

# Speech language therapists' experiences with subjective well- being in people with aphasia.

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## Abstract

**Background:** Subjective well-being (SWB) is an important aspect of quality of life (QoL). It is however, seldomly incorporated in health-related quality of life scales. Recently, researchers focussing on aphasia, proponed the need for inclusion of SWB to measurements of QoL to fully capture someone's well-being. However, it is unclear, both internationally and in the Netherlands, how SWB of the client informs clinical practice of SLTs. The current explorative research is set up to explore how Dutch SLTs operationalize SWB in current practice.

**Aim:** To describe how Dutch SLTs, working with people with aphasia in a private practice or a healthcare centre, address the patient's SWB during diagnosis and treatment, and identify barriers and facilitators they experience when measuring and operationalizing SWB.

**Method:** A qualitative research design with a phenomenological approach was used. SLTs from private practices and healthcare centres were invited to participate in individual interviews and a focus group. The data was analysed using a combination of inductive and deductive methods.

**Results:** Eight SLTs participated in the study. The SLTs' experiences were described through four themes that emerged: SLTs' responsibility, understanding someone's SWB, the concept SWB, and working in a team. The results showed that SLTs feel responsible to address SWB in patients, but they experience limits in their influence on someone's SWB.

**Conclusion:** SLTs consider SWB as a complex puzzle, which is reflected in many domains of life. Therefore, it is important for SLTs to be a part of a cooperative network to understand both the impact of aphasia on a patient's life and SLTs' influence on patients' SWB.

**Recommendations:** Further research should focus on the development of a valid measurement of SWB-, and clinical guidelines to guide SLTs in supporting patients in dealing with their aphasia.

**Keywords:** Aphasia, subjective well-being, speech-language therapists.

## Nederlandse samenvatting

**Titel:** Ervaringen van logopedisten met het subjectief welbevinden van mensen met afasie.

**Achtergrond:** Subjectief welbevinden (SWB) is een belangrijk aspect van een meting van kwaliteit van leven (KvL) bij mensen met afasie. Echter, SWB maakt zelden onderdeel uit van een meting van KvL. Recent onderzoek toont aan dat SWB een belangrijk onderdeel is van een meting van KvL om een valide beeld te krijgen van het gehele welbevinden van iemand. Echter, het is onduidelijk hoe SWB in Nederland en internationaal deel uit maakt van de logopedische zorgverlening. Het huidige onderzoek is daarom opgezet om te onderzoeken hoe Nederlandse logopedisten SWB in de praktijk operationaliseren.

**Doel:** Het beschrijven hoe Nederlandse logopedisten, die werken met mensen met afasie in zorginstellingen of eerstelijnspraktijken, omgaan met het welbevinden van patiënten in de diagnose en de behandeling, inclusief welke barrières zij daarbij ervaren.

**Methode:** Logopedisten uit zowel zorginstellingen als eerstelijnspraktijken zijn uitgenodigd voor deelname aan een individueel interview en een focusgroep aan het eind van het onderzoek. De data zijn geanalyseerd met een combinatie van inductieve en deductieve methoden.

**Resultaten:** Acht logopedisten participeerden in het onderzoek. De ervaringen van deze logopedisten zijn beschreven aan de hand van vier thema's die uit de resultaten naar voren kwamen: De verantwoordelijkheid van de logopedist, het begrijpen van iemands SWB, het concept SWB en werken in een team. De resultaten laten zien dat logopedisten zich verantwoordelijk voelen om het SWB van mensen aan te pakken, maar zij ervaren grenzen aan hun invloed op iemands welbevinden.

**Conclusie:** Logopedisten zien SWB als een complexe puzzel die verweven is in verschillende facetten van het leven. Daarom is het belangrijk om samen te werken met andere zorgprofessionals om zowel de impact van de afasie op iemands leven te begrijpen, als ook de invloed op iemands welbevinden.

**Aanbevelingen:** Vervolgonderzoek kan gericht worden op het ontwikkelen van een meting van het SWB en het ontwikkelen van klinische richtlijnen om logopedisten te ondersteunen in het helpen van patiënten bij het omgaan met de afasie.

