

ORIGINAL ARTICLE

# Associations between participation and personal factors in community-dwelling adults post-stroke

Melanie Hoyle<sup>1\*</sup> , Pamela Meredith<sup>1,2</sup> , Tamara Ownsworth<sup>3,4</sup> , Asaduzzaman Khan<sup>1</sup>  and Louise Gustafsson<sup>1,4,5</sup> 

<sup>1</sup>School of Health and Rehabilitation Sciences, The University of Queensland, Brisbane, Australia, <sup>2</sup>School of Health and Behavioural Sciences, University of the Sunshine Coast, Sippy Downs, Australia, <sup>3</sup>School of Applied Psychology, Griffith University, Brisbane, Australia, <sup>4</sup>Menzies Health Institute Queensland, Griffith University, Brisbane, Australia and <sup>5</sup>School of Health Sciences and Social Work, Griffith University, Brisbane, Australia

\*Corresponding author. Email: [m.hoyle@uq.edu.au](mailto:m.hoyle@uq.edu.au)

(Received 11 June 2021; revised 28 August 2022; accepted 9 October 2022; first published online 20 December 2022)

## Abstract

**Purpose:** To examine associations between post-stroke participation and personal factors, including demographic characteristics, self- and threat appraisals, and personality variables.

**Methods:** An exploratory cross-sectional study with purpose-designed survey was completed online or via mail. The survey was comprised of demographic and health-related questions and multiple questionnaires, including the Stroke Impact Scale Version 3.0 (SISv3) (participation/perceived recovery), Community Integration Questionnaire (CIQ) (participation), Head Injury Semantic Differential III (pre- vs post-stroke self-concept/self-discrepancy), Appraisal of Threat and Avoidance Questionnaire (threat appraisal), Life Orientation Test – Revised (optimism) and Relationships Questionnaire (adult attachment style) that measured variables of interest. Sixty-two participants, aged 24–96 years who had experienced a stroke (one or multiple events) and had returned to community living, completed the survey. Associations were examined using correlations, and univariate and multiple linear regression analyses.

**Results:** Regression analysis showed that greater participation, measured using the CIQ, was associated with younger age, female gender, lower self-discrepancy and higher perceived recovery, explaining 69% of the variability in CIQ participation. Further, greater participation on the SISv3 was associated with lower self-discrepancy and higher perceived recovery, explaining 64% of the variability in SISv3 participation.

**Conclusions:** Results indicate that personal factors, particularly self-appraisals like self-concept/self-discrepancy, in combination with perceived recovery may be important in explaining a large portion of variance in post-stroke participation. Specifically, findings highlight the interrelatedness of self-concept change, perceived recovery and post-stroke participation. Further longitudinal research is needed to clarify the directionality of these associations throughout the hospital-to-home transition.

**Keywords:** cerebrovascular accident; community; participation; personal factors; recovery; self-concept; stroke

## Introduction

Advances in stroke management, and an increasing incidence of stroke earlier in life, has resulted in a growing number of people living with the effects of stroke long-term (Béjot et al., 2014; Lakshminarayan et al., 2014). For most people, spontaneous and experience-dependent recovery is facilitated by acute and post-acute rehabilitation and re-engagement in home and community activities (Brock et al., 2009; Carod-Artal, Coral, Trizotto, & Moreira, 2002).

The International Classification of Functioning, Disability and Health (ICF; World Health Organization [WHO], 2001), proposes that function and disability are outcomes of interactions between health conditions and contextual factors. Although personal factors are highlighted as influential in the ICF; little consideration has been given to the relationship between these factors and post-stroke participation. This study examines the associations between personal factors, specifically demographics, self- and threat appraisals, and personality variables, and participation outcomes.

### **Participation post-stroke**

Participation in everyday life is frequently disrupted, restricted and more challenging after stroke (Eriksson, Baum, Wolf, & Tabor Connor, 2013; Fallahpour, Jonsson, Jognataei, Nasrabadi Alireza, & Tham, 2013; Hartman-Maeir, Soroker, Ring, Avni, & Katz, 2007; Rochette, Desrosiers, Bravo, St-Cyr-Tribble, & Bourget, 2007). Despite people returning, in part, to pre-stroke activities, physically demanding and community-based activities are retained less than home-based and sedentary activities (Tse, Lentin, Douglas, & Carey, 2020). Participation restrictions have been identified to persist up to five-years post-stroke, particularly in the areas of autonomy outdoors, social life and relationships and work/education (Palstam, Sjödin, & Stibrant Sunnerhagen, 2019). Participation is considered amenable to change even in the absence of further body function recovery and is an intervention priority for people with long-term health conditions and disability (Ezekiel et al., 2019; Whiteneck, 2006). As an area of concern (Bergström, Guidetti, Tham, & Eriksson, 2017) and an unmet need post-stroke (Andrew et al., 2014), participation warrants further empirical attention.

A stroke-specific scoping review identified participation as a troublesome construct due to diverse definitions and multiple measurement tools (Engel-Yeger, Tse, Josman, Baum, & Carey, 2018). Tse, Douglas, Lentin, and Carey (2013) identified 36 post-stroke participation measures, noting that the five most frequently used measures regularly covered community, social and civic life, domestic life and mobility domains, while learning and applying knowledge, general tasks and demands and communication were covered less often. A single measure of participation is considered unlikely to capture the breadth of this construct.

Despite the variability in conceptualisation and measurement, participation outcomes have consistently been associated with body functions/impairments, activity limitations, health conditions, level of independence and sociodemographic factors in adults' post-stroke (Ahn & Hwang, 2018; Carey, Matyas, & Baum, 2018; Ezekiel et al., 2019). In addition to objective indices of functioning, the client's perceived recovery has been identified as a significant predictor of participation and an important clinical consideration when determining barriers to post-stroke participation (Baseman, Fisher, Ward, & Bhattacharya, 2010; Wolf & Koster, 2013).

### **Personal factors and participation post-stroke**

*Personal factors* are '... the particular background of an individual's life and living, and comprise features of the individual that are not part of a health condition or health states' (WHO, 2001, p. 17). Personal factors can influence participation post-stroke (Norlander, Iwarsson, Jönsson, Lindgren, & Måsson Lexell, 2018) and may play a role in strengthening our understanding of functioning, disability and health (Geyh et al., 2011). However, unlike other ICF components, there is no system for categorising personal factors (Geyh et al., 2011; Hoyle, Gustafsson, Meredith, & Ownsworth, 2012). A systematic review identified 238 potential personal factors and concluded further standardisation of personal factors within the ICF was needed (Geyh et al., 2011). Grotkamp and colleagues (2012) subsequently proposed 72 personal factor categories organised into 6 chapters, but this has not been officially adopted.

Age and gender are personal factors often investigated in relation to post-stroke participation. A meta-analysis of factors associated with post-stroke participation identified that older age was most often associated with poorer participation (Ezekiel et al., 2019). Gender accounted for greater

variance in outcomes; however, the evidence was mixed, with women found to have both poorer and better participation than men across different studies (Ezekiel *et al.*, 2019). Other studies included in the meta-analysis also revealed no association between gender and participation (Ezekiel *et al.*, 2019).

The numerous and diverse nature of personal factors precludes consideration of all factors within a single study. Review of the empirical and theoretical literature informed selection of four additional personal factors for this study that have been previously overlooked in stroke research but are likely relevant to post-stroke participation; namely, self-concept, optimism, threat appraisal and adult attachment style. These factors depict how individuals relate to themselves (self-concept, optimism and attachment) and their social environment (threat appraisal and attachment). Two are cognitive appraisals that are potentially amendable to change (self-concept and threat appraisal) and are possibly responsive to therapeutic influence (modifiable), whereas two (optimism and attachment) reflect more enduring personality-related constructs (Badley, 2006; Grotkamp, Cibis, Nüchtern, von Mittelstaedt, & Seger, 2012; Howe, 2008). Many influences on participation previously examined are non-modifiable and not susceptible to intervention to improve participation outcomes. Selected factors were chosen as they are representative of individual features that do not relate to the health condition and investigation of their associations with participation outcomes may contribute to an improved understanding of life after stroke and guide the focus of novel interventions.

