

# Setting communication goals with people with aphasia and informal caregivers using Goal Attainment Scaling

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## **LIST OF ABBREVIATIONS AND RELEVANT DEFINITIONS**

<b>GAS</b>	<b>Goal Attainment Scaling</b>
<b>IC</b>	<b>Informal caregiver</b>
<b>METC</b>	<b>Medical research ethics committee (MREC); in Dutch: medisch ethische toetsing commissie (METC)</b>
<b>PACT</b>	<b>Partners van Afasiepatiënten Conversatietraining</b>
<b>PWA</b>	<b>People with Aphasia</b>
<b>SLT</b>	<b>Speech Language Therapist</b>

## **ABSTRACT**

**Title:** Setting communication goals with people with aphasia and informal caregivers using Goal Attainment Scaling

**Background:** Aphasia has a large impact on the social interaction of persons with aphasia (PWA) and their informal caregiver (IC). There is very little evidence on setting goals for improvement of communication between PWA and the IC. Goal Attainment Scaling (GAS) could be a feasible method for setting and measuring communication goals. However, there are no known studies using GAS as a measure for participation-based goals in PWA's rehabilitation, which makes it unclear if GAS is suitable for this group of patients. This study aims to explore the suitability of GAS by evaluating the SLT's experiences.

**Research question:** How do SLTs experience GAS in goal-setting for communication between PWA and IC.

**Method:** This study is a qualitative, explorative and phenomenological study. SLTs of various healthcare centres in the region of Utrecht - Rotterdam received training in GAS, after which the method was applied for setting goals in communication with PWA and IC. Experiences and opinions were collected by semi-structured interviews.

**Results:** Twelve SLTs were included. After analysis, four themes emerged in the data; timing is essential, identifying needs, applicability of GAS, and effect of GAS.

**Conclusion:** GAS stimulates the patient's control of their own goals and therapy, as well as the SLTs, being more aware of the steps in the goal-setting process. Some barriers raised for using GAS, such as specifying goals, time and suitability for subsets of PWA

**Recommendations:** Further research is necessary for evaluation of PWA's participation-based goals with GAS and usability for PWA's impairment-based goals. Before implementing GAS for participation-based goals, suitability should be considered based on the PWA's rehabilitation phase and healthcare facility they are in.

**Keywords:** Aphasia, Rehabilitation, Informal Caregivers, Participation goals, Goal Attainment Scaling.

## **SAMENVATTING (NL)**

**Titel:** Communicatie doelen stellen met personen met afasie en mantelzorger door middel van Goal Attainment Scaling.

**Achtergrond:** Afasie heeft een grote impact op de sociale interactie van personen met afasie (PMA) en hun mantelzorger (MZ). Er is weinig literatuur bekend over doelen stellen voor de verbetering van communicatie tussen de PMA en de MZ. Goal Attainment Scaling (GAS) zou een bruikbare methode kunnen zijn voor het stellen en meten van deze doelen. Echter zijn er geen studies bekend over het gebruik van GAS voor het evalueren van participatie-gerichte doelen in de PMA's revalidatie, wat het onduidelijk maakt of GAS bruikbaar is voor deze groep patiënten.

**Onderzoeksvraag:** Hoe ervaren logopedisten het doelen stellen met GAS voor de communicatie tussen PMA en MZ?

**Methode:** Dit is een kwalitatieve, exploratieve en fenomenologische studie. De geïnccludeerde participanten zijn logopedisten van verschillende soorten zorginstellingen in de regio Utrecht-Rotterdam. Logopedisten kregen training in GAS, waarna de methode toegepast is bij doelen stellen voor de communicatie tussen PMA en MZ. Ervaringen en meningen zijn verzameld door middel van semigestructureerde interviews.

**Resultaten:** Twaalf logopedisten zijn geïnccludeerd. Uit de data-analyse zijn vier thema's voortgekomen; timing is essentieel, bepalen hulpvraag, bruikbaarheid van GAS en effect van GAS.

**Conclusie:** GAS stimuleert de eigen regie van de patiënten, evenals het bewustzijn van de logopedisten tijdens het doelen stellen. Enige belemmeringen voor het gebruik van GAS zijn beschreven zoals: specificeren van doelen, tijd en bruikbaarheid voor bepaalde groepen PMA. Voor het implementeren van GAS voor participatiedoelen moet eerst de bruikbaarheid worden beoordeeld wat betreft de PMA's fase van revalidatie en de zorginstelling waar zij revalideren.

**Aanbevelingen:** Verder onderzoek is nodig naar de evaluatie van de PMA's participatie doelen met behulp van GAS, zowel als onderzoek naar de bruikbaarheid voor de PMA's stoornisgerichte doelen.

**Trefwoorden:** Afasie, Revalidatie, Mantelzorgers, participatiedoelen, Goal Attainment Scaling

## INTRODUCTION AND RATIONALE

Communication is essential for participating in social situations. However, for people with aphasia (PWA), communication is not as self-evident as it is for people without aphasia. Aphasia is a language disorder, caused by brain damage, which deeply affects communication. Approximately 30% of stroke patients are diagnosed with aphasia<sup>1</sup>. PWA perform fewer social activities than healthy people and some characterize their social participation by a lack of engagement, integration, and feelings of exclusion<sup>2-5</sup>.

Aphasia has been associated with poor life satisfaction in combination with loneliness, which is subsequently predictive of post-stroke depression<sup>2,4,6,7</sup>. Studies have shown that the social network of PWA also experiences an impact on their lives and the satisfaction of relatives about communication is closely related to quality of life of PWA<sup>8,9</sup>. Marriages are characterized by problems of interpersonal communication and loss of partnership<sup>10</sup>. Le Dorze and Brassard found that relatives and friends of PWA experience limitations in communication, relationships, responsibilities, work, and leisure activities<sup>11</sup>.

One of the main means of improving the lives of PWA is to optimize the communication between the PWA and their social environment<sup>12</sup>. This can be realized by improving (language) functioning of the PWA, which is typically the goal of impairment-based therapy. It can also be realized by optimizing the social communicative environment of PWA, which is the core of participation-based therapy. Essentially, the aim of the therapy is to improve communication in daily life, although this is rarely formulated in goal setting.

