gazes down in line 18, which might express disappointment or disagreement together with the long pauses. During the extract PWA 26 provides the decision "*I must stop*" herself, and maybe that is the reason she does not or cannot

question it. This explanation of why therapy needs to stop, during the extract and perhaps also earlier in therapy, indicated by SLT L's comment in line 17, can make the decision making progress easier for the parties, however, not necessarily as indicated by the silence and the gaze of the client.

Extract 4 resembles other instances in the dataset, namely that some of the decisions to be made are actually already made and nothing is really to be decided, but yet it is treated as if it can be discussed and negotiated (line 1). In some instances the payer, the client's municipality, announces prior to a course of therapy it will pay only for so many hours and additional funding of therapy is non-negotiable, whereas in other cases it seems to be the therapist's decision that cannot be discussed. In extract 4 the circumstances are not clear, but since PWA 26 got more therapy than initially agreed upon that could be the reason for deciding to end therapy. This indicates that attempts to involve clients and make joint decisions are not always genuine because the decisions sometimes are taken beforehand due to, for example, professional judgement or contextual limitations. Yet it is still framed as if it can be discussed, but perhaps it is rather the clinician pursuing agreement or acceptance of the decision presented for the client.

Barriers to involvement in shared decision making

According to the participating therapists efforts to engage people living with aphasia can also face hindrances or otherwise be challenged. Resistance to shared decision making from both professionals and clients is an often-mentioned barrier in other studies (e.g., Légaré, Ratté, Gravel & Graham, 2008). Reluctance from some clients was reported by a few of the clinicians. It occurs for example when the clients either do not understand the idea of being involved, do not want to or feel unable to be involved in decisions: *"I actually think that for many [clients] we are the ones who make the decisions"* (SLT I); *"They [people with aphasia] would really like to have someone taking responsibility and someone that can direct them (...). If you have had a stroke, then you*

might not have the surplus energy to have an opinion about how you should do things; instead it makes them unsecure” (SLT C).

It seems irrelevant to talk about resistance from the participating therapists, because they all expressed preferences for involving clients in outcome evaluation. However, a premise for involving clients in decision making is likely to let go of matters that could be regarded as professional responsibilities. For example, there appears to be a schism between being prepared and thereby a responsible clinician, but at the same time being sufficient flexible to take input from clients into consideration and maybe end up with a different decision than initially thought of or planned. For a therapist, it can hardly be regarded as unreasonable to prepare for any contact with a client and, in that sense, to make decisions: *“I think that I have a tendency to draw some conclusions before an end evaluation, because otherwise I am not able to be prepared” (SLT B).* Several clinicians mentioned their considerations being part of their professional responsibility: *“I think it would be professionally irresponsible if you did not do it [consider the outcome beforehand]” (SLT A).* The same clinician continued that she never made any decisions but just considerations: *“Well, I have made a professional estimate and that is it [pause], but that is not even true, because in some instances, I think I have actually (...) made a decision.”* Though several of the speech-language therapists emphasised that reasonable or strong arguments should be presented by clients and significant others in order to modify their considerations: *“When you then have this talk in the outcome evaluation, there have actually been some times when I have changed my mind a bit as opposed to what I thought beforehand. Because then you maybe have some other inputs” (SLT H); “They must be some good arguments for why they [people with aphasia] should continue [in therapy], but I can be swayed by what they say” (SLT D).* This indicates that the professional has a particular role as the one to judge either whether an argument from another person is strong enough to be taken into consideration.

In accordance with previous research (e.g. Berg et al., 2015; Leach et al. 2010) the interviewees report of difficulties with involving clients because of aphasia: *“There is hardly much interactive user involvement in it, but it is because they have difficulty expressing themselves.”*

(SLT F) Similarly language reception can also prevent the speech-language therapists from involving their clients: *“Well, for example, it can be really hard to evaluate with people with aphasia having difficulties in language comprehension. It is difficult, and I must evaluate without the affected being present. (...) It also happens that once in a while I must tell an affected person, ‘Now I will speak to your wife, and is that okay?’”* (SLT L)

Challenged involvement as described above by the therapists resonates in the video-data. The core of the organising structure in the decisions taken is the earlier described adjacency-pair sequences in which asymmetry is projected. When the professional takes the initiative by proposing a view of future plans, it is sequentially a challenge to reject the suggestion because there is an interactional preference for agreement seen in mundane as well as institutional interactions (e.g. Isaksen & Brouwer, 2015; Pomerantz, 1984). It is further challenged by the communicative barriers due to aphasia. This interactional asymmetry between speech-language therapists and people with aphasia seems to be a trait, both parties orient to. Decisions about the future of aphasia therapy are often made in an unproblematic atmosphere where a mutual acceptance of the clinician-proposed suggestion is more common than negotiation not to mention disagreement. In the following, the client directly states how he orients to the therapist as the decision maker:

Extract 5

- 1 SLT L: så (0.5) ja så mit forslag er at
 so yes so my suggestion is that
2 vi at at at vi starter med at holde en

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- we that that that we start with taking
- 3 pause (0.3) og ser hvad der sker
a break and see what is happening
- 4 WIFE: °ja° ((nods))
yes
- 5 PS: (4.8)
- 6 SLT L: hvad siger I til det
what do you say [think] about that
- 7 PS: (2.1)
- 8 PWA 28: ja det er jo dig der bestemmer
yes well you are the one who decides
- 9 SLT L: ja:h men det er ikke så meget med at bestemme
yeah but it is not so much about deciding
- 10 det er fordi jeg vurderer hvad du får ud af det
it is because I consider what you will gain from it

The explicit suggestion from SLT L in lines 1–3 is not readily accepted by the client or his wife (lines 4–5). This response could in principle have functioned as accept of the suggestion, but can rather be regarded as an acknowledgement token (Jefferson, 1983) or maybe be even disagreement since it is soft-spoken. The therapist continues in line 6 by requesting their opinion of her suggestion. Again her first pair part is followed by a long pause, before PWA 28 finally says in line 8 that the speech-language therapist is the one who decides. The clinician does not deny this statement in line 9-10, but instead gives an argument for her suggestion underpinning her professional stance in this case. So despite calling it a suggestion (line 1) and asking the couple for their opinion (line 6) it is still understood as a decision by all parties (line 8-10). This example

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underlines the asymmetry between the involved parties due to the preference for agreement and the function of the therapist making the first pair part, which are genuine challenges for involvement in decision making.

In the next extract the person with aphasia takes the initiative to ask a question about future therapy before anything is proposed by his therapist:

Extract 6

- 1 PWA 25: jeg vil meget gerne ko komme igen
I would very much like to co come again
- 2 SLT L: okay ((take up a pencil and starts to write))
- 3 PWA 25: ja ja (.) fordi jeg mangler al- noget altså (.)
yes yes because I need (al-)something right
- 4 eh jeg synes det har været meget godt i perioden
eh I think it has been very good for the time being
- 6 SLT L: mm ((still writing))
- 7 PWA 25: men har jeg nogen mulighed for det
but do I have any possibilities for that
- 8 SLT L: det er så det vi snakker om ((laughing))
it is what we are talking about

In this extract 1.5 minutes into the outcome evaluation session the person with aphasia makes this first pair part by stating that he would like to come back for more therapy (line 1). The minimal response he gets from his speech-language therapist in line 2 prompts him to elaborate his first statement (line 3-4). Again the therapist reply with a minimal response *mm* (line 6), and eventually PWA 25 asks if his wish to continue therapy is possible. The therapist's response is not a yes or no

as the question projected for, but is rather a postponement of it and is said with laughter. The responses okay or mm from the clinician in lines 2 and 6 to the initiative from PWA 25 in line 1 and eventually the lack of reply likely indicates that the initiative or suggestion should not come from him or maybe just not at this early point in the conversation. So despite the person with aphasia taking an interactional initiative here, that could support involvement, it is more treated as untimely by the therapist supporting that involvement initiatives should come from and be regulated by the clinician. Extract 5 and 6 both show, how the involved parties orient to the speech-language therapist as the decision maker or at least the initiator of decision making. Making the first pair part plays a great role in how the clinicians make their proposal for future decision and seek acceptance and only in one instance (excerpt 6) throughout the dataset a person with aphasia does that, but is turned down by his therapist.

The data points primarily in the direction of the speech-language therapists being in control of involvement and decision making, as shown in the sequential organisation where nearly all first-pair parts from the clinicians project for second-pair parts from clients or significant others accepting the first move. Clinician-driven decisions seem to be favoured by both the speech-language therapists and the clients. When comparing the observational data with the interviews, it is clear that this preference for clinician-made decisions, rather than being imposed deliberately or intentionally by the speech-language therapists, is employed through the organisational structure, which provides an illusion of a shared decision-making process. In the following, problem areas in decision making will be discussed.

Discussion

Unclear context

Referring back to one of the most cited definitions of shared decision making, from Charles, Gafni

and Whelan (1997), the prerequisites that at least two people are present, they share information and reach an agreement are seen met in the data. However, one last defining part according to Charles et al. (1997) is lacking here, and that is both parties taking steps to participate in shared decision making. Probably it is difficult to meet this criterion because of the institutional context where the professional is more likely to take interactional initiatives than the client as is also seen in this data set. Furthermore these clients can be additionally challenged by their aphasia when attempting to take initiative.

