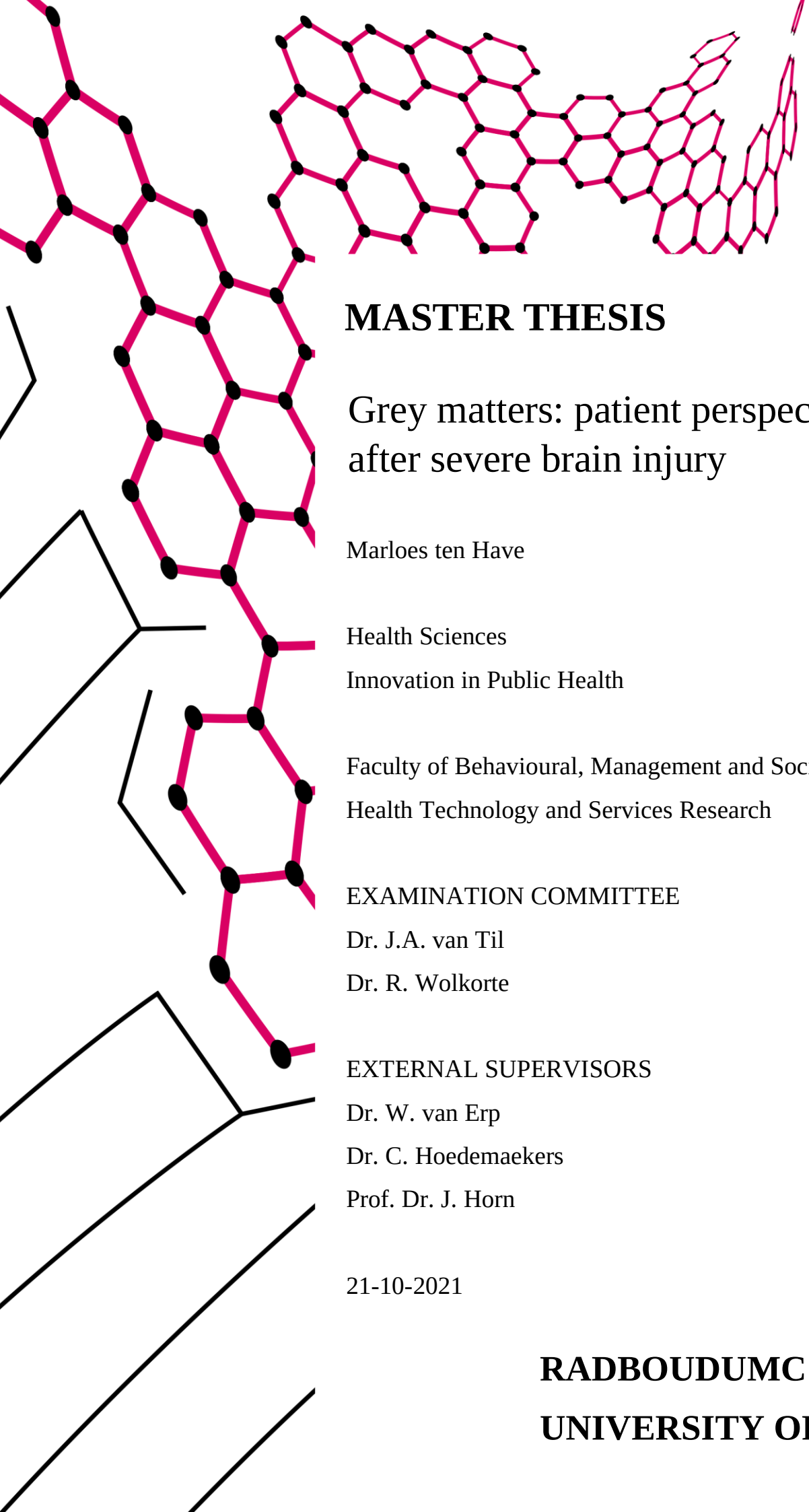

MASTER THESIS

Grey matters: patient perspectives after severe brain injury

Marloes ten Have

Health Sciences

Innovation in Public Health

Faculty of Behavioural, Management and Social Sciences

Health Technology and Services Research

EXAMINATION COMMITTEE

Dr. J.A. van Til

Dr. R. Wolkorte

EXTERNAL SUPERVISORS

Dr. W. van Erp

Dr. C. Hoedemaekers

Prof. Dr. J. Horn

21-10-2021

RADBOUDUMC

UNIVERSITY OF TWENTE

Abstract

Aim: To describe the perspectives of patients on living with the long-term consequences of aneurysmal subarachnoid haemorrhage (aSAH) and to explore the relations between the perspectives of patients and their health-related quality of life (HRQoL) and functional outcomes. This study will enhance the ability of physicians to inform patients and their relatives about living with the long-term consequences of aSAH.

Methods: The study population consisted of patients that experienced an aSAH at least 12 months ago. In case patients were not able to participate in the study independently, close relatives could participate as a proxy of the patient. This study had an explorative design, using a sequential mixed-methods approach. Insight into the perspectives of patients on living with the long-term consequences of aSAH was obtained by means of semi structured interviews. The extended Glasgow Outcome Scale (GOSE) and the Quality of Life after Brain Injury (QOLIBRI) were used to explore the relations between the perspectives of patients and their HRQoL and functional outcomes.

Results: A total of 39 patients were invited to participate in this study, of whom 12 patients agreed to participate. Five patients had poor functional outcomes and a low HRQoL and seven patients had good functional outcomes and a high HRQoL. The present study identified four themes that capture the perspectives of patients on living with the long-term consequences of aSAH. The themes were: 1. Being independent for everyday activities is most important for patients; 2. Leaving or avoiding situations due to sensitivity to external stimuli; 3. Being unable to remember anything that happened on the short-term or during youth is challenging; and 4. Due to fear of recurrence patients are less able to return back to a normal life. The themes give the impression that all patients had comparable perspectives on living with the long-term consequences of aSAH. However, that does not correspond to reality. For instance, sensitivity to external stimuli had impact on patients with good functional outcomes and a high HRQoL, while memory problems were challenging for patients with poor functional outcomes and a low HRQoL.

Discussion: The functional outcomes and HRQoL of aSAH patients included in this study varied. More than half of the patients had good functional outcomes and a high HRQoL, while other patients had poor functional outcomes and a low HRQoL. Overall, this study reveals that patients affected by aSAH are grateful to be alive. The results also indicate that the long-term consequences of aSAH have a major impact on patients and that the consequences and their impact differ partly per patient group. Thus, patients with poor functional outcomes and a low HRQoL have somewhat other perspectives on living with the long-term consequences of aSAH than patients with good functional outcomes and a high HRQoL. Patients have, irrespective of their functional outcomes and HRQoL, a desire to minimize

dependency or maintain independency for everyday activities. Sensitivity to external stimuli has impact on patients with good functional outcomes and a high HRQoL. Patients with poor functional outcomes and a low HRQoL suffer from memory problems and fear of recurrence. Since it is crucial for patients affected by aSAH to minimize dependency or maintain independency for everyday activities, physicians should inform patients and their relatives about all options regarding rehabilitation and aids that can improve the independence of patients.

Keywords: aneurysmal subarachnoid haemorrhage, prediction of consequences, patient and family counselling, patient perspectives, functional outcomes, health-related quality of life

Abbreviations

aSAH = aneurysmal subarachnoid haemorrhage; EMDR = Eye Movement Desensitization and Reprocessing therapy; EVD = external ventricular drain; DCI = delayed cerebral ischemia; GOS = Glasgow Outcome Scale; GOSE = extended Glasgow Outcome Scale; HRQoL = health-related quality of life; ICU = intensive care unit; QOLIBIRI = Quality of Life after Brain Injury; SAHIT = Haemorrhage International Trialists study; WFNS = World Federation of Neurosurgical Societies score

Introduction

Aneurysmal subarachnoid haemorrhage (aSAH) is a relatively uncommon but severe subtype of haemorrhagic stroke [1], which is characterized by the rupture of an intracranial aneurysm and the leakage of blood into the subarachnoid space [2]. ASAH is a subset of stroke that affects relatively young adults (median age between 50 and 55 years) compared to other subtypes of stroke [1][3][4]. Patients are often in their most productive years with regard to work, friends, and family. In the Netherlands, approximately 1.000 individuals are affected by an aSAH yearly [5]. The incidence of aSAH has remained stable over the last couple of decades, while mortality rates decreased significantly [5][6][7]. The declining mortality rates have increased the need to predict the long-term consequences of aSAH. Insight into long-term consequences of aSAH supports physicians in patient and family counselling [8][9]. It enhances the ability of physicians to inform patients and their relatives about living with long-term consequences of aSAH.

Currently, the World Federation of Neurosurgical Societies (WFNS) grading scale is the gold standard for predicting (long-term) consequences of aSAH [10]. Higher scores on this scale are associated with worse clinical consequences [3]. Nevertheless, various studies [11][12][13] indicate that the WFNS is unreliable, since 20% of the patients with WFNS grade V[1] recover without any physical, cognitive, or emotional limitations. For this reason, various prediction models have been developed over the last couple of years [8][14][15][16][17]. Prediction models are statistically derived tools based on a set of indicators obtained from medical records and clinical examination [9]. The most well-known model is based on the Haemorrhage International Trialists (SAHIT) [8][18][19] study conducted in 2018. This model predicts the probability of poor functional outcomes three months after being affected by aSAH. Functional outcome is a measure that summarizes the physical, cognitive, and emotional consequences of aSAH for patients [20]. Poor functional outcomes are defined as death, vegetative state, or severe disability as based on the Glasgow Outcome Scale (GOS) [8].

Several validation studies [21][22] indicate that the SAHIT model performs adequately to good on the cohort level. Nevertheless, two shortcomings of this model on the individual level were identified. First, the prediction of individual long-term outcomes based on the SAHIT model is inaccurate. For instance, studies by Mascitelli et al. [21] and Hostettler et al. [22] indicate that this model structurally underpredicts poor functional outcomes in approximately 25% of the aSAH patients. Second, the prediction of individual long-term outcomes based on the SAHIT model is imprecise. The measures used to predict and assess outcomes only distinguish between good functional outcomes and poor functional outcomes. Subsequently, valuable information regarding the actual physical, cognitive, and

[1] WFNS GRADE I = lowest grade; WFNS GRADE V = highest grade

emotional consequences of aSAH is lost [4]. Moreover, the model does not take into account the impact of the long-term consequences of aSAH on the quality of life of patients (e.g., health-related quality of life (HRQoL)) [8][14][17][23]. However, this seemed to be crucial, since various studies indicate that patients with poor functional outcomes can experience a high HRQoL [24][25]. In literature this phenomenon is known as the *disability paradox* [26]. Finally, the point of dichotomization is arbitrary and based on a value judgement [8][17][27]. For instance, consequences of aSAH that are classified as poor, could be acceptable for the patient.

The accuracy and the preciseness of the SAHIT model is thus insufficient for patient and family counselling. It is therefore recommended by Geurts et al. [23] and Creutzfeldt and Holloway [28] to gain insight into the perspectives of patients on living with the long-term consequences of aSAH. In addition, it was suggested that insight into the relations between the perspectives of patients and their HRQoL and functional outcomes, could be helpful by informing future patients and their relatives about living with the long-term consequences of aSAH [28][29].

