Experiences of participation in goal setting for people with stroke-induced aphasia in Norway. A qualitative study.

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Abstract

Purpose: The body of research into client participation in aphasia rehabilitation is increasing, but the evidence on how it is implemented into clinical practice is still scarce. Particularly, the importance of including the “insider's perspective” has been demanded. The aim of this study was to explore how people with aphasia experienced client participation during the process of goal setting and clinical decision making in language rehabilitation. Methods: 15 people with stroke-induced aphasia participated in semi-structured in-depth interviews. A qualitative analysis using Systematic Text Condensation was undertaken. Results: Analysis revealed four main themes: (1) Pleased with services, (2) Vagueness in language rehabilitation, (3) Personal goals exist, and (4) Desired level of participation. Conclusion: Even though people with stroke-induced aphasia overall are pleased with the language rehabilitation, there is a need for greater emphasis on making the framework of language rehabilitation less vague. Therapists should also spend more time on collaboration with people with stroke-induced aphasia and use available methods to support communication and collaboration. The findings underscore the need for further exploration of the potential outcomes of implementing client participation in goal setting and clinical decision making for persons with stroke-induced aphasia.

Introduction

According to Rosewilliam et al.[1] goal setting in rehabilitation is *"the process during which the patient and clinical members of the multidisciplinary team make a collective decision, following an informed discussion, of how and when to carry out rehabilitation activities"* (p.502). In addition to this, goal setting needs to be a dynamic process because goals change as the person learns to live with the condition and/or recovers [2]. And more importantly research has shown that person centred care such as collaborative goal setting may lead to positive outcomes for the client, with best effect for psychosocial outcomes, even if the evidence is still weak [3-5].When exploring the available literature, it is evident that clients with communication difficulties such as aphasia have been excluded from studies focusing on client participation in goal setting in the stroke population [1, 6]. Sugavanam et al.[6] concluded that communication and cognitive impairments were seen as the major barriers for involving clients with stroke in goal setting, even for those stroke survivors without any known language and communication impairments. Furthermore, the review conducted by Rosewilliam et al.[1] indicated that although clients perceived participation as important, and professionals believed that they involved the clients, current practice could not be described as client-centred. The awareness of client participation has risen over the last decades and it is now a term used within the Norwegian legislation in both health [7, 8] and education [9], as well as in the Norwegian guide-lines on management and rehabilitation of stroke [10].

Aphasia is an acquired language impairment that affects a person's ability to process language, such as speaking, understanding others, reading and writing [11, 12]. Even though there are several conditions that can cause aphasia, such as cancer and traumatic brain injury, stroke is the primary cause [12]. Stroke is a seriously disabling health condition [13, 14] often resulting in a persistent need for rehabilitation. Most people with aphasia, regardless of cause, experience activity limitations and participation restrictions caused by their communication disorder, something that is likely to make them less active both in social settings and when important decisions about their own life are to be made [15]. People with aphasia in Norway may meet speech pathologists in several different settings. According to the Norwegian guide-lines on management and rehabilitation of stroke [10] people with stroke-induced aphasia should preferably first meet with a speech pathologist in the hospital. When discharged from hospital some people will be referred to a rehabilitation centre for further speech pathology services, others will be sent home and will meet a municipal or private speech pathologist. Whether you are sent to a municipal or private speech pathologist is depending on whether your needs are defined within the educational [9] or health legislation [16]. There is no given length for speech pathology in Norway, every case should be decided based on the client`s needs and progress in form of an expert assessment from either the Educational and Psychological services or a doctor. Due to lack of qualified personnel in their local municipality not all persons will be offered services. Regardless of the setting it is offered in rehabilitation is aimed at reducing activity limitations [17] and according to Wade [18], one of the important goals of rehabilitation is to make the person undertaking it able to function as well as possible despite the presence of impairment. Patient-centred goal setting is a core component of the rehabilitation process to achieve this [18].

There is a growing body of research within the topic of goal setting for people with aphasia. For example, Worrall et al. [19] asked people with aphasia about their goals for rehabilitation. In order to categorize the results, the researchers considered how goals could be linked to the different components of the International Classification of Functioning, Disability and Health (ICF). The researchers found nine broad categories and most of these could be linked to the activities and participation part of the ICF, whereas goals linked to body functions and structures were less accentuated. It is important to note that all participants in Worrall et al.'s study were able to state meaningful goals when the necessary adjustments were made to compensate for their language impairments.

