Running Head: Individual versus Illness Belief Schema

Title: Do Individual versus Illness Belief Schema Differ in the Prediction of Post-Stroke Recovery?

Authors: N Aujla[1, 2, 3] PhD; M Walker[2] PhD; N Sprigg[3] DM; K Vedhara[1] PhD

[1]Division of Primary Care, University of Nottingham, UK

[2]Division of Rehabilitation and Ageing, University of Nottingham, UK

[3] Stroke, Division of Clinical Neuroscience, University of Nottingham, UK

Corresponding Author:

Dr Navneet Aujla

Division of Primary Care/Division of Rehabilitation and Ageing

c/o Room 1305, Tower Building

University Park, University of Nottingham

Nottingham, NG7 2RD

Tel: 07487738027

E-Mail: N.Aujla@warwick.ac.uk

Corresponding Author (Post-Publication):

Professor Kavita Vedhara

Division of Primary Care (School of Medicine)

University of Nottingham

Room 1305, Tower Building

University Park

Nottingham

NG7 2RD

Tel: 0115 846 6931

Fax: 0115 846 6904

E-Mail: kavita.vedhara@nottingham.ac.uk

Abstract word count: 100

Manuscript word count (excluding title page, abstract, references, and tables): 4078

Number of tables: 1

Number of figures: 0

Abstract

This longitudinal observational study examined how individual versus illness belief schema compare as predictors of post-stroke recovery. Forty-two stroke survivors (mean age=66.9 years/range=29-96 years; 68% male), were involved. The primary outcome, Health-Related Quality of Life (HRQL) was measured using EQ-5D-5L; mood using Patient Health Questionnaire-9; and disability using Nottingham Extended Activities of Daily Living Scale. Stroke Illness Perception Questionnaire-Revised measured illness beliefs. Linear regressions showed that individual illness beliefs significantly explained more of the variance in three-month post-stroke recovery than schema (7.4-22.5% versus 1.9-9.9%). Individual versus illness belief schema predict outcomes *differently*, but which approach predicts outcomes *better* remains unclear.

Keywords: Common Sense Model; Illness Beliefs; Illness Belief Schema; Stroke; Mood; Health-Related Quality of Life; Disability; Recovery; Cluster Analysis

Introduction

The Common Sense Model (CSM) suggests that when confronted with a threat to their health, such as the common cold, individuals experience a disequilibrium that they are motivated to resolve, and do so by constructing beliefs about their illness and treatment that inform what they do to cope and feel better (Leventhal et al., 1980).

Illness beliefs have five core domains (Leventhal et al., 1980). 'Identity' describes perceptions about the label of the illness, for example a cold, and associated symptoms (e.g., cough sore throat etc.) 'Timeline' refers to beliefs about an acute or chronic illness duration. 'Consequences' refer to beliefs about the seriousness of the disease and daily impact (e.g., pain, time-off work etc.). 'Cure/control' refers to perceptions about the amenability of the illness to cure/prevention/ treatment. 'Causes' describes views about internal (e.g., genes) or external (e.g., a germ or virus)causes of the illness. There is a wealth of evidence supporting these domains in a broad range of illnesses, including cancer, hypertension, and diabetes mellitus (e.g., Meyer et al. (1985)). These domains have since been extended to include: 'timeline-cyclical' beliefs around an episodic nature of illness; 'personal control' and 'treatment control' beliefs around peoples' own ability and that of their treatment (e.g., tablets) to manage their illness; 'illness coherence' beliefs around understanding of the illness; and 'emotional representations' referring to illness-related distress (Moss-Morris et al., 2002).

The CSM has been used widely for understanding treatment adherence, mood, and recovery in a range of acute and chronic illness groups. The present study focuses on stroke.

Stroke is an example of a condition where recovery is individual and highly variable (Lazar and Antoniello, 2008), and depends upon good patient adherence to complex long-term treatments (e.g., medication, lifestyle management and rehabilitation). Post-stroke recovery and treatment adherence can be explained in part by non-modifiable socio-demographic (e.g., age, income) and clinical variables (e.g., stroke severity, and initial impairment) (Bushnell et

al., 2011, Lazar and Antoniello, 2008). However, socio-demographic variables predict outcomes very weakly In a longitudinal observational study involving 180 survivors one-year post-stroke, O'Carroll et al. (2011) found that modifiable psychological factors (depression and treatment beliefs) explain significantly more (around 30%) of the additional variance in medication adherence.

Several systematic reviews and meta-analyses have synthesised the CSM literature to examine the relationship of individual illness belief domains with coping/treatment adherence. For example, Hagger and Orbell (2003) examined 45 studies across a range of acute and chronic conditions, and demonstrated that illness beliefs are inter-related, and these so-called illness belief schema are correlated with coping and illness outcomes. These findings were recently replicated for individuals with chronic illnesses (Hagger et al., 2017). However, Aujla et al. (2016) and Brandes and Mullan (2014) both showed that when examined individually, illness belief domains predict adherence to self-management in people with acute or chronic physical illnesses very weakly (<0.13).

Illness belief schema are a key premise of the CSM; they are stored in peoples' memory and help them to understand and respond to situations (Leventhal et al., 1980). There are now several studies utilising cluster analysis to group individuals with physical illnesses according to their illness belief schema (e.g., Medley et al. (2010); Lin and Heidrich (2012); and Snell et al. (2014)).While these studies have not involved stroke survivors, illness belief schema have consistently been shown to predict physical and psychological outcomes, and coping/treatment adherence.

In summary, illness beliefs outlined by the CSM are inter-related and held in schema. When examined individually illness beliefs predict outcomes such as adherence, weakly. Aujla et al. (2016) argued that the low effect sizes to have emerged in their review have been a result of examining the predictive utility of individual CSM components rather than of the model as

a whole. Therefore, we posit that individual and illness belief schema are likely to differ in their prediction of outcomes, where schema may have greater predictive power.

A previous study has examined this hypothesis, and showed that individual and illness belief schema perform comparably when predicting outcomes in people with type 2 diabetes mellitus (Skinner et al., 2011). However, this study did not include all illness belief domains. Specifically, treatment control beliefs and emotional representations were excluded; both of which are important predictors of post-stroke outcomes after stroke (e.g., mood (Twiddy et al., 2012) and medication adherence (O'Carroll et al., 2011)). In addition, the authors did not report on statistical comparisons between regression models containing individual versus illness belief schema (i.e., clusters). For example, goodness of fit, using the change in R^2 and likelihood ratio test. However, by carrying out these comparisons, one would be able to discern how well variables (or groups of variables) in each regression model perform, and therefore judge which approach (individual versus illness belief schema) better predicts (or explains more of the variability) in outcome(s). To our knowledge, this analysis has not yet been undertaken.