Communication is mainly addressed in speech-language therapy by training the communication partner, such as health care professionals or relatives, in adapting their communication to the PWA's ability. Training of primary communication partners, such as informal caregivers (IC), requires understanding the needs and wishes of PWA and their IC in improving communication and setting communication goals. However, no evidence is known about setting communication goals with PWA and their IC's.

One intervention in which the IC is part of the therapy is described in PACT (Partners van Afasiepatiënten Conversatietraining)<sup>13</sup>. PACT is a training program, which provides insight into the communication partner's (CP) communication habits with the PWA. PACT analyses the interaction between the PWA and the CP. The conversation analysis takes aspects such as recovery, turn taking, and topics into account, which is meant to improve the content and quality of the conversation. In conversation analysis, which is used to evaluate the therapy program, non-verbal as well as verbal communication behaviour is analysed based on

videotaped conversation. Although studies and interventions have been designed to address the issue of measuring conversational outcomes and produce quantitative measures, the designed conversation analyses still do not measure the PMA's and IC's experience of the interaction's quality in a quantitative way<sup>14</sup>.

Despite the fact that optimizing communication between PWA and communication partners is the ultimate goal of aphasia therapy, research on how this should be set as a goal and evaluated is scarce. To the author's knowledge, no research is available on measuring goal achievement on communication goals for aphasia therapy. A possible solution to this challenge may be the use of a method used in other domains of stroke care: Goal Attainment Scaling (GAS).

Using Goal Attainment Scaling (GAS) can be a suitable method to take experience, content, and quality of communication into account when setting goals, and to measure the progress of the goals in a quantitative way. GAS is a global outcome measure that takes individual rehabilitation needs into account. The method was first introduced by Kiresuk and Sherman in 1968<sup>15</sup>. GAS is used to incorporate the involvement of the patient and/or informal caregivers in goal-setting during rehabilitation in several care-settings. GAS is a method of setting goals with the patient and scoring (quantifying) the achievement of those goals, while it recognizes that sometimes achievement exceeds expectations, whereas achievement can also be less than expected. The approach is based on predicting the expected goal to be achieved, accompanied by two states above and two states below the expected outcome, one of which is usually the current state. After the determined period of intervention, the achieved level of the goal can be scored compared with the baseline measure on a 5-point scale.

The use of GAS could quantify the quality and experience of the interaction, so that progress in communication between communication partners can be measured more objectively. GAS also allows for patient involvement in goal setting, an important part of shared decision making and patient-centred care, which can result in better patient satisfaction according to Shay & Lafata<sup>16</sup>. Therefore, using quantitative measures to assess goal attainment for the patient and their relatives, such as GAS, is upcoming. Recently, GAS has been applied for goal-setting in patient groups suffering from various disorders<sup>17,18</sup>. Despite the increasing use of GAS, no research has been done on GAS as a measure for participation-based goals in the PWA's rehabilitation, or other goals in aphasia rehabilitation for that matter. Therefore, it remains unclear if GAS is a suitable method for PWA with communication goals.

To determine whether GAS is suitable in aphasia rehabilitation, the aim of this study is to develop a GAS training for SLTs and to describe the experiences of the speech-language therapist (SLT) using GAS as a method for setting communication goals between the PWA and ICs in various healthcare settings. This study will provide the first step in identifying the feasibility of using GAS in aphasia therapy.

## **METHOD**

### *Theoretical framework*

A qualitative design with a phenomenological character is used to describe and explore the experiences of SLTs with GAS as a method for setting communication goals for PWA and their ICs.

### *Participants*

The included population consist of SLTs in various healthcare centres in the region of Utrecht and Rotterdam. The healthcare centres ranged from hospital clinics to rehabilitation centres to nursing homes. Convenience sampling was used to get a sample of SLTs working in aphasia rehabilitation. A sample size calculation was not required due to the qualitative nature of this study. Contact details of SLT's were obtained through the main researcher's own network and the network of the second researcher (MR) and supervisor (LE). The SLTs were approached by the author throughout February and March by e-mail and phone calls. Participants were provided with an information letter.

### *Description of Goal Attainment Scaling*

Goal Attainment Scaling contains setting goals with the patient and link five possible SMART formulated endpoints. Previous studies showed that in using the complete GAS method, the amount of time necessary for formulating these 5 endpoints is a barrier for using it<sup>18-20</sup>. Therefore, it was decided to use GAS-light, in which only one SMART endpoint has to be formulated. This decision is expected to decrease the barrier of time and improve practical usability. For GAS-light a form (Figure 1) is available as well as a calculation form (Figure 2), which the SLT fills in and therefore guides the SLT during a goal-setting or evaluation moment.

### *Setting*

Participating SLTs were given training in GAS-light (Appendix A) at their work setting after which they applied GAS in clinical practice. The training was developed and provided by the main author and lasted approximately 1,5 hours. The training was provided in groups consisting of the participating SLTs per care centre, in March and early April. After one

month of using GAS, data on expectations and experiences concerning GAS was collected through semi-structured in-depth interviews, also at their work setting.

#### *Data collection*

Participants were interviewed by the main author. The interviews were guided by a topic-list, based on literature (Appendix B)<sup>21,22</sup>. The interviews lasted between 45 and 60 minutes. All interviews were audio-recorded for which consent was asked. Field notes were made during the interviews to capture observations for method-triangulation. The interviews were transcribed in verbatim shortly after the interview by the author after which a short recapitulation of the transcript was submitted for a member check. Transcripts were accordingly adjusted, if necessary. After the first interviews, data were analysed in order to supplement or adjust the topic-list when necessary.

#### *Data analysis*

Data analysis took place simultaneously with data collection as an iterative process. NVivo (version 12) was used to organise and analyse of data. Thematic analysis, as described in the six phases by Braun et al. was used to analyse the interviews<sup>23</sup>. The main researcher coded all data. The second researcher (MR) got familiar with the codes, checked and discussed the analysis of the codes and the coding tree with the main author until agreement was reached.

#### *Ethical Considerations*

The study was conducted according to the principles of the Declaration of Helsinki (version 2013)<sup>24</sup>. The Medical Research Involving Human Subjects Act was not necessary, in accordance with the research ethics committee (Protocol number: 18-159)

The participants gave their written informed consent prior to the training and received a certificate afterwards if desired. The participants were rewarded for participating in the training and interview with 10 points for the quality register for SLTs (Kwaliteitsregister Paramedici). Personal data of the participants were coded and anonymized, and was stored on a secured drive which was only accessible by the supervisor (LE) of this study.