Numerous studies have been performed that aim to explore the experiences and the perspectives of patients affected by aSAH [30][31][32]. These studies describe the perspectives of patients on rehabilitation and/or the transition from healthcare facility to home. For instance, studies from Brice and Brice [30] and Brice et al. [31] show that the transition from hospital to home was associated with negative feelings, since the expectations of life after aSAH at home did not match reality. Moreover, various studies have been executed that focus on describing HRQoL and functional outcomes after aSAH [33][34][35][36]. All these studies indicate that one year after being affected by aSAH patients still experience functional limitations and a significant lower HRQoL than the general population.

Nevertheless, no previous studies have been identified that focus on describing the perspectives of patients on living with the long-term consequences of aSAH or on exploring the relations between the perspectives of patients and their HRQoL and functional outcomes. The aim of this study is therefore twofold. First, this study will describe the perspectives of patients on living with the long-term consequences of aSAH. Second, this study will explore the relations between the perspectives of patients and their HRQoL and functional outcomes. By conducting this study, insight will be obtained in a research area that is underexplored. Moreover, this study will improve the support for physicians involved in patient and family counselling. It will enhance the ability of physicians to inform patients and their family members about living with the long-term consequences of aSAH.

Research questions

- What are the perspectives of patients on living with the long-term consequences of aSAH?
- What are the relations between the perspectives of patients on living with the long-term consequences of aSAH and their HRQoL and functional outcomes?

Methods

Design

This study had an explorative design, using a sequential mixed method approach [37]. A combination of questionnaires and interviews was used to meet the aims of this study. Insight into the perspectives of patients on living with the long-term consequences of aSAH was obtained by means of semi-structured interviews. Questionnaires were used to explore the relations between the perspectives of patients and their HRQoL and functional outcomes.

Study population and inclusion

The study population consisted of patients (≥ 18 years) that experienced an aSAH at least 12 months ago, requiring admission to the intensive care unit (ICU) of Radboudumc.

A senior physician (ICU, Radboudumc) compiled a list of patients that fitted within the description of the study population. All these patients received a letter introducing the study, including a patient information letter and an informed consent form. Within several days after sending these letters, every patient was called by the researcher. During this conversation, it was determined whether the patient was willing to take part in the study. In case patients were not able to participate in the study independently, close relatives could participate as a proxy of the patient.

Data collection

Background characteristics

To describe the background characteristics of the study population, information from the acute phase was collected from medical records of patients. Data regarding baseline characteristics (age & gender), pre-existing comorbidities (hypertension and diabetes mellitus), WFNS at hospital admission, length of ICU and hospital stay, duration of ventilation, treatment (coiling, clipping, and external ventricular drain (EVD)), neurological complications (rebleed, meningitis, delayed cerebral ischemia (DCI), and hydrocephalus) and non-neurological complications (fever, pneumonia, and sepsis) was extracted from medical files.

HRQoL and functional outcomes

The Quality Of Live after Brain Injury (QOLIBRI) was used to describe the HRQoL of patients. A study by Steinbüchel et al. [38] demonstrates that the QOLIBRI is reliable and valid for determining the HRQoL of patients that were affected by brain injury. The QOLIBRI questionnaire consist of two parts.

The first part of the questionnaire reflects patients' satisfaction with their cognition, self, daily life and autonomy, and social relationships. The second part of the questionnaire focuses on the impact of emotional and physical problems on the well-being of patients. In case patients were not able to fill in the QOLIBRI themselves, the PRO-QOLIBRI was used. The PRO-QOLIBRI is a variant of the QOLIBRI that is validated for proxies [39]. The QOLIBRI or PRO-QOLIBRI was sent to patients or proxies on paper before the interview, a return envelope included. See Supplemental File 1 for the QOLIBRI and Supplemental File 2 for the PRO-QOLIBRI.

The extended Glasgow Outcome Scale (GOSE) was applied to describe the functional outcomes of patients. Weir et al. [40] report that the GOSE is valid and reliable for assessing the functional outcomes of patients that experienced an aSAH. The GOSE consists of seven key items that capture the functional, cognitive, social, and emotional impairments of patients. The key items are: consciousness, independence in the home, independence outside the home, work or study, social and leisure activities, family and friendship, and return to normal life. The GOSE was administered to patients as a structured interview. In case a patient was unable to participate in the study independently, the GOSE was administered to the proxy of the patient. See Supplemental File 3 for the GOSE.

Perspectives of patients

Semi-structured interviews were used to gain insight into the perspectives of patients on living with the long-term consequences of aSAH. A semi-structured design was chosen, as it enabled the researcher to delineate the interview topics, but also left space for unexpected input of patients [41]. The interviews were conducted between May and August 2021. The topics of the semi-structured interview guide covered the long-term consequences of aSAH for the patient, the perspectives of the patient on living with long-term consequences, the quality of life of the patient, and the perspectives of the patient on the quality of life. In case a patient was unable to participate in the study independently, a proxy was interviewed. See Supplemental File 4 for the interview guide used.

It was desirable that the interviews were conducted face to face. However, this was complicated due to the COVID-19 pandemic. Study participants were therefore also offered the opportunity to conduct the interviews online or by telephone. All interviews were digitally recorded and transcribed verbatim, by using Amberscript, for data analysis.

Data analysis

QOLIBRI or PRO-QOLIBRI

The items on the QOLIBRI and PRO-QOLIBRI were scored on a scale from 1 to 5. The sub-scores and the total score on these measures were calculated as suggested by Truelle et al. [42]. First, all responses

were summed, after which the mean was calculated per sub-score as well as for the total measure. Second, the mean for both the sub-scores and the total scores was converted to a 0 (= worst possible quality of life) to 100 (= best possible quality of life) scale, by subtracting one from the mean after which the score was multiplied by twenty-five. In this study, a sub-score or total score below 60 [43][44] was considered to reflect a low HRQoL.

GOSE

The overall score on the GOSE was based on the lowest outcome category indicated in the questionnaire [45]. The outcome categories are: 1. vegetative state; 2. lower severe disability; 3. upper severe disability; 4. lower moderate disability; 5. upper moderate disability; 6. lower good recovery; and 7. upper good recovery. In this study, the scores vegetative state - lower moderate disability were considered to reflect poor functional outcomes.

Semi-structured interviews

A thematic analysis approach, drawing on the principles of the grounded theory of Strauss and Corbin, was used to understand the perspectives of patients on living with the long-term consequences of aSAH [46]. First, the open coding technique was used to organize the data. A specific code was attached to each of the relevant concepts identified in the transcripts. Second, the axial coding technique was applied to identify patterns in the data. Corresponding open codes were merged. In addition, open codes that shared related meanings were grouped. Third, the thematic coding technique was used to organize the codes. Overarching themes and subthemes were identified. Moreover, variations on themes and subthemes were determined. The analysis was conducted in ATLAS ti.9.

Data saturation

In this study, the method of Hennink et al. [47] was used to assess for data saturation. Hennink et al. demonstrate that meaning saturation instead of code saturation is needed to develop a full understanding of the study phenomenon. To confirm data saturation, each subtheme was examined to determine what was learned about it from successive interviews. For each interview, dimensions of subthemes were identified. Data saturation was reached when subsequent interviews did not provide additional dimensions of the subthemes.

Mixed methods analysis

During the mixed methods analysis it was investigated whether patients with corresponding HRQoL and functional outcomes, had comparable or deviant perspectives on living with the long-term consequences of aSAH.

Rigour

Various steps were taken to ensure that the data collection and the data analysis were rigorous. First, the questionnaires used were proven reliable and valid for determining outcomes of patients affected by brain injury. Second, the interviews were conducted by one researcher and the same interview-guide was used for all study participants. Third, an audit trail and a codebook were kept outlining all information contributing to the development of themes and subthemes.

Ethics

This study was conducted according to the principles of the Declaration of Helsinki [48] and was in accordance with the applicable law and regulation. All study participants provided informed consent before participating in the study. Research ethics approval was obtained from the review committee of the Radboudumc (file no. 2020-7232) and the ethics committee of the faculty of Behavioural, Management and Social Sciences of the University of Twente (file no. 210519).

Results

Study characteristics

Details regarding the inclusion and exclusion of study participants are presented in figure 1. A total of 39 patients were invited to participate in this study, of whom 12 patients took part. The main reasons for non-participation were; no time and too emotional. Seven patients participated individually, four patients were represented by close relatives, and one patient participated together with a close relative. The QOLIBRI was used seven times, while the PRO-QOLIBRI was applied five times. Six interviews were performed face-to-face, four interviews were conducted by telephone, and two interviews were performed using Microsoft Teams.

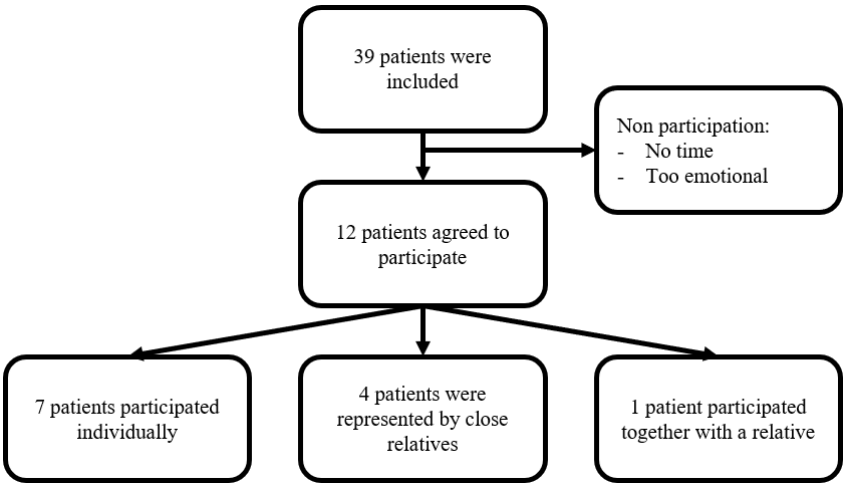

Figure 1 Details inclusion and exclusion study participants

Patient characteristics

Demographic and injury severity details of the study population are given in table 1. Patients were aged from 55 to 71 (median 63.50 years) at the time of the study. Half of the patients were women. Seven patients (58.4%) scored I or II on the WFNS at hospital admission. The hospital stay in days ranged from 11 to 78 days (median 19.50 days), while the ICU stay in days ranged from 1 to 45 days (median 5.00 days). Eight patients (66.7%) were treated with the endovascular coiling procedure and needed EVD insertion. Seven patients (58.3%) suffered from fever and eight patients (66.7%) were affected by hydrocephalus.