#### *Self-concept*

Studies have revealed that people tend to view themselves more negatively post-stroke. Ellis-Hill and Horn (2000) identified that people typically saw themselves as less active, capable, in control, independent, interested and satisfied following stroke. Holding more negative views of self has also been associated with higher levels of depression (Lapadatu & Morris, 2019) which has established relationships with functional outcomes (Pohjasvaara, Vataja, Leppävuori, Kaste, & Erkinjuntti, 2001) and social participation (D'Alisa, Baudo, Mauro, & Miscio, 2005; Schmid *et al.*, 2012). Negative changes in *self-concept* (i.e., negative '*self-discrepancy*') have been reported to be indirectly associated with occupational gaps via an association with greater anxiety following traumatic brain injury (TBI) (Beadle, Ownsworth, Fleming, & Shum, 2020a). Beadle and colleagues (2020a) postulated that anxiety related to lack of occupational engagement may contribute to more negative appraisals of the post- compared to pre-injury self. Self-reported or perceived level of recovery is another self-related construct for understanding how people view themselves, which may influence or be influenced by participation restrictions post-stroke (Baseman *et al.*, 2010; Wolf & Koster, 2013).

#### *Dispositional optimism*

*Dispositional optimism* relates to an individuals' life outlook, future expectations and subsequent approach to the world (Scheier & Carver, 1985). Lower optimism has been linked with higher levels of depressive symptoms (Chung, Bakas, Plue, & Williams, 2016) and revealed as a mediating factor between mental health and perception of overall physical health post-stroke (Shifren & Anzaldi, 2018). Optimism has also been related to better psychological functioning which can influence cognitive and functional outcomes post-TBI (Ramanathan, Wardecker, Slocomb, & Hillary, 2011). In the only known study to focus on optimism and participation post-stroke, Schmid *et al.* (2012) identified positive associations between optimism and social role functioning, which is an important aspect of participation.

### *Threat appraisal*

*Threat appraisal*, or the perception of an event or situation as potentially harmful, provides a means for understanding the relationship between anxiety and activity avoidance (Riley, Brennan, & Powell, 2004). Appraisal of task failure as a threat to one's sense of self can result in anxiety and avoidance of situations that may end in failure (Goldstein, 1952; Riley et al., 2004). Heightened threat appraisals after brain injury have been linked to greater use of maladaptive coping strategies, such as task avoidance or withdrawal, which restricts participation in valued pre-injury activities (Gracey, Evans, & Malley, 2009). People with acquired brain injury experience threat associated with activities related to 'personal safety', 'dealing with people', 'doing things' and 'awkward situations' (Riley et al., 2004). Individuals with more negative self-discrepancy following TBI reported higher threat appraisals ( $r = -0.50, p < 0.001$ ) (Beadle, Ownsworth, Fleming, & Shum, 2020b). There is limited information about post-stroke threat appraisals. One study demonstrated that although perceptions of threat related to stroke decreased in the first 6 months after stroke, a greater initial perceived threat was associated with lower participation at 6 months (Rochette, Bravo, Desrosiers, St-Cyr Tribble, & Bourget, 2007). These authors suggested that cognitive appraisals may be shaped or influenced by experiences, making them potentially responsive to therapeutic intervention. Thus, threat appraisals post-stroke may be susceptible to modification, possibly resulting in improved participation (Hoyle et al., 2012). While Rochette, Bravo et al.'s (2007) study included generalised post-stroke appraisals measured by the Stress Appraisal Measure (Peacock & Wong, 1990), the present study focuses on threat appraisals related to everyday activities and situations measured by the Appraisal of Threat and Avoidance Questionnaire (ATAQ; Riley et al., 2004).

### *Adult attachment style*

*Adult attachment styles*, are individualised schemas/internal working models, developed from infancy, that influence how an individual perceives themselves, others and the world (Bowlby, 1988, 1969; Meredith, Strong, & Feeney, 2005; Mikulincer, 1995). While these styles have not been widely researched in association with post-stroke participation, attachment theory has been increasingly applied within the medical field (Hunter & Maunder, 2001; Maunder & Hunter, 2001; Strauss & Brenk-Franz, 2016). Relationships have been demonstrated between adult attachment and, coping and adjustment in chronic conditions (Schmidt, Nachtigall, Wuethrich-Martone, & Strauss, 2002), including cancer (Cicero, Lo Coco, Gullo, & Lo Verso, 2009), chronic pain (Meredith, Ownsworth, & Strong, 2008), diabetes (Ciechanowski et al., 2004) and HIV/AIDS (Turner-Cobb et al., 2002). Fearful and dismissing attachment styles have been linked with threat appraisal (Meredith et al., 2005) which, as previously discussed, may be associated with participation restrictions. Attachment warrants further investigation in relation to post-stroke participation because of the potential links with coping, adjustment and threat appraisal. Although unlikely amenable to change as long-standing personality constructs, attachment style and optimism, are considerations that may influence clinical reasoning and support tailoring interventions specific to individual needs.

### **Present study**

The aim was to examine associations between demographic, self- and threat appraisal and personality variables and, post-stroke participation. It was hypothesised that higher levels of participation may be associated with younger age, higher levels of optimism, less difference between pre- and post-stroke self-concept (i.e., lower self-discrepancy), lower levels of threat appraisal and a more secure attachment style. Due to the inconsistent findings in the literature, a hypothesis for gender was not postulated. Finally, level of perceived recovery has been identified within

the literature as a significant predictor of participation (Baseman *et al.*, 2010; Wolf & Koster, 2013) and was recorded to explore associations with post-stroke participation further.

## Methods

### *Design*

This exploratory cross-sectional study represents the quantitative portion of a larger explanatory sequential mixed methods study (Creswell & Plano Clark, 2011). Ethical approval was granted by The University of Queensland's Behavioural and Social Sciences Ethical Review Committee (Project no. 2012001037/Project identifier 2012/HE001037).

### *Participants*

Participants were aged 18 or above, had experienced stroke (one or multiple events) and had returned to living in the community within Australia (either independently or assisted). Potential participants were excluded if inclusion criteria were not met, but were not excluded based on communication difficulties, as people with these challenges post-stroke are often under-represented in stroke-related research (Brady, Fredrick, & Williams, 2012). Recruitment used convenience and snowball sampling methods from November 2014 to December 2017 inclusive, through a variety of means, including print, social media and community-based presentations. Informed consent was obtained and all participants were asked to indicate their willingness to participate in further research opportunities. The structured purpose-designed survey was completed and returned via an online website, email or in hardcopy via mail, based on participant preference. Participants could complete the survey independently or have someone complete it on their behalf.

### *Measures*

The survey included demographic (e.g., age and gender) and general health questions and a variety of questionnaires regarding participation and the selected personal factors. Two self-report measures of participation were chosen to gain a more comprehensive insight into the construct of participation, both in terms of content examined and ways in which the construct is measured.

#### *Participation measures*

*Community Integration Questionnaire.* The Community Integration Questionnaire (CIQ), the first measure of participation, is a 15-item instrument that examines participation in home (five items), social (six items) and productive (four items) activities (Dalemans, de Witte, Beurskens, van den Heuvel, & Wade, 2010; Willer, Ottenbacher, & Coad, 1994; Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1993). Twelve items are scored on a 3-point scale which identifies who completes the task (0 = someone else, 1 = yourself and someone else, and 2 = yourself alone) or how often the task is completed (0 = Never, 1 = 1–4 times, 2 = 5 or more times). The remaining three items, relating to work, school and volunteering, are examined in combination and assigned a score between 0 and 5. The overall CIQ score (range: 0–29) is a summation of the scores with a higher score indicating a higher level of integration. The measure can be completed by a proxy (Kuipers, Kendall, Fleming, & Tate, 2004; Salter, Foley, Jutai, Bayley, & Teasell, 2008; Willer *et al.*, 1994). The reliability and validity of the CIQ has been established with adults with physical disabilities and TBI (Corrigan & Deming, 1995; Hirsh, Braden, Craggs, & Jensen, 2011; Willer *et al.*, 1994, 1993). Internal consistency for the total CIQ score was adequate ( $\alpha = 0.71$ ) for the present sample.