## **RESULTS**

A number of 12 SLTs, working in various settings participated in this study. Participant characteristics are listed in Table 1. After coding, a coding structure was made to give an overview of the emerging themes and corresponding codes (Table 2: Coding structure). Four main themes were found in the SLTs experiences with GAS-light for goal-setting for PWA and IC. Each theme will be described with quotes to illustrate the data.



### *Timing is essential*

The SLTs stated that the setting they work in is an important condition for goal-setting for participation goals between PWA and IC. For example, some SLTs experienced that participation needs of the PWA and IC are not apparent in the acute or subacute phase after stroke.

“Look, from the clinic’s perspective it is all just too short, those people have no idea of... well anyway, what they can do and where they want to go, so that’s too, yes that’s just too early in the acute phase.” P12

However, in primary care, nursing homes, and outpatient rehabilitation, SLTs stated that participation needs are present. Therefore, participation-based goals can be set in this phase after stroke.

“So yes ... the people I am treating are or still have minor problems, so that always has to do with participation and never really disorder-oriented. Uh, so the dots on the I, so to say” P9

Moreover, some SLTs also mentioned the lack of time for setting goals in various settings. Similar to the beforementioned factor, time is a barrier in the rehabilitation centre or hospital and thus the acute and subacute phase. Whereas in nursing homes, outpatient rehabilitation, and primary care, SLTs did not mention time as a barrier for setting participation-based goals.

"At this moment I have the idea that in the rehabilitation phase, because the whole process of treatment is a lot faster, it is more difficult to apply... but maybe not... But uh, it is another level of people with aphasia and what I said: yes, I think that here, in the nursing home, I could make more time to use it." P1

### *Identifying needs*

Most SLTs experienced that determining the needs of the PWA and IC was difficult. They experienced that some PWA do not actually have participation needs in the social environment when they were asked for their needs. Also, frequently mentioned was the patients having difficulty specifying their needs.

“Yes, but that is just uh... Obviously, I ask everyone every time: what is your need for therapy? To just describe that.. yes, well... mostly they say: I just want to talk again. Or uh... the way it was before... or uh... But not a specific question of a realistic goal. No, nearly no one can do that. That is my experience so far.” P3

Furthermore, in some cases, SLTs experienced a difference between the needs of the PWA and their IC when both were asked for their needs in communication with each other.

"This gentleman said: at home, I can talk much better than now. I am less stressed when I am at home... While his wife said: at home, you get stuck very often... So, there is quite a difference between the experiences. So you also get something different in terms of goals" *P6*

Consequently, several SLTs expressed the need for good communication techniques to identify the needs and goals of the PWA.

"Yes I think it is applicable but with help say ... from the speech therapist or from a partner or uh ... I mean yes ... you can hardly ask someone: hey, what is your goal? If someone cannot really express themselves." *P4*

Additionally, SLTs stated that the IC's participation in goal-setting is necessary to optimize the communicative environment of the PWA, and getting a clear view of the PWA's needs during the goal-setting moment.

"Yes, and uh... then you notice that the partner likes to be involved because he feels like he is being heard. And he actually really wants to help, but he feels a bit powerless like: I don't know how to help. So while talking you will find out: Hey, you really shouldn't forget that partner!" *P3*

However, most SLTs also mentioned that they need to be cautious when involving the IC due to the feelings of the IC, of which they will be confronted when asked for the difficulties in communication between them.

"Yes, so you need to consciously ask the partner. And the partner finds that really difficult. I noticed that too. He then starts very carefully: yes, well, things are going much better, but ... and then ... And I thought: yes, of course, that is something really difficult to say about your partner like: Sorry, but this is... this is something you are not good at yet uh... yes, well I don't understand you." *P3*

The SLT is not only supposed to be cautious of the IC's feelings. Also, the IC providing information on the functioning of the PWA is a sensitive topic for the IC and was experienced by the SLTs as confronting for the PWA.

"In some way, it was confronting... for most people. Because when your own partner, who you really trust and was very sweet until now... because you became ill and all... He suddenly says really clearly what the matter is: yes, but you really can't do this and this is also not going well. That is something that shocked the PWA." P3

Furthermore, the SLTs experienced they need to be cautious for the IC expressing only their needs. SLTs expressed their concern with losing the focus on the patient.

"The partner wants the client to pick up everything they used to do, but sometimes that is not realistic either. Or the partner voices a need for therapy and puts in the shoes of the PWA. I want that... he needs to speak more clearly. While he can actually make his message clear in his own way, within his aphasia. But the need for therapy actually comes from the partner and I think that is dangerous to involve the partner and only hear their goals." P2

"So I always find that very difficult. To depend on the environment, but you do need them, especially with the people who are affected more seriously. Because you have to say something (to formulate a goal). You just do your best together, so eh, yes. So I think that for the more complex aphasia you should talk to the environment in this case. But always be careful with specific formulation because you never know what the patient really wants" P9

#### *Applicability of GAS*

GAS was determined to be applicable for a subset of PWA. Multiple factors are barriers for using GAS, such as the severity of aphasia as well as PWA's awareness of their (in)abilities, pre-stroke cognitive abilities, and the GAS-form being confusing for severely affected PWAs.

"What makes it difficult is, uh, that the patient with aphasia has serious global aphasia, in which his comprehension of language is also affected, and I don't know... don't know enough... Well, because I think his awareness of illness is not as such... So I think... well, oh, how am I going to do that. What are you going to take into account... I am not going to lay this (GAS-form) form in front of him." P1

"It is difficult... If someone has cognitive-communication disorders and they have less awareness of illness and they say: I want to achieve that goal... and then you think, well that really cannot be achieved and the client says: yes, it must be achievable... That way you can get a discussion about the goal, which makes it harder to actually make your goal easier because someone really wants to hold on to this their goal..." P7

Furthermore, some organisational barriers were identified by the SLTs. They mentioned their own barriers as well as the IC's barriers to using GAS for goal-setting. Barriers for the SLTs were the extra time they needed to use GAS with PWA and IC, as well as the extra work it costs.

