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Illness perceptions and depression
after stroke

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Abstract

In the current study, it was investigated both the development of illness perceptions and depressive symptoms as well as the correlation of the respective constructs. Depression in stroke patients is a well-known phenomenon, which negatively impacts the course of the disease. Furthermore, earlier findings showed that illness perceptions are related to depressive symptoms in several diseases. However, the relation between the two constructs has never been examined with a sample of stroke patients. Therefore, it was executed a prospective observational cohort study with 51 stroke patients. It was examined the relation between depressive symptoms and illness perceptions as well as the development of the separate constructs. The constructs were assessed by means of questionnaires that were filled out one week after stroke, 3, 6 and 12 months after study onset. The main findings were that there is no significant change in the mean scores of the respective constructs over time. Furthermore, there were found multiple strong correlations between illness perceptions and depressive symptoms at several time points. The results have to be considered carefully because there was a high dropout rate. Consequently, only 25 participants finished the study to the end, and a selective dropout may have biased the results. Concludingly, the present study found a strong positive relation between perceived threat of the illness and depressive symptoms, which indicates that on average the more threatening stroke patients perceive their illness the more depressive symptoms they have and vice versa.

Introduction

Ischemic stroke is a severe damage to the nervous system, which impacts both physical as well as mental aspects of affected patients. One of the mental consequences is known as Post stroke Depression (PSD). Interestingly, the development of depression after stroke varies from patient to patient. One factor that may play a role in the development of depression is the illness perception of stroke patients, since in other chronic diseases illness perceptions are related to depression (Westbrook, Maddocks, & Andersen, 2016). Nevertheless, the correlation between illness perception and PSD has not been researched yet. Therefore, the aim of the present study was to investigate the relation between illness perceptions and depression of stroke patients.

Stroke: Etiology, Prevalence and Impact

Stroke is traditionally defined as a neurological dysfunction, which is caused by infarction or hemorrhage in a part of the brain, in the spinal cord or in the retina (Hankey, 2017). In the global ranking of the most burdensome diseases in 2010, stroke was ranked on the third place behind heart disease and respiratory infection (Murray et al., 2012). The number of stroke patients is rising significantly. Strong, Mathers and Bonita (2007) prognosed that without any intervention, the number of global first-ever strokes will rise to 23 million in 2030. Stroke leads to multiple severe health consequences, such as sensory, motor and cognitive difficulties. Furthermore, stroke patients generally have trouble to maintain their balance and to walk (Mansfield et al., 2018).

Besides physical restrictions, stroke also has a negative impact on patient's mental health. Narushima and Robinson (2002) showed that stroke is a clear risk-factor for depression. First, in order to prevent confusion, it has to be made a distinction between clinical depression and depressive symptoms. A clinical depression or major depressive disorder is a mental illness, which can only be diagnosed, if the patient displays five of the 9 DSM-5 criteria (American Psychiatric Association, 2013). In contrast, depressive symptoms do not imply a mental disorder but rather refer to specific symptoms related to depression such as fatigue or loss of energy. In the present study depressive symptoms are analyzed regarding their relation with illness perceptions.

Depressive symptoms in stroke patients

The prevalence of depressive symptoms in stroke patients varies across studies between 18% to 61% due to different samples, questionnaires or study-designs (Srivastava, Taly, Gupta, & Murali, 2010). Hackett, Yapa, Parag, and Anderson (2005) found in their systematic review of observational studies until 2004 that 33% of stroke patients experience significant depressive symptoms at any given time after stroke onset. Longitudinal studies, regarding the course of depression after stroke onset provide contradictory results. On the one hand, Verdelho, Henon, Lebert, Pasquier, and Leys (2004) found in a hospital-based study a gradual decrease of depressive symptoms in stroke patients. Thus, in the first assessment after 6 months 43% of the stroke patients displayed depressive symptoms. After 1 year the value decreased to 36%, after 2 years to 24% and finally to 18% after 3 years. In contrast, King, Shade-Zeldow, Carlson, Feldman, and Philip (2002) found an initial decrease of depressive symptoms after 1 year (from 30% to 17%) but an increase to 23% in the second-year post stroke.

PSD decreases mental recovery, physical recovery and increases the mortality risk of stroke patients (Narushima & Robinson, 2002). Consequently, PSD should be considered in the treatment of patients in order to improve the recovery process. There may be multiple reasons for the development of PSD. Westbrook et al. (2016) investigated the risk-factors of PSD by means of a meta-analysis. They found that the main risk factor is a history of mental illness. Moreover, female gender, severity of stroke and level of handicap are risk factors for the development of depression in stroke patients (Westbrook et al., 2016). Another factor that may be related to PSD are the illness perceptions, patients have about their disease. The relation between illness perception and PSD is unclear yet. However, studies constantly showed a relation between certain dimensions of illness perceptions and depression in other chronic diseases such as cancer (Westbrook et al., 2016; Llewellyn, McGurk, & Weinman, 2007). Hence, generally if patients perceive their disease as chronic severe and incurable, they are more likely to develop depressive symptoms (Westbrook et al., 2016; Llewellyn et al., 2007). In turn, depressive symptoms are associated with passive coping strategies, impacting the course of the disease negatively (Crane & Martin, 2004). Consequently, it is crucial to take illness perceptions into account to improve the recovery process. Accordingly, a study of a sample with the autoimmune disease SLE showed that a positive change of illness perceptions leads to reduced levels of stress and improved physical as well as mental well-being (Goodman, Morrissey, Graham, & Bossingham, 2005).