*Stroke Impact Scale Version 3.0.* The Stroke Impact Scale Version 3.0 (SISv3) examines the impact of stroke across eight domains (Duncan, Bode, Lai, & Perera, 2003; Lin *et al.*, 2010). A final item

assesses the person's global perception of recovery (0 = no recovery to 100 = full recovery). The original Stroke Impact Scale demonstrated fair to good convergent validity (Doyle et al., 2007; Kwon et al., 2006) and robust psychometric properties for the physical and participation domains (Duncan et al., 2003). Support for proxy completion has been reported (Carod-Artal et al., 2009; Duncan et al., 2002). The participation domain was the second measure of participation in the present study. Participants rated how much during the past four weeks they have been limited in work, social activities, quiet recreation, active recreation, role as a family member/friend, spiritual or religious activities, ability to control life as they wish and ability to help others. A summative score was produced for this domain and transformed into a scale score (range: 0–100) by using the formula:  $[(\text{actual raw score} - \text{lowest possible raw score}) / \text{possible raw score}] \times 100$ . Internal consistency for the present sample in this domain was good ( $\alpha = 0.89$ ). The global perception of recovery item (range: 0–100) was also recorded to enable consideration of the associations between perceived recovery and post-stroke participation outcomes.

#### *Personal factor measures*

*Head Injury Semantic Differential III.* The Head Injury Semantic Differential Scale III (HISD-III) measures self-concept and self-discrepancy. Participants rate themselves on 18 bipolar adjective/attribute pairs (e.g., Bored/Interested, Unhappy/Happy) on a 7-point scale (1 = negative pole and 7 = positive pole), according to past-self (i.e., six months prior to injury), present-self (i.e., over the past two weeks) and future-self (i.e., expectation for one year into the future) (Ownsworth, 2014; Tyerman, 1997). Total scores can be calculated for each self (range: 18–126), allowing for comparison between perceptions of past-, present- and future-selves (Ownsworth, 2014; Tyerman, 1997, 2008), and perceived change in self-concept (Reddy, Ownsworth, King, & Shields, 2015). For this study, only past- and present-self scales were administered to align with pre- and post-stroke selves. Self-discrepancy was calculated by subtracting the pre-stroke from the post-stroke score. A larger negative discrepancy score represented a more positively viewed past-self than present-self. The HISD-III and its prior iterations have demonstrated strong reliability for past- and present-selves and have been used with people with TBI and stroke (Beadle et al., 2020a, 2020b; Carroll & Coetzer, 2011; Lapadatu & Morris, 2019; Reddy et al., 2015). Internal consistency in the present sample was good for past-self ( $\alpha = 0.87$ ) and excellent for present-self ( $\alpha = 0.96$ ).

*Relationship Questionnaire.* The Relationship Questionnaire (RQ) is a self-report measure of adult attachment style comprising two parts (Bartholomew & Horowitz, 1991). First, participants identified which one of the four attachment styles best describes them. Second, participants rated how well the description of each style corresponds to their general relationship style on a 7-point Likert Scale (1 = not at all like me to 7 = very much like me). While only displaying moderate test–retest reliability (Herzberg et al., 1999; Scharfe & Bartholomew, 1994), the construct validity of the four-category model on which the RQ is based has been demonstrated (Bartholomew & Horowitz, 1991; Griffin & Bartholomew, 1994) and moderate to high correlations have been found between the RQ and the Relationship Styles Questionnaire (Bäckström & Holmes, 2001; Griffin & Bartholomew, 1994).

*Appraisal of Threat and Avoidance Questionnaire.* The ATAQ is a 41-item questionnaire that documents threat appraisals and associated activity avoidance in four categories: dealing with people, doing things, personal safety and awkward situations (Riley et al., 2004). Items are presented as statements, and participants are asked to reflect on the previous month and respond with yes or no. If yes, participants are asked to identify, whether they had avoided meeting people/going out/doing things due to the original appraisal (Riley et al., 2004). Threat appraisal and avoidance scores are calculated overall and for all four categories (Riley et al., 2004); only total threat appraisal scores (range: 0–41) were used in this study. Satisfactory internal consistency has been

established for overall threat appraisal and avoidance, and for the first three categories (Riley *et al.*, 2004). Internal consistency for the threat appraisal index in the present sample was excellent ( $\alpha = 0.92$ ).

*Life Orientation Test – Revised.* The Life Orientation Test – Revised (LOT-R) is a measure of participants' generalised sense of optimism. It is comprised of three 'optimism' items, three 'pessimism' items and four 'filler' items. Each item is rated on a 5-point Likert scale (0 = strongly disagree to 4 = strongly agree) (Scheier *et al.*, 1994). Totalled scores range from pessimistic (lowest possible = 0) to optimistic (highest possible = 24) (i.e., range: 0–24) (Ramanathan *et al.*, 2011). The LOT-R has displayed internal consistency at an acceptable level and moderate correlations with related scales of neuroticism, self-esteem, self-mastery and trait anxiety (Scheier *et al.*, 1994). Internal consistency for the present sample was good ( $\alpha = 0.80$ ).

### **Data analysis**

Each returned survey was inspected for missing or unclear responses and, where possible, clarification regarding responses were sought. Data were analysed using the IBM Statistical Package for Social Sciences (SPSS) Version 27 and as an exploratory, hypothesis-generating study, a power calculation for desired sample size was not conducted. Descriptive analyses and screening explored whether dependent variables (CIQ and SISv3 participation) met assumptions for parametric testing (i.e., Shapiro–Wilk test). Associations between independent variables (age, gender, self-concept/self-discrepancy, threat appraisal, optimism, adult attachment style and perceived recovery) and participation variables were determined using univariate linear regression and correlation (see [supplementary material](#)) analyses. Scatter plots with lines of best fit examined the directionality of the associations indicated by the univariate regression analyses. Time since stroke, a potential confounding variable, was investigated using correlations to determine whether it should be considered in further analyses. Two models, one for CIQ participation and one for SISv3 participation, were explored using multiple linear regression analyses. All independent variables that demonstrated significant associations ( $p < 0.05$ ) with each of the dependent variables in the univariate regressions were considered for entry into the relevant models. Variables included in the final models were chosen based on relevance to the aim of the study and the total variability they described in the univariate analyses. Both multiple linear regression analyses were examined for outliers. Outliers (studentised residuals  $> 2.6$ ) were removed one at a time (i.e., largest studentised residuals first) and the multiple regression models were re-run. Two outliers were removed from the CIQ participation model and one outlier was removed from the SISv3 participation model. The final models were checked for multicollinearity, homoscedasticity and normal distribution of residuals before finalisation.

## **Results**

### **Descriptive and sample characteristics**

Seventy-two people expressed interest and ten were excluded due to no diagnosis of stroke ( $n = 1$ ), not living in the community ( $n = 4$ ), completing less than 70% of the survey ( $n = 4$ ) or completing the survey twice ( $n = 1$ ). Sixty-two participants were subsequently included in data analysis, and demographics and stroke and health characteristics are shown in Tables 1 and 2, respectively.

Three participants (5%) reported having expressive aphasia, and two (3%) reported having both expressive and receptive aphasia. Nine (14.5%) indicated that another person completed the survey on their behalf. Of those nine, seven (78%) indicated that they had neither expressive and/or receptive aphasia, one (11%) identified they had expressive aphasia and one (11%) identified they had both expressive and receptive aphasia.

**Table 1** Demographics of Participants

Demographic	<i>N</i>	Minimum	Maximum	Mean (M)	Median	Std. Dev.
Age	60	24	96	66.47	69.50	14.04
Time Since Stroke <sup>†</sup>	59	1	608	124.39	101.00	124.01
Demographic	<i>N</i>	Descriptor		Freq.	%	
Gender	62	Male		31	50.00	
		Female		31	50.00	
Marital Status	62	Single		4	6.45	
		De facto		1	1.61	
		Married		36	58.06	
		Widowed		9	14.52	
		Divorced		9	14.52	
		Separated		3	4.84	
Living Situation	62	Alone		17	27.42	
		Not Alone		45	72.58	
Residence	62	Own Home		35	56.45	
		Retirement Village		12	19.35	
		Other		15	24.19	
Location	62	Major Cities of Australia		46	74.19	
		Inner Regional Australia		11	17.74	
		Outer Regional Australia		3	4.84	
		<i>Missing Data</i>		2	3.23	
Education Qualifications	62	No formal qualifications		4	6.45	
		Year 10 or equivalent		11	17.74	
		Year 12 or equivalent		11	17.74	
		Trade/apprenticeship		5	8.06	
		Certificate/diploma		14	22.58	
		University Degree		10	16.13	
		Higher University Degree		7	11.29	
Work Situation at Time of Stroke	62	Full-Time		25	40.32	
		Part-Time		7	11.29	
		Not working/actively looking		1	1.61	
		Not working/not looking		5	8.06	
		Carer		2	3.23	
		Not Applicable – Retired		20	32.26	
		Other		2	3.23	

Note. †measured in months; Freq., Frequency; *n*, number of participants; SD, standard deviation; %, percentage.