Several studies have looked at ways of supporting conversations with a special focus on person centred goal setting so that people with aphasia can be active participants in their own rehabilitation process. Haley et al.[20] used a non-linguistic, picture-based instrument (Life Interests and Values (LIV) Cards) to support conversation with people with aphasia about their participation and preferences in life. The study demonstrated that people with aphasia were able to provide information using the cards, and the authors concluded that this instrument could be a viable tool in collaborative goal setting. Bornman and Murphy [21] used Talking Mats to exemplify how people with aphasia could be empowered to participate in intervention goal setting according to the ICF. In a large, multi-centre Australian study, the Goals in Aphasia Project, Hersh et al. [22] explored how professionals can act to enhance collaborative goal setting, SMARTER goal setting, with the acronym describing a goal setting process that is Shared, Monitored, Accessible, Relevant, Transparent, Evolving and Relationship-centred. Even though all these methods have been suggested as frameworks, there is no evidence on how they have been implemented in the clinic and how people with aphasia experience collaborative goal setting. To date, the research on goal setting and aphasia has focused on the kind of goals people with aphasia have [2], goals speech pathologists think are important in aphasia rehabilitation [23], and the differences between the two sets of goals [24].

Over the recent years, the number of qualitative studies in the field of aphasia has increased, and the importance of the "insider's perspective" has been highlighted [25]. People with aphasia are still excluded from many studies, and especially interview studies, nevertheless, it is possible to perform in-depth interviews with people with aphasia as long as the interview situation is adapted to their needs [26, 27]. For example, through supporting the conversation by the active use of pictures, drawings, gestures and written key-words and in some cases written choices for answering, it is possible to involve people with aphasia in qualitative research and especially in research aiming to investigate how people with aphasia perceive their role in the collaboration with their speech pathologists in language rehabilitation. The aim of the current study was to explore how people with aphasia experienced client participation during the process of goal setting and clinical decision making in language rehabilitation.

Methods

A qualitative research approach using semi-structured interviews was chosen to gather in-depth information, focusing on the individual experiences of people with aphasia. Qualitative methods were chosen because they are suitable for gaining an in-depth insight into people`s experience [28]. The present study was approved by the regional committee for medical and health research ethics in Central Norway (REK no 2012/1739).

Sampling and participants

The sampling was purposive as all informants were recruited through their speech pathologists. The first author contacted a regional and a national network for speech pathologists working in the field of aphasia to invite members to recruit participants. Both networks were given a brief 15 minute presentation of the background and the aim of the study. The speech pathologists were asked to contact people with aphasia who met the inclusion criteria and give them the “aphasia friendly” written and oral information about the study provided by the research team. We began the recruitment process asking for people who met the inclusion criteria with mild to moderate aphasia so that these interviews might give us information and insight that could be used in interviewing people with more severe kinds of aphasia later in the study. As the study progressed we sought to ensure that the group of informants represented a wide range of people with aphasia including men and women, with a range of ages, time post onset and severity of aphasia. A total of 15 people with aphasia ranging in terms of gender, age, aphasia severity and time post onset were recruited to this study based on the following inclusion criteria: aphasia caused by a stroke, minimum six months post onset, receiving speech pathology at the time of interview or no more than six months post speech pathology. There were eight recruiting speech pathologists, one of them recruited three participants, while the others recruited one or two each. All participants had met with speech pathologists in more than one of the following settings; hospital, inpatient rehabilitation, outpatient rehabilitation, municipal adult learning centers or private. All except one were also receiving speech pathology weekly at the time of the interview. All participants gave informed consent to participate in the study. See table 1 for more detailed description of the participants.

Table 1 Characteristics of the informants (n=15)

Code	Sex	Age	Living condition1)	Level of education	Time post onset (months)	Aphasia2)	Fluent/ non-fluent
PWA1	M	70-79	single	primary	12-24	4	Fluent
PWA2	F	50-59	spouse	higher	>60	3	Non-fluent
PWA3	M	60-69	spouse	higher	25-36	4	Fluent
PWA4	F	40-49	family	secondary	>60	3	Non-fluent
PWA5	F	70-79	spouse	higher	12-24	3	Fluent
PWA6	M	60-69	spouse	higher	<12	3	Fluent
PWA7	F	50-59	spouse	secondary	<12	3	Non-fluent
PWA8	F	60-69	single	secondary	12-24	3	Non-fluent
PWA9	F	60-69	spouse	secondary	<12	3	Fluent
PWA10	M	70-79	single	secondary	12-24	1	Non-fluent
PWA11	M	50-59	spouse	higher	12-24	3	Non-fluent
PWA12	F	50-59	spouse	secondary	12-24	2	Fluent
PWA13	M	60-69	spouse	higher	<12	2	Non-fluent
PWA14	M	50-59	family	secondary	12-24	5	Normal
PWA15	F	70-79	single	primary	>60	4	Non-fluent
Median		61			19		
(Range)		(43-74)			(4-116)		