The present study has three aims. First, to examine whether stroke survivors can be grouped according to different illness belief schema. Second, to conduct a preliminary enquiry into how individual versus illness belief schema may compare as predictors of three-month post-stroke recovery (Health-Related Quality of Life (HRQL), mood, and disability). Third, to explore how much of the additional variability in post-stroke recovery is explained by individual versus illness belief schema, over and above that explained by socio-demographic and clinical variables.

Methods

Design and Participants

A longitudinal observational design was employed, and reported in accordance with the appropriate guidelines. Data were collected at baseline (after study enrolment) and follow-up (three-months post-stroke). Participants were recruited from consecutive admissions to acute stroke and rehabilitation wards and from outpatient clinics in one hospital in Nottingham, United Kingdom (UK). Inclusion criteria were: adults (>18 years); confirmed diagnosis of acute stroke (within 8-weeks); sufficient (English) language and cognitive ability to participate, assessed through liaison with the clinical care team and review of medical notes; and written informed consent. We excluded individuals involved in psychological intervention studies. Ethical approval was granted by the National Research Ethics Service (NRES) Committee East Midlands (UK) – Leicester (13/EM/0392).

We initially collected socio-demographic information, including age, sex, ethnicity, education/employment, and social deprivation (using the English Indices of Multiple Deprivation (IMD) (Department for Communities and Local Government, 2015)). Medical history, including stroke severity (National Institutes of Health Stroke Scale (NIHSS) (Duncan et al., 2005));; disability (Modified Rankin Scale (Rankin, 1957) and Barthel Index (Mahoney and Barthel, 1965)); and comorbidities was also gathered. In addition, we collected clinical information (blood pressure, blood glucose, cholesterol and Body Mass Index (BMI)); family history (first-degree relative); and lifestyle data (smoking status, alcohol consumption, physical activity and diet). Participants also completed the study measures (elaborated below) at baseline and follow-up. Most of the data were self-reported. Clinician-reported data (e.g., stroke severity, blood tests and BMI) are collected routinely locally, and were therefore extracted from patients' medical records.

Eligibility was assessed in 1085 patients over a 12-month period. Eighty-eight were eligible. The main reasons for non-eligibility were: non-stroke diagnosis (N=249); stroke onset over 8-weeks before (N=186); and enrolled in other research studies (N=141). Thirty-eight people declined, 50 consented; and attrition was 16%. Therefore, we had baseline data from 46 and follow-up data from 42 participants In brief, average age was 66.9 years (SD=14.5 years; range 29-96 years), with 68% male gender and 98% White-British ethnicity. IMD scores indicated that participants resided on average among the most deprived 70% of areas in England. The majority of participants reported a non-severe first-stroke (78%), and experienced low levels of disability and mild depressive symptomatology.

Measures

The International Classification of Functioning (ICF) framework for health and disability highlights important outcomes to assess in post-stroke recovery: '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). We selected our outcomes according to these domains. The choice of measures was guided by a series of papers (Salter et al. (2005a), Salter et al. (2005b), and Salter et al. (2005c)) that synthesised the most commonly used instruments across each ICF domain, and critically reviewed their psychometric and administrative properties.

ICF Participation: HRQL

We measured HRQL using EQ-5D-5L (Brooks, 1996). The first part, termed the 'Descriptive System,' comprises five items assessing Mobility, Self-Care, Usual Activities, Pain/Discomfort, and Anxiety/Depression domains of HRQL. Possible responses were "no problems," "slight problems," "moderate problems," "severe problems," to "unable." The second part, termed the 'Your health today' Visual Analogue Scale (VAS), comprises a picture of a thermometer with a scale ranging from 0 (worst) to 100 (best), and respondents mark

whereabouts on this scale they perceive their health to be on that day. Scores are converted to a percentage, where high scores represent the best health imaginable (van Hout et al., 2012). Responses on the 'Descriptive System' are considered to be health states, which are converted to a single index value, and interpreted as follows: 0=dead; 1=full health; and <0=worse than death (van Hout et al., 2012). The EQ-5D-5L is valid for stroke survivors (Golicki et al., 2015), and showed good internal consistency in our study (Cronbach alpha α=0.84).

ICF Impairments: Mood

Post-stroke mood was measured using the Patient Health Questionnaire (PHQ)-9. PHQ-9 includes nine items measuring the frequency of depressive symptomatology, according to nine of the main criteria for major depressive disorder defined by the American Psychiatric Association Diagnostic and Statistical Manual (DSM) (Kroenke et al., 2001). Respondents recall over a period of two-weeks, the frequency with which they have been bothered by various symptoms (e.g., "Little interest or pleasure in doing things"). Possible responses were "Not at all," "Several days," "More than half the days," to "Nearly every day." A total PHQ-9 score was obtained by summing scores on the individual items (Kroenke et al., 2001). High scores indicated a greater severity of depressive symptomatology. PHQ-9 has recently been advocated as a promising approach for measuring mood amongst stroke survivors (Meader et al., 2013). Internal consistency was good in the present study (α=0.72).

ICF Activities: Disability

The Nottingham Extended Activities of Daily Living Scale provided a stroke-specific measure of instrumental activities of daily living after stroke (i.e., disability) (Nouri and Lincoln, 1987). It comprises 22-items covering everyday activities that respondents have performed in the 'last few weeks' (e.g., 'walk around outside,' 'climb stairs' etc.) Possible responses were "Not at all," "With help," "On your own with difficulty," to "On your own." A total score was obtained by summing scores on the individual items, where high scores

represent greater independence/recovery from post-stroke disability (Nouri and Lincoln, 1987). This instrument is valid and reliable for stroke survivors (Nouri and Lincoln, 1987), and had good internal consistency in our study (α=0.93).