**Keywords:** Afasie, subjectief welbevinden, logopedisten.

## Introduction

Aphasia is a language disorder, caused by brain damage. Approximately 30% of stroke patients are diagnosed with aphasia.<sup>1</sup> Aphasia negatively influences social participation, emotional health, psychological well-being, and life satisfaction.<sup>2,3</sup> Moreover, among stroke survivors, people with aphasia (PWA) have an increased risk of developing a depression.<sup>4</sup> Attention for the negative consequences of aphasia on a patient's life has become important in aphasia care. To determine the impact of aphasia on the patient's life, very few instruments are available. Quality of life (QoL) has been described as an outcome measure that captures the influence of stroke and aphasia on life, and can be measured by the SAQOL-39-NLg.<sup>5</sup>

However, the SAQOL-39-NLg focuses on the patient's functioning and does not include a measurement of subjective well-being (SWB). SWB is defined as "An umbrella term for different valuations that people make regarding their lives, the events that happen to them, their bodies and minds, and the circumstances in which they live".<sup>6</sup> Where QoL focuses on how a person perceives and describes his own health, SWB focuses on how a person values his functioning. Therefore, SWB is more dependent on complex emotional and psychological processes.<sup>7</sup> Recently, Skevington et al. ascertained the need for SWB to be added to measurements of QoL to fully capture someone's well-being.<sup>8,9</sup>

SLTs, clients, and family also find SWB an important outcome.<sup>10</sup> SLTs are often confronted with emotional consequences of aphasia in patients, which often results in SLTs assisting patients in dealing with their aphasia in daily life.<sup>11</sup> It is however, unclear if and how SWB is addressed in diagnosis, and treatment of PWA. In fact, a recent systematic review showed that SLTs lack training to support PWA in coping with their aphasia.<sup>12</sup> Another study showed several barriers that British SLTs experience when addressing the patients' psychological well-being, a part of SWB that entails achieving a sense of purpose in life.<sup>12,13</sup> SLTs acknowledge their role in providing psychological support to their patients, but the boundaries between their services and mental healthcare professionals' services are unclear.<sup>13</sup>

The dearth of knowledge on the operationalization of SWB in clinical practice internationally, is also evident in the Netherlands. SLTs' approach to SWB has not been explored in the Netherlands. Therefore, the current explorative study is set up to describe the Dutch SLTs' experiences with SWB, including the barriers and facilitators in operationalizing SWB in

PWA. Due to its explorative nature, this study focuses on the broad definition of subjective well-being as provided above, because it captures all facets related to how someone experiences life. This study results in implications for further research into the integration of SWB in clinical practice.

## Objectives

The current study aims to describe how Dutch SLTs, working with people with aphasia in a private practice or a healthcare centre, address SWB in diagnosis and treatment, including barriers and facilitators they experience when measuring and operationalizing SWB.

## Methods

### Study design

A qualitative research design with a phenomenological approach was used to provide a description of the SLTs' experiences with the operationalization of SWB.<sup>14,15,16</sup> Data are reported according to consolidated criteria for reporting qualitative research.<sup>17</sup>

### Sampling procedure

A criterion sampling strategy was used to include SLTs who have worked with PWA for at least two years with at least one patient with aphasia a week. Furthermore, the SLTs were included if they were available to participate in both an individual interview and a focus group. To form a homogeneous group of participants, eight participants are generally recommended to be included.<sup>15,18</sup>

SLTs were contacted to participate in the study by sending the study invitation to ten organizations close to Utrecht and Amsterdam, who deliver speech language therapy, and by a publication of the study invitation on the website of AfasieNet. AfasieNet is a Dutch organisation that aims to improve quality of care for PWA. Around 206 SLTs are members of this organization.<sup>19</sup>

The study invitation entailed background information on the study, the aim, and the procedure. SLTs were informed that the interviews and the discussion would be recorded

and results anonymously incorporated into the study. Moreover, participating SLTs would receive 10 quality points for the Dutch professional registration system (10 vrije kwaliteitspunten).

## Data collection procedure

The data was collected through individual semi-structured interviews, followed by a focus group session. Due to problems in the availability to participate in the focus group, two focus groups of four SLTs were organised. The focus groups served two functions. Firstly, the focus groups functioned as a step of data-triangulation by collecting additional data in a different setting. The focus groups offered the possibility to elicit a discussion between SLTs, to get a deeper understanding of contradictory views. Secondly, the focus groups offered the possibility to check whether the researchers' interpretation of the results of the interviews was confirmed by the SLTs.

