Fatigue after acquired brain injury – a validation study of the Dutch Multifactor Fatigue Scale

Bachelor thesis

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Psychology, Health and Technology

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Author: Nina van den Berg (s1981331)

Supervisor 1: Dr. Christina Bode

Supervisor 2: Dr. Erik Taal

Abstract

Objective: Fatigue is one of the most common symptoms after acquired brain injury and is highly impacting on the patients' daily life. Despite its high prevalence, biological mechanisms of fatigue are not properly understood and treatment options are rare. The DMFS is the first questionnaire taking all aspects of fatigue into account and seems thus, to be promising of getting more insight into the symptom. Since the DMFS has only been validated once by its developers, this study aims to validate the questionnaire in another sample of ABI patients and test whether the results of the first study are replicable. Next, items of fatigue which have the highest impact as well as aspects which should be used for monitoring fatigue are intended to be identified.

Method: Besides the DMFS, the FSS and HADS were included into the study for validation purposes and applied to a sample (N=31) of ischemic stroke or intracerebral hemorrhage patients at the outpatient clinic six to eight months after the patients' admission.

Results: The results indicated good internal consistency for all subscales except for 'Coping with fatigue'. No appropriate construct validity was found since the DMFS correlated not only with the fatigue measure FSS but also with measures of pathological forms of distress like anxiety. Physical and mental fatigue were identified as the ones having the most impact on the patients' daily life. For monitoring, no meaningful result was found.

Discussion: The DMFS could have been validated in regard of reliability, however, the result was not as significant as in the first validation study which might be due to the small sample size. In a further study, this has to be improved. The sample seemed to indicate a low fatigue level which might explain the result of construct validity and the psychometric properties of the scale 'Coping with fatigue'. No aspect for monitoring fatigue could have been found since the research on this subject is poor and the design of this study did not allow to further investigate this topic. Still the results give insight into what aspects of fatigue are influencing the most which might be a good starting point for further research and interventions.

Introduction

Two months after her 50th birthday, Anouk was watching TV with her husband when she suddenly started to feel unwell. She fell from her chair and her left arm was uncontrollably waving around. Her husband called the ambulance immediately. She remembered that in the hospital, " I couldn't eat or drink and I slept for 90% of the day." Around 32 hours after her admission, the doctor confirmed her stroke. Fortunately, later in the day, Anouk was able to eat and walk without any help again. When leaving the hospital the next day, Anouk did not really realize what happened to her. But the impact on her daily life was huge. At home, she felt afraid and tired. Anouk was not able to drive and thus had to walk everywhere. Since trivial tasks were exhausting to her, she needed to sleep an extra 1-3 hours per day. Anouk said: "I really was not prepared for the tiredness." Her social life was suffering as well. Since she was neither able to go to the meetings nor prepare the food, she stopped going out and attending her slimming club. During a follow-up meeting at the hospital, Anouk reported her complaints and was hence, provided with questionnaires assessing her fatigue to get more insight into her fatigue. Additionally, her doctor suggested to start a diary and monitor the activities which exhaust her the most. Anouk was skeptical if these methods will help her.

The use of questionnaires assessing the fatigue of neurological patients is an option to get more insight into the symptom to help patients becoming more aware of their complaints and support them with targeted treatment options. One questionnaire which might be provided to patients like Anouk is the Dutch Multifactor Fatigue Scale (DMFS) developed by Visser-Keizer, Hogenkamp, Westerhof-Evers, Egberink, & Spikman, (2015). This scale is developed based on patient's experiences and is according to the authors, the only existing scale measuring all contributing factors of acquired brain injury (ABI) related fatigue and thus, is targeted to the patient's needs (Visser-Keizer et al., 2015). Other existing scales measuring fatigue do not include all dimensions of fatigue or are not developed specifically for ABI patients (Visser-Keizer et al., 2015). Thus, the quality of the DMFS has to be analyzed since it seems to be the only targeted scale for this patient group and can be thus, an important part in ABI related fatigue research.

Having a targeted scale is especially important since ABI differs from other neurological diseases. ABI refers to an injury to the brain caused by internal factors ("What is the difference between an acquired brain injury and a traumatic brain injury", 2015). This includes, for instance, strokes but also other neurological illnesses ("What is the difference between an acquired brain injury and a traumatic brain injury", 2015). A common symptom in ABI patients

is fatigue. Although some people may assume that fatigue is only characterized by tiredness and exhaustion, fatigue has been shown to impair both physical and mental-wellbeing in patients with ABI (Glader, Stegmayr, & Asplund, 2002). It can either be a direct consequence of the acquired injury or an indirect consequence due to other complaints such as medication, anemia, physical deconditioning, or pain which cooccur with a neurological symptom (Visser-Keizer et al., 2015). Speaking of fatigue as a primary symptom, ABI related fatigue arises due to changes in the whole brain functioning caused by the injury. These changes lead to problems or the inability to perform mentally demanding tasks which require more mental effort and hence, increased physical activity of the brain (Visser-Keizer et al., 2015). In order to compensate for cognitive impairments, the patient's brain is working harder than usual (Ulrichsen et al., 2016). Furthermore, fatigue is described by patients as one of the most challenging symptoms after acquired brain injury (Palm, & Rönnbäck, & Johansson, 2017). Thus, ABI related fatigue is not only the feeling of exhaustion but a clinical symptom and has to be taken seriously since it is prevalent in 68% of Dutch ABI patients (Cumming, Packer, Kramer & English, 2016). Moreover, fatigue is also prevalent in association with other diseases.

One disease which is in many studies associated with fatigue is depression. Prevalence rates of fatigue in studies in which depression is an exclusion criterion are consequently lower (Cumming et al., 2016). There are overlapping symptoms such as concentration difficulties, decreased sleep and lack of initiative (Johansson & Rönnbäck, 2014). Nonetheless, fatigue after acquired brain injury is also prevalent without depression (Kluger, Krupp & Enoka, 2013) indicating that depression and fatigue are two independent predictors for a poor functional outcome (Glader et al., 2002). Both conditions are associated in some way but that the role of depression for fatigue is a matter for further analysis. Beside depression, a study of Winnie et al. (2009) shows an association between anxiety as a psychological disorder and fatigue. Both are reducing the patient's quality of life (Kluger et al., 2013; Winnie et al., 2009) which might be due to their distressing nature. Moreover, some symptoms of anxiety disorder like sleeping difficulties, exhaustion or cognitive stress (Davey, 2014) are also found in people suffering from ABI related fatigue (Johansson & Rönnbäck, 2014). However, with or without depression/anxiety, fatigue has a huge impact on the patient's life and consequently changes the patient's daily routine.

Participation in everyday life is due to ABI related fatigue limited. Since the symptom appears very rapidly and is long-lasting, it makes it challenging for the patient to continue ongoing activities (Johansson & Rönnbäck, 2014). Common activities which are interfered by ABI related fatigue are seemingly trivial like reading a book, having a conversation, or

watching television (Johansson & Rönnbäck, 2014). Moreover, the affected person is unable to fully be part of a social interaction which decreases the overall well-being of a person due to feelings of isolation and loneliness (Curt, 2000). Hence, the fatigue is impacting the patient in different areas as for instance the physical, mental or social life. Moreover, fatigue interferes with the process of rehabilitation and hinders the patient to regain cognitive, emotional and social functions which were lost after the acquired brain injury (Glader et al., 2002). Thus, it can take years to accept the situation and to find the right balance between rest and activity (Johansson, Bjuhr, & Rönnbäck, 2015). In order to effectively help the patient recovering, all different aspects like emotional, social, cognitive or physical components which are influenced by the ABI related fatigue have to be taken into account by diagnostic instruments like the DMFS. This requires appropriate knowledge of all the concerning components of fatigue after ABI. If an component or aspect of ABI related fatigue which is impacting the patients more than others identified, interventions and treatment can focus on this and might lead to more success than general interventions. Therefore, it is crucial that measurement instruments cover many aspects of fatigue after ABI which impact the patients in their daily life.