Table 1 Demographic and injury severity details patients

Gender patients	**(N=12)**	**(100%)**
Men	6	50
Women	6	50
Year aSAH	**(N=12)**	**(100%)**
2018	6	50
2019	3	25
2020	3	25
WFNS at hospital admission	**(N=12)**	**(100%)**
I	5	41.7
II	2	16.7
III	0	0
IV	3	25.0
V	2	16.7
Treatment	**(N=12)**	**(100%)**
Coiling	8	66.7
Clipping	4	33.3
EVD	8	66.7
Pre-existing comorbidities	**(N=12)**	**(100%)**
Hypertension	6	50.0
Diabetes mellitus	1	8.3
Neurological complications	**(N=12)**	**(100%)**
Rebleed	1	8.3
Meningitis	1	8.3
DCI	3	25.0
Hydrocephalus	8	66.7
Non-neurological complications	**(N=12)**	**(100%)**
Fever	7	58.3
Pneumonia	2	16.7
Sepsis	0	0
	MEDIAN [IQR]	
Age	63.50 [58.50; 69.25]	
Hospital stay in days	19.50 [14.25; 48.50]	
ICU stay in days	5.00 [2.25; 19.50]	
Ventilation duration in day	0.50 [0.00; 25.00]	

Note 1: aSAH = aneurysmal subarachnoid haemorrhage; WFNS = World Federation of Neurosurgical Societies score; EVD = external ventricular drain; DCI = delayed cerebral ischemia; ICU = intensive care unit

HRQoL and functional outcomes

The functional outcomes and HRQoL of patients are presented in table 2. Five patients had poor functional outcomes, as well as a low HRQoL. Moreover, all patients with poor functional outcomes had low scores on the subscales *cognition, self, daily life and autonomy,* and *social relationships* of the QOLIBRI. Seven patients had good functional outcomes, as well as a high HRQoL.

Table 2 Functional outcomes and HRQoL

	P1	**P2**	**P3**	**P4**	**P5**	**P6**
GOSE	LSD*	UGR	LSD*	UMD	LSD*	LSD*
QOLIBRI total score	12*	97	42*	68	34*	14*
QOLIBRI sub-scores						
Cognition	7*	100	14*	86	21*	7*
Self	14*	100	29*	68	18*	4*
Daily life & autonomy	7*	100	7*	46*	0*	0*
Social relationships	21*	87.5	58*	83	58*	-
Emotional problems	5*	95	95	70	80	45*
Physical problems	20*	100	75	50*	50*	25*
	P7	**P8**	**P9**	**P10**	**P11**	**P12**
GOSE	LGR	UMD	USD*	LGR	UMD	UGR
QOLIBRI total score	82	74	50*	92	67	83
QOLIBRI sub-scores						
Cognition	79	89	50*	100	57*	82
Self	75	61	50*	79	67	86
Daily life & autonomy	79	68	50*	96	56*	88
Social relationships	75	58*	50*	95	71	80
Emotional problems	95	80	50*	95	80	80
Physical problems	100	90	50*	90	70	83

Note 1: LSD = lower severe disability; USD = upper severe disability UMD = upper moderate disability; LGR = lower good recovery; UGR = upper good recovery
Note 2: QOLIBRI = QOLIBRI & PRO-QOLIBRI
Note 3: * = poor functional outcomes; low HRQoL

Perspectives of patients

The analysis of the interviews produced four themes that capture the perspectives of patients on living with the long-term consequences of aSAH; 1. Being independent for everyday activities is most important for patients; 2. Leaving or avoiding situations due to sensitivity to external stimuli; 3. Being unable to remember anything that happened on the short-term or during youth is challenging; 4. Due to fear of recurrence patients are less able to return back to a normal life. Themes and subthemes are summarized in table 3.

Table 3 Themes and subthemes that capture the perspectives of patients

Themes and subthemes	Brief description
Being independent for everyday activities is most important for patients o Personal selfcare o Household chores o Mobility	For patients it was burdensome to be dependent on relatives or caregivers for toileting, showering, clothing, cooking, cleaning, hospital appointments, shopping, and family visits. Other patients were delighted being able to perform such tasks themselves.
Leaving or avoiding situations due to sensitivity to external stimuli o Multiple people o Light o Noise	Patients were sensitive to light flashes, noise, and groups of multiple people. Patients left or avoided situations in which they would get confronted with these stimuli.
Being unable to remember anything that happened on the short-term or during youth is challenging o Short-term memory problems o Long-term memory problems	Patients were unable to remember anything that happened a minute, an hour, a day, a week, a month, a year, or more than a year ago. Moreover, patients were unable to recognize family members.
Due to fear of recurrence patients are less able to return back to a normal life o Fear of worsening of disabilities o Fear of dying	Patients were afraid of recurrence of aSAH and its consequences as deterioration of disabilities or dying. To deal with fear of recurrence patients accepted help from a psychologist.

Being independent for everyday activities is most important for patients

Dependency, and thus independency, was the most important theme for patients.

Patients described that it was burdensome to be dependent on relatives or caregivers for their daily care. It was especially difficult for patients to be reliant on others for personal self-care activities as toileting and showering. *''She really hates being dependent on others for showering and toileting. She accepted it, but it is burdensome.''* (relative P5) Accepting help by such activities was embarrassing for patients.

Moreover, patients mentioned that it was tough to be dependent on relatives or caregivers for household chores. Patients had to ask for help by activities such as cooking and cleaning, which was difficult for them. *''I cannot do the household chores myself. I have to ask for help. (..) For me that is difficult, since I like to do it all myself. But I cannot do it all myself.''* (P4) It was important for patients be involved in performing the household chores, since assisting gave them a positive feeling.

In addition, patients indicated that it was challenging to be dependent on relatives for their mobility. Patients lost their ability to drive a car and were therefore dependent on friends and family for hospital appointments, shopping, and family visits. In particular the loss of freedom had major impact on patients. *''I still cannot drive, thus I am dependent on other people for my mobility. This is difficult for me, since I was used to go anywhere without help of others.''* (P4)

Finally, patients reported being delighted to be able to take care of themselves. *''Uh, paralysis and other disabilities. I am happy that I can take care of myself.''* (P8) For patients it was crucial to have a normal life. A life as they were used to. This included being able to work, doing the household chores independently, and maintaining a social life without help. *''Eh, inviting friends, cooking, and having a social life. I am happy being able to do all these things myself.''* (P2)

Leaving or avoiding situations due to sensitivity to external stimuli

Patients described being sensitive to noise and light flashes. For patients it was hard to cope with these stimuli. *''Sometimes I suffer from sensitivity to external stimuli. I am sensitive to noise and light flashes.''* (P10) Moreover, patients mentioned that it was difficult being in situations with multiple people. For instance, having conversations with numerous people was tough for patients. *''Having a conversation is hard sometimes. Mainly when more than one person participates (..). If a third person joins the conversation, sensitivity to stimuli is immediately remarkable.''* (P11)

Patients gave conflicting signals about the impact of sensitivity to stimuli on daily life. Patients mentioned that sensitivity to external stimuli did not hinder them, but acknowledged avoiding or leaving situations in which they would get confronted with noise, light flashes, and groups of people. *''Uh, well the only thing is, we have a school disco once a year. And after a short time with noise and light flashes, it is enough for me. Then I go home.''* (P7)

Being unable to remember anything that happened on the short-term or during youth is challenging

Patients reported that it is hard to cope with short-term memory problems. In particular during conversations with friends or unknown people, short-term memory problems had impact. During conversations patients were unable to remember anything about the topics already discussed. Patients therefore needed help from family members to have conversations with others. *''I have problems with my short-term memory. (..) When I talk with friends or unknown people, I completely lost what was said within a couple of seconds. Then my wife has to help me''* (P9)

Moreover, patients indicated that it is burdensome to suffer from long-term memory problems. For patients it was especially hard to accept being unable to remember anything that happened during their youth. *''Being unable to remember what happened during her past. (..) How we met and other things about her childhood, she does not know that anymore. That is difficult for her.''* (relative P6) Besides the impact of long-term memory problems on patients, relatives indicated that it was tough for them that patients were affected by long-term memory problems. For relatives it was hard to accept that patients were unable to recognize them due to problems with their long-term memory. *''He does not recognize me. Sometimes I am his mother, sometimes I am his sister, and sometimes I am his wife.''* (relative P3)

Due to fear of recurrence patients are less able to return back to a normal life

Patients indicated being anxious about recurrence of aSAH. Fear of recurrence was due to anxiety about the physical, mental, and cognitive consequences of recurrence and about dying. *''I am afraid of dying. I know when this (aSAH) happens again, I will die.''* (P9)

Fear of recurrence had major impact on patients' life. First, fear of recurrence had a negative impact on the energy level of patients. Due to a low energy-level patients were less able to participate in rehabilitation programmes, to perform hobbies such as jogging and bodybuilding, or to maintain contact with friends and family. Patients were no longer able to live their life as they were used to, which was hard to accept for them. *''Fear has a negative impact on my energy-level. I cannot build up a normal life, a life I was used to.''* (P4) Second, patients described that fear of recurrence caused stress. At the same time stress had to be avoided, since it increased the chance of recurrence of aSAH.

To deal with fear of recurrence some patients had undergone Eye Movement Desensitization and Reprocessing therapy (EMDR) and/or accepted help from a psychologist. *''During the rehabilitation period I did some EMDR sessions with my psychologist to deal with fear of recurrence. It helped me. But I have not fully processed fear yet. Therefore, I will be guided by a psychologist again.''* (P4) Moreover, it was reported by a patient that guidance by a physician and frequent scanning of the brain would be helpful for handling fear of recurrence.

Integration

The description of the themes and subthemes gives the impression that all patients had comparable perspectives on living with the long-term consequences of aSAH. However, that does not correspond to reality. For instance, table 4 shows that memory problems were challenging for patients with poor functional outcomes and a low HRQoL, while sensitivity to external stimuli had impact on patients with good functional outcomes and a high HRQoL.

Table 4 Functional outcomes, HRQoL, themes, and subthemes per patient

	P1	**P2**	**P3**	**P4**	**P5**	**P6**	**P7**	**P8**	**P9**	**P10**	**P11**	**P12**
Long-term outcomes												
GOSE	LSD*	UGR	LSD*	UMD	LSD*	LSD*	LGR	UMD	USD*	LGR	UMD	UGR
QOLIBRI total score	12*	97	42*	68	34*	14*	82	74	50*	92	67	83
QOLIBRI sub-scores												
Cognition	7*	100	14*	86	21*	7*	79	89	50*	100	57*	82
Self	14*	100	29*	68	18*	4*	75	61	50*	79	67	86
Daily life & autonomy	7*	100	7*	46*	0*	0*	79	68	50*	96	56*	88
Social relationships	21*	87.5	58*	83	58*	-	75	58*	50*	95	71	80
Emotional problems	5*	95	95	70	80	45*	95	80	50*	95	80	80
Physical problems	20*	100	75	50*	50*	25*	100	90	50*	90	70	83
Themes and subthemes												
Being independent for everyday activities is most important for patients												
Personal selfcare	X^{o}	X			X^{o}	X^{o}		X				
Mobility	X^{o}	X		X^{o}				X				
Household chores		X		X^{o}	X^{o}			X				X
Leaving or avoiding situations due to sensitivity to external stimuli.												
Multiple people	X									X	X	
Light							X			X		
Noise							X			X		
Being unable to remember anything that happened on the short-term or during youth is challenging.												
Short-term memory problems	X		X		X	X			X		X	
Long-term memory problems	X		X			X						
Due to fear of recurrence patients were less able to return back to a normal life												
Worsening of disabilities				X		X			X			
Dying									X			

Note 1: LSD = lower severe disability; USD = upper severe disability; UMD = upper moderate disability; LGR = lower good recovery; UGR = upper good recovery
Note 2: QOLIBRI = QOLIBRI & PRO-QOLIBRI
Note 3: * = poor functional outcomes; low HRQoL
Note 4: X^{o} = being dependent is burdensome

Discussion

Main findings

In the present study, it was aimed to describe the perspectives of patients on living with the long-term consequences of aSAH and to explore the relations between the perspectives of patients and their HRQoL and functional outcomes. The HRQoL and functional outcomes of aSAH patients included in this study varied. More than half of the patients had good functional outcomes and a high HRQoL, while the other patients had poor functional outcomes and a low HRQoL. The variety of patient outcomes in this study is consistent with the complex and heterogenous clinical course of aSAH in patients [11][33][35][49]. Patients differ with respect to aneurysm location, severity of haemorrhage, the incidence of neurological and non-neurological complications, and, thus, outcomes.

