

# Measuring Quality of Life in Aphasics – Development of the QoL–Aphasia 28 Items

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## **Abstract**

Until now, measuring quality of life in Dutch aphasics was not possible because of unsuitable questionnaires. The existing questionnaires do not focus on communication or the grammatical structure of the questions is far too complex. The aim of this study is to develop a Dutch questionnaire that measures the quality of life in aphasics. Therefore it has to cover all important domains and use questions with simple grammatical structures. To see whether it is possible to let the partner of the patient fill in the questionnaire when the patient is not able to, a proxy version was developed. The QoL–Aphasia 28 Items was developed in two stages. In the first stage, 35 aphasics and 25 partners participated. The questionnaire contained 38 questions. Reliability analysis showed a high Cronbach's alpha: .814. Item-to-Total correlations and Principal Component Analysis lead to the deletion of 10 questions. The adjusted version of the questionnaire was used in the second stage of this study. Seven aphasics and 4 partners participated and the questionnaire contained 28 questions. Reliability analysis showed that the questionnaire is homogeneous: Cronbach's alpha was .846. Validity was not officially checked. However, it can be assumed that the questionnaire is valid because the domains in the questionnaire correspond with the domains The WHOQoL Group (1994) defined in their definition of quality of life. Answers of patients and partners did not correspond: an average of 38% of the answers was identical in both stages. This means that the partner can not fill in the questionnaire when the patient is not able to. When the questionnaire developed in this study is further checked for reliability and validity, it is ready to be used.

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## Introduction

Brain injuries, caused for example by a stroke or trauma, can have major consequences. The most common consequence of a stroke is aphasia (Pedersen, 1999). There are different types of aphasia<sup>1</sup> but they all have one thing in common: language, and therefore communication, is disturbed. Because of the aphasia, someone is not able to make himself clear to other people and is misunderstood. Another thing that can be disturbed is the understanding of speech.

Most brain injuries come unannounced, so all the consequences this injury has are suddenly present. A person becomes suddenly a patient and has to learn to live with the disabilities he is experiencing. This can cause a lot of worries and stress which can have major consequences for the wellbeing of the patient. Therefore, it is important to measure this wellbeing.

## Quality of life

This wellbeing can be described as the 'quality of life'. However, what is the definition of quality of life? Several definitions of quality of life can be found in the literature. The World Health Organization describes quality of life as follows: *"An individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards and concerns. It is a broad-ranging concept, incorporating in a complex way the person's physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment"* (The WHOQoL Group, 1994a, p.43). Another definition of quality of life comes from Dalkey et al. (1973). They defined *'the term 'Quality Of Life' (QOL) to mean a person's sense of well-being, his satisfaction or dissatisfaction with life, or his happiness or unhappiness.'* Terhune (1973) said that *'quality of life refers to human experience, and the criteria of quality of life are those dimensions of life by which people experience levels of satisfaction-dissatisfaction (pleasure-pain, happiness-unhappiness, etc).'* The definition of McCall (1975) is as follows: *'Quality of life consists in the satisfaction of the general happiness requirements. To the extent that the General happiness requirements are met in a given society or region, what we shall understand by Quality of life is high in that society or region; to the extent that they are not met, Quality of life is low.'* Finally, Michell et al. (1973) described quality of life more briefly than the ones mentioned before. They meant by quality of life *'an individual's overall perceived satisfaction of his needs over a period of time.'*

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<sup>1</sup> For an overview of the different types of aphasia see for example Fedorov (2001).

The definitions mentioned above do not contradict each other. However, they differ in how elaborate they describe the term 'quality of life'. Aphasics show a very complex clinical picture because the brain injury they suffer often causes, next to language, other functions to be disturbed as well. So in order to get a good impression of the quality of life of aphasics, many domains must be taken into account. The definition of The WHOQoL Group (1994) is the most elaborate definition of quality of life and mentions several domains. When making a questionnaire that measures quality of life in aphasics, this definition will be the most appropriate one.

### Existing questionnaires

If there is knowledge about a patient's quality of life, and on what area the patient experiences a 'low' quality of life, then steps can be taken to improve the quality of life of the patient. By measuring the quality of life again after specific therapy, it will demonstrate whether or not the quality of life has improved. One way to measure the quality of life is by questionnaires or rating scales. For Dutch, several questionnaires are available. These will be described and discussed next.

- *The Frenchay Activities Index*

The Frenchay Activities Index (FAI) was developed by Holbrook and Skilbeck (1983). The purpose of this questionnaire was to measure the lifestyle of patients who have had a stroke, because other already existing scales did only measure a patient's ability for self-care. A scale that measures lifestyle would, according to Holbrook and Skilbeck (1983), be useful in determining rehabilitation goals. The FAI consists of 15 items and the patient can rate on a scale from 0 to 3 how many times a week/month he or she does a certain activity such as driving a car, gardening or doing the dishes. The FAI is a questionnaire that does not explicitly measure quality of life, as will be discussed below.

- *The Medical Outcomes Study 36-Item Short Form Health Survey*

The Medical Outcomes Study 36-Item Short Form Health Survey (SF-36) is a questionnaire developed by Ware et al. (1992). The Dutch translation is made by Aaronson (1992). The SF-36 contains 36 questions, divided in 8 dimensions: physical functioning, role limitation as a cause of physical health problems, pain, overall health experience, vitality, social functioning, role limitation as a cause of emotional problems, and mental health.

- *The RAND 36-Item Health Survey*

A questionnaire almost identical to the SF-36 is the RAND 36-Item Health Survey (RAND-36). This questionnaire is a shortened version of the RAND Health Insurance Study Questionnaire (Brook et al., 1979). It covers the same dimensions as the SF-36 and the Dutch translation, made by Van der Zee and Sanderman (1993), is almost identical to the Dutch translation of the SF-36 made by Aaronson (1992).

- *The Medical Outcomes Study 12-Item Short Form Health Survey*

The Medical Outcomes Study 12-Item Short Form Health Survey (SF-12) (Ware et al., 1998) is a modification of the SF-36, with only 12 questions. The Dutch translation is made by Van Hoecke (1999). With these 12 questions, the same 8 dimensions as in the SF-36 are covered. The SF-12 results in two total scores: one for the physical quality of life (the physical component score) and one for the psychological quality of life (the mental component score).

- *The EuroQol 5 Dimensions*

The EuroQol 5 Dimensions (EQ-5D) is developed by The EuroQol Group (1990). This instrument contains 5 dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension is covered by one question, and this question has three levels: no problems, some problems, and severe problems.

- *The Health Utilities Index Mark 3*

The Health Utilities Index Mark 3 (HUI3) is one of many Health Utility Indexes developed by Feeny et al. (1996). This HUI3 consists of 8 dimensions: vision, hearing, speech, ambulation, dexterity, emotion, cognition, and pain. Each item describes the ability or disability of a certain domain in 5 or 6 levels. Subjects can fill in the questionnaires by themselves (or with help) and there is another questionnaire especially for a proxy (most of the time the partner of the patient). All the questions bear on one week before filling in the questionnaire.

- *The Quality of Life and Aphasia*

The Quality of Life and Aphasia (QoL-A) was developed in 2005 by 5 speech therapist students of the Hogeschool van Arnhem en Nijmegen (Van Harten et al., 2005). This questionnaire was developed specifically for aphasics and consists of 56 items on 7 domains: level of independence, physical health, psychological health, social relations, communication, religion, and relations with notable features in the environment. The questions inquire after the satisfaction a patient is experiencing regarding a certain subject. To clarify the questions, pictures are shown and the speech therapist names several examples. The possible answers are indicated with 5 pictures of faces, very dissatisfied is indicated with a crying face and very

satisfied is indicated with a face with a large smile. It takes 45 minutes to fill in the complete questionnaire.

All these questionnaires are different in what they measure and for what kind of patients they are suitable. De Haan et al. (1993) reviewed several quality of life measures to find out which measure is best to use with stroke patients. One of those measures compared was the Frenchay Activities Index (FAI) (Holbrook et al., 1983), which is stroke specific. The other measures were: COOP Charts (Nelson et al., 1987); EuroQol (The Euroqol Group, 1990); Karnofsky Performance Status Scale (Schag et al., 1984); McMaster Health Index Questionnaire (Chambers et al., 1982); Medical Outcomes Study 20-Item Short-Form Health Survey (Stewart et al., 1988); Nottingham Health Profile (Ebrahim et al., 1986); Quality of Life Index (Spitzer et al., 1981); Quality of Well-being Scale (Anderson et al., 1989); and the Sickness Impact Profile (Bergner et al., 1981). According to De Haan et al. (1993) the FAI can be quite appropriate if one is interested primarily in measuring outcomes with an emphasis on disabilities. The FAI does not really measure the quality of life; it only gives an indication which activities the patient still can accomplish. The patient's feelings are not mentioned in the questionnaire. De Haan et al. (1993) suggest using the MOS-20 and the NHP when the aim of the study is to assess general perceptions of health and well-being. These questionnaires however, are not stroke-specific.