Participating SLTs were interviewed after giving informed consent. SLTs were asked to describe their experiences with measuring and incorporating SWB into a treatment plan, including the barriers and facilitators they have faced. An interview guide (Appendix A) was set up to structure the interviews. The guide was not pilot-tested, but adjusted to the themes that arose from the first three interviews, by adding and changing questions. These adjustments are indicated in Appendix A as well. The individual interviews were audio-recorded and transcribed in verbatim afterwards by the first researcher. A summary of each transcript was written and sent to the SLTs for a member check.

The content of the focus groups was developed by two researchers, based on the results of the interviews. From the results of the interviews it was unclear how SLTs defined SWB and whether their definitions would be similar. Therefore, the focus groups started with SLTs creating a mind map about their definition of SWB. The second part of the focus groups consisted of a discussion of several statements. The focus groups were video-recorded and transcribed afterwards by the first researcher. No field notes were taken during the data collection.

## Analysis

To enhance the reliability of the results, several steps in the analysis were performed by two researchers independently. All transcripts were coded by the first researcher. A junior

researcher independently coded one of the transcripts. Both researchers interpreted the data together and developed the final code tree (Appendix C). NVivo 12 was used to analyse the data.

In order to analyse the data in depth and to provide an exhaustive description of the SLTs' experiences with SWB, a combination of an inductive and a deductive analysis was chosen. Colaizzi describes a thematic analysis that suits a phenomenological research design.<sup>20</sup> Within this approach significant statements are extracted from the transcripts that answer the research question. Then, these statements are clustered into themes and compared between transcripts. This inductive approach leads to a description of the operationalization of SWB as it is currently experienced. Two researchers interpreted the data together by looking for explanations for SLTs' experiences within the data and by determining the relationships between themes. This led to a development of the final themes.

In addition, the resulting themes were used by the first researcher to further analyse the data based on a framework approach.<sup>21</sup> The themes were deductively analysed by creating a matrix, with each theme on separate rows and each respondent on a separate column. The matrix enabled the researcher to understand the data more in-depth by performing within- and cross-case analyses. This step led to a refinement of the developed themes.

### **Focus group**

After the analysis was finished, both researchers transformed the themes into statements that would elicit a discussion within the focus group. The transcript from the focus group was analysed according to the steps of Colaizzi.<sup>20</sup> These results were only used to affirm or adjust the results that emerged from the interviews. The final code tree shows four main themes, which all include sub-themes (Appendix C). The code tree and its development are further described below.

### **Ethical considerations**

This study is conducted according to the principles of the Declaration of Helsinki (2008) and in accordance with the Medical Research Involving Human Subjects Act (WMO). All participants gave informed consent before participating in the study. Participants were informed that they can withdraw from the study at any moment. The interviews and the focus group do not contain any confronting subjects. Handling and storage of collected data and

documents during this study will comply with the Dutch law of data protection (Wet bescherming persoonsgegevens).

## Results

### Participants characteristics

Participants were included based on a first come first serve basis. Eight female SLTs from different areas across the Netherlands were recruited. All SLTs met the inclusion criteria and had experience working in different settings throughout their careers. Participant characteristics are outlined in table 1.

### Setting

The interviews took place in a quiet room at the SLTs' work setting and took between 30-60 minutes. Only the SLT and the first researcher were present during the interview. One SLT was accompanied by her trainee, who observed the interview. The focus groups were organized at Hogeschool Utrecht. The focus groups were attended by four participating SLTs each, the first researcher and a moderator, who is a junior researcher.

### Description of results

The SLTs' experiences are successively described through four themes that emerged from the data: SLTs' responsibility, understanding someone's SWB, the concept SWB, and working in a team. These themes contain the results of the interviews that are adjusted according to the results from the focus groups. The themes are outlined with quotes that were edited for grammar and readability.

To provide a transparent insight into the researchers' interpretation of the data, an overview of the results of the interviews, the results of the matrix analysis, and the results of the focus groups are presented in table 2. One SLT asked for an adjustment of one sentence within the summary of her interview. This adjustment had no consequences for the final results.



