Factors associated with participation in life situations for adults with stroke: a systematic review.

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Keywords stroke, community participation, social support, activities of daily living, depression, cognitive dysfunctions, and chronic disease.

Abstract

Objectives: To identify biopsychosocial factors associated with participation outcomes for adults with stroke and to investigate factors associated with participation at different time points post stroke.

Data sources: Medline, CINAHL, AMED, PyschINFO and Web of Science were systematically searched using key words "stroke", "participation" and "outcomes" and their synonyms on 15th May 2017.

Study selection: Observational studies reporting on biopsychosocial factors and participation outcomes for community dwelling adults with stroke were selected. Studies were eligible for inclusion if participation outcomes were measured using indices that mapped to the participation domain of the ICF. Intervention studies were excluded. A second reviewer checked all studies against eligibility criteria at each stage.

Data extraction: Data were extracted on any statistically determined association between biopsychosocial factors and participation outcomes.

Data synthesis: The proportion of studies reporting significant associations with variables were classified according to the ICF. The exact binomial test was used to determine the probability that the proportion of studies reporting significant associations was due to chance alone. Qualitative descriptive summaries of each study allowed consideration of interactions between variables and changes in participation over time points.

Conclusions: Whilst depressive symptoms, cognitive functioning and mobility were found to have the strongest associations with participation, we found that other frequently occurring factors (such as fatigue and environmental factors) were less extensively considered. The diversity of outcome measures encountered within the review highlight the need for a consensus on a core set of outcome measures to evaluate long term participation in life situations after stroke.

Keywords: stroke, participation

Abbreviations: International classification of functioning (ICF). Cumulative Index of Nursing and Allied Health Literature (CINAHL), Allied and Complimentary Medicine Database (AMED).

Introduction

Advances in the prevention and management of stroke mean that more people are surviving and living with the long-term consequences of stroke[1]. Moreover, the number of people experiencing stroke at a younger age is increasing[2, 3] resulting in a considerable lifetime impact of stroke,

particularly around productivity and work[4]. These changes have been described as an epidemiological shift towards stroke becoming a long-term health condition[5].

There is considerable evidence that those surviving stroke experience difficulties retaining previous levels of participation in social, community, work and leisure activities[3]. Personal, environmental and stroke related factors have been reported as potential barriers to resuming participation in life roles one year after stroke[6]. The resulting restrictions in social and community participation are strongly associated with lower quality of life[7] .

Many overlapping terms are used to describe social and community participation [8]. The International Classification of Functioning (ICF) provides a taxonomy of activities and participation: where activities reflect performance at an individual level and participation in life situations reflects performance at a societal level[9-11]. For the purpose of this review, participation was operationalized using the ICF chapters 6 (domestic life), 7 (interpersonal interactions and relationships),8 (major life areas) 9 (community social and civic life)[12] [13].

Participation in life situations is potentially modifiable even when there is no further recovery in body functions and is therefore an important concept to consider for those living with long term health conditions[14]. Considering that participation in life situations is an important outcome of stroke rehabilitation,[15] there is surprisingly limited evidence of effective interventions for reducing participation restrictions in the longer term[3, 16, 17].There is considerable literature investigating factors associated with participation after stroke, but this hasn't sufficiently informed the use of participation measures within intervention studies and participation outcomes remain underutilised [18 19, 20]. Synthesis of the available evidence could inform the

development of more comprehensive approaches to improve participation outcomes for stroke survivors. Therefore, the aims of this study are:

- to identify biopsychosocial factors associated with or determining participation outcomes for adults with stroke
- to investigate associations with participation at different time points post stroke.

Methods

Search strategy and Selection criteria. This systematic review was registered with PROSPERO[21] and is reported following PRISMA guidelines[22].

We searched for and included studies involving stroke patients that met the following criteria:

- community dwelling stroke survivors (all strokes) aged 18 and over. Studies with mixed populations were included if 90% of participants had stroke
- observational studies
- investigated biopsychosocial factors associated with participation outcomes
- written in English.

Intervention studies were excluded.

We searched Medline, CINAHL, AMED, Psych INFO and Web of Science on 1st January 2015 (updated on 17th May 2017). The literature search was not limited by date; results dated back to 1946. We used keywords 'stroke', 'participation', 'measures' and their associated synonyms and terms (please see supplementary appendix I). We hand searched three most cited journals from our eligible studies between May 2016 and May 2017. Additional studies were located through reference lists of eligible studies.

The primary outcome of interest was participation in life situations. An initial list of measures relevant to stroke was collated from literature that had evaluated psychometric properties and mapped participation instruments to the ICF [23-26] .

Two reviewers then independently mapped the content of each measure to chapters six to nine of the activity and participation domain of the ICF (domestic life, interpersonal interactions and relationships, major life areas, community social and civic life). Learning and applying knowledge, general tasks and demands, communication, self-care and mobility were not included [27]. This was to ensure that participation was the primary focus of each measure. Participation outcomes were included if fifty percent or more of the questions in the measure mapped to chapters six to nine. Differences in reviewers' assessments were discussed until agreement was reached.

A total of 24 measures were reviewed and 14 were eligible for inclusion (table 1). Interrater agreement was very good (Cohens kappa 0.81, 95% CI. 0.47-0.69). All included measures were standardized questionnaires. It is beyond the scope of this review to report on psychometric properties.

Study selection process. Figure 1 summarises the selection process. A second reviewer (LF) independently reviewed all studies against eligibility criteria at each stage. Any disagreements were resolved through discussion between reviewers. Agreement was assessed using Cohen's kappa. Inter-rater agreement of eligibility by abstracts was moderate (kappa 0.65, 95% CI.,0.58 to 0.73) [28]. Inter-rater agreement of eligibility by full text was also moderate (kappa 0.58 95% CI. 0.47 to 0.69).

