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The Relation of Fatigue and Illness Perceptions among Stroke Survivors

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Abstract

Introduction: Stroke has shown to be the second leading cause of death across the globe and the third major cause of disability. Especially fatigue has shown to be a common health complaint post-stroke, which can have a major impact on the overall quality of life or the health outcome of the diseases. Other factors contributing to the health outcome can be identified as psychological factors such as the patient's illness perceptions. Among other diseases, fatigue and illness perceptions have shown to be interrelated and the exploration of such has contributed to the design of effective treatment options including e.g. Cognitive Behavioral Therapy. However, the constructs combined have not been explored among stroke-patients yet. Therefore, the aim of this study was to examine the relationship between the severity of the stroke, patients´ illness perceptions and post-stroke fatigue.

Methods: In a prospective longitudinal observational cohort study a sample of 51 stroke patients was assessed. The severity of stroke (National Institute of Health Stroke Scale), symptoms of fatigue (the Checklist Individual Strength) and illness perceptions (Brief Illness Perception Questionnaire) were studied. Data were analyzed by means of linear regression, ANOVA and Pearson Correlation.

Results: Despite a high dropout rate of 24 participants over the course of this study, participants of each level were still present until the last measurement point. The main findings of this study revealed that there was a relationship between the severity of the stroke and the illness perception, however, in contrast to the expectations, not between the severity of the stroke and the degree of fatigue. Further, the degree of both, fatigue and illness perceptions stayed rather steady over time, even among severely fatigued patients, implying stability to be natural for the constructs when untreated. The last main finding revealed a positive relationship between the degree of fatigue and one's illness perceptions over time at the different measurement points

Implications: Findings of this study were in line with previous studies that examined the relation among patients of other diseases such as Multiple Sclerosis or Chronic Lymphocytic Leukaemia. This study provided a basis to the not yet explored field combining post-stroke fatigue and illness perception. As at least every fourth stroke survivor is still affected by severe post-stroke fatigue, findings of this research might be the first step for future research that aims at improving treatment options through for example introducing Cognitive Behavioral Therapy to more detailed research.

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Introduction

The medical condition stroke has shown to be the second leading cause of death across the globe and the third major cause of disability (Feigin et al., 2015). Among the survivors of stroke, consequences can assume various forms such as impairments in functioning, constraints regarding activities as well as participation (Geyh et al., 2004). One common impairment after stroke is embodied by the post-stroke symptom fatigue, that is "strongly related to poor quality of life" (Cumming et al., 2018) and which can turn into an exhausting and long-lasting issue. The prevalence of post-stroke fatigue ranges from 23% to 75% among patients (Choi-Kwon, 2011 as cited in Wu, Mead, Macleod, & Chalder, 2015 B). Beyond that, other factors exist that are contributing to the health outcome of a stroke patient such as psychological factors. Those factors can influence the health outcome by means of a patient´s illness perception, as a negative perception e.g. might result in distress or lower medication adherence (Groeneveld et al., 2019).

Stroke

Even though different types of stroke exist, this paper is focusing on ischemic strokes. To explain what an ischemic stroke is, one can say that the medical condition emerges once a vessel is blocked that supplies the brain with blood (American Stroke Association, 2019). Once a certain region of the brain is not supplied with blood for a few minutes, the brain cells of that region may die and may leave the patient impaired regarding the function of that area. As stated by the authors Feigin et al. (2015), the number of people suffering from consequences of stroke or dying because of it was increasing throughout the last two decades and still is all around the world. The results showed that in 2013 alone, 10.3 million new strokes occurred globally. There were about 25. million stroke survivors globally, 6.5 million deaths due to stroke, and a sum of 113 million disability-adjusted life years (DALYs) because of it. For each of those numbers, at least half of the amount can be accounted for by the form of an ischemic stroke (Feigin et al., 2015).

Stroke and Fatigue

As aforementioned, the occurrence of ischemic stroke may result in impairments such as the patients struggling with fatigue. Living with the post-stroke symptom one experiences "a lack of physical and mental energy" (Lerdal et al., 2009). A meta-analysis showed that approximately 50% of all stroke survivors experience elevated levels of fatigue (Cumming et

al., 2009). Being fatigued might not only impede the process of the rehabilitation but the outcome as well. Furthermore, research has shown that the severity of a stroke has an impact on the degree of fatigue (Elf, Eriksson, Johansson, Koch, & Ytteerberg, 2016). The authors stated that a person with a more severe stroke, was more likely to suffer from fatigue since more energy was required along daily activities to be performed properly when compared to less severely impaired survivors. Moreover, did a study by Zedlitz, Rietveld, Geurts, & Fasotti (2012) reveal that the degree of post-stroke fatigue does not change over time when kept untreated.

Stroke and Illness Perceptions

There are several factors contributing to the patient outcome such as a patient's demographics, his/her strokes characteristics and physical impairments, which mostly are accounted for as the determinants of quality of life (Mierlo, Heugten, Post, Kort, & Visser-Meily, 2015). However, differences were found in the level of experienced quality of life between severely impaired and less severely impaired stroke patients, which could be accounted for by other factors than only the severity (Mierlo et al., 2015). This prompts the question, where those differences might stem from.

One possible solution to explain the health outcome lies in the illness perceptions of the patient. According to Groeneveld et al. (2019), the concept indicates that "a patient forms mental representations of symptoms and disease, in order to make sense of and manage the illness". One factor that might contribute to perceiving one´s illness as more or less threatening is the objective severity of the disease or in this case the severity of the stroke itself (Moss-Morris, Weinman, Petrie, Horne, Cameron, & Buick, 2002). However, there are other factors, contributing to the representations one has about his/her illness, as well.

Leventhal has created a theoretical framework for those factors, which is called the Self-Regulatory Model of Illness Behavior (Leventhal, Meyer, & Nerenz, 1980, as cited in Morris et al., 2002). Within the model it is suggested that individuals develop an inner network of beliefs, the so-called illness perceptions, having both cognitive as well as emotional subject matter. Those inner representations evolve due to the perception of a threat to one´s health. Further, do those representations influence the level of self-care and coping and therefore have an impact on the health outcome, psychologically as well as physically. As identified by the authors Broadbent, Petrie, Main, and Weinman (2006), eight different dimensions exist, on which illness perceptions are represented, namely the perceived

consequences, timeline, personal control, treatment control, identity, concern, understanding, and emotional response.