However, even though there is a huge impact of fatigue on the patient's daily life, and fatigue being one of the most common symptoms in neurological disorders, mechanisms of fatigue are poorly understood (Kluger et al., 2013; Visser-Keizer et al., 2015). The biological correlates of associated conditions like depression, lack of sleep, or mood disturbances with fatigue after acquired brain injury are also mostly unknown (Visser-Keizer et al., 2015). Besides, there is still uncertainty about how to treat fatigue effectively (Glader et al., 2002) since the current treatment options, which can be divided into medical interventions concerning the disease and (non-) pharmacological treatments concerning the symptoms of the disease, rarely lead to successful and satisfying outcomes (Kluger et al., 2013). Since ABI related fatigue is very impacting on the quality of life of the patients it is important to do more research on the currently poorly understanding of the mechanism in order to improve treatments. Questionnaires like the DMFS might help in gaining more insight into the experiences with the symptom and its impact.

Another option, related to the use of questionnaires and to discover the phenomenon of ABI related fatigue further is monitoring patients with fatigue. Patient monitoring is defined as the tracking of an activity's progress in form of observing of a disease, condition or vital parameter of a patient and can be implemented in different ways (Gardner, Clemmer, Evans & Mark, 2014). Patients who are already at home but still suffer from conditions or have chronic diseases which need to be monitored, observe their activities and complaints on a regular basis

(Jacqui & Malley, 2008). This type refers to self-monitoring as the patient itself or the people in the patient's environment can collect this data (Malley, Wheatcroft & Gracey, 2014). In the case of measuring fatigue, the first step is to recognize the fatigue and the stimuli or activities which are triggering it (Jacqui & Malley, 2008). Related to this, common signs of worsening are losing concentration or attention, a blurry vision, getting irritable or a feeling of sickness in the stomach. Afterwards, monitoring the fatigue can be done by reporting the activity and the perceived impact or tiredness. The aim is to identify activities which are more or less exhausting in order to establish a daily routine (Jacqui & Malley, 2008). Since fatigue is impacting a patient on different aspects as for instance physically or mentally, it is useful to know which aspect is the most uncontrollable and get back control and improve the patient's quality of life. Additionally, aspects which should be monitored can be identified by applying questionnaires like the DMFS which is assessing different aspects of fatigue after ABI and could give orientation for monitoring. More precisely, single items of the questionnaire could be identified which seem most useful and appropriate for monitoring.

However, to measure fatigue properly and to obtain a well-established overview, the questionnaire needs to fulfill certain criteria to ensure its quality. In particular, the questionnaire needs to indicate high reliability and validity in order to diagnose the symptom of fatigue accurately. Firstly, reliability refers to the consistency of a measure (Cherry, 2020). A part of reliability is internal consistency. An adequate internal consistency means that the single items in the questionnaire are all measuring aspects or facets of the same construct (Babbie, 2015). Secondly, validity is part of indicating the quality of an instrument. Validity describes the degree to which the measure reflects the content it is intended to measure (Babbie, 2015). Validity has different aspects. The one which will be covered in this study is construct-related validity. A high construct-related validity indicates the quality that the questionnaire measures a theoretical construct (Groth-Marnat,, Wright, 2009). A questionnaire measuring fatigue needs to measure all variables and factors which belong to the theoretical construct of the symptom. Two measures which measure the same construct, as for example fatigue, should have a high correlation. In regard to fatigue after acquired brain injury, a questionnaire should also cover the different components of fatigue which impact the patient's life. This makes it able to identify aspects which engage or impair the patients the most.

Regarding the DMFS, different factors of ABI related fatigue are taken into account. The scale was established based on the mentioned lack of specific questionnaires for ABI related fatigue. More precisely, different factors were developed, conceptualized and tested

based on patient and partner interviews which resulted in 5 factors and 38 items which should be answered by patients on a 5-point Likert scale (table 1) (Visser-Keizer et al., 2015).

Table 1. Factors of the DMFS and examples of items

Factor	Example item	N of items
Impact of fatigue	I am often tired	11
Mental fatigue	Thinking makes me fatigued	9
Signs and direct consequences of fatigue	When fatigued, I get a headache	7
Physical fatigue	I have little energy	6
Coping with fatigue	I consciously plan when I will rest	5

Moreover, the DMFS was once validated in the study of Visser-Keizer et al. (2015) which was a cross-sectional survey study aiming at the development and the subsequent validation of the DMFS. The authors analyzed the scale's psychometric properties in a mixed group of patients with ABI in the setting of an academic rehabilitation center. In order to measure the psychometric properties, the authors used several questionnaires like the Hospital Anxiety and Depression Scale (HADS), the CIS which measures fatigue during the last two weeks and the Dutch Personality Questionnaire and found good reliability as well as good convergent validity to a fatigue scale and good divergent validity with mood and self-esteem measures which let them conclude that the DMFS might improve the diagnostic process of fatigue after ABI (Visser-Keizer et al. 2915). This conclusion seems to be a positive statement in regard to the strong need for improvement of measurement and treatment options for ABI related fatigue.

This validation study aimed to test if the results of the first DMFS study are replicable when applicated on another sample of ABI patients. Therefore, one of the questionnaires used by Visser-Keizer et al. (2015) was used for the validation in this study. The Hospital Anxiety Depression Scale (HADS) measures anxiety and depression (table 2). As in the study of Visser-Keizer et al. (2015), the scale is used as a validated measure to test the association between different fatigue factors and anxiety as well as the above mentioned controversial association of fatigue. Additionally, the Fatigue Severity Scale is included in the research for validation purposes (table2). This questionnaire is the most commonly used fatigue scale (Valko, Bassetti, Bloch, Held, & Baumann, 2008). In addition, the scale seems to be useful as fatigue is described as a subjective experience and in order to capture the individual's experiences, the Fatigue

Severity Scale measures the construct of fatigue in form of a self-report (Cumming et al., 2016). Since the FSS was already validated in studies concerning participants with different disease types (autoimmune, neurological) including stroke patients (Valko et al., 2008), the scale qualifies as an appropriate medium for validating the psychometric properties of the DMFS.

Table 2. Psychometric properties of the questionnaires

	items	subscales	scale	psychometrics
DMFS	38	5 factors which measure a different factette of fatigue	5-point Likert scale Ranging from 1 to 5	Good reliability ($\alpha/\lambda \geq .80$, for factor 1,2,3), ($.70 \leq \alpha/\lambda \geq .80$, factor 4,5) and validity, different for different factors
FSS	9	no	7-point Likert scale	Good reliability Moderate validity
HADS	14	2 subscales: anxiety & depression with 7 items each	4-item scale Ranging from 0 to 3	High test-retest reliability Acceptable validity

Note. Data are from Visser-Keizer et al. (2015) Rietberg, Van Wegen, & Kwakkel (2010); Spinhoven et al., (1997); Luciano et al., (2014)

The psychometric properties of the Dutch Multifactor Scale were in the focus of this paper because the DMFS is the only existing measurement assessing all factors of fatigue which make it an important tool in ABI related fatigue diagnostic and thus, has to be validated. Since the study of Visser-Keizer et al. (2015) was the only one reporting psychometric characteristics of the DMFS until now, this study additionally aimed to validate the DMFS in regard to its reliability and validity and aims to replicate the results of Visser-Keizer et al. (2015).

