Title: The Relationship between Patients' Illness Beliefs and Recovery after Stroke

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Abstract

The Common Sense Model (CSM) is a useful framework for understanding adjustment (mood and treatment adherence) amongst survivors in the acute phase of stroke (≤three-months). CSM stroke studies have thus far focused on the single outcomes, mood and medication adherence, neglecting other pertinent aspects of post-stroke recovery (i.e., Health-Related Quality of Life (HRQL) and disability)**.** The purpose of this study was to examine relationships between baseline illness beliefs and three-month post-stroke HRQL, mood and disability. A longitudinal observational design was adopted, involving 50 survivors (mean age=66.9 years, 68% male). The primary outcome, HRQL, was measured using EQ-5D-5L. The secondary outcome, mood was measured using the Patient Health Questionnaire-9; and disability, using the Nottingham Extended Activities of Daily Living Scale. A stroke-specific version of the Illness Perception Questionnaire-Revised measured illness beliefs. Spearman's correlations showed that beliefs about the fluctuating effects of stroke ($\rho=0.50$, $p<0.001$) and perceptions of considerable distress at baseline were significantly associated with worse mood three-months post-stroke ($\rho=0.41$, $p<0.001$). Baseline illness beliefs were not significantly related to three-month post-stroke HRQL or disability. Despite being limited by a modest sample size, the findings reiterated the need for routine clinical assessment of mood immediately after stroke, and indicated that simultaneous measurement of timeline-cyclical beliefs and emotional representations may also be beneficial.

Keywords: Common Sense Model; Illness Beliefs; Stroke; Mood; Depression; Recovery; Disability; Health-Related Quality of Life.

Introduction

The Common Sense Model (CSM) suggests that when individuals suffer illness, they experience a disequilibrium that they become motivated to resolve, and do so by constructing beliefs about their illness and treatment that guide how they cope with their condition (Leventhal, Meyer, & Nerenz, 1980). Illness beliefs have five core domains: 'identity' – beliefs about the label of illness; 'timeline' – beliefs about illness duration; 'consequences' – beliefs about illness severity/impact; 'cure/control' – beliefs about amenability to cure, prevention or treatment; and 'causes' – beliefs about internal (e.g., genes) and external (e.g., germ or virus) causes of illness. These have been extended to include: 'timeline-cyclical' – beliefs of an episodic illness; 'personal control' and 'treatment control' – beliefs about own ability and that of treatment to manage the illness; 'illness coherence' – understanding of the illness; and 'emotional representations' – illness-related distress (Moss-Morris et al., 2002).

Eleven studies have thus far examined relationships between illness beliefs and the single post-stroke outcomes, mood and medication adherence (Ford, 2007; Johnston et al., 2007; Johnston, Morrison, Macwalter, & Partridge, 1999; Joice, Bonetti, MacWalter, & Morrison, 2003; Joice, Johnston, & Bonetti, 2002; Klinedinst, Dunbar, & Clark, 2012; O'Carroll, Chambers, Dennis, Sudlow, & Johnston, 2013; O'Carroll et al., 2011; Phillips, Diefenbach, Abrams, & Horowitz, 2015; Sjölander, Eriksson, & Glader, 2013; Twiddy, House, & Jones, 2012). These identified multiple illness beliefs that are significantly associated with post-stroke mood and medication non-adherence, including perceptions of a highly symptomatic condition; serious consequences; chronicity; fluctuating effects of stroke; inability of treatment to manage effects of stroke; poor disease understanding; and stroke-related distress.

This short report examines relationships between illness beliefs and mood, as well as other important markers of post-stroke recovery (HRQL and disability) that have been defined by the International Classification of Functioning (ICF) framework for health and disability (World Health Organization, 2001), but have mostly been neglected in CSM stroke studies to date.