1) all living at home, 2) BDAE Aphasia Severity Rating Scale – 0=severe aphasia – 5=mild aphasia

Data collection procedures

Data was collected through individual in-depth semi structured interviews. For three of the informants it was most convenient that the interview took place in their home. For these, contact information was communicated between the first author and the recruiting speech pathologist. For the rest of the informants, the interviews were conducted at the location where they attended speech pathology and time for the interview was arranged through the speech pathologist.

All interviews were performed by the first author, an experienced speech pathologist with special training in conducting supported conversations. Only the informant and the first author were present during the interviews and each interview lasted between 30 and 60 minutes. As recommended by Luck and Rose [27] techniques of supported conversation were used so that people with different types and degrees of aphasia were better able to understand and respond to questions. The techniques included simplification of sentences, materials to support non-verbal responses for the informants (pen and paper, yes and no cards), written key words and drawings. An interview protocol consisting of key questions was used to guide the interviews. The main questions are displayed in Table 2. Since no new topics were raised during the three last interviews, recruitment of new participants ceased as we considered we had reached data saturation. All interviews were both video and audio recorded.

Table 2 Main questions from the question guide

- Do you remember what your expectations where when you met with a speech pathologist for the first time?
- What`s important to you now in speech pathology?
- What are you doing in speech pathology now? What are you targeting?
- How are decisions on what to do in therapy made?
- Do you have common goals with your speech pathologist?
- Is there anything else you would have liked to target?
- How will you describe the interaction between you and your speech pathologist?
- When I say client participation, what does it mean to you?

Participants’ recent formal aphasia assessments were not always available due to the different stages and types of speech pathology they were receiving. We therefore decided that a classification of aphasia type made by the recruiting speech pathologists would be sufficient. The first author and three independent, experienced speech pathologists rated the participants` aphasia according to the Boston Diagnostic Aphasia Examination (BDAE) Aphasia Severity Rating Scale [29] and whether the speech could be characterized as fluent or non-fluent based on samples from each interview. BDAE severity rating scale ranges from 0 which means “No usable speech or auditory comprehension” to 5, “Very slight language impairment, which is only perceived by the patient himself”. Non-fluent speech is characterized by halting or effortful production of speech, whereas a person who has fluent aphasia may continue to speak not noticing when to pause to let the communication partner into the conversation [30]. All the raters made individual ratings of each participant and afterwards compared the ratings. Comparisons showed 80 % of agreement on the BDAE Aphasia Severity Rating Scale and 93% agreement on fluency. In cases of disagreement a consensus discussion was conducted amongst the raters. The final ratings are displayed as part of Table 1.

Data analysis

Interviews were transcribed verbatim using the audio recordings. Video recordings were used for clarification in a few cases when it was difficult to comprehend what the participant was expressing just by listening to the audio recordings. In these cases gestures and body language were written into the transcripts in parentheses to provide a visual cue to discerning the full meaning of the expression. The data material was analyzed using Systematic text condensation (STC) [31]. STC is based on Georgi`s phenomenological analysis and is a structured and well described four step method for analysis of qualitative data. STC was chosen because it has shown to be suited for presenting the experience of the participants as expressed by themselves, rather than exploring the possible underlying meaning of what was said [31].

In the first step, the first (KB) and last author (MBR) read all 15 transcripts to get an overall impression of the data. 8 preliminary themes connected to goal-setting and clinical decision making were agreed upon and written down. It was important for the researchers to try to bracket their pre-understandings; a principle of phenomenological research where the researchers are open minded when they look into the data to be sure that they were searching for the voice of the participants [32]. In the second step of the analysis the first author (KB) reread the 15 transcripts and conducted a line by line analysis, searching for units of meaning that represented the participants’ experience with collaborative goal setting and decision making in language rehabilitation. All meaning units were noted and possible new themes and sub-themes were written down. In the third step condensed descriptions were written down for each theme to ensure that the voice of the participants was still heard. Finally, the contents of each condensed description were summarized into four main themes and five sub-themes. Several times during the analysis process, preliminary results were presented and discussed with the three other authors as well as a research-group focused on patient education and patient involvement of which the first (KB) and last (MBR) author are members. This was done to see possible alternative ways to group and analyze the results. See table 3 for an example of the analysis process.