Lack of knowledge of what involvement and shared decision making are for both professionals and clients might partly explain why it can be difficult if neither party knows or is aware of, what is actually possible to decide. Extract 1 is the initiation of an interaction where ten hours of continued therapy is offered by the speech-language therapist, which the client immediately accepts. Later she tells, she was afraid to be told to stop therapy. This shows that this person with aphasia did not know what her options were. If she had been told from the beginning that they was going to evaluate her therapy and make decisions about her future, then she might could have contributed in another manner.

This mentioning of hours of therapy is also seen in other extracts (3a/b, 4) in contrast to how therapy is described by speech-language therapists and in the legislation, both of which state that aphasia therapy is supposed to be goal-driven and not driven by a certain number hours. Such findings point toward another unclear contextual barrier: what is up for negotiation? There is no point in negotiating whether therapy should stop or continue if, for example, the speech-language therapist or funder has already decided that therapy will stop. A greater transparency in general about the services being offered and what is up for negotiation is needed.

In some cases (e.g. excerpt 3a/b) the context is outlined by the therapist as candidate answers. However in this specific case the candidate answers (stop therapy or apply for more

therapy) were an attempt to support the person with aphasia's language difficulties rather than providing a context. What is at stake is important to put on the table to generate a genuine negotiation of future plans rather than pretending that everything is possible if it is not.

SLT G touched upon a significant factor for successful involvement, when she in the interview mentioned the importance of communication and transparency around therapy, including honesty if one thinks there is no more to do. I am aware that most speech-language therapists do communicate a lot with their clients, but do they also communicate about issues that can be problematic? Hersh (2009) has outlined eight reasons for why discharge is hard from the speech-language therapists' point of view, e.g. inadequate explanations, limitations to negotiate, and discharge as an unclear phenomenon. Some of Hersh's results are in keeping with, why involvement or shared decision making is difficult in the context of this study. Clear communication of what is expected in the situation of outcome evaluation from both the clinicians, but also the other participants, is crucial for being able to participate genuinely.

Resistance is dispreferred

Reaching agreement between the parties is, as stated above, a part of Charles et al.'s (1997) definition of shared decision making. Earlier studies show strong preferences for agreement in mundane as well as institutional interactions (Isaksen & Brouwer, 2015; Pomerantz, 1984; Sacks, 1987). Hersh (2009) also has implied that some things are hard to talk about when moving towards ending therapy and might therefore not be addressed. Those studies together with Stivers' (2005) description of resistance being treated as problem behaviour in medical encounters and findings from the data lead to the assumption that resistance is something that is actively avoided and suppressed. For instance, in extract 4, the client might not protest against the fact that she is ending therapy, because prior to the news of therapy discharge the speech-language therapist states that she

has already received far more therapy than initially agreed on. This avoidance of resistance seems paradoxical because it closes down genuine discussions of, what is the best decision for the client.

The role of the speech-language therapist

Professional autonomy can be challenged by any kind of client-involving activities and is often mentioned as a barrier for involvement (Légaré et al., 2008). This leads to an issue worth discussing in this context, namely aphasia and the inequality between the parties because of their very different language skills. Hersh (2009) has found that aphasia contributes to the difficulty in shared decision making around discharge, but we know that there are many benefits of shared decision making and that people with aphasia want to be involved in therapy, goal setting and decision making in general (Nordehn et al., 2006; Worrall et al., 2011). The participants with aphasia in the Nordehn et al. (2006) study suggested that sufficient time and respect, among others, supported them in communicative involvement. In other areas of medical care, decision making tools are often promoted as a good facilitator. Within aphasia therapy there are not any specific decision making tools described in the literature, but communication with people with aphasia is though seen supported in various ways. An example of visual support is seen in extract 3a/b, when the question is whether the client wants more therapy or not, in contrast to extracts 4 and 5, where two clients are not supported in providing their opinions on the ending or pausing of therapy. However it can be because of those clients' remaining verbal abilities, but might also be due to avoiding problem behaviour i.e. protest against the decisions.

Visual support and other types of tools might be supportive, but these and any upcoming decision making tools still require verbal communication. Most likely conscious ways of involving people with aphasia in communication, like Talking Mats (Murphy & Cameron, 2006) or Supported Conversation for Adults with Aphasia (Kagan, 1998) would be beneficial in many complex

interactions as shared decision making. However, facilitating communication as seen excerpt 3a/b also inherently has constraints due to the reduced numbers of options the therapists provides. So at the same time visual support is giving a potential context, but is also at risk of limiting free responses from the person with aphasia.

