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# Group activities for people with aphasia – experiences and impact on psychosocial well-being

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## SAMMANFATTNING

Afasi är en språkstörning som främst uppstår till följd av en stroke och drabbar cirka 30 % av alla strokepatienter i Sverige. Personer med afasi upplever ofta besvär med det psykosociala välmåendet, exempelvis depression, förlust av arbete och påverkade relationer. Gruppverksamheter för personer med afasi kan öka känslan av gemenskap i grupp, bidra med en stödjande miljö som hjälper till att upprätthålla identitet och välmående hos personer med afasi. Syftet med studien var att undersöka den upplevda effekten av deltagande i en gruppverksamhet på det psykosociala välmåendet hos personer med afasi. I denna intervjustudie deltog sju personer med afasi. Studien genomfördes på en gruppverksamhet för personer med afasi i centrala Sverige. Medelåldern för deltagarna var 63 år. Resultaten visar att deltagande i gruppverksamheten hade flera positiva effekter på det psykosociala välmåendet hos personerna med afasi. Deltagarna uttryckte känsla av samhörighet och trygghet i gruppverksamheten. Positiva effekter som framkom var känslan av att bli förstådd inom gruppen och att ha rutiner på gruppverksamheten. Studien belyser hur gruppverksamheter kan gynna det psykosociala välmåendet hos personer med afasi. Studien lyfter även utmaningar såsom gruppdynamik och olika preferenser för aktiviteterna inom gruppverksamheten. Studien förespråkar ökad tillgänglighet till gruppverksamheter som personer med afasi kan komma till under en längre period.

*Nyckelord:* afasi, rehabilitering, gruppaktiviteter, psykosocialt, välmående

## ABSTRACT

Aphasia is a language disorder predominantly resulting from brain damage, notably after a stroke, affecting around 30% of stroke patients. People with aphasia experience difficulties with their psychosocial well-being, including depression, loss of employment, and affected relationships. Community-based aphasia groups may facilitate a supportive community that aids in maintaining identity and well-being for people with aphasia. The aim of the study was to explore the perceived effects of rehabilitation group activities on the psychosocial well-being in people with aphasia. In this study, seven people with aphasia participated in a semi-structured interview at an aphasia center in central Sweden. The participants' mean age was 63 years. The results indicate that group activities are perceived to have several positive effects on the psychosocial well-being in people with aphasia. Participants expressed feeling fellowship and safety at the aphasia center. Positive effects of routines and feeling understood within the group were identified. The study highlights how group activities benefit the psychosocial well-being in people with aphasia. However, the study also highlights challenges such as creating group dynamics and different preferences for activities that may affect participation. The study advocates for an increased access to group activities beyond healthcare settings to support psychosocial well-being in people with aphasia.

**Keywords:** aphasia, group activities, rehabilitation, psychosocial, well-being

# 1. Background

Aphasia is a language disorder caused by acquired brain damage, and the most common cause of aphasia is stroke (Brady et al., 2016). In Sweden, approximately 25,000 people get stroke each year (Socialstyrelsen, 2020). Around 30% of all stroke patients get aphasia after a stroke (Grönberg et al., 2022). The population of people that get aphasia is heterogeneous and the language impairment varies in terms of severity and degree of involvement across the different language modalities; expression, and comprehension of spoken and written language (Brady et al., 2016). Aphasia may also coexist with apraxia of speech (Ziegler et al., 2022), which is a motor disorder that affects the planning and programming of motor movements involved in speech (Basilakos, 2018). People with aphasia face challenges when communicating their needs (Le & Lui, 2023), and can struggle to communicate with others and to socialize (Socialstyrelsen, 2020). Pike et al. (2017) report in their study the difficulties that people with aphasia encounter in their daily life, such as having loss of friendships and changes in the quality of their spousal relationships. Aphasia varies in severity, which may range from occasional word-finding difficulties to no verbal communication at all. The severity of aphasia may reduce as time pass, given that certain components of their language ability may recover, while others may remain impaired to the same level (Brady et al., 2016). Even if a person has mild aphasia, it may negatively affect them and have a significant impact on their mood, quality of life and social participation, as well as their ability to return to work (Sheppard & Sebastian, 2020). As the population ages, the prevalence of stroke is estimated to increase, which will result in a greater number of cases of aphasia (Wilson et al., 2021). The aphasia, alongside with other impairments caused by the brain damage (e.g. motor and sensory impairments), may negatively impact their quality of life. Studies have revealed that people with aphasia face challenges in their daily activities and struggle to participate in certain tasks, and often require assistance from family members and caregivers with these tasks and with self-care (Ravi et al., 2018).

## 1.1. Psychosocial well-being in persons with stroke and aphasia

Psychosocial well-being includes both psychological well-being and social well-being (Eiroa-Orosa, 2020). Among stroke patients, depression, anxiety, fatigue, and apathy affects at least 30% of the individuals (Hackett et al., 2014). Numerous studies have documented the psychosocial effects of stroke, which affects long-term functioning (Kirkevold et al., 2014) and leads to low satisfaction with one's social network and a poor quality of life after a stroke (Hilari et al., 2012). Individuals with stroke have described feelings of emptiness and abandonment upon returning home. It was noted that addressing psychosocial issues was more challenging in rehabilitation than addressing physical concerns (Guo et al., 2021). Worrall et al. (2017) described in their study that psychosocial factors were the most significant predictors of managing life with aphasia in the first 12 months post aphasia onset. Aphasia can affect several factors of one's life; for example, speech impediment can be detrimental to one's social life (Doogan et al., 2018). People with aphasia report experiencing various challenges with their psychosocial well-being, loss of employment, emotional changes, and a detrimental impact on their interpersonal relationships, and these difficulties tend to persist and require support (Ford et al., 2023). Previous studies report that the main causes of friendship breakdown after stroke were due to a loss of shared activities, changing social desires, language impairment and physical disability. The people that had aphasia had even greater difficulty maintaining friendships, and they experienced

negative reactions when attempting to make new friends (Northcott & Hilari, 2011). Positive relationships have been associated with improved psychosocial outcomes. In their study Ford et al. (2023), highlighted the importance of a strong support within one's inner circle, which minimizes the risk of loneliness and attains positive psychosocial outcomes. Elderly people with aphasia communicate with friends less frequently and have a smaller social group than before aphasia onset. The friendships often end post-stroke due to the fact that friends are unsure of how to communicate with the person with aphasia. Davidson et al. (2008) mention in their study that it is important to research and create an intervention program to focus on communication with friends for elderly people with aphasia. To maintain an adequate quality of life, participation in personally significant activities is an important factor (Spaccavento et al., 2014). To achieve this, people with aphasia may require long-term service provision, for instance through community-based interventions. One model for delivering such services can be aphasia group centers.

## **1.2. Aphasia group centers**

Group therapy has been proven to be useful in different clinical contexts. This type of clinical work is expected to become more common in the treatment of patients with medical illness (Leszcz, 2020). In their study, Jackson et al. (2019) discovered that group participation proved to be beneficial in improving mental health symptoms and overall quality of life for individuals dealing with chronic illnesses. Holmes et al. (2000) specifies in their study how group treatment gives the essentials for the development of relationships for every group member. During group treatment, there are more people to learn from, identify with, connect to, and with whom to form meaningful relationships (Holmes et al., 2000). According to research done by Elman (2007) aphasia group centers provide advantages that an individual treatment does not, such as it allows groups of people with aphasia to become part of a community that accepts and nurtures them. According to Simmons-Mackie et al. (2014), people with aphasia who undergo group therapy receive support from a trained clinician which can permit them to engage in conversations with other participants. Elman (2007) states that participants that joined group activities noticed progress with their speech, reading and writing abilities - and this was positively influenced by group activities. However, participants reported that sessions lasting three hours were too long (Elman, 2007). According to Elman (2007), group therapy for people with aphasia is a profitable way of providing therapy. Furthermore, people with aphasia included in group therapy have reported improved confidence, mood, and an increase in communication-related outcome measures (Wilson et al., 2021). MacKenzie et al. (2016) found that during group sessions, people with severe aphasia displayed more facial expressions and more communicative initiative, as opposed to during individual sessions. A community involves a group of people who share common perspectives and engage in joint action in geographical settings (MacQueen et al., 2001). Community aphasia groups have proven to be useful to support the maintenance of identity and wellbeing for individuals with chronic aphasia. To meet the variety of needs for people with aphasia, it is favorable to have group services led by speech-language pathologists, as well as peer and volunteer-led aphasia groups (Pettigrove et al., 2022). Research conducted by DeDe et al. (2019) reports that participation at an aphasia center positively influences people with aphasia regarding their views of their quality of life and communication.