Illness perceptions

Illness perceptions are part of a broader model: The Common-Sense Model of self-regulation (CSM) (Hale, Treharne, & Kitas, 2007). Leventhal and colleagues developed the CSM to investigate the perception of health threats, coping mechanisms and the appraisal of coping mechanisms in the face of diseases. The model is hierarchically organized and consists of three main constructs. The first construct “representation” refers to the illness perceptions patients have, based on their experience. On the basis of these illness perceptions, patients try to manage the impact of their disease, which is summarized under the second construct “coping”. Finally, the third construct “appraisal” implies an assessment and eventual modification of the former used coping strategies (Leventhal et al., as cited in Hale et al., 2007).

Illness perceptions are the core concept of the CSM because they are the foundation for coping and planning strategies, patients use to deal with their disease. Accordingly, Heijmans (1999) found that patients who perceive their illness as being chronic, severe and uncontrollable were more likely to engage in passive coping strategies. Thus, considering illness perceptions

is crucial because they influence coping mechanisms and in turn the course of the disease. Illness perceptions are divided in five dimensions: Identity, Cause, Time-line, Consequences, Curability/controllability (Hale et al., 2007). The first dimension “identity” is about labeling the disease with all of its related symptoms. The second component is the “cause” of the disease, which is developed by personal experiences, the opinion of doctors and significant others as well as media sources. The third concept “time-line” describes the belief of patients of how long the disease will last. The “consequences” are the patients beliefs about the physical and social impact their disease will have in the future. The “curability/controllability” is not only the patients perception of the curability of their disease but also the extent to which they believe to have control over their disease (Hale et al., 2007).

The main questionnaire measuring the five dimensions of illness perception is the IPQ-R (Illness Perception Questionnaire-Revised). However, in the present study the brief IPQ is used for the measurement. In contrast to the IPQ-R, the brief IPQ contains 9 dimensions. Namely, in the brief IPQ there are added the dimensions: coherence, emotional representation, concern and the dimension of control is divided into personal control and treatment control (Broadbent, Petrie, Main, & Weinman, 2006).

Relation between illness perceptions and depressive symptoms

Research shows that the illness perceptions, patients hold about their disease are related to depression (Westbrook et al., 2016; Llewellyn et al., 2007). However, in most of the studies about illness perception’s relation to depression, the subjects consist of cancer patients. Since the disease of cancer differs significantly from stroke, the results of the studies have to be applied carefully. Nevertheless, the studies can be used as an indication for stroke patients because both diseases are similar in some respects. Both stroke and cancer are chronic diseases that have a severe impact on patients mental and physical health. Furthermore, in both conditions patients tend to withdraw from social activities (Mansfield et al., 2018).

First, the results of Hagger and Orbell (2006) showed a relation between the different dimensions of illness perception and depression in cervical- and colorectal cancer patients. They found that perceived control was significantly correlated both with anxiety and depression in the colorectal sample. Thus, patients who thought they were not able to influence their bowel problems were more prone to depression. Additionally, identity was significantly associated with depression. Hence, the more patients perceived their symptoms as severe the more likely they were to display depression. Finally, time-line had a significant correlation with depression. Hence, patients who perceived their disease as chronic, suffered from more depressive

symptoms. The dimensions ‘cause’ and ‘consequences’ were not significantly related to depression.

Furthermore, Westbrook et al. (2016) investigated the relation between the separate dimensions of illness perceptions and depressive symptoms in leukemia patients. Their cross-sectional study showed a significant correlation between consequences and depressive symptoms. Nevertheless, in contrast to Hagger and Orbell (2006), it was not found any significant relation between identity nor control with depressive symptoms (Westbrook et al., 2016). Llewellyn et al. (2007) provided a longitudinal study design regarding the impact of dimensions of illness perceptions on depression in head and neck cancer patients. Patients were assessed before treatment and finally 6-8 months after treatment. Interestingly, their main finding was that timeline before treatment is a significant predictive factor for depression 6-8 months after treatment. Thus, patients who regarded their condition as long lasting were more prone to develop depression.