**Table 2** Stroke and Health Characteristics of Participants

Characteristic	N	Descriptor	Freq.	%
Type of Stroke	62	Ischaemic	30	48.39
		Haemorrhagic	16	25.81
		Unknown	8	12.90
		Other	7	11.29
		<i>Missing Data</i>	1	1.61
Side of Body Impacted	62	Left	26	41.94
		Right	25	40.32
		Both Sides	5	8.06
		Neither	5	8.06
		<i>Missing Data</i>	1	1.61
Dominant Side	62	Left	6	9.68
		Right	56	90.32
Dominant Side Impacted	62	Yes	30	48.39
		No	31	50.00
		<i>Missing Data</i>	1	1.61
Time in Hospital	62	<1 week	9	14.52
		At least 1 week, <a month	14	22.58
		At least a month, <3 months	17	27.42
		At least 3 months, <6 months	18	29.03
		At least 6 months, <1 year	4	6.45
Number of Medical Conditions	62	No conditions	15	24.19
		1 or 2 conditions	25	40.32
		3 or 4 conditions	11	17.74
		5 or more conditions	11	17.74
Current Overall Health	62	Poor	1	1.61
		Fair	17	27.42
		Good	20	32.26
		Very Good	19	30.65
		Excellent	5	8.06
Impact of Current Health on Doing Things	62	Not at all	16	25.81
		A little	20	32.26
		A lot of the time	13	20.97
		Most of the time	11	17.74
		All of the time	2	3.23
Health Compared to Before Stroke	62	Much Worse	10	16.13
		Worse	26	41.94
		About the same	15	24.19

*(Continued)*

Table 2 (Continued)

Characteristic	N	Descriptor	Freq.	%
Impact of Stroke Related Difficulties on Doing Things	62	Better	10	16.13
		Much Better	1	1.61
		Not at all	5	8.06
		A little	18	29.03
		A lot of the time	19	30.65
		Most of the time	11	17.74
		All of the time	9	14.52
SISV3 Recovery	62	0–30%	9	14.52
		40–60%	21	33.87
		70–90%	29	46.77
		100%	3	4.84

Note. Freq., frequency; n, number of participants; %, percentage.

CIQ participation data were normally distributed ( $p = 0.33$ ) while SISv3 participation data were not ( $p = 0.007$ ) pre-multiple regression. Regression diagnostics showed that residuals for both CIQ and SISv3 participation data were normally distributed ( $p = 0.81$ ,  $p = 0.44$  respectively). Thus, parametric tests were utilised for all regression analyses. Time since stroke did not show significant correlations with either CIQ participation ( $r(49) = 0.08$ ,  $p = 0.59$ ) or SISv3 participation ( $r_s(58) = 0.14$ ,  $p = 0.29$ ) and was not included in further analyses.

### Univariate regression analyses

#### CIQ participation univariate regression analyses

Self-discrepancy and perceived recovery and were significantly positively related with CIQ participation (Table 3). Age was significantly negatively related with CIQ participation. A significant association was seen between CIQ participation and gender, such that women were more likely to report higher participation than men (female  $M = 16.36$ ; male  $M = 13.36$ ). No other variables were significantly associated with CIQ participation.

#### SISv3 participation univariate regression analyses

Secure attachment, self-discrepancy and perceived recovery demonstrated significant positive associations with SISv3 participation (Table 4). Threat appraisal, and preoccupied attachment were significantly negatively related with SISv3 participation.

### Multiple regression analyses

Results of multiple regression analyses (Table 5) identified relevant personal factors and the associated percentage of explained variability for CIQ and SISv3 participation. In the multiple variable modelling, age ( $p = 0.02$ ), gender ( $p = 0.008$ ), self-discrepancy ( $p = 0.02$ ) and perceived recovery ( $p < 0.001$ ) were significantly associated with CIQ participation. Only age had an inverse relationship indicating that increased age was associated with decreased CIQ participation, while increases in perceived recovery were associated with increased CIQ participation. If pre-stroke self-concept was greater than post-stroke self-concept, greater discrepancy between the two

**Table 3** Univariate Analyses Between Participation (CIQ) and Independent Variables

Relationship between participation (CIQ) and:	Model Summary	ANOVA			Coefficients			
	<i>R</i> <sup>2</sup>	df	<i>F</i>	<i>p</i>	<i>B</i>	<i>t</i>	95% LB	95% UB
Age	0.15	1,48	8.58	0.005	-0.14	-2.93	-0.24	-0.04
Gender	0.09	1,50	4.74	0.03	3.01	2.18	0.23	5.79
Self-Concept	0.12	1,37	5.23	0.03	0.08	2.29	0.01	0.15
Threat Appraisal	0.01	1,48	0.48	0.49	-0.06	-0.69	-0.23	0.11
Optimism	0.01	1,45	0.51	0.48	0.12	0.72	-0.21	0.45
Secure Attachment	0.05	1,45	2.59	0.11	0.60	1.61	-0.15	1.34
Fearful Attachment	0.01	1,45	0.27	0.61	-0.22	-0.52	-1.08	0.64
Preoccupied Attachment	0.00	1,46	0.00	0.96	-0.02	-0.05	-0.90	0.86
Dismissing Attachment	0.01	1,46	0.39	0.53	0.21	0.63	-0.46	0.87
Perceived Recovery	0.19	1,50	11.90	0.001	0.10	3.45	0.04	0.15

Note. *B*, unstandardised beta; CIQ, Community Integration Questionnaire; df, degrees of freedom; *F*, *F* value; *p*, Significance; *R*<sup>2</sup>, *R* squared; *t*, *t* value; 95% LB = Lower Bound of 95% Confidence Interval for *B*; 95% UB = Upper Bound of 95% Confidence Interval for *B*.

**Table 4** Univariate Analyses Between Participation (SISv3) and Independent Variables

Relationship between participation (SISv3) and:	Model Summary	ANOVA			Coefficients			
	<i>R</i> <sup>2</sup>	df	<i>F</i>	<i>p</i>	<i>B</i>	<i>t</i>	95% LB	95% UB
Age	0.01	1,57	0.68	0.41	0.16	0.82	-0.23	0.54
Gender	0.00	1,59	0.19	0.66	2.32	0.44	-8.33	12.97
Self-Concept	0.34	1,43	22.07	<0.001	0.43	4.70	0.26	0.66
Threat Appraisal	0.30	1,54	22.63	<0.001	-1.26	-4.76	-1.79	-0.73
Optimism	0.00	1,52	0.20	0.66	-0.25	-0.45	-1.39	0.88
Secure Attachment	0.08	1,51	4.18	0.05	2.57	2.04	-0.05	5.09
Fearful Attachment	0.00	1,49	0.05	0.83	-0.32	-0.21	-3.38	2.74
Preoccupied Attachment	0.12	1,50	6.54	0.01	-3.94	-2.56	-7.03	-0.85
Dismissing Attachment	0.00	1,51	0.06	0.81	0.31	0.25	-2.20	2.82
Perceived Recovery	0.36	1,59	33.80	<0.001	0.51	5.81	0.33	0.68

Note. *B*, unstandardised beta; df, degrees of freedom; *F*, *F* value; *p*, significance; *R*<sup>2</sup>, *R* squared; SISv3, stroke impact scale version 3.0; *t*, *t* value; 95% LB = Lower Bound of 95% Confidence Interval for *B*; 95% UB = Upper Bound of 95% Confidence Interval for *B*.

was associated with decreased participation. If post-stroke self-concept was greater than pre-stroke self-concept, greater discrepancy was associated with increased participation. Gender was positively associated with CIQ participation, indicating that women were more likely to report higher participation than men (female *M* = 17.22; male *M* = 12.15). The multiple variable modelling for SISv3 participation demonstrated similar associations between SISv3 participation and self-discrepancy (*p* = 0.002) and perceived recovery (*p* < 0.001).