Post-stroke Fatigue and Illness Perceptions

Findings of a meta-analysis conducted by Wu et al. (2015 A) showed that no sufficient treatment options for post-stroke fatigue have been found yet, even though it is such a prevalent symptom that has been recognized to have a major impact on a stroke-survivors quality of life. As part of their meta-analysis pharmacological as well as educational or psychological treatment approaches have been tested, which did not prove to be significantly efficient treatment options, though (Wu et al., 2015A). The method of Cognitive Behavioral Therapy (CBT) has been applied in many cases yet. The study implemented by Zedtlitz et al. (2012) e.g. tested the efficacy of treatment options for post-stroke fatigue. Those treatment options comprised cognitive therapy (CO), which includes elements of CBT. In contrast to the findings of Wu et al. (2015 A) did the research of Zedlitz provide support for a significant favorable effect of the tested treatment on post-stroke fatigue. However, only the degree of fatigue was assessed during the intervention. No empirical measurements had been taken with regards to whether the patients´ beliefs underwent an actual change and whether a change of the degree of fatigue could be explained through the development of more rational beliefs or through other factors (Pertl, Hevey, Donhoe, & Collier, 2012). It is worthy to mention, that CBT has officially found its way into treatment of other diseases, where it has proven to reduce the level of fatigue, e.g. in patients with Multiple Sclerosis (MS) and cancer (Elf et al., 2016). As CBT has proven to be effective not only among other disease but post-stroke fatigue as well but has not been explored in post-stroke fatigue with regards to its underlying mechanism of changing one's beliefs, one could do so by recognizing a patient's illness perceptions. Hence, it might be interesting, based on the abovementioned aspects, to introduce the concept of illness perceptions into the research field of post-stroke fatigue as well.

Until now, the integration of illness perceptions into the rehabilitation process of post-stroke fatigue has not been done yet. However, one advantage can be seen in former research, which provided support for the assumption that e.g. reducing maladaptive feelings can improve a stroke patients life satisfaction and thereof his or her health outcome in general (Mierlo et al., 2015). Beyond that, giving an example, altering one's illness perception itself has proven to be effective among patients of myocardial infarction as it enhanced the recovery process, and among diabetes and AIDS patients their health outcomes were improved as well (Broadbent et al., 2006). Further, it has been recognized that illness perceptions have a role in

developing, retaining and changing the chronic fatigue syndrome (Mierlo et al., 2015).

As one can see, a gap exists in the current scientific knowledge that opts for better treatment options of stroke patients, especially since the prevalence rates of ischemic stroke are increasing. Up to this point, research in the field of treatment of other disease has shown to be more efficient with regards to illness perceptions and fatigue.

A cross-sectional study among Chronic Lymphocytic Leukaemia (CLL) patients, for example, demonstrated that the interference from fatigue that arose due to CLL was higher among those patients that accounted stronger weight of CLL on their emotions and identified to a greater extent with their illness (Westbrook, Maddocks, & Andersen, 2016). Within their study, the authors indicated that a reduction of negative emotional reaction towards the illness may facilitate the degree of fatigue. One might wonder, where similarities between CLL and ischemic stroke patients could be found. The authors Evans, Ziebland, and Pettitt (2011) found that diagnosed patients mostly experienced fatigue with the onset of symptoms. This onset was followed by consequences such as an early retirement from work, a reduction of housekeeping, hobbies, going out, having contact with friends and family, which occasionally even might result in isolation. As stated by the authors Zedlitz and colleagues (2012), common underlying mechanisms were identified concerning fatigue among stroke as well as cancer patients based on the similarity of the psychological profiles (as cited in Wu et al., 2015 B). When comparing the following aspects of cancer patients to the aftermath of a stroke, one can see certain resemblances. Giving examples, the functional status of stroke patients often remains on a lower level, which in turn does not allow them to keep up their former life in terms of work, household or social life, where their impairments become noticeable.

Another comparison might be made with Multiple Sclerosis patients, as found by Zedlitz and colleagues (2012). As described by Akker et al., " Multiple Sclerosis is a neurodegenerative disease with clinical manifestations in the motor, visual, sensory and autonomic system, although symptoms may also occur in many other systems" (2018). Therefore, a connection between MS and ischemic stroke patients might be made based on the similarity of physical impairments, as symptoms of MS and stroke can overlap. During the treatment of MS patients, CBT had been applied, which addressed the patient's perceptions of fatigue, increased the physical activity, led to a decrease in sleepiness and helplessness and enhanced the physical functioning (Akker et al., 2018). As a result, a decrease in the level of fatigue could be noticed among the patients partially due to the change in the way they

perceived their illness.

Another cross-sectional study conducted by Abdollahi, Shagholian, and Baheshmat (2016) provided support for the assumption that illness perceptions are associated with fatigue in MS patients. They assume that an “increase in the degree of depression and fatigue will strengthen a patients’ belief that the disease affects their overall QOL (the outcome of the disease), resulting in greater concern and negative emotional response".

So far, the current scientific knowledge about the correlation of illness perceptions and fatigue, independently of the disease related to, has been conducted in a cross-sectional manner. Therefore, one cannot draw conclusions on which variable might have an effect on the other one. However, hypotheses concerning the nature of relationships are deviating among the studies conducted so far. Some researchers assume that illness perceptions predict the degree of fatigue and in other studies the degree of fatigue predicts the illness perceptions. Dependent on the actual causality, one might be able to improve treatment options once indications can be established about which factor to draw on or if both factors are essential in order to reach a significant difference with regards to the general health outcome.

Current Study

As previous research has provided support for the assumption that the two factors illness perception and fatigue might contribute to health outcomes of different kinds of diseases and even correlate with each other, it is of interest to explore whether this holds to be true for stroke patients as well. Therefore, describing the association of illness perceptions and fatigue among stroke patients might contribute to the improvement of rehabilitation and treatment programs of stroke patients in order to achieve better health outcomes.

Since the two factors have not been combined so far among stroke patients, it adds a unique value to this study. Further, it is to mention, that the following research is conducted in collaboration with the department of neurology of the Medisch Spectrum Twente, where patients of ischemic strokes were assessed within the first week of the stroke, as well as 3, 6 and 12 months afterward. Due to the fact that the majority of research assessing the relationship of fatigue and illness perceptions among other diseases, as well as those assessing either one or the other factor in relation with stroke has been conducted in form of cross-sectional studies rather than longitudinal studies, there is even greater importance of the current research.

Beyond that, one should notice the early data acquisition, which took place only one week after the onset of a patients stroke and hence might allow to find out about the direction

of effects of the two factors, provided that a correlation can be found in stroke patients as well. Until now it has mostly been stated that a change in illness perceptions might have an impact on the degree of fatigue. A few studies, however, indicated, that the effect occurs in the opposite direction. For that reason, it is important to explore the relation between the two factors in every possible direction.

Based on the findings of previous research, the model depicted in Figure 1 was created. Hence, in the first step, one might assume a relationship between the severity of a stroke and the degree of fatigue as well as between the severity of a stroke and the degree to which the illness is perceived as threatening.