Methods and Materials

We employed a longitudinal observational design, collecting data at baseline (after study enrolment) and three-months after stroke. Participants were recruited from acute stroke and rehabilitation wards and outpatient clinics in one hospital in the United Kingdom (UK). Inclusion criteria were adults (>18 years) with a confirmed diagnosis of acute stroke (within 8-weeks) and sufficient language and cognitive ability to participate. Ethical approval was granted by the National Research Ethics Service Committee East Midlands – Leicester (13/EM/0392).

Measures

Our outcomes were defined according to ICF domains (‘impairments’ – problems or loss in body function; ‘activities’ – performance of a task or action; and ‘participation’ – involvement in a life situation) (World Health Organization, 2001).

HRQL (ICF Participation) was measured using EQ-5D-5L (Brooks, 1996). Patient Health Questionnaire-9 (PHQ-9) measured mood (ICF Impairments). We measured disability (ICF Activities) or ‘instrumental activities of daily living’ (such as shopping, cooking etc.) using the stroke-specific Nottingham Extended Activities of Daily Living Scale (Nouri & Lincoln, 1987). Illness beliefs were measured using a version of the IPQ-R adapted to stroke (Stroke IPQ-R) (Aujla, Vedhara, Walker, & Sprigg, 2018).

After providing written informed consent, we collected socio-demographic; medical and family history; clinical and lifestyle data. Participants also completed the EQ-5D-5L, PHQ-9, Nottingham Extended Activities of Daily Living Scale, and Stroke IPQ-R, which were repeated at three-months post-stroke. Data were mostly collected via self-report, with exception of clinician-reported data (e.g. stroke severity) which were abstracted from medical records.

Statistical Analysis

The primary outcome was three-month post-stroke HRQL –a now prioritised outcome in acute stroke studies (Deshpande et al., 2011). The secondary outcomes were mood and disability. We estimated needing 55 participants to detect a correlation of 0.4 between illness beliefs and markers of post-stroke recovery (e.g., mood), with 80% power, alpha=0.05 and 20% attrition.

Analyses were conducted using STATA 13 (StataCorp LP College Station, TX, USA). Statistical significance was assessed at the 5% level ($p<0.05$), and a Bonferroni adjustment corrected for multiple testing. We examined associations between illness beliefs and post-stroke HRQL, mood and disability using Spearman's rho (ρ).

Results

Sample characteristics are summarised in Table 1 and elaborated elsewhere (Aujla, Walker, Sprigg, & Vedhara, 2018). In brief, 88 of 1085 patients assessed for eligibility over a 12-month period were eligible and approached for participation. The main reasons for non-eligibility were non-stroke diagnosis (N = 249) and stroke onset over 8 weeks before (N = 186). Fifty patients consented, with 16% attrition. Average age was 66.9 years (SD=14.5 years), with 68% males and 98% White-British ethnicity. Around 78% reported a first stroke and 18% a recurrence. The majority of participants reported few symptoms, but believed their stroke to be chronic, with fluctuating effects, greatly impacting on their lives, and leading to considerable distress, and despite having an unsatisfactory understanding (particularly of the causes) of their stroke, perceived that it was controllable.

Our analysis used complete cases. Following Bonferroni adjustment, Spearman's correlations showed that participants who perceived the effects of their stroke to be episodic (ρ=0.50, $p<0.001$) and causing considerable distress (ρ=0.41, $p<0.001$) at baseline also reported worse mood three-months after stroke. No significant correlations emerged between baseline illness beliefs and three-month post-stroke HRQL and disability (see Table 2).

Discussion

We have shown that mood during the acute phase of recovery after stroke is affected by maladaptive beliefs about the episodic nature of stroke and stroke-related distress. These findings were consistent with prior CSM stroke studies, including Ford (2007), Joice et al. (2003), Klinedinst et al. (2012) and Twiddy et al. (2012). We also uniquely examined relationships between illness beliefs, HRQL and disability within the first three-months of stroke. It was surprising that significant associations did not emerge given findings from the wider CSM literature on physical illnesses (e.g., Damman, Liu, Kaptein, Rosendaal, and Kloppenburg (2014); Dalbeth et al. (2011); and Spain, Tubridy, Kilpatrick, Adams, and Holmes (2007)). We suspect that this is likely to relate to our sample. In addition to being modest in size and inevitably resulting in inadequate statistical power and inflated risk of type 2 error, it also comprised highly functioning survivors of a less severe stroke. An important limitation of ours and prior CSM stroke studies.