Overall, this study reveals that patients affected by aSAH are grateful to be alive. Nevertheless, the results of this study also indicate that the long-term consequences of aSAH have a profound impact on patients' lives. The long-term consequences of aSAH that have most impact on patients are dependency for everyday activities, sensitivity to external stimuli, memory problems, and fear of recurrence. The study also suggests that the long-term consequences of aSAH and the impact of the consequences differ partly per patient group. That is, patients with poor functional outcomes and a low HRQoL have somewhat other perspectives on living with the long-term consequences of aSAH than patients with good functional outcomes and a high HRQoL.

Being independent for everyday activities is important for patients with good functional outcomes and a high HRQoL and for patients with poor functional outcomes and a low HRQoL. Patients affected by aSAH have, irrespective of their functional outcomes and HRQoL, a desire to minimize dependency or maintain independency in personal selfcare activities, household chores, and mobility. Besides individuals affected by an aSAH or other severe conditions [50][51][52], healthy individuals [53][54] also place great value on their independence or self-reliance with regard to everyday activities. Chen et al. [55] argue that independency, and thus self-reliance, for everyday activities is important for individuals, since it provides them with the ability to take care of themselves. It gives individuals the ability to fulfil own needs and desires.

Sensitivity to external stimuli is an important consequence of aSAH for patients with good functional outcomes and a high HRQoL. However, this does not mean that patients with poor functional outcomes and a low HRQoL are not affected by this consequence of aSAH. In patients with poor functional outcomes and a low HRQoL other long-term consequences, as memory problems or fear of recurrence,

might dominate. Another explanation might be that patients with poor functional outcomes and a low HRQoL live in a protected environment and are therefore not exposed to noise, light flashes and large groups of people. In this study, patients gave conflicting signals about the impact of sensitivity to stimuli on their daily life. For instance, patients left or avoided situations in which they would get confronted with light flashes, noise, and groups of people, but also indicated that sensitivity to stimuli did not hinder them. These findings are in contrast with those of a study by Shepherd et al. [56], which reports that sensitivity to light flashes and noise affects daily life after brain injury significantly.

Patients with poor functional outcomes and a low HRQoL (and their relatives) suffer from memory problems. Both short-term and long-term memory problems have impact on the lives of patients and their close relatives. Memory loss is a common consequence of aSAH [4][57][58]. As in this study, Tang et al. [57] report that patients are unable to have conversations individually and/or lose their ability to recognize family members due to memory problems. Moreover, Tang et al. [57] and Nakling et al. [58] add that memory loss, due to an aSAH or other subtypes of stroke, can result in restrictions in daily life activities (e.g., washing, cooking, cleaning). Patients are not or less able to remember in what way everyday activities should be performed and thus need help from relatives. The restrictions in daily life activities may therefore explain the relation between memory problems and poor functional outcomes and a low HRQoL.

Fear of recurrence is another long-term consequence of aSAH that has impact on patients with poor functional outcomes and a low HRQoL. Patients are anxious about recurrence of aSAH and its consequences as deterioration of disabilities or dying. Fear of recurrence resulted in a low energy-level and stress. Studies by Verberne et al. [59], Chun et al. [60], and Von Vogelsang et al. [61] also indicate that anxiety about recurrence has a profound impact on the lives of patients affected by a stroke (e.g., aSAH, haemorrhagic stroke, ischaemic stroke). However, Verbene et al. [59] and Von Vogelsang et al. [61] also show that patients that are anxious about recurrence can have good functional outcomes and a high HRQoL. It can therefore be argued that fear of recurrence is not related to specific outcomes. The causes of fear of recurrence in patients affected by a stroke, and thus an aSAH, are not completely understood. Nevertheless, various studies [4][62][63] suggest that anxiety about recurrence could be related to a depression or depressive symptoms. Fear of recurrence is not disease or condition specific. Numerous studies report that patients that were affected by cancer [64][65][66], a heart attack [67], or the clostridium difficile bacteria [68] are also anxious about being affected by one of these conditions again.

A closer examination of the QOLIBRI[2] [38][42] indicates that some impactful long-term consequences of aSAH are not included in this instrument. For instance, the QOLIBRI does not pay attention to

[2] QOLIBRI = QOLIBRI and PRO-QOLIBRI

sensitivity to external stimuli, while this study and studies by Al-Khindi et al. [4] and Shepherd et al. [56] suggest that sensitivity to external stimuli has impact on the lives of some aSAH patients. It can therefore be argued that the QOLIBRI is probably not fully appropriate for determining the HRQoL of patients affected by aSAH. After all, to establish the impact of a disease or condition on the quality of life, an HRQoL instrument should include all disease or condition-related factors that have a proven impact on the patient [69].

Strengths and limitations

This study had several strengths and limitations. A strength of this study was that a mixed-methods approach was applied. The integration of the qualitative and quantitative data provided in-depth insight into the perspectives of patients on living with the long-term consequences of aSAH. Moreover, data saturation was reached for most of the subthemes, and thus themes, identified in the qualitative analyses. Almost no new dimensions of the subthemes emerged in interview 9, 10, and 11 (See Supplemental File 5). Only the dimensions of the subthemes household chores[3] and multiple people[4] varied until the last interviews. It is therefore plausible that the perspectives of patients on living with the long-term consequences of aSAH can be captured by the discussed themes and subthemes. Another strength was that the questionnaires used to describe the HRQoL and the functional outcomes of patients were proven valid and reliable for determining outcomes after brain injury [38][40]. Moreover, the analysis and the interpretation of the data obtained by means of these instruments was based on scientific evidence [42][43][44][45]. Nevertheless, it should be taken into account that this study indicates that the QOLIBRI is probably not valid for determining the HRQoL of patients affected by an aSAH. For instance, it can be argued that the scores on the QOLIBRI would be different, if sensitivity to external stimuli was included in this measure.

A limitation of this study was that the age and gender distribution of the patients included in this study was not fully comparable to the aSAH patient population. In this study, the median age of patients was 64 years, while literature shows that the median age of patients affected by aSAH is between 50 and 55 years [1][3][4]. Moreover, in this study the men/women distribution was equal. Nevertheless, literature suggests that aSAH is more common in women than in men [5][6][7]. Furthermore, patients and proxies described that the QOLIBRI or PRO-QOLIBRI were difficult to complete. For patients it was hard to determine whether the physical or the cognitive limitations were due to the aSAH or to the aging process. Proxies mentioned that it was hard to empathize with the position of the patient. As a result, some items on the questionnaires were left open or filled in the same way, which could have biased the results. An alternative explanation for the difficulties with completing the QOLIBRI or the PRO-QOLIBIRI, might be that these questionnaires do not include all consequences of aSAH that have

[3] Theme: being independent for everyday activities is most important for patients
[4] Theme: leaving or avoiding situations due to sensitivity to external stimuli

impact on patients. Another limitation was that, due to the COVID-19 pandemic, some interviews were taken by telephone. This could have influenced the results of this study, since it was difficult for the researcher to empathize with the situation of patients while having an interview by telephone.

Conclusion and implications

Despite the limitations, it can be concluded that the long-term consequences of aSAH have a major impact on patients. The long-term consequences and their impact differ partly per patient group. Thus, patients with poor functional outcomes and a low HRQoL have somewhat other perspectives on living with the long-term consequences of aSAH than patients with good functional outcomes and a high HRQoL. Patients have, irrespective of their functional outcomes and HRQoL, a desire to minimize dependency or maintain independency for everyday activities. Sensitivity to external stimuli has impact on patients with good functional outcomes and a high HRQoL. Patients with poor functional outcomes and a low HRQoL suffer from memory problems and fear of recurrence.

The results of this study provide important insights into the perspectives of patients on living with the long-term consequences of aSAH. First, it is crucial for patients to minimize dependency or maintain independency for everyday activities. It is therefore important that physicians inform patients and their relatives about all rehabilitation options and aids (e.g., electric wheelchairs and adjustment in and outside the home) that can improve the independence of patients with regard to everyday activities. Second, fear of recurrence can have a profound impact on patients' lives. It is thus important that physicians inform patients and their relatives about fear of recurrence and options, as EMDR and/or guidance by a psychologist, to deal with this consequence of aSAH.

This study also indicates that aSAH and its consequences have a major impact on the lives of close relatives of patients. Nevertheless, relatives were underrepresented in this study. As a result, it was not possible to identify themes that capture the perspectives of relatives. Future studies should therefore focus on describing the perspectives of close relatives on living with the long-term consequences of an aSAH. In addition, in subsequent studies attention should be paid to the validation of the QOLIBRI in specific groups of patients (e.g., ischaemic stroke, aSAH) affected by brain injury.

Acknowledgements

I would like to thank the study participants for sharing their personal experiences of living with the long-term consequences of aSAH. Their stories were inspirational. Furthermore, I would like to thank Janine van Til, Ria Wolkorte, Willemijn van Erp, Astrid Hoedemaekers, and Janneke Horn for their guidance and feedback.