Data extraction. Data were extracted on any statistically determined association between participation outcomes and biopsychosocial variables under study. Where studies were reported in more than one paper, data was extracted, pooled and treated as one study.

Risk of bias in individual studies. Risk of bias was assessed using the Quality Assessment Tool for Observational and Cross-sectional studies[29,30]. The tool provides a rating for low, fair or high risk of bias. A second researcher reviewed (LP) ten per cent of the risk of bias assessments, interrater agreement of risk of bias was moderate (kappa 0.56, 95% CI 0.02-1). Risk of bias assessments informed the interpretation of our findings, particularly where studies reported anomalous results.

Analysis. Variables investigated were grouped (by LE) according to the ICF classification[31]: contextual factors (personal or environmental factors), health condition (type of stroke, time since stroke), stroke related impairments in body functions and structures (e.g. cognitive deficits, movement deficits) and activity limitations (i.e. limitations in mobility or in daily activities)[9]. For example, Fugl Meyer assessment of lower limb function was labelled as "control of voluntary movement" from the ICF chapter "neuromusculoskeletal and movement functions", whereas the six-meter timed walk test was labelled as "walking and moving" from the ICF chapter "mobility". As the presence of depressive symptoms was determined by depression scales, it was mapped to "emotional functions" within the ICF chapter "mental functions", rather than assuming the presence of depression as a health condition[31].

For each study, we determined which factors had a significant association ($p< 0.05$) with participation outcomes. In longitudinal studies with multiple data time points, we counted each association once. We then used an exact binomial test to calculate the probability that the

observed proportion of studies reporting associations deviated from the expected proportion by chance alone (assuming that there was no association and no publication bias) [32,33]. The expected proportion of studies finding an association with $p<0.05$, would be 0.05[34]. We also determined whether studies were adequately powered to detect a weak association (correlation of 0.2), alpha at 0.05 (two tailed), and power of 0.8. Factors which were investigated once only were not included in the binomial test analysis (please see supplementary appendix IV).

Descriptive summaries of the results of each study were coded and analyzed for evidence of interactions between biopsychosocial factors within each study [35]. Findings from cohort studies were summarized by time points to provide a descriptive summary of how factors associated with participation outcomes changed over time.

Results

In total, 92 papers (reporting on 81 studies) were eligible for inclusion (figure 1).

Study Characteristics. Thirty-three of the studies in the review were cross-sectional and collected data from participants who were from three months to 31 years post stroke. Forty-two were prospective cohort studies and seven were retrospective cohort studies. Of the cohort studies, 11 studies assessed participants' outcomes at multiple time points, ranging from three months [36] to six years post stroke [37]. The total number of study participants was 11,815. Studies included people from 18 to 99 years old and stroke severity from minor to severe, residing at home or in a care facility (please see supplementary appendix II). Fourteen participation measures assessed aspects of participation in life situations (table 1). Studies employed a range of statistical analyses including correlation, univariate and regression analysis.

145 **Table 1**: Outcomes measures mapped to Activity Participation domain of ICF.

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Outcome measures	**Activity and Participation chapters ICF**								
	Learning & knowledge	General tasks	Communication	Mobility	Self- care	Domestic life	Interpersonal relationships	Major life areas	Community, social and civic life
Activity Card Sort (ACS)[*1]	✓		✓	✓	✓	✓	✓	✓	✓
Community Integration questionnaire [2]		✓		✓		✓	✓	✓	✓
Frenchay Activities Index [3]				✓		✓		✓	✓
IMPACT-S (participation subscale)[4]					✓	✓	✓	✓	✓
Impact on Participation &Autonomy Questionnaire (IPAQ)[5]					✓	✓	✓	✓	✓
LIFE-H (assessment of life habits) [6]			✓	✓	✓	✓	✓	✓	✓
London Handicap Scale[7]			✓	✓	✓	✓	✓	✓	✓
PAR- Pro [8]				✓		✓	✓	✓	✓
Re-integration to normal living index [9]							✓	✓	✓
Short Form 36 (social role functioning subscale only) [10]									✓
Sickness Impact Profile			✓	✓	✓				

(psychosocial subscale only) [11]									
Stroke Impact Scale (social subscale) [12]						✓	✓	✓	✓