Besides the impact of illness perceptions in cancer patients, there are multiple studies of other illness populations such as noncardiac chest pain (NCCP) and systemic lupus erythematosus (SLE) that show a significant relation between illness perceptions and depressive symptoms (Israel, White, & Gervino, 2015; Nowicka-Sauer et al., 2018). In their cross-sectional study, Israel et al. (2015) tested the relation of the dimensions of illness perceptions with depression in NCCP patients. They used the IPQ-R to evaluate illness perceptions and the DASS- depression scale for the assessment of depression. The main result was a weak but significant relation between the dimension ‘consequences’ and depression. The other dimensions of the IPQ-R were not related to depression. Additionally, in 2018, Nowicka-Sauer et al. studied the relation between illness perceptions and depressive symptoms in patients with SLE. In contrast to the other studies illness perceptions were regarded in total and not in separate dimensions. It was found a strong relationship between threatening illness perceptions and depressive symptoms.

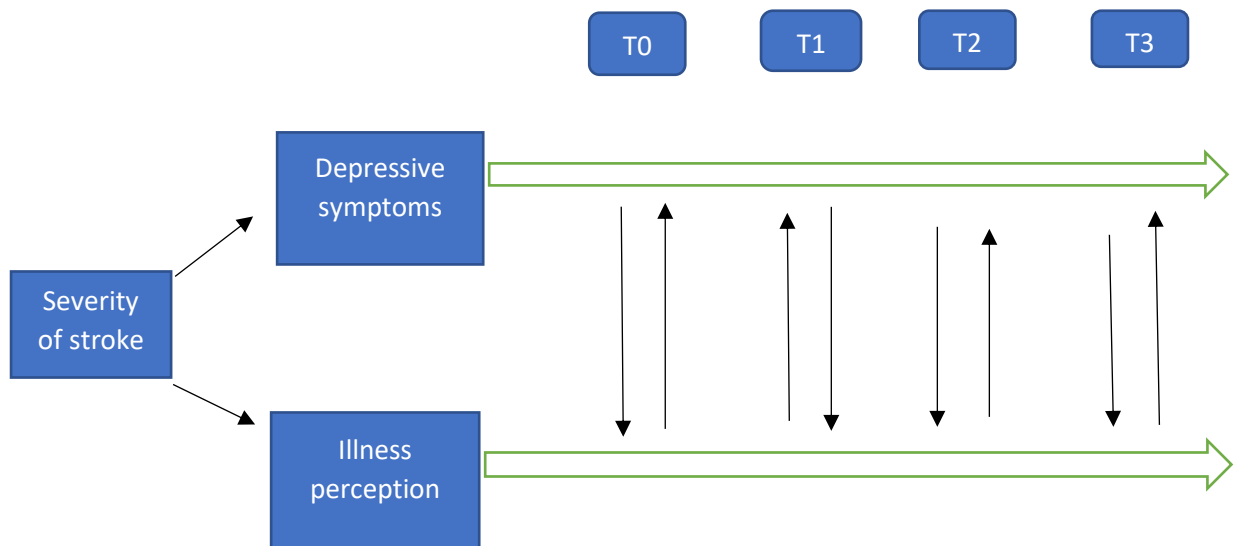
Concludingly, the reported literature showed that there is a relationship between illness perceptions and depressive symptoms in several diseases. However, the specific dimensions of illness perceptions that were related to depressive symptoms differed from study to study. These differences may be caused by different kinds of samples and diseases that were examined in the studies. The purpose of the present study was to investigate the relation between illness perceptions and depressive symptoms in a sample of stroke patients. Accordingly, 4 research questions were posed to examine this relation:

1. Are illness perceptions related to depressive symptoms at every measurement point?

2. How do depressive symptoms and illness perceptions develop over time?
3. Are illness perceptions a predictive factor for depressive symptoms in stroke patients at every measurement point?
4. How is stroke severity related to illness perceptions and depressive symptoms at every point of measurement?

There were multiple possible outcomes regarding the relationship of the two constructs illness perception and depressive symptoms, as it is represented in Figure 1. First, the severity of the stroke may influence both depressive symptoms and illness perception and consequently stroke severity may act as a confounding variable. The different times of measurement are represented in Figure 1 as T0, T1 etc. The model does not only show a separate development of both constructs over time but also it shows an interrelation between depressive symptoms and illness perception.

Figure 1. possible relationship between depressive symptoms and illness perception



Methods

Design

For the present study, a prospective observational cohort study-design was employed. In total, there were performed 4 measurements over time. The first measurement was done one week after stroke, the following ones were executed 3, 6 and 12 months post stroke.

Participants

Initially, the purposive sample consisted of 51 stroke patients (34 male 17 female). However, merely 27 (19 male, 8 female) patients completed the study till the end. The participants of the study consisted of clinically diagnosed first ever ischemic stroke patients. In Table 1 the age distribution of the patients is reviewed. Furthermore, participants were required to display a significant stroke severity. Hence, only participants with a score of ≥ 2 on the National Institutes of Health Stroke Scale (NIHSS) were included into the sample. In table 1 the distribution of the NIHSS score is displayed.