### **1.3. The community aphasia rehabilitation center in the study**

The community aphasia rehabilitation center (which is known as "the aphasia center" in the following text) where the current study was conducted is situated in a medium sized town in a central part of Sweden. The aphasia center is for adults with aphasia that are in need of continued rehabilitation for their language, or to reestablish social community after the acute rehabilitation. In order to participate in the aphasia center, the participants need to live in the county and have sufficient language comprehension. The aim of the aphasia center is to offer a variety of activities three times a week to encourage communication and other cognitive functions. The enrollment period is two years, and every six month there is a follow-up call with the staff where the participant can reflect over the activities, as well as set goals. Before the participant is discharged from the aphasia center, there is a discharge meeting where the staff together with the participant discuss the completion of their participation.

Activities at the aphasia center include:

- Couch-talk: the aim of the activity is to practice communication and turn taking to increase participation in group.
- Reading newspaper: the aim of the activity is to practice reading and language comprehension and to discuss the news.
- Communication group: the aim is to practice more specific communicative language abilities in group.
- Digital language training: the aim is to individually practice specific language abilities through exercises on a computer/tablet or phone.
- Paper and pen: the aim of the activity is to practice language abilities and fine motoric skills with writing activities.
- Other activities at the aphasia center are activities of personal choice, cooking, grocery shopping, mindfulness, and afternoon activities where the participants usually play games (attachment 6) (Lisa Mellenthin, personal communication, June 2023).

### **1.4. Rationale for the study**

As discussed in the text earlier, patients with aphasia often have a reduced psychosocial well-being such as loneliness and depression, and that basic rehabilitation does not help to the same extent that an aphasia rehabilitation center would. There are studies that suggest that group activities are beneficial for this.

It appears that there is no previous study in Sweden regarding the effect of group activities on the psychosocial well-being of people with aphasia from their own perspectives. Given that there are very few aphasia centers similar to the one in this study, there may be a lack of information regarding the effects that these types of aphasia centers have on the psychosocial well-being of people with aphasia. This study aims to gain knowledge that can allow further development of aphasia rehabilitation and how the needs of people with aphasia can be met.

## **2. Aim**

The aim of this study was to explore the perceived effects of aphasia and group activities at an aphasia rehabilitation community center.

### **2.1. Research questions**

1. What is the perceived effect of aphasia on psychosocial well-being?
2. What is the perceived effect of group activities on the psychosocial well-being of people with aphasia?

## **3. Methods and Materials**

The author conducted semi-structured, individual interviews using a qualitative study design. The author was at the time of the interviews a speech and language pathology student who had completed courses and clinical training related to aphasia. The author also received training from the supervisor, who is well-experienced in working with people with aphasia. The author received information prior to the interviews regarding which participant they would interview, and the level at which the participants could communicate.

### **3.1. Setting**

The author visited the aphasia center three months prior to the planned interviews and participated in activities such as communication group, newspaper reading and afternoon activities. The participants knew prior to the visit that the author was a speech and language pathology student with the aim to do a research study. The purpose of this visit was to allow the participants to become familiar with the author, as well as the author to become familiar with the activities at the center, and as a part of the consent procedure (Paterson et al., 2002). The interviews took place in a separate, quiet room at the community aphasia rehabilitation center. This allowed the participants to feel safe to talk about their experiences, given that the location was familiar to them (Topping et al., 2021). The interviews took place on a day when the participants were already scheduled to be at the aphasia center. Therefore, it was more convenient for them to participate. During the interviews, only the author and the participant were present in the room.

### **3.2. Participants**

The inclusion criteria for recruiting participants in this study consist of:

- Participants who had aphasia caused by stroke (mainly cerebral infarction stroke).
- Currently participating in the group activities for > 3 months and participating 1-3 days per week in the activities at the aphasia center.
- The participant should be able to communicate intelligibly with a trained interviewer.

The exclusion criteria involved any disability that was severe enough to restrict participation in the interview, such as cognitive impairment, visual impairment, or hearing difficulty.

Data was gathered from seven participants that were recruited from the aphasia center in central Sweden. The staff at the aphasia center assisted with the recruitment based on their knowledge about the participants. The participant received written information regarding the study, which the staff read aloud to them (attachment 2 and 3). The staff asked the participant beforehand for consent to participate in the study, and they

discussed the information regarding consent together with each participant (Topping et al., 2021). At the start of the interview, the author received informed written consent from two participants, while the others had given their written consent beforehand to the staff of the aphasia center.

### **3.3. Material**

The interview questions were designed to reflect the participants' experiences of the aphasia center, and what perceived effect it had on their psychosocial well-being. The author and her supervisor, created the interview guide (attachment 1). Supporting material for the interviews was prepared by the author, such as a communication picture aid for the participants to facilitate the understanding of the interview questions and how to answer them (Brown & Thiessen, 2018). The communication picture aid consisted of one interview question per page and a related picture to the question. This would be a picture that could graphically represent the question to aid the participants in the understanding of the question (for example of one question, see attachment 8). There was also a self-rating scale for the participants to use as an aid when answering questions, as well as a writing board and a pen. The self-rating scale was utilized on a conversation basis to aid the participant when answering the questions; they could point to the scale when answering questions if they had difficulties articulating their emotions and feelings. For example, the author could ask the participant, "Where on this scale would you say that your social life is?" (attachment 7). The scale had colors from red to green, where red represented something negative such as "bad" or "difficult", while green was feeling "good" or "at ease", and in the middle there was yellow that was neutral. Below the colors, there were faces that aimed to suit the colors. The equipment that was used during the interviews was a video camera.

### **3.4. Procedure**

The author gave each participant information regarding the interview content and process (attachment 4). All interviews were conducted in Swedish and had a duration of 20 to 45 minutes. The interviews were video-recorded to allow transcription of both verbal and non-verbal communication. The author used an interview guide (attachment 1) when asking the questions. The wording, the follow-up questions and the order of questions could differ depending on the participant. The author introduced herself at the beginning of each interview. In order to reduce the number of questions during the interview and not spend too much time or energy on eliciting background information, information about how many times a week they attended was received afterwards from the staff (Paterson et al., 2002).

### **3.5. Data Analysis**

The author used an inductive approach when analyzing the data, and a qualitative content analysis (Graneheim & Lundman, 2004) has been done to identify the patterns in the data.

The analysis was carried out in these steps:

1. The interviews were recorded and transcribed verbatim.
2. Once the interviews were transcribed, they were thoroughly examined several times to allow the author to have a complete perspective of the interviews and a sense for what kind of themes may appear.



3. Meaning units were extracted from the transcribed interviews. Meaning units are words or sentences that contain aspects that are related to each other through their content or context (Graneheim & Lundman, 2004). As the participants have communication difficulties, it was necessary to base the analysis not only on what they actually say verbatim, but also to make an interpretation of what they mean as well as through their non-verbal communication. This then required the author to ask questions to confirm that the author understood them correctly, and sometimes even include the questions in the meaning units.
4. From the meaning units, the author formulated condensed meaning units that were interpreted with a code that were sorted into subcategories and then categories before being labeled with a theme (table 1). The analysis is an iterative process where the author has been alternating between the transcribed interview and the categories to constantly ensure that the analysis is clearly anchored in the data. The supervisor was involved in the analysis process.
5. The author was then able to identify associations and differences between the participants' answers whilst utilizing the themes and categories that were created based on the codes.

**Table 1.**

*Examples on identifying codes from the meaning units (I: interviewer, P: participant).*

Meaning units	Condensed meaning units	Codes
I: Hur är det att umgås med släkt? P: Bra	Informant uppger att det går bra att umgås med släkt.	Går bra att umgås med släkt.
I: How is it to spend time with relatives? P: Good	The informant states that it goes well to spend time with relatives.	Goes well to spend time with relatives.
I: När du fick afasi hur var ditt psykiska mående då.. P: Jobbigt...	Informant uppger att det psykiska måendet har blivit sämre efter afasi.	Sämre psykiskt mående efter afasin.
I: How was your psychological well-being when you got aphasia P: Difficult...	Informant states that the psychological well-being has become worse after aphasia.	Worse psychological well-being after aphasia.

### 3.6. Ethics

The Swedish Ethical Review Authority has approved this research project (DNR 2023-01864-01).

Video recordings and data in the form of transcribed interviews will be saved on a password-protected and encrypted server. Only those who have been directly working on the project had access to the data. Personal information is handled according to GDPR (EU679/2016) (attachment 2).