In addition, the different factors of fatigue which are measured by the DMFS are analyzed regarding their impact on the patients in order to find the component of ABI related fatigue which is most impacting. As mentioned above, fatigue is highly impacting the patients in their everyday life and makes it difficult to follow a daily routine. Different areas of life are concerned, as for instance the social, mental or physical life of a patient. In order to target interventions to the need of ABI patients, aspects which are most impacting for the patients

need to be identified. This is assumed to bring more success into treatment and intervention options.

The third purpose of this study is to identify aspects of fatigue which are in need to be monitored in order to alleviate symptoms. As reported by, Jacqui and Malley (2008), monitoring fatigue aims to identify activities which are exhausting to get control over the impact and be better able to plan the day. Questionnaires like the DMFS which are covering different aspects might help in identifying aspects which seem to be useful for monitoring. However, finding items for monitoring is not applicable in a single measurement but have to be identified over time in order to identify fluxions and impact in the long-term. In the scope of this report, which is a single measurement, it is assumed that the items which should be monitored are observable by having the greatest distribution in their scores. Distribution might be a good first indicator for monitoring an item since it shows that patients experience the aspect which has an unusual distribution differently, meaning that this item or aspect is not clearly representing fatigue and is worth for further investigation in form of monitoring. However, this is only a first step since it is not possible in this study to identify fluxions in fatigue aspects over time.

Besides, the research is targeted to brain injury outpatients who display the symptom of ABI related fatigue. Therefore, the research addresses the following questions and expectations:

1. **How properly measures the Dutch Multifactor Fatigue Scale fatigue after acquired brain injury?**
    a) **How is the internal consistency of the DMFS and its subscales in comparison to the literature of Visser Keizer et al. (2015)?**

    It is expected that the internal consistency of this study is similar to the internal consistency measured by Visser-Keizer et al. (2015) since the same items are used as well as the questionnaire is applied to a comparable sample.

    b) **How is the correlation of the DMFS subscales with the FSS in comparison to the correlation between the DMFS subscales with the HADS including their subscales?**

    As found in the study of Visser-Keizer et al. (2015), the correlation of the two fatigue measurement is assumed to be higher than the correlation between the DMFS and the HADS. The DMFS and the FSS both measure the construct of fatigue whereas, the HADS is assessing depression and anxiety which might be related to fatigue but still are assumed to be distinct constructs. Regarding the subscales of the HADS, the correlation

between fatigue and depression is based on the literature assumed to be higher than the correlation between fatigue and anxiety.

2. **Which factor of the DMFS has the most impact on the patients?**

It is expected that the factor which is rated the highest by the participants and therefore has the highest mean score, is the one which is most impacting on the patients' daily life.

3. **Which items of the DMFS should be used for monitoring?**

It is assumed that the items with the largest distribution in their scale or the one which deviates most from a normal distribution should be used for monitoring according to the expectation that items for which the participants have the most varying experiences are the items which might are most interesting to monitor in order to get more insight and to be able to control this aspect.

Method

Design

A cross-sectional questionnaire survey design was conducted. More precisely, a face to face data collection in a hospital setting with stroke outpatients, executed by a nurse practitioner of the outpatient clinic in Isala Zwolle.

Procedure

Before starting the study, the decision was made to only include patients who are Dutch native speaking and above 18 years old. Patients were eligible for inclusion if they had a clinical diagnosis of ischemic stroke or intracerebral hemorrhage with a direct discharge after hospital admission and who came to the outpatient clinic between January and April 2020. Next to that, ethical approval was requested and thereupon sustained by the ethical committee. This was necessary in order to ensure that the data collection was held according to ethical requirements. The study was judged by the local institutional review board of the Isala Hospital Zwolle as "outside the scope of WMO". After requiring approval, data on ischemic stroke, quantification of stroke severity according to the National Institutes of Health stroke scale (NIHSS), demographic data, vascular risk factors, history and use of medication was recorded. Patients were enrolled at the outpatient clinic in Isala Zwolle six to eight weeks after their admission. During this appointment, the participants were given the informed consent in which they were informed about the confidentiality of their private data (Appendix 1) and provided with a brief informational letter (Appendix 2). The nurse practitioner, who is specialized in stroke patients,

informed the participants properly about the different questionnaires and also answered their questions. Furthermore, participants received questionnaires which were filled out by them at home. There was no time limit. After completing the questionnaires, participants brought them directly to the hospital or sent their scanned answers via e-mail. The data was collected and transferred into the two programs “research manager” and IBM SPSS statistics 24.

Participants

The study was performed at the outpatient clinic of the Isala hospital in Zwolle, Netherlands. In total, the study consisted of a convenient sample of 33 Dutch participants since 7 cases from originally 40 participants had to be excluded. All remaining participants were ischemic stroke or intracerebral hemorrhage patients who were directly discharged home after their admission in the hospital and who then visited the outpatient clinic six weeks after their stroke. The mean age of the participants was 72 years within a range from 54 to 88. In total, 11 (33,3%) female and 22 (66,6%) male participants were included in the analysis. Moreover, everyone received informed consent form from a nurse practitioner specialized in strokes which informed them about the confidentiality of their personal data.

Materials

Three questionnaires were used for the purpose of this study. The Dutch Multifactor Fatigue Scale is a self-report questionnaire measuring ABI related fatigue. It includes 38 items on a 5-point Likert scale ranging from 1 (no, totally disagree) to 5 (yes, totally agree) with higher scores indicating greater fatigue (Visser-Keizer et al., 2015). The DMFS intends to assess five different factors of fatigue, each factor giving a specific insight into the symptom of ABI related fatigue (table 1). Nine items (2,3,5,9,11,14,16,22,24) were negatively formulated and have to be recoded. The calculation of the scores is done by calculating each score distinctively by adding up the scores of the concerned items since a total score of the whole questionnaire does not give any meaningful insight. The factors vary in the number of items from five items to eleven. For some analyses, an average score had to be calculated in order to compare the factors. Furthermore, the authors report good reliability for the subscales in general (table 2). More precisely, for the factors Impact of fatigue, Mental fatigue, and Signs and Direct consequences of fatigue good reliability was reported ($\alpha/\ \lambda \geq .80$). However, for the factors concerning Physical fatigue and Coping with fatigue the reliability is a little lower but still acceptable ($.70 \leq \alpha/\ \lambda \geq .80$). Next to that, the questionnaire shows good validity with regard to its correlation with another fatigue scale (Visser-Keizer et al., 2015).

To measure the psychometric quality of the DMFS, another two questionnaires were included. The Fatigue Severity Scale is also a self-report measurement and includes 9 items on a 7-point Likert scale varying from 1 (strongly disagree) to 7 (strongly agree) (Ettinger et al., 1998). It measures overall fatigue and its impact on activity including questions as for instance: "Fatigue interferes with my physical functioning" (Stone et al., 1999). The total scores are calculated by adding the single items scores up with higher scores imply greater fatigue (Stone et al., 1999). The scale shows good reliability and moderate concurrent validity according to a Dutch validation study by Rietberg, Van Wegen, & Kwakkel (2010) (table 2).

Next to that, the Hospital Anxiety Depression Scale (HADS) was added. The scale consists of two subscales, one measuring depression and the other one anxiety with 7 items each on a 4-point Likert scale ranging from 0 to 3 (Spinhoven et al., 1997). The depression subscale includes, for example, the item "I still enjoy the things I used to enjoy". The total scores are calculated per subscale by summing up the concerned items. The higher the score on the scale, the greater the likelihood of the presence of anxiety and/or depression. The scale indicates a high test-retest reliability (Spinhoven et al., 1997) and an acceptable validity (Luciano, Barrada, Aguado, Osma, & García-Campayo, 2014) (table 2).