Table 3 Example of stepwise analysis using STC

Step 1: **Preliminary theme**	**Step2:** **Unit of meaning**	**Step 3:** **Condensed description**	**Step 4:** **Final description**
Lack of goals	*We`ve never, she has probably got goals, because she knows how I used to be, but she`s never talked to me about it.*	I don`t know if we have common goals. The speech pathologist might have goals, maybe we have talked about it, but it`s not clear to me. We have made a plan, but I don`t think we have any goals.	Vagueness in language rehabilitation
No timeframe	*I would be really scared if she [speech pathologist] was ending therapy. They don't know how long I`m here for, they have no idea at all.*	I don`t know how long I`m here for. Others might need it more than me, but it`s the speech pathologists decision and sometimes the doctors. I hope that I get to stay for a while.	
Unclear content	*"It`s almost nothing, but we are sitting there, talking about what goes on in our families"*	We are doing different tasks and talking, and then we use pictures	

Results

Analyses resulted in four main themes. Theme 1 Pleased with services: the overall impression was that the participants with stroke-induced aphasia were pleased with the services delivered by the speech pathologists. This was despite the fact that the participants struggled to articulate common goals between themselves and the speech pathologists and what they were doing during the therapy sessions. Theme 2 Vagueness in language rehabilitation: the majority of the participants described the content and time frames of therapy as being somewhat unclear. Theme 3 Personal goals exist: most of the people with stroke-induced aphasia in this study were able to express their own goals for rehabilitation. These goals could be grouped as language goals and life goals. Theme 4 Desired level of participation: the participants in this study divided into two groups regarding their wish for collaboration with their speech pathologist; those who wanted to participate in goal setting and treatment planning and those who wanted to trust the expert. Quotes from the data material are presented to illustrate the findings.

Pleased with services

The majority of participants (12) talked about their speech pathologists in positive terms. They expressed their satisfaction with the language rehabilitation and described their speech pathologists as skilled professionals, who had both expert competence in language rehabilitation and personal abilities that made them capable of communicating with people with stroke-induced aphasia. Even though only some of the participants were specific about what made them satisfied, words as; pleased, really good, clever, and inventive were used through several of the interviews. As an example PWA6 described his speech pathologist like this: *"She is so clever and inventive all the time"*.

Three of the participants described both positive and negative experiences of language rehabilitation, but all of these talked about the current situation as pleasing. PWA2 first talked about the early stages of rehabilitation: *"The period at X [name of rehabilitation institution] is so terrible, and so, I`m not. F [husband] got lessons from the speech p.. pa.. pa [speech pathologist] and it was nothing",* and then later about the present situation: *"I`m so pleased, so pleased with the speech pathologist"*. Only two of the participants did not talk explicitly about how they felt about their speech pathologist or what they thought about the services delivered in language rehabilitation.

Two of the participants emphasized the experience of being seen and heard by their speech pathologist as something they appreciated and valued. Both these participants had a moderate degree of aphasia, but one had lived with the aphasia for a long time and the other only for a few months. The speech pathologist talking to them and not their partner was mentioned as important and was described as something that gave the participant a good feeling.

> *She didn`t talk to my husband, she talked to me.* (PWA4)
>
> *I`ve always been heard, so you can say that I am, I am impressed by them and very pleased that I`m always being heard.* (PWA9)

In opposition to this, one participant talked solely about his negative experience with language rehabilitation, and described the speech pathologist only talking to his wife and not to him as a reason for him to end speech pathology.

> *Yes, but I, my wife is at home, and then my wife and the speech pathologist are talking and I`m just sitting there (PWA13).*

Even though the participants had mixed experiences with language rehabilitation and their collaboration with speech pathologists, the main impression from the interviews was that most of the participants in general were pleased with services delivered by their present speech pathologists and it was not possible to see any differences in the group looking at aphasia severity or time post onset.

Vagueness in language rehabilitation

In almost all the interviews it was clear that some aspects of language rehabilitation were perceived as vague. According to the participants common goals were rarely discussed, it was difficult for many of the participants to explain the content of therapy, and several did not know for how long they could expect to receive language rehabilitation.