The SF-36, RAND-36, SF-12 and the EQ-5D do measure the quality of life, but are not stroke-specific either. These questionnaires are not suitable for patients who have had a stroke. Most of the time, these patients also are aphasics. Communication plays an important role in these patients, which means that communication can also influence their quality of life. If a questionnaire does not incorporate questions about communication, a distorted view may arise: on all the other domains the patient may score well, while he isn't happy at all because of his disability to communicate. In the HUI3, questions about mood and feelings are included. This indicates that quality of life is part of the questionnaire, according to the previously mentioned definition of quality of life by Dalkey et al. (1973). Furthermore, the HUI3 pays attention to communication with questions about speech and understanding; this makes it an appropriate questionnaire for aphasics. Although the HUI3 seems an appropriate questionnaire to measure the quality of life of aphasics, the formulation of the questions is not adequate at all for aphasics. Questions like 'Welke van de onderstaande uitspraken beschrijft het beste hoe goed u gedurende de afgelopen week kon zien om gedrukte tekst (bv.

de krant) te lezen?' ('Which of the following statements describes best how well you could see to read printed text (e.g. the newspaper) during the last week?')<sup>2</sup> are too difficult for aphasics because the syntax of these questions is rather complex. Such a complex syntax asks a lot of a person's memory and concentration which may be impaired in aphasics (Burningham et al., 1997; King et al., 1996). Reading these questions will be problematic for aphasics. Even when these questions are read aloud by a speech therapist, it will be hard to follow such a complex question. That way, retrieving reliable answers is impossible. The QoL-A seems a proper questionnaire for measuring quality of life in aphasics. It is developed especially for aphasics and wants to measure quality of life. However, the QoL-A was never tested for reliability and validity, which makes it unsuitable. Further, it contains 56 items which makes it a very long questionnaire. It takes 45 minutes to fill in the complete questionnaire; therefore it asks a lot of a patient's concentration. As mentioned before, most aphasics have a short concentration span, which makes a shorter questionnaire necessary.

#### Reliability of proxy responses

Sometimes, aphasics are not capable to fill in a questionnaire by themselves. This can for example be due to comprehension deficits. In that case, it will be useful to have a questionnaire which can be filled in by a proxy of the patient.

The reliability of the answers given by proxies is investigated in several studies. However, the outcomes differ. Andresen et al. (2001) investigated responses of several proxies on health related quality of life questionnaires. Healthcare proxies were least reliable (.40), followed by friends (.51). Relatives appeared to be the most reliable (.68). However, this reliability is still low and therefore the authors conclude to be cautious when using proxy respondents for measuring quality of life. Moinpour et al. (2000) looked at the responses on quality of life measures of proxies from cancer patients. Among them were spouses and daughters. There was poor to moderate agreement between the answers of the patients and their proxies: .50. Becchi et al (2004) investigated the quality of life of schizophrenics and looked whether the responses of their proxies were the same. On the physical area, agreement was highest: .41. On the psychological area the agreement was lowest: .29. Novella et al. (2001) compared answers on a health related quality of life measurement of patients with Alzheimer's disease and different proxies. With a maximum of 52% exact agreement it appeared to be not reliable.

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<sup>2</sup> The English translations of the Dutch questions mentioned in this article are added to give the reader an impression of the questions. These translations are not validated and can therefore not be used with English patients.

What they did find is that the partners of the patients are more reliable proxies than children of the patients. These studies show that agreement about the quality of life in patients and their proxies is poor. In most of the cases the quality of life was underestimated by the proxies and the impairment was overestimated.

That proxies are reliable respondents is shown by Varni et al. (2007). They showed that in measuring health related quality of life in children, parents are reliable proxies (.90). Stancliffe (1999) compared answers on the Quality of Life Questionnaire of adults with an intellectual disability and community living staff. They found positive correlations between the consumers and staff and no significant difference between the total scores of the patients and the community living staff.

#### Aim of this study

As mentioned above, the existing questionnaires are not appropriate for stroke patients who are aphasics; they do not focus on communication or their syntax is far too complex to be understood by aphasics. The aim of this study is to develop a suitable Dutch questionnaire that measures the quality of life in aphasics and consists of the smallest number of questions possible. As mentioned before, aphasics show a very complex clinical picture and suffer from several disabilities as a result of their brain damage. Therefore, it is important that the questionnaire focuses on all domains that are important for aphasics, such as communication and mobility. Another aim of this study is that the developed questionnaire is useful for almost all of the aphasics; regardless the type of aphasia, whether they are in-patient or out-patient, or whether it is 2 weeks post onset or 6 months post onset. This way, the questionnaire will be useful for a broad group of patients.

#### General outline of this study

In order to develop a suitable questionnaire, several issues must be taken into account. First, the grammatical form of the questions should be as simple as possible, so the patients will be able to understand the questions. To be sure the patients indeed understand the questions and give therefore reliable answers, there are two criteria for the inclusion of patients. The Stichting Afasie Nederland developed a scale from 1 to 7 to indicate how well a patient is able to communicate (Fleurke et al., 2004). The patients in this study need to have a communication level of 3 or more on this scale. The limiting value of 3 was chosen because at this level, the patient is able to have a conversation with help and is therefore able to

communicate. The second inclusion criterion has to do with the language comprehension of the patients. The Akense Afasie Test (AAT) (Graetz et al., 1987) includes a subtest that measures language comprehension. The score on this subtest must be at least average, for which their rough score needs to be 67 or higher.

Because the questionnaire should be useful for a large group of aphasics, the questions must be neutral according to living situation, e.g.: 'Komt het voor dat u niet goed begrepen wordt?' ('Does it occur that you are misunderstood?') instead of: 'Komt het voor dat u niet goed begrepen wordt in de supermarkt?' ('Does it occur that you are misunderstood in the supermarket?'). The possible answers are divided on a scale from -2 to +2, from very dissatisfied to very satisfied. It is assumed that not all aphasics will be able to rely on numbers because of cognitive deficits. That is why pictures of faces are used to indicate the five possible answers. All the answers of the patients will result in some subscores and a total score. With the subscores it is possible to see on which domains the patient is most unhappy so the therapy can focus on those domains. After the therapy, the questionnaire can be filled in again, and progress can be noticed.

To see whether there is agreement between patient and proxy responses, a proxy version of the questionnaire was made. In this study, the proxy was the partner of the patient, because those proxies proved to be best in assessing the quality of life of the patient (Novella et al., 2001). This proxy version contained the same questions as the questionnaire for the patient only was it directed to the partner of the patient. If partners do give the same answers as the patients, it might be possible to use the proxy version for measuring quality of life in patients who are not able to fill in the questionnaire themselves.

In order to get information about how the patients and partners think about the questionnaire, a short survey was added at the end of the questionnaire. In this survey, they were asked about their opinion about certain features of the questionnaire, such as the difficulty of the questions.

As mentioned before, the definition of quality of life stated by the WHOQoL Group (1994) will be used in this study. This definition is the most complete and defines several domains which are important. The QoL-A also used the definition of quality of life as stated by the WHOQoL Group (1994). The domains used in that questionnaire are the same as the domains the WHO mentions in the definition of quality of life. Because the QoL-A is probably a useful questionnaire, if adjusted, this questionnaire was used to help formulate the questions. Adjustments were made: some questions were removed, others were combined and the



formulation of the questions was adjusted. Further, the option 'not applicable' is not present in the new questionnaire.

This study consists of two stages. In the first stage the QoL-A was adjusted and the questionnaire was filled in for a first group of patients. After statistical analyses and looking at the surveys, the questionnaire was shortened and adjusted so it was ready to be used in the second stage. In this second stage the new questionnaire was filled in for a new group of patients and statistical analyses showed whether or not the questionnaire is reliable.

## **Methods**

As mentioned above, this study consists of two stages. These will be described next.

### Stage 1

#### *Materials*

With the use of the QoL-A questionnaire, a new questionnaire was developed. This was done in cooperation with two speech therapists of rehabilitation centre Groot Klimmendaal in Arnhem. First, a selection was made out of the existing questionnaire QoL-A which is given in Appendix A. Questions 2, 5, 7, 8, 12, 15, 37, 39, 40, 42, 49, 51, 53 and 56 were deleted for different reasons:

Question 2 does not add new information, standing up has to do with the ability to stand and keep your balance. This information is already covered by questions 3 and 6.

Questions 5, 7 and 8 are already covered by question 4 which covers the ability to walk.

Question 12 is covered by question 13 because when someone is not able to eat with fork and knife, he probably is not able to prepare his food.

Questions 15 and 37 are not appropriate for every patient. Patients who are still living in a rehabilitation centre do not do the shopping and not all of them will be confronted with the traffic. Further, the question about traffic is already covered by questions 35, 36 and 38: participation in traffic is dependant on the ability to concentrate, remember and making decisions.

Question 39 is also covered by questions 35, 36 and 38: being able to plan activities depends on concentration, making decisions and memory. So question 39 does not add new information.

Questions 40 and 42 are covered by question 41: when the family home is added to the personal contacts, question 40 does not add something new.

Questions 49 and 51 are covered by question 48 which asks about the ability to make a conversation.

Question 53 is deleted because it was thought that the ability to arrange money does not influence the quality of life.

Question 56 is being covered by the whole domain about independency.

After this selection was made, some of the remaining questions were adjusted or combined:

Questions 3 and 6 are combined, by adding the example about balance in the question about standing both are covered in one question.

In question 4 the example is adjusted: 'walking through the house' is replaced for 'walking through the room'. This way it is suitable for every living situation.

Questions 9, 10 and 11 are combined in one question about personal care, in the examples the three elements are covered: dressing up, wash themselves and going to the toilet.

Question 13 is adjusted: 'Hoe gaat het eten?' (How goes the eating?) became: 'Hoe gaat het eten met mes en vork?' (How goes the eating with fork and knife?) because there is another question about eating, focused on swallowing and chewing.

Question 14 is about the housekeeping. To make this question more suitable for patients who are not living at home, the question is adjusted and focuses on small domestic jobs like dusting or wiping off a table.

Questions 16 and 17 needed to be adjusted because not every patient uses medication or a wheel chair. Because the option 'not applicable' will not be available in this questionnaire, these questions must ask how dependant someone is on medication or help such as a wheel chair. When someone is not dependant on medication or help it is likely that he will be satisfied about this dependency.

Question 18 is adjusted because not every patient will be working. So instead of asking how it goes with their job the question will be how they feel about their work perspective.

Question 21 is adjusted: 'Hoe gaat het met uw ogen' (How are your eyes?) became 'Hoe gaat het met kijken?' (How does it go with looking?). This change was made because question 20, which is about hearing, does not ask for their ears either but asks directly about the hearing.

Questions 23 and 24 are combined in one question about eating. The chewing and swallowing are mentioned as examples.