"It is ... it is fun, it is good, it is very useful but it also takes some time. Because it is not normal yet, to you... Yes, you just have to spend a little more time on it and you are busy with it for a while." P4

Additionally, some SLT's expressed they did not notice an apparent additional value when using GAS in comparison with their usual goal-setting process, due to the habits or standards they already have for goal-setting such as setting SMART goals or asking the PWA for their goals.

"Yes, I set that kind of goal anyway and therefore I don't really know if I think this has an added value. I mean, if they (clients) are in the system with us, I know every time: oh yes, I am working on this and that, I keep seeing that in the file... I wonder if I would use this, additionally." P5

Some SLTs also stated that time can be a barrier for the IC, who is not able to get time off from work when goals need to be set or has other responsibilities at the time of the goal-setting moment.

"Yes. Sometimes with work... that they (partners) cannot come because they say: yes my partner is at work, he cannot come every week or maybe only one time... Yes, then you can also set some of the goals, yes, discuss the goals, but then you cannot evaluate the follow-up process if the partner is not there. So we regularly run into that." P7

Most SLTs also indicated that choosing the right scale within the GAS method was difficult. They experienced difficulty with scoring the scales, due to the formulation and subsequently the interpretation of the formulation and scoring. This particularly proved to be challenging for the baseline, due to the choice between the PWA having 'function' or 'no function'.

"Yes, for example, the goal is: I want eh, well, eh, to be able to have a conversation with more than 1 person ... Well, now he may not be able to do that because it doesn't work at all yet, well then it's just 'not' (no function). But suppose he makes attempts, he notices that he actually gets stuck. Yes, then it actually doesn't work either, yet. So yes then I think: when is it "some function". Yes, it still is a bit of a vague description..." P3

The SLTs experienced that the received training was prerequisite for using and applying GAS. They stated that a training would be less time consuming than reading a manual.

"And then I thought: oh yes if I read all this like yes... then I would... if I haven't had that training then I would have thought: ok, what should I do with this... What is this... So no, certainly... nice to have some basic knowledge of... yes absolutely. Yes, but I really have... after that training, I thought: well I understand this and uh, this will work." P5

"Well, depending on uh, whether you see the training with this form or also some kind of written support. Because yes, I mean then you read and then you discover it, but I think that the time investment is out of proportion to when you get a training." P2

Also, they mentioned they appreciated the discussion with colleagues during the training about appropriate (SMART) goals and goal-setting in general.

However, the SLTs stated that the knowledge and skills they had gathered, was slowly decreasing along time. Therefore, repetition of the training or evaluating the usage of the training could be advised.

"Eh, no, I think I need a little more training to make it run smoothly. Because I have done it now... It was some time ago since the training and I had to look through the papers: how did it work again. And eh, then it's just nicer, if you really want to use it to have a clear reference, or a slightly longer training" P11

### *Effect of using GAS*

One of the effects SLTs mentioned about the use of GAS for goal-setting was that it seemed to give the PWA control over his goals and hence his treatment plan. Asking the PWA for their needs and the PWA being able to voice what they want their therapy-plan to look like were the main factors for this statement. Some SLTs suggested that this might lead to improved motivation for therapy.

"I especially think that a patient, uh, the patient comes to you to let you know: something is not going well. And I think that this does contribute to the patient keeping his own control. That he feels like: ok, I come here with my question and hey, my input is asked. It is not like: I come to a care provider and the care provider takes over, and he tells me what to do. (...) but I think patients are very happy that they are being heard and that they keep a little control. P6

"I very much believe that it (asking for their goals/needs) stimulates them to think about what they suffer from in daily life or with other people, they are ultimately more motivated to follow eh ... yes those weekly or multi-weekly therapies. If they do that more motivated, they are committed to it .. it is easier for you, as a therapist, to catch up if you do an exercise that they do not immediately see need for. Uh, so I think this initial conversation (setting goals with PWA) is very important for that." P12

Furthermore, some SLTs stated that identifying the needs and goals of the PWA by using GAS has led to awareness in the PWA about his needs and goals.

"Well, that the core of the problem can be solved much better because when the patient is aware of: oh yes, uh on a birthday, I don't say anything at all or I never actually start a conversation again. Well, then you have a specific goal to work on." P3

Moreover, using GAS led to more awareness in the SLTs about the needs and goals of the PWA, and the goal-setting process in itself and the steps it entails.

"Eh, I think it mainly brought me, the importance scale and the difficulty of achieving, to take a good look at that. I thought that was really nice, because also ... because you fill in how important it is for the patient, and you want to come up with a goal with the patient yourself, but perhaps that is not very important for the patient, but you decided that. Um, that really brought me to see: how important is this and how feasible is this. Yes. So I like that." P10

## **DISCUSSION & CONCLUSION**

The aim of this study was to describe the experiences of the SLT using GAS as a method for setting communication goals between the PWA and ICs. The results of this study showed that four themes emerged in the data; timing is essential, identifying needs, applicability of GAS and effect of GAS. The answers of the participants showed that setting participation goals and using GAS for this, is not always feasible in their healthcare centre or in the phase after stroke. One of the main barriers to implementing GAS in healthcare centres is the ability of the PWA to express their needs as well as the ability or willingness of the partner to express their needs. Carefulness and communication techniques seem to be necessary for the SLT to identify needs for both PWA and IC. From the perspective of SLTs, the use of GAS might be difficult due to organizational problems such as time and extra work for SLT and IC. Also, they mentioned the challenge of scoring and interpreting the GAS scale. The usability of the GAS method is limited for people with severe (receptive) aphasia or cognitive problems, according to SLTs. All SLTs stated that training in GAS is prerequisite for using

the method. The SLTs do express positive effects of GAS on the PWA's control and awareness of goals as well as on the SLT's awareness during the goal-setting process.