Vagueness in collaborative goal setting

Vagueness in collaborative goal setting between the participants with stroke-induced aphasia and their speech pathologists was a theme that emerged in many of the interviews. Only a few of the respondents talked spontaneously about goals and goal setting. To get them started they were prompted to talk about it by being asked whether they and their speech pathologist had any shared or common goals. Some of the participants immediately responded negatively to this question, expressing that there were no common goals that they knew of. *"[Common goals] No, I haven't heard of any".* (PWA5). One participant was sure that the speech pathologist had goals, but that she`d never discussed it with him. *"We`ve never, she has probably got goals, because she knows how I used to be, but she`s never talked to me about it".* (PWA14). Another participant said that he felt that common goals were not possible as long as no one could tell him his prognosis. *"Considering the fact that I don`t know if I`ll be able to read or write, you know … goal setting is not possible.* (PWA6). Only a few of the participants were clear about the fact that there were common goals for language rehabilitation between them and the speech pathologist. One of them was not able to recall what it was, but he emphasized that it usually was the speech pathologist suggesting things based on what he had told her that he wanted to work on. *"[Common goals] We`ve had that, but it`s hard to remember … she arranges it, but she talks about, what do you want".* (PWA3).

Vague content of therapy

In several of the interviews it was difficult to get a grasp of what went on in language rehabilitation, and the content of therapy was perceived as vague. It seemed hard for participants within all severity groups to explain what they were doing during the speech pathology sessions. Talking and tasks were general terms that recurred. A few of the participants expressed that almost nothing happened, and that there was only what they perceived as casual talk about family and life. *"It`s almost nothing, but we are sitting there, talking about what goes on in our families"*. (PWA5). One of the participants was not able to say anything specific, but could confirm when the interviewer gave examples. *"Yes, you said it, lots of pictures and stuff, different stuff, repeating and repeating"*. (PWA1). Only a few were able to talk more precisely about the content of therapy, each giving examples of tasks undertaken. PWA11 said he was working with *"words and sentences"*. Looking at the transcripts the tasks could be linked to what they expressed themselves that they were struggling with, suggesting that the speech pathologists in these cases were targeting therapy well and making therapy relevant to people's needs.

Vague timeframe of therapy

Vague timeframe of therapy was something that was mentioned by several of the participants. For some the decision of continuing or ending therapy was entrusted to the speech pathologist, the health authorities and/or the doctor. Two of the participants said that they didn't know for how long they could expect to receive speech pathology, but they both hoped that they were nowhere close to the endpoint.

> *"I don`t know, it`s the doctor, the doctor and the speech pathologist who decides if I get to continue"*. (PWA3)
> *"No, no, I continue, I want to, but NAV [health authority] and the doctor [deciding]"*. (PWA2)

Both of these participants had lived with aphasia for more than two years. Another participant expressed that not knowing the timeframe of therapy made him insecure, and that he was expecting that he would have to change speech pathologist at some time. *"I would be really scared if she [speech pathologist] was ending therapy. They don't know how long I`m here for, they have no idea at all".* (PWA6). A few participants just said that they didn't know the timeframe, but had no thoughts around it. For one of these the interview was conducted in June and it was still not clarified for her whether she could come back after the summer vacation that started the week later. *"[Speech therapy after summer] no, I haven`t heard anything yet".* (PWA8). Only one participant talked about a set timeframe, indicating that he knew how many sessions he could expect before language rehabilitation ended. *"I think it`s good, I`ve got a letter saying I will have 130 lessons".* (PWA14).

Personal goals exist

Almost all of the participants described that their initial hope was that the speech pathologists would help them recover from aphasia, and that through language rehabilitation they would be able to talk as before the stroke. When talking about their goals at the time of the interview, the picture was a bit more nuanced. The present time goals could be divided into two groups. The first group consisted of the participants with language goals. Some of the participants still had wide, unspecific language goals, and others had more specific language goals. The second group could be characterized as having life goals. A few of the participants had more than one goal, and hence one person's goals could be linked to more than one group.

Language goals

As described earlier most of the participants had an initial hope of recovery. When talking about their goals at the time of the interview none of the participants described total recovery from aphasia as their goal. One of the participants talked about how his goal was to be understood, and if he experienced that others understood him, his goal would be reached. *“I want people to understand me, then my goal is reached”.* (PWA1). Another talked about her wish to get better. She just wanted to take one step at a time and gradually be able to talk and communicate better with her family and friends. *“Language back, no joke, but get better, get better … talk to people, discuss”*. (PWA2). This participant expressed clearly that she did not find specific goals necessary as long as she felt that they, the speech pathologist and she, had a plan for her to get better.