Analysis

The data gathered from the scores of the questionnaires was first transformed from the nurse practitioner into the research program "research manager" and afterwards, due to the researcher's preference, transmitted to the statistical program IBM SPSS statistics 24. In SPSS the data was partly translated from Dutch language into English and incomplete value labels were added. Before analyzing, data cleaning was executed in two steps. First, it was checked whether data lied in possible range and secondly missing values were identified by the computation of a Nmiss variable. From the sample of 40 participants, 13 cases with missing values were detected. Since the DMFS is in the focus of this research, 7 cases which did miss out the majority of the items of the DMFS, were deleted completely. After excluding this data, 33 (82,5%) participants remained, though including 6 cases with missing values on several items. When the missing value of the item was below 5%, the value was replaced by the mean of the remaining items of the scale. In order to leave the data set as large as possible, the rest, which concerned 2 cases, was kept and will be automatically deleted by SPSS depending on

the analyses. Descriptive statistics were used to calculate means and standard deviation of the scores for each questionnaire and their subscales.

The internal consistency of the DMFS' factors, the FSS and the HADS including its subscales was calculated (in order to answer research question 1a) with Cronbach's alpha and Guttman's Lambda 2. Cronbach's alpha is the most common measure for internal consistency and Guttman's Lambda 2 is similar and thus comparable to alpha. Lambda 2 is an alternative measure and will always be equal or greater than the alpha for the same test (Stephanie, 2016). Both are included for validation purposes as done by the study of Visser-Keizer et al. (2015). If the measures show high values, it can be concluded that the items are measuring aspects of the same construct and indicate high internal consistency with a coefficient of >.70 regarded as acceptable.

A correlation analysis between the DMFS subscales and the FSS as well as between the DMFS and the HADS and their subscales was conducted (to answer the research question 1b). Therefore, the relationship of the data has to be checked by a scatterplot to see if the assumptions for the correlation coefficient are confirmed. Spearman correlation coefficient is the preferred coefficient since it is used for non-parametric tests and ordinal variables like Likert scales.

An average score of each factor of the DMFS was calculated by computing a new variable. Next, a frequencies analysis of the items of the 5 factors was conducted in order to analyze mean and standard deviation of the different factors of the DMFS (to answer research question 2). It was assumed that the higher the mean score of the factor the more impact the factor has on the participants.

Finally, the distribution of answers for each item of the DMSF was analyzed by the item's frequencies and standard deviation and it was checked for floor or ceiling effects.(to answer research question 3) which would be the case when more of 15% of the scores are distributed to the lowest or highest answer.

Results

Participants

After excluding cases due to missing values, 33 participants were included into the present study. Table 3 shows demographical data of the participants.

Table 3. Participant demographics

Variable	n=33 (%)	Minimum	Maximum	Mean	Std. deviation
Gender					
Female	11 (33.3%)				
Male	22 (66.7%)				
Age in years	33 (100%)	54	88	72	9.321
Education					
No education	1 (3%)				
Primary education	6 (18.2%)				
Secondary education	13 (39.4%)				
MBO	6 (18.2%)				
HBO	6 (18.2%)				
Different	1 (3%)				

Table 4 shows descriptive statistics of the three questionnaires including the total and subscale score of the surveys. Mean Fatigue Severity scale score was 28.9 (SD=12.61). The scores of the HADS subscales range from 0 to 11 (depression) and 0 to 17 (anxiety), whereby both mean scores are below 7 which indicated normal states. Furthermore, it was found excellent internal consistency for the Fatigue Severity Scale and the Hospital Anxiety and Depression Scale. The depression subscale ($\alpha/ \lambda \geq .70$) and the anxiety subscale of the HADS ($\alpha/ \lambda \geq .80$) indicated acceptable to good internal consistency. All scales showed good psychometric quality and proved to be useful as validation materials for the DMFS.

Table 4. Descriptive statistics of all scales and reliability coefficients

Variable	N items	Min.	Max.	Mean	Std. Deviation	Cronbach's alpha	Guttman's Lambda 2	Alpha Visser-Keizer	Lambda 2 Visser-Keizer
Total score FSS	7	7	48	28.9	12.6	.96	.97		

Total score HADS	14	0	28	9.1	6.5	.9	.9		
Depression Subscale	7	0	11	4.3	2.9	.78	.79		
Anxiety Subscale	7	0	17	4.8	3.9	.87	.88		
Impact of fatigue	11	11	49	28.3	9.9	.89	.91	.91	.91
Mental fatigue	7	7	31	19	6.4	.84	.84	.86	.87
Signs and direct Consequences of Fatigue	9	8.78	33	21.4	6.2	.79	.82	.83	.83
Physical fatigue	6	6	24	16.4	4.9	.72	.74	.77	.78
Coping with fatigue	5	7	19	13.5	2.8	.29	.53	.69	.7

Research question 1a

"How is the internal consistency of the DMFS and its subscales in comparison to the literature of Visser Keizer et al. (2015)?

A reliability analysis was carried out on each factor of the DMFS. More precisely, a Cronbach's and a Guttman's analysis was conducted (table 4) whereby higher scores are indicating greater internal consistency.

High internal consistency was found for the factor 'Impact of Fatigue' ($.80 \leq \alpha/\lambda \geq .90$) and also for 'Mental fatigue' ($\alpha/\lambda \geq .80$) which can be classified in the same category as the reliability measured by Visser-Keizer et al. (2015) (table 4). The factor 'Signs and direct consequences' had an alpha level of .774 which indicates acceptable internal consistency but a Lambda 2 of $\lambda \geq .80$ indicating good reliability. Further analysis showed that by deleting item 15 "Other people notice that I am fatigued before I do" or 11 "Even if I am very tired, I recover easily", the alpha level of this subscale would increase to $\alpha \geq .80$ as also assessed by the comparison study. For 'Physical fatigue' it was found that the factor's internal consistency is acceptable ($\alpha/\lambda \geq .70$). The internal consistency of this factor in the study of Visser-Keizer et al. is in the same category. The factor with the lowest internal consistency ($.20 \leq \alpha/\lambda \geq .50$) is

‘Coping with Fatigue’. This factor showed unacceptable reliability which was unexpected since Visser-Keizer et al. (2015) measured acceptable internal consistency. By deleting item 2 “I consciously plan when I will rest”, the alpha level can be increased to .70 which would be acceptable as well. The item correlated negatively with all other items belonging to the factor ‘Coping with fatigue’ and the item-total correlation for item 2 is -.387, even though it is correctly recoded according to the DMFS instructions. In general, the internal consistency measured by Visser-Keizer et al. (2015) is even or slightly higher than the results of this study. In the present study, only four of the five factors showed good internal consistency.

Research question 1b

“How is the correlation of the DMFS subscales with the FSS in comparison to the correlation of the DMFS subscales with the HADS and its subscales?”

Figure 1 shows two examples of the relationships between the factors of the DMFS with the FSS and HADS including its subscales which all met the assumptions of Spearman’s correlation since the relationships between the variables are monotonic.