Illness Beliefs

Illness beliefs were assessed using a stroke-specific version of the IPQ-R (Stroke IPQ-R) (Aujla et al., In Press). This measures nine domains of illness beliefs. Twenty-one items assessed illness identity. Yes/no responses for each item (e.g., 'Weakness or paralysis in arm or leg') were summed to obtain a total score for stroke-related symptom burden. Sixty-six items assessed the remainder of domains (timeline acute-chronic, consequences, timeline-cyclical, personal control, treatment control, illness coherence, emotional representations and causal beliefs). Possible responses were "strongly disagree," "disagree," "I don't know," "agree," and "strongly agree" (Moss-Morris et al., 2002). 'The effects of my stroke will last for a short time' is an example question for the timeline acute-chronic domain. The remainder of questions are summarised in Aujla et al. (In Press). Scores for each sub-scale were generated by summating the scores for individual items. Items with negative wording were reversed. High scores on the illness identity, timeline acute-chronic, timeline-cyclical, consequences, and emotional representations sub-scales indicated more negative beliefs about stroke, while those on the personal control, treatment control, and illness coherence sub-scales represented more positive beliefs (Moss-Morris et al., 2002). Internal consistency for all except the treatment control sub-scale (α=0.42) was good ($\alpha \geq 0.77$) in our study.

Statistical Analysis

The primary outcome was three-month post-stroke HRQL – arguably the best way to elicit how well survivors are recovering from the perspective of patients themselves (Deshpande et al., 2011). The secondary outcomes were mood and disability. Sample size was informed by findings from existing CSM stroke studies (e.g., O'Carroll et al. (2011); and

Twiddy et al. (2012)). Based on detecting a correlation of 0.4 between illness beliefs and markers of post-stroke recovery (e.g., mood); power=80%; alpha=0.05; and 20% attrition, we calculated a minimum sample of 55 participants.

The analyses were conducted in STATA 13 (StataCorp LP, College Station, TX, USA). In view of our low participant numbers, our analyses should be considered exploratory. Statistical significance was assessed at the 5% level ($p<0.05$). A Bonferroni adjustment corrected for multiple testing. We assessed normality using histograms and skewness/kurtosis tests. Logarithmic (base 10) transformations were attempted for skewed variables, without fruition. The mean and standard deviation (or where data were non-normal, median and interquartile range) were calculated for all continuous variables, and frequency/percentages for categorical variables. A series of non-parametric Wilcoxon signed rank tests (or parametric paired sample t-tests for normal data) examined differences in our outcomes between baseline and follow-up.

The remaining analyses were undertaken in two stages. Causal beliefs (16 separate attributions) were excluded in view of our modest sample size. First, we performed hierarchical agglomerative cluster analysis; the optimal method for clustering illness beliefs data (Clatworthy et al., 2007). Illness belief scores were standardised to Z-scores prior to clustering to ensure that all IPQ-R sub-scale scores had equal weight (Clatworthy et al., 2007). Clusters were formed based on similarities between participants on scores for each IPQ-R sub-scale, which were assessed using the Euclidean distance (i.e., the actual distance between two points if measured with a ruler). The optimum number of clusters was visually determined on a dendrogram (hierarchical tree-like structure). Clusters were combined using Ward's method; the most common linkage rule used for illness beliefs data (Clatworthy et al., 2007). Participants were subsequently partitioned into 'k' clusters using k-medians; a partitioning method suitable for non-normal data. Cluster characteristics were summarised using the

mean/standard deviation (or median/interquartile range for non-normal data). A series of one-way Analysis of Variance (ANOVA) plus Scheffe post-hoc comparisons (or Kruskal Wallis for non-normal variables) examined between-cluster differences.

Second, multiple linear regression models were fitted. Socio-demographic and clinical variables were selected based on prior evidence. The analysis initially examined individual illness belief domains (not schema). The order of entry was socio-demographic variables at the first step; clinical variables at the second step; and illness beliefs at the third step, as per O'Carroll et al. (2011). Models were compared using the change in R^2 and likelihood ratio test, which provided a Chi-squared p-value to assess the statistical significance of variables added at each step. The analyses were subsequently repeated using clusters (step 4).

Results

Descriptive Analyses

Our analyses used complete cases. Following Bonferroni adjustment, neither HRQL, mood nor disability differed significantly between baseline and follow-up (Appendix Table A). In terms of illness beliefs, participants reported few symptoms of their stroke at baseline and significantly fewer at follow-up ($p<0.001$). The majority perceived their stroke to be chronic, with fluctuating effects, greatly impacting upon their lives, and causing considerable distress. Most participants believed in their own ability and that of their treatment to control the effects of their stroke, though seemed to have an unsatisfactory understanding of their stroke. Participants tended to attribute their stroke to 'Ageing' or 'Chance or bad luck' rather than many of the modifiable risk factors for stroke (e.g., 'High cholesterol,' and 'High blood pressure.')

Identification of Illness Belief Schema

Three clusters emerged (see Appendix Figure A), that were named as follows: Cluster 1 – 'Low Adjusters;' Cluster 2 – 'Moderate Adjusters;' and Cluster 3 – 'High Adjusters'. Each cluster was characterised by specific illness belief schema (Appendix Table B). 'Low Adjusters' perceived their stroke to be chronic, with fluctuating effects, associated with a lot of symptoms, serious consequences and considerable distress. 'Moderate Adjusters' also perceived their stroke to be chronic, with serious consequences, associated with some symptoms and distress, but believed their stroke had non-fluctuating effects. 'High Adjusters' perceived their stroke as an acute condition with non-fluctuating effects, associated with few symptoms, less serious consequences, and little distress. All participants strongly believed in their own ability (personal control) and that of their treatment (treatment control) to control the effects of their stroke, but had a less than satisfactory understanding of stroke (illness coherence). Despite statistical non-significance, these domains were retained in the schema characterising each group of stroke survivors.

The demographic and clinical characteristics of participants within each cluster are summarised in Appendix Table C. Three non-statistically significant trends were identified. First, 'High Adjusters' were older (mean=72.1, SD=15.1) than 'Moderate Adjusters' (mean=69.5, SD=12.3) and 'Low Adjusters' (mean=57.2, SD=13.5). Second, 'High Adjusters' were more likely to be retired; university educated; have a history of stroke or transient ischaemic attack; and a first-degree relative with stroke. Third, 'Low Adjusters' were more likely to have had a severe stroke; history of depression/anxiety; be an ex-smoker; drink more alcohol; and exercise less. 'Low Adjusters' were also more likely to have worse HRQL, mood, and disability compared to the other clusters.