GAS can be used as a patient-centred method for evaluating individual goals of patients. This study's findings confirm that, according to SLTs, PWA seem to get control over their own goals and therapy-plan when using GAS for goal-setting. This statement is supported by other studies, who stated that patients expressed they want to be actively involved in planning their rehabilitation<sup>25,26</sup>. The SLTs mentioned that by asking the PWA about his needs and goals, the SLTs became more aware of the goals PWA have in addition to the difficulties they encounter during communication. This corresponds with the findings of Steven et al. who conducted a systematic review on patient-specific measurement instruments in the process of goal-setting<sup>19</sup>. They stated that GAS amongst others was found to facilitate a patient-centred approach. In addition, they found that patients became aware of their problems, which also led to increased motivation and responsibility for their own therapy. This was also suggested by the SLTs in this study. Berg et al. also mentioned the importance of patient-centred care and that it can be improved by using tools, such as GAS, in which patients are asked for their needs and thoughts<sup>27</sup>. Although tools can increase patient-centred care, some SLTs mentioned that the time needed to use GAS is a barrier. They experienced they needed more time than in usual goal-setting which is a known barrier for GAS mentioned in other studies<sup>19,20</sup>.

In other studies, healthcare professionals and patients expressed that PWA were not able to participate in the goal-setting in the acute or subacute phase after stroke, because of their expressive and/or receptive aphasia or cognitive impairments<sup>27-29</sup>. According to the SLTs in the current study, using GAS does not provide a solution to this problem. Using GAS for people with severe aphasia was not feasible, according to the SLTs. This may also be one of the main reasons that using GAS in acute stroke settings, such as hospitals and rehabilitation centres, was not relevant and why there is very little evidence on the use and effects of GAS these phases<sup>30</sup>.

According to the SLTs, one of the challenges in identifying the PWA's participation needs for therapy is the differing needs between PWA and IC when it comes to participation-based goals for their communication. These findings correspond with other studies, in which differing needs is identified as a highly relevant challenge or even barrier in goal-setting with a partner<sup>27,29,31</sup>. In the current study, the IC was perceived to be cautious at times, when providing information about the PWA's communication, in fear of confronting the PWA with their inabilities. This might be an explanation for the different needs between PWA and IC.

Levack et al. even state that family sometimes come with their own agenda and are not always acting in the patients' interest<sup>31</sup>. This was also experienced by some SLTs in this study, who stated that IC expressed their own needs instead of the PWA's needs. They expressed that caution was needed when identifying needs with the IC. However, all SLTs agreed that participation of the IC is necessary for setting participation-based and interpersonal communication goals which was also emphasized by Hallé<sup>32</sup>. The author expressed that, even though it may be difficult to engage IC in goal setting due to lack of time or other obligations for IC, partner participation is a bonus in goal-setting.

To ensure trustworthiness of this study, the criteria of Lincoln & Guba and COREQ-checklist were used<sup>33,34</sup>. However, the current study has some limitations. Only twelve SLTs were included due to the short time period that was available for this study. Furthermore, all included SLTs were from the region Utrecht-Rotterdam, which could mean limited generalizability. However, it is expected that opinions in other areas of the Netherlands will not differ.

Another limitation is that the GAS-light training was developed and offered by the main researcher, as were the interviews. This could possibly have led to socially desirable answers. However, before the interviews started, the respondents were asked to share any opinion or experiences with the main researcher, either positive or negative.

A strength of this study is the variety of settings the SLTs work in. As a result of the range of work settings, a first estimation of the suitability of GAS in varying healthcare settings can be provided. To ensure that the right experiences and opinions were captured during the interview, a short recapitulation was sent to the participants to check for any misinterpretations. This member check was used to ensure dependability of the results which is a strength of this study.

Another strength is the recording in minutes of all decisions made about the method or analysis of the study after meetings, which ensures an audit trail and therefore the dependability of the study. Furthermore, another strength was the guaranteed confirmability, by executing the analysis of the collected data by the main researcher (MA) and another researcher (MR). Both researchers established the same results after discussing the codes & coding structure.

A side effect of the current study is that SLTs mentioned they got more aware of involving the partner in their goal-setting process. Although this is a positive effect, it is probably not due to using GAS per se, but rather a consequence of the scope of the study which focussed on participation-based goals with PWA and IC.



The current study shows how SLTs experience goal-setting when GAS is used to support this. According to the results, one of the effects is that patients regain control of their goals and therapy, which implies that before using GAS patients were less involved in goal-setting. Therefore, GAS could improve patient-centred care in aphasia rehabilitation.

The experiences and opinions of SLTs on setting goals with GAS for PWA and their IC have been explored. However, the need to explore the other half of the GAS method remains, namely: exploring the opinions of SLTs on evaluating and scoring the results of the goals that were set with GAS. This could give more information on the usability of GAS by SLTs for evaluating communication partner training. Furthermore, the SLTs who were trained and used GAS in clinical practice interpreted GAS as a method for participation goals, due to the nature of this study. Therefore these results do not provide evidence for setting impairment-based therapy goals, for which further research is recommended.

In conclusion, SLTs experience using GAS for goal-setting with PWA and IC as a tool that stimulates the patient's control of their own goals and therapy, as well as themselves being more aware of the steps in the goal-setting process. Furthermore, they experienced some barriers for using GAS, such as identifying goals, time and suitability for subsets of PWA. In addition to that, before implementing GAS for participation-based goals, suitability should be considered on account of the PWA's rehabilitation phase and healthcare facility they are in.

## REFERENCE LIST

1. Engelter ST, Gostynski M, Papa S, Frei M, Born C, Ajdacic-Gross V, et al. Epidemiology of aphasia attributable to first ischemic stroke: Incidence, severity, fluency, etiology, and thrombolysis. *Stroke*. 2006;37(6):1379–84.
2. Åström M, Adolfsson R, Asplund K, Åström T. Life before and after Stroke. *Cerebrovasc Dis [Internet]*. 1992;2(1):28–34.
3. Nätterlund BS. A new life with aphasia : everyday activities and social support. 2014;8128.
4. Repository LI. City Research Online City , University of London Institutional Repository. 2011;33:211–8.
5. RJP, De Witte L, Wade D, Van Den Heuvel W. Social participation through the eyes of people with aphasia. *Int J Lang Commun Disord*. 2010;45(5):537–50.
6. Åström M, Asplund K, Åström T. Psychosocial function and life satisfaction after stroke. *Stroke*. 1992;23(4):527–31.
7. Hilari K, Northcott S, Roy P, Marshall J, Wiggins RD, Chataway J, et al. Psychological distress after stroke and aphasia: The first six months. *Clin Rehabil*. 2010;24(2):181–90.