References

1. Gijn J van, Kerr RS, Rinkel GJE. Subarachnoid haemorrhage. Lancet. 2007;369(9558):306-318. DOI: 10.1016/S0140-6736(07)60153-6
2. Macdonald RL, Diringer MN, Citeria G. Understanding the disease: aneurysmal hemorrage. J Intensive Care Med. 2014;40(12):1940-1943. DOI 10.1007/s00134-014-3483-5.
3. Muehlschlegel S. Subarachnoid Hemorrhage. Neurocrit care. 2018;24(6):1623-1657. DOI: 10.1212/CON.000000000000679
4. Al-Khindi T, Macdonald RL, Schweizer TA. Cognitive and functional outcome after aneurysmal subarachnoid hemorrhage. Stroke. 2010;41:e519-e536. DOI: 10.1161/STROKEAHA.110.581975
5. Risselada R, Vries LM de, Dippel DWJ, Kooten F van, Lugt A van der, Niessen WJ, et al. Incidence, treatment, and case-fatality of non-traumatic subarachnoid haemorrhage in the Netherlands. Clin. Neurol. Neurosurg. 2011;113(6):483-487. DOI: 10.1016/j.clineuro.2011.02.015
6. Nieuwkamp DJ, Setz LE, Algra A, Linn FHH, Rooij NK de, Rinkel G. Changes in case fatality of aneurysmal subarachnoid haemorrhage over time, according to age, sex, and region: a meta-analysis. Lancet Neurol. 2009;8(7):635-642. DOI: 10.1016/S1474-4422(09)70126-7
7. Nieuwkamp DJ, Vaartjes I, Algra A, Bots ML, Rinkel GJ. Age- and gender-specific time trend risk of death of patients admitted with aneurysmal subarachnoid hemorrhage in the Netherlands. Int J Stroke. 2013;8(SA100):90-94. DOI: 10.1111/ijs.12006
8. Jaja BNR, Saposnik G, Lingsma HF, Macdonald E, Thorpe KE, Mamdani M, et al. Development and validation of outcome prediction models for aneurysmal subarachnoid haemorrhage: the SAHIT multinational cohort study. BMJ. 2018;360:j5745. DOI: 10.1136/bmj.j5745
9. Dengler NF, Sommerfeld J, Diesing D, Vajkoczy P, Wolf S. Prediction of cerebral infarction and patient outcome in aneurysmal subarachnoid hemorrhage: comparison of new and established radiographic, clinical and combined scores. Eur. J. Neurol. 2017;25(1):111-119. DOI: 10.1111/ene.13471
10. Donkelaar CE van, Bakker NA, Veeger JGM, Uyttenboogaart M, Metzemaekers JDM, Eshgni O, et al. Prediction of outcome after subarachnoid hemorrhage: timing of clinical assessment. J Neurosurg. 2016;126(1):52-59. DOI: 10.3171/2016.JNS152136
11. Haug T, Sorteberg A, Finset A, Lindegaard K-F, Lundar T, Sorteberg W. Cognitive functioning and health-related quality of life 1 year after aneurysmal subarachnoid hemorhage in preoperative comatose patients (Hunt and Hess grade V patients). J. Neurosurg. 2010;66(3):475-485. DOI: 10.1227/01.NEU.0000365364.87303.AC
12. Schwartz C, Pfefferkorn T, Ebrahimi C, Ottomeyer C, Fesl G, Bender A, et al. Long-term Neurological Outcome and Quality of life after World Federation of Neurosurgical Societies Grades IV and V aneurysmal subarachnoid hemorrhage in an interdisciplinary treatment concept. J. Neurosurg. 2017;80(6):967-974. DOI: 10.1093/neuros/nyw138
13. Sasahara A, Suziki K, Takahashi Y, Koseki H, Hirota K, Ohbuch H, et al. Prognostic Assessment of Aneurysmal Subarachnoid patients with WFNS Grade V by CT perfusion on arrival. J. W. Neurosurg. 2016;92:1-6. DOI: 10.1016/j.wneu.2016.04.097
14. Witsch J, Frey HP, Patel S, Park S, Lahiri S, Schmidt JM, et al. Prognostication of long-term outcomes after subarachnoid hemorrhage: the FRESH score. Ann neurol. 2016;80(1):46-58. DOI: 10.1002/ana.24675
15. Mocco J, Ransom ER, Komotar RJ, Schmidt JM, Sciacca RR, Mayer SA, et al. Preoperative prediction of long-term outcome in poor-grade aneurysmal subarachnoid hemorrhage. J. Neurosurg. 2006;59(3):529-538. DOI: 10.1227/01.NEU.0000228680.22550.A2
16. Zafar SF, Postma EN, Biswal S, Fleuren L, Boyle EJ, Bechek S, et al. Electronic Health data predict outcomes after aneurysmal subarachnoid hemorrhage. Neurocrit care. 2018;28:184-193. DOI:10.1007/s12028-017-0466-8
17. Donkelaar CE van, Bakker NA, Birks J, Veeger NJGM, Metzemaekers JDM, Molyneux AJ, et al. Prediction of Outcome after Aneurysmal suabrachnoid hemorrhage. Development and Validation of the SAFIRE grading scale. Stroke. 2019;50(4):837-844. DOI: 10.1161/STROKEAHA.118.023902
18. Shen J, Yu J, Huang S, Mungur R, Huang K, Pan X, et al. Scoring model to predict functional outcome in poor-grade aneurysmal subarachnoid hemorrhage. Front Neurol. 2021;12(601966):1-10. DOI: 10.3389/fneur.2021.601996
19. Dijkland SA, Jagt M van der, Lingsma HF. Letter by Dijkland et al Regarding article ‘’Prediction of outcome after aneurysmal subarachnoid hemorrhage: development and validation of the SAFIRE grading scale. Stroke. 2019;50:e224. DOI: 10.1161/STROKEAHA.199.025847
20. Quinn TJ, Walters DMR, Lees KR. Functional outcome measures in contemporary stroke trails. Stroke. 2009;4(3):200-205. DOI: 10.1111/j.1747-4949.2009.00271.x
21. Mascitelli J, Cole T, Yoon S, Nakaji P, Albuquerque FC, McDougall CG, et al. External validation of the Subarachnoid hemorrhage International Trialists (SAHIT) predictive Model Using the barrow ruptured aneurysm trial (BRAT) cohort. J. Neurosurg. 2020;86(1):101-106. DOI: 10.1093/neuros/nyy600
22. Hostettler IC, Pavlou M, Ambler G, Alg VS, Bonner S, Walsh DC, et al. Assessment of the subarachnoid hemorrhage international trialists (SAHIT) models for dichotomized long-term functional outcome prediction after aneurysmal subarachnoid hemorrhage in a United Kingdom Multicenter Cohort study. J. Neurosurg. 2020;87(6):1269-1276. DOI: 10.1093/neuros/nyaa299
23. Geurts M, Macleod MR, Thiel GJMW van, Gijn J van, Kappelle J, Worp B van der. End-of-life-decisions in patients with severe acute brain injury. Lancet Neurol. 2014;13(5):515-524. DOI: 10.1016/S1474-4422(14)70030-4
24. Patel MD, Tilling K, Lawrence E, Rudd AG, Wolfe CD, McKevitt C. Relationships between long-term stroke disability, handicap and health-related quality of life. Age Ageing. 2006;35(3):273-279. DOI: 10.1093/ageing/afj074.

25. Bruno MA, Bernheim JL, Ledoux D, Pellas F, Demertzi A, Laureys S. A survey on self-assessed well-being in a cohort of chronic locked-in syndrome patients: happy majority, miserable minority. BMJ Open. 2011;1(1):1:e000039. DOI:10.1136/bmjopen-2010- 00003.
26. Albrecht GL, Devlieger PJ. The disability paradox: high quality of life against all odds. Soc. Sci. Med. 1999;48(8):977-988. DOI: 10.1016/S0277-9536(98)00411-0
27. Zink BJ. Traumatic brain injury outcome: concepts for emergency care. Medicine. 2001;37(3):318-332. DOI: 10.1067/mem.2001.112505
28. Creutzfeldt CJ, Holloway RG. Predicting decline and survival in severe acute brain injury: the fourth trajectory. BMJ. 2015;351:h3904. DOI: 10.1136/bmj.h.3904
29. Scholten AC, Haagsma JA, Andriessen TMJC, Vos PE, Steyerberg EW, Beeck EF van, et al. Health-related quality of life after mild, moderate and severe traumatic brain injury: patterns and predictors of suboptimal functioning during the first year after injury. Injury. 2015;46(4):616-624. DOI: 10.1016/j.injury.2014.10.064
30. Brice RG, Brice A. Recovery from a subarachnoid hemorrhage: patients and spouse perspectives. Commun. Disord. Q. 2017;38(2):119-128. DOI: 10.1177/1525740116638658
31. Brice AE, Brice RG, Wallace SE. Recovery from a subarachnoid hemorrhage: days 1 through 22. Commun. Disord. Q. 2016;38(1):46-51. DOI: 10.1177/1525740116638637
32. Persson HC, Törnbom K, Sunnerhage KS, Törnbom M. Consequences and coping strategies six years after subarachnoid hemorrhage- a qualitative study. PLOS ONE. 2017;12(8):e0181006. DOI: 10.1371/journal.pone.0181006
33. Visser-Meily JMA, Rhebergen ML, Rinkel GJE, Zandvoort MJ van, Post MWM. Long-term Health-related quality of life after aneurysmal subarachnoid hemorrhage. Stroke. 2009;40(4):1526-1529. DOI: 10.1161/STROKEAHA.108.531277
34. Greebe P, Rinkel GJE, Hop JW, Visser-Meily JMA, Algra A. Functional outcome and quality of life 5 and 12.5 years after aneurysmal subarachnoid haemorrhage. J Neurol. 2010;257;2059-2064. DOI: 10.1007/s00415-010-5660-y
35. Wilson DA, Nakaji P, Alburquerque FC, McDougall CG, Zabramski JM, Spetzler RF. Time course of recovery following poor-grade SAH: The incidence of delayed improvement and implications for SAH outcome study design. J Neursosurg. 2013;119(3):606-612.
36. Rinkel GJE, Algra A. Long-term outcomes of patients with aneurysmal subarachnoid haemorrhage. Lancet Neurol. 2011;10(4):349-356. DOI: 10.1016/S1474-4422(11)70017-5
37. Creswell JW. Research Design. Qualitative, Quantitative, and Mixed Methods Approaches. Second Edition. Thousand Oaks: Sage Publications; 2003.
38. Steinbüchel N von, Wilson L, Gibbons H, Hawthorne G, Höfter S, Schmidt S, et al. Quality of Life after Brain Injury (QOLIBRI): scale validity and correlates of quality of life. J. Neurotrauma. 2010;27(7):1157-1165. DOI: 10.1089/neu.2009.1077
39. Truelle JL, Wild KRH von. Advancement of the QOLIBRI use and applications. Neuropsy. 2017;7(3):228-235. DOI: 10.4172/Neuropsychiatry.1000203
40. Weir J, Steyerberg EW, Butcher I, Lingsma HF, McHug GS, Roozenbeek B, et al. Does the Extended Glasgow Outcome Scale add value to the Conventional Glasgow Outcome Scale. J. Neurotrauma. 2012;29(1):53-58. DOI: 10.1089/neu.2011.2137.
41. Baarda B. Dit is onderzoek. Handleiding voor kwantitatief en kwalitatief onderzoek. Groningen: Noordhoff Uitgevers; 2014
42.Truelle JL, Koskinen S, Hawthorne G, Sarajuuri J, Formisano R, Von Wild K, et al. Quality of life after Traumatic brain injury: the clinical use of the QOLIBRI a novel disease specific instrument. Brain Inj. 2010;24(11):1272-1291. DOI: 10.3109/02699052.2010.506865
43. Rauen K, Reichelt L, Probsts P, Schäpers B, Müller F, Jahn K, et al. Quality of life up to 10 years after traumatic brain injury: a cross-sectional analysis. Health Qual. Life Outcomes. 2020;18(166):3-12. DOI: 10.1186/s12955-020-01391-3
44. Wilson L, Marsden-Loftus I, Koskinen S, Bakx W, Bullinger M, Formisano R, et al. Interpreting Quality of Life after Brain Injury (QOLIBRI) scores: Cross-walk with the Short-Form-36. J. Neurotrauma. 2017;34:59-65. DOI: 10.1089/neu.2015.4287
45. Wilson JTL, Pettigrew LEL, Teasdale GM. Structured interviews for the Glasgow Outcome Scale and the Extended Glasgow Outcome scale: Guidelines for their use. J. Neurotrauma. 1998;15(8):573-661. DOI: 10.1089/neu.1998.15.573
46. Charmaz K, Belgrave LL. Grounded Theory. The Blackwell Encyclopedia of Sociology; 2015.
47. Hennink MM, Kaiser BN, Marconi VC. Code saturation versus meaning saturation- how many interviews are enough? Qual. Health. Res. 2017;27(4):591-608. DOI: 10.1177/1049732316665344
48. World Medical Association. WMA declaration of Helsinki-Ethical Principles for medical research involving human subjects [Internet]. Available from: https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/. [Accessed 2021 February 25th].
49. Fontanella M, Rainero I, Panciani PP, Schatlo B, Benevello C, Garbossa D, et al. Subarachnoid hemorrhage and negative angiography: clinical course and long-term follow-up. Neurosurg Rev. 2011;34(477):477-484. DOI: 10.1007/S10143-011-03230-8
50. Mierlo ML van, Heugten CM van, Post MWM, Hajos TRS, Kappelle LJ, Visser-Meily J. Quality of life during the first two years post stroke: the restore4stroke cohort study. Cerebro. Dis. 2016;41(1-2):19-26. DOI: 10.1159/000441197
51. Ayis S, Wellwoord I, Rudd AG, McKevitt C, Parkin D, Wolfe CDA. Variations in Health-related quality of life (HRQOL) and survival 1 year after stroke: five European population-based registers. BMJ open. 2015;5(6):e007101. DOI: 10.1136/bmjopen-2014-007101
52. Cowan CK, Pierson JM, Leggat SG. Psychosocial aspects of the lived experience of multiple sclerosis: personal perspectives. Disabil. Rehabil. 2018;42(3):349-359. DOI: 10.1080/09638288.2018/1498545
53. Kooiker SE. Nederlanders aan het woord over gezondheid en gezond level. Achtergrondrapport bij de VTV 2010 van gezond naar beter. 2010. Available from: https://www.rivm.nl/bibliotheek/rapporten/270061010.pdf [Accessed 2021 October 11th].