Secondly, one might assume that no changes occur in the degree of fatigue when kept untreated, as the study conducted by Zedlitz et al. (2012) has indicated. In favor of this research, Zedlitz´ study had been implemented in the Netherlands as well, which offers a proper basis for comparison, as the initial conditions and living situations might be comparable. If unaffected or untreated, the same might hold to be true for the degree to which the stroke is perceived as threatening over time. At last, one might assume a relationship between the degree of fatigue as well as the degree to which the stroke is perceived as threatening by its survivor, as several studies with the comparable disease have indicated so.

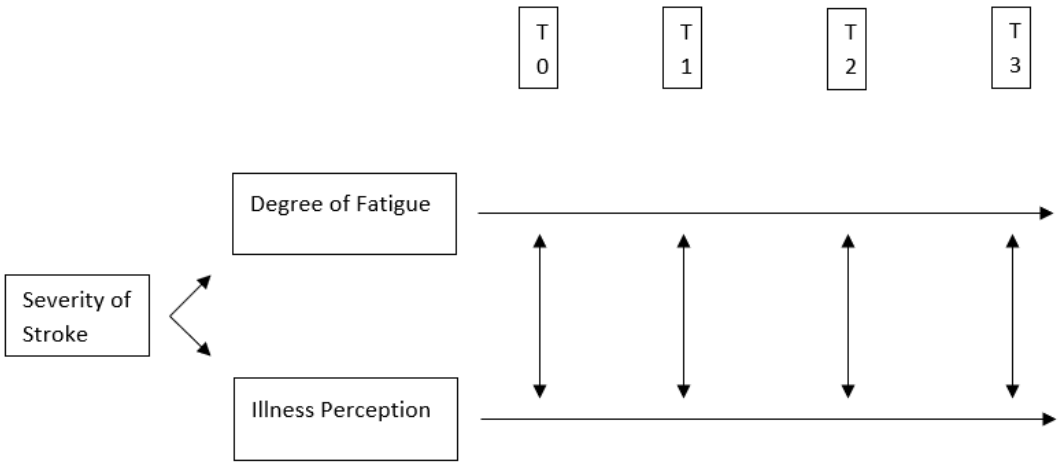

Figure 1 The relationship between the Severity of Stroke, the Degree of Fatigue and Illness Perceptions throughout time

Therefore, the current study addresses limitations in existing research by examining how illness perceptions and fatigue are related among stroke patients by aiming to answer the following research questions.

Q1: Is the severity of stroke related to the degree of fatigue within one week after the onset of stroke (T0)?

Q2: Is the severity of stroke related to the degree to which stroke is perceived as threatening within one week after onset of stroke (T0)?

Q3: Does the degree of fatigue change over the course of one year after the onset of stroke (T0, T1, T2, T3)?

Q4: Does the degree to which stroke is perceived as threatening change over the course of one year after the onset of stroke (T0, T1, T2, T3)?

Q5: What is the strength of association between the variables fatigue and illness perception

a) one week after the onset of stroke (T0)?
b) 3 months after the onset of stroke (T1)?
c) 6 months after the onset of stroke (T2)?
d) 12 months after the onset of stroke (T3)?

Methods

The following information is based on the report of a currently running trial that investigates the association of Fatigue after ischemic stroke with pituary dysfunction (den Hertog et al., 2019)

Design

The design of this study is a prospective longitudinal observational cohort study. In terms of the current study, this means that subjects of interest, namely stroke survivors, are assessed on two conditions, namely the degree of post-stroke fatigue as well as the degree to which their illness is perceived as threatening. As data is assessed during four measurement points in a time period of one year (1 week, 3 months, 6 months, and 12 months after the onset of stroke), checking for the same information at each measurement point, this study represents a longitudinal study. Further, since no manipulation is taking place, this study design is an observational one.

Participants

The sample of this study consisted of patients who were 18 years or older and had a clinical diagnosis of first-ever ischemic stroke as well as an onset of symptoms within one week. Further, it had to be expectable that the patients were discharged to a rehabilitation center or back home. A more detailed list of exclusion criteria can be found in the Appendices (Appendix 1). As represented in Table 1, the sample size of the participants was 51 at T0, 32 at T1, 32 at T2, and 31 at T3. There were 34 male and 17 female participants in the sample at T0. The age varied from 45 to 86 years (M=66.8, SD=8.9.67). The score of the severity of stroke ranged from 0-10 (M=3.37, SD=2.72). Further, Table 1 demonstrates the frequency with regards to the severity of stroke among the patients as assessed by means of the National Institute of Health Stroke Scale (NIHSS). One can see that more than half of the participants are scoring in the lower range from 0-3 points on the scale of the NIHSS.

Table 1 Demographics of the Sample at the first measurement point (T0)

Variable	N		Percentage
Gender	51		
Male	34		66.7
Female	17		33.3
	N	Range	Mean ± SD
Age	51	45-86	66.8 ± 9.67
Severity of Stroke	51	0-10	3.37 ± 2.71
	Frequency	Percent	Cumulative Percent
Score on the NIHSS			
0	5	9.8	9.8
1	11	21.6	31.4
2	8	15.7	47.1
3	6	11.8	58.8
4	8	15.7	74.5
5	1	2.0	76.5
6	2	3.9	80.4
7	7	13.7	94.1
9	1	2.0	96.1
10	2	3.9	100.0
Total	51	100	

Materials

The stroke severity was assessed using the National Institute of Health Stroke Scale (NIHSS), which consists of 15 items resulting in scores ranging from 0 to 42 where a higher value is an indication for greater severity of stroke.

Moreover, fatigue was assessed with the Checklist Individual Strengths (CIS), that has proven to be a valid and reliable measurement tool with an internal consistency of (α=0.84-0.95) (Worm-Smeitink et al., 2017). The scale consists of 20 items that are responded to in form of a self-report questionnaire, operating on four dimensions of fatigue, namely subjective experience of fatigue, reduction in motivation, reduction in activity and reduction in concentration. For this study, the score of the first subscale, the subjective experience of fatigue, will be applied only, which consists of 8 items of the overall test. The data of the current sample proved to be reliable as well, with α=0.928. Statements are rated on a seven-point Likert scale ranging from 1= "Yes, that is true" to 7="NO, that is not true". The total score can be drawn from the mean of the item scores and can range from 7 to 56, with 7 indicating no fatigue and 56 indicating very severely fatigue. As a cut-off point, the value of 35 is selected to differentiate between patients from being fatigued and not fatigued (Worm-Smeitink et al., 2017).