**Table 5** Summary of Final Multiple Regression Analyses for Variables Associated with Participation as Measured by the CIQ ( $n = 36$ ) and SISv3 ( $n = 41$ )

Independent Variables	CIQ Participation			SISv3 Participation		
	<i>B</i>	<i>SE B</i>	$\beta$	<i>B</i>	<i>SE B</i>	$\beta$
Age	-0.10	0.04	-0.27*			
Gender	3.42	1.21	0.32**			
Self-Concept	0.06	0.02	0.26*	0.27	0.08	0.34**
Perceived Recovery	0.12	0.02	0.52***	0.55	0.09	0.60***
$R^2$	0.72			0.66		
$\Delta R^2$	0.69			0.64		
<i>F</i>	20.53***			39.26***		

Note. *B*, unstandardised beta; CIQ, Community Integration Questionnaire; *F*, *F* value; *SE B*, standard error for the unstandardised beta; SISv3, stroke impact scale version 3.0;  $\beta$ , standardised beta;  $\Delta R^2$ , adjusted R squared value.

\* $p < 0.05$ .

\*\* $p < 0.01$ .

\*\*\* $p < 0.001$ .

### Correlations between participation measures

In response to the different findings revealed for the two participation measures, a Spearman's rank-order correlation was conducted to investigate the relationship between the two participation measures. The result,  $r_s = 0.34$ ,  $p = 0.02$ , demonstrated a significant but weak correlation between the measures.

### Discussion

The study aimed to identify demographic, self- and threat appraisal and personality variables that were strongly associated with participation for people living in the community post-stroke. Findings at a univariate level demonstrated that a range of personal factors, including age, gender, self-concept, threat appraisal, secure attachment and pre-occupied attachment were variably associated with CIQ and SISv3 participation. However, at a multivariate level, self-concept, age and gender were the only personal factors related to participation outcomes. Results highlight the potential need for greater consideration of the influence of personal factors on participation outcomes.

Consistent with the hypothesis, self-discrepancy demonstrated a strong positive association with both CIQ and SISv3 participation. A low self-discrepancy score was associated variably with participation dependent on which self-concept was scored higher. When pre-stroke self-concept was greater than post-stroke self-concept, a lower self-discrepancy score was associated with increased participation. When post-stroke self-concept was greater than pre-stroke self-concept a lower self-discrepancy was associated with decreased participation. Whilst there is no established causal relationship, findings indicate that people who perceive their pre-stroke self to be better than their post-stroke self and have higher self-discrepancy may be at higher risk of poor participation outcomes. Equally, people with low participation may be susceptible to a greater change in self-concept. While previous literature has indicated that people post-stroke tend to experience challenges in participation (Eriksson et al., 2013; Palstam et al., 2019; Wolf & Koster, 2013) and hold more negative views of themselves (Ellis-Hill & Horn, 2000; Lapadatu & Morris, 2019) this study is the first known to demonstrate the association between these two constructs post-stroke.

Associations were expected between younger age and increased participation, while no hypothesis for gender was postulated. Results revealed that younger age and female gender were associated with increased participation as measured by the CIQ; however, no association was found with the SISv3. Variation in associations with *gender* were consistent with previous literature and warrant additional attention in stroke research. The lack of association between *age* and SISv3 participation was unexpected given that older age has consistently been associated with poorer participation outcomes in earlier research (Ezekiel *et al.*, 2019). Differences in the focus and structure of the two participation measures, discussed below, could have contributed to differences seen in findings. As a range of participation measures exist, further investigation into the construct, its operationalisation in measures and associations with personal factors would be valuable.

The hypotheses that increased optimism, decreased threat appraisal and secure attachment would be associated with increased participation were partially supported. In contrast with previous studies which have found associations between *optimism* and better psychological functioning (Ramanathan *et al.*, 2011) and social role functioning (Schmid *et al.*, 2012), optimism was not directly associated with either CIQ or SISv3 participation at a univariate level. Variations in results may relate to different participant samples or differences in outcome variables measured. While a direct association was not evident, optimism may indirectly impact on participation through mediating factors, and this would benefit from further investigation.

Attachment variables were not directly associated with CIQ participation. In contrast, *secure attachment* was positively associated, and *preoccupied attachment* was negatively associated, with SISv3 participation at a univariate level. Associations with secure attachment were anticipated based on previous research (Meredith *et al.*, 2005), however, identified relationships between threat appraisal and insecure attachment had been seen for fearful and dismissing attachment rather than preoccupied attachment. Differences in results may relate to differences in participant samples or different dependent variables of interest.

As expected, people who reported higher levels of threat appraisal were more likely to report lower levels of participation as measured by the SISv3; however, this association did not persist in multiple variable analyses. It is possible that, given the theoretical association between threat appraisal and self-concept (Goldstein, 1952; Riley *et al.*, 2004), self-concept could have accounted for the variance in participation attributed to threat appraisal.

Perceived recovery, a possible alternative approach for examining view of self, was positively associated with both CIQ and SISv3 participation. Recovery from stroke incorporates inter-linked physical, psychological and social features and is defined at an individual level by people with stroke, rather than determined by population norms or other external standards (Dowswell *et al.*, 2000). A person's perception of their recovery, if poor, is a possible barrier to participation after mild stroke (Wolf & Koster, 2013) and thus may be a barrier to participation for the wider stroke population. Eriksson and colleagues (2013) suggested that perceived recovery might be related to participation in two ways. Firstly, people post-stroke might perceive recovery as necessary before participating in activities. Conversely, as people become aware of increased engagement in pre-stroke activities, they may perceive a higher level of recovery. Regardless of directionality, the association between recovery and participation warrants further investigation. Future work may also examine the difference between 'perceived recovery' of the individual and 'measured recovery' determined by clinical assessment in relation to post-stroke participation outcomes.

Previous literature has identified the challenges in conceptualising and operationalising participation (Dijkers, 2010; Engel-Yeger *et al.*, 2018; Whiteneck, 2010). While both participation measures were associated with self-concept and perceived recovery, variations in associations were also evident suggesting that there were differences in the operationalisation of participation across the two measures (Dijkers, 2010; Engel-Yeger *et al.*, 2018; Whiteneck, 2010). The CIQ measures how people participate in home and community activities and how often particular activities are completed. In contrast, the SISv3 measures how often a person has been limited in participating in

specific activities. Despite some similarity between activities examined there are also notable differences. The CIQ has a greater focus on home-related activities and includes education which is not addressed in the SISv3. The SISv3, conversely, includes questions about spirituality/religion and 'ability to control your life as you wish', which are not present in the CIQ. These observed differences, supported by the relatively weak correlation between the measures, suggest that the consistent associations between both measures and self-concept and perceived recovery are particularly important.

Despite challenges in operationalisation, associations between participation and personal factors are important considerations for practice. Modifiable personal factors, like self-concept, may be susceptible to clinical intervention; thus, clinically based research could consider whether interventions targeted at these factors can improve participation outcomes. Likewise, interventions supporting improvements in participation may positively influence modifiable personal factors and are also worthy of further exploration. The increasing number of people living in the community post-stroke (Béjot et al., 2014; Lakshminarayan et al., 2014) and greater focus on reducing participation restrictions, highlights the importance of research to understand and address this largely unmet need (Andrew et al., 2014).

### **Strengths and limitations**

The original sample was small ( $n = 62$ ), and further reduced in some analyses due to missing data. The collection of data using a self-report, cross-sectional research design can increase risk of bias due to common method variance. Despite this, sense of self measurement can be useful in gaining insight into people's experience of their condition, which can lead to more effective intervention (Ownsworth, 2014). Sampling bias may also be present as participants who volunteered may be more likely to represent people with higher participation levels and most participants lived in metropolitan regions of Queensland or Northern New South Wales. The HISD-III assesses a specific range of behavioural and emotional attributes, does not incorporate all domains relevant to self-concept, and reliance on retrospective data for establishing past-self is also a limitation. Data were not collected on stroke severity, a variable commonly associated with poorer participation outcomes (Ezekiel et al., 2019), due to the explicit focus on personal factors rather than the health condition. The inclusion of people with aphasia and the different data collection methods promoted participation of a diverse, representative group. Participants indicated if someone else completed the survey on their behalf, but it is unknown if a communication partner recorded responses or if responses were completed by proxy. Proxy completion has been found acceptable for both the CIQ and SISv3 (Carod-Artal et al., 2009; Kuipers et al., 2004; Willer et al., 1994), but has not been established for the included self- and threat appraisal and personality variable measures. Finally, it is unknown if completion of the chosen questionnaires in the online format impacted the responses.

Despite these limitations, the study findings are a preliminary contribution towards understanding the relationships between demographic, self- and threat appraisal and personality variables and, participation post-stroke. This study adds to the expanding knowledge-base to improve understanding of factors that influence participation in the community after stroke. Future research may benefit from employing methods of data collection that increase participant numbers, decrease potential for missing data and minimise potential for biases, thereby improving power and confidence in findings.