The author received informed consent in written form from all participants before proceeding with interviewing them. People with aphasia are a vulnerable group, and with that in mind, the author aimed to be prepared as best as possible for the interviews and to aid the participant with the communication. Given that the study addressed personal and sensitive topics, it was essential that the participants were enabled to feel safe and comfortable during their participation. The author informed the participants about the aim of the study. Additionally, the author advised each participant that they could stop the interview at any time and could decide whether or not to answer any of

the questions presented, and this could be done without an explanation to the author. During the interview, the author confirmed with the participants several times if they had any concerns, and if they were happy to proceed with the interview. This was done in order to establish an ongoing consent (Topping et al., 2021). Participants were permitted to relay feedback, give comments and to ask any queries. For example, one participant enquired what would happen with the study, and so the author answered this.

The quotations add emotion, personal language, and examples. However, there is a potential risk of the participants being identified. Hence, it is crucial to contemplate whether a quote might inadvertently disclose the participants' identity. With the awareness that this aphasia center does not exist in many places in Sweden, the author has been meticulous with not exposing participants whether it is in quotations or information regarding the participants.

## 4. Results

### 4.1. Participants

The participants' ages varied between 35 to 78 years, and the mean age was 63 years. There were four female and three male participants with a variation of age, gender and time at the aphasia center, as well as how their lives varied before their stroke. There were four participants that had non fluent aphasia and three that had fluent aphasia.

### 4.2. Results of the analysis

The categories in each theme (table 3) are used as subheadings to aid the reader when reading the results. In the quotes three dots (...) is used to indicate a pause, while (//) means that misstatements and doubts have been removed for the convenience of the reader as well as personal detail. (I) means interviewer while (P) means participant. The meaning units include both what the author and the participant said to attain an entire perspective. The presenting quotes of the participants were translated to English (for original quotes in Swedish, see attachment 5).

**Table 2.***Themes and categories that were created.*

Themes	Main category	Sub-category
Comparison with the time pre-aphasia onset		
Challenges and changes post-aphasia onset	Challenges post aphasia onset	
	Identity changes	
	Communication abilities	
Psychosocial well-being post-aphasia onset	Experience of psychological well-being	
	Experience of social life	Relationships with friends
		The importance of family
	Factors affecting psychosocial well-being	Being able to feel a connection
Physical activity outside the aphasia center		
Participation at the aphasia center	Participation at the aphasia center gives structure in daily life	
	Experience of being in a group	Group dynamics
	Experience of the staff	
	Positive experience of the aphasia center	
	Negative experience of the aphasia center	
	Statements regarding the activities	
	Suggestions for the aphasia center	
Ending participation at the aphasia center	Experience of ending participation	
	Facilitate the ending at the aphasia center	

#### 4.2.1. Theme 1: Comparison with the time pre-aphasia onset

This theme contains information about the participants' perceived well-being before aphasia onset. All the participants expressed that their well-being was better before aphasia onset.

*I: "I: And before aphasia...you told me that you were forward as a person... did you feel better then or have you had periods where...  
P: No there (points at the right (green) end of the self-rating scale)  
I: Yes you felt better  
P: Mm"*

#### 4.2.2. Theme 2: Challenges and changes post-aphasia onset

The theme post-aphasia onset contains information regarding the challenges the participants felt after onset of their aphasia, as well as changes in their identity that could be important.

*Challenges post aphasia onset.*

Most participants faced challenges with their aphasia, and described uncertainty if others understood them correctly. Some participants expressed concerns that they could no longer participate in their previous activities. Other challenges discussed were difficulties with their social life and a dependency of help with daily activities, such as household chores and cooking.

2: *"P: Ehh... I try to keep up as much as possible but sometimes I can get tired and then I think...uh now I can't do this...it's too much...but I...uh...I...I exercise...I force myself to go out...so I don't stay seated..."*

#### *Identity changes.*

Most participants experienced an identity change after aphasia. The majority felt that their personality had changed in a negative way, for instance that they had changed from extroverted to introverted. One participant however described a positive personality change and felt more confident than before, especially in talking to health care professionals.

3: *"I: Before aphasia...were you shy, or social or were you forward as a person or something else?"*

*P: I was really forward*

*I: Very forward*

*P: Yes*

*I: ...and how are you today?"*

*P: No...then I am much worse...yes...it is...really sad...that I have gotten so much...worse"*

#### *Communication abilities.*

Some participants expressed differences in their communication abilities after aphasia and felt limitations in their communication. Augmentative and alternative communication was used by one participant, while another participant expressed that the communication had improved.

5: *"P:... because it will be too..then I couldn't speak...the language has changed a lot so that you couldn't communicate in the way you can now either..."*

#### *4.2.3. Theme 3: Psychosocial well-being post-aphasia onset*

##### *Experience of psychological well-being.*

Most participants experienced a decline in their psychological well-being post-aphasia onset, and that their psychological well-being was affected by aphasia. One participant explained that she experienced feelings of loneliness and shock during the illness.

6: *"Participant: You don't understand... that you're going to be in the hospital for like a week and now I'm going to go to plenty of.. and like... from one day you're healthy and the next day you're not healthy.. like.. you can't.. it's hard to grasp"*

Overall, participants felt that their psychological well-being after the illness was fluctuating; some days they felt fine, and on other days, they did not feel "fine". Some participants mentioned feeling emotional stable in their daily life, and that their

motivation has helped them during their rehabilitation. One participant mentioned that feeling independent in their daily life has helped them during their rehabilitation.

4: *"I: Do you feel that you are independent in your daily life or do you need help with certain things  
P: Yes eh...yes certain things...eh...yes...but I can manage myself..."*

#### *Experience of social life.*

After aphasia onset, most participants felt that their social life had gotten worse, and had to work hard for it to become better.

7: *"I: Do you think having aphasia has affected your social life?  
P: Yes...a lot... not many people anymore..."*

Two subcategories that were found were relationships with friends and the importance of family.

#### *Relationships with friends.*

The participants experienced changes within their friendship dynamics, and some had a loss of their friendships post-aphasia onset.

8: *" I: Do you experience that having aphasia has affected your social life?  
P: Eh...well...a part...then...yes...eh...yes... absolutely  
I: In what way?  
P: Eh.. some friends who...eh..yes..are reluctant to ask about...eh...mm...and so  
I: There are friends that are reluctant to ask about how it is?  
P: Yes..."*

Though there were few participants that had friends who remained despite their new illness, and some had friends who would readily listen to them.

#### *The importance of family.*

Participants spent more time with family post-stroke, and the impact of this was valuable for the participants mood and well-being.

9: *"I: And this question is similar to the previous one... but is there anything else that has helped you to keep the mood up?  
P: It's family...of course... absolutely"*

Most participants felt that communication with family was satisfactory, and that they were feeling understood by their family members.

#### *Factors affecting psychosocial well-being.*

Participants experienced that the aphasia center had a positive effect on their psychosocial well-being, and there was one participant who explained that they could be themselves at the aphasia center. Consistent practice and activities at the aphasia center were noted for improving one's well-being and social life.

10: "I: Yes... and then talking with...you talk about other things...what has happened in the world and what we are going to do on the weekend... so it is communication all the time even though it isn't on... the schedule... yes you understand."

One participant, however, was unsure of the benefits of the aphasia center, while another participant was grateful for the improvement in well-being and the center's structured schedule.

*Being able to feel a connection.*

Feeling a connection with other people in a group was important for well-being. One participant explained it as being able to feel understood by people who share similar experiences due to the consequences of aphasia.

12: "I: What do you think has caused that // made an impression on your life...is it routines.. that you got some routines...

P: To meet people... and one thing I haven't mentioned... one thing that has made a big impact is to meet people that are like me.. that also had stroke. "

*Physical activity outside the aphasia center.*

Physical activity has been important and helpful for most participants and for their psychosocial well-being. Some participants worked out together with a trainer, while others took walks in nature. The physical activity that is mentioned is not at the aphasia center but on leisure time.

13: "I: Except for //, what other things in your life have affected that your psychosocial well-being has become better.... you said that spending time with family and friends and that you go out for walks and watch tv.... is it something else that has helped you after aphasia onset...

P: Sports \*points at the word "sports"\*"

#### 4.2.4. Theme 4: Participation at the aphasia center

Another theme that emerged was the participation at the aphasia center. It was noted how important the participation at the aphasia center was and the comradery, as well as the experience of the staff members.

*Participation at the aphasia center gives structure in daily life.*

Participants felt that having structure and routines in their daily life was beneficial to their psychosocial well-being.

11: "I: How do you think it has been since you started at //... similar, better or worse?

P: No, it has gotten better.. precisely because I get to have some routines too.."

*Experience of being in a group.*

The participants were able to feel seen and heard in a group, as well as to feel that other participants were helpful.