Concluding remarks and future directions

Involving clients in decision making is according to the 12 participating speech-language therapists important for them. Throughout the video data the clients are getting numerous possibilities to pose viewpoints, but all initiated by the therapists. When the therapists produce the first pair part there is according to Schegloff (2007) a chance for them to prompt the specific answers by the clients in their second pair part. As mentioned earlier studies have shown, reaching agreement is preferred to disagreement (Pomerantz, 1984). This can make it awkward for the client to disagree with the suggestion proposed by the speech-language therapist. Furthermore the therapists often provide options or candidate answers likely either to support the person with aphasia linguistically or to communicate the context for involvement. This points towards involvement and shared decision making as a clinician induced process (e.g. excerpt 1, 2a, 3a, 5, 6) where agreement or acceptance from the clients is pursued rather than negotiating from unlimited free choices (extract 2a/b). Instead client involvement can be 1) have the opportunity to accept the therapist's suggestion (extract 1, 4, 5) or more unlikely protest against it; 2) choose between given options limited by e.g. institutional context and communicative support (extract 3a/b). A clarification of what involvement is and what is expected from the participants would likely help all parties move from illusory to genuinely shared decisions, as attempted in extract 2a/b.

Additional studies of how shared decision making is conducted and how it can be supported by speech-language therapists and contexts are needed to support and expand the findings above, as well as increase clinical awareness of how involvement is created in and through interaction.

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7. FINDINGS, DISCUSSION AND IMPLICATIONS

This final chapter is divided into three parts: Firstly, a summary and discussion of the main findings will be presented for all four research questions. Secondly, the strengths and limitations of the study and its methods will be discussed. Lastly, clinical implications and further research needs are presented.

7.1 Overview and discussion of main findings

The overarching aim of this thesis was to scrutinise outcome evaluation in aphasia therapy from the speech-language therapists' point of view and their interactional practices. As described in chapter 1, the motivation for the study came from different directions: interactional research and different changes in the profession of speech-language therapists as well as in local and global contexts. The following research questions were answered via the three studies in chapters 4 (study 1), 5 (study 2) and 6 (study 3):

1. *Why are speech-language therapists conducting outcome evaluation according to themselves? (7.1.1)*
2. *What role does outcome evaluation – and the action of making it – play in aphasia therapy according to the speech-language therapists? (7.1.2)*
3. *How is outcome evaluation constituted in and through interactional sequences with speech-language therapists and people living with aphasia? (7.1.3)*
4. *How is involvement of people living with aphasia taking place in outcome evaluation according to the speech-language therapists and their actions? (7.1.4)*

As an inductive, data-driven and ethnographic-inspired project meanings and interests, conveyed by interviews with speech-language therapists as well as observations, have generated themes and insights, leading to further studies of recorded outcome evaluation sessions by means of conversation analysis. The three studies provide new understanding and awareness of the roles outcome evaluation in aphasia therapy can play in clinical practice according to the speech-language therapists including how, and by what means, they are made.

7.1.1 Outcome evaluation as a natural part of clinical practice

The results from the interview study (chapter 4) suggest an interesting relationship between political and managerial policy and the therapy practice relating to outcome evaluation in answering the first

research question: *Why are speech-language therapists doing outcome evaluation according to themselves?* Guidelines to current legislation recommend outcome evaluations are performed in order to document progress and therapy effectiveness (Ministry of Education, 2009). The majority of the participating speech-language therapists describe outcome evaluation as something externally induced to them. Whether this stems from the political system or from the local management is, however, unclear. Nonetheless, it is an activity they have taken to heart. The therapists found outcome evaluation to be very meaningful, and it is seen as an inherent part of therapy and would have been performed despite no external demand for it.

The scenario described by Sarno (2004) of financing – ruling the aphasia therapy agenda using outcome evaluation as a tool – has, according to this study, not been shown to be the entire truth. The therapists in the study describe funders being interested in outcomes of therapy but, aside from spending too much time on report writing after outcome evaluation, the therapists do not seem to mind the process itself – almost the contrary. Instead, outcome evaluation has become a natural part of the therapy process, which could be considered to show that the profession has matured, as noted by Worrall (1999), or at least has changed due to both external and internal circumstances. However, now that outcome evaluation seems to be a natural part of the researched population in Denmark, it might create other discussion points such as, for example, how will the activity influence the rest of the therapy course? Outcome evaluation is at the end of a therapy process, but it can still have an impact on how therapy methods are selected. If the clinician knows that, at the end of the day, he/she needs to show results, the therapy methods might be more carefully selected for the benefit of those living with aphasia in conjunction with the so-called washback or backwash effect known from teaching (i.e. the impact of testing on teaching) (Cheng & Curtis, 2004).