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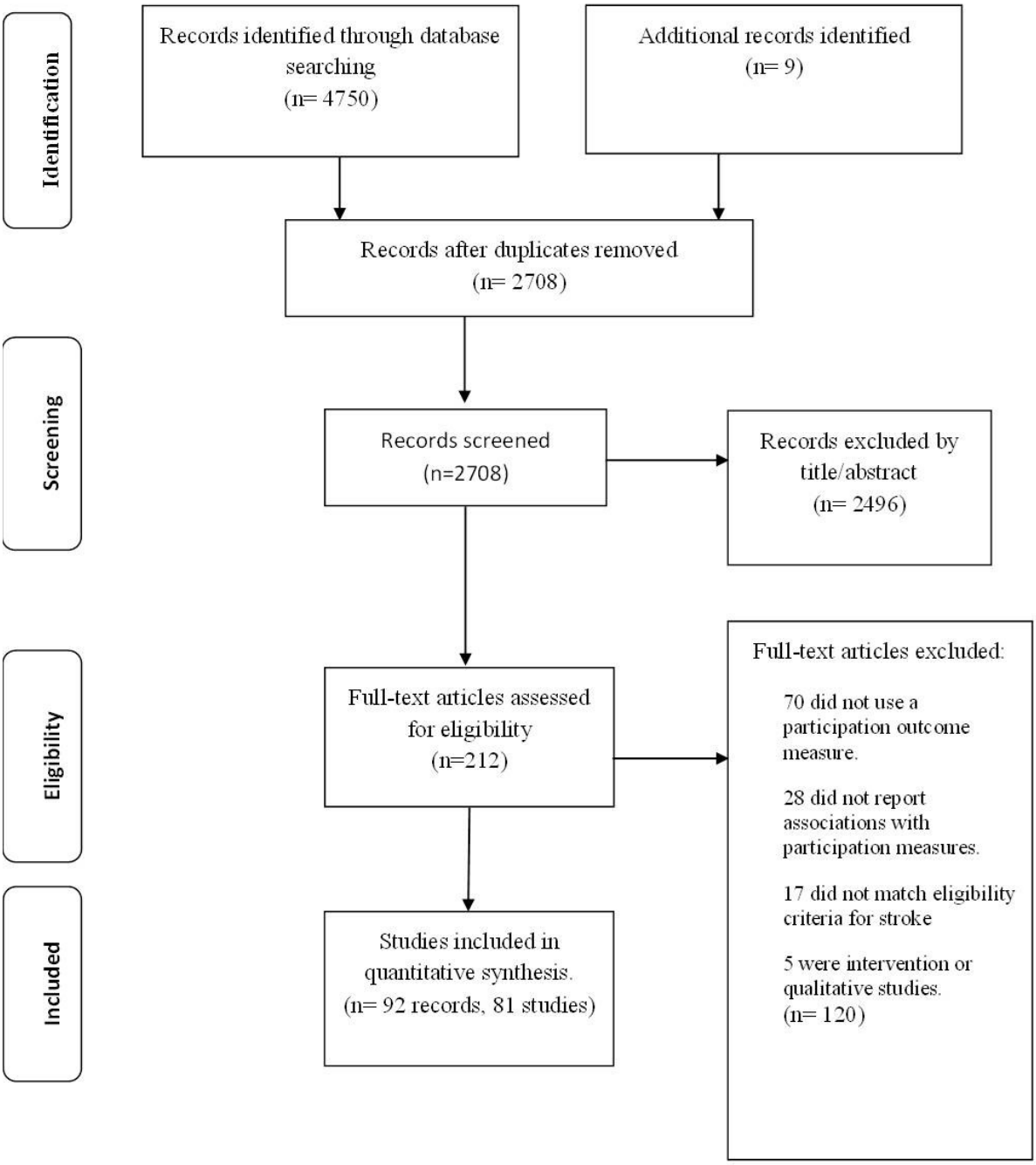
Figure 1: PRISMA 2009 Flow Diagram [21]



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Analysis of factors associated with participation outcomes. Participation outcomes were associated with sociodemographic factors, health conditions, body function impairments and activity limitations (please see supplementary appendix III). Type of stroke was the only factor where the proportion of studies finding associations with participation was likely to be a chance occurrence. The direction of the associations was mostly consistent across the studies with sex being the only exception. Poorer participation outcomes were associated with older age, increased stroke severity, more comorbidity, greater degree of stroke related impairment and more activity limitations (Table 2).

Table 2: Results of exact binomial test.

Associations with biopsychosocial factors and participation in all studies compared to those found in sufficiently powered studies (n>194 for a correlation size of 0.2). Effect sizes are categorised by Cohens rule of thumb were d = 0.2 small, 0.5 medium, 0.8 large or r <0.3 small, 0.31<r>0.5 medium, r>0.5 large[15]. NR (not reported).

	Total number of studies.	**No. of studies with a significant association**	**Binomial test, significance at p< 0.05**	**Association found in (n) studies with sufficient power*.**	**Effect size**	**No association found in (n)studies with sufficient power**	**Effect size**
Contextual Factors							
Age	58	33	**p<0.001**	9	small – medium.	3	small
Sex	35	10	**p<0.001**	2	small	2	NR
years of education	22	8	**p<0.001**	3	small	3	Small
Employment	9	3	**p =0.001**	2	small	0	
Social support	7	4	**p<0.001**	0		0	
Health condition							
comorbidities	11	7	**p<0.001**	2	small	2	small
Type of stroke (haemorrhagic or ischemic)	14	2	p=0.12	2	small	2	NR
Stroke severity	22	21	**p<0.001**	7	medium-large	2	NR

	Total number of studies.	No. of studies with a significant association	Binomial test, significance at p< 0.05	Association found in (n) studies with sufficient power*.	Effect size	No association found in (n)studies with sufficient power	Effect size
Number of strokes	5	3	**p=0.001**	3	small-large	1	NR
Time since stroke	13	4	**p=0.003**	0		1	NR
Body functions.							
Impairment in movement related functions	14	14	**p<0.001**	3	small-large	0	
Involuntary movement reaction functions: balance	6	6	**p<0.001**	0		0	
Impairment in movement related functions: arm	7	5	**p<0.001**	1	NR	1	NR
Impairment in specific mental functions (cognition)	30	24	**p<0.001**	6	medium-large	2	NR

Contextual Factors. Older age was associated with worse participation outcomes. Whilst there was inconsistency in study results, we found a small effect size for associations between age and participation in sufficiently powered studies with a fair to low risk of bias.

Associations between sex and participation outcomes were also inconsistent. Ten studies reported significant associations, with women being at greater risk of poor participation outcomes than men. However, the effect size was small (r =0.1 -0.27)[38, 39] and two adequately powered studies found no association between the persons sex and participation[40, 41]. One study reported better participation outcomes for women[42] and one study reported a differential effect of marriage on participation according to sex[43].

Four studies found positive associations between social support and participation. These studies were underpowered but nevertheless reported small to medium effect sizes (r= 0.21- 0.41)[44, 45].

Stroke factors. Stroke severity and increased number of comorbidities were consistently, and moderately associated with worse participation outcomes. The type of stroke (ischemic or hemorrhagic) was not found to be associated.