Table 1. Descriptive statistics of age and NIHSS score (N=51)

	Minimum	Maximum	Mean	Std. Deviation
NIHSS	0	10	3.37	2.70
Age	45	86	66.88	9.67

Patients were excluded from the study, if they were engaging in certain types of therapy such as chemotherapy; they had severe speaking problems due to aphasia, cognitive disabilities, or did not had sufficient skills in the Dutch language; were pregnant; had a history of diseases such as multiple sclerosis or Cushing's disease. The complete exclusion criteria are displayed in Appendix A.

Materials

In order to investigate the severity of stroke in the patients, the 15-item scale NIHSS was used (Williams, Yilmaz, & Lopez-Yunez, 2000). The scale ranges from 0 to 42, in which higher values indicate higher stroke severity. Patients were assessed one-week post stroke and 3, 6 and 12 months after stroke onset. These assessments included a physical examination, a

questionnaire, blood test, a hormone screening protocol and a urine osmolality test. Furthermore, the use of medication was considered. Additionally, the functional status of the patients was assessed by means of the modified Rankin scale (mRS) ranging from 0 (no symptoms) to 5 (severe symptoms) A score of 2 or more indicated an unfavorable functional outcome. The questionnaires that were used for the assessment took 30-45 minutes and covered the following constructs: Demographic features, Treatment for depression (drugs and/or psychological treatment), Menstruation, Fatigue, Quality of sleep, Depression, Illness perception and pain. The present study was part of a broader research setting. Hence, for the present study there were only analysed the questionnaires for depression and illness perception. Furthermore, the scores of the NIHSS were considered.

To measure depressive symptoms, the CES-D (Center for Epidemiologic Studies Depression Scale) was used (Andresen, Malmgren, Carter, & Patrick, 1994). The CES-D contains 20 items that measure the frequency of depressive symptoms. The items are short statements and the patients had to indicate how often they behaved or felt in accordance to the statement. Consequently, patients had to indicate on a scale from 0 to 3 how often they had the respective feelings or thoughts, while 0 represents low frequency and 3 represents the highest frequency of displaying the specific behaviour or feeling. The complete scale of the CES-D is shown in Appendix C.

A summary score indicated the severity of depressive symptoms, in which higher values implied more severe symptoms. The maximal score is 60 and a score of 16 or more indicates significant depressive symptoms of the patients. Regarding the psychometric properties, the CES-D has a satisfactory reliability with a Cronbach's alpha of .80-.90 (Beekman, Van Limbeek, Deeg, Wouters, & Van Tilburg, 1994). Accordingly, in the present study it was calculated a Cronbach's alpha of .89.

Illness perceptions were assessed by means of the brief IPQ. The brief IPQ has significant values for test-retest reliability, predictive validity and concurrent validity (Broadbent et al., 2006). Moreover, a Cronbach's alpha value of .74 was reported (Nowicka-Sauer et al., 2018). Accordingly, a reliability analysis in the present study provided a Cronbach's alpha value of .70. The brief IPQ questionnaire contains 9 items, each measuring one of the nine dimensions: consequences, timeline, personal control, treatment control, identity, concern, coherence, emotional response and cause (Broadbent et al., 2006). The brief IPQ questionnaire is displayed in Appendix B. Additionally, a total score of the brief-IPQ may be calculated by recoding items 3,4,7 and finally adding the scores of each item. The final score describes how threatening the disease is perceived by the participant. The original brief IPQ is

assessed on a scale from 0 to 10. However, in the current study, each of the items except cause is scored on a Likert scale from 0 to 9 and consequently the maximal total score is 72. Even though each item measures a different dimension, the total score indicates the psychological threat patients are perceiving through their disease. Besides the 8 items that are measured on a scale, the ninth item, which measures the perceived cause for the illness is nominal. Thus, patients were asked to indicate factors that may have caused their disease. These potential causes were grouped into categories by two researchers, which are represented in table 2.

Table 2. Categories of the IPQ item 'cause'

Code	Subcategories
Disease	Diabetes, Cardiovascular disease
Physical Impairments	
Medication	
Psychological factors	Stress, fear, depression, fatigue
Age	
Heredity	
Lifestyle	Smoking, alcohol, nutrition, weight, sport
No idea	
Misfortune	
Other	

Data analysis

The gathered data were analyzed by means of SPSS. First, certain items of the CES-D and brief IPQ had to be recoded in order to calculate a total score. Thereupon, in order to investigate the reliability of both questionnaires, the Cronbach's alpha value was calculated through a reliability analysis. After there was calculated a total score for both questionnaires, descriptive statistics were calculated for the total scores of depressive symptoms, illness perceptions and stroke severity at the first measurement point(T0) to get an overview of the data. Next, mean scores and standard deviations of the separate items of the IPQ were calculated. Before any further analysis, depressive symptoms-, illness perceptions- and stroke severity sum scores were checked for a normal distribution by means of a Kolomogorov-