7.1.2 Multiple purposes of outcome evaluation

When studying the second research question, *What role does outcome evaluation – and the action of making it - play in aphasia therapy according to the speech-language therapists?* it was found that assessment of everyday communication and documentation of progress for record keeping purposes are seen as useful products of outcome evaluation, yet outcome evaluation has also shown to serve other purposes in a clinical process. Aside from the more obvious purpose of using outcome evaluation to document therapy processes, the perspectives of the participating speech-language therapists revealed purposes such as creating insight for the person with aphasia in his/her

individual situation, and keeping track of where therapy is, and should be going, for the therapist, thus giving voice to clients, involving them and making shared decisions about the future. Such findings contribute towards broadening earlier descriptions of outcome evaluation as yet another way to control speech-language therapy (Hesketh & Sage, 1999). The clinicians in the study express how something potentially involuntary, and perhaps without much clinical purpose, at least on the surface, can become an activity they prefer to perform, and even because it serves several clinical purposes.

The interaction-based outcome evaluation seen in this study might fit into, and cover, a need for outcome evaluations tailored for complex interventions. Aphasia therapy is, amongst clinicians and researchers alike, regarded as a complex intervention because of the many interacting components (Craig et al., 2006, 2008). A number of requirements for what makes intervention complex have been set and some of them also target outcomes (Craig et al., 2006). In their article, Craig et al. also state that a single primary outcome measure in trials of complex interventions needs to be supplemented by other measures in the attempt to uncover the different outcomes of therapy, i.e. serving other purposes. The nature of interaction-based evaluation also taps into the mindset from New Public Management, where every move in public services needs to be purposeful, albeit more from an economic point of view rather than from the perspective of individuals. Combining and acknowledging interaction-based evaluation with other types of outcome evaluation tools, meets needs and becomes purposeful to the large number of stakeholders and not only for the researched population of clinicians in this study.

7.1.3 Interaction as an outcome evaluation tool

Diverging from earlier studies of outcome evaluation in the U.S., Canada, Australia, Norway and the U.K. in focusing on assessment tools used for evaluating outcomes, the present studies reveal outcome evaluation to be accomplished by talk-in-interaction (Hesketh & Hopcutt, 1997; Worrall & Egan, 2001; Simmons-Mackie et al., 2005; Lind & Haaland-Johansen, 2013). Formal tools or known methods are only marginally present in these therapists' perceptions of outcome evaluation (the interviews as presented in chapter 4). The finding from the interview studies, that tools were relatively absent, is supported by the recordings of outcome evaluation. With conversation analysis as the applied method for analysis, it was possible to describe *how outcome evaluation constituted in and through interactional sequences with speech-language therapists and people living with aphasia* (research question 3). Two different stages during the outcome evaluations were subject to

scrutiny: a recurrent agreement reaching process of the personal outcomes for the person with aphasia (chapter 5) and shared or attempted shared decisions about the future therapy course or termination of therapy (chapter 6).

In and through sequences of conversational assessments, agreement of the personal communicative outcomes of therapy – usually specified by goals set prior to therapy – was reached (chapter 5). These recurrent sequences were initiated and prompted by the therapists by asking the person with aphasia for an assessment. The assessment was generally provided in a hesitant manner by the person with aphasia. Immediate second assessments, as seen in everyday conversation, (Pomerantz, 1984) are withheld by the therapists. In this way, the assessment is treated as a subjective claim that needs to be substantiated. The substantiation makes the claim valid, since the person with aphasia refers to the claimed skill as being either performed inside the therapeutic setting or in a natural context.

The interactional organisation of the sequences shows a preference from the therapist for allowing the person with aphasia to ‘go first’ in order to assess his/her own skills and again make the assessment valid by substantiating via reports of lived experiences. By asking for substantiation, the therapists seek information outside their own epistemic domain – namely in the domain of their clients. Accordingly, a basis for agreement amongst the interlocutors is set. The sequences of interactional created outcome evaluations meet the requirements for producing a valid account in which the person with aphasia has been heard. Specifically, hearing what the person with aphasia says is crucial for the speech-language therapists (chapters 4 and 6). Furthermore, it is an excellent example of a systematic outcome evaluation not based on the use of specific tools, but rather on interactional logic.

Does the systematicity in this institutional talk of outcome evaluation mean, however, that interaction is an adequate outcome evaluation tool? For example, in terms of obtaining quantitative results for comparison with either the client’s own pre-therapy data or with other results from research or clinical practice, it might be regarded as insufficient and biased (Kovarsky & Curran, 2007). Moreover, this type of outcome evaluation does not meet Brady et al.’s (2016) call for better tools measuring functional communication in a globally accepted, valid, reliable and comprehensive manner. However, interaction-based outcome evaluation can certainly be considered a method with high internal validity, or at least it has the potential to be. It is the evaluation of language achieved by means of language, which on the one hand, can be ideal if the all participants in the interaction are aware of that premise, however, on the other, it is not unproblematic, since the

person with aphasia is likely to be disadvantaged in such a type of evaluation. The disadvantages can be due to the aphasia, but also because it can be awkward to evaluate yourself in front of an expert or challenging to evaluate the therapy in front of the therapist, especially if you are not satisfied.