Stroke related impairments. Cognitive functioning and presence of depressive symptoms were the factors most frequently investigated. Most studies investigating depressive symptoms found significant associations with participation outcomes; the effect size range from small to large. One sufficiently powered study did not find an association with depressive symptoms (as measured by the Centre for Epidemiological studies depression scale[46]) but did find a significant association between positive affect and better participation outcomes.[47] Depressive symptoms were determined through the administration of depressions scales (for example Geriatric Depression scale[46, 48]); mean scores on the depression scales reflected the presence of mild depressive symptoms with only two studies reporting mean scores indicating moderate to severe depression [49, 50].

Cognitive functioning was determined through cognitive screening tools and assessment of specific cognitive functions. Most studies found significant relationships of impaired cognitive functions with participation, with effect sizes ranging from small to large.

Movement related functions and balance were consistently associated with poorer participation outcomes. Associations between hand and arm function and participation tended to be weaker than associations with impaired lower limb function or balance.

Nine out of ten studies reported significant associations between aphasia and participation outcomes. Effect sizes range from small to large.

Fatigue and pain were less frequently investigated but were consistently significantly associated with poorer participation outcomes.

Activity limitations. Limitations in activities of daily living and mobility were strongly associated with poor participation with studies reporting medium to large effect sizes. Only one investigated frequency of falls and found a moderate association between participation outcomes and the number of falls or fear of falling[51].

Factors associated with participation at different time points post stroke.

Participation scores for most stroke survivors were stable at one year or more post stroke [52,53, 54]. There seems to be improvement in participation outcomes when comparing mean participation scores at three months to six months[55] but little variation in participation scores overall from 1 year on[, 52, 53,56, 57, 58] . However, this does not reflect changes in participation at an individual level. Jansen et al[57] found that participation deteriorated in 11% and increased for 12% of participants. Lo et al [40] found that 17.8% of participant's participation scores deteriorated from three months to one-year post stroke. Egan[42] found improvement in participation scores over time but only for participants with higher incomes. Older age was associated with deterioration in participation[40] [37]. Nevertheless, participation outcomes remained significantly different from matched controls[59] [60] and poor participation outcomes at one year were strongly associated with poor outcomes three years post stroke [57].

214 **Table 3:** Biopsychosocial factors associated with participation outcomes at different time points
215 in longitudinal studies.

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Factors associated with participation at time points post stroke					
	<3 months	**4-6months**	**7-11 months**	**12-23 months**	**>24 months**
Clarke et al (1999)[16]	Stroke severity, depressive symptoms, cognition, limitations in adls			Stroke severity, depressive symptoms, cognition, limitations in adls, sex	
Egan et al (2015)[17]		Mobility, female, low income	Mobility, female, low income, emotional well being	Mobility, female, emotional well being	Female, emotional well being
Harwood et al (1997)[18]				Depressive symptoms, stroke severity, limitations in adls, age, sex	Depressive symptoms, stroke severity, limitations in adls,
Mercer et al (2009)[19]	Motor function	Not significant			
Patel & Tilling (2006)[20]				Depressive symptoms, mobility, pain	Depressive symptoms, mobility, energy functions
Sturm et al (2002)[21]	Limitations in adls			Limitations in adls	
Tse et al (2017b)[22]	Limitations in adls, cognition, depressions, mobility	Limitations in adls.			

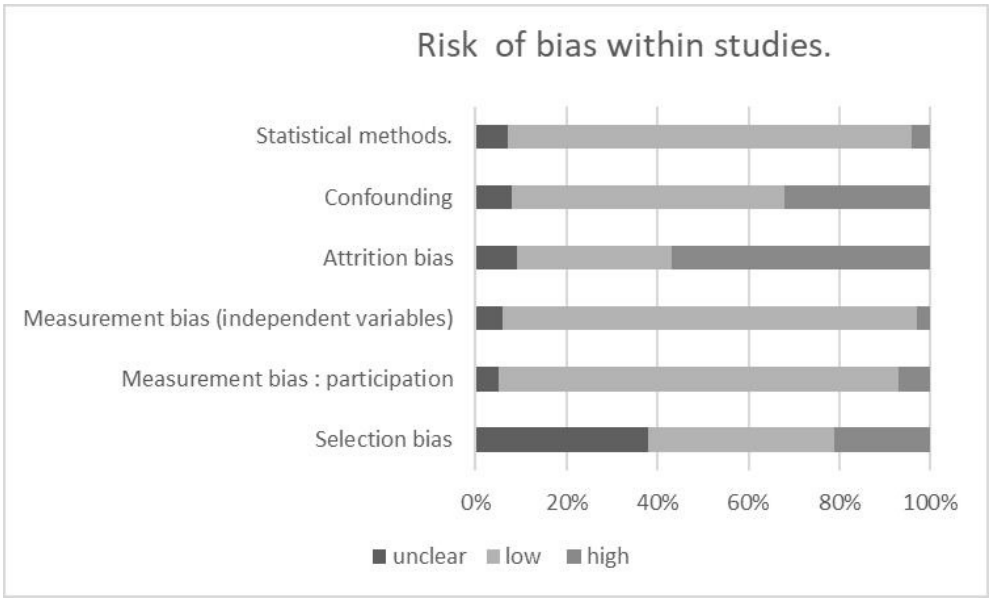
Seven studies compared biopsychosocial factors associated at different time points after stroke (time points from three months to three years). No single factor was consistently associated with participation at all time points (table 3).

Descriptive analysis findings. From the narrative descriptive analysis, the presence of cognitive impairments was reported as an independent predictor of participation but was also found to predict depression and were associated with limitations in activities of daily living [52, 61, 62].

Four studies reported associations with subdomains of participation and found depression to be strongly associated with social functioning domains[60, 63]. One study found that participation outcomes at six months post stroke predicted emotional wellbeing up to two years post stroke[64].

Risk of bias within studies. Forty-six studies were assessed as being low to fair for risk of bias, 35 as high risk of bias and 11 studies where risk of bias was unclear. The main sources of bias were selection bias and attrition bias (figure 2). Death and deterioration in health were the main causes of attrition in longitudinal studies with 57 % of studies losing 20% or more participants.[30]

Figure 2: Percentage of studies with risk of bias for each domain.