Smirnow test. It was found that the sum scores of both stroke severity and depressive symptoms were not normally distributed at multiple time points. Therefore, for the following correlational analyses, there was used bootstrapping. Consequently, a Pearson's r correlation tested the relation between depressive symptoms illness perceptions and stroke severity in the first measurement with a sample of 51 participants. For the following calculations it was only used a sample of 25 participants because this is the number of participants who finished the study completely. Next, it was tested for a significant change in the mean scores of the separate variables over time. Hence, the mean scores of depressive symptoms and illness perceptions were calculated for the four measurement points. An ANOVA with repeated measures was applied for the illness perception total score. In contrast, for both the depressive symptoms total score and the separate items of the IPQ the non-parametric alternative of a Friedman test was applied.

A Pearson's r correlation was run to test the relation between depressive symptoms, illness perceptions and stroke severity at all 4 measurement points. For any correlational analysis, it was only used the total score of the brief IPQ, which was referred to as threatening illness perceptions. The separate dimensions were not included in the correlation analysis, since their reliability was not acceptable regarding the present sample size. A regression analysis was not necessary because the NIHSS score was not related to depressive symptoms at any measurement point. Consequently, stroke severity could be excluded as a confounding variable.

Results

Descriptives of the first measurement

The analysis was executed with a total sample of 51 participants. The properties of the sample are reviewed in the participants section. In table 3 it can be concluded from the standard deviations that there is a high variation in the sample regarding depressive symptoms, stroke severity and illness-perceptions. Furthermore, the mean score for depressive symptoms is 12.6 and 17 participants (28%) have a score higher than 15, which indicates significant depressive symptoms. Table 4 shows that except for treatment control and identity, participants score on the separate dimensions of the brief IPQ on average between 4 and 5.

Table3. Descriptive statistics of depressive symptoms, stroke severity and illness perceptions in 51 participants after stroke at T0

	Minimum	Maximum	Mean	Std. Deviation
Depressive symptoms ¹	0	37.00	12.60	9.99
Stroke severity ²	0	10	3.37	2.70
Illness perception ³	9.00	57.00	32.98	12.34

1 Depressive symptoms refer to the total score of the CES-D questionnaire

2 Stroke severity is derived from the total NIHSS score

3 Illness perceptions refer to the total score of the brief IPQ

Table 4. Means and standard deviations of the separate IPQ items with N=51

	Mean	Std. Deviation
Timeline	4.66	2.81
Consequences	4.84	3.05
Concern	4.88	2.92
Emotional response	4.62	2.83
Coherence	4.44	2.60
Personal control	4.70	2.63
Identity	2.86	2.66
Treatment control	1.98	2.06

An executed Pearson's r correlation does not show any significant relation between depressive symptoms and illness perceptions at the first measurement (Table 5). However, illness perceptions are moderately positively related to stroke severity ($r=.38$, $p=.006$).

Table5. Pearson correlation with bootstrapping between illness perceptions, depressive symptoms and stroke severity at T0 (N=51)

	Depressive symptoms	Illness perceptions	Stroke severity
Illness perceptions r		.27	
	95% CI		
	Lower	-.01	
	Upper	.52	

Stroke severity	r		.08	.38**
	95% CI	Lower	-.28	.11
		Upper	.42	.60

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

Development of the separate constructs over time

In table 6, sum scores of the CES-D questionnaire show the average development of depressive symptoms over time. For this measurement it was only used the sample of participants who finished the study to the end (n=25). Especially at the third(T2) and fourth(T3) measurement it can be observed a slight decrease of the average score of depressive symptoms in the sample. However, a Friedman test did not provide a significant result ($X^2=2.89$, $p=.409$). Hence, a significant change of depressive symptoms over time can be excluded.

Table 6 also displays the development of the average sum score of the brief IPQ. The main observation is that during the first measurement, patients perceive their illness as most threatening with a mean of 34.96 (13.01). Nevertheless, based on the one-way ANOVA it cannot be observed a significant change of illness perceptions over time ($F=1.04$, $p=0.37$). Regarding the separate dimensions of the brief IPQ, a significant change over time in the item treatment control was found ($X^2=17.6$, $p=.001$). It was observed a significant increase of the recoded item, which equals an increase of the unmodified item: (T0: M=2.68, SD=1.77, T1: M=3.24, SD=1.74, T2: M=4.6, SD = 2.59, T3: M=4.5, SD=2.66).

Table6. mean scores and standard deviations of depressive symptoms and illness perceptions over the four time points (n=25)

	IP ¹ T0	IP T1	IP T2	IP T3	DS ² T0	DS T1	DS T2	DS T3
M	34.96	31.32	33.24	30.72	11.76	11.60	9.76	9.96
SD	13.01	12.39	11.43	13.09	9.45	8.636	7.39	9.25

1 IP = Illness perceptions

2 DS = depressive symptoms

The development of the nominal item ‘cause’ is displayed in table 7. The factors: disease, psychological factors and lifestyle were the main perceived causal factors for the

development of patients' stroke. However, it can be observed a decline in psychological factors and lifestyle over time. In the first and second measurement psychological factors made up 31% while in the third and fourth it declined to 20%. In contrast the perceived cause 'physical impairments' and 'disease' increased slightly over time (Table 7).