In question 41 the examples are extended by mentioning the contacts with the family home, family and friends.

In question 48 the examples are extended by mentioning 'being understood'. This way question 49 could be deleted.

The original questionnaire used the scale 'very dissatisfied - dissatisfied - neutral - satisfied - very satisfied' for every question. However, there were several questions where this scale seemed inappropriate, for example questions 28 - 33 about a patient's feelings. A question like 'Heeft u gevoelens van schaamte en wat vindt u hiervan?' (Do you have feelings of shame and what do you think of this?) can not be answered with the scale very dissatisfied - very satisfied. So for the questions 26, 28, 29, 30, 31, 32 and 33, the question is slightly changed and the scale used for the answers is adjusted to 'very unpleasant - unpleasant - neutral - pleasant - very pleasant'. The question to introduce this scale was changed into 'Hoe ervaart u dit?' (How do you experience this?). Because these questions use a different scale, they are placed at the end of the questionnaire instead of their original place in the questionnaire. This way, the change of scale can be introduced and the patient will be less confused.

The original questionnaire used examples and pictures to clarify the questions. The new version of the questionnaire only uses the examples and not the pictures. This decision was made because it was assumed that the pictures will not be necessary to clarify the questions. The examples that are used are clear and the comprehension of the patients is average or above average, which makes it reasonable to assume that the patients will understand the questions and their examples. In the survey, patients can indicate how well they understood the questions. That way it was possible to check whether they really understood the questions.

To indicate the possible answers for the patients, the same faces were used as in the original questionnaire. Because there were two scales that were used in this questionnaire, there were two different sets of faces which will be shown to the patients. These sets are shown in figures 1 and 2.

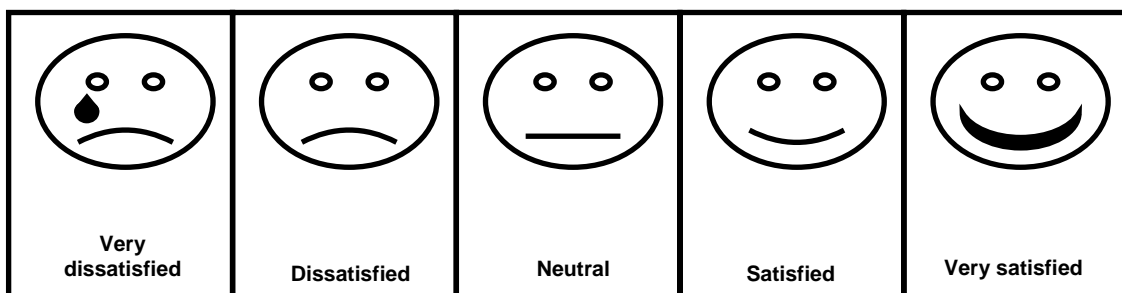


Figure 1: Set of faces to indicate the possible answers on a scale from very dissatisfied to very satisfied. The Dutch version is added in Appendix B.

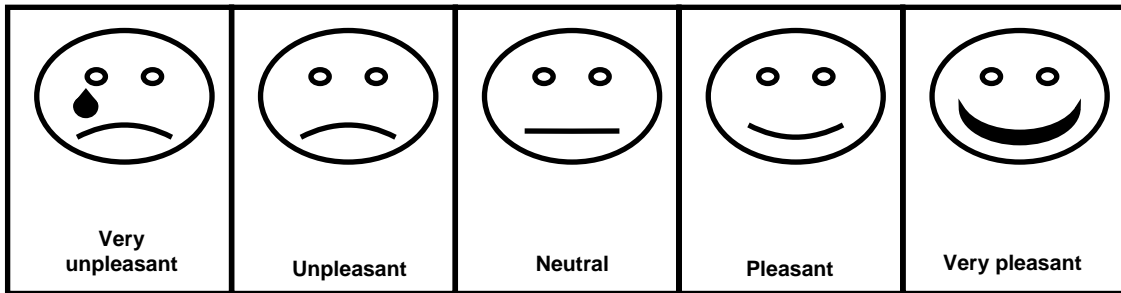


Figure 2: Set of faces to indicate the possible answers on a scale from very unpleasant to very pleasant at all. The Dutch version is added in Appendix C.

Eventually, a questionnaire consisting of 38 questions was developed. Questions 1 to 31 used the set of faces shown in figure 1 and questions 32 to 38 used the set of faces shown in figure 2. This questionnaire is added in Appendix D.

A proxy version of this questionnaire was also developed. This questionnaire contained the same questions, only these questions were directed to the partner of the patient. There were two versions of this proxy questionnaire, one for the partner of a male patient and one for the partner of a female patient.

#### *Participants*

In stage 1 of this study, 35 aphasics participated. Nineteen of them were male, and sixteen were female. Their mean age was 62.2 years (range 41–87). Ten of the aphasics were recruited via rehabilitation centre Groot Klimmendaal in Arnhem, three via the aphasia group in Arnhem, seven via the aphasia centre in Utrecht, fourteen via the aphasia centre in Apeldoorn and one via nursing centre Ragina Pacis in Arnhem. Fifteen of the participants had a Broca's aphasia, twelve had an Anomic aphasia, three had a Wernicke's aphasia and five had a global aphasia with good comprehension. There was no specific screening for the patients to control for a normal spread of aphasia type or living situation. When a patient met the inclusion criteria, he was included in the study regardless their aphasia type or living situation. This was possible because, as mentioned before, this questionnaire will be useable for almost every patient and it does not matter what the living situation or the type of aphasia of the patient is. The only two criteria to include the subjects were their score on the subtest 'language comprehension' of the AAT and their communication level on the Stichting Afasie Nederland Schaal. All subjects scored average or above (rough score 67 and higher) on the subtest 'language comprehension' of the AAT. Their mean score was 88.4 (range 67 – 112). The communication

level of the subjects on the Stichting Afasie Nederland Schaal needed to be 3 or more. The mean communication level was 3.8 (range 3 – 6).

When the patient had a partner, the partner could serve as a proxy and fill in the proxy version of the questionnaire. In this case, 25 of the patients had a partner who was willing to participate in this study.

Before the subjects agreed to participate in this study, they were briefly instructed about the purpose of this study. The subjects and their partners received a letter with further information and a consent form they needed to sign before they could participate in the study.

### *Procedure*

The patient and researcher/speech therapist were seated at a table. A form with the set of faces corresponding to the possible answers was in front of the patient (see figures 1 and 2) in such a way the patient had a clear view on the form. Before the questionnaire began, the procedure was explained to the patients. They were told that the questionnaire consisted of several domains and that they could point to the face that corresponds best with the way they feel about something. The researcher or speech therapist read the questionnaire aloud to every patient, because not every patient was able to read. By reading the questions aloud to all the patients, the conditions were the same for every patient. When a new domain started, this domain was shortly introduced. After question 31, the other set of faces was shown to the patient and it was explained that the scale was slightly different from the one used before. The answers the patient gave were filled in on a scoring form. The partners of the patients filled in their own questionnaire. Before they could fill in the questionnaire, an instruction explained that they needed to answer in such a way they expected their partners to answer.

When the patient or partner completed the questionnaire, some questions were asked about the questionnaire. These questions asked about the difficulty of the questions in the questionnaire, the length of the questionnaire, the faces that were used to indicate the possible answers, the different scales used and about the absence of pictures to clarify the questions. The outcomes of this short survey were taken into account for the improvement of the questionnaire.

### *Analysis*

The answers given by the partners and patients were coded as follows; -2 for very dissatisfied/very unpleasant, -1 for dissatisfied/unpleasant, 0 for neutral, 1 for

satisfied/pleasant, and 2 for very satisfied/very pleasant. In the last set of questions (32–38) some of the patients said to have no feelings of loneliness or shame. When that happened, a score of 2 was assigned for that answer. Cronbach's alpha was used to measure the homogeneity of the questionnaire. The answers of the partners were not included in this analysis. Item-to-Total correlation and Cronbach's alpha if item deleted were used to decide which questions could be removed. Principal Component Analysis was used to see which questions correlate and could possibly be combined to reduce the number of questions.

The answers of the partners were compared with the answers of the patients. The percentage similar answers was calculated.

The outcomes of the surveys the patients and partners completed were taken into account to improve the questionnaire even further.

### *Results stage 1*

#### Homogeneity

Cronbach's alpha was .814 and according to the Item-Total statistics there were 8 questions which would, when deleted, improve the homogeneity. These questions were questions 7, 9, 24, 28, 29, 30, 33, and 36. When looking at the Item-to-Total correlation, it appeared to be that all these questions, except question 36, had a very low Item-to-Total correlation. In table 1 these correlations are shown.

Question	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
Question 7	.074	.816
Question 9	.078	.818
Question 24	.009	.819
Question 28	-.319	.829
Question 29	-.075	.818
Question 30	-.044	.818
Question 33	.042	.821
Question 36	.154	.816

*Table 1: Lowest Item-to-Total Correlations and the Cronbach's Alpha if Item Deleted on the reliability analysis of stage 1.*

According to these results, there are 8 questions which can be deleted because they do not highly correlate with the total score. However, question 36 covered the question about shame,

which was thought to be an important question, and had a slightly higher Item-to-Total correlation. Therefore, 7 questions were deleted. When the Cronbach's alpha was measured without these 7 questions, the homogeneity indeed improved to .855. The question with the highest Item-to-Total correlation was question 22: .672.

#### Principal Component Analysis

The remaining 31 questions were entered into a Principal Component Analysis (Jolliffe, 1986). This analysis resulted in several components of questions. Component 1 contained questions 10, 11, 12, 14, 16, 17, 18, 19, 20, 21, 22, 31, 32, 34, 35, and 37. Component 2 contained questions 1, 2, 3, 4, and 5. Component 3 contained questions 23, 25, 26, and 27. Questions 6, 8, 13, 15, 36 and 38 were spread among 6 other components, so each of these 6 other components contained one of these questions. When looking briefly at these questions, it was decided to delete question 4 about the dependency on some form of help, such as a wheel chair. Question 1 felt in the same cluster and asks about the ability to walk, so it seemed reasonable to assume that this question covered the same concept. The Inter-Item correlation between question 1 and 4 was .596. When a new Cronbach's alpha is being measured without question 4, the homogeneity improved to .856.