Discussion

To our knowledge, this is the first comprehensive synthesis of research exploring factors associated with participation outcomes after stroke. We found that participation in life situations was associated with a wide range of biopsychosocial factors and remained limited in the longer term after stroke with most improvement occurring in the first six months. Furthermore, this review exposes that associations between participation outcomes and factors other than body functions are rarely considered.

The initial gains in participation after stroke maybe explained by the recovery of body functions but we found that participation outcomes stabilised for most stroke survivors after six months post stroke [52, 53, 56 57, 58.]This finding is explained by qualitative literature on life after stroke. Wood et al[65] reveals how stroke survivors adjust their lives to match changes in their abilities once their recovery from stroke has slowed. Furthermore, Salter [66] describes a process of relinquishing roles

and meaningful activities because of a loss of ability and this is likely to be reflected in participation outcomes. However, the relative stability of participation from one-year post stroke could also be affected by long term stroke survivors being younger with less severe stroke [56] . Over half of the cohort studies in this review were at risk of attrition bias, with death and worsening health being cited as the main reasons for high attrition rates.

The ICF framework explains participation as arising from the dynamic, non-linear and multiple interactions between health conditions, the person and their given context[14]. Hence the wide range of biopsychosocial associated with changes in participation after stroke found in this review are illustrative of the ICF framework and suggest the need for an interactionist perspective to intervention studies[67]. Further research is needed to investigate how participation outcomes are influenced by the interrelationships of factors, rather than by any one single factor.

The studies included in the review tended to reflect a biomedical focus with relatively few studies investigating environmental factors. Nevertheless, we found social support to be positively associated with participation after stroke. Other studies have found satisfactory social support to be protective of well-being and health related quality of life [68] and may enable successful return to social and community activities[6]. We propose that knowledge of social support, along with considering the presence of other factors such older age and comorbidities helps to identify those at greater risk of poor participation outcomes.

There was insufficient evidence to draw conclusions about associations between other environmental factors and participation considered in the review: for example, type of residence, whether the person lives alone, quality of physical and social environments and societal attitudes. This may reflect a historical focus on recovery of body functions and personal care activities

within stroke research, as well as the difficulties encountered in developing meaningful and reliable measures of environmental factors[3,69]. Further research utilising validated environmental measures is needed to develop our understanding of how the environment enables or restricts stroke survivors' participation.

Of the other contextual factors investigated, we found age and sex are most likely to be associated with participation. In line with others findings,[70,71] we found that participation outcomes for older stroke survivors were worse than those for sociodemographic and comorbidity matched peers.[59] The relationship between age and participation is complex, with older people experiencing more comorbidities and activity limitations prior to their stroke, as well increased likelihood of severe stroke[72]. Whilst, sex was less consistently associated with participation amongst studies, there was a small effect size for women to experience worse participation outcomes than men. However, Dehelendorf[73] found that women experience more severe stroke and have better survival rates than men, thus explaining this finding.

All the investigated impairments in body functions were associated with participation, with depressive symptoms and cognitive impairment being most frequently investigated and consistently associated. It is probable that there are confounding relationships between different body function impairments, however the narrow focus of studies in the review and the statistical methods employed meant is was not possible for us to explore confounding relationships between different stroke related impairments. Indeed, the studies within the review tended to reflect a split between more physically focused factors and those related to cognition and mood. Only four studies within the review considered problems with movement functions as well as depression and cognitive functioning[44, 63, 74, 75].

Limitations in mobility, self-care and activity were consistently associated with poor participation outcomes. This may be due in part to overlapping constructs within activity and participation measures. We minimised this by including only participation measures with a focus on domestic, social and community life. However, the strong associations between mobility, activity limitations and participation outcomes may also indicate a potential area amenable to interventions focused on adaptation and modifications of environmental factors and activities. Participation is theoretically modifiable and achievable even in the presence of disability[76].

The review also identified factors that are likely influential but underrepresented in the literature. For example, fatigue is highly prevalent after stroke (incidence of fatigue has been reported as between 35% and 92% [77]), yet was investigated by only six studies within this review.

Measuring participation outcomes.

Defining and measuring participation continues to be problematic with a lack of consensus as to the operationalisation of participation [15] and blurring of participation and activity within the ICF[78] . Older participation measures frequently include constructs outside of the activity and participation domain as they are not underpinned by the ICF framework[24]. Furthermore, measures included in this review captured different aspects of participation such as participation restriction, frequency or satisfaction[79]. The included measures all relied on self- report which compounds issues of unreliability[15] and is particularly problematic for this group because of the frequency of language, vision and cognitive deficits.

As a result of these issues, we have been cautious in our interpretation of the reviews results, particularly where findings are less consistent across the studies or where factors have been

311 infrequently investigated. However, we suggest that factors such as depressive symptoms,
312 cognitive functioning and limitations in mobility (which were frequently investigated and found
313 to have strong associations with participation outcomes) are likely to be associated with poor
314 participation outcomes. Further research is needed to explore potential causative relationships
315 between these factors and participation.

316 Participation in life situations is widely recognised as an important outcome of stroke
317 rehabilitation yet participation outcomes remain underutilised in intervention studies[18,19, 20].
318 Whilst the measurement of participation outcomes remains limited, we would urge more routine
319 and judicious use of participation outcome measures in intervention studies and suggest wider
320 use of the ICF to develop causative explanatory models, thereby enabling a better fit between
321 research aims, concepts of participation and measurement of outcomes.

322 Thus, whilst a consensus is needed on a core set of outcome measures after stroke, our findings
323 do not support a focus only measuring participation at 90 days post stroke as recently proposed[81].

324
325 ***Limitations.*** The broad scope of this review is both a strength and a limitation. Whilst primary
326 research has focused on selected key areas, this review enabled examination of a wide range of
327 factors to explore associations and potential risks for poor participation after stroke.