The interactional insights from this, and other studies in the future, can perhaps refine interaction-based outcome evaluation and should certainly be respected for their systematicity, flexibility and potential realistic features.

7.1.4 Involvement of people with aphasia in outcome evaluation

The purpose of using outcome evaluation as a method or time point in the therapeutic process for involving people living with aphasia was enhanced by the clinicians and is also present in the video observations. Themes such as person-centred approaches and client involvement are earlier present in the aphasia literature with, in particular, goal setting as a crucial point (e.g., Haley & Wangerman, 2012; Simmons-Mackie and Damico, 2011; Worrall et al., 2010). However, findings from this thesis answering the last research question *How is involvement of people living with aphasia taking place in outcome evaluation according to the speech-language therapists and their actions* point towards outcome evaluation as an equally important procedure for involvement, since many decisions still need to be taken for the person with aphasia. At the same time, study 3 (chapter 6) also highlights some of the difficulties that can be met in involvement during outcome evaluation. This means that, despite the view on outcome evaluation as an opportunity to involve people with aphasia, the clinicians are also facing a complex task that potentially excludes people with aphasia rather than including them (Andersen & Isaksen, in press; chapter 6).

The methods and systematicity seen in the assessment sequences differ from those in the interactions around future decisions, which study 3 (chapter 6) treats. The findings here reveal the therapists as initiators of involvement such as in the process of agreement reaching. What differs is the fact that therapists predominantly go first when it comes to initiating decisions about the future, as possibilities for continuation or termination of therapy. This means the therapists are taking the opportunity to prompt specific answers for the people with aphasia to provide in the second pair part (Schegloff, 2007). Additionally, speech-language therapists frequently provide options or candidate answers for people with aphasia. This is a procedure earlier described for conversations with linguistically challenged people (Svennevig, 2013). However, apart from supporting the involvement of people with aphasia, it also points towards involvement in decision

making as being something the professional can conduct within some limitations rather than negotiating, for example therapeutic future, with no set limits. The involvement of people with aphasia also proves to be challenged at points, since agreement in interactions is preferred over disagreement (Pomerantz, 1984). The findings in chapters 5 and 6 reveal awkward moments when disagreement is proposed, or agreement when disagreement was likely preferred. The findings from interviews with the therapists (chapter 4 and 6) also point to involvement as being difficult, but at the same time of utmost necessity to them. In particular, the methodological triangulation in chapter 6 has revealed new insights into the involvement of people with aphasia. If it were not for the clinicians' emphasis on the purpose of client involvement in outcome evaluation, the second conversation analytic study would probably not have centred upon this topic. Furthermore, the combination of methods underpins the results of prior studies of clinicians' perception of client involvement (Berg, Rise, Balandin, Armstrong & Askim, 2016) and contributes to an under-researched perception of how client involvement takes place in aphasia therapy.

An exploration of interaction as a means or method by which outcome evaluation and client involvement is accomplished adds layers of knowledge, but also, at the same time, complexity to the actions. Drew, Chatwin and Collins (2001) state that we still need to understand what is contributing to success and failures of different interactional styles and strategies, in order to know and describe what, for example, how an appropriate involving interactional style would look.

Back in 2012, the Danish researcher and sociologist, Rasmus Willig, wrote a feature in a widely read Danish newspaper about the negative consequences of New Public Management (Willig, 2012). He notes how this philosophy of governance has brought a focus of results instead of process into public services. This risk is also faced in the whole idea and agenda of conducting outcome evaluation in aphasia therapy. Willig observes how the opportunities for user involvement have been replaced with surveys of consumer satisfaction, evaluations, standards and procedures, all of which are also seen in aphasia therapy and other areas of healthcare. This study, however, shows how the therapists making outcome evaluations try to navigate between standardised and individual therapy by specifically using outcome evaluation as a method for involving people with aphasia. This study therefore contributes to how speech-language therapists become better decision-makers in clinical practice for the benefit of, and together with, clients with aphasia. These findings are in accordance with medical historians' descriptions of medical education and development: the

nineteenth century was a diagnosis era, and the twentieth century was an era of interventions, where methods for assessment and intervention were generated, while they predict the twenty-first century to be an era of decision-making. The challenge will be to offer research-based knowledge to practitioners through which decisions for selecting and sequencing treatment can be made (Yorkston and Beukelman, 2000).