54. Steckermeier LC. The value of autonomy for the good life. An empirical investigation of autonomy and life satisfaction in Europe. Soc. Indic. Res. 2012;154;693-723. DOI: 10.1007/s11205-020-02565-8
55. Chen L, Ye M, Kahana E. A self-reliant umbrella: defining successful aging among the old-old (80+) in Shanghai. J. App. Geront. 2020;39(3):242-249. DOI: 10.1177/0733464819842500
56. Shepherd D, Landon J, Kalloor M, Barker-Collo S, Starkey N, Jones K, et al. The association between health-related quality of life and noise or light sensitivity in survivors of a mild traumatic brain injury. Qual. Life Res. 2019;29(3):665-672. DOI: 10.1007/S11136-019-02346-Y
57. Tang EYH, Price C, Stephan BCM, Robinson L, Exley C. Impact of Memory problems Post-stroke on Patients and their Family Carers: A qualitative study. Front. Med. 2020; 267(7):1-8. DOI: 10.3389/fmed.2020.00267
58. Nakling AE, Aarsland D, Naess H, Wollschlaeger D, Fladby T, Hofstad H, et al. Cognitive Deficits in Chronic Stroke Patients: Neuropsychological Assessment, Depression, and Self-Reports. Dement. Geriatr. Cogn. Disord. Extra. 2017;7:283-296. DOI: 10.1159/000479951
59. Verberne DPJ, Ponds RWHM, Kroese MEAL, Wijenberg MLM, Barten DG, Pasmans R, et al. Long-term psychosocial outcome following mild traumatic brain injury and minor stroke: a direct longitudinal comparison. J. Neurol. 2021;268(6):2132-2140. DOI: 10.1007/S00415-020-10385-6
60. Chun HYY, Whiteley WN, Dennis MS, Mead GE, Carson AJ. Anxiety after stroke- the importance of subtyping. Stroke. 2018;49(3):556-564. DOI: 10.1161/STROKEAHA.117.0200078
61. Vogelsang AC von, Forsberg C, Svensson M, Wengström Y. Patients experience high levels of anxiety 2 years following aneurysmal subarachnoid hemorrhage. World Neurosurg. 2015;83(6):1090-1097. DOI: 10.1016/j.wneu.2014.12.027
62. Morris PG, Wilson JTL, Dunn L. Anxiety and depression after spontaneous subarachnoid hemorrhage. J. Neurosurg. 2004;54(1):47-54.
63. Schöttke H, Giabbiconi CM. Post-stroke depression and post-stroke anxiety: prevalence and predictors. Int. Psychogeriatr. 2015;27(11):1805-1812. DOI: 10.1017/S1041610215000988
64. Humphris GM, Rogers S, McNally D, Lee-Jones C, Brown J, Vaughan D. Fear of recurrence and possible cases of anxiety and depression in orofacial cancer patients. Int. J. Oral Maxillofac. Surg. 2003;32(5):486-491. DOI: 10.1054/IJOM.2002.0399
65. Lebel S, Beattie S, Arès I, Bielajew C. Young and Worried: Age and Fear of recurrence in Breast Cancer survivors. J. Health Psychol. 2013; 32(6):695-705. DOI: 10.1037/a0030186
66. Dunn LB, Langford DJ, Paul SM, Berman MB, Shumay DM, Kober K, et al. Trajectories of fear of recurrence in women with breast cancer. Support Care Cancer. 2015;23:2033-2043. DOI: 10.1007/S0520-014-2513-8
67. Peterson JC, Allegrante JP, Pirraglia PA, Robbins L, Patrick Lane K, Boschert KA, et al. Living with heart disease after angioplasty: a qualitative study of patients who have been successful or unsuccessful in multiple behaviour change. Heart & Lung. 2010;39(2):105-115. DOI: 10.1016/j.hrtlng.2009.06.017
68. Hecker MT, Ho E, Donskey CJ. Fear of failure: Engaging patients in antimicrobial stewardship after Fecal transplantation for recurrent Clostridium difficile Infection. ICHE. 2017;38(1):127-129. DOI: 10.107/ICE.2016.236
69. Eiser C, Morse R. Quality-of-life measures in chronic diseases of childhood. Health Tech Ass. 2001;5(4):1-158.

Supplemental File 1- QOLIBRI

Respondentnummer……..

Introductie- Vragenlijst indien u zelf patiënt bent
Aan de hand van deze vragenlijst wordt onderzoek gedaan naar de kwaliteit van leven van mensen die niet aangeboren hersenletsel hebben

De vragenlijst bestaat uit drie onderdelen. In deel 1 wordt naar algemene persoonsgegevens gevraagd. In deel 2 van de vragenlijst zal worden achterhaald in welke mate u tevreden bent over verschillende aspecten van uw leven sinds uw hersenletsel. In deel 3 van de vragenlijst willen we graag duidelijker weten hoeveel last u heeft van problemen met uw gevoelens, uw beperkingen en met uw lichamelijk functioneren sinds uw hersenletsel.

De vragenlijst bestaat uit 42 vragen en het invullen hiervan zal ongeveer 20 minuten duren. De antwoorden blijven anoniem, alleen de onderzoekers hebben toegang tot de informatie. Als u problemen hebt met het invullen van de vragenlijst, vraag dan om hulp aan een naaste of aan de onderzoeker na afloop van het interview.

Aan de hand van de resultaten van de vragenlijst zal een onderzoeksverslag worden opgesteld. Na afloop kan het onderzoeksverslag met u gedeeld worden.

Bij deze willen wij u alvast bedanken voor uw deelname aan dit onderzoek.

Deel 1

1. Wat is uw geslacht?
   - ☐ Vrouw
   - ☐ Man
   - ☐ Anders

2. Wat is uw leeftijd?

   ---

3. Op welke leeftijd werd u getroffen door het hersenletsel?

   ---

4. Wat is uw hoogst afgeronde opleiding?
   - ☐ Geen opleiding
   - ☐ Basisonderwijs
   - ☐ VMBO/MAVO
   - ☐ HAVO
   - ☐ VWO
   - ☐ MBO
   - ☐ HBO
   - ☐ Universiteit
   - ☐ Anders

5. Wilt u de resultaten van de studie na afloop van het onderzoek ontvangen?
   - ☐ Ja, via de mail. Mijn e-mailadres is:

   - ☐ Ja, via de post.
   - ☐ Nee

Deel 2

In deel 2 van de vragenlijst willen wij graag weten in welke mate u tevreden bent met verschillende aspecten van uw leven sinds uw hersenletsel. Kies de mogelijkheid die het beste weergeeft hoe u zich op dit moment (inclusief de afgelopen week) voelt door in het bijpassende vakje een kruisje (''X'') te zetten.

A. Deze vragen gaan over uw vermogen om te denken en uw hersenen te gebruiken op dit moment (inclusief de afgelopen week).	Helemaal niet	Een beetje	Enigszins	Nogal	Heel erg
1. Hoe tevreden bent u over uw vermogen u te concentreren, bijvoorbeeld bij lezen of bij het volgen van een gesprek?					
2. Hoe tevreden bent u over uw vermogen om uzelf in een gesprek te uiten en anderen te begrijpen?					
3. Hoe tevreden bent u over uw vermogen om alledaagse dingen te onthouden, bijvoorbeeld waar u uw spullen hebt gelaten?					
4. Hoe tevreden bent u over uw vermogen om oplossingen te bedenken en uit te voeren voor praktische, alledaagse problemen, bijvoorbeeld wat te doen als u uw sleutels kwijt bent?					
5. Hoe tevreden bent u over uw vermogen om beslissingen te nemen?					
6. Hoe tevreden bent u over uw vermogen om de weg te vinden in de omgeving?					
7. Hoe tevreden bent u over uw denksnelheid?					

B. Deze vragen gaan over uw gevoelens en zelfbeeld op dit moment (inclusief de afgelopen week).	Helemaal niet	Een beetje	Enigszins	Nogal	Heel erg
1. Hoe tevreden ben u momenteel over uw energieniveau (fitheid)?					
2. Hoe tevreden bent u over de mate van motivatie die u hebt om dingen te doen?					
3. Hoe tevreden bent u over hoe waardevol u zich voelt?					
4. Hoe tevreden bent u over uw uiterlijk?					
5. Hoe tevreden bent u over wat u hebt bereikt sinds u getroffen werd door uw hersenletsel?					
6. Hoe tevreden bent u over hoe u zichzelf ervaart?					
7. Hoe tevreden bent u over u toekomstverwachtingen?					

C. Deze vragen gaan over uw mate van onafhankelijkheid en functioneren in het dagelijks leven op dit moment (inclusief de afgelopen week).

	Helemaal niet	Een beetje	Enigszins	Nogal	Heel erg
1. Hoe tevreden bent u over de mate waarin u onafhankelijk bent van anderen?					
2. Hoe tevreden bent u over uw vermogen om erop uit te gaan?					
3. Hoe tevreden bent u over uw vermogen om huishoudelijke taken uit te voeren, bijvoorbeeld koken of kleine reparaties uitvoeren?					
4. Hoe tevreden bent u over uw vermogen om uw geldzaken te regelen?					
5. Hoe tevreden bent u over uw deelname aan werk (of het volgen van een opleiding)?					
6. Hoe tevreden bent u over uw deelname aan sociale- en vrijetijdsactiviteiten bijvoorbeeld sporten, hobby's en feestjes?					
7. Hoe tevreden bent u over de mate waarin u controle hebt over uw eigen leven?					