The specific language goals were for some of the participants closely connected to what was done in language rehabilitation. One of the participants talked about how he and the speech pathologist had agreed that working with sentence building was the goal for language rehabilitation and this reflected what he described as activities of the speech pathology sessions. *“[Your goals] Sentences and writing”.* (PWA11). Another talked about how the ability to read was his personal goal. He was not able to say that this was a common goal for him and his speech pathologist, but reading was one of the activities he could list. *“I want to read … the most important is to be able to read”.* (PWA6). For a third participant it was a goal to get better at speaking in sentences. *“I would have wanted to work on sentence building”.* (PWA4). For her this was neither a common goal with her speech pathologist or something that was specifically worked on during speech pathology as she was attending conversation groups with more general goals for the whole group.

Life goals

Three participants had life goals connected to getting back to work. Two of them also expressed thoughts about to what degree it would be realistic for them to go back to full time work or doing the same job as before.

> *"I might want to get back to work, not full time … I haven`t talked to anyone about this yet".* (PWA9)
>
> *"I have always said that I would get back to my baby [own business], I have worked there for 27 years, but I might struggle with that, it will be too much for me, but we will find a solution".* (PWA14)

One participant wanted to learn how to use his computer and especially Facebook: *"I`ve got a computer and then Facebook, but trouble, I will try".* (PWA1). And another wanted to be able to drive again. *"I don`t know if it is realistic, but I want to be able to drive again".* (PWA5). What was characteristic of these goals was that the participants had not discussed them with their speech pathologist or their personal goals had not been incorporated into the language rehabilitation. However, none of the participants with these goals expressed any dissatisfaction with this situation.

Desired level of participation

Involvement in goal setting and clinical decision making was described as difficult in certain situations and at particular times during the progress of rehabilitation. Despite this, several of the participants expressed a clear view of their desired level of participation in the different rehabilitation stages, if and when they wanted to be an active decision-maker or to trust the expert.

Two of the participants described situations where they said it was obvious that they were not able to be an active collaborator.

> *"… it`s a bit different now [than earlier], remember my ability to talk was not good when I was at X [name of rehabilitation unit] so it`s a bit different, I can`t remember if it was my decision or, no they [the speech pathologists] had the papers telling what we were supposed to do".* (PWA3)
>
> *"[collaborative goal setting]I was mute, totally mute [early stage]".* (PWA4)

These situations were linked to the acute or subacute phase of rehabilitation. They described that because of their inability to talk/their language difficulties, they were not able to be involved in these first stages of rehabilitation, a situation that they accepted even though they expressed that they weren't necessarily pleased with it. The acute or subacute phase was also described by several as the phase where they felt the need of support from their next of kin when decisions were to be made. This was again clearly linked to the lack of ability to communicate. This was in opposition to later stages in the rehabilitation process where they felt able to speak for themselves. *"At first … difficult … no language. Then important you know [husband* *participated], but now I`m able to manage myself".* (PWA2). At the time of the interviews none of the participants expressed the need of support from next of kin when talking about language rehabilitation.

Still a majority of the participants expressed that they trusted suggestions given and decisions made by the speech pathologists. Some of the participants talked about how meeting a speech pathologist who was experienced and showed that she had knowledge about aphasia instilled trust in this person. They expressed how they felt it best to hand over the responsibility of goal setting and treatment planning to the professional. *"I left it all to her. It worked for me, I`m not the speech pathologist, she is".* (PWA4). One participant talked about how he sometimes felt that he talked too much and interfered too much in therapy planning, and that this might not be to the best as the speech pathologist was the expert.

> *"Maybe I`m using too much, I`m saying too much about what I want us to do. And that might not be good, that I`m doing it. Because she is the experienced one, she`s the speech pathologist. If I hadn't listened to her I don't think I would have reached this far, I really don't know what to do in therapy".* (PWA3).

Another expressed that he didn't think that it was necessary that he was involved in all the decisions, because the speech pathologists had the right knowledge to make these decisions and that this was the best way to do it. He said that he was not asked for his opinion, but that this didn't feel like the speech pathologists were making decisions that were not right for him.