Table 7. Frequencies (percentages for the categories of the IPQ item 'cause')

Code	T0	T1	T2	T3
Disease	16(23)	10(20)	10(23)	17(36)
Physical Impairments	3(4)	2(4)	4(10)	5(12)
Medication	1(2)	2(4)	0(0)	0(0)
Psychological factors	22(31)	16(31)	9(20)	10(20)
Age	1(2)	1(2)	2(4)	3(7)
Hereditiy	5(7)	1(2)	4(10)	3(7)
Lifestyle	14(19)	17(33)	6(13)	5(12)
No idea	2(3)	0(0)	3(7)	0(0)
Misfortune	5(7)	2(4)	4(10)	3(7)
Other	1(2)	0(0)	1(3)	1(3)

Correlation between the constructs over time

The correlations between illness perceptions, depressive symptoms and stroke severity over the 4 time points was investigated by means of a Pearson's r correlation. Table 8 shows clearly that except for the first measurement(T0), there is a significant relation between illness perceptions and depressive symptoms. Thus, the relations between the two questionnaires at the second measurement ($r=.52$, $p=.008$), third measurement ($r=.60$, $p=.002$) and fourth measurement ($r=.55$, $p=.004$) are significant and strong. Interestingly, there is not only a relation between illness perceptions and depressive symptoms at the same measurement time, but Table 7 shows clearly a correlation between the two factors across time. Hence, depressive symptoms at T1 are moderately related to illness perceptions at T2 ($r=.50$, $p=.012$), illness perceptions at T2 are strongly positively related to depressive symptoms at T3($r=.60$, $p=.006$) and depressive symptoms at T2 are moderately related to illness perceptions at T3 ($r=.40$,

p=.048). Therefore, both illness perception predict depressive symptoms at certain time points and the other way around. Stroke severity was not significantly related to depressive symptoms at any time point and illness perceptions and stroke severity were only significantly related at T0.

Table 8. Pearson correlations with bootstrapping over time between depressive symptoms, illness-perceptions and severity of stroke (n=25).

		DS T0	DS T1	DS T2	DS T3	IP T0	IP T1	IP T2	IP T3
DS ¹ T1	r	.66**							
	95% CI Lower	.16							
	Upper	.90							
DS T2	r	.67**	.73**						
	95% CI Lower	.30	.32						
	Upper	.87	.92						
DS T3	r	.56**	.79**	.71**					
	95% CI Lower	.05	.40	.27					
	Upper	.84	.93	.90					
IP ² T0	r	.19	.03	.28	-.02				
	95% CI Lower	-.17	-.30	-.05	-.38				
	Upper	.52	.30	.61	.34				
IP T1	r	.28	.52**	.30	.33	.21			
	95% CI Lower	-.15	.19	-.19	-.03	-.18			
	Upper	.61	.73	.63	.61	.57			
IP T2	r	.27	.50*	.60**	.59**	.40*	.47*		
	95% CI Lower	-.16	.12	.32	.35	.02	.02		
	Upper	.66	.75	.77	.78	.71	.78		
IP T3	r	.17	.37	.40*	.55**	.36	.35	.82**	
	95% CI Lower	-.25	-.04	.01	.26	-.06	-.05	.69	
	Upper	.54	.65	.63	.75	.72	.70	.91	
NIHSS ³	r	.04	.00	.22	-.16	.42*	-.15	.32	.08
	95% CI Lower	-.33	-.33	-.10	-.43	.00	-.57	-.12	-.43
	Upper	.44	.39	.59	.15	.64	.26	.63	.44

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

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

1 DS = depressive symptoms

2 IP = Illness perceptions

3 NIHSS= stroke severity

Discussion

Main results of the study

The present study was conducted to investigate relationships of illness perceptions and depressive symptoms over time. Furthermore, the separate development of the two variables over one year was evaluated. The present study was the first to consider the relation between the respective constructs in stroke patients and therefore provides novel data in this regard. In the first week after stroke 28% of the patients displayed significant depressive symptoms. However, the results did not show any major changes in the development of depressive symptoms over time. Since, there is no information about the treatment of depressive symptoms it cannot be concluded whether the treatment was helpful or not. Similar results were found for the development of illness perceptions. Hence, overall illness perceptions did not show significant variations over the four measurement times. Only the recoded item treatment control increased significantly at the third and fourth measurement, implying that patients perceive their disease as less controllable by treatment over time.