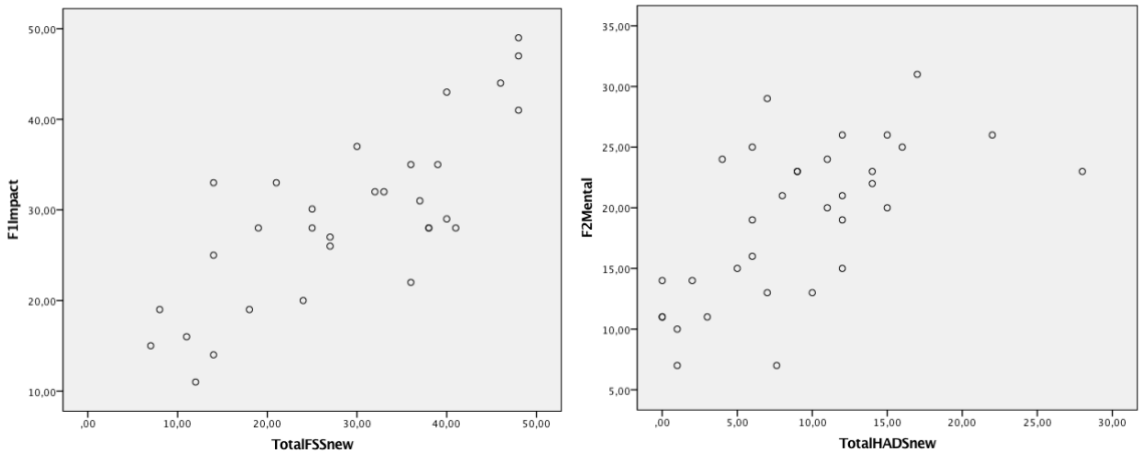

Figure 1. Scatterplot of the relationship F1 Impact & TOTAl FSS /F2 Mental & TOTALHADS

Table 5. Spearman’s rho correlations between DMFS factors and scales included for validation purposes

Scale	HADS	Anxiety	Depression	FSS
Impact	.484**	.419*	.423*	.742**
Mental	.65**	.714**	.423*	.543**

Signs	.703**	.716**	.532**	.557**
Physical	.487**	.39*	.521**	.688**
Coping	.394*	.468*	.163	.355

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

Table 5 illustrates that all factors except the Coping scale correlated moderately to strongly with the other fatigue scale, the FSS. This shows good construct validity for these factors. The result was expected since both questionnaires are assessing fatigue and especially the Impact scale, r (30) =.742, $p < .01$, reflects the severity of fatigue which is measured by the FSS. The correlation between coping with fatigue and the FSS was weak and non-significant which was not unexpected due to the different content of both scales.

The correlation between the HADS and the DMFS subscales were, as expected, strong to moderate, except for Coping which shows weak but still significant correlation with the HADS, r (30) =.394, $p < .01$. This correlation as well the correlations between the HADS and 'Mental fatigue' and 'Signs and direct consequences of fatigue' were higher than with the FSS and these factors, which is against expectations since it was assumed that the two fatigue scales correlate stronger than a fatigue questionnaire with a scale measuring anxiety and depression. Only regarding the impact of fatigue and physical fatigue, is the FSS correlated stronger with the DMFS than the two scales with the HADS.

Concerning the two subscales of the HADS, the anxiety scale correlates with the subscales 'Mental fatigue', Signs and direct consequences of fatigue' and 'Coping with fatigue' higher than the depression subscale which is against expectations since based on the literature it was assumed that depression and fatigue correlate higher than anxiety and fatigue. Especially strong correlations were found between anxiety and mental fatigue and signs and direct consequences of fatigue, r (30) =.71, $p < .01$. These results were different than the one found by Visser-Keizer et al. (2015) which showed only moderate correlations between anxiety and the factors 1 – 4 and a very weak correlation for 'Coping with fatigue'. The depression subscale only showed moderate correlations to the factors 1 – 4, and can thus, be distinguished from fatigue, even though the association of depression and fatigue was assumed to be higher than the one of fatigue and anxiety. This result is similar as the correlations found in the study of Visser-Keizer et al. (2015) who reported weak to moderate correlations between depression and the fatigue scales except for the coping scale which indicated according to the authors, very

weak correlations to depression. This weak correlation between coping and depression was replicated by this study with a non-significant correlation of r (30) =.163.

Generally, there was found no meaningful differences between the correlation of two fatigue measurements (DMFS and FSS) and the fatigue measurement DMFS with a scale measuring psychological distress in form of depression and anxiety (HADS). The correlation of the DMFS with the other fatigue scale is not strong enough in order to conclude a good construct validity.

Research question 2

"Which factor of the DMFS is the most impacting for the participants?"

The five factors of the DMFS (Impact of fatigue, Mental fatigue, Signs and direct consequences of fatigue, Physical fatigue and Coping with fatigue) cover each a specific facet of fatigue. Data of all 33 participants were available. After running a frequencies analysis of averages of the different factor variables, Table 6 shows that the mean scores of the factors do not differ significantly. Participants scored highest on the factor 'Physical fatigue' but also on 'Mental fatigue' or 'Coping with fatigue' since the differences between these score was 0.1 and 0.2 which can be seen as no real difference. The participants obtained the lowest scores for the factor 'Signs and direct consequences of fatigue' with 2.39 (SD = .69) which was also no big difference to the highest mean score but still more discriminable than 'Physical fatigue', 'Mental fatigue' and 'Coping with fatigue'. Since the mean scores were below 3, no factor can be considered as having a really high impact on the patients. Therefore, no single factor which is most impacting the participants could have been identified and it has to be concluded that 'Physical fatigue' in terms of physical fitness, exertion and energy, but also 'Mental fatigue' and 'Coping with fatigue' are impacting the patient's life mostly.

Table 6. Frequencies of average factor scores

Scale	Mean	Standard deviation
Impact of fatigue	2.57	.9
Mental fatigue	2.72	.92
Signs and direct consequences of fatigue	2.39	.69
Physical fatigue	2.73	.82
Coping with fatigue	2.7	.56

Research question 3

"Which item of the DMFS should be used for monitoring"

Table 7 shows the distribution of answers for the single items of the DMFS. Generally, the majority of items has answers which are distributed to the left meaning that they more often contain low score answers like 1 (totally disagree) or 2 (disagree) instead of 4 (agree) and 5 (totally agree). This demonstrates that for the most items the fatigue score was rather low, meaning that patients in this sample do not suffer tremendously from fatigue. In line with this, a floor effect were detected for 29 items since the answers belonging to the items are more than 15% distributed at the lowest category which is in the case of 33 participants, min. 5 answers. Especially high was the floor frequency for item 37 "When I am too fatigued, I suddenly can't think anymore" and item 33 "Fatigue affects my whole life". This result indicated that the fatigue in this sample is really low. Seven items have a ceiling effect with item 18 "Physical exertion makes me tired" having the most answers on the highest category which is in line with the result that the impact of physical fatigue is really high on the patients.

Furthermore, one item showed a more interesting distribution. Item 17 "A lot of impressions, such as bustle or noise, make me fatigued", indicates a split distribution (table 7) with 14 answers for 1&2 and 15 answers for 4 & 5 and only 4 answers for 3 (neutral). This indicated that this item was experienced differently by the participants. However, the standard deviation of 1.46 did not show any significant difference to the standard deviations of the other items. Moreover, all standard deviations resembled each other and thus, did not give any insight for an unusual distribution of an item which might have been interesting for being monitored. However, in general the distribution was rather to the left meaning that the fatigue is low but since 29 items were identified with a floor effect, no special item could be found for monitoring.