In order to assess the participants´ illness perceptions, the brief Illness Perception Questionnaire (IPQ) is applied. The data of the current sample produces a value of Cronbach's alpha of α=0.701. The IPQ is a nine-item scale, that represents eight factors in the first eight items on a Likert-scale, namely consequences, timeline, personal control, treatment control, identity, coherence, emotional representation, and concern. The response options for those items range from 0-10 with a higher value indicating a higher degree. The score on the test is computed by means of the total score and indicates the degree to which stroke is perceived as threatening. The ninth item has the form of an open question and is asking for the perceived top three causes of the appearance of the patient's stroke, which could be interpreted in a rather exploratory manner. With regards to the practicability of evaluation, they were grouped into categories after checking the participants given answers. Those categories were 1. Disease as for example Diabetes or Cardiovascular Disease, 2. physical impairments, 3. medication, 4. psychological factors such as stress, fear, depression, and fatigue. Further categories formed out of reasons mentioned by the participants, were 5. age, 6. heredity and 7. lifestyle (e.g. Smoking, drinking alcohol, nutrition, level of physical activity), 8. no idea, 9. misfortune and 10. other.

Procedure

Patients were assessed within one week after onset of the stroke for the first time, followed by an assessment after 3,6 and 12 months. The assessment was composed of parts such as a general physical examination including measurements of height, weight and blood pressure, blood tests with regards to aspects such as the electrolytes and a hormone screening, several questionnaires, including the NIHSS, IPQ, and CIS.

Statistical Analysis

The gathered data was analyzed by means of IBM SPSS Statistics Version 25. Items of the IPQ and CIS were recoded, which were formulated in the reversed direction, in order to be able to compute the correct total score. By means of answering research questions 1 and 2 a linear regression analysis was conducted. In order to assure the suitability of the test, it was checked for homoscedasticity, normality of residuals and outliers.

In order to answer research question 3 and 4, a one-way repeated measures ANOVA was conducted for all four measurement points. As participants were dropping out during the data assessment, only participants that completed all four assessments were included in the ANOVA analysis. The data were checked for outliers and whether it was normally distributed by means of the Shapiro-Wilk test ($p > 0.5$). Sphericity was assessed by Mauchly´s test of sphericity and when not met corrected according to Greenhouse & Geisser (1959).

For the last research question, a Pearson's product-moment correlation was run. In contrast to the regression analysis run for the first research question, the correlation approach was chosen because the correlation between multiple variables can be displayed at once. In order to include as much data as possible despite the great dropout rate throughout time, every completed assessment per measurement point was entered, even though this implied that the correlations were computed with a varying sample size between the different measurement points.

Results

Despite the high dropout rate, participants of each level of fatigue, illness perceptions and the severity of stroke remained present throughout the study, as demonstrated in Appendices 2,3 and 4.

In order to find results for research question 1, a linear regression was run to understand the effect of the severity of a patient´s stroke on the degree of fatigue after one week of onset of the stroke. The sample size for this analysis consisted of all 50 Participants,

that completed the assessment during T0. To assess linearity a scatterplot of the severity of stroke against the degree of fatigue superimposed regression line was plotted, that already displayed a negative slope as depicted in Figure 2. The severity of stroke did not statistically significantly predict the degree of fatigue, F (1, 48) = 0.04, $p < .84$, implying that there is no linear relationship between the two variables.

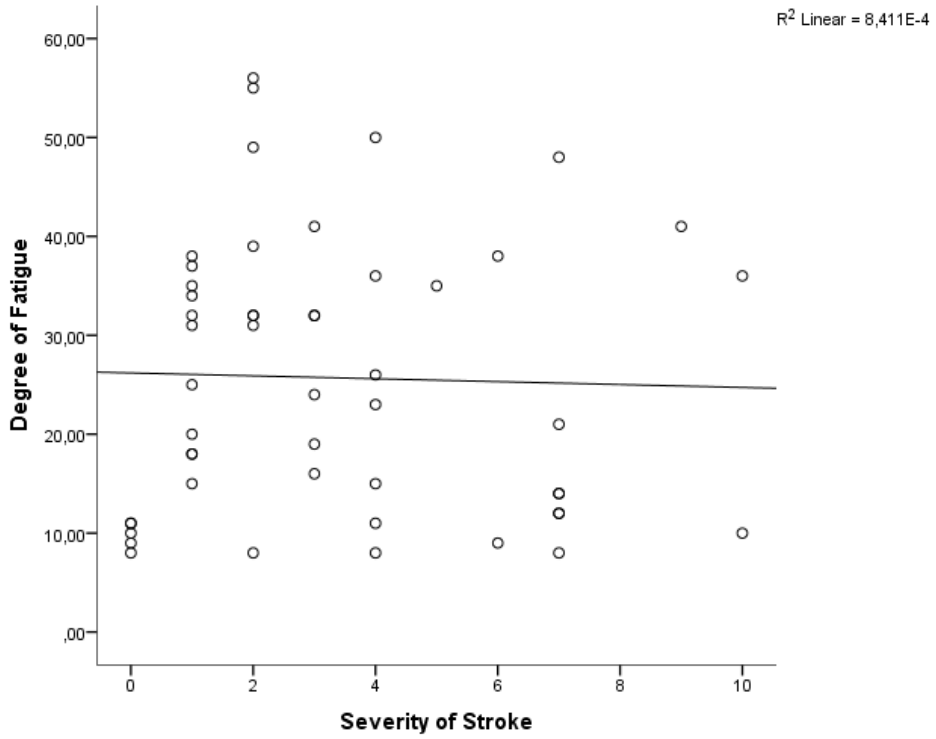

Figure 2 – Relationship between the degree of Fatigue measured with the Checklist Individual Strength and the Severity of Stroke assessed by means of the NIHSS

In order to answer research question 2, a linear regression was run to understand the effect of the severity of a patient´s stroke on the degree to which the illness is perceived as threatening after one week of onset of the stroke. Again, the sample size was N=50, as described in the previous analysis. To assess linearity a scatterplot of the severity of stroke against the degree of fatigue a superimposed regression line was plotted as represented in Figure 3. The severity of stroke statistically significantly predicted the degree to which stroke was perceived as threatening, $F(1, 48) = 8.21$, $p < .01$, accounting for 12.8% of the variation in the illness perception with adjusted $R^2 = 12.8\%$, a medium-size effect according to Cohen (1988).