There were also two questions which would not influence the homogeneity when they were deleted. The Cronbach's alpha would remain .814 when questions 5 and 15 would be removed. Because one of the aims of this study was to get a questionnaire with as few questions as possible, Cronbach's alpha was measured with these two questions deleted. The homogeneity turned out to be improved to .858.

#### Comparison answers patient and partner

When the answers of the patients and their partners were compared, it appeared that giving the exact same answers is uncommon: an average of 40% identical answers with a range from 21, 1% to 60,5% is rather low. To see whether this agreement improved when there was only checked for the positivity and negativity of an answer, the -2 and -1 answers and the +1 and +2 answers were combined. This means that when the patient gave a -2 answer and the partner a -1 answer, this was still correct. In that case, there was a larger percentage of identical answers: 62% (range: 39,5%-81,6%). The total scores were also compared; none of the total scores were alike and calculation showed that 65,4% of the partners gave a lower

total score than the patients. The other 34,6% gave a higher total score than their aphasic partners.

#### Outcome surveys

Patients and partners were asked for their opinion about the questionnaire in a short survey, following the questionnaire. This survey asked about several topics to improve the questionnaire. First it was asked if the questions were clear enough and not too hard to understand. None of the patients said to have problems with the difficulty of the questions. However, there were a couple of questions which were not clear enough according to some of the partners: questions 4, 8, 29, 30, 32, 33, 34, 35, 36, 37. Next, the length of the questionnaire was being discussed. There were only a few patients and partners who found the questionnaire too long. When the patients and partners were asked if there were questions which were not appropriate, almost everyone answered 'no'. However, there was a patient who found the questions about mobility inappropriate, one of the partners found question 29 not appropriate ('what to do when you are not spiritual?'), and one of the partners thought that question 22 was not relevant for the quality of life. The patients thought the faces used to indicate the possible answers were clear enough. The last question of the survey was about the used scales. Some of the partners and patients indicated that the used scales were not appropriate in some of the questions, especially when some topic did not apply to the patient, for example questions 9 and 29. The patients were asked whether pictures would have helped to clarify the questions. The majority of the patients said that pictures are not necessary (75%).

#### Stage 2

With the results from the first stage of this study, it was possible to further adjust the questionnaire. How the questionnaire was adjusted and tested in stage 2, is described next.

#### *Materials*

The statistical analysis of stage 1 suggested that there are 10 questions which may be deleted from the questionnaire, without negatively affecting the homogeneity. The homogeneity would even improve if questions 4, 5, 7, 9, 15, 24, 28, 29, 30, and 33 are deleted. Some of these questions were mentioned in the surveys as 'causing some trouble' while filling in the questionnaire. Because of the statistical analysis these problematic questions could be deleted. One of the partners said that question 22 is not relevant for the quality of life. However, this



question was not deleted from the questionnaire because it had the highest Item-to-Total correlation of all questions: .672.

Taking into account the other outcomes of the surveys, where the scale of questions 32 – 37 is being criticized, that scale is adjusted. For these questions, a yes/no answer will be more appropriate. When someone answers 'yes', and thus is experiencing anger or sadness, he can indicate how he is experiencing this anger or sadness. Question 8 was slightly adjusted and added to the last scale. This way a patient can first indicate whether he needs medication and then how he is experiencing this. Because the majority of the patients did not find pictures necessary, there were no pictures in this version of the questionnaire.

This results in a questionnaire which contains 28 questions, 21 of which have the scale very dissatisfied – very satisfied. The other 7 questions have a 'yes/no' answer and in the case of 'yes', they have a scale from very unpleasant – very pleasant.

Just as in the first stage, a proxy version of the questionnaire was made. At the end of the questionnaire, the same short survey as used in the first stage was added.

The questionnaire that was used for the second stage is added in Appendix E.

### *Participants*

Because of practical reasons, only 7 patients participated in the second stage of this study. These participants were different patients than the ones that participated in the first stage of this study. Three of them were female and four were male. Their mean age was 59 years (range: 52–65) and their mean score on the language comprehension task was 78 (range: 67–89). These patients also needed to have a communication level of at least 3 on the SAN-Scale; their mean communication level was 4, with a range from 3 to 5. Three of the patients had a Broca's aphasia, two had an Anomic aphasia and one had a Wernicke's aphasia. One of the patients was diagnosed as having dysarthria. This patient was still included in the study because he experiences the same problems as patients with aphasia: disturbed communication. Five of the participants in the second stage of this study were recruited via an activity centre in Rheden. Two of the participants were recruited via rehabilitation centre Groot Klimmendaal in Arnhem. Again, there was no specific screening for the patients to control for a normal spread of aphasia type or living situation, because of the reasons mentioned before. Four of the patients had a partner who was willing to serve as a proxy in this study and therefore filled in the proxy version of the questionnaire.

Again, a letter with supplementary information was given to the subjects and their partners, and they needed to sign a consent form to participate in the second stage of this study.

### *Procedure*

The procedure of the second stage was the same as the procedure of the first stage of this study. Again, partners of the patients were asked to fill in a questionnaire about their partner and their opinion was being asked through a short survey.

### *Analysis*

The given answers were coded from -2 to +2. When a patient said 'no' to one of the last 7 questions, the answer was coded as +2 because it was a positive answer. Reliability analysis was performed to discover the Cronbach's alpha of the second questionnaire. The answers of the patients and their partners were compared and the outcomes of the surveys were being taken into account.

### *Results stage 2*

#### Homogeneity

The Cronbach's alpha of the second version of the questionnaire was .846. According to the Item-to-Total statistics, there were no questions which needed to be deleted.

#### Comparison answers patient and partner

In the second stage 36,2% of the answers were exactly the same. When the percentage of the same positive and negative answers was being measured, this percentage did not improve much: 45,5%. The total scores differed: 75% of the partners gave a lower total score than their partner and 25 percent gave a higher total score.

#### Outcome surveys

None of the patients had complaints about the questionnaire. One of the partners said that she missed some questions about activities outside the house and about the activity centre her husband is visiting regularly.

## Discussion

The most important outcome of this study is the high homogeneity of the questionnaire. After the first stage the Cronbach's alpha was .814 and after the second stage it was .846. While looking at this last Cronbach's alpha, it has to be considered that the second stage only used 7 participants. Because of this small amount of subjects, conclusions must be drawn with care. However, the homogeneity after the first stage of this study was already very high what makes it reasonable to assume that the final version of the questionnaire will be homogeneous as well. In order to check for this, it will be useful to repeat the second stage of this study with a greater amount of subjects.

When looking at the agreement between the answers partners and patients gave, it must be concluded that this agreement is very low. A total of 66,7% of the partners gave a lower score than the patient and 33,3% of the partners gave a higher score than the patient. So the majority of the partners thought that their aphasic partner experiences a lower quality of life than the patient actually does. This would suggest that partners are not able to estimate the quality of life of their aphasic partner. A consequence of this disagreement is that it is not possible to give the partner a questionnaire when the patient is not able to fill it in himself. The questionnaire developed in this study can only be used with patients who have at least an average language comprehension and a communication level of at least 3 on the Stichting Afasie Nederland Schaal. Outcomes will not be reliable when this questionnaire is used with patients who do not meet these criteria.

Another explanation for the disagreement between the answers of the patients and their partners could be that the patients were not able to understand the questions. As a result, the answers would be unreliable. However, at the beginning of this study it was assumed that the patients would be able to understand the questions of the questionnaire because of their (at least) average language comprehension. To make sure this was true, patients were asked about their opinion about the difficulty of the questions. The patients said in the survey that they had no difficulties with understanding the questions. According to this, it still can be concluded that the patients were able to understand the questions which resulted in reliable answers. Therefore, it seems more reasonable to assume that partners are indeed not able to estimate the quality of life of their aphasic partner.

The validity of this questionnaire has not yet been officially checked. Unfortunately, in this case it is not possible to use the normal measure to check for validity: using another questionnaire which measures quality of life next to the developed questionnaire and compare

both outcomes. As mentioned before, the existing questionnaires are not suitable to use with aphasics and will therefore give no reliable outcomes. One possible method to check for validity of this questionnaire is adding one question to the questionnaire: 'How would you rate your quality of life on a scale from one to ten?' That rating can then be compared with the total score of the questionnaire. However, when using this method it must be clear whether the cognitive abilities of the patient are sufficient enough to use numbers as a scale. Another point that needs consideration is the location of the question in the questionnaire. It can be placed at the beginning or at the end of the questionnaire. When the question is asked at the end, it is possible that the rating will be lower than when the question is asked at the beginning of the questionnaire; the other 28 questions in the questionnaire can have a huge impact on the patient what may cause a lower rate. Another possible method to check for validity of this questionnaire may be asking for the opinion of speech therapists and psychologists. Both groups see a lot of different patients and are familiar with the term quality of life. By letting two large groups of speech therapists and psychologists judge the questionnaire on its ability to measure quality of life, it may be possible to check for its validity. Even though this questionnaire is not officially checked for validity, it is assumed that it is valid. The questionnaire contains several domains: level of independence, physical health, psychological health, social relations, communication, and relations with notable features in the environment. These domains correspond with the domains The WHOQoL Group (1994) mention in their definition of quality of life. This means that all issues which are important to determine someone's quality of life according to the definition of The WHOQoL Group (1994) are included in the questionnaire developed in this study. As a result, it could be concluded that this questionnaire does measure quality of life.