Prediction of Post-Stroke Recovery: Individual versus Illness Belief Schema

Findings from the multiple linear regression models for each outcome are reported in this section and summarised in Table 1 The primary outcome, HRQL, will be considered first.

HRQL

Baseline socio-demographic and clinical variables significantly explained 51.4% of the overall variance in three-month EQ-5D-5L Descriptive System – Index score and EQ-5D-5L 'Your health today' VAS score. When individual illness beliefs were entered, none emerged as significant independent predictors of HRQL. However, when examining the change in R^2, individual illness beliefs significantly explained a further 17.5% of the overall variance in three-month EQ-5D-5L Descriptive System – Index score, over and above that explained by baseline socio-demographic and clinical variables. When illness belief schema were entered, none of the clusters independently predicted HRQL. Inclusion of clusters in the model significantly explained only a further 0.60% and 5.7% of the overall variance in three-month EQ-5D-5L Descriptive System – Index score and 'Your health today' VAS score (respectively), over and above that explained by baseline socio-demographic and clinical variable.

Mood

Baseline socio-demographic and clinical variables significantly explained 47.7% of the overall variance in three-month post-stroke mood. When individual illness beliefs were entered, only timeline-cyclical beliefs were a significant independent predictor of mood (β=0.71, 95%CI=0.08-1.34), controlling for socio-demographic and clinical variables. When illness belief schema were entered, 'Moderate Adjusters' had significantly better mood at three-months than 'Low Adjusters' (β=-4.74, 95%CI=-9.31-(-0.17)). In examining the change in R^2, individual versus illness belief schema significantly explained an additional 22.8% and 9.9%

of the overall variance in three-month mood, respectively, over and above that explained by baseline socio-demographic and clinical variables (Table 3).

Disability

Baseline socio-demographic and clinical variables significantly explained 79.8% of the overall variance in our other secondary outcome, three-month post-stroke disability. Neither individual nor illness belief schema significantly predicted post-stroke disability. When examining the change in R^2, individual versus illness belief schema significantly explained only an additional 7.4% and 1.9% of the overall variance in three-month disability, respectively, over and above that explained by baseline socio-demographic and clinical variables.

Discussion

Our study identified three distinct illness belief schema: 'Low Adjusters;' 'Moderate Adjusters;' and 'High Adjusters.' In contrast to 'High Adjusters', 'Low Adjusters' perceived their stroke to be chronic, with fluctuating effects, associated with a lot of symptoms, serious consequences and considerable distress. We showed that when individual illness beliefs were examined in a series of multiple linear regression models, they significantly explained more of the variance in three-month post-stroke recovery (HRQL, mood and disability) than illness belief schema, over and above that explained by baseline socio-demographics and clinical variables.

The evidence to date has consistently shown that individual and illness belief schema predict coping/treatment adherence and recovery in a range of conditions, including stroke (Hagger and Orbell, 2003, Twiddy et al., 2012, Medley et al., 2010, Snell et al., 2014, Lin and Heidrich, 2012). Our findings supported this premise. We too found that timeline-cyclical beliefs significantly predict mood three-months after stroke (consistent with Twiddy et al.

(2012)), and that post-stroke mood is significantly better amongst 'Moderate' than 'Low Adjusters' (consistent with Snell et al. (2014)). Our schema also comprised many of the illness beliefs (i.e., identity, chronicity, and consequence beliefs, and emotional representations) that have emerged in prior studies.

However, unlike earlier papers (e.g., Medley et al. (2010)), we did not find a statistically significant role for personal and treatment control beliefs in any of our clusters. Nor did these domains significantly predict post-stroke HRQL, mood or disability. There may be three reasons for these findings. First, our participants generally demonstrated strong personal and treatment control beliefs (i.e., ceiling effect). Second, the treatment control sub-scale of the Stroke IPQ-R had poor internal consistency. Third, the study was limited by a modest sample size, meaning a high risk of Type 2 error.

Nonetheless, our study is the first to show that there are differences in the amount of variability in post-stroke recovery explained by individual versus illness belief schema. This analysis was of theoretical relevance given the literature on inter-relatedness of illness beliefs (Hagger and Orbell, 2003, Hagger et al., 2017); existence of illness belief schema (Leventhal et al., 1980); and growing interest in the use of cluster analysis to examine whether illness belief schema predict outcomes. However, given that the traditional approach to analysing illness beliefs has been to consider them individually (i.e., the same manner in which they have been measured), it was important to formally examine which approach most usefully predicts outcomes. Contrary to earlier findings by Skinner et al. (2011), our study showed that if the amount of variability explained by these two approaches is the only consideration, individual illness beliefs have the potential to outperform illness belief schema in the prediction of post-stroke outcomes.

Three notable problems exist with our analysis. The first is sample size, which limited statistical power. A second issue is generalisability of our findings. There is a need for further

research to be undertaken with larger and more diverse samples of stroke survivors. As illness belief schema are different for different illnesses, comparable work in other conditions should also be carried out to see if consistent findings emerge. The third relates to the cluster analysis approach, which is inherently a data reduction technique. However, dichotomising data in this way is likely to result in a loss of sensitivity (Skinner et al., 2011). Therefore, it is unsurprising that less of the variability in outcomes was explained by clusters rather than individual illness beliefs. Other, more sensitive, ways of analysing these data (currently unknown) are worth exploring in future research.

It is apparent though, at least in the context of stroke, that non-modifiable clinical variables still explain the largest amount of variability in post-stroke recovery (Lazar and Antoniello, 2008). However, the fact that our study showed that illness beliefs (individual or schema) explain even small to moderate amounts of variability in post-stroke recovery, suggests that there is still scope to intervene and modify maladaptive beliefs to improve outcomes. As has been considered in belief-based intervention studies to date (e.g., O'Carroll et al. (2013)).

Strengths and Limitations

A strength of our work is that it is the first to examine whether individual or illness belief schema differ in their prediction of post-stroke recovery. In addition, our study was conducted rigorously; employed validated instruments (e.g., EQ-5D-5L); measured multiple aspects of post-stroke recovery, as recommended by the ICF framework; and utilised robust statistical methods.