328 Interrater agreements for eligibility and risk of bias judgements were moderate and reflect the
329 diversity of methodologies and participation outcome measures used by studies included in the
330 review. However, differences between two reviewers were resolved through discussion without
331 need for recourse.

Nevertheless, the heterogeneity of participation measures and inconsistency in the reporting of statistical findings meant meta-analysis was not viable. Therefore we determined proportions of studies with significant associations[32]. This approach is limited as it gives higher relative weighting to small studies and does not account for publication bias[32]. Consequently, we reported the number of insufficiently powered studies to aid interpretation.

Selection and attrition bias means that the studies in this review reflects outcomes for those with mild to moderate stroke. Further targeted research is needed to establish participation outcomes and restrictions for those living with more severe stroke and disability.

Problems with defining and operationalising participation in life situations are well-documented[15, 82] and the lack of a clear delineation between activity and participation has already been discussed. Furthermore, the psychometric properties of commonly used participation measures within stroke research are limited[80] thereby introducing measurement bias in our findings.

We examined associations between biopsychosocial factors and participation outcomes with the participation measures reflecting different aspects of participation. Hence, we viewed participation outcomes in the broadest terms and did not delineate between satisfaction with participation or restrictions in participation.

Conclusion

In summary, our findings suggest that there are multiple factors impacting on participation outcomes and underscore that stroke survivors may experience participation restrictions long term, particularly when they have impairments across a range of body functions. As such,

interventions to improve participation outcomes should be person centred, deliver gains across a range of body functions and focus on the resolution of community participation restrictions[17].

This review identified that older people with more severe stroke and stroke related impairments are most at risk of poor participation. There is little change in participation outcomes from one-year post stroke for most stroke survivors and variability as to the factors associated with participation at different time points after stroke. The presence of depressive symptoms, problems in cognitive functioning, mobility and activity limitations were most frequently and consistently associated with poor participation outcome but how these factors impact on participation remains unclear and is inconsistent over time since stroke. The results of this review also reflect a biomedical focus of research in this area and we suggest further research is needed to understand the potential role of environmental factors in mitigating poor participation outcomes.

The considerable variability in how participation is operationalized is a barrier to measuring this important outcome after stroke interventions. With this in mind, a consensus is needed on defining and measuring participation outcomes relevant to stroke survivors, along with wider use of participation outcomes in research to build a body of evidence for effective interventions.

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References

1. Lakshminarayan K, Berger A, Fuller C, Jacobs DJ, Anderson D, Steffen L et al. Trends in 10-year survival of patients with stroke hospitalized between 1980 and 2000: the Minnesota stroke survey. Stroke 2014;45(9):2575-81.
2. Bejot Y, Daubail B, Jacquin A, Durier J, Osseby GV, Rouaud O et al. Trends in the incidence of ischaemic stroke in young adults between 1985 and 2011: the Dijon Stroke Registry. J Neurol Neurosurg Psychiatry 2014;85(5):509-13.
3. Wolf T, Brey J, Baum C, Connor L. Activity Participation Differences Between Younger and Older Individuals with Stroke. Brain Impairment 2012;13(1):16-23.
4. Coole C, Radford K, Grant M, Terry J. Returning to work after stroke: perspectives of employer stakeholders, a qualitative study. Journal of occupational rehabilitation 2013;23(3):406-18.
5. Crichton SL, Bray B, McKevitt C, Rudd A, Wolfe CD. Patient outcomes up to 15 years after stroke: survival, disability, quality of life, cognition and mental health. J Neurol Neurosurg Psychiatry 2016;87(10):1091-8.
6. Walsh M, Galvin R, Loughnane C, Macey C, Horgan NF. Factors associated with community reintegration in the first year after stroke: a qualitative meta- synthesis. Disability and rehabilitation 2015;37(18):1599--608.
7. Mayo NE, Wood-Dauphinee S, Côté R, Durcan L, Carlton J. Activity, participation, and quality of life 6 months poststroke. Archives of Physical Medicine & Rehabilitation 2002;83(8):1035-42.
8. Levasseur M, Richard L, Gauvin L, Raymond É. Inventory and Analysis of Definitions of Social Participation Found in the Aging Literature: Proposed Taxonomy of Social Activities. Social science & medicine 2010;71(12):2141-9.
9. World Health Organization. The International Classification of Functioning, Disability and Health(ICF). 2001. Available from: URL: http://www.who.int/classifications/icf/en/.
10. Atler K, Malcolm M, Greife C. A follow-up study on the relationship among participation, activity and motor function in survivors of stroke following constraint-induced therapy. Disability & Rehabilitation 2015;37(2):121-8.
11. Butler A, Blanton S, Rowe V, Wolf S. Attempting to improve function and quality of life using the FTM Protocol: case report. Journal Of Neurologic Physical Therapy: JNPT 2006;30(3):148-56.
12. WHO. Towards a Common Language for Functioning, Disability and Health:ICF. Geneva: World Health Organisation; 2002.
13. Perenboom R, Chorus A. Measuring participation according to the International Classification of Functioning, Disability and Health (ICF). Disability and rehabilitation 2003;25(11-12):577--87.
14. Whiteneck G. Conceptual Models of Disability: Past, Present, and Future. In: Field M, Jette A, Martin L, editors. Workshop on Disability in America: A New Look Summary and Background Papers. Washington DC: National Academies Press; 2006. p 50-66.
15. Dijkers MP. Issues in the conceptualization and measurement of participation: an overview. Archives of physical medicine and rehabilitation 2010;91(9 Suppl):S5--16.
16. Obembe A, Eng J. Rehabilitation Interventions for Improving Social Participation after Stroke: a Systematic Review and Meta-analysis. Neurorehabilitation and Neural Repair 2016;30(4):384-92.
17. Graven C. Are rehabilitation and/or care co-ordination interventions delivered in the community effective in reducing depression, facilitating participation and improving quality of life after stroke? Disability and rehabilitation 2011.
18. Teasell R, Mehta S, Pereira S, McIntyre A, Janzen S, Allen L et al. Time to rethink long-term rehabilitation management of stroke patients. Top Stroke Rehabil 2012;19(6):457-62.
19. Veras M, Kairy D, Rogante M, Giacomozzi C, Saraiva S. Scoping review of outcome measures used in telerehabilitation and virtual reality for post-stroke rehabilitation. J Telemed Telecare 2017;23(6):567-87.
20. Sivan M, O'Connor R, Makower S, Levesley M, Bhakta B. Systematic review of outcome measures used in the evaluation of robot-assisted upper limb exercise in stroke. Journal of Rehabilitation Medicine 2011;43(3):181-9.
21. Ezekiel L, Dawes H, Collett J. Protocol: Factors associated with participation for community dwelling adults with stroke. 2015. Available from: URL: http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42015017909.