### **Conclusion**

This study provides preliminary evidence of associations between post-stroke participation and demographic, self-and threat appraisal and personality variables. While nearly all included personal factors demonstrated associations with participation post-stroke, these associations varied

based on the way that participation was conceptualised and subsequently operationalised in each participation measure. Nevertheless, demographics, self-appraisals (i.e., self-concept and perceived recovery), explained a significant portion of the variability in post-stroke participation. This supports the value of further research to investigate associations between personal factors and participation post-stroke which may, in turn, contribute to an improved understanding of life after stroke and support future development of participation-focused interventions.

**Supplementary material.** To view supplementary material for this article, please visit <https://doi.org/10.1017/BrImp.2022.31>

**Acknowledgments.** This study was completed as part of a Doctor of Philosophy program at The University of Queensland. The authors thank the study's participants, who kindly volunteered their time to provide the valuable data for this study.

**Financial support.** This research received no specific grant from any funding agency, commercial or not-for-profit sector.

**Conflicts of interest.** Melanie Hoyle, has no conflicts of interest to disclose. Pamela Meredith has no conflicts of interest to disclose. Tamara Ownsworth has no conflicts of interest to disclose. Asaduzzaman Khan has no conflicts of interest to disclose. Louise Gustafsson has no conflicts of interest to disclose.

**Ethical standards.** The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008.

## References

- Ahn, S. N., & Hwang, S. (2018). An investigation of factors influencing the participation of stroke survivors in social and leisure activities. *Physical Therapy Rehabilitation Science*, 7(2), 67–71. <https://doi.org/10.14474/ptrs.2018.7.2.67>
- Andrew, N. E., Kilkenny, M., Naylor, R., Purvis, T., Lalor, E., Moloczij, N., & Cadilhac, D. A. (2014). Understanding long-term unmet needs in Australian survivors of stroke. *International Journal of Stroke*, 9(SA100), 106–112. <https://doi.org/10.1111/ijss.12325>
- Bäckström, M., & Holmes, B. M. (2001). Measuring adult attachment: A construct validation of two self-report instruments. *Scandinavian Journal of Psychology*, 42, 79–86. <https://doi.org/10.1111/1467-9450.00216>
- Badley, E. M. (2006). More than facilitators and barriers: Fitting the full range of environmental and personal contextual factors into the ICF model. In *12th Annual North American Collaborating Center Conference on ICF*, Vancouver, British Columbia.
- Bartholomew, K., & Horowitz, L. M. (1991). Attachment styles among young adults: A test of a four-category model. *Journal of Personality and Social Psychology*, 61(2), 226–244. <https://doi.org/10.1037/0022-3514.61.2.226>
- Baseman, S., Fisher, K., Ward, L., & Bhattacharya, A. (2010). The relationship of physical function to social integration after stroke. *Journal of Neuroscience Nursing*, 42(5), 237–244. <https://doi.org/10.1097/JNN.0b013e3181eeca>
- Beadle, E. J., Ownsworth, T., Fleming, J., & Shum, D. H. K. (2020a). The nature of occupational gaps and relationship with mood, psychosocial functioning and self-discrepancy after severe traumatic brain injury. *Disability and Rehabilitation*, 42(10), 1414–1422. <https://doi.org/10.1080/09638288.2018.1527954>
- Beadle, E. J., Ownsworth, T., Fleming, J., & Shum, D. H. K. (2020b). Personality characteristics and cognitive appraisals associated with self-discrepancy after severe traumatic brain injury. *Neuropsychological Rehabilitation*, 30(3), 393–411. <https://doi.org/10.1080/09602011.2018.1469416>
- Béjot, Y., Daubail, B., Jacquin, A., Durier, J., Guy-Victor, O., Rouaud, O., & Giroud, M. (2014). Trends in the incidence of ischaemic stroke in young adults between 1985 and 2011: The Dijon stroke registry. *Journal of Neurology, Neurosurgery and Psychiatry*, 85, 509–513. <https://doi.org/10.1136/jnnp-2013-306203>
- Bergström, A. L., Guidetti, S., Tham, K., & Eriksson, G. (2017). Association between satisfaction and participation in everyday occupations after stroke. *Scandinavian Journal of Occupational Therapy*, 24(5), 339–348. <https://doi.org/10.1080/11038128.2016.1245782>
- Bowlby, J. (1988). *A secure base: Parent-child attachment and healthy human development*. New York, NY: Basic Books.
- Bowlby, J. A. (1969). *Attachment and loss: Attachment*. New York, NY: Basic Books.
- Brady, M. C., Fredrick, A., & Williams, B. (2012). People with aphasia: Capacity to consent, research participation and intervention inequalities. *International Journal of Stroke*, 8(3), 193–196. <https://doi.org/10.1111/j.1747-4949.2012.00900.x>
- Brock, K., Black, S., Cotton, S., Kennedy, G., Wilson, S., & Sutton, E. (2009). Goal achievement in the six months after inpatient rehabilitation for stroke. *Disability Rehabilitation*, 31(11), 880–886. <https://doi.org/10.1080/09638280802356179>
- Carey, L. M., Matyas, T. A., & Baum, C. (2018). Effects of somatosensory impairment on participation after stroke. *American Journal of Occupational Therapy*, 72, 1–10. <https://doi.org/10.5014/ajot.2018.025114>