Despite these strengths, our sample size was modest. This limited statistical power and means that our results should be interpreted cautiously. In addition, our sample comprised individuals with a non-severe stroke, mild residual disability and strong personal and treatment control beliefs, which may be non-representative of survivors in the acute phase of stroke. This

issue has also affected prior CSM stroke studies. Therefore, we recommend that future researchers examine ways in which a more diverse and representative sample of stroke survivors can be engaged in illness belief studies moving forward.

Implications and Conclusion

We have demonstrated that individual versus illness belief schema differ in the amount of variability in post-stroke recovery explained. However, we cannot advocate which is the best approach for dealing with illness beliefs data henceforth. This remains an unanswered but important question to clarify as it could help to shape the way in which future belief-based interventions are developed (i.e., continue addressing individual maladaptive illness beliefs or begin dealing more holistically with maladaptive illness belief schema).

Acknowledgements: This research was undertaken as part of a PhD Studentship awarded to FIRST AUTHOR by the NAME OF UNIVERSITY. We would like to thank the participants of this research for giving up their time to be involved.

Disclosures: None of the authors have any conflicts of interest to declare.

References

AUJLA, N., VEDHARA, K., WALKER, M. & SPRIGG, N. In Press. Evaluating a Stroke-Specific Version of the Illness Perception Questionnaire-Revised, using the Think-Aloud method *Journal of Health Psychology*.

AUJLA, N., WALKER, M., SPRIGG, N., ABRAMS, K., MASSEY, A. & VEDHARA, K. 2016. Can illness beliefs, from the common-sense model, prospectively predict adherence to self-management behaviours? A systematic review and meta-analysis. *Psychology & Health,* 31**,** 931-958.

BRANDES, K. & MULLAN, B. 2014. Can the common-sense model predict adherence in chronically ill patients? A meta-analysis. *Health Psychology Review,* 8**,** 129-153.

BROOKS, R. 1996. EuroQol: the current state of play. *Health Policy,* 37**,** 53-72.

BUSHNELL, C. D., OLSON, D. M., ZHAO, X., PAN, W., ZIMMER, L. O., GOLDSTEIN, L. B., ALBERTS, M. J., FAGAN, S. C., FONAROW, G. C., JOHNSTON, S. C., KIDWELL, C., LABRESH, K. A., OVBIAGELE, B., SCHWAMM, L. & PETERSON, E. D. 2011. Secondary preventive medication persistence and adherence 1 year after stroke. *Neurology,* 77**,** 1182-90.

CLATWORTHY, J., HANKINS, M., BUICK, D., WEINMAN, J. & HORNE, R. 2007. Cluster analysis in illness perception research: a Monte Carlo study to identify the most appropriate method. *Psychology and Health*, 22**,** 123-142.

DEPARTMENT FOR COMMUNITIES AND LOCAL GOVERNMENT 2015. The English indices of deprivation. London, UK: Crown Copyright.

DESHPANDE, P. R., RAJAN, S., SUDEEPTHI, B. L. & ABDUL NAZIR, C. P. 2011. Patient-reported outcomes: a new era in clinical research. *Perspectives in Clinical Research,* 2**,** 137-144.

DUNCAN, P. W., ZOROWITZ, R., BATES, B., CHOI, J. Y., GLASBERG, J. J., GRAHAM, G. D., KATZ, R. C., LAMBERTY, K. & REKER, D. 2005. Management of adult stroke rehabilitation care: a clinical practice guideline. *Stroke,* 36**,** e100-e143.

GOLICKI, D., NIEWADA, M., BUCZEK, J., KARLIŃSKA, A., KOBAYASHI, A., JANSSEN, M. F. & PICKARD, A. S. 2015. Validity of EQ-5D-5L in Stroke. *Quality of Life Research,* 24**,** 845-850.

HAGGER, M. S., KOCH, S., CHATZISARANTIS, N. L. D. & ORBELL, S. 2017. The common-sense model of self-regulation: Meta-analysis and test of a process model. *Psychological Bulletin*.

HAGGER, M. S. & ORBELL, S. 2003. A meta-analytic review of the common-sense model of illness representations. *Psychology and Health,* 18**,** 141-184.

KROENKE, K., SPITZER, R. L. & WILLIAMS, J. B. 2001. The PHQ-9: validity of a brief depression severity measure. *Journal of General Internal Medicine,* 16**,** 606-13.

LAZAR, R. M. & ANTONIELLO, D. 2008. Variability in recovery from aphasia. *Current Neurology and Neuroscience Reports,* 8**,** 497-502.

LEVENTHAL, H., MEYER, D. & NERENZ, D. R. 1980. The common sense representation of illness danger. *In:* RACHMAN, S. (ed.) *Contributions to medical psychology*. New York, United States of America: Pergamon.

LIN, F. & HEIDRICH, S. M. 2012. Role of older adult's illness schemata in coping with Mild Cognitive Impairment. *Journal of Psychosomatic Research,* 72**,** 357-363.

MAHONEY, F. I. & BARTHEL, D. W. 1965. Functional evaluation: the Barthel Index. *Maryland State Medical Journal,* 14**,** 61-5.

MEADER, N., MOE-BYRNE, T., LLEWELLYN, A. & MITCHELL, A. J. 2013. Screening for poststroke major depression: a meta-analysis of diagnostic validity studies. *Journal of Neurology, Nurosurgery, and Psychiatry,* 0**,** 1-9.

MEDLEY, A. R., POWELL, T., WORTHINGTON, A., CHOHAN, G. & JONES, C. 2010. Brain injury beliefs, self-awareness, and coping: a preliminary cluster analytic study based within the self-regulatory model. *Neuropsychological Rehabilitation,* 20**,** 899-921.

MEYER, D., LEVENTHAL, H. & GUTMANN, M. 1985. Common-sense models of illness: the example of hypertension. *Health Psychology,* 4**,** 115-135.

MOSS-MORRIS, R., WEINMAN, J., PETRIE, K. J., HORNE, R., CAMERON, L. D. & BUICK, D. 2002. The revised illness perception questionnaire (IPQ-R). *Psychology & Health,* 17**,** 1-16.

NOURI, F. M. & LINCOLN, N. B. 1987. An extended activities of daily living scale for stroke patients. *Clinical Rehabilitation,* 1**,** 301-305.