## **SLTs' responsibility**

The scope of SLTs' responsibility regarding the patient's SWB was an important topic during both the interviews and the focus groups. The degree to which SLTs felt responsible for PWAs' well-being was influenced by several factors. These included the degree to which the SLT may relate to, and is emotionally involved with the patient's situation, and the presence of colleagues to share responsibility with. However, all SLTs agreed that their main responsibility within the domain of SWB is to facilitate patients to connect with their social environment. SLTs shared the belief that as a therapist you should deliver good care to optimize the patient's capabilities to communicate, as far as your profession allows:

*"When someone would be happier if he can buy groceries independently and this is dependent on his linguistic capabilities, then I think I can influence that."*

(Interview SLT 4)

On top of that, SLTs considered themselves the designated professional to signal any problems in patients' well-being that may need to be addressed by other healthcare professionals:

*"During other treatments, communication is less prominent, so when I think of the rehabilitation setting, we [the SLTs] are the first persons to offer patients a chance to talk about it."*

(SLT 5 in focus group 2)

*"I think when people express themselves, I have to take that seriously, because who else will do this? Maybe nurses or family members have time in the evening."*

(Interview SLT 8)

SLTs also felt responsible to incorporate the patients' social network into their treatment, to both increase the awareness of the communication with PWA and to stimulate patients to initiate conversations with people. SLTs aimed to prevent PWA from getting isolated:

*"I also incorporate the patient's ability to participate in activities (...) for example I say the lady who is sitting with you in the living room is a nice lady, go talk to her."*

(Interview SLT 2)

## Understanding someone's SWB

SWB is a broad concept that captures different facets of life. Some SLTs mentioned using instruments to measure the patient's SWB sometimes, which are presented in the final code tree (Appendix C). However, all SLTs felt that the available instruments were not sufficient to fully capture the patients' well-being. SLTs gained insight into patients' SWB through conversations with the patient and their family about the patient's daily life:

*"I gain insight into the patient's daily life, his social contacts, his occupations, his hobbies."*

(Interview SLT 1)

*"The patient and I looked at every day of the week and identified moments the patient felt good and moments when the patient felt bad."*

(Interview SLT 5)

SLTs experienced misinterpretations of how patients experience their disease, because the SLTs' interpretation interfered with their own values and expectations. It was therefore important for SLTs to listen to patients' experiences and to bracket their own thoughts. However, aphasia makes these conversations complex. Persons with a less severe aphasia are better able to express themselves verbally, and will often initiate a conversation about their well-being. When the aphasia is more severe, SLTs experienced they become more dependent on non-verbal signals, which are often a reason to ask people about their problem. SLTs used supporting conversation techniques (such as yes/no questions) to gain insight into the well-being of their patient. However, sometimes these signals are not clear or missed, which may cause patients to suppress their emotions:

*"You don't necessarily need language, but when I think of a man who had severe aphasia his situation escalated, so after the problem unfolded I was alerted. Persons with light aphasia express themselves quicker and as an SLT you start talking about it to prevent an escalation."*

(SLT 1 in focus group 2)

SLTs also felt dependent on receiving information from the patients' social network, because these people know the patient well and have a better understanding of the patient's personality. When SLTs were getting familiar with the patient's daily life, they understood the consequences of aphasia on the patient's life better. Moreover, SLTs found it easier to understand the impact of aphasia on the patient's life when they could relate to the patient's

situation, for example when they were the same age. However, even when people know each other well, misinterpretations were common:

*“A common mistake is you think you know someone (...) therapists and family members tend to think for the patient and they forget to ask the patient what he wants.”*

(Interview SLT 4)

SLTs agreed language is a big facilitator in capturing someone’s well-being. Other sources of information complete a complex puzzle, as SWB is viewed by some SLTs:

*“I think it is not just about asking people, but you need a broad view, a broad observation to complete the puzzle.”*

(SLT 8 in focus group 1)

### **The concept SWB**

The concept SWB was extensively discussed within the focus groups, which aids the understanding of SLT’s approach to SWB. SLTs described SWB in three different ways. Firstly, they described SWB as an internally-oriented concept, reflected by personal factors as coping style and life attitude. Secondly, they described SWB as someone’s valuation of their position in society. Thirdly, they described SWB as being able to do what you want to do, which is dependent on factors such as the financial situation or health status. SLTs experienced SWB as being mostly dependent on pre-morbid personal factors. Therefore, SLTs experience a limited influence on patients’ SWB. As one SLTs puts it:

*“It [SWB] depends on your character and your life-attitude, and I can’t influence those things as an SLT.”*

(SLT 4 in focus group 1)

SLTs experienced that every patient prioritises different aspects of well-being. Therefore, SLTs felt it is important to be able to set aside their own values and ideas when developing a treatment plan, as people respond to their new situation in varying ways.