14: *"I: Do you feel that sometimes it can be difficult, fun or intensive in the group*

*P: No, I wouldn't say that.... just fun."*

However, there were participants who did not feel comfortable speaking out in front of the group mentioning during the interview that their challenges with communicating was making it more difficult for them to feel understood by other participants.

15: *" I: When you meet in groups like this, do you feel that you can speak up?*

*P: Eh no (points at mouth) No."*

#### *Group dynamics.*

Most of the participants had a positive experience of being in a group with other participants and felt a fellowship with other participants whilst being in the group. One participant reported that it is important to have a similar communication ability when being in the groups, since someone that have easier to communicate may easily occupy most of the conversation when talking in a group.

16: *" P:...because when you have a communication group some know more and some know less, then you need to have a group that is roughly the same because otherwise...well, it can also become weird*

*I: A balance in the group?*

*P: Yes, a balance exactly... so that it is on the same level.. exactly.. linguistically.. otherwise it's easy to take over if someone have to think a lot after a word... then I sit and wait for them all the time because I know exactly and then it's easy to take over... but those who are thinking... then you have to wait for each other.. that we are roughly the same... "*

The size of the group was important for some participants, who expressed that the groups should not be too large. Another participant expressed that they would prefer to have a group with not too few participants.

17: *" P:...and then...then there are smaller groups every now and then and they are... I think it is good when we make small groups... oh... so there are not too many of us because then it gets m...me...messy for me.. so that I think it's good.. and then the big groups it's good for me too.. even if it's not very big... because I can handle it even when it's not too big "*

#### *Experience of the staff.*

All the participants had a positive experience of the staff, and they felt that the staff were supportive and compassionate during their interaction.

18: *"I: How has your interaction been with the staff?*

*P: It has been really good"*

#### *Positive experience of the aphasia center.*

The aphasia center provided an environment where the participants could feel seen and heard. They felt a sense of belonging, appreciated the activities, and highlighted the positive influence on their psychosocial well-being.

19: *"P: Sometimes I get tired... but I am grateful to be able to go here... I think that's good."*

#### *Negative experience of the aphasia center.*

The negative experiences that the participants expressed included the intensity at the aphasia center, and how the long journeys to the aphasia center could be tiring for the participants. Some participants said that they could encounter difficult topics especially during the conversations in the afternoons when they felt tired.

20: *"I: Are there difficult subjects in the afternoons?  
P: Yes...because sometimes I don't understand much "*

#### *Statements regarding the activities.*

Most participants felt that the activities were goal-oriented, and that it was beneficial to be able to practice their speech, especially aspects that were difficult. Activities that were most popular were "communication groups", where the participants had the opportunity to communicate with each other regarding various topics.

21: *"P: ... when you are all alone at home... then you don't talk as much...my partner... he has been at work all day and is tired... so you can't really talk as much...(giggles) I want to talk a lot... so here I can talk a lot (points at the communication-group on the schedule)..yes...so that is very very..."*

Other activities that the participants seemed to enjoy were "paper and pen" and "digital language training". The opinions varied regarding "mindfulness" where some participants thought it was helpful while others did not like it.

#### *Suggestions for the aphasia center.*

Most participants expressed that they were satisfied with how the aphasia center is and that nothing could have been done differently. Though one participant did mention that they desired the activities to be arranged differently especially after lunch. Another participant mentioned that it would be better to include physical activity at the aphasia center.

22: *"I: Is there anything you think that they should do different here at the //?  
P: (writes on the board)  
I: Sports?  
P: Yes  
I: You think that they should do more sports?  
P: Yes"*

#### *4.2.5. Theme 5: Ending participation at the aphasia center*

The theme that emerged reflected the negative feelings that the participant felt when thinking about ending their participation at the aphasia center.



*Experience of ending participation.*

Participants expressed reluctance and negative feelings about ending their participation at the aphasia center.

23: "I: Mm.. and you are participating here at the aphasia center... you will eventually quit..

P: Mm.. (shaking their head)

I: How does it feel... does it feel scary or fun

P: (gets sad) \*points at the word scary\*

I: Mm.. scary.. I understand..."

*Facilitate the ending at the aphasia center.*

The majority of the participants stated that they could not think of anything to facilitate ending their participation at the aphasia center. Proposals to improve this transition comprised of having regular follow-ups and being prepared for the end.

24: "I: Was there something that could have made your ending at the aphasia center easier... or did you feel that it was...

P: No, there was nothing that could have been done differently.... I don't think so.."

## 5. Discussion

### 5.1. Discussion of the results

Using a qualitative design, the author investigated the perceived effect of aphasia on psychosocial well-being and perceived effect of group activities on the psychosocial well-being in people with aphasia. The reason for this was to obtain genuine and significant insights into their lived experiences and perspectives (Topping et al., 2021). This study highlights that aphasia had an influence on the psychosocial well-being of the participants. For example, they had a reduced sense of well-being, a negative impact on their social life and even a loss of opportunities to be involved in certain leisure activities. Furthermore, this study provides insight into the perceived effect of group activities on psychosocial well-being. The results of this study demonstrate a positive relationship between group activities and the psychosocial well-being in people with aphasia.

#### 5.1.1. What is the perceived effect of aphasia on psychosocial well-being?

The results demonstrated that several participants experienced that aphasia has had a negative effect on their psychosocial wellbeing. The participants described feeling as if their identity had changed. Specifically, there were descriptions of changing from being extroverted to being more introverted. This aligns with the findings by Moss et al. (2021), where the participants commonly expressed that they felt an identity change post-aphasia onset. Most participants in this study felt that it was a negative change.

Findings add to the existing literature in several ways. The negative impact of aphasia on identity was demonstrated through the loss of their previous activities and changes in their social interactions. These changes in their social life may be due to the perceived change of identity in these participants, although this study did not focus on this.

This study demonstrated that the majority of participants experienced a change in their friendships or a loss of them after aphasia onset. Participants in this study expressed that they spend more time with family as opposed to friends, given the difficulties that they would encounter post aphasia onset. For example, they may experience not being understood effectively. These changes in friendships were perceived to be related to the communication problems caused by the aphasia. People with aphasia have greater difficulty maintaining friendships (Northcott & Hilari, 2011). In addition, they expressed that they spend more time with family as opposed to friends, given the difficulties that they would encounter post aphasia onset. For example, they may experience not being understood effectively. These changes in friendships were perceived to be related to the communication problems caused by the aphasia. People with aphasia have greater difficulty maintaining friendships (Northcott & Hilari, 2011). For the majority of the participants their families were the only social relationship they had. The loss of friendships may lead to a deterioration in psychosocial well-being. However, losing friendships can lead to additional risks. According to Ford et al. (2023), having a lack of strong connections within the inner circle might imply a heightened risk of experiencing negative consequences, poor psychosocial outcomes such as isolation.

Several people with aphasia may face depression and other mental health issues (Kristo & Mowll, 2022). This study did not investigate presence of depression or anxiety. However, as previously mentioned, the participants experienced worse psychological well-being after aphasia onset. The results indicated that a relationship with family and additional physical activity (activities not included in the aphasia center's schedule) had a positive impact on the participants' psychosocial well-being. Previous studies have highlighted that physical activity can prevent common mental health disorders, such as anxiety and depression (Schuch & Vancampfort, 2021). Physical activity is integral for some participants, although this study did not specifically investigate the effects of it. Some participants mentioned that physical activity boosted their mood, while another mentioned that the aphasia center should incorporate a greater variety of physical activities. This indicates that it could be beneficial to ensure that those with aphasia are appropriately supported so that they can find opportunities to remain physically active.

Personal factors such as personality and emotional stability may influence well-being and social life post aphasia. This was noted in the results where some participants expressed being more emotionally stable, and also had a greater life satisfaction post aphasia. In general, these participants seemed not to be affected by their aphasia in the same way as other participants. Previous research has demonstrated that some people with aphasia experience posttraumatic growth after aphasia onset, for example in the shape of increased appreciation of life (Sherratt & Worrall, 2020). According to Sherratt & Worrall (2020), it would be beneficial to accept personal strengths and skills in order to renegotiate one's identity and to reinforce recovery post-aphasia.

#### *5.1.2. What is the perceived effect of group activities on the psychosocial well-being of people with aphasia?*

According to the results in this study, participants perceived that the aphasia center proved to be beneficial for their psychosocial well-being, as well as their ability to live well with aphasia (Lanyon et al., 2018). Group activities allowed a sense of community, provided routines, and positively influenced psychosocial well-being. However,

challenges related to communication impairments, varied preferences of activities and size of the groups should be considered for a more inclusive participation at the aphasia center.