8. Hilari K, Needle JJ, Harrison KL. What are the important factors in health-related quality of life for people with aphasia? A systematic review. *Arch Phys Med Rehabil* [Internet]. 2012;93(1 SUPPL.):S86-S95.e4.
9. Cruice M, Worrall L, Hickson L, Murison R, Cruice M, Worrall L, et al. Finding a focus for quality of life with aphasia : Social and emotional health, and psychological emotional health , and psychological well-being. 2010;7038.
10. Kinsella GJ, Duffy FD. Psychosocial readjustment in the spouses of aphasic patients. A comparative Survey of 79 subjects. *Scand J Rehabil Med*. 1979;11(3):129–32.
11. Le Dorze G, Brassard C. A description of the consequences of aphasia on aphasic persons and their relatives and friends, based on the WHO model of chronic diseases. *Aphasiology*. 1995;9(3):239–55.
12. Simmons-mackie N, Kagan A, Simmons-mackie N, Huijbregts M, Shumway E, Mcewen S, et al. Counting what counts : A framework for capturing real-life outcomes of aphasia intervention Counting what counts : A framework for capturing real-life outcomes of aphasia intervention Travis Threats. 2014;(January 2007).
13. Wielaert S, Wilkinson R. Partners van afasiepatiënten conversatie training (PACT). 2012.
14. Best W, Maxim J, Heilemann C, Beckley F, Johnson F, Edwards SI, et al. Conversation Therapy with People with Aphasia and Conversation Partners using Video Feedback: A Group and Case Series Investigation of Changes in Interaction. *Front Hum Neurosci*. 2016;10(November):1–14.
15. Kiresuk TJ, Sherman RE. Goal attainment scaling: A general method for evaluating comprehensive community mental health programs. *Community Ment Health J*. 1968;4(6):443–53.
16. Shay LA, Lafata JE. Where is the evidence? A systematic review of shared decision making and patient outcomes. 2016;35(March 2013):114–31.
17. Hurn J, Kneebone I, Cropley M. Goal setting as an outcome measure: A systematic review. *Clin Rehabil*. 2006;20(9):756–72.
18. Turner Stokes L. Goal Attainment Scaling ( GAS ) in Rehabilitation A practical guide Further information and advice may be obtained from : North West London Hosp NHS Trust. 2009;44(0):1–14.
19. Stevens A, Zuyd H, Beurskens AJ, Zuyd H, Zorggroep A. The use of patient-specific measurement instruments in the process of goal-setting : a systematic review of available instruments and their feasibility. 2013;(December).
20. Plant SE, Tyson SF, Kirk S, Parsons J. What are the barriers and facilitators to goal-setting during rehabilitation for stroke and other acquired brain injuries ? A systematic review and meta-synthesis. 2016;

21. Atkins L, Francis J, Islam R, Connor DO, Patey A, Ivers N, et al. A guide to using the Theoretical Domains Framework of behaviour change to investigate implementation problems. 2017;1–18.
22. Peters M, Wensing M. Barriers and facilitators assessment instrument Introduction , instructions and instrument Mirjam Harmsen. 2005;
23. Heaton JPW, Lording D, Liu SN, Litonjua AD, Guangwei L, Kim SC, et al. Using thematic analysis in psychology. *Int J Impot Res.* 2001;13(6):317–21.
24. World Medical Association. World Medical Association Declaration of Helsinki Ethical Principles for Medical Research Involving Human Subjects, 5th (Edinburgh) amendment and Note of Clarification. 2002;9–12.
25. Berg K, Askim T, Balandin S, Armstrong E. aphasia in Norway . A qualitative study Experiences of participation in goal setting for people with stroke-induced aphasia in Norway . A qualitative study. 2016;(June).
26. Peoples H. Stroke survivors ' experiences of rehabilitation : A systematic review of qualitative studies Stroke survivors ' experiences of rehabilitation : A systematic review of qualitative studies. 2011;(September 2014).
27. Berg K, Rise MB, Balandin S, Armstrong E. Speech pathologists ' experience of involving people with stroke-induced aphasia in clinical decision making during rehabilitation Speech pathologists ' experience of involving people with stroke-induced aphasia in clinical decision making during rehabili. 2016;8288.
28. Leach E, Cornwell P, Fleming J, Haines T, Leach E, Cornwell P, et al. Patient centered goal-setting in a subacute rehabilitation setting Patient centered goal-setting in a subacute rehabilitation setting. 2010;8288.
29. Clancy L, Povey R, Rodham K. “ Living in a foreign country ”: experiences of staff – patient communication in inpatient stroke settings for people with post-stroke aphasia and those supporting them. *Disabil Rehabil [Internet].* 2018;0(0):1–11.
30. Simmons-mackie N, Raymer A, Cherney LR. Communication Partner Training in Aphasia : An Updated Systematic Review. *Arch Phys Med Rehabil [Internet].* 2016;97(12):2202-2221.e8.
31. Levack WMM, Siegert RJ, Dean SG, Kath M. Goal planning for adults with acquired brain injury : How clinicians talk about involving family. 2009;9052.
32. Hall M, Dorze G Le, Mingant A. Speech – language therapists ' process of including significant others in aphasia rehabilitation. 2014;748–60.
33. Korstjens I, Moser A. Series : Practical guidance to qualitative research . Part 4 : Trustworthiness and publishing. *Eur J Gen Pract [Internet].* 2018;0(0):120–4.
34. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research ( COREQ ): a 32-item checklist for interviews and focus groups. 2007;19(6):349–57.

## FIGURES

				<u>Computerisation</u>	
<b>At Baseline</b>	With respect to this goal do they have?	Some function	<input type="checkbox"/>	-1	
		No function (as bad as they could be)	<input type="checkbox"/>		-2
<b>At Outcome:</b>  Was the goal achieved?	Yes	A lot more	<input type="checkbox"/>	+2	+2
		A little more	<input type="checkbox"/>	+1	+1
		<b>As expected</b>	<input type="checkbox"/>	0	0
	No	Partially achieved	<input type="checkbox"/>	(-1)	-1
		No change	<input type="checkbox"/>	-1	-2
		Got worse	<input type="checkbox"/>	-2	

Figure 1: GAS-light form

Goals	Goal description	Importance	Difficulty	Weight	WSq	Baseline	W x base	Acheived	W x Ach
Goal 1		1		0	0		0		0
Goal 2				0	0		0		0
Goal 3				0	0		0		0
Goal 4				0	0		0		0
Goal 5				0	0		0		0
Goal 6				0	0		0		0
<b>SumW</b>				0	0		0		0
Sum (Wsq)					0				
Factor				0					
Sqrfactor				0,0					
GAS calculation		Baseline	Achieved	Change					
		#DEEL/0!	#DEEL/0!	#DEEL/0!					