22. Moher D, Liberati A, Tetzlaff J, Altman D. *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 2009;6(7).
23. Noonan V, Kopec J, Noreau L, Singer J, Dvorak M. A review of participation instruments based on the International Classification of Functioning, Disability and Health. Disability and Rehabilitation 2009;31(23):1883-901.
24. Tse T, Douglas J, Lentin P, Carey L. Measuring participation after stroke: A review of frequently used tools. Archives of Physical Medicine and Rehabilitation 2013;94(1):177-92.
25. Kessler D, Egan M. A review of measures to evaluate participation outcomes post-stroke. British Journal of Occupational Therapy 2012;75(9):403-11.
26. Salter K, Jutai J, Teasell R, Foley N, Bitensky J, Bayley M. Issues for selection of outcome measures in stroke rehabilitation: ICF Participation. Disability and Rehabilitation 2005;27(9):507-28.
27. WHO. How to use the ICF: A practical manual for using the International. Classification of Functioning, Disability and Health (ICF). Exposure draft for comment. Geneva: WHO; 2013.
28. McHugh ML. Interrater reliability: the kappa statistic. Biochem Med (Zagreb). 2012. p 276-82.
29. NHLBI. Background: Development and Use of Study Quality Assessment Tools. 2014 13.04.15]. Available from: URL: https://www.nhlbi.nih.gov/health-pro/guidelines/in-develop/cardiovascular-risk-reduction/tools/background.
30. NHLBI. Quality Assessment Tool for Observational Cohort and Cross-sectional Studies. 2014 [cited 2015 13.04.15]. Available from: URL: https://www.nhlbi.nih.gov/health-pro/guidelines/in-develop/cardiovascular-risk-reduction/tools/cohort.
31. Cieza A, Szilvia G, Somnath C, Nenad K, Bedirhan S, Gerold S. ICF linking rules: An update based on lessons learned. Journal of Rehabilitation Medicine 2005;37:212--8.
32. Cooper HHLV, JC. The Handbook of Research Synthesis and Meta-Analysis. Sage; 2009.
33. Poole C, Greenland S, Luetters C, Kelsey J, Mezei G. Socioeconomic status and childhood leukaemia: a review International Journal of Epidemiology 2006;35:370-84.
34. Greenland S, O'Rourke K. Meta-Analysis. In: Kenneth J, Rothman., Sander G, Timothy L, Lash, editors. Modern Epidemiology. Third ed. Philadelphia: Lippincott, Williams & Wilkins; 2008. p 652-82.
35. Popay J, Sowden A, Petticrew M, Arai L, Britten N, Rodgers M. Guidance on the conduct of narrative synthesis in systematic reviews: Final report. Swindon: ESRC Methods Programme; 2006.
36. Mercer V, Freburger J, Chang S, Purser J. Step Test scores are related to measures of activity and participation in the, first 6 months after stroke. Physical Therapy 2009;89(10):1061-71.
37. Singam A, Ytterberg C, Tham K, von Koch L. Participation in Complex and Social Everyday Activities Six Years after Stroke: Predictors for Return to Pre-Stroke Level. PLoS One 2015;10(12):e0144344.
38. Gum A, Snyder CR, Duncan PW. Hopeful thinking. Psychology & Health 2006;21(3):319-34.
39. Schepers VP, Visser-Meily AM, Ketelaar M, Lindeman E. Prediction of social activity 1 year poststroke. Arch Phys Med Rehabil 2005;86(7):1472-6.
40. Lo RS, Cheng JO, Wong EM, Tang WK, Wong LK, Woo J et al. Handicap and its determinants of change in stroke survivors: one-year follow-up study. Stroke (00392499) 2008;39(1):148-53.
41. Carod-Artal FJ, Trizotto DS, Coral LF, Moreira CM. Determinants of quality of life in Brazilian stroke survivors. Journal Of The Neurological Sciences 2009;284(1-2):63-8.
42. Egan M, Kubina L, Dubouloz C, Kessler D, Kristjansson E, Sawada M. Very low neighbourhood income limits participation post stroke: preliminary evidence from a cohort study. BMC Public Health 2015;15:528-.
43. Clarke PJ, Black SE, Badley EM, Lawrence JM, Williams JI. Handicap in stroke survivors. Disability and rehabilitation 1999;21(3):116-23.
44. Desrosiers J, Noreau L, Rochette A, Bravo G, Boutin C. Predictors of handicap situations following post-stroke rehabilitation. Disability and rehabilitation 2002;24(15):774-85.
45. Gottlieb A, Golander H, Bar-Tal Y, Gottlieb D. The influence of social support and perceived control on handicap and quality of life after stroke. Aging (Milan, Italy) 2001;13(1):11-5.
46. Radloff L. The CES-D Scale: A Self-Report Depression Scale for Research in the General Population. Applied Psychological Measurements 1977;1(3):385-401.
47. Berges I-M, Seale GS, Ostir GV. The role of positive affect on social participation following stroke. Disability And Rehabilitation 2012;34(25):2119-23.
48. Yesavage JA, Brink TL, Rose TL, Lum O, Huang V, Adey M et al. Development and validation of a geriatric depression screening scale: a preliminary report. Journal of psychiatric research 1982;17(1):37-49.