Regarding the item 'cause' of the brief IPQ it could be observed a probable change in multiple aspects. First, psychological factors as a perceived cause decreased after the second measurement. This may be related to a better understanding of the disease because patients were probably confronted with their disease through meetings with their doctor and acquirement of knowledge about the disease. Interestingly, lifestyle as a perceived cause decreased over time as well, even though lifestyle is actually one of the main risk factors for stroke disease (Chiuve et al., 2008). In contrast, patients perceived over time that other diseases like diabetes or cardiovascular problems are major causes for their stroke. As Prabhakaran and Chong (2014) showed, these diseases are indeed risk factors for stroke and may indicate a better understanding by participants about their disease over time.

Additionally, it was found a strong relationship between depressive symptoms and illness perceptions at every measurement point except the first one. Therefore, patients who perceive their illness as more threatening experience more depressive symptoms and vice versa. Interestingly, at the first measurement, there was not found any correlation between the two constructs. One possible explanation for this outcome may be that at the beginning of the disease illness perceptions are not stable because patients first have to develop them over time. Partly, the two constructs were related across time. Hence, depressive symptoms at T1 and T2 were related to illness perceptions at T2 and T3 respectively. Furthermore, measurements of illness perceptions at T1 were strongly related to depressive symptoms at T2. Therefore, relations between illness perceptions and depressive symptoms over time were found. However,

the direction of the causality between the constructs is not clear. Hence, no conclusion can be drawn about the prediction of depression by illness perceptions. Unexpectedly, it was not found any significant relation between stroke severity with depressive symptoms nor with threatening illness perceptions. One possible reason for this result may be the selective dropout. Namely, patients with low stroke severity may have been more likely to cancel the study, which may have biased the results.

Relating the results to former literature

Multiple studies have already investigated the relation between illness perceptions and depressive symptoms in many diseases such as NCCP, SLE, cancer etc. (Israel et al., 2015; Nowicka-Sauer et al., 2018, Llewellyn et al.). However, the current study was the first to test this relatedness in stroke patients. Nevertheless, there were found many differences in the relation between the variables compared to former studies, which used different samples.

As in the present study, Nowicka-Sauer et al. (2018) found in their cross-sectional study a strong positive relation between threatening illness perceptions and depressive symptoms. In the mentioned study it was also used the brief IPQ and for the assessment of depressive symptoms it was used the Beck Depression Inventory. However, in the mentioned study it was used a sample of SLE patients. Even though SLE is a chronic disease like stroke, there are multiple physiological and psychological differences regarding the impact of the disease, which impedes the comparison to the current study.

Israel et al. (2015) studied the relation between the separate dimensions of illness perceptions and depressive symptoms in patients with NCCP. It was found a weak but significant relation between the dimension ‘consequences’ and depressive symptoms. However, Israel et al. (2015) only considered the separate dimensions of illness perceptions, while the present study evaluated the total score of illness perceptions. Both Hagger et al. (2006) and Westbrook et al. (2016) studied the relation between separate dimensions of illness perceptions and depressive symptoms. the current study found a relation between depressive symptoms and illness perceptions. While Hagger et al. found a significant relation between the dimensions control identity and timeline with depressive symptoms, Westbrook et al. (2016) only found that the dimension ‘consequences’ was significantly related to depressive symptoms. As in the present study, Hagger et al. (2006) and Westbrook et al. (2016) found significant relations between illness perceptions and depressive symptoms. However, comparison of the results is limited because the mentioned studies used the separate dimensions of illness perceptions, while the present study only considers the total score. Furthermore, in contrast to the present

study, Hagger et al. (2006) considered cervical- and colorectal cancer patients and Westbrook et al. studied a sample of Leukemia patients.

Like in the current study, Llewellyn et al. (2007) used a longitudinal design to test the causal effects between depressive symptoms and illness perceptions. Nevertheless, in contrast to the present study, they used a sample of head and neck cancer patients. It was found a predicting effect of illness perceptions on depressive symptoms, more specifically they found that the dimension identity significantly predicted depressive symptoms. In contrast, in the present study the direction of causality between threatening illness perceptions and depressive symptoms was not clear and should be further investigated in future research.

In contrast to the present study, Hackett and Anderson (2005) found in their systematic review of population-, hospital-, and rehabilitation-based stroke studies that stroke severity is significantly related to depression. The reason for the missing relation between stroke severity and depressive symptoms is unclear. One possible explanation may be the selective dropout, which is further discussed in the limitations section.

Strengths, limitations and future research

The present study was the first to investigate the longitudinal relation between threatening illness perceptions and depressive symptoms in stroke patients. The study provided multiple strengths, which should be highlighted. First, the selection criteria for participants were very detailed and specific. Patients were assessed in multiple regards, such as stroke severity, overall health etc. and only if they met the specific criteria, they were assigned to the study. Furthermore, at every measurement point, patients had to go through a thorough assessment of both physical and psychological examination. Thus, the physical and mental conditioned was checked throughout the whole study. In addition, the CES-D and brief IPQ had to be filled out by the patients at every measurement point, giving an adequate overview of the development of depressive symptoms and illness perceptions over time. Additionally, through the longitudinal design relations between depressive symptoms and illness perceptions could be observed not only at one time point but at multiple time points as well as across time.