Figure 2: GAS- calculation form

## TABLES

**TABLE 1: Participant characteristics**

<b>PARTICIPANT</b>	<b>SEX (M/F)</b>	<b>WORK SETTING</b>
<b>P1</b>	F	Nursing home /primary care
<b>P2</b>	F	Nursing home/rehabilitation centre
<b>P3</b>	F	Nursing home/primary care
<b>P4</b>	F	Nursing home/ rehabilitation centre
<b>P5</b>	F	Nursing home/rehabilitation centre/ primary care
<b>P6</b>	F	Outpatient clinic / hospital
<b>P7</b>	F	Outpatient clinic/ hospital
<b>P8</b>	F	Hospital
<b>P9</b>	F	Outpatient clinic/ hospital
<b>P10</b>	F	Outpatient clinic/ hospital
<b>P11</b>	F	Outpatient clinic
<b>P12</b>	F	Hospital

**TABLE 2: Coding Structure**

**HOW DO SLTS EXPERIENCE GOAL ATTAINMENT SCALING IN GOAL-SETTING FOR COMMUNICATION GOALS BETWEEN PWA AND INFORMAL CAREGIVER.**

<b>THEMES</b>	<b>Codes</b>	
<b>TIMING IS ESSENTIAL</b>	Participation needs	No participation needs in rehabilitation
		Participation needs in nursing home
		Participation needs in primary care
		Participation needs in outpatient rehabilitation
	Time in healthcare facility	No time in hospital setting
		No time in rehabilitation centre
		Time in outpatient rehabilitation
		Time in nursing home
<b>IDENTIFYING NEEDS</b>	Good communication techniques are necessary	
	No needs apparent	No participation needs apparent between partner & PWA
	Difficult to specify needs	Surreal goals
	SLT must be cautious	Partner has difficulty with confronting PWA with disability
		Needs are voiced by partner
		Difference between needs PWA and partner
<b>APPLICABILITY OF GAS</b>	Not applicable for all PWA	Aphasia
		Awareness of illness
		Insight in possibilities
		Cognitive abilities
	Organisational problems	
	- SLT	No additions to normal goal setting
		Time
		Extra work
	- Partner	Suits normal goal-setting method
		Lack of time
Choosing right scale is difficult	Scoring	
	Interpretation	

	Training is prerequisite for application	Time
		Interaction colleagues
		Repetition is important
<b>EFFECT PROM METHOD LIKE GAS</b>	PWA gets control over goals	Increased motivation for therapy
	PWA gets aware of goals	
	SLT more aware of steps in goal-setting process	

## APPENDIX

### APPENDIX A: GAS TRAINING

#### Goal attainment scaling – light - Training

Doelen stellen voor en met Personen Met Afasie en naasten

##### Achtergrond

- Ontwikkeld door Kiresuk & Sherman in 1968
- Ontwikkeld om geestelijke gezondheidsinterventies te evalueren
- Sindsdien ook gebruikt in revalidatie, onderwijs, geneeskunde, verpleegkunde en sociaal werk

##### Doel Goal Attainment Scaling (GAS)

- Scoren in hoeverre de gestelde doelen van de patiënt zijn behaald
- Scoren op een gestandaardiseerde manier
- Patiënt en naasten betrekken bij het stellen van doelen.
- Nadeel: tijdsintensief

##### Methode

- Doel identificeren
- Wat is het uiteindelijke doel van de patiënt?
- Maximaal 1 variabele per GAS schaal

##### Methode

- Weeg de doelen
- Moeilijkheidsgraad van het doel (0-3)
- Prioriteit van het doel (0-3)

##### Methode

- Uitgangssituatie bepalen
- Wat kan de patiënt nu, met betrekking tot het doel wat hij heeft?
- Is er iets van functie aanwezig
- Is er geen functie

##### Methode

- Uitkomst doel bepalen (SMART)
- Bepaal samen met de patiënt wat de verwachte uitkomst van het doel wordt
  - Capability : uitvoering in dagelijks leven
  - Capacity : uitvoering in therapie sessie
  - Performance : integratie van activiteit in dagelijks leven
- Zo objectief mogelijk beoordelen (eventueel VAS-schaal)
- Participatie-doelen beoordelen op basis wat partner/ patiënt zegt.

##### SMART

Tips voor het opstellen van een SMART doel:

- Neem de patiënt of direct betrokkenen als onderwerp van de zin: "Tom'..."
- Beschrijf het resultaat van de behandeling in concreet gedrag/actieve taal: "Tom loopt..."
- Beschrijf de situatie waarin de revalidant de activiteit moet uitvoeren: "Tom loopt thuis..."



- Beschrijf hoe de revalidant de activiteit moet uitvoeren: “Tom loopt thuis met rollator...”
- Geef een maat (afstand/tijd) aan waardoor het doel geëvalueerd kan worden: “Tom loopt thuis met rollator van woonkamer naar het toilet...”
- Voeg de tijd waarin je het doel wilt bereiken toe

### Schaal

		<u>Computerisation</u>	
<b>At Baseline</b>	With respect to this goal do they have?	<u>Some function</u>	<input type="checkbox"/>
		<u>No function</u> (as bad as they could be)	<input type="checkbox"/>
<b>At Outcome:</b>  Was the goal achieved?	<b>Yes</b>	A lot more	<input type="checkbox"/>
		A <u>little more</u>	<input type="checkbox"/>
		<b>As expected</b>	<input type="checkbox"/>
	<b>No</b>	<u>Partially achieved</u>	<input type="checkbox"/>
		No change	<input type="checkbox"/>
		Got <u>worse</u>	<input type="checkbox"/>
		-1	
			-2
		+2	+2
		+1	+1
		<b>0</b>	<b>0</b>
		(-1)	-1
		-1	-2
		-2	

Figure 1: GAS-light form

### Scoring

Goals	Goal description	Importance	Difficulty	Weight	WSq	Baseline	W x base	Acheived	W x Ach
Goal 1		1		0	0		0		0
Goal 2				0	0		0		0
Goal 3				0	0		0		0
Goal 4				0	0		0		0
Goal 5				0	0		0		0
Goal 6				0	0		0		0
<b>SumW</b>				<b>0</b>	<b>0</b>		<b>0</b>		<b>0</b>
Sum (Wsq)					0				
Factor					0				
Sqrfactor					0,0				
GAS calculation		<b>Baseline</b>	<b>Achieved</b>	<b>Change</b>					
		#DEEL/0!	#DEEL/0!	#DEEL/0!					