*“It is good to think to yourself these are my values and it doesn’t mean the patient feels the same way (...) the treatment plan is adjusted to what the patient thinks is important.”*

(Interview SLT 3)

Even though SLTs agreed they always pay attention to patients' well-being, the way in which the patients' well-being is defined and addressed differs depending on the patients' time post onset. SLTs mostly considered SWB to reflect long term needs of patients, which patients are aware of in the chronic phase of aphasia. At that moment, SLTs start having conversations with their patients about their needs to live successfully with aphasia. SLTs described the patient's SWB in the acute phase in terms of patients' lack of comfort with the current situation.

### **Working in a team**

SLTs noticed the responsibility towards their patients' well-being is related to the presence of other healthcare professionals to share responsibility with. As previously mentioned, SLTs described SWB as a complex concept that captures many facets in life. Therefore, SLTs felt that in some situations, patients' needs were too extensive to be tackled by one therapist alone. Most SLTs worked together with the patients in multi-disciplinary cooperative networks. One of the respondents worked in a private practice and was not a part of a cooperative network. She felt like she carried too much responsibility:

*"Because I don't have that network, I carry more responsibility (...) I think I take it [The patients' situation] home more often, because I feel like I'm the only therapist who contributes to it."*

(SLT 7 in focus group 1)

*"It [SWB] is intertwined into many facets of life so you can't say I treat this part or I will pay attention to it during therapy."*

(SLT 3 in focus group 1)

In the first focus group, SLTs agreed they experience a lack in healthcare service provision between private practices and healthcare centres. Sometimes, patients lack the required indication to be admitted to a nursing home or rehabilitation centre, but they show more problems than an SLT alone can treat. SLTs agreed working in a team reduced that load, because the responsibility for the patient's well-being was shared. On top of that, when other healthcare professionals were easy to access, it created a possibility to share thoughts on a situation. SLTs described reaching out to other healthcare professionals to gain insight into how patients function in different contexts.

Many SLTs contacted a psychologist on a regular basis when they suspect psychological issues in their patients that they cannot address. Because SLTs were often confronted with patients discussing their thoughts and feelings, SLTs experienced a blurred boundary between their services and a psychologists' services.

*"You bring your personality, your compassion, your empathy (...), but you're not equipped to solve that part [the patient expressing being unsatisfied with her life]."*

(Interview SLT 6)

Sometimes this boundary is clear, for example when patients express suicidal thoughts or deeper issues that interfere with the patient's motivation to get therapy. However, SLTs also found themselves intermediating between a patient and his/her spouse and talking about confronting subjects, activities SLTs often feel unequipped for.

## Discussion

This study aimed to describe SLTs' experiences with the operationalization of SWB in PWA. The results of this study show that SWB is a complex concept. SWB was described by SLTs through three dimensions of people's life: 1) personal factors like life attitude, 2) the patient's position in society, and 3) the patient's capabilities to do what he wants to do. All these elements were identified by SLTs in a previous study to influence a successful life with aphasia.<sup>22</sup> The current study added knowledge by differentiating between three dimensions of patients' SWB, which aids an understanding of the SLTs' role regarding SWB.

The three dimensions of SWB are related in a complex manner, which caused SLTs to experience a limited understanding of, and a limited influence on patients' SWB. SLTs experienced they can only contribute to the third dimension, by enhancing the patient's capabilities to communicate. An important facilitator of addressing SWB in both diagnosis and treatment was the ability to share thoughts with colleagues within a cooperative network. A multidisciplinary team took away some of the complexity of SWB, because the different views of healthcare professionals on the patient's situation created a more complete image of the patients' needs regarding their SWB. On top of that, SLTs were often the first person to signal any problems with patients' SWB that needed to be consulted by other healthcare professionals, which was also found in another study.<sup>13</sup> Despite the advantages of collaborating with other professionals, SLTs experienced blurred boundaries between

different healthcare professionals' services, which was previously mentioned in a qualitative study.<sup>13</sup>

In terms of the clinical relevance of this study, the current study creates a new vision on speech-language therapy, by showing the importance of acknowledging SWB as a key outcome. This study raises awareness of discussing the impact of aphasia with the patient and other healthcare professionals to create a holistic view of a patient. The current study highlights a need for a clear guideline regarding the collaboration between different healthcare professionals. This guideline should not sharpen boundaries between professionals, but rather be founded on a sense of shared responsibility, that strengthens the care delivered to PWA by SLTs. A focus group with multiple healthcare professionals might be the first step to explore the factors that facilitate a successful collaboration to address SWB in PWA.