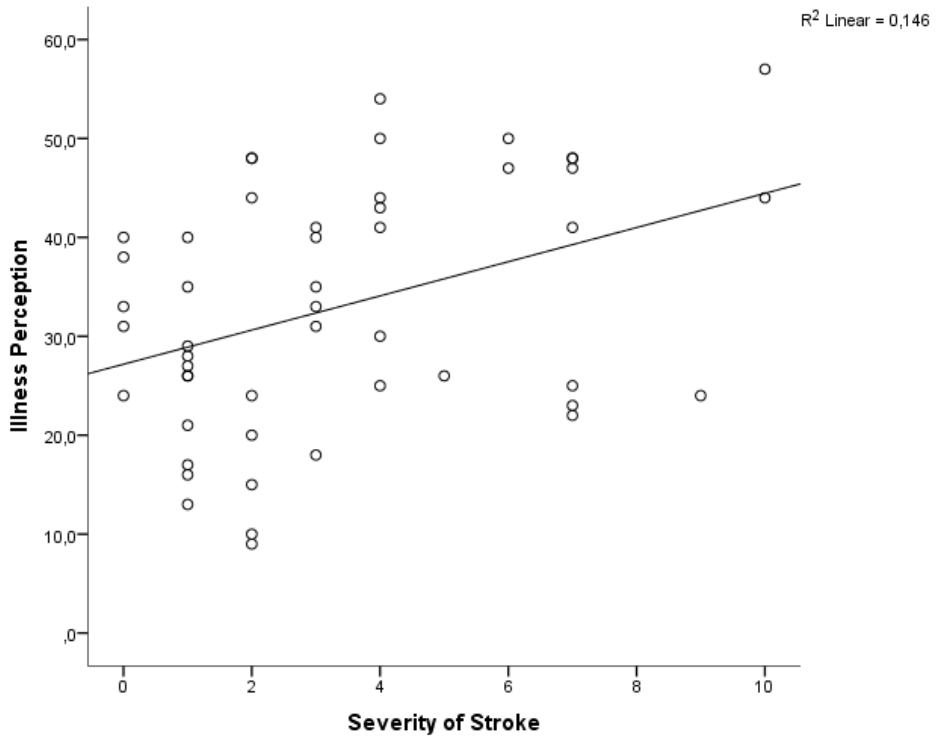

Figure 3- Relationship between the degree to which stroke is perceived as threatening (B-IPQ) and the Severity of Stroke assessed by means of the NIHSS

In order to receive an answer to research question 3 a one-way repeated measures ANOVA was conducted to determine whether there was a statistically significant difference in the degree of fatigue over the course of one year. The sample size for this analysis was N=27, as only data was included of participants that completed every test at each measurement point. As demonstrated in Figure 4, over time, no statistically significant changes occurred in the means of the degree of fatigue, $F(3, 78) = 0.03$, $p = .99$, with the degree of fatigue only slightly increasing from one week after onset of stroke ($M = 26.92$, $SD = 14.43$) to 3 months ($M = 27.55$, $SD = 13.86$) to 6 months ($M = 27.55$, $SD = 12.62$) and slightly decreasing to 12 months ($M= 27.18$, $SD= 12.70$). When applying the cut-off score of 35 on the participants´ scores on the CIS on this sample, one can see that the average of the participants was not severely fatigued (see Appendix 2). However, 26% scored higher than the cut-off score at the first measurement, 31.6% at the second, 25% at the third and 25.8% at the fourth measurement.

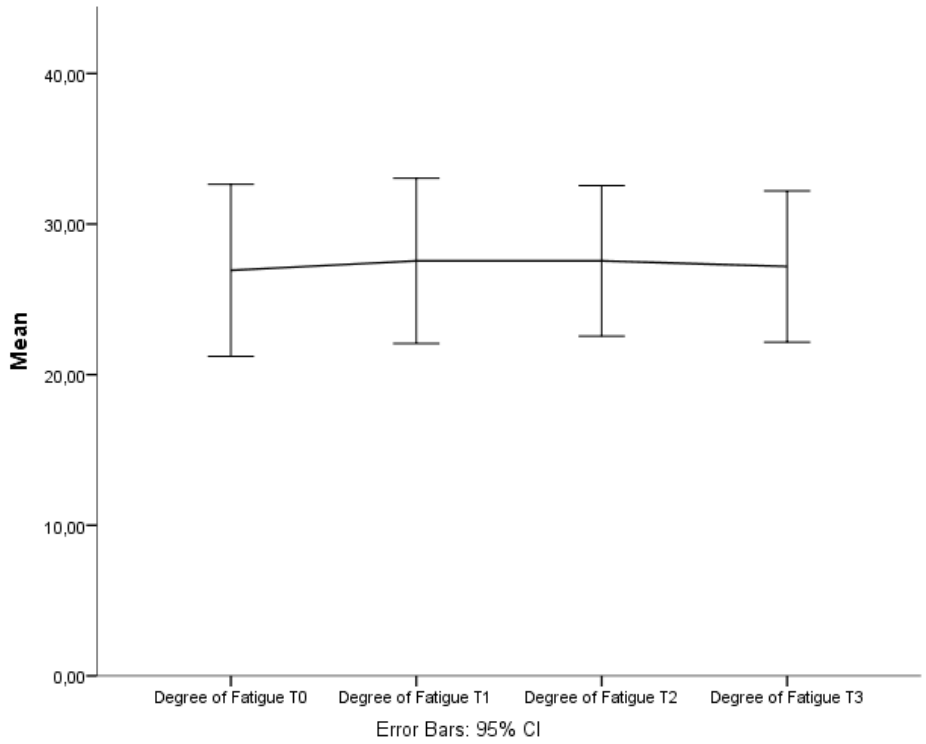

Figure 4 - Course of Fatigue over a one-year period

Testing for research question 4, a one-way repeated measures ANOVA was conducted again, to determine whether there was a statistically significant difference in the degree to which stroke was perceived as threatening over the course of one year. Just as described in the previous analysis, the sample size for this one consisted of 27 participants.

As demonstrated in Figure 5, over time, no statistically significant changes occurred in the means of the degree to which the illness was perceived as threatening, $F(2.33, 60.56) = 1.55$, $p = .22$, with the degree to which the illness was perceived as threatening only decreasing from one week after onset of stroke ($M = 31.74$, $SD = 12.54$) to 3 months ($M = 27.67$, $SD = 12.90$), increasing again at 6 months ($M = 30.92$, $SD = 11.36$) and slightly decreasing at 12 months ($M= 27.29$, $SD= 13.22$).