The external validity of this questionnaire is rather high. To check for its reliability, a diverse group of patients was used in this study; different types of aphasia, different living situations and different ages. Further, the patients were recruited from six organizations, all with a different purpose; in Groot Klimmendaal the patients are still rehabilitating while in the activity centers, patients can practice their hobbies. Because this study used such a diverse group of patients, it seems reasonable to assume that the results of this study are generalizable.

During this study, it was observed that some patients said not to feel sad, lonely, ashamed, anxious, angry or impotent while others said they do have these feelings. This observation led to the question: what makes someone feel that way? It is possible that patients without a

partner have more feelings of loneliness than patients with a partner or that patients who are living at home feel more helpless than patients who are living in a rehabilitation centre or nursing home. To see how these conditions affect the patients' feelings, percentages were calculated for each situation. The most prominent result was the fact that almost every patient felt impotent (81% of all patients). When someone had a partner, this feeling of impotence was slightly higher than when someone had no partner: 83,9% versus 72,7%. Patients who were living at home felt more impotent than patients living in a rehabilitation centre or nursing home: 82,8% versus 76,9%. The fact that these patients felt more impotent when they are living at home may be caused by the environment. In a rehabilitation centre, everyone around the patient knows about the disability and staff of the centre knows how to deal with that disability. At home, the patient is back in society again and needs to deal with people who do not understand the disability.

Another notable result is the small amount of patients who said to have feelings of shame: 33,3% of all subjects. The fact that someone has a partner or is living at home made no difference. It seems that most of the patients do realize they have no reason to feel ashamed, which is positive.

When looking at feelings of loneliness, another remarkable result appeared. Patients who do have a partner felt more alone than patients who do not have a partner: 54,8% versus 36,4%. The living situation also played a role in feeling lonely: 53,8% of the patients who live in a rehabilitation centre said to feel alone, while 48,3% of the patients who live at home said to feel lonely. In this case, it could be that the combination of having a partner and living at a rehabilitation centre causes the most feelings of loneliness. Therefore, percentages were calculated for patients who have a partner and live at home (52,4% said to feel lonely), for patients who do not have a partner and live at home (37,5% said to feel lonely), for patients who do have a partner and live in a rehabilitation centre (60% said to feel lonely), and for patients who do not have a partner and live in a rehabilitation centre (33,3% said to feel lonely). This shows that the combination of having a partner and living in a rehabilitation centre causes the most feelings of loneliness. This seems a reasonable outcome; patients who are living in a rehabilitation centre are going through a very difficult time in their lives. Not being able to spend day and night with the person you love in this difficult time can cause feelings of loneliness.

The last notable result is the number of patients who experienced feelings of sadness: 61,9% of all patients said to feel sad. Having a partner or not did not have a large influence: 61,3%

versus 63,6% . The living situation of the patient, however, did have a large influence: 75,9% of the patients who are living at home said to have feelings of sadness while only 30,8% of the patients who are living in a rehabilitation centre said to have feelings of sadness. An explanation for this outcome may be that patients who are living in a rehabilitation centre are working on their progress and they still have a chance to improve their situation. This may give them hope that things still can get better. When someone is living at home, the progress often has reached a top and the state they are in is probably the best state they will be in. Realizing that the chance of improvement is getting smaller can cause feelings of sadness. The result that having a partner has no effect on feelings of sadness seems a strange outcome. One would expect that feelings of sadness would occur more in patients who do not have a partner because maybe loneliness can cause sadness. But on the other hand, the patients without a partner were already alone before they got aphasia, so maybe having no partner does not contribute to the feelings of sadness they are experiencing because of the aphasia.

The questionnaire developed for the second stage of this study will be the final version of the questionnaire. This means that the outcomes of the last surveys will not be used to adjust the questionnaire. This is possible because the questions that were said to be missed are not appropriate for this questionnaire. Asking about activities outside the house or an activity centre is not suitable for every patient. Activities are being covered by the question about the patient's hobbies. This final version can be used to further test for reliability and validity.

## **Conclusion**

A Dutch questionnaire which measures the quality of life in aphasics was developed in this study. With 28 questions covering six important domains, an average duration of 15 minutes and a Cronbach's alpha of .846, it is suitable to use with aphasic patients. A total score between -56 and +56 will give an indication of the quality of life of a patient and in each domain, a subscore can be calculated.

After its reliability and validity are further checked, this questionnaire is ready to be used.

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Appendix A: The Quality of Life and Aphasia (QoL-A)

Domein niveau van onafhankelijkheid			
	n.v.t	erg ontevreden ⊗	erg tevreden ☺
<b>Beleving van mobiliteit:</b>  1. Hoe gaat het met zitten? <i>Bijvoorbeeld het zitten op een stoel of op een bank.</i> Hoe tevreden bent u hierover? ..... .....	0	_ _ _ _	_ _ _ _
2. Hoe gaat het opstaan? <i>Bijvoorbeeld als u gaat staan of als u uit een stoel omhoog komt.</i> Hoe tevreden bent u hierover? ..... .....	0	_ _ _ _	_ _ _ _
3. Hoe gaat het staan? <i>Bijvoorbeeld als u in een rij staat of als u staat te wachten op de lift of op de bus.</i> Hoe tevreden bent u hierover? ..... .....	0	_ _ _ _	_ _ _ _
4. Hoe gaat het lopen? <i>Bent u goed ter been? Kunt u goed lopen, bijvoorbeeld door uw huis?</i> Hoe tevreden bent u hierover? ..... .....	0	_ _ _ _	_ _ _ _
5. Hoe gaat het traplopen? <i>Bijvoorbeeld uw trap thuis of een opstapje van een paar treden?</i> Hoe tevreden bent u hierover? ..... .....	0	_ _ _ _	_ _ _ _
6. Hoe gaat het met het bewaren van uw evenwicht? <i>Kunt u rechtop blijven staan? Wankelt u veel, bijvoorbeeld als u iets pakt of moet bukken?</i> Hoe tevreden bent u hierover? ..... .....	0	_ _ _ _	_ _ _ _
7. Hoe gaat het met het verplaatsen binnenshuis? <i>Bijvoorbeeld het verplaatsen van de keuken naar de kamer, van boven naar beneden of van de bank naar de deur.</i> Hoe tevreden bent u hierover?	0	_ _ _ _	_ _ _ _

<p>8. Hoe gaat het met het verplaatsen buitenshuis?  <i>Bijvoorbeeld het verplaatsen naar de winkel, naar de burens, met de auto of bus/trein.</i>  Hoe tevreden bent u hierover?  .....  .....</p>	<p>0</p>	<p> _ _ _ _ _ _ _ _ _ </p>
<p><b>Beleving van ADL:</b></p>		
<p>9. Hoe gaat het met het bezoek aan het toilet?  <i>Bijvoorbeeld met uitkleden, gaan zitten op het toilet en opstaan van het toilet.</i>  Hoe tevreden bent u hierover?  .....  .....</p>	<p>0</p>	<p> _ _ _ _ _ _ _ _ _ </p>
<p>10. Hoe gaat het wassen van uzelf?  <i>Bijvoorbeeld het wassen van uw gezicht, handen of benen.</i>  Hoe tevreden bent u hierover?  .....  .....</p>	<p>0</p>	<p> _ _ _ _ _ _ _ _ _ </p>
<p>11. Hoe gaat het aankleden?  <i>Bijvoorbeeld het aantrekken van een trui, broek, jas of sokken.</i>  Hoe tevreden bent u hierover?  .....  .....</p>	<p>0</p>	<p> _ _ _ _ _ _ _ _ _ </p>
<p>12. Hoe gaat het klaarmaken van het eten?  <i>Bijvoorbeeld het smeren van uw brood, het bakken van vlees of het koken van groente.</i>  Hoe tevreden bent u hierover?  .....  .....</p>	<p>0</p>	<p> _ _ _ _ _ _ _ _ _ </p>
<p>13. Hoe gaat het eten?  <i>Bijvoorbeeld het eten met mes, vork en lepel.</i>  Hoe tevreden bent u hierover?  .....  .....</p>	<p>0</p>	<p> _ _ _ _ _ _ _ _ _ </p>
<p>14. Hoe gaat het met het huishouden?  <i>Bijvoorbeeld het afwassen, stofzuigen, afstoffen of dweilen.</i>  Hoe tevreden bent u hierover?  .....  .....</p>	<p>0</p>	<p> _ _ _ _ _ _ _ _ _ </p>
<p>15. Hoe gaat het boodschappen doen?  <i>Kunt u dingen kopen, bijvoorbeeld eten?</i>  Hoe tevreden bent u hierover?</p>	<p>0</p>	<p> _ _ _ _ _ _ _ _ _ </p>

<b>Beleving van afhankelijkheid van medicijnen en medische hulpmiddelen:</b>		
16. Hoe gaat het met het gebruik van uw medicijnen? <i>Bijvoorbeeld de werking van uw pillen, het aantal in te nemen pillen en de manier waarop u het medicijn tot u neemt.</i> Hoe tevreden bent u hierover? ..... .....	0	_ _ _ _
17. Hoe gaat het met het gebruik van uw hulpmiddel? <i>Bijvoorbeeld uw rollator, rolstoel of stok.</i> Hoe tevreden bent u hierover? ..... .....	0	_ _ _ _
<b>Beleving van werk:</b>		
18. Hoe gaat het met uw werk? <i>Bijvoorbeeld uw werk als kapper, leraar of chauffeur.</i> Hoe tevreden bent u hierover? ..... .....	0	_ _ _ _
<b>Domein fysieke gezondheid</b>		
<b>Beleving van energie en vermoeidheid:</b>	<b>n.v.t</b>	erg ontevreden      erg tevreden
19. Hoe gaat het met uw energie? <i>Bijvoorbeeld bent u vaak moe? Heeft u voldoende puf? Bent u fit genoeg?</i> Hoe tevreden bent u hierover? ..... .....	0	☹      ☺  _ _ _ _
<b>Beleving van pijn en ongemak:</b>		
20. Hoe gaat het met uw gehoor? <i>Kunt u goed horen? Kunt u goed verstaan, bijvoorbeeld tijdens het luisteren naar de radio of als u met iemand praat of belt?</i> Hoe tevreden bent u hierover? ..... .....	0	_ _ _ _
21. Hoe gaat het met uw ogen? <i>Kunt u goed zien? Kunt u goed kijken? Bijvoorbeeld naar de televisie of de mensen om u heen?</i> Hoe tevreden bent u hierover? ..... .....	0	_ _ _ _