According to the results, most participants had a positive experience of being a member of a group, feeling a sense of community and connection with others that shared similar experiences. Tarrant et al. (2016) revealed in their study that it is ideal for individuals with aphasia to establish psychological connections and to attain a feeling of group-belonging in order to help reduce anxiety.

In this study, it was shown in participants that maintaining a routine and structure in daily life is essential for psychosocial well-being. Routines are shown to increase motivation (Koome et al., 2012). It was noted that having structure at the aphasia center was important for the participants to aid them in knowing where they will be at a certain time and what they would be doing and may even increase the participants' motivation to attend the aphasia center. This in turn may affect the participants' psychosocial well-being and being able to come out their home to meet other people regularly, given that they may feel obligated to attend when they have the sense of comradery. This may be important for well-being even if the participant feels that they can cope alone. Other studies have shown that people with aphasia perceived joining group programs as important for supporting self-worth (Lou & Chau, 2023).

The participants at the aphasia center shared various preferences and opinions of the activities held. "Communication group" was one of the most preferred activities, because this activity allowed participants to practice their communication. This study did not focus on the communication training itself, but it was, unsurprisingly, repeatedly mentioned by the participants as being important. Aphasia centers have been proven to positively influence psychosocial adjustment for people with aphasia, especially when the sessions are interactive (Plourde et al., 2019). This may be another reason why the "communication group" was the most popular activity at the aphasia center given that the sessions were interactive. One may feel a sense of belonging and a positive connection with others while being in a group to practice communication. However, participants who have different types of aphasia may perceive participation in group activities differently. It is likely that if a participant believes that they have made progress in their language skills, they also experience greater satisfaction in group activity participation (Harvey et al., 2022).

Mindfulness was an activity at the aphasia center which the participants shared mixed feelings about. Certain participants perceived the sessions to be useful, whereas others did not. Mindfulness has previously been shown to potentially decrease negative emotional states and increase the feeling of calmness (Panda et al., 2020). A study conducted by Wang et al. (2002) displayed similar comments regarding mindfulness, and these comments were quite mixed. The feedback that was given regarding the aphasia center suggested to arrange a different schedule of the activities in the afternoon, where mindfulness is one of the activities during the afternoon.

Long journeys to the aphasia center and intense schedule at the aphasia center may influence participation at the aphasia center. Being able to rest at the aphasia center may be crucial for people with aphasia to be able to participate in the aphasia centers' activities.

Even though the activities at the aphasia center are specifically adapted to be accessible to people with aphasia, the communication impairment can still make participation in the group challenging. Those participants that did express that they did not feel a positive experience in a group also felt that their challenges with communicating was making it more difficult for them to feel understood by other participants. Lou & Chau, (2023), reported in their study that people with aphasia who would experience failure in engaging throughout group sessions would accumulate feelings of low self-worth, which led to a decrease in their willingness to participate.

Research shows that small groups of three or four people can form close relationships, but they also might make it harder for new participants to join and affect the group dynamic (Lanyon et al., 2018). It seems that group size is an important factor, given that having too large group sizes can negatively impact participants during their participation as they would raise concern when experiencing this (Lanyon et al., 2018). The participants mentioned that the groups shouldn't be too big since it may affect their participation, but not too small either. In addition, having similar communication abilities seemed to be important for the dynamic in the group. This may be important to take into consideration when creating groups and for creating a good group dynamic. Lanyon et al. (2018) mentioned that an important part of group integration is the use of routine and structure, which was revealed to enable individuals to participate in the group. Lanyon et al. (2018) also found that people with aphasia seek opportunities to support other group members and to achieve the group dynamic. Lou & Chau (2023) discussed in their study that it may be beneficial to have smaller groups for a more positive group experience as well as encouraging those with aphasia to express their concerns.

Participants expressed reluctance and negative feelings about ending their participation at the aphasia center. This may be due to feeling a loss of security and identity. Participants may also express concerns regarding that they would have to independently continue learned routines and would be anxious whether people outside of the aphasia center would be able to comprehend them. Suggestions to improve this transition comprised of having regular follow-ups and being prepared for the end of their participation. The aphasia center prepares individuals through a discharge meeting, where the staff together with the participant discuss the completion of their participation. To the best of my knowledge, research does not exist regarding people with aphasia who have experienced ending their participation at an aphasia center. Research in other populations has shown that ending group therapy may trigger feelings of grief and loss (Schermer & Klein, 1996).

In summary, the study highlights the influence of aphasia on the psychosocial well-being of people with aphasia, revealing changes in personality and personal identity among the participants and difficulty maintaining friendships, with many experiencing a shift in social interactions. Regarding group activities, the routines at the aphasia center, social connections, and consistent communication practice positively influenced participants' psychosocial well-being. However, individual preferences regarding activities, challenges with communication in group also emerged.

## 5.2. Discussion of the method

To interview people with aphasia may be difficult, and there may be limited ways to perform the interview. The majority of research on post-stroke depression either completely or partially overlook individuals with aphasia (Townend et al., 2007), even if there is evidence that they are willing to participate if given the opportunity (Alexander et al., 2018).

In order to be able to conduct interviews with people with aphasia, communication-supporting strategies need to be used, e.g. visual support, offering answer options, etc. This also means a risk of the interviewer controlling the answers. The use of communication support strategies requires the interviewer to have adequate knowledge and experience (Carlson et al., 2007). The interviewer in this study has some experience of meeting people with aphasia but has not previously conducted interviews. This could affect what kind of response options were given to the participant during the interviews to assist the participant during the communication. This may have affected what the participants were able to express and the answers that were given to the author. Given the communication impairments of people with aphasia, assisting them during a conversation and acknowledging their experiences in life may be crucial for the interview to continue. However, this could affect the results in the study due to the fact that examples that were given were limited and may be influenced by the interviewers' preconceptions.

The communication support needs to be adapted based on the needs of each participant, which means that different amounts of communication support are offered. The participants that needed more support were also given more options of answers as an aid to the questions, and their answer may then be shorter as well as more specified since the participant may be given two or three options to choose from. Although the author ensured to always give the option "something else" if any of the presented options did not suit the participants, it may still be difficult for some participants to express another option. One participant did once choose "something else", and when the author asked what it was and tried to assist, the participant was not sure. Since the participants did have limitations in their communication, and even though the author asked questions to confirm that the author did understand what the participants said, it is still difficult to conclude whether the author understood everything that the participants said or had the intention to say. Receiving information about the participants' communication abilities prior to the interviews can both be positive as well as negative. The author of this study received information before each interview regarding the participants' communication abilities. This could limit the study, as the author unconsciously receives a preconception of the participants' communication abilities and can make assumptions due to this bias, such as not using any communication aid although a participant may need one. The positive side of receiving information prior to the interviews can be that the author becomes more prepared of who they will meet and what communication aid works best for them, as well as making them comfortable during the interview. None of the included participants had severe aphasia, and this was due to the criteria of the aphasia center itself. This is important to note regarding the results of this study, as the result may not be transferable to more severe aphasia. The participants formed an ethnically, culturally and linguistically homogeneous group and the results cannot therefore be transferable to the whole aphasia population.

Meeting participants beforehand allows the interviewer to introduce the study's aims and methods (Paterson et al., 2002). Meeting participants and getting familiarized with the aphasia center facilitated the author to ask questions that were related to the aphasia center, as well as to have an easier understanding of what the participants are trying to convey. Meeting the author before the study may have allowed the participants to feel more at ease during the interview. The author has tried to stay as neutral as possible in this research process. However, a certain bias, related to the author's knowledge, experiences and assumptions, is inevitable. In order to support reflexivity, the author has highlighted the importance of being aware of one's own expectations. For example, the author had an expectation that aphasia may negatively impact psychosocial well-being, whereas group activities may have a positive effect. This is important to take into consideration and to be aware of results that contradict this. The author shared her thoughts and expectations with her supervisor, who aided her in this process to support reflexivity to the best of her ability. Given that this was the author's first research interview with people with aphasia, the author may have struggled to remain unbiased. The author together with the supervisor collaborated on the analysis to reduce subjectivity as far as possible. The author has been very conscious when translating the participants' quotes to ensure that there was no loss or change of the participants' meaning or emotions that were expressed.

One of the limitations in the study was that there were no pilot interviews, and this may have affected how the interviews were executed. Piloting the interview permits the researchers to evaluate the sequencing and phrasing of the interview questions, as well as to develop their interviewing skills with the sample population (Paterson et al., 2002).

These are methodological challenges that are inevitable in research with people with aphasia. However, involving people with communication impairments yields valuable contributions to advancing this field (Carlsson et al., 2007), hence the importance of including people with aphasia in these kinds of studies.