D. Deze vragen gaan over uw sociale relaties op dit moment (inclusief afgelopen week)

	Helemaal niet	Een beetje	Enigszins	Nogal	Heel erg
1. Hoe tevreden bent u over uw vermogen om genegenheid en affectie te voelen voor anderen zoals partner, familie en vrienden?					
2. Hoe tevreden bent u over de relaties met uw familie?					
3. Hoe tevreden bent u over de relaties met uw vrienden?					
4. Hoe tevreden bent u over de relatie met uw partner of met het feit dat u geen partner hebt?					
5. Hoe tevreden bent u over uw seksleven?					
6. Hoe tevreden bent u over de houding die anderen tegenover u innemen?					

Deel 3

In deel 3 van de vragenlijst willen we graag duidelijker weten hoeveel last u heeft van problemen met uw gevoelens, uw beperkingen en met uw lichamelijk functioneren sinds uw hersenletsel. Kies de mogelijkheid die het beste weergeeft hoe u zich nu (inclusief de afgelopen week) voelt door in het bijpassende vakje een kruisje (''X'') te zetten.

E. Deze vragen gaan over de mate waarin u last hebt van uw gevoelens.	Helemaal niet	Een beetje	Enigszins	Nogal	Heel erg
1. Hoeveel last hebt u van gevoelens van eenzaamheid, zelfs wanneer u in gezelschap van anderen bent?					
2. Hoeveel last hebt u van gevoelens van verveling?					
3. Hoeveel last hebt u van angstgevoelens?					
4. Hoeveel last hebt u van gevoelens van verdriet of somberheid?					
5. Hoeveel last hebt u van gevoelens van boosheid of agressie?					

F. Deze vragen gaan over de mate waarin u op dit moment (inclusief de afgelopen week) last hebt van lichamelijke problemen.	Helemaal niet	Een beetje	Enigszins	Nogal	Heel erg
1. Hoeveel last hebt u van traagheid en/of onhandigheid tijdens het bewegen?					
2. Hoeveel last hebt u van de gevolgen van andere letsels tegelijkertijd opgelopen met uw hersenletsel?					
3. Hoeveel last hebt u van pijn (inclusief hoofdpijn)?					
4. Hoeveel last hebt u van problemen met zien of horen?					
5. Hoeveel last hebt u, over het geheel genomen, van de gevolgen van uw hersenletsel?					

Dit is het einde van de vragenlijst. Bedankt voor het invullen. U kunt de vragenlijst retourneren in de bijgeleverde antwoordenvelop. U kunt de vragenlijst ook meegeven aan de onderzoeker tijdens het interview.

Supplemental File 2- PRO-QOLIBRI

Respondentnummer……..

Introductie – Vragenlijst indien u de vertegenwoordiger van de patiënt bent.
Aan de hand van deze vragenlijst wordt onderzoek gedaan naar de kwaliteit van leven van mensen die niet aangeboren hersenletsel hebben. Deze variant van de vragenlijst is speciaal ontwikkeld voor naasten.

De vragenlijst bestaat uit drie onderdelen. In deel 1 wordt naar algemene persoonsgegevens van uw naaste gevraagd. In deel 2 van de vragenlijst zal worden achterhaald in welke mate uw naaste tevreden is over verschillende aspecten van zijn/haar leven sinds het hersenletsel. In deel 3 van de vragenlijst willen we graag duidelijker weten hoeveel last uw naaste heeft van problemen met zijn/haar gevoelens, zijn/haar beperkingen en met zijn/haar lichamelijk functioneren sinds het hersenletsel.

De vragenlijst bestaat uit 42 vragen en het invullen hiervan zal ongeveer 20 minuten duren. De antwoorden blijven anoniem, alleen de onderzoekers hebben toegang tot de informatie. Als u problemen hebt met het invullen van de vragenlijst, vraag dan om hulp aan familieleden of aan de onderzoeker na afloop van het interview.

Aan de hand van de resultaten van de vragenlijst zal een onderzoeksverslag worden opgesteld. Na afloop kan het onderzoeksverslag met u gedeeld worden.

Deel 1

1. Wat is het geslacht van uw naaste?
   - ☐ Vrouw
   - ☐ Man
   - ☐ Anders

2. Wat de leeftijd van uw naaste?

   ---

3. Wat is de hoogst afgeronde opleiding van uw naaste?
   - ☐ Geen opleiding
   - ☐ Basisonderwijs
   - ☐ VMBO/MAVO
   - ☐ HAVO
   - ☐ VWO
   - ☐ MBO
   - ☐ HBO
   - ☐ Universiteit
   - ☐ Anders

4. Wilt u de resultaten van de studie na afloop van het onderzoek ontvangen?
   - ☐ Ja, via de mail. Mijn e-mailadres is:

   - ☐ Ja, via de post.
   - ☐ Nee

Deel 2

In deel 2 van de vragenlijst willen wij graag weten in welke mate uw naaste tevreden is over verschillende aspecten van het leven sinds het hersenletsel. Kies de mogelijkheid die het beste weergeeft hoe uw naaste zich waarschijnlijk op dit moment (inclusief de afgelopen week) voelt door in het bijpassende vakje een kruisje (''X'') te zetten.

A. Deze vragen gaan over het vermogen van uw naaste om te denken en zijn/haar hersenen te gebruiken op dit moment (inclusief de afgelopen week).	Helemaal niet	Een beetje	Enigszins	Nogal	Heel erg
1. Hoe tevreden is uw naaste, volgens u, over zijn/haar vermogen zich te concentreren, bijvoorbeeld bij lezen of bij het volgen van een gesprek?					
2. Hoe tevreden is uw naaste, volgens u, over zijn/haar vermogen om zichzelf in een gesprek te uiten en anderen te begrijpen?					
3. Hoe tevreden is uw naaste, volgens u, over zijn/haar vermogen om alledaagse dingen te onthouden, bijvoorbeeld waar hij/zij spullen heeft gelaten?					
4. Hoe tevreden is uw naaste, volgens u, over zijn/haar vermogen om oplossingen te bedenken en uit te voeren voor praktische, alledaagse problemen, bijvoorbeeld wat te doen als uw naaste zijn/haar sleutels kwijt is?					
5. Hoe tevreden is uw naaste, volgens u, over zijn/haar vermogen om beslissingen te nemen?					
6. Hoe tevreden is uw naaste, volgens u, over zijn/haar vermogen om de weg te vinden in de omgeving?					
7. Hoe tevreden is uw naaste, volgens u, over zijn/haar denksnelheid?					

B. Deze vragen gaan over de gevoelens en zelfbeeld van uw naaste op dit moment (inclusief de afgelopen week).	Helemaal niet	Een beetje	Enigszins	Nogal	Heel erg
1. Hoe tevreden is uw naaste, volgens u, over zijn/haar energieniveau (fitheid)?					
2. Hoe tevreden is uw naaste, volgens u, over de mate van motivatie die hij/zij heeft om dingen te doen?					
3. Hoe tevreden is uw naaste, volgens u, over hoe waardevol hij/zij zich voelt?					
4. Hoe tevreden is uw naaste, volgens u, over zijn/haar uiterlijk?					
5. Hoe tevreden is uw naaste, volgens u, over wat hij/zij heeft bereikt sinds hij/zij getroffen werd door hersenletsel?					
6. Hoe tevreden is uw naaste, volgens u, over hoe hij/zij zichzelf ervaart?					
7. Hoe tevreden is uw naaste, volgens u, over zijn/haar toekomstverwachtingen?					

C. Deze vragen gaan over de mate van onafhankelijkheid en functioneren in het dagelijks leven op dit moment (inclusief de afgelopen week).

	Helemaal niet	Een beetje	Enigszins	Nogal	Heel erg
1. Hoe tevreden is uw naaste, volgens u, over de mate waarin hij/zij onafhankelijk is van anderen?					
2. Hoe tevreden is uw naaste, volgens u, over zijn/haar vermogen om erop uit te gaan?					
3. Hoe tevreden is uw naaste, volgens u, over zijn/haar vermogen om huishoudelijke taken uit te voeren, bijvoorbeeld koken of kleine reparaties?					
4. Hoe tevreden is uw naaste, volgens u, over zijn/haar vermogen om eigen geldzaken te regelen?					
5. Hoe tevreden is uw naaste, volgens u, over deelname aan werk (of het volgen van een opleiding)?					
6. Hoe tevreden is uw naaste, volgens u, over zijn/haar deelname aan sociale- en vrijetijdsactiviteiten bijvoorbeeld sporten, hobby's en feestjes?					
7. Hoe tevreden is uw naaste, volgens u, over de mate waarin hij/zij controle heeft over het eigen leven?					

D. Deze vragen gaan over de sociale relaties van uw naaste op dit moment (inclusief de afgelopen week)

	Helemaal niet	Een beetje	Enigszins	Nogal	Heel erg
1. Hoe tevreden is uw naaste, volgens u, over zijn/haar vermogen om genegenheid en affectie te voelen voor anderen zoals partner, familie en vrienden?					
2. Hoe tevreden is uw naaste, volgens u, over de relaties met zijn/haar familie?					
3. Hoe tevreden is uw naaste, volgens u, over de relaties met zijn/haar vrienden?					
4. Hoe tevreden is uw naaste, volgens u, over de relatie met zijn/haar partner of met het feit dat hij/zij geen partner heeft?					
5. Hoe tevreden is uw naaste, volgens u, over zijn/haar seksleven?					
6. Hoe tevreden is uw naaste, volgens u, over de houding die anderen tegenover hem/haar innemen?					

Deel 3

In deel 3 van de vragenlijst willen we graag duidelijker weten hoeveel uw naaste last heeft van problemen met zijn/haar gevoelens, zijn/haar beperkingen en met zijn/haar lichamelijk functioneren sinds het hersenletsel. Kies de mogelijkheid die het beste weergeeft hoe uw naaste zich nu waarschijnlijk (inclusief de afgelopen week) voelt door in het bijpassende vakje een kruisje (''X'') te zetten.

E. Deze vragen gaan over de mate waarin uw naaste op dit moment (inclusief de afgelopen week) last heeft van zij/haar gevoelens.	Helemaal niet	Een beetje	Enigszins	Nogal	Heel erg
1. Hoeveel last heeft uw naaste, volgens u, van gevoelens van eenzaamheid, zelfs wanneer hij/zij in gezelschap van anderen is?					
2. Hoeveel last heeft uw naaste, volgens u, van gevoelens van verveling?					
3. Hoeveel last heeft uw naaste, volgens u, van angstgevoelens?					
4. Hoeveel last heeft uw naaste, volgens u, van gevoelens van verdriet of somberheid?					
5. Hoeveel last heeft uw naaste, volgens u, van gevoelens van boosheid of agressie?					