<p>22. Hoe gaat het met uw eetlust?  <i>Heeft u trek of zin in eten?</i>  Hoe tevreden bent u hierover?  .....  .....</p> <p>23. Hoe gaat het kauwen?  <i>Kunt u het eten goed fijn kauwen?</i>  Hoe tevreden bent u hierover?  .....  .....</p> <p>24. Hoe gaat het slikken?  <i>Verslikt u zich?</i>  Hoe tevreden bent u hierover?  .....  .....</p> <p>25. Hoe gaat het met uw controle over uw blaas en darmen?  <i>Kunt u uw urine en ontlasting ophouden.</i>  Hoe tevreden bent u hierover?  .....  .....</p> <p>26. Heeft u pijn tijdens dagelijkse activiteiten?  <i>Heeft u pijn overdag, bijvoorbeeld tijdens het huishouden, koken of boodschappen doen?</i>  Hoe tevreden bent u hierover?  .....  .....</p>	<p>0</p> <p>0</p> <p>0</p> <p>0</p> <p>0</p>	<p> _ _ _ _ </p> <p> _ _ _ _ </p> <p> _ _ _ _ </p> <p> _ _ _ _ </p> <p> _ _ _ _ </p>
<p><b>Beleving van slapen en rusten:</b></p> <p>27. Hoe gaat het slapen?  <i>Kunt u doorslapen? Kunt u goed in slaap vallen? Bent u goed uitgerust na het slapen?</i>  Hoe tevreden bent u hierover?  .....  .....</p>	<p>0</p>	<p> _ _ _ _ </p>

<b>Domein psychologische toestand</b>		
<p><b>Beleving van gevoelens:</b></p> <p>28. Heeft u gevoelens van verdriet?  <i>Heeft u gevoelens van bedroefdheid of treurigheid?</i>  Wat vindt u hiervan?  .....</p>	<p>n.v.t</p> <p>0</p>	<p>erg ontevreden                      erg tevreden</p> <p>☹    ☺</p> <p> _ _ _ _ </p>

<p>29. Heeft u gevoelens van angst?  <i>Heeft u gevoelens van ongerustheid of bezorgdheid?</i>  <i>Bent u vaak bang?</i>            Wat vindt u hiervan?            .....            .....</p> <p>30. Heeft u gevoelens van boosheid?  <i>Heeft u gevoelens van kwaadheid of woede?</i>            Wat vindt u hiervan?            .....            .....</p> <p>31. Heeft u gevoelens van eenzaamheid?  <i>Voelt u zich alleen? Voelt u zich eenzaam?</i>            Wat vindt u hiervan?            .....            .....</p> <p>32. Heeft u gevoelens van schaamte?  <i>Schaamt u zich wel eens voor anderen?</i>            Wat vindt u hiervan?            .....            .....</p> <p>33. Heeft u gevoelens van machteloosheid?  <i>Heeft u wel eens het gevoel dat u het niet meer in de hand heeft? Heeft u gevoelens van onmacht?</i>            Wat vindt u hiervan?            .....            .....</p>	<p>0</p> <p>0</p> <p>0</p> <p>0</p> <p>0</p>	<p> _ _ _ _ </p> <p> _ _ _ _ </p> <p> _ _ _ _ </p> <p> _ _ _ _ </p> <p> _ _ _ _ </p>
<p><b>Beleving van zelfvertrouwen:</b></p> <p>34. Hoe is het met uw zelfvertrouwen?  <i>Bent u zeker van uzelf?</i>            Hoe tevreden bent u hierover?            .....            .....</p>	<p>0</p>	<p> _ _ _ _ </p>
<p><b>Beleving van denken, leren, geheugen en concentratie:</b></p> <p>35. Hoe gaat het met uw concentratie?  <i>Kunt u uw aandacht of gedachten bij één onderwerp houden?</i>            Hoe tevreden bent u hierover?            .....            .....</p>	<p>0</p>	<p> _ _ _ _ </p>

<p>36. Hoe is het met uw geheugen?  <i>Kunt u dingen onthouden?</i>  Hoe tevreden bent u hierover?</p> <p>.....</p> <p>.....</p>	0	_ _ _ _
<p>37. Hoe gaat het met uw deelname aan het verkeer?  <i>Kunt u verkeerssituaties overzien? Kunt u zich veilig in het verkeer begeven? Kunt u veilig oversteken?</i>  Hoe tevreden bent u hierover?</p> <p>.....</p> <p>.....</p>	0	_ _ _ _
<p>38. Hoe gaat het nemen van beslissingen?  <i>Kunt u goed beslissingen nemen? Bijvoorbeeld over wat u wilt eten, lezen of aantrekken?</i>  Hoe tevreden bent u hierover?</p> <p>.....</p> <p>.....</p>	0	_ _ _ _
<p>39. Hoe gaat het met het plannen van uw werkzaamheden?  <i>Bijvoorbeeld met het plannen van uw activiteiten of afspraken op een dag?</i>  Hoe tevreden bent u hierover?</p> <p>.....</p> <p>.....</p>	0	_ _ _ _

<b>Domein sociale relaties</b>		
	n.v.t	<div style="display: flex; justify-content: space-between;"> <span>erg ontevreden</span> <span>erg tevreden</span> </div> <div style="display: flex; justify-content: space-between; margin-top: 5px;"> <span>☹</span> <span>☺</span> </div>
<p><b>Beleving van persoonlijke relaties:</b></p> <p>40. Wat vindt u van uw rol binnen uw gezin?  <i>Voelt u zich op uw plaats binnen uw gezin?</i>  Hoe tevreden bent u hierover?</p> <p>.....</p> <p>.....</p>	0	_ _ _ _
<p>41. Wat vindt u van uw persoonlijke contacten?  <i>Voelt u zich op uw gemak bij uw vrienden? Heeft u contact met anderen?</i>  Hoe tevreden bent u hierover?</p> <p>.....</p> <p>.....</p>	0	_ _ _ _



<p><b>Beleving van sociale steun:</b></p> <p>42. Wat vindt u van de steun van uw omgeving?</p> <p><i>Heeft u veel steun aan uw familie en vrienden? Krijgt u veel hulp van uw familie en vrienden? Hoe tevreden bent u hierover?</i></p> <p>.....</p> <p>.....</p>	0	<p> _ _ _ _ </p>
<p><b>Beleving van seksuele activiteit:</b></p> <p>43. Wat vindt u van uw seksuele leven?</p> <p><i>Hoe gaat het vrijen? Bent u tevreden over uw intimiteit? Hoe tevreden bent u hierover?</i></p> <p>.....</p> <p>.....</p>	0	<p> _ _ _ _ </p>

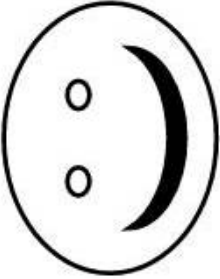
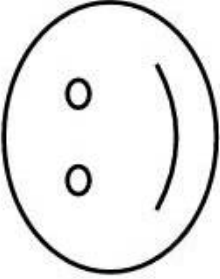
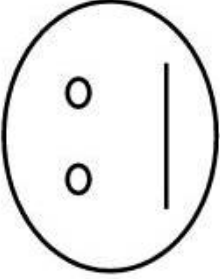
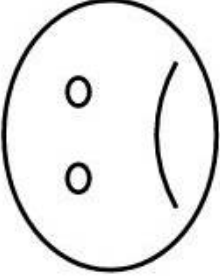

<b>Domein communicatie</b>		
	n.v.t	<div style="display: flex; justify-content: space-between;"> <span>erg ontevreden</span> <span>erg tevreden</span> </div> <div style="display: flex; justify-content: space-between; align-items: center;"> <span>☹</span> <span>☺</span> </div>
<p><b>Beleving van receptieve vaardigheden:</b></p> <p>44. Hoe gaat het met het begrijpen van anderen?</p> <p><i>Begrijpt u het als iemand iets tegen u zegt of als u televisie kijkt? Hoe tevreden bent u hierover?</i></p> <p>.....</p> <p>.....</p>	0	<p> _ _ _ _ </p>
<p>45. Hoe gaat het lezen?</p> <p><i>Bijvoorbeeld het lezen van de krant, een boek, een brief of de ondertiteling op de televisie? Hoe tevreden bent u hierover?</i></p> <p>.....</p> <p>.....</p>	0	<p> _ _ _ _ </p>
<p><b>Beleving van productieve vaardigheden:</b></p> <p>46. Hoe gaat het praten?</p> <p><i>Hoe gaat het spreken? Kunt u woorden en/of zinnen zeggen? Verstaan anderen u? Hoe tevreden bent u hierover?</i></p> <p>.....</p> <p>47. Hoe gaat het contact leggen met anderen?</p> <p><i>Kunt u makkelijk contact maken met andere mensen? Hoe tevreden bent u hierover?</i></p> <p>.....</p>	0	<p> _ _ _ _ </p> <p> _ _ _ _ </p>