- Carod-Artal, F. J., Coral, L. F., Trizotto, D. S., & Moreira, C. M. (2009). Self- and proxy-report agreement on the Stroke Impact Scale. *Stroke*, 40(10), 3308–3314. <https://doi.org/10.1161/STROKEAHA.109.558031>
- Carod-Artal, F. J., González-Gutiérrez, J. L., Egido Herrero, J. A., Horan, T., & Varela de Seijas, E. (2002). Functional recovery and instrumental activities of daily living: Follow-up 1-year after treatment in a stroke unit. *Brain Injury*, 16(3), 207–216. <https://doi.org/10.1080/02699050110103337>
- Carroll, E., & Coetzer, R. (2011). Identity, grief and self-awareness after traumatic brain injury. *Neuropsychological Rehabilitation*, 21(3), 289–305. <https://doi.org/10.1080/09602011.2011.555972>
- Chung, M. L., Bakas, T., Plue, L. D., & Williams, L. S. (2016). Effects of self-esteem, optimism, and perceived control on depressive symptoms in stroke survivor-spouse dyads. *Journal of Cardiovascular Nursing*, 31(2), E8–E16. <https://doi.org/10.1097/JCN.0000000000000232>
- Cicero, V., Lo Coco, G., Gullo, S., & Lo Verso, G. (2009). The role of attachment dimensions and perceived social support in predicting adjustment to cancer. *Psycho-Oncology*, 18(10), 1045–1052. <https://doi.org/10.1002/pon.1390>
- Ciechanowski, P., Russo, J., Katon, W., Von Korff, M., Ludman, E., Lin, E., . . . Bush, T. (2004). Influence of patient attachment style on self-care and outcomes in diabetes. *Psychosomatic Medicine*, 66(5), 720–728. <https://doi.org/10.1097/01.psy.0000138125.59122.23>
- Corrigan, J. D., & Deming, R. (1995). Psychometric characteristics of the Community Integration Questionnaire: Replication and extension. *Journal of Head Trauma Rehabilitation*, 10(4), 41–53. <https://doi.org/10.1097%2F00001199-199508000-00005>
- Creswell, J. W., & Plano Clark, V. L. (2011). *Designing and conducting mixed methods research*. Los Angeles, CA: SAGE Publications Inc.
- D'Alisa, S., Baudo, S., Mauro, A., & Miscio, G. (2005). How does stroke restrict participation in long-term post-stroke survivors? *Acta Neurologica Scandinavica*, 112(3), 157–162. <https://doi.org/10.1111/j.1600-0404.2005.00466.x>
- Dalemans, R. J., de Witte, L. P., Beurskens, A. J., van den Heuvel, W. J., & Wade, D. T. (2010). Psychometric properties of the Community Integration Questionnaire adjusted for people with aphasia. *Archives of Physical Medicine and Rehabilitation*, 91(3), 395–399. <https://doi.org/10.1016/j.apmr.2009.10.021>
- Dijkers, M. P. (2010). Issues in the conceptualization and measurement of participation: An overview. *Archives of Physical Medicine and Rehabilitation*, 91(9), S5–S16. <https://doi.org/10.1016/j.apmr.2009.10.036>
- Dowswell, G., Lawler, J., Dowswell, T., Young, J., Forster, A., & Hearn, J. (2000). Investigating recovery from stroke: A qualitative study. *Journal of Clinical Nursing*, 9, 507–515. <https://doi.org/10.1046/j.1365-2702.2000.00411.x>
- Doyle, P. J., McNeil, M. R., Bost, J. E., Ross, K. B., Wambaugh, J. L., Hula, W. D., & Mikolic, J. M. (2007). The Burden of Stroke Scale (BOSS) provided valid, reliable, and responsive score estimates of functioning and well being during the first year of recovery from stroke. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation*, 16(8), 1389–1398. <https://doi.org/10.1007/s11136-007-9247-8>
- Duncan, P. W., Bode, R. K., Lai, S. M., & Perera, S. (2003). Rasch analysis of a new stroke-specific outcome scale: The Stroke Impact Scale. *Archives of Physical Medicine and Rehabilitation*, 84(7), 950–963. [https://doi.org/10.1016/s0003-9993\(03\)00035-2](https://doi.org/10.1016/s0003-9993(03)00035-2)
- Duncan, P. W., Lai, S. M., Tyler, D., Perera, S., Reker, D. M., Studenski, S. (2002). Evaluation of proxy responses to the Stroke Impact Scale. *Stroke*, 33(11), 2593–2599. <https://doi.org/10.1161/01.STR.0000034395.06874.3E>
- Ellis-Hill, C. S., & Horn, S. (2000). Change in identity and self-concept: A new theoretical approach to recovery following a stroke. *Clinical Rehabilitation*, 14(3), 279–287. <https://doi.org/10.1191/026921500671231410>
- Engel-Yeger, B., Tse, T., Josman, N., Baum, C., & Carey, L. M. (2018). Scoping review: The trajectory of recovery of participation outcomes following stroke. *Behavioural Neurology*, 2018, 1–22. <https://doi.org/10.1155/2018/5472018>
- Eriksson, G., Baum, M. C., Wolf, T. J., & Tabor Connor, L. (2013). Perceived participation after stroke: The influence of activity retention, reintegration, and perceived recovery. *American Journal of Occupational Therapy*, 67, E131–E138. <https://doi.org/10.5014/ajot.2013.008292>
- Ezekiel, L., Collett, J., Mayo, N. E., Pang, L., Field, L., & Dawes, H. (2019). Factors associated with participation in life activities for adults with stroke: A systematic review. *Archives of Physical Medicine and Rehabilitation*, 100, 945–955. <https://doi.org/10.1016/j.apmr.2018.06.017>
- Fallahpour, M., Jonsson, H., Jognataei, M. T., Nasrabadi Alireza, N., & Tham, K. (2013). “I am not living my life”: Lived experience of participation in everyday occupations after stroke in Tehran. *Journal of Rehabilitation Medicine*, 45, 528–534. <https://doi.org/10.2340/16501977-1143>
- Geyh, S., Peter, C., Muller, R., Bickenbach, J. E., Kostanjsek, N., Ustun, B. T., . . . Cieza, A. (2011). The personal factors of the international classification of functioning, disability and health in the literature – A systematic review and content analysis. *Disability and Rehabilitation*, 33(13–14), 1089–1102. <https://doi.org/10.3109/09638288.2010.523104>
- Goldstein, K. (1952). Effect of brain damage on personality. *Psychiatry*, 15, 245–260.
- Gracey, F., Evans, J. J., & Malley, D. (2009). Capturing process and outcome in complex rehabilitation interventions: A “Y-shaped” model. *Neuropsychological Rehabilitation*, 19(6), 867–890. <https://doi.org/10.1080/09602010903027763>
- Griffin, D., & Bartholomew, K. (1994). Models of the self and other: Fundamental dimensions underlying measure of adult attachment. *Journal of Personality and Social Psychology*, 67(3), 430–445. <https://doi.org/10.1037/0022-3514.67.3.430>

- Grotkamp, S. L., Cibis, W. M., Nüchtern, E. A. M., von Mittelstaedt, G., & Seger, W. K. F. (2012). Personal factors in the international classification of functioning, disability and health: Prospective evidence. *The Australian Journal of Rehabilitation Counselling*, 18(1), 1–24. <https://doi.org/10.1017/jrc.2012.4>
- Hartman-Maier, A., Soroker, N., Ring, H., Avni, N., & Katz, N. (2007). Activities, participation and satisfaction one-year post stroke. *Disability and Rehabilitation*, 29(7), 559–566. <https://doi.org/10.1080/09638280600924996>
- Herzberg, D. S., Hammen, C., Burge, D., Daley, S. E., Davila, J., & Lindberg, N. (1999). Attachment cognitions predict perceived and enacted social support during late adolescence. *Journal of Adolescent Research*, 14(4), 387–404. <https://doi.org/10.1177/0743558499144001>
- Hirsh, A. T., Braden, A. L., Craggs, J. G., & Jensen, M. P. (2011). Psychometric properties of the Community Integration Questionnaire in a heterogeneous sample of adults with physical disability. *Archives of Physical Medicine and Rehabilitation*, 92(10), 1602–1610. <https://doi.org/10.1016/j.apmr.2011.05.004>
- Howe, T. J. (2008). The ICF contextual factors related to speech-language pathology. *International Journal of Speech-Language Pathology*, 19(1–2), 27–37. <https://doi.org/10.1080/14417040701774824>
- Hoyle, M. F., Gustafsson, L. A., Meredith, P. J., & Ownsworth, T. (2012). Participation after stroke: Do we understand all the components and relationships as categorised in the ICF? *Brain Impairment*, 13(1), 4–15. <https://doi.org/10.1017/BrImp.2012.9>
- Hunter, J. J., & Maunder, R. G. (2001). Using attachment theory to understand illness behavior. *General Hospital Psychiatry*, 23, 177–182. [https://doi.org/10.1016/s0163-8343\(01\)00141-4](https://doi.org/10.1016/s0163-8343(01)00141-4)
- Kuipers, P., Kendall, M., Fleming, J., & Tate, R. (2004). Comparison of the Sydney Psychosocial Reintegration Scale (SPRS) with the Community Integration Questionnaire (CIQ): Psychometric properties. *Brain Injury*, 18(2), 161–177. <https://doi.org/10.1080/0269905031000149524>
- Kwon, S., Duncan, P. W., Studenski, S., Perera, S., Lai, S. M., & Reker, D. (2006). Measuring stroke impact with SIS: Construct validity of SIS telephone administration. *Quality of Life Research*, 15(3), 367–376. <https://doi.org/10.1007/s11136-005-2292-2>
- Lakshminarayan, K., Berger, A. K., Fuller, C. C., Jacobs, D. R., Anderson, D. C., Steffen, L. M., . . . Luepker, R. V. (2014). Trends in 10-year survival of patients with stroke hospitalized between 1980 and 2000. *Stroke*, 45, 2575–2581. <https://doi.org/10.1161/STROKEAHA.114.005512>
- Lapadatu, I., & Morris, R. (2019). The relationship between stroke survivors' perceived identity and mood, self-esteem and quality of life. *Neuropsychological Rehabilitation*, 29(2), 199–213. <https://doi.org/10.1080/09602011.2016.1272468>
- Lin, K. C., Fu, T., Wu, C. Y., Hsieh, Y. W., Chen, C. L., & Lee, P. C. (2010). Psychometric comparisons of the stroke impact scale 3.0 and stroke-specific quality of life scale. *Quality of Life Research*, 19(3), 435–443. <https://doi.org/10.1007/s11136-010-9597-5>
- Maunder, R. G., & Hunter, J. J. (2001). Attachment and psychosomatic medicine: Developmental contributions to stress and disease. *Psychosomatic Medicine*, 63, 556–567. <https://doi.org/10.1097/00006842-200107000-00006>
- Meredith, P., Ownsworth, T., & Strong, J. (2008). A review of the evidence linking adult attachment theory and chronic pain: Presenting a conceptual model. *Clinical Psychology Review*, 28(3), 407–429. <https://doi.org/10.1016/j.cpr.2007.07.009>
- Meredith, P. J., Strong, J., & Feeney, J. A. (2005). Evidence of a relationship between adult attachment variables and appraisals of chronic pain. *Pain Research and Management*, 10(4), 191–200. <https://doi.org/10.1155/2005/745650>
- Mikulincer, M. (1995). Attachment style and the mental representation of the self. *Journal of Personality and Social Psychology*, 69(6), 1203–1215. <https://doi.org/10.1037/0022-3514.69.6.1203>
- Norlander, A., Iwarsson, S., Jönsson, A.-C., Lindgren, A., & Måsson Lexell, E. (2018). Living and ageing with stroke: An exploration of conditions influencing participation in social and leisure activities over 15 years. *Brain Injury*, 32(7), 858–866. <https://doi.org/10.1080/02699052.2018.1463561>
- Ownsworth, T. (2014). *Self-identify after brain injury - Neuropsychological rehabilitation: A modular handbook*. London, UK: Psychology Press and Taylor & Francis Group.
- Palstam, A., Sjödin, A., & Stibrant Sunnerhagen, K. (2019). Participation and autonomy five years after stroke: A longitudinal observational study. *PLoS One*, 14(7), 1–13. <https://doi.org/10.1371/journal.pone.0219513>
- Peacock, E. J., & Wong, P. T. P. (1990). The Stress Appraisal Measure (SAM): A multidimensional approach to cognitive appraisal. *Stress Medicine*, 6, 227–236. <https://doi.org/10.1002/smi.2460060308>
- Pohjasvaara, T., Vataja, R., Leppävuori, A., Kaste, M., & Erkinjuntti, T. (2001). Depression is an independent predictor of poor long-term functional outcome post-stroke. *European Journal of Neurology*, 8(4), 315–319. <https://doi.org/10.1046/j.1468-1331.2001.00182.x>
- Ramanathan, D. M., Wardecker, B. M., Slocomb, J. E., & Hillary, F. G. (2011). Dispositional optimism and outcome following traumatic brain injury. *Brain Injury*, 25(4), 328–337. <https://doi.org/10.3109/02699052.2011.554336>
- Reddy, A., Ownsworth, T., King, J., & Shields, C. (2015). A biopsychosocial investigation of changes in self-concept on the Head Injury Semantic Differential Scale. *Neuropsychological Rehabilitation*, 27(8), 1103–1123. <https://doi.org/10.1080/09602011.2015.1114499>
- Riley, G. A., Brennan, A. J., & Powell, T. (2004). Threat appraisal and avoidance after traumatic brain injury: Why and how often are activities avoided? *Brain Injury*, 18(9), 871–888. <https://doi.org/10.1080/02699050410001671829>