The main limitation of the current study was the high attrition rate. Merely 25 patients, which is less than half of the total sample(N=51) completed the study completely. Consequently, development of depressive symptoms and illness perception over time could only be analyzed with 25 patients, which is a rather small sample. Moreover, causality between the constructs could not be checked through sophisticated analysis due to the small sample size. Furthermore, there may have been a selective dropout. Namely, patients with certain

characteristics such as high depression, or negative perception of their illness may have been more likely to stop the study than other participants. Moreover, patients with high stroke severity may have died in the time period of the study, leading to another selective dropout. Consequently, the generalizability of the results is limited.

Another limitation was the use of the brief IPQ. While, the brief IPQ is normally rated on a scale from 0 to 10, in the present study it was used a scale from 0 to 9. This small difference may have led to different psychometric properties of the questionnaire in terms of lower reliability. Namely, in other literature it was reported a Cronbach's alpha value of .74, while in the present study it was calculated a value of .70 (Nowicka-Sauer et al., 2018). Furthermore, the brief IPQ only contains one question per dimension. Consequently, illness perceptions could only be regarded as a whole and not in separate dimensions because one question per dimension does not provide sufficient reliability in case of the present sample size.

In the present study it was found a strong positive relation between illness perceptions and depressive symptoms in stroke patients. Future research should focus on the type of relationship in terms of causality between the two constructs with a larger sample size. Furthermore, future studies should focus more on the separate dimensions of illness perceptions. Thus, it should be used the extended version of the IPQ in order to see, which dimensions of illness perceptions are related to depressive symptoms.

Conclusion

The present study investigated the relationship between illness perceptions, depressive symptoms and stroke severity. Furthermore, the development of the separate constructs over time was evaluated. First, in the sample nearly one third of the patients presented depressive symptoms at the first measurement point. The development of the separate constructs illness perceptions and depressive symptoms seemed to be stable over time. Namely, it was not found a significant change of the mentioned constructs over the four measurement points. Furthermore, it was found a strong positive relation between depressive symptoms and illness perceptions at multiple measurement points. Moreover, there were found significant relations across time between the two constructs. However, the direction of causality is not clear because it could not be tested with complex analysis due to the small sample size. In contrast to former research, it was not found any significant relation between stroke severity and depressive symptoms at any measurement point. Future research should investigate the direction of causality between illness perceptions and depressive symptoms by using a larger sample size.

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Appendix A. Exclusion criteria

Patients were excluded from the study if they were 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. (den Hertog & Martina 2019).

Appendix B. brief IPQ

How much does your illness affect your life?

0 1 2 3 4 5 6 7 8 9 10

no affect at all

severely affects my life

How long do you think your illness will continue?

0 1 2 3 4 5 6 7 8 9 10

a very short time

forever

How much control do you feel you have over your illness?

0 1 2 3 4 5 6 7 8 9 10

absolutely no control

extreme amount of control

How much do you think your treatment can help your illness?

0 1 2 3 4 5 6 7 8 9 10

not at all

extremely helpful

How much do you experience symptoms from your illness?

0 1 2 3 4 5 6 7 8 9 10

no symptoms at all

many severe symptoms

How concerned are you about your illness?

0 1 2 3 4 5 6 7 8 9 10

not at all concerned

extremely concerned

How well do you feel you understand your illness?

0 1 2 3 4 5 6 7 8 9 10

don't understand at all

understand very clearly

How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)

0 1 2 3 4 5 6 7 8 9 10

not at all affected emotionally

extremely affected emotionally

Please list in rank-order the three most important factors that you believe caused your illness.

The most important causes for me:-

1. _____

2. _____

3. _____

Appendix C. CES-D

Derived from <http://www.chcr.brown.edu/pcoc/cesdscale.pdf>

Center for Epidemiologic Studies Depression Scale (CES-D), NIMH

Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.

	During the Past			
	Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
1. I was bothered by things that usually don't bother me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I did not feel like eating; my appetite was poor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I felt that I could not shake off the blues even with help from my family or friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I felt I was just as good as other people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I had trouble keeping my mind on what I was doing.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I felt depressed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I felt that everything I did was an effort.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I felt hopeful about the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I thought my life had been a failure.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I felt fearful.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. My sleep was restless.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I was happy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I talked less than usual.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I felt lonely.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. People were unfriendly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. I enjoyed life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. I had crying spells.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I felt sad.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. I felt that people dislike me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. I could not get "going."	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SCORING: zero for answers in the first column, 1 for answers in the second column, 2 for answers in the third column, 3 for answers in the fourth column. The scoring of positive items is reversed. Possible range of scores is zero to 60, with the higher scores indicating the presence of more symptomatology.