Not all the participants were ready to be passive recipients of speech pathology. *"You know it was them [speech pathologists] who decided what I should do, I felt like I was back in 3rd grade".* (PWA3). A few clearly described how they wanted to be in a dialogue with the speech pathologists in planning content of treatment, and they gave examples of situations where they had experienced less influence on goal setting and treatment planning than they wanted. One of the informants described how she was more content when she came to a speech pathologist who started working with what she felt was important. This was opposite to what she had experienced earlier, were they had worked on things that didn't feel relevant for her.

> *"During rehabilitation I wanted to work with sounds, but you know [soughs] … but it`s important when back home [with speech pathologist] then, started working with sounds and that felt right you know. No, I want to decide myself, at least now I want to … but sounds that were important, and now sentences as well".* (PWA 2).

A couple of the participants described how they had made an active decision to end therapy in cases where they felt that their expectations or needs were not fulfilled. The way they spoke of it, ending therapy was their way of telling the speech pathologist that this didn't work as expected. As one participant clearly expressed it:

> *When I feel that things are decided on behalf of me, den I stop talking. At that point I don't want to come here anymore. (PWA4)*

Discussion

Although overall the participants were pleased with the services delivered by the speech pathologists, the results showed that the participants experienced the framework of language rehabilitation as vague, with little focus on collaborative goal setting and uncertainty about the timeframe and content of therapy. Furthermore the participants stated that their personal goals were not always mentioned or discussed by their speech pathologist. When discussing the degree of participation in their therapy, the participants divided into two main groups, one group that wanted to be active participators and one group that wanted the speech pathologists to make the decisions about rehabilitation goal setting and treatment planning.

The findings regarding personal goals, and lack of clarity around therapy activities and anticipated length of therapy are in line with what Ottenbacher and Cusick [33] found regarding goal setting, where goals were often not stated and timeframes were vague. Clients describing therapy as diffuse is known from earlier studies as well. Hersh [34] who interviewed 21 people with aphasia and 16 of their family members found that some of the participants were able to describe certain areas of therapy, but that several were vague in their descriptions. In interview studies with the main group of respondents having aphasia we can expect that the nature of aphasia will make it difficult for some of the interviewees to express themselves. On the other hand, in this study, the descriptions of therapy are vague not only for participants with moderate to severe aphasia, but for the group as a whole.

Since some of the participants were uncertain about the duration of language rehabilitation, the impact of this on therapy and the extent to which a client dares to question the chosen approach or focus is unknown. In a study examining the 'frail elderly’s' preference for participation, Ekdahl et al. [35] discussed whether non-empowered patients, i.e. patients who had chosen not to participate, did this because of fear of challenging the professional power or knowledge. At least for two of the participants in this present study it was evident that they were afraid that therapy would end, even if they did not express that they linked this to whether they chose to follow the advice of the professional or not. It is also important to be aware that people who have recently acquired aphasia are in a vulnerable phase of life. This might make them more willing to lean on suggestions given by the professionals.

Results from this study demonstrated that there could be situations where participants felt that they had to take a passive role in the collaboration with their speech therapists. This was especially linked to the early stages of rehabilitation when their aphasia had been severe. The nature of aphasia has in itself been noted as one of the main barriers for people with aphasia to take an active role in goal setting and clinical decision making [6, 36, 37]. Some of the participants in this study talked about situations, especially in the early phases of rehabilitation, where they felt that it was natural that they were not able to participate because of the aphasia. The ability to speak was seen as the main and maybe the only possible key to participation for some of the participants in this present study. In light of this it would seem that at least some participants with aphasia were willing to hand the responsibility over to the professionals in this early phase because of their inability to express themselves verbally.

Studies have shown that a majority of patients want to participate in goal setting and treatment planning [38, 39] even though factors such as health literacy, numeracy skills, and educational level may make an influence [40]. At the same time a study looking at first-time stroke survivors and their caregivers concluded that the participants showed low health literacy about stroke and rehabilitation and that this insufficiency in knowledge, skills and information in the acute phase in many cases prevented them from engaging actively in the rehabilitation process [41]. In line with what was found in this present study clinicians should assume that clients or patients want to participate and at the same time make sure that they are able to participate through enhanced focus on preparing them for participation. Another aspect that needs to be taken into account is the fact that clients` wish for participation might change during the continuum of rehabilitation. Some of the participants in this present study were expressing that they were not ready to become an active participant until later in the rehabilitation process.