### **5.3. Future research**

Ideas for future research would involve having a larger study sample size, where more participants are included to have a saturated sample. A longitudinal study to either follow the participants under a longer time frame would be ideal, yet one should be aware that it may be difficult since all of the participants have different times of enrollment at the aphasia center. Future research may also benefit from comparing the participation at the aphasia center and non-participation at a rehabilitation group activity, and what differences may occur in the psychosocial well-being. The author is aware that it is a sensitive subject and it may be hard to recruit participants to these kinds of studies. Interviewing staff at the aphasia center and investigating their experiences of group dynamics would be beneficial in future planning of group activities for people with aphasia. Receiving the perspective of close relatives of the participants at the aphasia center can possibly give information about how they perceive the effect of the aphasia center. One may take into consideration the significance of interviewing participants that had completed their participation at aphasia center. It may be worthwhile to ask about their emotions, lifestyle, any changes once they had stopped attending the aphasia center, and any long-term effect of participation at the aphasia center.

## 6. Conclusions

This study presents and discusses what effect aphasia has on the psychosocial well-being and the perceived effects of group activities on the psychosocial well-being of people with aphasia. The study highlights that psychosocial well-being was negatively affected by aphasia, and had a detrimental effect on relationships with friends, leisure activities and identity. The study also emphasizes and concludes that group activities do have perceived benefits, supporting a sense of fellowship and connection, routines and being able to consistently practice communication. However, the study identifies nuances, including communication impairments affecting participation in group activities and participants' varied activity preferences, which may require attention for more comprehensive participation. Finally, the study highlights the crucial role of group activities in supporting people with aphasia, not only in rehabilitation, but also in supporting psychosocial well-being. This research advocates for an extended access to group activities outside healthcare settings.

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## 8. Disclosure Statement

The author has no conflicts of interest.

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## 10. Attachments

**Attachment 1:** Interview guide (Intervjuguide).

**Attachment 2:** Information for research participants (Forskningspersonsinformation).

**Attachment 3:** Information for research participants - Visual/Image support.  
(Forskningspersonsinformation - bildstöd).

**Attachment 4:** Consent Form (Samtyckesformulär).

**Attachment 5:** Original quotes in Swedish.

**Attachment 6:** Schedule of the activities.

**Attachment 7:** Rating Scale.

**Attachment 8:** Example of question (image support).

## Intervjuguide studie – person med afasi

Jag kommer att ställa frågor till dig om hur det är/var att vara med i gruppverksamhet här på //, och särskilt om det har påverkat ditt liv, hur du mår psykiskt och hur ditt sociala liv ser ut. Även om du har tackat ja till att delta i den här intervjun så väljer du själv vilka frågor du vill svar på. Du kan också avbryta intervjun när du vill, och du behöver inte förklara varför.

Jag kommer att hjälpa till med kommunikationen efter bästa förmåga, och vi har inte bråttom.

Vi tar paus närhelst du vill.

Jag kommer att filma intervjun. Sen kommer vi att skriva ut intervjun ordagrant, då kommer vi att använda en kod istället för ditt namn. Ingen utanför forskargruppen kommer att kunna veta vilka som har blivit intervjuade, eller vad just du har sagt.

<b>Syfte</b>	<b>Huvudfrågor</b>	<b>Exempel på frågor för fördjupning eller förtydligande</b>
Kvarstående funktionsnedsättningar efter stroke	Var det något annat än kommunikationen som blev svårt för dig efter stroke?	Hur var det precis efter din stroke? Vad var svårt då? Vad behövde du träna på?
	Hur fungerar det nu?	Hur är det nu? Vad har blivit bättre? Vad är fortfarande svårt?
	Är det något som fortfarande hindrar dig i vardagen?	Kan du göra det du vill, på ett sätt som du trivs med? Behöver du någon hjälp i vardagen?
Syssetätning (arbete, fritid)	Arbetar du?	
	Vad gör du på fritiden?	Tränar? Träffar vänner? Umgås med familj? Deltar i andra aktiviteter?
Upplevd psykisk hälsa efter strokeinsjuknandet	Hur man mår psykiskt varierar ju över tid, man kan ha bättre och sämre perioder. Hur tycker du allmänt att ditt psykiska mående har varit sedan du fick afasi?	Hur mådde du under tiden precis efter att du fått afasi, under rehabiliteringsperioden? Har du haft perioder då du mått bättre eller sämre, eller har det varit ungefär lika?
Förekomst av psykisk ohälsa före insjuknandet	Hur var det innan du fick din afasi? Hur var ditt psykiska mående då?	Mådde du generellt bra? Hade du bättre och sämre perioder?
Upplevd påverkan på socialt liv efter insjuknandet	Upplever du att ditt sociala liv har påverkats sen du fick afasi?	Hur fungerar det att umgås med släkt och vänner?

		Har du kvar dina vänner och bekanta?
Deltagande i gruppverksamhet på //	Hur länge har du gått/gick du på //?	
	Hur många gånger i veckan är/var du på //?	
	(för deltagare som slutat) Hur länge är det sedan du slutade på // ?	
Upplevelse av deltagande i gruppverksamhet på //	Hur har det varit för dig att delta i gruppverksamhet på // ?	Har det varit roligt? Jobbigt? Har du känt dig som en del av gruppen, eller har du känt dig utanför? Har du kunnat komma till tals? Hur har kontakten med personalen varit? Hur har kontakten med de andra deltagarna varit?
Gruppdeltagandets eventuella påverkan på psykisk hälsa	Att gå här på //, har det påverkat hur du har mått psykiskt?	Hur mår du psykiskt nu jämfört med när du började på // ? Likadant, bättre, sämre? Vad tror du det beror på?
Gruppdeltagandets eventuella påverkan på socialt liv	Att gå här på //, har det påverkat ditt sociala liv?	Hur ser ditt sociala liv ut nu jämfört med när du började på //? Likadant, bättre, sämre? Vad tror du det beror på?
Om upplevd påverkan: Vilka aspekter av gruppverksamheten har varit betydelsefulla	Vad tror du det är som gjort att gruppverksamheten påverkat dig/ditt liv?	
Avslutande av insatsen	Hur känns det när du tänker på att så småningom sluta gå på //? (för deltagare som har slutat: Hur var det att sluta gå på // ?)	
Andra faktorer som påverkar psykosocialt välbefinnande	Vilka andra saker i ditt liv har påverkat ditt psykiska mående och ditt sociala liv efter att du fick afasi?	Vad har hjälpt dig att hålla humöret uppe? Vill du berätta om något som har påverkat ditt mående negativt?
Deltagarnas förslag på förbättringar av gruppverksamheten på //	Finns det något du tycker man borde göra annorlunda här på// ?	
Avslutande kommentarer	Är det något mer du vill berätta?	

## Information till forskningspersoner om studien *”Gruppaktiviteters betydelse för psykosocialt välmående hos personer med afasi”*

Vill du delta i ett forskningsprojekt? I det här dokumentet får du information om projektet och om vad det innebär att delta.

### Vad är det för studie och varför vill ni att jag ska delta?

Varje år insjuknar ungefär 25 000 personer i stroke i Sverige. En stroke kan ge många olika svårigheter. En vanligt följd av stroke är afasi.

Det är också många som mår psykiskt dåligt efter att ha fått afasi, och för många förändras det sociala livet.

Den studie som vi ber dig delta i heter *”Gruppaktiviteters betydelse för psykosocialt välmående hos personer med afasi”*. Den handlar om vilka erfarenheter personer med afasi har av att delta i gruppverksamhet på //, och om det har påverkat livet psykiskt och socialt. Vi frågar dig om du vill delta eftersom du har afasi efter en stroke och är eller har varit deltagare i gruppverksamhet på //. Vi har fått ditt namn från //.

Uppsala universitet är den organisation som är ansvarig för projektet (forskningshuvudman). Projektet är godkänt av Etikprövningsmyndigheten (diarienummer 2023-01864-01).

### Hur går studien till?

Att delta i studien innebär att du blir intervjuad av logopedstudenten Samra Mujkanovic. Intervjuerna kommer att planeras av Samra tillsammans med hennes handledare Camilla Olsson, som är logoped och forskare vid Institutionen för folkhälso- och vårdvetenskap, Uppsala universitet.

Intervjun genomförs vid ett tillfälle och tar ungefär en timme. Du träffar Samra på //.

Samra Mujkanovic är nästan färdig logoped och kunskap om att samtala med personer med afasi. Bilder och annat som underlättar kommunikationen kommer vid behov att användas under intervjun.

Intervjun kommer att handla om hur du har upplevt det att delta i gruppverksamhet på //, och om/hur det har påverkat ditt psykiska mående och ditt sociala liv. Du kan vara med i studien oavsett om du mår psykiskt bra eller dåligt just nu, men det är viktigt att du känner dig bekväm med att prata om ditt psykiska mående.