CSM theory argues that illness beliefs form when people experience illness (Leventhal et al., 1980). This implies that if people do not experience symptoms (i.e., are functioning well post-illness), the health threat may not be considered enough of a problem for (mal)adaptive illness beliefs to manifest. In order to gain a more thorough picture of how illness beliefs relate to these specific aspects of post-stroke recovery, it may instead be better to examine patients most affected by stroke (i.e., survivors of more severe strokes).

However, this is a hard group to reach in acute stroke research (Newington & Metcalfe, 2014). The post-stroke impairments that commonly affect these patients (e.g., paralysis, perceptual difficulties, and impaired cognition) undoubtedly limit their ability to engage with and provide informed consent for complex studies such as ours. Therefore, it is necessary for future research to consider ways other than questionnaires to elicit illness beliefs in stroke survivors with complex needs. One possibility is the ‘Talking Mats’ framework, which supports people with communication problems (including stroke survivors with aphasia) to express their views (Murphy, 2000; Murphy, Gray, van Achterberg, Wyke, & Cox, 2010).

In view of these limitations, our findings should be considered exploratory. Nonetheless, we have shown that the CSM may be a useful framework for understanding psychological adjustment during the acute phase of stroke, and in particular, that early post-stroke mood may be affected by maladaptive timeline-cyclical beliefs and emotional representations. These relationships were found even in survivors of a less severe stroke with little residual disability and mild depressive symptomatology. Therefore, our findings further emphasise an already recognised need to identify patients with low mood early after stroke and tie in with the most recent UK stroke clinical guidelines (Intercollegiate Stroke Working Party, 2016).

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Table 1: Baseline characteristics of the study sample

	N **Mean (SD)/Frequency (%), unless otherwise stated**
Socio-Demographics	
Age	N=50 66.9 (14.5)
Sex-Male	N=50 34 (68.0%)
Ethnic group-White	N=50 49 (98.0%)
University or higher education	N=44 9 (20.5%)
Employment status Unemployed Employed full-time Employed part-time Self-employed Retired	N=46 6 (13.0%) 7 (15.2%) 3 (6.5%) 5 (10.9%) 25 (54.4%)
IMD rank*	N=44 Median=20706.5 (IQR=17158.0)
IMD decile*	N=44 Median=7 (IQR=6)
Medical history	
National Institute of Health Stroke Scale score¥	N=44 Median=2 (IQR=4.5)
Pre-morbid Modified Rankin Scale score¥¥	N=48 0 (0)
Previous stroke	N=46 36 (78.3)
Previous TIA	N=46 13 (28.3)
History of heart attack	N=46 6 (13.0%)
History of hypertension	N=46 31 (67.4%)
History of high cholesterol	N=46 24 (52.2%)
History of atrial fibrillation	N=46 10 (21.7%)
History of blood clots	N=46 5 (10.9%)
History of angina	N=46 6 (13.0%)
History of diabetes	N=46 11 (23.9%)
History of depression	N=46 11 (23.9%)
History of anxiety	N=46 9 (19.6%)
Co-morbidities	N=49 34 (69.4%)
Family history-first degree relative (mother, father, sibling)	
History of stroke	N=45 15 (33.0%)
History of TIA	N=46 4 (8.7%)
Clinical data	
Systolic blood pressure (mm/HG)	N=48