<p>48. Hoe gaat het met het voeren van een gesprek?  <i>Kunt u een praatje maken met iemand? Hoe gaat het praten in een groep, bijvoorbeeld tijdens een verjaardag?</i></p> <p>Hoe tevreden bent u hierover?  .....  .....</p>	0	_ _ _ _ _
<p>49. Kunnen anderen u goed begrijpen?  <i>Kunt u zich duidelijk maken bij anderen?</i></p> <p>Hoe tevreden bent u hierover?  .....  .....</p>	0	_ _ _ _ _
<p>50. Hoe gaat het met het schrijven?  <i>Bijvoorbeeld met het schrijven van een brief(je) of een boodschappenlijstje?</i></p> <p>Hoe tevreden bent u hierover?  .....  .....</p>	0	_ _ _ _ _
<p>51. Hoe gaat het met telefoneren?  <i>Hoe gaat het bellen met iemand?</i></p> <p>Hoe tevreden bent u hierover?  .....  .....</p>	0	_ _ _ _ _

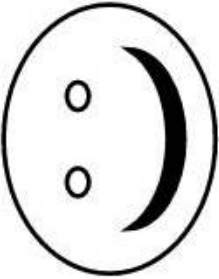
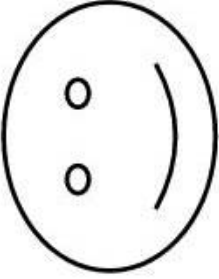
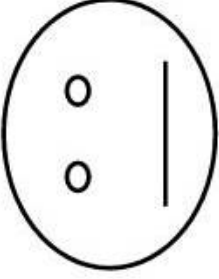
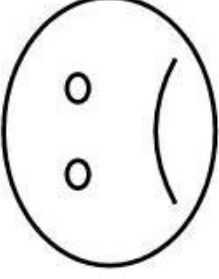

<b>Domein persoonlijke overtuiging</b>		
	n.v.t	erg ontevreden                      erg tevreden
<b>Beleving van religie, spiritualiteit en levensovertuigingen:</b>		⊗    ☺
<p>52. Heeft u steun aan uw levensovertuiging?  <i>Heeft u veel aan het bidden, uw geloof of het naar de kerk/synagoge/moskee gaan.</i></p> <p>Hoe tevreden bent u hierover?  .....  .....</p>	0	_ _ _ _ _

Domein relaties met opvallende kenmerken in de omgeving			
	n.v.t	erg ontevreden	erg tevreden
<p><b>Beleving van financiële middelen:</b></p> <p>53. Hoe gaat het met het regelen van uw geldzaken?  <i>Bijvoorbeeld met het betalen in de winkel, pinnen, geld storten of rekeningen betalen.</i></p> <p>Hoe tevreden bent u hierover?  .....  .....</p>	0	⊗	☺
<p><b>Beleving van gezondheid en sociale zorg: kwaliteit:</b></p> <p>54. Wat vindt u van de gegeven zorg?  <i>Bijvoorbeeld fysiotherapie, ergotherapie, logopedie of de verpleging.</i></p> <p>Hoe tevreden bent u hierover?  .....  .....</p>	0	_ _ _ _	
<p><b>Beleving van deelname aan en mogelijkheden voor recreatie/vrije tijd:</b></p> <p>55. Hoe gaat het met het uitoefenen van uw hobby's?  <i>Bijvoorbeeld spelletjes spelen, schilderen, handwerken, lezen of tuinieren.</i></p> <p>Hoe tevreden bent u hierover?  .....  .....</p>	0	_ _ _ _	
<p><b>Beleving van afhankelijkheid:</b></p> <p>56. Wat vindt u er van om afhankelijk te zijn van anderen?  <i>Bijvoorbeeld dat een ander u moet wassen of aankleden.</i></p> <p>Hoe tevreden bent u hierover?  .....  .....</p>	0	_ _ _ _	

Appendix B: Form used to indicate the possible answers very dissatisfied - very satisfied

	erg tevreden
	tevreden
	neutraal
	ontevreden
	erg ontevreden

Appendix C: Form used to indicate the possible answers very unpleasant - very pleasant

	helemaal niet vervelend
	niet vervelend
	neutraal
	vervelend
	erg vervelend

Appendix D: The questionnaire used in the first stage of this study

Vragen bij antwoordformulier 1	erg ontevreden	erg tevreden
<b><u>Domein niveau van onafhankelijkheid</u></b>		
<b>Beleving van mobiliteit:</b>	☹	☺
1. Hoe gaat het lopen? <i>(Bent u goed ter been? Kunt u goed lopen, bijvoorbeeld door de kamer?)</i> Hoe tevreden bent u hierover?	_ _ _ _	_ _ _ _
2. Hoe gaat het staan? <i>(Kunt u uw evenwicht bewaren? Kunt u rechtop blijven staan?)</i> Hoe tevreden bent u hierover?	_ _ _ _	_ _ _ _
3. Hoe gaat het met zitten? <i>(Bijvoorbeeld het zitten op een stoel of op een bank)</i> Hoe tevreden bent u hierover?	_ _ _ _	_ _ _ _
4. Hoe afhankelijk bent u van een hulpmiddel? <i>(Bijvoorbeeld een rollator, rolstoel of stok)</i> Hoe tevreden bent u hierover?	_ _ _ _	_ _ _ _
<b>Beleving van ADL</b>		
5. Hoe gaat het met uw persoonlijke verzorging? <i>(Bijvoorbeeld wassen, aankleden en naar het toilet)</i> Hoe tevreden bent u hierover?	_ _ _ _	_ _ _ _
6. Hoe gaat het eten met mes en vork? Hoe tevreden bent u hierover?	_ _ _ _	_ _ _ _
7. Hoe gaat het met lichte huishoudelijke klusjes? <i>(Bijvoorbeeld afstoffen of de tafel afnemen)</i> Hoe tevreden bent u hierover?	_ _ _ _	_ _ _ _

<b>Beleving van afhankelijkheid van medicijnen</b>	erg ontevreden	erg tevreden
<p>8. Hoe afhankelijk bent u van medicijnen? <i>(Heeft u medicijnen nodig?)</i> Hoe tevreden bent u hierover?</p>	☹	☺
	_ _ _ _	
<b>Beleving van werk</b>		
<p>9. Hoe ziet u uw werktoekomst? Hoe tevreden bent u hierover?</p>		
	_ _ _ _	
<b><u>Domein fysieke gezondheid</u></b>		
<b>Beleving van energie en vermoeidheid</b>		
<p>10. Hoe gaat het met uw energie? <i>(Bent u vaak moe, heeft u voldoende puf?)</i> Hoe tevreden bent u hierover?</p>		
	_ _ _ _	
<b>Beleving van pijn en ongemak</b>		
<p>11. Hoe gaat het met uw gehoor? <i>(Kunt u goed horen? Kunt u goed verstaan, bijvoorbeeld tijdens het luisteren naar de radio of als u met iemand praat of belt?)</i> Hoe tevreden bent u hierover?</p>		
	_ _ _ _	
<p>12. Hoe gaat het met kijken? <i>(Kunt u goed zien? Kunt u goed kijken, bijvoorbeeld naar de televisie of de mensen om u heen?)</i> Hoe tevreden bent u hierover?</p>		
	_ _ _ _	
<p>13. Hoe gaat het met uw eetlust? <i>(Heeft u trek of zin in eten?)</i> Hoe tevreden bent u hierover?</p>		
	_ _ _ _	

	erg ontevreden					erg tevreden
<p>14. Hoe gaat het eten? (<i>Bijvoorbeeld het slikken en het kauwen?</i>) Hoe tevreden bent u hierover?</p>	☹					☺
<p>15. Hoe gaat het met uw controle over uw blaas en darmen? (<i>Kunt u uw urine en ontlasting ophouden?</i>) Hoe tevreden bent u hierover?</p>						
<b>Beleving van slapen en rusten</b>						
<p>16. Hoe gaat het slapen? (<i>Kunt u doorslapen? Kunt u goed in slaap vallen? Bent u goed uitgerust na het slapen?</i>) Hoe tevreden bent u hierover?</p>						
<b><u>Domein psychologische toestand</u></b>						
<b>Beleving van zelfvertrouwen</b>						
<p>17. Hoe is het met uw zelfvertrouwen? (<i>Bent u zeker van uzelf?</i>) Hoe tevreden bent u hierover?</p>						
<b>Beleving van denken, leren, geheugen en concentratie</b>						
<p>18. Hoe is het met uw concentratie? (<i>Kunt u uw aandacht of gedachten bij één onderwerp houden?</i>) Hoe tevreden bent u hierover?</p>						
<p>19. Hoe is het met uw geheugen? (<i>Kunt u dingen onthouden?</i>) Hoe tevreden bent u hierover?</p>						



	erg ontevreden	erg tevreden
<p>20. Hoe gaat het nemen van beslissingen? (Kunt u goed beslissingen nemen? Bijvoorbeeld over wat u wilt eten, lezen of aantrekken?) Hoe tevreden bent u hierover?</p>	☹	☺
	_	_
<p><b><u>Domein sociale relaties</u></b></p>		
<p><b>Beleving van persoonlijke relaties</b></p>		
<p>21. Wat vindt u van uw persoonlijke contacten? (Bijvoorbeeld met het gezin, de familie of vrienden) Hoe tevreden bent u hierover?</p>	_	_
<p><b>Beleving van seksuele activiteit</b></p>		
<p>22. Wat vindt u van uw seksuele leven? (Hoe gaat het vrijen? Bent u tevreden over uw intimiteit?) Hoe tevreden bent u hierover?</p>	_	_
<p><b><u>Domein communicatie</u></b></p>		
<p><b>Beleving van receptieve vaardigheden</b></p>		
<p>23. Hoe gaat het met het begrijpen van anderen? (Begrijpt u wat er tegen u gezegd wordt? Of begrijpt u wat er op tv gezegd wordt?) Hoe tevreden bent u hierover?</p>	_	_
<p>24. Hoe gaat het lezen? (Bijvoorbeeld het lezen van de krant, een boek, een brief of de ondertiteling op de televisie?) Hoe tevreden bent u hierover?</p>	_	_
<p><b>Beleving van productieve vaardigheden</b></p>		
<p>25. Hoe gaat het praten? (Hoe gaat het spreken? Kunt u woorden en/of zinnen zeggen? Verstaan anderen u?) Hoe tevreden bent u hierover?</p>	_	_