- Rochette, A., Bravo, G., Desrosiers, J., St-Cyr Tribble, D., & Bourget, A. (2007). Adaptation process, participation and depression over six months in first-stroke individuals and spouses. *Clinical Rehabilitation*, 21(6), 554–562. <https://doi.org/10.1177/0269215507073490>
- Rochette, A., Desrosiers, J., Bravo, G., St-Cyr-Tribble, D., & Bourget, A. (2007). Changes in participation after a mild stroke: Quantitative and qualitative perspectives. *Topics in Stroke Rehabilitation*, 14(3), 59–68. <https://doi.org/10.1310/tsr1403-59>
- Salter, K., Foley, N., Jutai, J., Bayley, & Teasell, R. (2008). Assessment of community integration following traumatic brain injury. *Brain Injury*, 22(11), 820–835. <https://doi.org/10.1080/02699050802425428>
- Scharfe, E., & Bartholomew, K. (1994). Reliability and stability of adult attachment patterns. *Personal Relationships*, 1(1), 23–43. <https://doi.org/10.1111/j.1475-6811.1994.tb00053.x>
- Scheier, M. F., & Carver, C. S. (1985). Optimism, coping and health: Assessment and implications of generalized outcome expectancies. *Health Psychology*, 4(3), 219–247. <https://doi.org/10.1037//0278-6133.4.3.219>
- Scheier, M. F., Carver, C. S., & Bridges, M. W. (1994). Distinguishing optimism from neuroticism (and trait anxiety, self-mastery, and self esteem): A reevaluation of the life orientation test. *Journal of Personality and Social Psychology*, 67(6), 1063–1078. <https://doi.org/10.1037/0022-3514.67.6.1063>
- Schmid, A. A., Damush, T., Tu, W., Bakas, T., Kroenke, K., Hendrie, H. C., & Williams, L. S. (2012). Depression improvement is related to social role functioning after stroke. *Archives of Physical Medicine and Rehabilitation*, 93(6), 978–982. <https://doi.org/10.1016/j.apmr.2011.12.012>
- Schmidt, S., Nachtigall, C., Wuethrich-Martone, O., & Strauss, B. (2002). Attachment and coping with chronic disease. *Journal of Psychomatic Research*, 53, 763–773. [https://doi.org/10.1016/S0022-3999\(02\)00335-5](https://doi.org/10.1016/S0022-3999(02)00335-5)
- Shifren, K., & Anzaldi, K. (2018). Optimism, well-being, depressive symptoms, and perceived physical health: A study among stroke survivors. *Psychology, Health & Medicine*, 23(1), 46–57. <https://doi.org/10.1080/13548506.2017.1325505>
- Strauss, B., & Brenk-Franz, K. (2016). The relevance of attachment theory in medical care. In J. Hunter & R. Maunder (Eds.), *Improving patient treatment with attachment theory: A guide for primary care practitioners and specialists* (pp. 39–52): Springer International Publishing. [https://doi.org/10.1007/978-3-319-23300-0\\_4](https://doi.org/10.1007/978-3-319-23300-0_4)
- Tse, T., Douglas, J., Lentin, P., & Carey, L. (2013). Measuring participation after stroke: A review of frequently used tools. *Archives of Physical Medicine and Rehabilitation*, 94(1), 177–192. <https://doi.org/10.1016/j.apmr.2012.09.002>
- Tse, T., Lentin, P., Douglas, J., & Carey, L. M. (2020). Understanding activity participation 3-months after stroke: A mixed methodology study. *Disability and Rehabilitation*, 22, 1–11. <https://doi.org/10.1080/09638288.2020.1849429>
- Turner-Cobb, J. M., Gore-Felton, C., Marouf, F., Koopman, C., Kim, P., Israelski, D., & Spiegel, D. (2002). Coping, social support, and attachment style as psychosocial correlates of adjustment in men and women with HIV/AIDS. *Journal of Behavioral Medicine*, 25(4), 337–353. <https://doi.org/10.1023/a:1015814431481>
- Tyerman, A. (1997). *Head Injury Semantic Differential III*. Aylesbury, Buckinghamshire, UK: Community Head Injury Service.
- Tyerman, A. (2008). Facilitating psychological adjustment. In A. Tyerman & N. S. King (Eds.), *Psychological approaches to rehabilitation after traumatic brain injury* (pp. 320–348): Blackwell Publishing Ltd. <https://doi.org/10.1002/9781444301762.ch13>
- Whiteneck, G. G. (2006). Conceptual models of disability: Past, present, and future. In M. Field, A. Jette, & L. Martin (Eds.), *Workshop on disability in America: A new look summary and background papers* (pp. 50–66). Washington, DC: Academies Press.
- Whiteneck, G. G. (2010). Issues affecting the selection of participation measurement in outcomes research and clinical trials. *Archives of Physical Medicine and Rehabilitation*, 91(9), S54–S59. <https://doi.org/10.1016/j.apmr.2009.08.154>
- Willer, B., Ottenbacher, K. J., & Coad, M. L. (1994). The Community Integration Questionnaire: A comparative examination. *American Journal of Physical Medicine and Rehabilitation*, 73, 103–111. <https://doi.org/10.1097/00002060-199404000-00006>
- Willer, B., Rosenthal, M., Kreutzer, J. S., Gordon, W. A., & Rempel, R. (1993). Assessment of community integration following rehabilitation for traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 8(2), 75–87. <https://doi.org/10.1097/00001199-199308020-00009>
- Wolf, T., & Koster, J. (2013). Perceived recovery as a predictor of physical activity participation after mild stroke. *Disability and Rehabilitation*, 35(14), 1143–1149. <https://doi.org/10.3109/09638288.2012.720635>
- World Health Organization. (2001). *ICF: International classification of functioning, disability and health*. Geneva, Switzerland: World Health Organization.

---

**Cite this article:** Hoyle M, Meredith P, Ownsworth T, Khan A, and Gustafsson L (2023). Associations between participation and personal factors in community-dwelling adults post-stroke. *Brain Impairment* 24, 456–473. <https://doi.org/10.1017/BrImp.2022.31>