Du väljer själv vilka frågor du vill svara på och hur mycket du vill berätta under intervjun. Intervjuerna kommer att filmas för att vi sen ska kunna skriva ner och analysera dem.



## Möjliga följder och risker med att delta i studien

Det finns inga uppenbara risker med att delta i studien. Eftersom intervjun handlar om ditt psykiska mående och ditt sociala liv kan det hända att smärtsamma eller svåra känslor väcks. Personalen på // som känner dig väl kommer att finnas till hands under intervjun, och du kan vid behov ha uppföljande samtal med dem.

Intervjun kommer att filmas och en del personer känner sig ibland lite obekväma med att bli filmade.

Det finns ingen omedelbar nytta för dig personligen att delta i studien, men vissa personer kan uppleva att det är skönt att prata om hur man mår eller har mått. Resultaten av studien förväntas bidra med kunskap som kan förbättra vårdens omhändertagande av personer med afasi efter stroke.

## Vad händer med mina uppgifter?

Projektet kommer att samla in och spara information om dig.

Intervjuerna kommer att filmas och därefter skrivas ut och analyseras. Utöver själva intervjuerna kommer vi att behöva en del bakgrundsinformation om dig, till exempel din ålder, när du fick afasi och hur länge och hur ofta du gått på //.

Vi kommer bara att samla in information som är relevant för projektet. Dina svar och all information om dig kommer att behandlas så att inga obehöriga kan ta del av dem.

Informationen sparas i 10 år efter att projektet är avslutat. Insamlad information förvaras på Institutionen för folkhälso- och vårdvetenskap vid Uppsala universitet. Allt insamlat material kommer att hanteras och lagras i enlighet med de regler för sekretess och säker datahantering som föreligger vid Uppsala universitet. Personuppgifter hanteras i enlighet med Dataskyddsförordningen GDPR (EU 679/2016).

Ändamålet med behandlingen av dina personuppgifter är att kunna genomföra den aktuella studien. Uppsala universitets rättsliga grund för att behandla dina personuppgifter är att behandlingen är nödvändig för att utföra en uppgift av allmänt intresse (bedriva forskning).

Ansvarig för dina personuppgifter är Uppsala universitet.

Enligt EU:s dataskyddsförordning har du rätt att kostnadsfritt få ta del av de uppgifter om dig som hanteras i projektet, och vid behov få eventuella fel rättade. Du kan också begära att uppgifter om dig raderas samt att behandlingen av dina personuppgifter begränsas. Rätten till radering och till begränsning av behandling av personuppgifter gäller dock inte när uppgifterna är nödvändiga för den aktuella forskningen. Om du vill ta del av uppgifterna ska du kontakta Ellika Schalling, Institutionen för folkhälso- och vårdvetenskap, Logopedi, Box 564, 751 22 Uppsala, tel 018-471 4644.

Dataskyddsombud nås på [dataskyddsombud@uu.se](mailto:dataskyddsombud@uu.se). Om du är missnöjd med hur dina personuppgifter behandlas har du rätt att lämna klagomål till Integritetsskyddsmyndigheten, som är tillsynsmyndighet.

## Hur får jag information om resultatet av studien?

För att ta del av resultaten i sin helhet är du välkommen att vända dig till Camilla Olsson (kontaktuppgifter finns nedan).

Resultaten av studien kommer att presenteras i vetenskapliga artiklar samt vid vetenskapliga konferenser. Eventuellt kommer de även presenteras i populärvetenskapliga forum.

## Försäkring och ersättning

Uppsala universitet är en statlig myndighet, eventuella anspråk på ersättning för personskada hanteras av Kammarkollegiet (enligt förordning 1995:1301). Ingen ersättning betalas ut för deltagande i studien.

## Deltagandet är frivilligt

Ditt deltagande är frivilligt och du kan när som helst välja att avbryta deltagandet. Om du väljer att inte delta eller vill avbryta ditt deltagande behöver du inte uppge varför, och det kommer inte heller att påverka din kontakt med //.

Om du vill avbryta ditt deltagande ska du kontakta de ansvariga för projektet (se nedan).

## Ansvariga för studien

Ansvarig forskare för studien "*Gruppaktivitetens betydelse för psykosocialt välmående hos personer med afasi*": med. dr Camilla Olsson, Institutionen för folkhälso- och vårdvetenskap, Uppsala universitet, [camilla.olsson@uu.se](mailto:camilla.olsson@uu.se), 018-471 76 97.

Kontaktperson: Samra Mujkanovic, [samra.mujkanovic.7812@student.uu.se](mailto:samra.mujkanovic.7812@student.uu.se), //

# Vill du delta i forskning om gruppaktiviteter på // ?

## BILD

Jag heter Samra Mujkanovic.  
Jag är logopedstudent.

## BILD

Jag heter Camilla Olsson.  
Jag är logoped och forskar om afasi.  
Jag är Samras handledare.



Efter en stroke kan många olika svårigheter uppstå.



Många som har haft en stroke får afasi.



Det är också vanligt efter stroke att man mår psykiskt dåligt. Man kan känna sig ledsen, deprimerad eller orolig, till exempel.

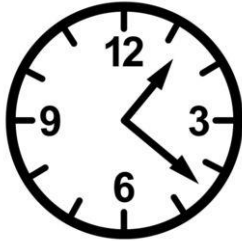


Det är också många som förlorar vänner och känner sig ensamma.

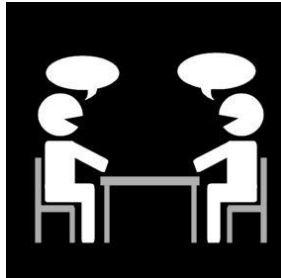


Vi vill ta reda på om gruppverksamhet på // påverkar hur man mår psykiskt, och hur ens sociala liv fungerar.

# Hur går det till?



1 timme



Att vara med i studien innebär att du träffar Samra 1 gång, ungefär 1 timme. Tiden anpassas efter din ork, det går bra att ta pauser. Ni träffas på //.

Samra kommer att intervjua dig om hur det varit att delta i gruppverksamhet på //, och om det har påverkat ditt psykiska mående eller ditt sociala liv.



Intervjun kommer att filmas. Det är för att vi inte ska missa något viktigt. Vi kommer att titta på filmerna och skriva ner allt som sägs.

# Viktig information



10 år

Allt material sparas inlåst i 10 år efter att studien avslutats. Materialet hanteras och lagras enligt de regler som finns vid Uppsala universitet.

Personuppgifter hanteras enligt Dataskyddsförordningen GDPR (EU679/2016).

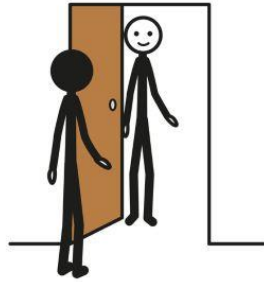
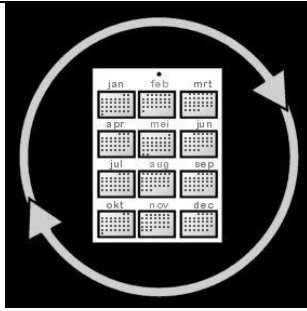


Alla uppgifter kommer att hanteras konfidentiellt. Ingen obehörig kommer att få ta del av dina svar.



UPPSALA  
UNIVERSITET

Personuppgiftsansvarig är Uppsala universitet, som också är forskningshuvudman.



Enligt Dataskyddsförordningen (GDPR) har du rätt att gratis en gång per år få ta del av samtliga uppgifter om dig som hanteras, och vid behov få eventuella fel rättade.

Kontaktpersoner är:

Camilla Olsson [camilla.olsson@uu.se](mailto:camilla.olsson@uu.se)

018-471 76 97

Ellika Schalling [ellika.schalling@uu.se](mailto:ellika.schalling@uu.se)

018-471 46 44



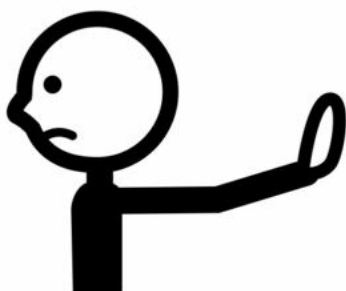
Det är helt frivilligt att delta. Du väljer själv vilka frågor du vill svara på, och hur mycket du berättar.

Du kan när som helst avbryta om du ångrar dig. Du behöver inte berätta varför. Det kommer inte att påverka den vård du får.

Gruppaktiviteters betydelse för psykosocialt välmående hos personer med afasi



Jag har fått muntlig och skriftlig information om studien och har haft möjlighet att ställa frågor.  
Jag får behålla den skriftliga informationen.