	147.6 (33.7)
Diastolic blood pressure (mm/HG)	N=48 78.6 (20.0)
Blood glucose (mmol/L)	N=37 Median = 6.6 (IQR=2.8)
Total cholesterol (mmol/L)	N=44 4.74 (1.30)
HDL cholesterol (mmol/L)	N=40 Median = 1.3 (IQR=0.6)
LDL cholesterol (mmol/L)	N=38 Median = 2.7 (IQR=1.9)
BMI (kg/m^2)	N=40 Median = 28 (IQR=9.7)
Lifestyle	
Current smoking status Non/never smoked Ex-smoker Current smoker	N=41 18 (39.1%) 24 (52.2%) 4 (8.7%)
Number smoked daily	N=22 10 (13)
Units of beer	N=41 0 (7)
Units of wine	N=41 0 (2)
Units of spirits	N=41 0 (0)
30-minutes of exercise x4 times a week	N=41 36 (78.3%)
Low-fat diet	N=41 24 (52.2%)
Low-sugar diet	N=41 29 (63.0%)
Low-salt diet	N=41 29 (64.4%)

Symbols and abbreviations: *: Computed using postcode data collected from participants; ¥: High NIHSS scores indicate a more severe stroke; ¥¥: High Modified Rankin Scale scores indicate greater disability; ¥¥¥: High Barthel Index scores indicate greater independence; ¥¥¥¥: BMI: Body mass index; HDL; High Density Lipoprotein; IMD: Index of Multiple Deprivation; IQR: Interquartile range; LDL; Low Density Lipoprotein; SD: Standard deviation; TIA: Transient Ischaemic Attack

Table 2. Correlation matrix for baseline illness belief domains and follow-up markers of recovery (N=41)

	Identity	**Timeline acute-chronic**	**Timeline -cyclical**	**Consequences**	**Personal control**	**Treatment control**	**Illness coherence**	**Emotional representations**	**EQ-5D-5L Descriptive System - Index score**	**EQ-5D-5L 'Your health today' VAS score**	**Mood**	**Nottingham Extended ADL**
Identity												
Timeline acute-chronic	0.47 p<.01											
Timeline-cyclical	0.62 p<.001*	0.26 p=0.10										
Consequences	0.66 p<.001*	0.45 p<.01	0.35 p<.05									
Personal control	0.19 p=0.23	-0.19 p=0.22	0.12 p=0.45	0.06 p=0.73								
Treatment control	-0.04 p=0.78	-0.17 p=0.30	-0.12 p=0.47	-0.00 p=0.99	0.30 p=0.05							
Illness coherence	0.17 p=0.28	0.00 p=0.99	-0.09 p=0.57	0.11 p=0.49	0.30 p=0.06	0.11 p=0.48						
Emotional representations	0.56 p<.001*	0.27 p=0.09	0.51 p<.001*	0.63 p<.001*	-0.07 p=0.65	-0.16 p=0.30	-0.00 p=0.98					
EQ-5D-5L Descriptive System - Index score	-0.27 p=0.09	-0.41 p<.01	-0.34 p<.05	-0.19 p=0.24	0.17 p=0.29	-0.11 p=0.49	0.26 p=0.10	-0.26 p=0.10				
EQ-5D-5L 'Your health today' VAS score	-0.11 p=0.49	-0.22 p=0.18	-0.28 p=0.08	-0.10 p=0.53	0.09 p=0.58	0.06 p=0.69	0.17 p=0.30	-0.27 p=0.09	0.51 p<.001*			
Mood	0.26 p=0.10	0.04 p=0.80	0.50 p<.001*	0.28 p=0.07	-0.06 p=0.71	-0.06 p=0.69	-0.13 p=0.43	0.41 p<.001*	-0.21 p=0.18	-0.20 p=0.22		
Nottingham Extended ADL	-0.18 p=0.26	-0.27 p=0.09	-0.02 p=0.90	-0.04 p=0.77	0.02 p=0.88	-0.17 p=0.29	-0.27 p=0.09	-0.03 p=0.84	0.49 p<.01	0.32 p<.05	0.05 p=0.78	

Symbols and abbreviations: *: P-value significant at the Bonferroni-adjusted significance level (p<0.002); ADL: Activities of Daily Living; VAS: Visual Analogue Scale