7.2 Strengths and limitations of the study and its findings

In this section, the strengths and limitations of the study and generalisability of its findings will be discussed.

7.2.1 Strengths and limitations in study design

The present study has employed qualitative methods (thematic analysis/qualitative content analysis and conversation analysis) in order to be able to provide in-depth descriptions of the phenomenon of outcome evaluation in aphasia therapy and the interactional practices used to accomplish it. These methods constituted a platform to study outcome evaluation from the participants' perspective, as initially stated in the aims.

Participants: Despite stating an aim of investigating outcome evaluation from the participants' point of view, this aim has only partly been fulfilled, albeit by deliberate choice. All participants (speech-language therapists, people with aphasia and significant others) are included in the conversation analytic studies, although I took the choice of only interviewing speech-language therapists from an early stage. This choice was taken since outcome evaluation was viewed as a clinician-driven activity, and therefore presumably not a topic the remaining participants would have many views upon, but also due to time restrictions. However, it should be acknowledged that the other participants' views would have provided valuable insights. Sufficiency of numbers of participating speech-language therapists and clinics involved in the study can also be considered. By closely monitoring data saturation with the time available, the number of participants was settled at 12 therapists and four clinics.

One aspect that would be different if the study was to be repeated was the type of information and consent form presented to the participants with aphasia. In hindsight, the documents could have been made to be more aphasia-friendly. The written material could certainly be clearer if knowledge from later research and guidelines was used (e.g., Rose, Worrall, Hickson,

& Hoffmann, 2012; Stroke Association, 2012). However, I thought giving a sufficient, but not an overwhelming amount, of information was most suitable. The speech-language therapists were also involved in explaining the study and the terms for participation prior to signing their consent. This meant no one signed a consent form without being knowledgeable about their rights and role and hence common practices for ethical research procedures were still followed and the research procedures are not considered to be affected by the lack of an aphasia-friendly consent form.

Data collection: The initial point of departure in ethnography has meant that more data has been generated, but not used directly in the three parts of this study (observations of different types of clinical work, field notes, informal talks with participants, their colleagues and participating people with aphasia and their significant others, documents). If the choice had been to continue down the ethnographic road, more of that data might have been used. Instead, it means this study can continue beyond the submission of the thesis. The data collected has, furthermore, been influenced by the researcher through some data more than others. The interview data was, as described, co-created between participant and researcher. From some quotes from the data, it becomes clear the speech-language therapists start to think and create meanings during, and because of, the interview. However, as long as the researcher's agenda does not obstruct what the participants want to say or contribute, this type of co-creation of data is still able to provide valuable insights into the participants' experiences and views on the researched topic (Hesse-Biber & Levy, 2011). The feedback received from the participating therapists after presenting them with the research findings from the interview, confirmed they recognised what they earlier stated regarding outcome evaluation in aphasia therapy.

The video observations are perhaps less influenced by the researcher despite being present, but there are still examples of a few of the participants (both clinicians and a person with aphasia) expressing following the sessions that the participation of a researcher affected them. The presence of a researcher can cause a so-called reactive effect (here influencing the observed sessions of outcome evaluation). Despite this feedback from a few participants, it is not considered to have influenced the activity and thereby the data collected and, ultimately, the findings.

Data analysis: The choice of analytic methods and, not least, the combination of methods has both strengthened and limited the study. The use of two well described and used analytical approaches have allowed the analysis to be rigid and systematic. The novel combination of the methods – in

general across the studies in the thesis, and specifically within the last single study (chapter 6) – has, however, presented challenges. Many considerations were put into the structure and order of analysis without a described model or earlier study on which to lean. An example being that the interviews set the agenda for what to explore in the video data as opposed to the order of the data collection. Common to all three studies were presentations of the data analysis to the participating clinics and fellow researcher through data sessions and conferences before writing up the findings.

7.2.2 Generalisability of the findings

The results of qualitative research are not commonly regarded as suitable for generalisation, at least not when it comes to the so-called statistical generalisation or representativeness. Nevertheless, qualitative findings are generalisable or transferable to existing knowledge in the area or theories, which is named analytic generalisation (Yin, 2003). With this in mind, the findings from this study – based on the relatively low number of interviews of participating speech-language therapists (n=12) in a limited number of outcome evaluation sessions (n=34 session and 17 hours) – contribute to both existing and new knowledge concerning outcome evaluation and client involvement in clinical decision-making. Lastly, it might be worth noting that, despite the low number of clinics (n=4) participating and the lack of attempt at making statistical generalisation, they, at the time of data collection in 2010/2011, constituted 20% of all outpatient clinics in Denmark.