O'CARROLL, R. E., CHAMBERS, J. A., DENNIS, M., SUDLOW, C. & JOHNSTON, M. 2013. Improving adherence to medication in stroke survivors: a pilot randomised controlled trial. *Annals of Behavioural Medicine,* 46**,** 358-68.

O'CARROLL, R. E., WHITTAKER, J., B, H., JOHNSTON, M., SUDLOW, C. & DENNIS, M. 2011. Predictors of adherence to secondary preventive medication in stroke patients. *Annals of Behavioral Medicine,* 41**,** 383-390.

RANKIN, J. 1957. Cerebral vascular accidents in patients over the age of 60. II. Prognosis. *Scottish Medical Journal,* 2**,** 200-15.

SALTER, K. L., JUTAI, J. W., TEASELL, R., FOLEY, N. C. & BITENSKY, J. 2005a. Issues for selection of outcome measures in stroke rehabilitation: ICF body functions. *Disability and Rehabilitation,* 27**,** 191-207.

SALTER, K. L., JUTAI, J. W., TEASELL, R., FOLEY, N. C., BITENSKY, J. & BAYLEY, M. 2005b. Issues for selection of outcome measures in stroke rehabilitation: ICF activity. *Disability and Rehabilitation,* 27**,** 315-340.

SALTER, K. L., JUTAI, J. W., TEASELL, R., FOLEY, N. C., BITENSKY, J. & BAYLEY, M. 2005c. Issues for selection of outcome measures in stroke rehabilitation: ICF participation. *Disability and Rehabilitation,* 27**,** 507-528.

SKINNER, T., CAREY, M., CRADOCK, S., DALLOSSO, H., DALY, H., DAVIES, M., DOHERTY, Y., HELLER, S., KHUNTI, K. & OLIVER, L. 2011. Comparison of illness representations dimensions and illness representation clusters in predicting outcomes in the first year following diagnosis of type 2 diabetes: results from the DESMOND trial. *Psychology and Health,* 26**,** 321-335.

SNELL, D. L., SURGENOR, L. J., HAY-SMITH, E. J. C., WILLIMAN, J. & SIEGERT, R. J. 2014. The contribution of psychological factors to recovery after mild traumatic brain injury: is cluster analysis a useful approach? *Brain Injury,* 29**,** 291-299.

TWIDDY, M., HOUSE, A. & JONES, F. 2012. The association between discrepancy in illness representations on distress in stroke patients and carers. *Journal of Psychosomatic Research,* 72**,** 220-225.

VAN HOUT, B., JANSSEN, M. F., FENG, Y.-S., KOHLMANN, T., BUSSCHBACH, J., GOLICKI, D., LLOYD, A., SCALONE, L., KIND, P. & PICKARD, A. S. 2012. Interim scoring for the EQ-5D-5L: mapping the EQ-5D-5L to EQ-5D-3L value sets. *Value in Health,* 15**,** 708-715.

WORLD HEALTH ORGANIZATION 2001. International classification of functioning, disability and health. Geneva, Switzerland: World Health Organization.

Table 1. Summary of goodness of fit statistics for HRQL, Mood and Disability at each model step in

	HRQL (EQ-5D-5L Descriptive System Index Score)		HRQL (EQ-5D-5L 'Your health today' VAS Score)		Mood (PHQ-9 Score)		Disability (Nottingham Extended Activities of Daily Living Scale Score)	
	Total R^2 for the Model	**Change in R^2 for the Step (P-value✖**)**	**Total R^2 for the Model**	**Change in R^2 for the Step (P-value✖**)**	**Total R^2 for the Model**	**Change in R^2 for the Step (P-value✖**)**	**Total R^2 for the Model**	**Change in R^2 for the Step (P-value✖**)**
STEP 1: Addition of Socio-Demographic Variables + Age + Gender + Deprivation	0.073	0.073 (p=0.39)	0.055	0.055 (p=0.52)	0.068	0.068 (p=0.44)	0.149	0.149 (p=0.09)
STEP 2: Addition of Clinical Variables + Co-morbidities + National Institute of Health Stroke Scale score + Baseline EQ-5D-5L Descriptive System- Index score + Baseline EQ-5D-5L 'Your health today' VAS score + Baseline PHQ-9 score + Baseline Modified Rankin Scale score + Baseline Barthel Index score + Baseline Nottingham Extended Activities of Daily Living Scale score	0.514	0.441 (p=0.009)	0.514	0.459 (p=0.007)	0.477	0.409 (p=0.02)	0.798	0.649 (p=0.000)
STEP 3: Addition of Individual Illness Belief Variables + Identity + Timeline acute-chronic + Timeline cyclical + Consequences + Personal control + Treatment control + Illness coherence + Emotional representations	0.689	0.175 (p=0.003)	0.590	0.076 (p=0.04)	0.705	0.228 (p=0.002)	0.872	0.074 (p=0.000)
STEP 4: Addition of Illness Belief Schema Variables + Moderate Adjusters*** + High Adjusters***	0.520	0.006 (p=0.01)	0.571	0.057 (p=0.004)	0.576	0.099 (p=0.02)	0.817	0.019 (p=0.000)

Symbols and abbreviations: *: Bonferroni-adjusted significance level (p<0.002); **: Bonferroni-adjusted significance level (p<0.02); ***: Compared to Low Adjusters group; ✖: Likelihood ratio test; CI: Confidence interval; HRQL; Health-Related Quality of Life; PHQ-9: Patient Health Questionnaire-9; VAS: Visual Analogue Scale.

APPENDIX

Table A. Descriptive statistics, and differences between, baseline and three-month HRQL, mood, disability and illness belief scores