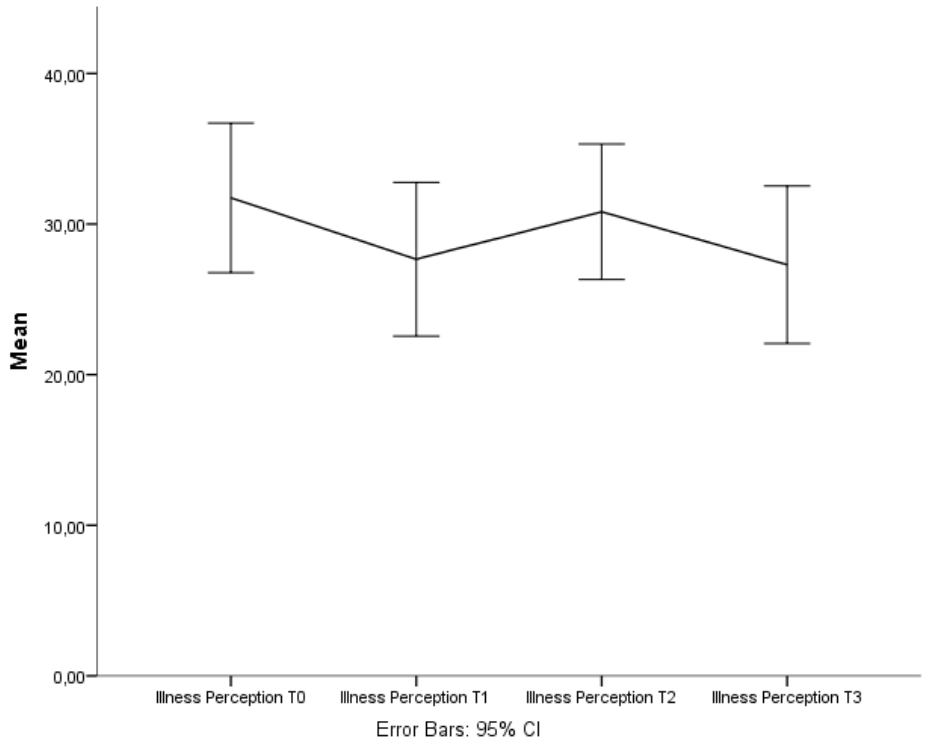

Figure 5 - Course of Illness Perception over a one-year period

Table 2 Frequency of aspects mentioned as causes for the onset of stroke as assessed by item 9 of the B-IPQ

Code	T0	T1	T2	T3
Disease	16 (21.62%)	10 (19.6%)	10 (23.3%)	17 (36.17%)
Physical Impairments	3 (4.05%)	2 (2.9%)	4 (9.32%)	5 (10.6%)
Medication	1 (1.35%)	2 (2.9%)	0 (0%)	0 (0%)
Psychological factors	22 (29.73%)	16 (31.3%)	9 (20.9%)	10 (21.2%)
Age	1 (1.35%)	1 (1.96%)	2 (4.65%)	3 (6.38%)
Heredity	6 (8.10%)	1 (1.96%)	4 (9.32%)	3 (6.38%)
Lifestyle	15 (20.27%)	17 (33.3%)	6 (13.9%)	5 (10.63%)
No idea	2 (2.70%)	0 (0%)	3 (6.9%)	0 (0%)
Misfortune	5 (6.75%)	2 (3.9%)	4 (9.32%)	3 (6.38%)
Other	3 (4.09%)	0 (0%)	1 (2.3%)	1(2.13%)
Total	74	51	43	47

Evaluating the open item of the IPQ, the answers to it are represented in Table 2. It might be difficult to compare the total amounts scored per categories between the different

time measurement points statistically significantly, as the size of the sample decreased from time to time and even within the sample answers were not always given to the open item. However, when comparing the percentages of the given answers in an exploratory manner, one can identify some prevalence's in perceived causes. The ones that were mostly mentioned at T0, are psychological factors (31.3%), disease (21.62%) and lifestyle (20.27%). Further, there is an increase over time, diseases were mentioned as a primary cause, rising from 21.62 percent at T0 to 36.17% at T3. For the category psychological factor, a decrease can be identified from 29.73% at T0 down to 21.2% at T3. The same holds to be true for the category of Lifestyle, which starts at 20.27% at T0, rises to 33.3% at T1 and drops down to 10.63% at T3. This supports the conclusion, that the perception of the assumed causes changes over time from holding psychological factors and one´s own lifestyle responsible first to thinking that former diseases were responsible.

A Pearson's product-moment correlation was run to assess the relationship between the degree of Fatigue and the degree to which the stroke is perceived as threatening at the different measurement points of one week after onset of stroke (N=50), 3 months (N=32), 6 months (N=32) and 12 months (N=31) (see Table 3).

At T0 a negative small correlation was found between the two factors fatigue and illness perception. However, the correlation one week after the onset of stroke is not statistically significant with values of (T0), r (48) = -.13, p = .36. There was a statistically significant, medium positive correlation between the degree of fatigue and the degree to which the stroke was perceived as threatening 3 months after the onset of the stroke (T1), r (30) = .42, p < .01. At T2, 6 months after the onset of the stroke, a correlation value of 0.32 could be computed, which did not prove to be statistically significant at a significance level of α= 0.05. Nonetheless, the computed p-value is not far off from the significance level with a p-value of r (30) = .32, p = .07. Further, There was a statistically significant, moderate positive correlation between the degree of fatigue and the degree to which the stroke was perceived as threatening 12 months after the onset of the stroke (T3), r (29) = .37, p < .04. Even though it had not been proposed in this study´s model, a significant positive moderate relationship was detected over time between the Illness perceptions at T2 and the degree of fatigue at T3 r (29) = .37, p = .05. In sum, moderate positive relations between the degree of fatigue and the illness perceptions could be identified throughout the period of 3 till 12 months after the onset of stroke.

Table 3 - Relation between the degree of fatigue and the illness perceptions at the measurement points 1 week, 3 months, 6 months and 12 months after the onset of stroke

Correlations

		IP T0	IP T1	IP T2	IP T3	Fatigue T0	Fatigue T1	Fatigue T2	Fatigue T3
IP T0	Pearson Correlation	1	,289	,460**	,356	-,130	,103	,109	,091
	Sig. (2-tailed)		,092	,008	,053	,367	,558	,558	,634
	N	50	35	32	30	50	35	31	30
IP T1	Pearson Correlation	,289	1	,516**	,421*	,133	,415*	,218	,269
	Sig. (2-tailed)	,092		,003	,023	,447	,012	,247	,158
	N	35	36	31	29	35	36	30	29
IP T2	Pearson Correlation	,460**	,516**	1	,800**	,244	,206	,319	,371*
	Sig. (2-tailed)	,008	,003		,000	,179	,267	,076	,047
	N	32	31	33	29	32	31	32	29
IP T3	Pearson Correlation	,356	,421*	,800**	1	-,206	,032	,001	,370*
	Sig. (2-tailed)	,053	,023	,000		,274	,870	,995	,041
	N	30	29	29	31	30	29	29	31
Fatigue T0	Pearson Correlation	-,130	,133	,244	-,206	1	,540**	,754**	,494**
	Sig. (2-tailed)	,367	,447	,179	,274		,001	,000	,006
	N	50	35	32	30	50	35	31	30
Fatigue T1	Pearson Correlation	,103	,415*	,206	,032	,540**	1	,625**	,681**
	Sig. (2-tailed)	,558	,012	,267	,870	,001		,000	,000
	N	35	36	31	29	35	36	30	29
Fatigue T2	Pearson Correlation	,109	,218	,319	,001	,754**	,625**	1	,755**
	Sig. (2-tailed)	,558	,247	,076	,995	,000	,000		,000
	N	31	30	32	29	31	30	32	29
Fatigue T3	Pearson Correlation	,091	,269	,371*	,370*	,494**	,681**	,755**	1
	Sig. (2-tailed)	,634	,158	,047	,041	,006	,000	,000	
	N	30	29	29	31	30	29	29	31