Table 7. Descriptive Statistics of DMFS and item distribution

	N on the 5 point Likert scale						
Item	Totally disagree	Mostly disagree	Neutral	Mostly agree	Totally agree	Mean	Standard Deviation
1 I am often tired	7	5	8	9	4	2.94	1.35
2 I consciously plan when I will rest (recoded)	5	10	11	1	6	3.21	1.29

Item	N on the 5 point Likert scale						
	Totally disagree	Mostly disagree	Neutral	Mostly agree	Totally agree	Mean	Standard Deviation
3 I can follow conversations without getting tired (recoded)	9	9	8	6	1	2.42	1.17
4 I get fatigued in the afternoon	6	3	10	13	1	3.00	1.17
5 I feel physically fit (recoded)	6	7	13	7	0	2.61	1.02
6 Fatigue hinders my doings	8	7	8	6	4	2.73	1.35
7 Things that move me emotionally make me tired	9	2	10	10	2	2.81	1.31
8 I always let myself get tired out	8	9	10	6	0	2.42	1.06
10 Thinking makes me fatigued	9	3	9	11	1	2.76	1.28
11 Even if I am very tired, I recover easily (recoded)	3	12	11	4	3	2.75	1.09
12 I finish what I am doing, even if I am tired	2	3	7	16	5	3.58	1.06
13 I can be overcome by fatigue	8	5	13	2	5	2.73	1.33
14 After a good night sleep, I wake up rested (recoded)	12	6	11	4	0	2.21	1.08

Item	N on the 5 point Likert scale						
	Totally disagree	Mostly disagree	Neutral	Mostly agree	Totally agree	Mean	Standard Deviation
15 Other people notice that I am fatigued before I do	6	10	10	5	2	2.61	1.14
16 I avoid becoming overtired (recoded)	7	13	10	3	0	3.73	.91
17 A lot of impressions […] make me fatigued	7	7	4	9	6	3.00	1.46
18 Physical exertion makes me tired	4	2	8	12	7	3.48	1.25
19 When fatigued, I get headache	13	4	7	8	1	2.39	1.32
20 I am tired every day	10	8	7	4	4	2.52	1.37
21 Fatigue makes me react emotionally	7	9	7	6	4	2.73	1.33
22 I can easily get over my fatigue (recoded)	4	11	12	5	1	2.64	.99
23 When fatigued, I have difficulty letting my thoughts go	6	8	11	4	4	2.76	1.25
24 I don’t need to have a rest to make it through the day (recoded)	6	5	6	10	6	3.15	1.39

Item	N on the 5 point Likert scale						
	Totally disagree	Mostly disagree	Neutral	Mostly agree	Totally agree	Mean	Standard Deviation
25 My body aches when fatigued	11	7	4	8	3	2.55	1.42
26 I suffer from severe fatigue	13	8	6	4	2	2.21	1.27
27 When fatigued, I have difficulty concentrating	7	2	9	11	4	3.1	1.33
28 When I am fatigues, I say […]	12	7	10	2	2	2.24	1.20
29 Fatigue is my most serious complaint	8	8	9	4	4	2.64	1.32
30 I have little energy	9	6	6	6	6	3.82	1.49
31 After a lot of thinking, fatigue still bothers me the next day	12	6	11	4	0	2.21	1.09
32 When fatigued, I make mistakes	7	4	11	9	2	2.85	1.23
33 Fatigue affects my whole life	14	9	5	3	2	2.09	1.23
34 My complaints get worse when I am fatigued	9	4	10	9	1	2.67	1.24
35 When I am too fatigued, all of a sudden, I can’t go further	12	4	10	6	1	2.39	1.25
36							

Item	N on the 5 point Likert scale						
	Totally disagree	Mostly disagree	Neutral	Mostly agree	Totally agree	Mean	Standard Deviation
37 When I am too fatigued, I suddenly can't think anymore	15	3	10	3	2	2.21	1.3
38 I suffer terribly from my fatigue	13	7	6	5	2	2.27	1.31

Discussion

Findings

In order to respond to the demand of research in ABI related fatigue, this study was executed to validate the Dutch Multifactor Fatigue Scale which is the first questionnaire taking into account all aspects of fatigue after acquired brain injury and therefore, can be seen as a step towards discovering the phenomenon of ABI related fatigue further. Taking the gathered information into consideration, the DMFS showed good psychometric properties. Three factors (Physical, Mental and Coping) were found which have the highest impact on the patients. However, one of them (Coping with fatigue) is distinguishable due to its content regarding fatigue and should be treated differently. Therefore, no meaningful insight into what specific aspect of fatigue is impacting the patients the most or which item should be used for monitoring could be found. Nonetheless, the gained knowledge can be used for further research and interventions. In the following, the findings in regard to the different research questions will be described more precisely.

Regarding the psychometric quality of the DMFS, two measures were conducted. Firstly, concerning the internal consistency, it can be concluded that all factors except one showed excellent to good reliability and were in the same category as the reliability measured in the study of Visser-Keizer et al. (2015). One exception was the factor 'Coping with fatigue' since it indicated unacceptable reliability which differs from the acceptable reliability coefficient measured by Visser-Keizer et al. (2015). Indeed, this factor had also the lowest internal consistency reported by the authors but its coefficient was distinctly lower in this validation study. This is due to the item "I consciously plan when I will rest" which was not

consistent with the other items of this factor, even though it was correctly recoded. In the study of Visser-Keizer et al. (2015) no item was found to be inconsistent with the others. By deleting this item the internal consistency would rise to the same level as in the first validation study. According to Visser-Keizer et al. (2015), the coping factor showed less internal consistency due to its small numbers of items. Nonetheless, it remained in the questionnaire since coping is another distinct aspect contributing to fatigue and therefore, an essential part for the measurement instrument. Nevertheless, the expectation that the internal consistency is similar to the one measured by Visser-Keizer et al. (2015) is only true for four out of five factors of the DMFS which might be explained by the difference in sample size which was much larger in the first validation study (N=134) than in the present study (N=31). However, this report showed that the DMFS is, except for subscale 'Coping with fatigue', validated in regard of its internal consistency since the positive psychometric results of Visser-Keizer et al. (2015) were proven to be replicable.

Secondly, the validity of the DMFS was measured by assessing its correlation with other scales. The result that the FSS is not significantly correlating stronger with the DMFS than the HADS with the DMFS was quite unexpected since it was assumed that fatigue scales correlate higher than scales measuring different constructs. Even though it was not expected, the strong correlation between mental fatigue and pathological forms of distress like especially anxiety is reasonable since mental fatigue has overlapping cognitive symptoms with anxiety (Johansson & Rönnbäck, 2014). Regarding the HADS subscales, a correlation between fatigue and depression was assumed to be stronger than the correlation between fatigue and anxiety. However, results showed the opposite for the factors 'Mental fatigue' and 'Signs and direct consequences of fatigue'. Since cognitive distress is an overlapping symptom of fatigue and anxiety (Davey, 2014), it can be concluded that ABI patients might felt anxious about their condition and the fatigue brings a lot of cognitive distress due to its unfamiliar impact on the daily life which resulted in a strong association between mental fatigue and anxiety. Besides, one exception is factor 'Coping with fatigue' which showed weak and partly nonsignificant correlations with all other scales. This could be due to the same reasons, mentioned regarding the reliability, namely that coping is distinct to the other factors measured by the DMFS since it assesses how to deal with the symptom instead of the symptom itself and thus, did not correlate with measures of fatigue severity or psychiatric distress. Nevertheless, the results showed that the DMFS is not only correlating with the questionnaire about severity of fatigue but also with measurements about pathological forms of distress indicating that especially anxiety had significant overlap with fatigue, in particular regarding certain aspects of ABI

related fatigue like the mental component. Since Visser-Keizer et al. (2015) reported significant higher correlations between two fatigue measurements than between fatigue and anxiety/depression measurements it was assumed that the samples of both studies differed in their fatigue levels. The correlations indicate that the fatigue of the patients in this study might be rather low but that they instead suffer more from mental problems like anxiety. Since mental problems are covered by the DMFS via the factor 'Mental fatigue' and the HADS but not by the FSS, the unexpected high correlations between the DMFS and the HADS were reasonable. Therefore, the result of this study does not truly replicate the outcomes of Visser-Keizer et al. (2015). The DMFS scale showed a positive correlation to the other fatigue measurements, however, for good construct validity the correlation was expected to be higher than the results of this study indicated. Hence, it can be concluded that insufficient construct validity might be explained by the sample's characteristics of lower fatigue but higher mental problems.