Figure 2: GAS calculation form

### Interpreten GAS-score

- GAS-score is een T-score
- T-score ≠ 50 → Doelen waren realistisch en uitdagend genoeg
- T-score > 50 → Doelen waren te makkelijk, of functies patiënt zijn onverwacht verbeterd
- T-score < 50 → Doelen waren te uitdagend, of de patiënt is onverwacht achteruit gegaan

### **Casus 1**

- Dhr. P. heeft een lichte afasie die zich uit in problemen met auditief zinsbegrip.
- Hij heeft daardoor moeite met het begrijpen van zijn vrouw wanneer zij hem uitlegt wat zij van hem verwacht in het huishouden.
- Uitgangssituatie: Het auditief woordbegrip van dhr. is goed en schriftelijk taalbegrip is onaangedaan. Mw. vergeet soms wel eens dat dhr. afasie heeft en past daarom haar taalgebruik niet aan.

### **Casus II**

- Dhr. C. ervaart na zijn CVA dat hij moeite heeft met het deelnemen aan gesprekken door fonematische parafasieën, waardoor hij niet altijd begrepen wordt.
- Hij zou graag weer begrijpelijk kunnen praten met zijn beste vriend over de wedstrijd van zijn favoriete club.
- Uitgangssituatie: Dhr. C. merkt dat hij moeite heeft met het juist uitspreken van speltermen met meerdere lettergrepen zoals 'buitenspel', 'scheidsrechter', 'keeper'. Hij gebruikt hierbij ook neologismen. De vriend van dhr. C. weet niet zo goed hoe hij dhr. C kan helpen.

### **Casus III**

- Mw. A heeft een matig/ernstige afasie die zich uit in een stoornis van het auditieve woordbegrip.
- Mw. wil graag weer in staat zijn om de dag door te nemen met haar man als hij thuis komt uit werk.
- Uitgangssituatie: Mw. A. begrijpt geschreven taal wel. Dhr. A. vermijdt inhoudelijke gesprekken en maakt geen gebruik van ondersteunende communicatie.

### **Na de training**

- Toepassen van GAS in de praktijk
- Probeer GAS minstens 3x toe te passen
- Op communicatie tussen PMA en communicatiepartner
- Interview na toepassing GAS

## APPENDIX B: TOPIC-LIST

### Topiclijst bij onderzoek: “Doelen maken met personen met afasie door middel van GAS”

Kwalitatief onderzoek naar de ervaringen van logopedisten met het gebruik van Goal Attainment Scaling (GAS) voor het maken en vaststellen van doelen bij personen met afasie (PMA) en hun naasten.

#### **Doel en Onderzoeksvraag:**

Beschrijven van de ervaringen van logopedisten met het gebruik van GAS als methode voor het maken van doelen voor communicatie tussen PMA en communicatiepartner.

- Hoe ervaren logopedisten die werken met PMA in de revalidatie of chronische fase, het gebruik van GAS voor doelen stellen voor communicatie tussen PMA en communicatiepartner.

#### **Topiclijst**

- Introductie en kennismaking:
  - a. Toestemming vragen voor opname van het interview
  - b. Gegevens worden geanonimiseerd.
  - c. Laat alles weten wat je kwijt wilt. Op zoek naar de ervaringen, zowel positief als negatief. Alles blijft bij mij.
- Openingsvraag: **Kun je vertellen wat je vooral hebt onthouden van de training vorige maand?**
- Topics:

Hoofdtopics:

  - a. **Bruikbaarheid/haalbaarheid GAS**
    - Relevantie van de training.
      - Training nodig om GAS te doen? Waarom?
      - Wat heb je aan de training gehad?
        - Doorvragen naar: kennis, vaardigheden en motivatie.
          - Kennis gekregen, hoe moet ik dat zien?
        - Wat waren factoren die daaraan bijdroegen?
  - b. **Methode**
    - Wat vind je van de methode?
      - Inhoud/vorm.
      - Is GAS nodig om doelen te stellen?
        - Doorvragen naar en vergelijken met huidige methode.
    - Wat heb je aan GAS gehad?
      - Niet het effect van GAS, maar meer wat het deed met de participant
        - Wat betekent het toepassen van GAS voor de PMA?
      - Wat heb jij gehad aan GAS in je dagelijks handelen.
        - Laat de methode genoeg ruimte om zelf afwegingen te maken?
        - Past deze manier van werken bij je gebruikelijke manier van werken?
    - Kan je vertellen hoe je GAS hebt toegepast
      - Is GAS toepasbaar bij het doelen stellen voor PMA?
        - Knelpunten en voordelen?

- Waarom was dat een knelpunt/voordeel?
- Doorvraag:
  - Denk je, met alles wat je nu hebt verteld, dat GAS moet worden toegepast binnen...
    - Waarom wel/niet?
- Afsluiting:
  - a. Wil je nog iets toevoegen, wat je nog niet kwijt kon in het interview?
  - b. Uitleg transcriberen en analyse;
  - c. Membercheck: Het interview zal worden uitgewerkt en samengevat. Graag zou ik willen checken of het juist is opgeschreven/geïnterpreteerd. Je ontvangt hiervoor na het transcriberen een korte samenvatting per vraag van je antwoorden. Ga je hiermee akkoord?
  - d. Het certificaat van deelneming zal na afronding van de analyse (half juni) toegestuurd worden per mail.

**Probes:**

- Hoe heb je dat ervaren?
- Waarom is dat belangrijk?
- Kun je daar wat meer over vertellen?
- Wat bedoel je met...?
- Kun je dat uitleggen?
- Dus ik begrijp dat je dit zegt, klopt dat?
- Kun je daar een voorbeeld van geven?
- Wat viel je op?