**. Correlation is significant at the 0-01 level (2-tailed). *. Correlation is significant at the 0-05 level (2-tailed)

Overall, the degree of fatigue stayed rather steady over time. Further, the average of the sample did not display a severe degree of fatigue. However, throughout time there was a slight increase and afterward a decrease in the degree of fatigue among the severely fatigued patients. Numbers increased from approximately one fourth to one third as being severely fatigued from the first to the second measurement point. Afterward, a decrease took place again and approximately one fourth was severely fatigued during the last two measurement points. Hence, this might imply a decrease in the degree of fatigue, especially when having a higher initial level. For the factor of the illness perceptions, the scores stayed steady as well, implying no large change in the degree to which the illness perceptions were perceived as threatening over time. No relationship could be found between the severity of a stroke and the degree of fatigue. However, the severity of stroke appears to be meaningfully related to illness perceptions. Further, no correlation was found between the degree of fatigue and illness perceptions at 1 week and 6 months after the onset of stroke, but a correlation was found at 3 and 12 months after the onset of stroke. An alternative interpretation might be no correlation within one week after the onset of the stroke but a small to medium correlation at the measurement points 3,6 and 12 months after the onset, because of the proximity towards the significance level.

Discussion

The aim of this study was to identify the course of the two factors illness perception and post-stroke fatigue throughout one year after stroke as well as to explore the relationships between the two. Further, it was aimed to explore the relationship between the severity of a stroke and the two variables.

This study revealed that there was only a positive relationship between the severity of the stroke and the illness perceptions and not the severity of the stroke and the degree of fatigue. Further, did the findings show, that both factors did not display a significant change over time and hence were rather steady. The last main result of this research provided support for the assumption that a positive relationship exists between the degree of fatigue as well as the illness perceptions.

The first finding, namely that the severity of the stroke is positively related to the degree to which the illness is perceived as threatening is in line with the findings of the authors Groeneveld (2019) and Morris et al. (2002). Groeneveld namely stated that a patient is forming mental representations of the symptoms of their disease. A stronger severity of the stroke usually should be accompanied by greater symptoms, which in return are the basis for

patients beliefs about the disease. The same holds to be true for the findings of Morris et al (2002), who suggested that one´s beliefs are dependent on the objective severity of the disease. What is more striking though, is that the second finding of no relationship between the severity of the stroke and the degree of fatigue does not accord with the findings proposed by the authors Elf et al. (2016). Those implied a positive relationship between exactly those two factors. One explanation for the absence of the relationship within this study might be that also participants were included with zero or only minor symptoms caused by the stroke and less patients with a higher degree of severity. This might have biased the results in such a way as that the absence of great severity also should not lead to a follow-up symptomatic of post-stroke fatigue. As described by Elf et al. (2016), the odds of developing post-stroke fatigue were higher among patients that suffered a moderate to severe stroke. Hence, one might still expect a relation between the two variables, which, however, rather becomes noticeable with a more severe stroke.

The second main finding of this research demonstrated that there is no statistically significant change in the degree of both factors, post-stroke fatigue as well as the illness perceptions, over time. This might imply that the nature of post-stroke fatigue and illness perceptions is to stay setady. Hence, a stable mean might be an indication for the absence of additional treatment or the inefficacy of a treatment. However, as no information was provided with regards to a conducted treatment among the sample of this study, one might rather adhere to the first alternative. As aforementioned, Cognitive Behavioral Therapy, for example, might have an impact on the degree of fatigue among other comparable diseases such as Multiple Sclerosis, as proposed by Elf et al. (2016) and hence might have resulted in a change in the degree of post-stroke fatigue as well. Even though the majority of the sample was not severly fatigued, approximately one fourth suffered from severe post-stroke fatigue, which is in line with the findings of Choi-Kwon (2011 as cited in Wu et al. 2015 B). While attempting a rather qualitative approach that explored the perceived causes of the disease, one could see a change throughout time in the patient's beliefs with regards to this subject. At the beginning, patients addressed psychological factors as well as their lifestyle to be responsible for the occurrence of their stroke. Throughout time, however, this perception changed and they rather blamed previous disease and health conditions to be the cause of the onset. Even though the outcome of the numerical responses did not change significantly over time, the individual opinions still might deviate when asking for in a qualitative manner.

The last finding of an association of the two factors post-stroke fatigue and illness perceptions is in line with the findings of the authors Westbrook, Maddock, and Andersen

(2016) , who described a relationship between Illness perceptions and fatigue among Chronic Lymphocytic Leukaemia (CLL) patients as well as with the findings of Abdullahi, Shagholian and Baheshmat (2016) that had a sample of Multiple Sclerosis patients. The former ones stated that a higher degree of CLL-imposed fatigue was found among those patients that identified to a greater extent with their disease and viewed CLL as having a great impact on their emotions. Further, did the authors indicate that a decrease in the negative perception of the disease might alter the degree of fatigue. As a positive relationship could be identified among the sample of this study as well, one might assume that changing one's negative perceptions concerning the stroke and its impact towards rather positive ones, might also reduce the degree of post-stroke fatigue. The authors of the study however, assessed the 8 dimensions of illness perceptions separately as in contrast to this study, which made use of the total score. Hence, drawing conclusions due to the comparability of those two studies might be more difficult. As both studies indicate the same direction of the relationship between the two constructs, they still might prove suitable for comparison.

The authors Abdollahi, Shagholian and Baheshmat (2016) identified a relationship between the two constructs in their cross-sectional study, which they proposed to be interpreted the opposite way. They hypothesize that illness perceptions are predicted by fatigue among MS patients, as an increase in fatigue enhances the patient's perception of the effect of the disease on the overall outcome of the disease in form of a patients´ quality of life. Those perceptions in return create greater concern and negative emotional response. Taking a perspective from this approach, one would have to treat the patients´ post-stroke fatigue first. No optimal solution for treatment could be found yet in order to improve post-stroke fatigue directly without altering one's beliefs through e.g. CBT.