Furthermore, the results showed that the mean scores of the DMFS factors are almost equally high. 'Physical fatigue' has next to 'Mental fatigue' and 'Coping with fatigue', slightly higher scores. An explanation for higher physical fatigue might be the fact that when patients begin to feel less fatigued, they engage in more activity which makes them feel more exhausted and tired even though other parts of their symptom like their quality of life or self-efficacy increase (Malley, Wheatcroft & Gracey, 2014). Thus, the perception of physical fatigue might be the higher than for other aspects of fatigue after ABI. However, the mean score of 'Mental fatigue' as well as 'Coping with fatigue' were not significantly smaller, meaning that the most impacting factor cannot be identified clearly. According to literature, a lot of research was done on mental fatigue, indicating that mental fatigue is an important aspect. It has an influence on the total activity of a patient since the mental state has an influence on our body and general feeling (Johansson & Rönnbäck, 2014). Next, many interventions are based on treating mental aspects of fatigue as for instance mindfulness programs which include yoga, relaxation exercises or meditation and improve cognitive functioning. Moreover, as mentioned above, the sample of this study seems to have some mental problems which is also in line with 'Mental fatigue' having one of the highest mean scores. In regard to coping, the result might be due to problems of the patients in handling and coping with their condition. According to Visser-Keizer et al. (2015), "coping with fatigue is especially difficult because this type of fatigue after brain injury is new for the patient" (p.1062). However, since coping is distinct to the other factors it cannot properly be compared to the impact of the other factors. Furthermore, 'Coping with fatigue' showed poor psychometric quality which let the mean score be less meaningful for this research question. Next to that, when the participants do not suffer as much from fatigue

as expected, coping with fatigue would not be relevant for them since they are not concerned with this aspect. Concluding, one factor with the most impact could not been significantly assessed in this study. The mean scores are quite similar, so all factors can be considered as important. Nevertheless, mental fatigue seems to be an important and impacting aspect as well as physical fatigue. Therefore, interventions should include all factors of fatigue after ABI but might concentrate on mental and physical features more.

Moreover, the study aimed at identifying items which can be used for monitoring. The assumption that items of the DMFS with the largest distribution in their scale or one which deviates from a normal distribution should be used for monitoring cannot be confirmed since no clear result was found. In line with previous discussion, the distributions showed floor effects for many items which additionally indicates that the level of fatigue in this sample was rather low. However, this does not give insight into an item which is suitable for monitoring. Nevertheless, that an item which should be used for monitoring can be identified by a not normal or large distribution in their answers was only an assumption of the researcher since no literature about which aspects of ABI related fatigue are suitable for monitoring was available. In general, finding information about monitoring related to fatigue after ABI was difficult. No clear definition of fatigue monitoring was provided which made it difficult to define a concept of how to analyze if an item is suitable for monitoring. Thus, this study was only an explorative trial of identifying an item for monitoring by one-time measurement via questionnaires which unfortunately lead to no meaningful results. The lack of literature can be related to the lack of knowledge about ABI related fatigue. Mechanisms of fatigue are poorly understood (Kluger et al., 2013) and since the basics of ABI related fatigue are not fully discovered, research on monitoring might be rare. Nonetheless, monitoring fatigue seems to be useful for patients. A study by Cooper, Reynolds & Bateman (2009) demonstrated the effectiveness of monitoring fatigue. Their study included an eight-week program combining lessons, handouts and diaries to monitor fatigue at home. The results of the comparison of pre- and post-measurements showed an improvement in quality of life and self-management of fatigue (Cooper et al., 2009). This showed that patients with ABI related fatigue benefit from interventions which include monitoring and puts emphasis on the urgency to improve those methods. However, using diaries and identifying items of questionnaires are two different methods for monitoring ABI related fatigue. Diaries are more open but also time intensive and have questionable reliability (Okupa, Sorkness, Mauger, Jackson & Lemanske, 2013) whereas questionnaires can be subject to poor recall when applied with delay (Okupa et al. 2013). Comparison studies of both methods for different disease types showed different results. Okupa et al. (2013) report diaries as being more

sensitive whereas Libman, Fichten, Bailes, & Amsel, (2000), state that the right method depends on the purpose of monitoring. Regarding ABI related fatigue, monitoring aims on finding aspects which are most exhausting in order to gain control over them (Jacqui & Malley, 2008). The use of questionnaires for identifying items which are most exhausting and should be used for monitoring might be more standardized and thus, easier to compare to other cases as well as giving the patient an orientation but not as open and targeted as diaries. Using diaries as a method in regard to monitoring is more subjective and gives individual insight into the experiences of patients with fatigue. Since ABI related fatigue is a subjective experience (Cumming et al., 2016), diaries might give more valuable results than the use of questionnaires. However, the most efficient result might be reached by a combination of both when first applying questionnaires and with the insight of them, using specific diaries for monitoring.

However, even though aspects or items which have the most impact as well as should be used for monitoring were not clearly identified, the results of this study can give insight into monitoring fatigue, in regard to the demand of more research and literature due to the lack of knowledge and proper interventions and treatment options. Existing treatment options can be seen as a good starting point since they cover different parts of fatigue but still showed little success (Kluger et al., 2013). Nonpharmacological interventions which address the symptoms of a disease like mindfulness training or energy management strategies indicate some worth but are rarely applied (Kluger et al., 2013). The DMFS which has proven to have good psychometric qualities can be used for further research on this topic. The scale can help in identifying components of fatigue which impact the patients the most and can be seen as an approach for monitoring in order to develop interventions helping patients to control the impacting components of their fatigue.

Limitations

One limitation of this study was the small sample size. Due to the current situation with COVID-19, the sample size of this study was smaller as expected in the beginning. Studies like the one of Anthoine, Moret, Regnault, Sébille, and Hardouin, (2014), recommended the sample size for validation studies to be at least 100 to 250 subjects or 2 to 20 subjects per item which would be sample size from 76 to 750 participants instead of 31 for this study. With a larger sample size, the study would have been more generalizable regarding the results since it enables to better control errors (Anthoine, et al., 2014). Under different circumstances, the sample size of this study might have been higher and therefore, more suitable to properly validate the DMFS

and test the results from the first study by Visser-Keizer et al. (2015). Furthermore, the collaboration between the researcher and the nurse practitioner of the outpatient clinic was impeded by the COVID-19 restrictions. Since the data was collected and transferred into the research program by the nurse practitioner, the researcher was confronted with unclarity regarding the data set and the exact procedure of the data collection. Personal meetings would have been contributed to better communication.

Advice for further research

Taking the findings and limitations into account, advise for further studies can be divided into three points. Firstly, another validation study with a larger sample size might give other but more generalizable results in regard to the validation. A longer period for sampling data may be supportive. Next to that, it might be helpful if the researcher is more involved in the procedure of data collection and transformation. The instruments proved their quality and should be kept in further studies. However, another questionnaire assessing coping might be useful for comparison with factor five. Secondly, it might be convenient to have a sample of different groups. On the one hand, patients with other neurological diseases can be included. Since the prevalence rates of fatigue for neurological illnesses like strokes, multiple sclerosis or traumatic brain injury are quite similar (Kluger et al., 2013), it would be interesting to see how the different groups score on the DMFS and its subscales. Furthermore, it would give insight into underlying mechanisms of fatigue as reported by the study of Holmqvist, Lindstedt, & Möller (2018), who found out that fewer stroke patients reported fatigue in comparison with groups of other neurological illnesses as well as that more patients with posterior and non-specific lesions experienced fatigue compared with those with subcortical/frontal injuries. On the other hand, including healthy participants or non-neurotypical patients would give further insight into ABI related fatigue and its components. It might help to differentiate between this disease and specify the profile of ABI related fatigue even more. Cross sectional studies like the one of Norup et al. (2017), divided participants in patients and a control group which resulted in a clear distinction of what level of fatigue might be normal and what might be due to the injury. Thirdly, in order to identify items which can be used for monitoring, a longitudinal study is suggested. By measuring fatigue scores and impact more often over a specific period of time, it might be possible to find out which item scores have the largest fluxions but also which ones are the highest and therefore are the most impacting. Besides, the participants have the possibility to monitor the fatigue with a dairy in form of self-monitoring. It would be

interesting to see if the results of the self-monitoring method match the scores of the questionnaire. The insights would help to develop targeted interventions and treatments. Moreover, a longitudinal study would enable a pre-measurement directly after the admission of the patient and afterwards give the opportunity to divide patients according to their results respectively their fatigue level in different groups. A pre-measure might give insight into the general level of fatigue without the impact of the brain injury and thus shows how the injury influences the patient over time. When having different groups according to the fatigue level, a difference regarding 'Coping with fatigue' might be visible and the researcher is better able to interpret this factor.