In addition, further research may focus on a revision of the SAQOL-39-NLg by incorporating a multidisciplinary assessment of SWB, that fits the SLTs' perspectives on which information is important to support their patient. This may prevent misinterpretations from occurring, as well as patients suppressing emotions, by offering professionals a guide to gain insight into the impact of aphasia on the patient's SWB. This study may even lead to a debate on the question whether it is realistic to standardize SWB as an outcome measure. Exploring the underlying psychological processes to understand SWB might be necessary, but many researchers have attempted to conduct this research for SWB or life satisfaction, which has not yet cleared our understanding of this concept.<sup>2,3,7,23</sup>

### **Strengths and limitations**

Usually, six to eight persons participating in a focus group is recommended.<sup>15,18</sup> Due to practical issues, the current study entailed two focus groups of four SLTs. This is a limitation of the study, since bigger focus groups would have created a larger diversity of experiences and views within the group discussion. However, the focus groups were only used to collect additional data and to test the researchers' interpretation of the results of the interview, which in turn strengthens the study. Another strength of the study is the combination of inductive and deductive analysis methods, which led to a thick description of the results (table 2). In addition, SLTs from different settings were included, which enhances the credibility of the results. A transparent research process was pursued by performing a member check. On top of that, two researchers have performed the analysis independently and together, which enhances the reliability of the results.

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## Tables

Table 1. Participant characteristics

	Years of experience	Setting	Focus group
SLT 01	<10	Geriatric rehabilitation + private practice	2
SLT 02	20-30	Geriatric rehabilitation	2
SLT 03	20-30	Poly-clinical rehabilitation	1
SLT 04	20-30	Rehabilitation + teacher at higher education	1
SLT 05	<10	Rehabilitation + long-term neuro-rehabilitation	2
SLT 06	20-30	Nursing home + geriatric rehabilitation + private practice	2
SLT 07	<10	Private practice	1
SLT 08	10-20	Nursing home	1