	N Median (IQR), unless otherwise stated		Z, unless otherwise stated P-value*
	Baseline	**Follow-up**	
HRQL			
EQ-5D-5L Descriptive System- Index score	N=46 0.74 (0.44)	N=42 0.77 (0.28)	z=-2.84 p=<0.01
EQ-5D-5L 'Your health today' VAS score	N=46 58.3 (22.7)	N=42 70 (30)	z=-2.05 p=0.04
Mood			
PHQ-9 Total depressive symptomatology score	N=45 6 (6)	N=41 4 (3)	z=3.22 p<0.01
Disability			
Nottingham Extended Activities of Daily Living Scale score	N=46 17 (9)	N=42 17 (7)	z=-1.81 p=0.07
Illness Beliefs			
Identity	N=42		z=3.83 p<.0.001
	9 (7)	7 (8)	
Timeline acute-chronic	N=42		-2.34 p=0.02
	Mean=15.4 (SD=4.2)	16 (8)	
Timeline-cyclical	N=42		z=2.72 p<0.01
	10 (6)	8 (4)	
Consequences	N=42		t=1.91 p=0.06
	Mean=30.8 (SD=6.5)	Mean=29.8 (SD=5.3)	
Personal control	N=42		z=-0.97 p=0.33
	Mean=32.7 (SD=4.4)	34 (3)	
Treatment control	N=42		z=0.57 p=0.57
	20 (2)	20 (3)	
Illness coherence	N=42		z=-0.97 p=0.33
	19 (4)	19.5 (4)	
Emotional representations	N=42		z=2.57 p<0.01
	24 (7)	22 (8)	
Cause 1: Stress or worry, including family problems	N=42		z=0.34 p=0.73
	3 (2)	3 (2)	
Cause 2: Heredity – it runs in my family	N=42		z=0.15 p=0.88
	2 (0)	2 (1)	
Cause 3: Diet or eating habits	N=42		z=1.32 p=0.18
	2 (2)	3 (2)	
Cause 4: Poor medical care in my past	N=42		z=-0.37 p=0.71
	2 (0)	2 (2)	
Cause 5: My mental attitude e.g., thinking about life negatively	N=42		z=0.14 p=0.89
	2 (0)	2 (0)	
Cause 6: Overwork	N=42		z=0.49 p=0.63
	2 (2)	2 (2)	
Cause 7: My emotional state e.g., feeling down, lonely, anxious, empty	N=42		z=-0.63 p=0.53
	2 (0)	2 (0)	
Cause 8: Ageing	N=42		z=-1.38 p=0.17
	4 (2)	4 (2)	
Cause 9: Alcohol	N=42		z=0.53

	2 (0)	2 (0)	p=0.60
Cause 10: Smoking	N=42		z=-0.37 p=0.71
	2 (2)	2 (2)	
Cause 11: High cholesterol	N=42		z=-2.01 p<0.05
	3 (2)	3 (2)	
Cause 12: High blood pressure	N=42		z=0.01 p=0.99
	3 (2)	3.5 (2)	
Cause 13: Diabetes	N=42		z=-0.38 p=0.71
	2 (0)	2 (0)	
Cause 14: Problems with my heart, such as an irregular heartbeat	N=42		z=-0.91 p=0.36
	2 (0)	2 (2)	
Cause 15: Chance or bad luck	N=42		z=0.22 p=0.83
	4 (2)	4 (2)	
Cause 16: Not taking enough exercise	N=42		z=0.33 p=0.75
	2 (2)	2 (2)	

Symbols and abbreviations: *: Bonferroni-adjusted significance level (p<0.002); HRQL: Health-Related Quality of Life; IQR: Interquartile range; PHQ-9: Patient Health Questionnaire-9; SD: Standard deviation; VAS: Visual Analogue Scale

Table B. Descriptive statistics for illness belief scores, including between-cluster differences, split according to 'Low,' 'Moderate' and 'High' Adjuster groups

	N Median belief scores (IQR)				
Illness beliefs	**Cluster 1: 'Low adjusters' N=13**	**Cluster 2: 'Moderate adjusters' N=11**	**Cluster 3: 'High adjusters' N=20**	**Chi-squared (DF)**	**P-value***
Identity	14 (5)	9 (3)	4 (5)	29.0 (2)	<.001
Timeline acute-chronic	18 (6)	17 (8)	12 (3.5)	16.5 (2)	<.001
Timeline-cyclical	16 (2)	8 (0)	8 (2)	30.2 (2)	<.001
Consequences	37 (4)	34 (8)	25 (4)	30.1 (2)	<.001
Personal control	34 (5)	32 (2)	34 (5)	3.7 (2)	0.16
Treatment control	18 (3)	20 (1)	20 (2)	4.1 (2)	0.13
Illness coherence	19 (4)	20 (2)	18 (6)	1.8 (2)	0.41
Emotional representations	32 (7)	24 (10)	22 (5)	19.8 (2)	<.001

Symbols and abbreviations: *: Bonferroni adjusted significance level (p<0.002); DF: Degrees of freedom; IQR: Interquartile range

Table C. Summary of the baseline participant characteristics for each cluster

	N **Mean (SD)/Frequency (%), unless otherwise stated**				
Demographics	**Cluster 1: 'Low adjusters'** **N=13**	**Cluster 2: 'Moderate adjusters'** **N=11**	**Cluster 3: 'High adjusters'** **N=20**	**F (DF), unless otherwise stated**	**P-value***
Age	57.2 (13.5)	69.5 (12.3)	72.1 (15.1)	4.66 (2)	<0.05
Sex-*Male*	11 (84.6%)	7 (63.6%)	12 (60.0%)	Chi^2=2.34 (DF=2)	0.31
University or higher education	2 (16.7%)	3 (27.3%)	4 (21.1%)	Chi^2=0.39 (DF=2)	0.82
Employment status					
Unemployed	4 (30.8%)	1 (9.1%)	1 (5.0%)	Chi^2=11.39 (DF=8)	0.12
Employed full-time	3 (23.1%)	1 (9.1%)	2 (10.0%)		
Employed part-time	1 (7.7%)	2 (18.2%)	0 (0%)		
Self-employed	1 (7.7%)	1 (9.1%)	3 (15.0%)		
Retired	4 (30.8%)	6 (54.6%)	14 (70.0%)		
Index of Multiple Deprivation rank	Median=16401 (IQR=17730)	Median=21243 (IQR=19183)	Median=20835 (IQR=15764)	Chi^2=1.16 (DF=2)	0.56
Index of Multiple Deprivation decile	Median=5 (IQR=6)	Median=7 (IQR=6)	Median=7 (IQR=5.5)	Chi^2=1.31 (DF=2)	0.52
National Institute of Health Stroke Scale score	Median=5 (IQR=10)	Median=2 (IQR=1)	Median=2 (IQR=4)	Chi^2=6.15 (DF=2)	<0.05
Pre-morbid Modified Rankin Scale score	Median=0 (IQR=0)	Median=0 (IQR=1)	Median=0 (IQR=0)	Chi^2=0.73 (DF=2)	0.69
Modified Rankin Scale score	Median=2 (IQR=1)	Median=2 (IQR=1)	Median=1 (IQR=1)	Chi^2=8.4 (DF=2)	<.05
Barthel Index score	Median=20 (IQR=1)	Median=20 (IQR=0)	Median=20 (IQR=0)	Chi^2=0.9 (DF=2)	0.64
Clinical data					
Systolic blood pressure (mm/HG)	137.7 (21.0)	157.4 (44.0)	150 (35.9)	1.01	0.37
Diastolic blood pressure (mm/HG)	71.7 (18.3)	84.6 (22.2)	80.5 (21.5)	1.26	0.29
Blood glucose (mmol/L)	Median=6.4 (IQR=5.6)	Median=7.3 (IQR=3.3)	Median=6.3 (IQR=2)	Chi^2=0.82 (DF=2)	0.67
Total cholesterol (mmol/L)	4.7 (1.4)	4.7 (1.0)	4.7 (1.5)	0.00	0.99
HDL cholesterol (mmol/L)	Median=1.1 (IQR=0.5)	Median=1.2 (IQR=0.4)	Median=1.4 (IQR=0.70)	Chi^2=1.20 (DF=2)	0.55