In the discussions above, several connections between other research findings and the findings from the three studies are indicated, but now follows a more comprehensive overview:

Study 1 (chapter 4): Other studies have surveyed outcome evaluation from the speech-language therapists' point of view, but a similar interview study of why they are performing outcome evaluation, and the overall role this action plays in the therapy process, is not seen elsewhere. However, some of the findings match earlier results, but also more seminal views in textbooks and commentaries researching, for example, the finding that outcome evaluation is externally motivated (Hesketh & Sage, 1999; Sarno, 2004). Outcome evaluation as being something a clinician would perform is not explicitly backed up by earlier findings, although it is known that outcome evaluation is performed by a significant percentage of clinicians (e.g., Simmons-Mackie et al., 2005; Verna et al., 2009). Perhaps the most interesting finding in this study regards to what purpose the multiple purposes outcome evaluation is used. Similar findings have not been seen in other studies, but can perhaps be ascribed to this study design going into greater depth into why outcome evaluation is

conducted instead of having a starting point where the documentation of effectiveness is the purpose of aphasia, as would be more common.

Study 2 (chapter 5): This description of the core outcome evaluation sequences, where the interacting participants end with an agreement of the extent to which the person with aphasia has improved and the according reason for assessing is, at some point, similar to the interactional analysis of assessment sequences in mundane conversation (Pomerantz, 1984). The most striking similarity is the preference for agreement. The findings in study 2, however, differ from earlier findings in the interactional literature by: 1) not being an assessment sequence occasioned by the situational or interactional context itself, but are pre-planned and prompted. The assessment prompt explicitly outlines the referent to be assessed. 2) The referent of the assessment is then proposed by a different speaker than the speaker who is to perform the assessment. 3) This referent is a trait of the assessor's own functionality, rather than an object, person, or event as it usually is in everyday conversation. 5) By assessing something, the speaker of the assessment claims knowledge of the referent, and can be held accountable for the assessment. However, in the data, presumably the other speaker is in a better position to actually assess the referent, since he/she is the speech-language therapist and the expert on how people may do well or not so well in the light of them having aphasia. Nonetheless, this expert asks the client to assess him-/herself, how his/her own communicative conduct is in relation to how it has been, and how it might have been. 6) The client needs to do this assessment by means of oral communication, the same skill with which they are having problems.

By describing how the assessments in outcome evaluations in this data set diverge from assessments in everyday conversations, a described framework is used as the point of departure for this extraordinary or diverging sequence. Since the diversions are found across many of the 33 sessions, they are likely to be found in some kind of similar formats in similar contexts. More research is needed to substantiate this claim.

Study 3 (chapter 6): This last study perhaps reveals the most novel findings yet is comparable with some findings from other studies. For example, Berg et al. (2016) and Leach, Cornwell, Fleming and Haines (2010) describe in their interview studies how speech-language therapists involve clients in goal setting prior to aphasia and other therapies. Both studies emphasise, as with study 3, some of the barriers present in the attempt to involve clients in clinical decision-making. Berg et al.

(2016) call for more research on how to involve people, especially those with severe aphasia, in joint goal setting. Despite not being the precise aim of this study, it does enlighten at least some conducive elements for client involvement, although in outcome evaluation and not merely in goal setting for people with not particularly severe aphasia, but also those with severe aphasia.

7.3 Future implications

7.3.1 Clinical implications

It is to be hoped that gaining knowledge of, and insight into, how the current clinical practice of outcome evaluation is conducted will prompt a number of implications. First of all, knowledge of the current practice of other therapists may promote critical reflection of clinicians' own practice, which will potentially improve the practice as a whole. Secondly, the opportunity for a more structured development of either models of and/or clinical practice into outcome evaluation is present in this contribution to the knowledge of how and why outcome evaluation is performed from the participants' view. Furthermore, I hope that the identification of barriers and facilitators in involvement of people with aphasia can be inspiring for further and more effective involvement. Lastly, my wish is that this detailed description of outcome evaluation, or any other clinical practices, will inspire clinicians to continue the good work they are already doing with people living with aphasia, because they are able to see themselves reflected in the research and hence feel a sense of community with fellow clinicians.

7.3.2 Research implication

As with most other pieces of research, this study opens up for yet other types of research and additional research in continuation of its findings. Amongst other issues, the findings of outcome evaluation of a multi-purpose action in aphasia therapy would be interesting to investigate in an international context. The numerous purposes of outcome evaluation and, furthermore, combined with complex therapy types typical for aphasia interventions, calls for well-educated therapists within this area. However, before this can be achieved we need to know more about the research gaps in outcome evaluation, clinical communication and involvement in decision-making with people with aphasia. Accordingly, it is important to study interaction in, and beyond, outcome evaluation to be more knowledgeable with, amongst other elements, the aim of being able to teach future clinicians to become good clinical interlocutors skilled in involving people with aphasia.

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