Table 2. The development of the results within different steps of the analysis

Results of the interviews	Interpretation/explanation of the results	Matrix analysis (framework approach)	Focus group analysis
<p><b>Barriers in the operationalization of SWB</b></p> <ul style="list-style-type: none"> <li>-Severe aphasia (linguistic skills)</li> <li>-Cognition</li> <li>-Patients too emotional</li> <li>-Social network has different views</li> <li>-No good instrument available</li> <li>-Sensitive subject</li> <li>-Some settings</li> <li>-<u>Misinterpretation</u></li> </ul> <p><b>SLTs' views on SWB</b></p> <ul style="list-style-type: none"> <li>-SWB is becoming more important</li> <li>-SWB is different for everyone</li> </ul> <p><b>Measuring SWB</b></p> <ul style="list-style-type: none"> <li>-Brought up in conversations</li> <li>-Discussing daily life (now &amp; pre-morbid)</li> <li>-Discussing with social network</li> <li>-Getting to know someone</li> <li>-SAQOL, ICB, CAT-NL, Dysmix</li> <li>-Signals</li> </ul> <p><b>Dealing with a patient's SWB</b></p> <ul style="list-style-type: none"> <li>-Advises</li> <li>-Motivating patients/being there</li> <li>-Indirect treatment</li> <li>-Group therapy</li> <li>-Increasing participation capabilities</li> <li>-Listening to what patient wants</li> <li>-Working in a team</li> <li>-Consulting a psychologist</li> </ul> <p><b>Rehabilitation phase vs. chronic phase</b></p> <ul style="list-style-type: none"> <li>-Different ideas on how to address SWB in patients depending on time post onset.</li> <li>-SWB is addressed differently depending on what setting the SLT works in.</li> </ul>	<p><b>SLTs' responsibility</b></p> <ul style="list-style-type: none"> <li>-SLTs feel responsible for someone's well-being and will always deliver care that answers the patient's needs.</li> <li>-SLTs want to be there for a patient.</li> </ul> <p><b>SLTs have different ideas of their tasks related to SWB.</b></p> <ul style="list-style-type: none"> <li>-Overall SLTs experience unclear boundaries to their services.</li> <li>-Some SLTs find it important to directly address someone's SWB, while other SLTs only describe their influence in terms of language therapy.</li> <li>-SLTs prefer working together with other professionals in addressing SWB.</li> </ul> <p><b>SLTs view SWB as a negative influence on patients' motivation.</b></p> <p><b>SLTs have different definitions of SWB.</b></p> <ul style="list-style-type: none"> <li>-SLTs have different experiences related to different phases post onset.</li> <li>-SLTs seem to differ in their definition of SWB, with some SLTs focussing more on the patient's emotions and some SLTs focussing more on the patient's participation.</li> </ul> <p><b>SWB can only be captured by language.</b></p> <p><b>To improve a patient's SWB, the patient's social network should adapt to the patient's needs.</b></p>	<p>The matrix shows that SLTs have different attitudes towards SWB, which is reflected in the way they address SWB. Some SLTs are more focused on the emotional aspect, which results in them spending more time discussing the patient's feelings and assisting the patient in finding life activities that make the patient happy. Other SLTs are focused more on the patient's needs to be able to participate in society as the patient wishes. These SLTs describe their influence on SWB in terms of delivering therapy to increase the patient's capabilities to participate in daily activities. The first group of SLTs consider the patient's SWB as the main concern, which is addressed in both the acute phase and the chronic phase. The latter group of SLTs think SWB is not yet addressed in the acute phase, because patients in the acute phase are not aware of the consequences of aphasia on their SWB.</p>	<p><b>SLTs' responsibility</b></p> <ul style="list-style-type: none"> <li>-SLTs agreed they are responsible for delivering good care to increase the patient's capabilities to communicate.</li> <li>-However: SWB is dependent on personal factors SLTs cannot influence.</li> <li>-SLTs discussed factors that influence the degree to which they feel responsible: being able to relate to the patient's situation, emotional involvement, sharing responsibility in a team.</li> <li>-SLTs agreed they are responsible for signalling problems that need to be consulted by other professionals.</li> </ul> <p><b>The concept SWB</b></p> <ul style="list-style-type: none"> <li>-There was consensus on how to define SWB.</li> <li>-SWB is mostly dependent on personal factors SLTs cannot influence.</li> </ul> <p><b>Understanding someone's SWB</b></p> <p>SLTs agreed language is important to be able to understand someone's SWB, but they think non-verbal signals are important as well. Knowing a patient facilitates understanding what a patient is going through. The limited linguistic skills of PWA causes them to suppress emotions.</p> <p><b>Working in a team facilitates to address a patient's SWB.</b></p> <ul style="list-style-type: none"> <li>-This relieves some of the complexity of SWB, because responsibility is shared.</li> </ul>

## Appendix A. Interview guide

### **1. Background information on setting → 5 minutes**

- Experience with PWA.
- Is the SLT specialized in a specific type of disease or treatment?
- What kind of patients does the SLT see?
  - How long post onset?
- Does the SLT deliver a specific type of treatment?

### **2. Vision on recently developed conceptual model QoL → 10 minutes**

Explain that QoL can be measured by incorporating an objective and a subjective evaluation of the patient's functioning in combination with subjective wellbeing.

- What does the SLT think of adding SWB to a measurement of QoL?

### **3. Experiences with the operationalization of subjective well-being → 25 minutes**

- How does the SLT experience the current method of measuring QoL? How does she measure QoL?
- How does the SLT gain insight into someone's well-being?
- How is SWB reflected within the therapy plan?
- How does the SLT cope with someone's SWB?
- What aspects of SWB does the SLT think she can influence?
- To what degree does the SLT feel responsible for the patient's SWB?

### **4. Barriers and facilitators → 20 minutes**

- What barriers did the SLT face when gaining insight into someone's SWB?

- What barriers did the SLT face during treatment of a patient, related to someone's SWB?
- What does the SLT think is needed within an instrument to measure SWB in PWA?

### **Adjustments to the interview guide.**

#### *Questions removed:*

- What does the SLT think is needed within an instrument to measure SWB in PWA?
- This question is not relevant for the research question.

#### *Questions added:*

- How does working in a multi-disciplinary team influence measuring/treating someone's SWB?
- Does the SLT initiate a conversation about someone's SWB or does she wait for the patient to do so?
- Why is SWB so difficult to capture in PWA?

## Appendix B. Focus group guide

During the first part of the focus groups, SLTs are asked to create a mind map, which contains every word they can think of that defines SWB.