F. Deze vragen gaan over de mate waarin uw naaste op dit moment (inclusief de afgelopen week) last heeft van lichamelijke problemen.	Helemaal niet	Een beetje	Enigszins	Nogal	Heel erg
1. Hoeveel last heeft uw naaste, volgens u, van traagheid en/of onhandigheid tijdens het bewegen?					
2. Hoeveel last heeft uw naaste, volgens u, van de gevolgen van andere letsels tegelijkertijd opgelopen met uw hersenletsel?					
3. Hoeveel last heeft uw naaste, volgens u, van pijn (inclusief hoofdpijn)?					
4. Hoeveel last heeft uw naaste, volgens u, van problemen met zien of horen?					
5. Hoeveel last heeft uw naaste, volgens u, van de gevolgen van zijn/haar hersenletsel?					

Dit is het einde van de vragenlijst. Bedankt voor het invullen. U kunt de vragenlijst terugsturen in de bijgeleverde antwoordenvelop. U kunt de vragenlijst ook meegeven aan de onderzoeker tijdens het interview.

Supplemental File 3- GOSE

Respondentnummer……
Respondent: Enkel de patiënt / Enkel de naaste / Patiënt en naaste

Bewustzijn

1. Is de patiënt / respondent in staat om simpele commando's op te volgen dan wel te praten?

☐ Nee (VS)
☐ Ja

Onafhankelijkheid in huis

2a. Is de hulp van een ander persoon nodig om essentiële dagelijkse taken uit te voeren?

☐ Nee (ga naar vraag 3a)
☐ Ja

Om nee te kunnen antwoorden moet de respondent in staat zijn om ADL (wassen, aankleden, bereiden en nuttigen van maaltijden) gerelateerde activiteiten uit te voeren zonder daar aan herinnerd te worden. Tevens moet men in staat zijn om de nacht alleen door te brengen.

2b. Is frequente hulp of de aanwezigheid van een ander persoon gedurende de dag nodig?

☐ Nee (Upper SD)
☐ Ja (Lower SD)

Om nee te kunnen antwoorden moet de respondent in staat zijn om maximaal 8 uur per dag alleen te zijn.

2c. Was frequente hulp of aanwezigheid van een ander persoon gedurende de dag nodig voor het letsel?

☐ Nee
☐ Ja

Onafhankelijkheid buiten huis

3a. Is de respondent in staat om zelfstandig boodschappen te doen?

☐ Nee (Upper SD)
☐ Ja

Om ja te kunnen antwoorden is het van belang dat de respondent in staat is zelfstandig te kunnen bepalen wat men wil kopen en man toe kan zien op de uitgaven

3b. Was de respondent in staat om zelfstandig boodschappen te doen voor het letsel?

☐ Nee
☐ Ja

Reizen

4a. Is de respondent in staat zelfstandig lokaal te reizen?

- ☐ Nee (Upper SD)
- ☐ Ja

Om ja te kunnen antwoorden, is het voldoende dat men zelfstandig met het OV of taxi kan reizen, onder voorwaarde dat men zelf de reis kan plannen en een taxi kan reserveren.

4b. Was de respondent in staat om zelfstandig te reizen voor het letsel?

- ☐ Nee
- ☐ Ja

Werk / studie

5a. Is de respondent in staat om werk- / studiegerelateerde taken in dezelfde mate uit te voeren als voor het letsel?

- ☐ Nee
- ☐ Ja (ga naar 6a)

Als de respondent voor aanvang van het onderzoek geen werk had, moet de kans op het krijgen van werk niet beïnvloed worden door het verworven letsel.

5b. Hoe beperkt is de respondent

- ☐ Verminderd (Upper MD)
- ☐ De respondent is enkel in staat om te werken in een beschermde omgeving, in een '*non competitive job'* of is niet in staat om te werken.

5c. Werkte dan wel zocht de respondent werk voor het letsel?

- ☐ Nee
- ☐ Ja

Sociale activiteiten

6a. Is de respondent in staat om sociale- en vrijetijdsactiviteiten buiten huis weer op te pakken?

- ☐ Nee
- ☐ Ja

Men moet geen fysieke of psychische belemmeringen ervaring. Dit betreft ook interesse en motivatie.

6b. In welke mate wordt de respondent beperkt met betrekking tot de sociale- en vrijetijdsactiviteiten?

- ☐ Iets minder, maximaal de helft minder (Lower GR)
- ☐ Veel minder (meer dan de helft minder (Upper MD)
- ☐ Niet in staat om sociale en vrijetijdsactiviteiten op te pakken (Lower MD)

6c. Nam de respondent voor het letsel deel aan sociale vrijetijdsactiviteiten buiten huis?

- ☐ Nee
- ☐ Ja

Familie & vriendschap

7a. Zijn er persoonlijkheidsveranderingen die geresulteerd hebben in problemen in vriendschap en familie relaties?

- ☐ Nee
- ☐ Ja

Veelvoorkomende persoonlijkheidsveranderingen zijn opvliegendheid, prikkelbaarheid, angst, ongevoeligheid richting naasten, stemmingswisselingen, depressies en onredelijk of kinderlijk gedrag.

7b. In welke mate zijn er problemen?

- ☐ Soms, minder dan wekelijks (Lower GR)
- ☐ Vaak, wekelijks of vaker maar het is tolereerbaar (Upper MD)
- ☐ Constant, dagelijks maar niet tolereerbaar (Lower MD)

7c. Waren er problemen in de relaties met familie en vrienden voor het letsel?

- ☐ Nee
- ☐ Ja

Normaal leven

8a. Zijn er andere problemen gerelateerd aan het letsel die het dagelijkse leven beïnvloeden?

- ☐ Nee (Upper GR)
- ☐ Ja (Lower GR)

Veelvoorkomende problemen zijn: hoofdpijn, duizeligheid, moeheid, overgevoeligheid voor geluid en licht, traagheid, geheugenproblemen en concentratieproblemen.

8b. Had de respondent voor het letsel zulke problemen?

- ☐ Nee
- ☐ Ja

Als er voor het letsel problemen waren, en deze problemen zijn erger geworden sinds het letsel antwoord dan Nee op vraag 8b.

Supplemental File 4- INTERVIEW GUIDE

Respondentnummer ……

Goedemorgen/middag, ik ben Marloes
Allereerst wil ik u hartelijk bedanken dat u ingestemd heeft met dit interview. Ik zal eerst nog een keer vertellen wat het doel is van het interview. Ik wil graag informatie verzamelen over de gevolgen van uw hersenbloeding. Ik wil graag in kaart brengen welke gevolgen de hersenbloeding op uw leven heeft. Alles wat u mij vertelt hebt, wordt vertrouwelijk behandeld. De opname wordt alleen gebruikt om het interview uit te werken. Nadat het is afgeluisterd en verwerkt, wordt de opname gewist. Als alle interviews zijn uitgewerkt wordt een verslag gemaakt. Tijdens het interview zal ik af en toe aantekeningen maken om voor mezelf de lijn van het gesprek vast te houden. Het gesprek duurt maximaal anderhalf-uur. Heeft u tot zover vragen? Stelt u het op prijs als ik u zeg of heeft u liever dat ik jij zeg?

Dan start ik nu de opname.

Topic 1 Introductie

- Ik vind het eerst wel fijn om een algemene vraag te stellen; hoe gaat het nu met u / jou ?
- Een poosje geleden heeft u/ heb jij als gevolg van een hersenbloeding op de intensive care van het Radboudumc gelegen. Zou u/jij mij iets meer over deze periode kunnen vertellen?

Notities topic 1

Topic 2 Gevolgen

- Welke veranderingen hebben in uw / jouw dagelijks leven plaatsgevonden sinds uw / jouw hersenbloeding?
- Wat vindt u / jij van deze veranderingen?
    - Welke veranderingen hebben het meeste impact op uw / jouw dagelijks leven?
        - Waarom?
    - Welke veranderingen hebben het minste impact op uw / jouw dagelijks leven?
        - Waarom?
- Let op: Doorvragen!!

Notities topic 2

Topic 3 Kwaliteit van leven

- Wat is uw / jouw kwaliteit van leven?
- Kunt u / kan jij mij vertellen waarom uw / jouw kwaliteit van leven goed / matig / slecht is?
- Let op: Doorvragen!

Notities topic 3

Ter afsluiting heb ik nog enkele gesloten vragen die ik met u zou willen doornemen. Dit zal nog maximaal 10 minuten van uw tijd in beslag nemen.

Einde

Dit is het eind van het interview, ik wil u hartelijk bedanken voor de tijd en de moeite. Heeft u nog iets gemist of wat toe te voegen?

- Is het invullen van de vragenlijst gelukt?
- Vermelden dat de geïnterviewde altijd contact kan opnemen voor vragen of verdere informatie die hij/zij vergeten is te vertellen.
- Emailadres en telefoonnummer achterlaten

Supplemental File 5- DATA SATURATION

Table 5 Meaning saturation method Hennink et al. [47]

Dimensions					
Theme	**Subtheme**	**By interview 3**	**By interview 6**	**By interview 9**	**After interview 9**
Being independent for everyday activities is most important for patients	Personal self-care	- being dependent on others for dressing is burdensome (1) - happy being independent for personal selfcare activities (2)	- being dependent on others to get out of bed is burdensome (5) - being dependent on others for showering is burdensome (5) - being dependent on others for toileting is burdensome (5)		
	Household chores	- happy being able to cook independently (2)	- being dependent on others for cleaning is burdensome (4) - being dependent on others for cooking is burdensome (4)		- happy being able to clean the windows independently (12)
	Mobility	- being unable to drive a car is burdensome (1) - happy being independent for mobility (2)	- being dependent on others for mobility is burdensome, since it limits freedom (4) - being dependent on others for mobility is burdensome, since patients are no longer able to visit family members independently (4)		

Leaving or avoiding situations due to sensitivity to external stimuli	Multiple people	- being in a group with multiple people is too busy (1)			- conversations with multiple people are tough (11)
	Noise			- sensitive to noise (7) - avoiding or leaving situations with noise (7)	
	Light flashes			- sensitive to light flashes (7) - avoiding or leaving situations with light flashes (7)	
Being unable to remember anything that happened on the short-term or during youth is challenging	Short-term memory problems	- having short-term memory problems (1)	- being unable to remember that family members visited is hard (6)	- being unable to remember what was said during conversations (9) - in need of help of relatives while having a conversation (9)	
	Long-term memory problems	- having long-term memory problems (1) - unable to recognize close relatives (3)	- being unable to remember what happened during youth is hard (6)		
Due to fear of recurrence patients are less able to return back to a normal life	Fear of dying			- fear of dying (9) - fear of dying causes stress (9) - scan of the head to deal with fear of dying (9)	
	Fear of worsening of disabilities		- fear of the physical, emotional, and cognitive consequences of recurrence (4) - fear of worsening of disabilities causes a low energy-level (4)	- fear of worsening of disabilities causes stress (9) - scan of the head to deal with fear of worsening of disabilities (9)	

			- a low energy-level due to fear of worsening of disabilities is hard to regulate (4) - a low energy-level due to fear of worsening of disabilities is hard to accept (4) - EMDR to deal with fear of worsening of disabilities (4) - guidance by a psychologist to deal with fear of worsening of disabilities - flattened life due to fear of worsening of disabilities (4) - being less able to participate in rehabilitation programmes due to fear of worsening of disabilities (6)		

Note 1: Between () is the number of the interview in which the dimension was first identified