The fact that some of the participants in the present study did not always tell the speech pathologists about their goals and were not always asked about their goals by the speech pathologists could be examples underscoring this suggestion. In contrast to this, some studies [21, 22] have shown that people with even moderate to severe aphasia are able to participate if the situation is adapted to their needs. Simmons-Mackie [15] identified that even with a minimum of training in supporting communication for people with aphasia, health care professionals were able to increase the participation of people with aphasia in decision making regarding their own health care. In the paper by Berg et al. [36] it was described how speech pathologists saw aphasia as a barrier to client participation. Through this present study it is shown that the participants with stroke-induced aphasia themselves saw aphasia as a barrier to collaborative goal setting. This suggests that the beliefs of both the people with stroke-induced aphasia and the professionals can be a barrier to client participation if the professionals are not aware of how to support collaborative goal setting and clinical decision making. It should be questioned whose responsibility it is to make sure that participation is for all clients, and not only for those who are able to express their needs and wishes verbally.

Limitations of the study

This study included a small group of Norwegians with stroke-induced aphasia. Although we endeavoured to cover a wide range of participants in terms of age, time post onset and degree of aphasia, as in any small qualitative study the generalizability of the findings is limited to the participants and the contexts in which data were collected.

Another bias with this study could be the fact that we recruited the participants through their speech pathologist. This might have led to the speech pathologists only contacting the clients that they felt they had succeeded with, the ones that they felt that they had a good relationship with. Still all of the participants had met with several speech pathologists during their rehabilitation process, something that made them not only talk about the recruiting speech pathologists but several different ones. It is also important to mention that many of the participants showed that they were able to express both what they were pleased with and what they had disliked in this process.

The fact that some of the participants were more than five years post onset could give us reason to question how much they were able to remember from their long rehabilitation journey. It is reasonable to question whether this had an impact on the description of aphasia rehabilitation as diffuse. On the other hand a majority of the participants were within two years post onset, and their impression supported the finding. It is also important to mention that all of the participants in the very chronic phase were still receiving speech pathology weekly at the time of the interview, giving them a long experience as receivers of speech pathology.

It is challenging to interview people with stroke-induced aphasia given their language and communication difficulties. To ensure that they understood the questions and that their experience was captured the interviews were conducted by the first author who is an experienced speech pathologist, trained in using techniques of supported conversation. However, we cannot exclude the fact that some of the participants may not have been able to fully express how they experienced client participation and how client participation was ensured by their speech pathologists during the process of goal setting and clinical decision making in language rehabilitation. In addition, it was challenging to translate the quotes given by the participants without additional interpretations of meanings by the translator. A word by word translation would have given less meaning to the reader. Still, given the fact that the main part of the analysis was conducted on the basis of the quotes written in Norwegian we have tried to ensure that the expressions are given a proper interpretation.

The first author being a speech pathologist herself might have influenced the research process; from framing questions in the interview guide, to how the interviews were conducted and data interpreted. Awareness and reflexivity on this issue was part of the research process in order to address this potential risk. An interview-guide was used to ensure that the same topics were covered in all interviews. Although the first author's background is a potential bias we found this background necessary as the interviewer needed knowledge about supportive communication techniques to conduct most of the interviews in this study. Another step that was taken to address potential risks of bias was that data was analysed in a group of researchers with different professional backgrounds.

Conclusion

In conclusion, this study highlights how people with stroke-induced aphasia experienced client participation in goal setting and clinical decision making during language rehabilitation. According to the examples most of the participants were pleased with services delivered by the speech pathologists, but at the same time they described the content, timeframes and collaborative goal setting in language rehabilitation as vague, something that implies that there is a need for greater emphasis on involving people with stroke-induced aphasia in the framework of language rehabilitation.

In addition the results show that there were two groups of participants, the ones who wanted to be an active participant and the ones who preferred to trust the expert. The question is whether clinicians look into who wants to be an active participator and who are pleased with following the expert? The results also showed that patients who had goals did not always reveal these goals for their therapist. This result might indicate that therapists should spend more time on collaboration with the patient and also use available methods to support communication and collaboration.

Even though this study focused on the collaboration between people with stroke-induced aphasia and speech pathologists we expect them to be relevant for all professionals working with these clients in rehabilitation. The findings underscore the need for further exploration of the implementation and the potential outcomes of client participation in goal setting and clinical decision making for persons with stroke-induced aphasia. And there is still a need for increased focus on the clinical implications of collaborative goal setting and clinical decision making for people with stroke-induced aphasia.

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Declaration of interest

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