The second part of the focus groups is a discussion of several statements:

- As an SLT I feel responsible for the patient's well-being.
- One of the tasks for an SLT is to discuss with patients the emotional consequences of aphasia.
- SLTs find subjective well-being to be a difficult/confronting subject to talk about with patients.
- SLTs prefer waiting for the patient to initiate a conversation about their well-being instead of bringing it up themselves.
- The patient's well-being strongly affects the degree to which therapy goals are achievable.
- Well-being can only be captured verbally.
- To enhance someone's well-being, the patient's environment should adjust to the patient's capabilities and needs.
- Being a part of a multi-disciplinary team is essential to be able to cope with patients' well-being.
- Coping with patients' well-being is easier working in a private practice over a healthcare institution.

## Appendix C. Code tree in Dutch

### Nodes

Name
<b>De rol van een multidisciplinair team</b>
- Een stap tussen eerste lijn en instelling mist
- In de eerste lijn is ook steeds meer multidisciplinaire samenwerking
- In de eerste lijn zit je nog meer op participatieniveau
- In een team deel je de verantwoordelijkheid
- In een team krijg je een beter beeld van PMA in verschillende situaties
- Je verhaal kwijt kunnen bij een collega
- Samenwerking met psycholoog/onduidelijke grenzen
- Te grote verantwoordelijkheid in je eentje
<b>Iemands SWB begrijpen</b>
- Familie maakt ook misinterpretaties
-De familie beleeft de stoornis anders
-De familie heeft er een ander belang bij
-Familie is niet altijd aanwezig
- Herkenbaarheid als facilitator
- Input van de omgeving is nodig
- Interferentie van eigen visie
- Logopedisten proberen iemands situatie te begrijpen

- Dagelijks leven in kaart brengen
-Iemand leren kennen
-Premorbide persoon in kaart brengen
- Meetinstrumenten zijn niet ideaal
-Beperkingen SAQOL
-Focus op scoren
-Niet individueel bruikbaar
-Niet representatief
-Tijdrovend
-CAT-NL lijst QoL te moeilijk
-Hulpvragen worden gemist zonder een goed instrument
-Instrument als facilitator
-Je bent als logopedist uitbehandeld, maar het instrument zegt dat het nog niet goed genoeg is.
-Middelen die logopedisten nu gebruiken
-Aangepaste SAQOL helpt cliënt spreken
-CAT-NL lijst
-Domeinen zorgleefplan uitvragen
-ICB als handvat
-QoL score
-Vragenlijsten dysmix
- Non-verbale signalen zijn ook informatief



- Taal is een facilitator

- Welbevinden is abstract en breed

- Welbevinden is een inschatting

- Zelf-inzicht als barrière

### SWB is breed en voor iedereen verschillend

- Behandelplan in samenspraak

- Hoe logopedisten SWB zien

- Welbevinden afhankelijk van middelen

- Welbevinden is afhankelijk van persoonlijke factoren

- Welbevinden vanuit je rol in een groep

- Welbevinden vanuit jezelf

- Korte en lange termijn SWB

- Acuut is er nog hoop en komen emoties wel ter sprake, maar werk je stoornisgericht

- Chronisch weten mensen waar ze tegenaan lopen en wordt welbevinden meer expliciet

- Welbevinden pak je wel altijd mee, maar op een andere manier

- Welbevinden wordt door ieder anders ervaren

### Verantwoordelijkheid logopedist

- De aangewezen professional om SWB te bespreken

- Aanvoelen of je het bespreekbaar maakt

- Alert op tekenen van emotie

- Inventariseren van problemen

-Je hebt medeleven
-Monitoren
-Motivatie bespreekbaar maken
-Ruimte bieden aan mensen
- Gedeelte SWB waar invloed op uit te oefenen is
-Afhankelijk van premorbide persoonskenmerken
-Logopedisten motiveren de cliënt
-Logopedisten voelen zich verantwoordelijk voor dat stuk dat zij kunnen oplossen
-SWB is lastig te beïnvloeden
- Mensen verbinden
-Betrokkenen informeren en adviseren
-De omgeving moet zich aanpassen
-PMA ondersteunen in participatie
-Groepstherapie
-Ervaringsdeskundigen
-Indicatie groepstherapie
-Participatiemogelijkheden vergroten
-Behandeldoelen aanpassen
-Cliënten stimuleren te communiceren
-Werken aan participatie
-Welbevinden van omgeving is ook een taak voor de logopedist