The previously assumed model presented in the introduction (Figure 1) was only slightly readjusted and resulted in the following newly proposed model (Figure 6). The first mechanism is a relationship between the severity of a stroke and the degree to which the illness is perceived as threatening. Additionally, the relationship between the severity of the stroke and the degree of fatigue was retained despite the findings of this study due to the as aforementioned possible explanations. Further, especially after 3 and 12 months, a relation between the degree of fatigue and the degree to which stroke is experienced as threatening can be found, with a possible relationship in between, after six months. When untreated, no changes occur among the degrees of both factors. Hence, altering the degree of one of the factors through an external influence might alter the degree of the other one.

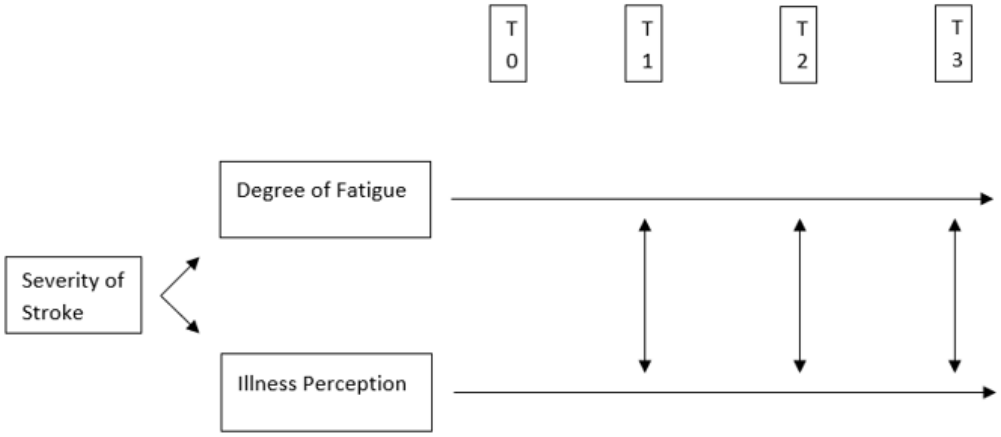

Figure 6- The relationship of the severity of stroke, fatigue and illness perceptions over a one-year period

One limitation of this study might be seen in its rather small sample size, which was even decreasing throughout time due to the longitudinal design and its concomitant drop-out rate. However, a strength of this study can be seen in its quick data acquisition, which occurred only one week latest after the onset of the stroke and hence might allow to rule out at least other factors that occurred after the onset of the stroke and might have influenced the illness perceptions or post-stroke fatigue. Despite, one should not rule out the possibility of patients to have formed illness beliefs already before the occurrence of the stroke or to have been fatigued beforehand. Though, another unique factor of this study is its design, as there have not been any studies combining a longitudinal as well as cross-sectional approach among stroke survivors and their illness perceptions as well as fatigue, which allowed to rule out natural causes for the development of both factors on its own as well as to detect a relationship between them throughout time.

A suggestion for further research would be to explore the relationship of post-stroke fatigue and illness perceptions more in-depth, as findings might help to improve the treatment options in ongoing steps and thereof the overall quality of life of a stroke survivor. One way of doing so might be to assess the relationship between the single dimensions of the illness perceptions and post-stroke fatigue. Moreover, while opting for an improvement in the treatment of post-stroke fatigue, one might apply Cognitive Behavioural Therapy, as it has shown to be helpful among patients with fatigue implied through other diseases. Moreover, the study implemented by Zedlitz et al. (2012) revealed the effectiveness of cognitive therapy on post-stroke fatigue. However, none of the studies tested yet, whether an actual change among the patients´ illness beliefs occurred that could explain the effect of CBT on post-

stroke fatigue. Hence, by doing so, one might be able to draw more concrete conclusions with regards to the relationship and if possible, even causality between the two factors.

In conclusion, this study added new findings to the not yet explored field of post-stroke fatigue and illness perceptions and can be seen as a first step in the combined research of the two factors and maybe even as a first step towards improved treatment options for severe post-stroke fatigue, which approximately at least every fourth stroke survivor is affected by.

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Appendices

Appendix 1

Patients were not eligible for the study if one or more of the following conditions was the case. They:

- are treated with chemotherapeutics;
- are receiving (oral or intravenous) corticosteroid therapy for more than 1 month;
- are pregnant;
- are not able to complete a questionnaire due to severe aphasia, non-Dutch speaking or severe cognitive disturbances;
- have a history of:
    - hypothalamic/pituitary disease that significantly affects the study results, e.g. Cushing's disease;
    - cranial irradiation or another significant intracranial lesion;
    - multiple sclerosis;
    - chronic fatigue syndrome;
    - psychiatric condition that interferes with interpretation of the study

Appendix 2

Table 4- Severity of Fatigue- Scores of the CIS

	Range	Cumulative Percent (Frequency)			
		T0	T1	T2	T3
Valid					
	8-21	46.0 (23)	38.9 (14)	34.4 (11)	25.8 (8)
	22-34	70.0 (12)	66.7 (10)	68.8 (11)	71.0 (14)
	35-47	90.0 (10)	88.9 (8)	93.8 (8)	93.5 (7)
	48-56	100.0 (5)	100.0 (4)	100.0 (2)	100.0 (2)
	Total	50	36	32	31
Missing	System	1	15	19	20
Total		51	51	51	51

Appendix 3

Table 5- Degree of Illness Perception- Scores of the B-IPQ

	Range	Cumulative Percent (Frequency)			
		T0	T1	T2	T3
Valid					
	4-14	6.0 (3)	16.7 (6)	6.1 (2)	19.4 (6)
	15-28	42.0 (18)	50.0 (1)	39.4 (11)	48.4 (9)
	29-42	72.0 (15)	86.1 (13)	81.8 (14)	87.1 (12)
	43-57	100.0 (14)	100.0 (5)	100.0 (6)	100.0 (4)
	Total	50	36	33	31
Missing	System	1	15	18	20
Total		51	51	51	51

Appendix 4

Table 6- Severity of the Stroke – completed assessment of Fatigue and Illness Perception

Score	Frequency			
	T0	T1	T2	T3
0	5	5	5	5
1	11	7	7	7
2	8	6	6	6
3	6	6	5	5
4	8	3	4	5
5	1	1	1	1
6	2	2	2	2
7	7	5	1	-
8	0	-	-	-
9	1	1	-	-
10	2	-	1	-
Total	51	36	32	31