Conclusion

Fatigue is one of the most common symptoms for patients after acquired brain injury. The prevalence rates are high and the impact on patient's daily life is huge since the ABI related fatigue interferes with normal activities like reading or having a conversation (Johansson & Rönnbäck, 2014). Social, emotional and cognitive components are impacted by the symptom which additionally interferes with the rehabilitation process (Glader et al., 2002). Many patients struggle in adapting to their situation (Johansson, Bjuhr, & Rönnbäck, 2015). Nevertheless, there is a huge knowledge gap regarding mechanisms of fatigue (Kluger et al., 2013; Visser-Keizer et al., 2015) as well as regarding treatment (Glader et al., 2002). Indeed, some treatment options exist but effective options for patients suffering from ABI related fatigue are not available. Therefore, questionnaires are a good opportunity to measure the patient's experiences with fatigue. Since ABI related fatigue can be distinguished from other diseases, it cannot properly be measured by generic scales (Visser-Keizer et al., 2015). The DMFS is the first scale measuring specifically the symptom of fatigue after ABI since it includes all contributing factors (Visser-Keizer et al., 2015). This study validated the DMFS and proved that the results of Visser-Keizer et al., (2015), in regard of internal consistency are with one exception, replicable to another sample of ABI patients. Concerning construct validity, the current results were not as significantly definite than the ones measured by Visser-Keizer et al. (2015) which might be due to the difference in sample (size). According to the results, the DMFS might need a small adjustment regarding the factor 'Coping of fatigue'. It is important to develop the scale further, in order to provide assistance in the research of fatigue and consequently in improving the patient's quality of life. Better insight into the complex of ABI related fatigue will also support development in interventions and treatments. The patients could learn how to cope with the fatigue or be provided with different treatment options which can reduce the huge impact.

Moreover, the study identified physical and mental fatigue as most impacting for the sample. With this knowledge, the research in ABI related fatigue can be additionally improved since it provides an aspect on which it is worth focusing on in regard to developing support or treatment options. When controlling this aspect through interventions or treatments, a big part of the suffering might be reduced and one is getting closer towards the aim of increasing the patient's quality of life. Furthermore, it might help in research for monitoring. This study was not able to identify an item which should be used for monitoring due to the design of the study but also because of the lack of research regarding this topic. The found insight could help in investigating monitoring ABI related fatigue further. Concluding, the scale can be seen as a good measurement instrument to develop research in ABI related fatigue further by assessing components of fatigue and gaining more insight in order to establish targeted treatment which can facilitate the life with ABI related fatigue.

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Appendices

Appendix 1

Bijlage B: toestemmingsformulier proefpersoon

Vragenlijst over de CVA nazorg

- Ik heb de informatiebrief gelezen. Ook kon ik vragen stellen. Mijn vragen zijn voldoende beantwoord. Ik had genoeg tijd om te beslissen of ik meedoe.
- Ik weet dat meedoen vrijwillig is. Ook weet ik dat ik op ieder moment kan beslissen om toch niet mee te doen of te stoppen met het onderzoek. Daarvoor hoef ik geen reden te geven.
- Ik geef toestemming voor het verzamelen en gebruiken van mijn (medische) gegevens op de manier en voor de doelen die in de informatiebrief staan
- Ik geef toestemming om mijn medische gegevens nog 15 jaar na dit onderzoek te bewaren. Mogelijk kan dit later nog voor meer onderzoek worden gebruik, zoals in de informatiebrief staat.
- Ik weet dat voor de controle van het onderzoek sommige mensen toegang tot al mijn gegevens kunnen krijgen. Die mensen staan vermeld in deze informatiebrief. Ik geef toestemming voor die inzage door deze personen
- Ik wil meedoen aan dit onderzoek en ik geef mijn mantelzorger/partner toestemming om vragen over mij en mijn ziekte te beantwoorden.

Naam proefpersoon:
Handtekening: Datum: __ / __ / __

Ik verklaar dat ik deze proefpersoon volledig heb geïnformeerd over het genoemde onderzoek.

Als er tijdens het onderzoek informatie bekend wordt die de toestemming van de proefpersoon zou kunnen beïnvloeden, dan breng ik hem/haar daarvan tijdig op de hoogte.

Naam onderzoeker:
Handtekening: Datum: __ / __ / __

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* Doorhalen wat niet van toepassing is.

De proefpersoon krijgt een volledige informatiebrief mee, samen met een kopie van het getekende toestemmingsformulier.

Appendix 2

Informatie voor deelnemers, Zwolle, januari 2020

Geachte meneer en /of mevrouw,

Bij deze vragen wij u vriendelijk of u een vragenlijst wilt invullen over de ontvangen nazorg die u en uw naasten hebben gekregen na uw CVA. Dit onderzoek wordt uitgevoerd door de afdeling Neurologie van de Isala in Zwolle.

U beslist zelf of u mee wilt doen en deelname is vrijwillig. Voordat u een beslissing neemt, kunt u deze informatiebrief rustig doorlezen, om meer te weten te komen over het onderzoek. Heeft u na het lezen van deze informatiebrief nog vragen over het onderzoek? Dan kunt u contact opnemen met de onderzoeker Gina van Vemde (verpleegkundig specialist in opleiding). Onderaan deze brief vindt u haar contactgegevens.

Deelname aan het onderzoek is geheel vrijwillig, behalve het invullen van de vragenlijst zal het u geen extra inspanning kosten. Het invullen van de vragenlijst kost circa 5-10 minuten. U kunt tussentijds altijd, zonder opgaaf van reden, stoppen met uw deelname. Als u besluit om niet deel te nemen hoeft u verder niets te doen. Indien u meedoet vragen we u de toestemmingsverklaring voor deelname te tekenen en samen met de ingevulde vragenlijst in te vullen.

Doel van het onderzoek

Veel patiënten met een CVA gaan na opname uit het ziekenhuis direct met ontslag naar huis. Ook deze patiëntengroep ervaart gevolgen van een beroerte, zoals verlammings-verschijnselen, taalproblemen, somberheid, problemen met het denken en begrijpen, vermoeidheid en krijgen hiervoor nazorg aangeboden. Het doel van dit onderzoek is om in kaart te brengen welke nazorg en patiëntenvoorlichting er wordt gegeven en of dit voldoende aansluit bij de behoefte van de patiënt en zijn naasten.
Ook uw naaste wordt gevraagd om een vragenlijst in te vullen, hier geeft u dan ook toestemming voor.

Wie voert het onderzoek uit?

Het onderzoek wordt uitgevoerd door Gina van Vemde. Zij is in opleiding tot Verpleegkundig Specialist. De begeleider van het onderzoek is dr. H.M. den Hertog (neuroloog)

Privacy

Uw persoonlijke gegevens en antwoorden worden vertrouwelijk behandeld. Alle gegevens worden strikt vertrouwelijk en anoniem verwerkt en zijn niet te herleiden naar personen. Na het onderzoek worden de gegevens nog 15 jaar bewaard.

Met vriendelijke groet,
Gina van Vemde
038-4242458
E-mail: g.van.vemde@isala.nl