Jag vet att det är helt frivilligt att delta.  
Jag kan när som helst avbryta.  
Jag behöver inte ange någon orsak.



Jag samtycker till att delta i studien  
*"Gruppaktiviteters betydelse för psykosocialt välmående hos personer med afasi"*

Plats och datum:

.....



Underskrift:

.....

Namnförtydligande:

.....



## Appendix: Quotes from the participants in Swedish.

### I: intervjuare D: deltagare

1: "I: Och innan afasi.. du berätta att du var framåt.. mår du bättre då eller hade du perioder där..

D: Nej där (pekar på första på vänster)

I: Ja du mår bättre

D: Mm "

2: "D: ehh... jag försöker hålla på så mycket som möjligt men ibland blir jag trött och då tänker jag...uhh nu orkar jag inte göra det här.. blir för mycket...men jag...eh... jag.. jag tränar... jag tvingar mig själv att jag måste gå ut att göra det... så att jag inte blir sittande.."

3: "I: Innan afasin... var du blyg, eller social, eller var du mycket framåt som person eller något annat?

D: Jag var mycket framåt

I: Mycket framåt

D: Ja

I: .. och hur känner du idag?

D: Nä... då är jag ju mycket sämre.. jaa... de är ju... bedrövtligt egentligen..att jag blivit så pass.. dålig"

4: "I: Upplever du att du ändå känner dig självständig i vardag eller behöver du hjälp med vissa saker..

D: Aa eh... aa vissa saker.. ehh..aa.. men kan klara mig själv hela jaa.."

5: "D:...för det blir för..då kunde jag inte prata...språket har hänt jätte jättemycket så det var ju inte att man kunde förmedla sig på de sättet som man kan nu heller... "

6: "D: Man fattar inte...att man ska liksom en vecka på sjukhus och nu ska jag iväg på massa.. och liksom....från en dag så är man frisk och ena dagen är man inte frisk.. liksom.. man kan inte.. gå inte greppa de "

7: "I: Tycker du att afasin har påverkat ditt sociala liv?

D: Ja... mycket.. inte mycket folk längre.."

8: "I: Upplever du att ditt sociala liv har blivit påverkat sen du fick afasi?

D: Eh... nja... en del... o sen...ja...eh...ja...absolut

I: På vilket sätt då?

D: Eh.. vissa kompisar som..ehm..aa..drar sig att fråga om..ee...mm..o så..

I: Det finns vissa som drar sig från att fråga hur det är

D: Ja.... "

9: "I: Och det här är lite likt frågan innan... men är det något mer som har hjälpt att hålla humöret uppe

D: Det är väl familj... såklart..absolut "

10: "D: Ja..och sen prata med..man pratar ju andra saker heller.. vad som har hänt i världen och vad vi ska göra i helgen.. så det är ju kommunikation hela tiden även fast inte på.. schema...ja förstår du "

11:” I: Hur tycker du att det har blivit sedan du började på //... likadant, bättre eller sämre?  
D: Nej det har blivit bättre... just för att jag får ha lite rutiner också...”

12: “ I: Vad tror du har gjort att // har påverkat ditt liv.. påverkat dig/ditt liv... är det just rutinerna... att du fick rutiner..

D: Att träffa folk.. de är asså.. de jag inte sagt om.. det jag tycker har påverkat jätte jättemycket är att man träffar folk som är som jag förstår du.. som också haft stroke. “

13: ”I: Bortsett från //, vilka andra saker i ditt liv har påverkat ditt psykiska mående och ditt sociala liv att det blivit bättre... du nämnde att du umgås med familj och vänner och tar promenader och tittar tv... är det något annat som har hjälpt dig efter afasin..

D: Idrott (pekar)...”

14: “I: Upplever du ibland att det kan ha varit jobbigt, roligt, intensivt i grupp

D: Nej det skulle jag inte säga.. roligt bara”

15: ”I: När ni träffas i grupp så här, känner du att du kan komma till tals?

D: Eh nej (pekar på munnen) Nej ”

16:” D:...för om man har en kommunikationsgrupp så en del kan mer och en del kan mindre så måste man ha en grupp som är ungefär lika för annars så... nä det blir också konstigt

I: En balans i gruppen

D: Ja en balans precis... så det är på samma nivå.. precis.. språkligt.. annars är det lätt att man tar över om en måste tänka mycket efter ett ord...då sitter jag och väntar på de hela tiden för jag vet precis och då är det lätt att man tar över.. men dem som tänker efter... då måste man ju vänta in varandra.. att vi är ungefär samma... förstår du

I: Ja jag förstår”

17: ”D: ...sen såå...sen blir det mindre grupp emellanåt och de är.. de tycker jag är bra när vi ska göra smågrupp... åå... så vi inte är för många för då blir det r..ru.ruu...rörigt för mig.. så det tycker jag är bra.. och sen de stora grupperna är bra det också för mig.. fast det inte så mycket stort... för det klarar jag också fast när det är skapligt stort ”

18: “I: Hur tycker du kontakten med personalen har varit

D: Har varit jättebra”

19: “D: ibland lite trött sådär.. men det är ju tur att jag får gå här.. o sådär...det tycker jag är bra.”

20: ”I: Är det svåra ämnen på eftermiddagen?

D: Jaa... för jag förstår inte mycket ibland...”

21: “D:...när man är själv hemma.. man pratar ju inte typ..sambo.. han har ju jobbat hela dagen och jätetrött.. så kan man liksom inte.. (fniss) bara jag vilja prata jättemycket... så kan man ju prata här (pekar på kommunikationsgruppen)..ja.. så det var jätte jätte...”

22: ”I: Finns det något du tycker man borde göra annorlunda här på //

D: (skriver på tavlan)

I: Idrotta?

D: Ja

I: Du tycker att man kanske borde idrotta mer

D: Mm ”

23: “I: Mm... och du går ju här på //..så småningom ska du sluta

D: Mm (skakar på huvudet)

I: Hur känns det.. känns det läskigt, roligt

D: (blir ledsen) \*pekar på läskigt\*

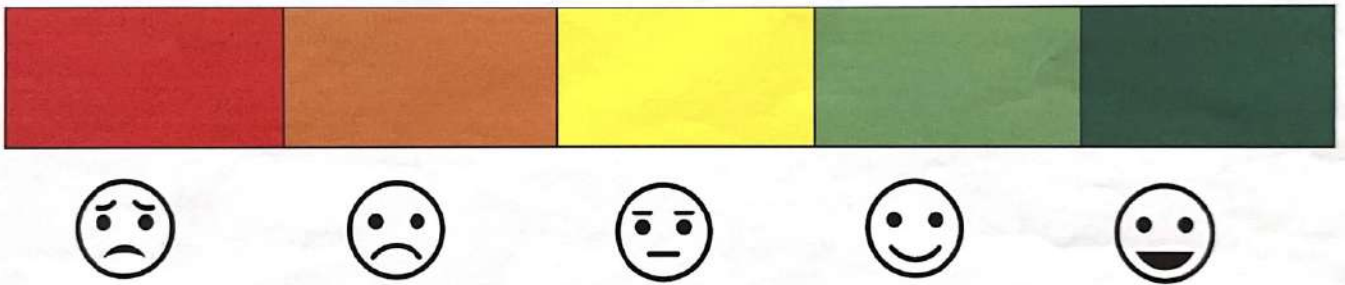
I: Mm läskigt.. jag förstår det... ”

24: “I: Var det något som hade kunnat underlätta ditt avslut på gruppverksamheten... eller kände du att det var..

D: Nej, de kunde inte göra något annorlunda..det tror jag inte.. “

	Måndag			Onsdag			Fredag		
09.00-09.30	Fika			Fika			Fika		
09.30-10.00	Soffprat			Soffprat			Soffprat		
10.00-10.30	Tidningsläsning			Tidningsläsning			Tidningsläsning		
10.30-11.45	Handling	Komm.- grupp	Papper & Penna Digital språkträning	Mat- lagning	Komm.- grupp	Papper & Penna Digital språkträning	Mat- lagning	Komm.- grupp	Papper & Penna Digital språkträning
11.45-12.15	Lunch			Lunch			Lunch		
12.15-13.00	Fri aktivitet			Fri aktivitet			Fri aktivitet		
13.00-13.30	Mindfulness			Mindfulness			Mindfulness		
13.30-14.30	Em-aktivitet			Em-aktivitet			Em-aktivitet		
14.30-15.00	Fika			Fika			Fika		

# SKATTNINGSSKALA



# Socialt liv

Hur fungerar det att umgås med släkt och vänner?