LDL cholesterol (mmol/L)	Median=2.2 (IQR=1.5)	Median=3.05 (IQR=1.5)	Median=2.35 (IQR=2.1)	Chi^2=2.46 (DF=2)	0.29
BMI (kg/m^2)	Median=29 (IQR=10.3)	Median=24 (IQR=6)	Median=25 (IQR=5)	Chi^2=1.33 (DF=2)	0.52
Family history-first degree relative (mother, father, sibling)					
History of stroke	3 (23.1%)	4 (36.4%)	8 (40.0%)	Chi^2=1.04 (DF=2)	0.60
History of TIA	1 (7.7%)	1 (9.1%)	1 (5.0%)	Chi^2=0.21 (DF=2)	0.90
Medical history*					
First stroke	3 (23.1%)	3 (27.3%)	3 (15.0%)	Chi^2=0.73 (DF=2)	0.70
Previous TIA	1 (7.7%)	2 (18.2%)	3 (15.0%)	Chi^2=0.61 (DF=2)	0.74
History of hypertension	8 (61.5%)	4 (36.4%)	13 (65.0%)	Chi^2=2.54 (DF=2)	0.28
History of atrial fibrillation	1 (7.7%)	5 (45.5%)	2 (10.0%)	Chi^2=7.36 (DF=2)	<0.05
History of high cholesterol	6 (46.2%)	6 (54.6%)	8 (40.0%)	Chi^2=0.61 (DF=2)	0.74
History of depression	6 (46.2%)	2 (19.2%)	2 (10.0%)	Chi^2=6.98 (DF=4)	0.14
History of anxiety disorders	4 (30.8%)	1 (9.1%)	3 (15.0%)	Chi^2=2.13 (DF=2)	0.34
Previous therapy	8 (61.5%)	4 (36.4%)	9 (45.0%)	Chi^2=1.62 (DF=2)	0.44
Co-morbidities	9 (69.2%)	7 (63.6%)	16 (80.0%)	Chi^2=1.07 (DF=2)	0.59
Lifestyle					
Current smoking status** *Never smoked* *Ex-smoker* *Current smoker*	 4 (30.8%) 8 (61.5%) 1 (7.7%)	 5 (45.5%) 6 (54.6%) 0 (0%)	 9 (45.0%) 9 (45.0%) 2 (10.0%)	Chi^2=1.95 (DF=4)	0.75
Number smoked daily	Median=20 (IQR=10)	Median=17.5 (IQR=17.5)	Median=7.5(IQR=10)	Chi^2=3.64 (DF=2)	0.16
Current alcohol intake (units/week)¥	Median=6 (IQR=10.2)	Median=4 (IQR=21)	Median=0.75(IQR=14)	Chi^2=1.04 (DF=2)	0.59

Units of beer	Median=3 (IQR=11.2)	Median=0.25 (IQR=7)	Median=0 (IQR=3)	Chi^2=2.79 (DF=2)	0.25
Units of wine	Median=0 (IQR=0)	Median=0.25 (IQR=4)	Median=0 (IQR=1.25)	Chi^2=4.15 (DF=2)	0.13
Units of spirits	Median=0 (IQR=0)	Median=0 (IQR=0)	Median=0 (IQR=0)	Chi^2=0.61 (DF=2)	0.74
30-minutes of exercise x4 times a week	10 (76.9%)	7 (63.6%)	17 (85.0%)	Chi^2=1.85 (DF=2)	0.40
Low-fat diet	8 (61.5%)	6 (54.5%)	9 (45.0%)	Chi^2=0.89 (DF=2)	0.64
Low-sugar diet	10 (76.9%)	7 (63.6%)	10 (50.0%)	Chi^2=2.44 (DF=2)	0.30
Low-salt diet	10 (76.9%)	6 (60.0%)	12 (60.0%)	Chi^2=1.14 (DF=2)	0.57
HRQL					
EQ-5D-5L Index score	Median=0.68 (IQR=0.18)	Median=0.77 (IQR=0.20)	Median=0.88 (IQR=0.40)	Chi^2=5.5 (DF=2)	0.06
EQ-5D-5L 'Your health today' VAS score	Median=60 (IQR=20)	Median=70 (IQR=20)	Median=75 (IQR=20)	Chi^2=2.7 (DF=2)	0.26
Mood					
PHQ-9 Total depressive symptomatology score	Median=6 (IQR=5)	Median=4 (IQR=5)	Median=3 (IQR=5)	Chi^2=8.2 (DF=2)	<.05
Disability					
Nottingham Extended Activities of Daily Living Scale score	Median=15 (IQR=9)	Median=17 (IQR=7)	Median=17 (IQR=4)	Chi^2=1.8 (DF=2)	0.41

Symbols and abbreviations: *: Bonferroni adjusted significance level (p<0.002); **: Self-reported; ¥: Extracted from medical records; BMI: Body Mass Index; DF: Degrees of freedom; IQR: Interquartile range; HDL: High Density Lipoprotein; HRQL: Health-related quality of life; IQR: Interquartile range; LDL; Low Density Lipoprotein; Interquartile range; PHQ-9: Patient Health Questionnaire-9; SD: Standard deviation; VAS: Visual Analogue Scale