	erg ontevreden	erg tevreden
<p>26. Hoe gaat het contact leggen met anderen? (Kunt u makkelijk contact leggen met andere mensen?) Hoe tevreden bent u hierover?</p>	☹	☺
<p>27. Hoe gaat het met het voeren van een gesprek? (Kunt u een praatje maken met iemand? Wordt u begrepen?) Hoe tevreden bent u hierover?</p>		
<p>28. Hoe gaat het met schrijven of typen? (Kunt u een boodschap duidelijk maken op papier? Bijvoorbeeld een briefje schrijven?) Hoe tevreden bent u hierover?</p>		
<p><b><u>Domein persoonlijke overtuiging</u></b></p>		
<p><b>Beleving van religie, spiritualiteit en levensovertuigingen</b></p>		
<p>29. Heeft u steun aan een levensovertuiging? (Heeft u veel aan bidden, uw geloof of het naar de kerk/synagoge/moskee gaan?) Hoe tevreden bent u hierover?</p>		
<p><b><u>Domein relaties met opvallende kenmerken in de omgeving</u></b></p>		
<p><b>Beleving van gezondheid en sociale zorg: kwaliteit</b></p>		
<p>30. Wat vindt u van de gegeven zorg? (Bijvoorbeeld fysiotherapie, ergotherapie, logopedie of de verpleging?) Hoe tevreden bent u hierover?</p>		
<p><b>Beleving van deelname aan en mogelijkheden voor recreatie/vrije tijd</b></p>		
<p>31. Hoe gaat het met het uitoefenen van uw hobby's? (Bijvoorbeeld spelletjes spelen, schilderen, handwerken of lezen) Hoe tevreden bent u hierover?</p>		

<b>Vragen bij antwoordformulier 2</b>	erg vervelend ⊗	helemaal niet vervelend ⊙
<b><u>Domein psychologische toestand</u></b>		
<b>Beleving van gevoelens</b>		
32. Voelt u zich wel eens verdrietig? (Heeft u gevoelens van bedroefdheid of treurigheid?) Hoe ervaart u dit?	_ _ _ _	
33. Voelt u zich wel eens angstig? (Heeft u gevoelens van ongerustheid of bezorgdheid, bent u vaak bang?) Hoe ervaart u dit?	_ _ _ _	
34. Bent u wel eens boos? (Heeft u gevoelens van kwaadheid of woede?) Hoe ervaart u dit?	_ _ _ _	
35. Voelt u zich wel eens eenzaam? (Voelt u zich alleen? Voelt u zich eenzaam?) Hoe ervaart u dit?	_ _ _ _	
36. Schaamt u zich weleens? Hoe ervaart u dit?	_ _ _ _	
37. Voelt u zich wel eens machteloos? (Heeft u wel eens het gevoel dat u het niet meer in de hand heeft? Heeft u gevoelens van onmacht?) Hoe ervaart u dit?	_ _ _ _	
<b><u>Domein fysieke gezondheid</u></b>		
<b>Beleving van pijn en ongemak</b>		
38. Heeft u pijn tijdens dagelijkse activiteiten? (Heeft u pijn overdag, bijvoorbeeld tijdens het aankleden of wassen?) Hoe ervaart u dit?	_ _ _ _	

Appendix E: The questionnaire used in the second stage of this study

Vragen bij antwoordformulier 1	erg ontevreden	erg tevreden
<p><b><u>Domein 1: Niveau van onafhankelijkheid</u></b></p>	☹	☺
<p>1. Hoe gaat het lopen? (Bent u goed ter been? Kunt u goed lopen, bijvoorbeeld door de kamer?) Hoe tevreden bent u hierover?</p>	_ _ _ _	_ _ _ _
<p>2. Hoe gaat het staan? (Kunt u uw evenwicht bewaren? Kunt u rechtop blijven staan?) Hoe tevreden bent u hierover?</p>	_ _ _ _	_ _ _ _
<p>3. Hoe gaat het met zitten? (Bijvoorbeeld het zitten op een stoel of op een bank) Hoe tevreden bent u hierover?</p>	_ _ _ _	_ _ _ _
<p>4. Hoe gaat het eten met mes en vork? Hoe tevreden bent u hierover?</p>	_ _ _ _	_ _ _ _
<p><b><u>Domein 2: Fysieke gezondheid</u></b></p>		
<p>5. Hoe gaat het met uw energie? (Bent u vaak moe, heeft u voldoende puf?) Hoe tevreden bent u hierover?</p>	_ _ _ _	_ _ _ _
<p>6. Hoe gaat het met uw gehoor? (Kunt u goed horen? Kunt u goed verstaan, bijvoorbeeld tijdens het luisteren naar de radio of als u met iemand praat of belt?) Hoe tevreden bent u hierover?</p>	_ _ _ _	_ _ _ _
<p>7. Hoe gaat het met zien? (Kunt u goed kijken, bijvoorbeeld naar de televisie of de mensen om u heen?) Hoe tevreden bent u hierover?</p>	_ _ _ _	_ _ _ _
<p>8. Hoe gaat het met uw eetlust? (Heeft u trek of zin in eten?) Hoe tevreden bent u hierover?</p>	_ _ _ _	_ _ _ _
<p>9. Hoe gaat het eten? (Bijvoorbeeld het slikken en het kauwen?) Hoe tevreden bent u hierover?</p>	_ _ _ _	_ _ _ _

	erg ontevreden					erg tevreden
<p>10. Hoe gaat het slapen?  <i>(Kunt u doorslapen? Kunt u goed in slaap vallen? Bent u goed uitgerust na het slapen?)</i>            Hoe tevreden bent u hierover?</p>	☹					☺
<b><u>Domein 3: Psychologische gezondheid</u></b>						
<p>11. Hoe is het met uw zelfvertrouwen?  <i>(Bent u zeker van uzelf?)</i>            Hoe tevreden bent u hierover?</p>						
<p>12. Hoe is het met uw concentratie?  <i>(Kunt u uw aandacht of gedachten bij één onderwerp houden?)</i>            Hoe tevreden bent u hierover?</p>						
<p>13. Hoe is het met uw geheugen?  <i>(Kunt u dingen onthouden?)</i>            Hoe tevreden bent u hierover?</p>						
<p>14. Hoe gaat het nemen van beslissingen?  <i>(Kunt u goed beslissingen nemen? Bijvoorbeeld over wat u wilt eten, lezen of aantrekken?)</i>            Hoe tevreden bent u hierover?</p>						
<b><u>Domein 4: Sociale relaties</u></b>						
<p>15. Wat vindt u van de persoonlijke contacten met mensen om u heen?  <i>(Bijvoorbeeld met het gezin, de familie of vrienden)</i>            Hoe tevreden bent u hierover?</p>						
<p>16. Wat vindt u van uw seksuele leven?  <i>(Hoe gaat het vrijen? Bent u tevreden over uw intimiteit?)</i>            Hoe tevreden bent u hierover?</p>						
<b><u>Domein 5: Communicatie</u></b>						
<p>17. Hoe gaat het met het begrijpen van anderen?  <i>(Begrijpt u wat er tegen u gezegd wordt? Of begrijpt u wat er op tv gezegd wordt?)</i>            Hoe tevreden bent u hierover?</p>						

	erg ontevreden	erg tevreden
18. Hoe gaat het praten? <i>(Hoe gaat het spreken? Kunt u woorden en/of zinnen zeggen? Verstaan anderen u?)</i> Hoe tevreden bent u hierover?	☹	☺
	_	_
19. Hoe gaat het contact leggen met anderen? <i>(Kunt u makkelijk contact leggen met andere mensen?)</i> Hoe tevreden bent u hierover?		
	_	_
20. Hoe gaat het met het voeren van een gesprek? <i>(Kunt u een praatje maken met iemand? Wordt u begrepen?)</i> Hoe tevreden bent u hierover?		
	_	_
<b><u>Domein 6: Relaties met opvallende kenmerken in de omgeving</u></b>		
21. Hoe gaat het met het uitoefenen van uw hobby's? <i>(Bijvoorbeeld spelletjes spelen, schilderen, handwerken of lezen)</i> Hoe tevreden bent u hierover?		
	_	_

<b>Vragen bij antwoordformulier 2</b>		erg vervelend ☹	helemaal niet vervelend ☺
<b><u>Domein 3: Psychologische gezondheid</u></b>			
22. Voelt u zich wel eens verdrietig? (Heeft u gevoelens van bedroefdheid of treurigheid?) Hoe ervaart u dit?	Nee	Ja:	_ _ _ _
23. Bent u wel eens boos? (Heeft u gevoelens van kwaadheid of woede?) Hoe ervaart u dit?	Nee	Ja:	_ _ _ _
24. Voelt u zich wel eens eenzaam? (Voelt u zich alleen? Voelt u zich eenzaam?) Hoe ervaart u dit?	Nee	Ja:	_ _ _ _
25. Schaamt u zich weleens? Hoe ervaart u dit?	Nee	Ja:	_ _ _ _
26. Voelt u zich wel eens machteloos? (Heeft u wel eens het gevoel dat u het niet meer in de hand heeft? Heeft u gevoelens van onmacht?) Hoe ervaart u dit?	Nee	Ja:	_ _ _ _
<b><u>Domein 2: Fysieke gezondheid</u></b>			
27. Heeft u pijn tijdens dagelijkse activiteiten? (Heeft u pijn overdag, bijvoorbeeld tijdens het aankleden of wassen?) Hoe ervaart u dit?	Nee	Ja:	_ _ _ _
<b><u>Domein 1: Niveau van onafhankelijkheid</u></b>			
28. Bent u afhankelijk van medicijnen? (Heeft u medicijnen nodig?) Hoe ervaart u dit?	Nee	Ja:	_ _ _ _