49. Feigin VL, Barker-Collo S, Parag V, Senior H, Lawes CMM, Ratnasabapathy Y et al. Auckland Stroke Outcomes Study. Part 1: Gender, stroke types, ethnicity, and functional outcomes 5 years poststroke. Neurology 2010;75(18):1597-607.
50. Cooper CL, Phillips LH, Johnston M, Whyte M, MacLeod MJ. The role of emotion regulation on social participation following stroke. The British Journal Of Clinical Psychology / The British Psychological Society 2015;54(2):181-99.
51. Liu T-W, Ng SS, Kwong PW, Ng GY. Fear Avoidance Behavior, Not Walking Endurance, Predicts the Community Reintegration of Community-Dwelling Stroke Survivors. Archives of Physical Medicine & Rehabilitation 2015;96(9):1684-90 7p.
52. Blomer A, Van Mierlo M, Visser-Meily J, CM VH, Post M. Does the frequency of participation change after stroke and is this change associated with the subjective experience of participation? Archives of Physical Medicine and Rehabilitation 2015;90(3):456-63.
53. Patel M, Tilling K, Lawrence E, RG. R, Wolfe C, McKevitt C. Relationships between long-term stroke disability, handicap and health-related quality of life. Age and Ageing 2006;35:273-9.
54. Gall SL, Dewey HM, Sturm JW, Macdonell RAL, Thrift AG. Handicap 5 years after stroke in the North East Melbourne Stroke Incidence Study. Cerebrovascular diseases (Basel, Switzerland) 2009;27(2):123-30.
55. Sturm JW, Dewey HM, Donnan GA, Macdonell RAL, McNeil JJ, Thrift AG. Handicap after stroke: how does it relate to disability, perception of recovery, and stroke subtype?: the north North East Melbourne Stroke Incidence Study (NEMESIS). Stroke; A Journal Of Cerebral Circulation 2002;33(3):762-8.
56. Desrosiers J, Rochette A, Noreau L, Bourbonnais D, Bravo G, Bourget A. Long-term changes in participation after stroke. Topics In Stroke Rehabilitation 2006;13(4):86-96.
57. Jansen HE, Schepers VP, Visser-Meily JM, Post MW. Social Activity One and Three Years Post-Stroke. Journal of Rehabilitation Medicine 2012;44(1):47-50.
58. van Mierlo ML, van Heugten CM, Post MWM, Hajós TRS, Kappelle LJ, Visser-Meily JMA. Quality of Life during the First Two Years Post Stroke: The Restore4Stroke Cohort Study. Cerebrovascular Diseases (Basel, Switzerland) 2016;41(1-2):19-26.
59. Chahal N, Barker-Collo S, Feigin V. Cognitive and functional outcomes of 5-year subarachnoid haemorrhage survivors: comparison to matched healthy controls. Neuroepidemiology 2011;37(1):31-8.
60. Naess H, Waje-Andreassen U, Thomassen L, Nyland H, Myhr K-M. Health-related quality of life among young adults with ischemic stroke on long-term follow-up. Stroke; a journal of cerebral circulation 2006;37(5):1232-6.
61. Desrosiers J, Demers L, Robichaud L, Vincent C, Belleville S, Ska B. Short-term changes in and predictors of participation of older adults after stroke following acute care or rehabilitation. Neurorehabilitation And Neural Repair 2008;22(3):288-97.
62. Carter BS, Buckley D, Ferraro R, Rordorf G, Ogilvy CS. Factors associated with reintegration to normal living after subarachnoid hemorrhage. Neurosurgery 2000;46(6):1326-33.
63. Fallahpour M, Tham K, Joghataei MT, Jonsson H. Perceived participation and autonomy: aspects of functioning and contextual factors predicting participation after stroke. Journal Of Rehabilitation Medicine 2011;43(5):388-97.
64. Egan M, Davis C, Dubouloz C, Kessler D, Kubina L. Participation and well-being poststroke: Evidence of reciprocal effects. Archives of Physical Medicine and Rehabilitation 2014;95(2):262-8.
65. Wood JP, Connelly DM, Maly MR. 'Getting back to real living': A qualitative study of the process of community reintegration after stroke. Clin Rehabil 2010;24(11):1045-56.
66. Salter K, Hellings C, Foley N, Teasell R. The experience of living with stroke: a qualitative meta-synthesis. Journal of rehabilitation medicine 2008;40(8):595--602.
67. Bartlett DJ, Macnab J, Macarthur C, Mandich A, Magill-Evans J, Young NL et al. Advancing rehabilitation research: an interactionist perspective to guide question and design. Disability and rehabilitation 2006;28(19):1169-76.
68. Northcott S, Moss B, Harrison K, Hilari K. A systematic review of the impact of stroke on social support and social networks: associated factors and patterns of change. Clinical Rehabilitation 2016;30(8):811-31.
69. Heinemann AW, Magasi S, Hammel J, Carlozzi NE, Garcia SF, Hahn EA et al. Environmental Factors Item Development for Persons With Stroke, Traumatic Brain Injury, and Spinal Cord Injury. Archives of physical medicine and rehabilitation 2015;96(4):589-95.
70. Skolarus LE, Burke JF, Brown DL, Freedman VA. Understanding stroke survivorship: expanding the concept of poststroke disability. Stroke 2014;45(1):224-30.

71. Desrosiers J, Bourbonnais D, Noreau L, Rochette A, Bravo G, Bourget A. Participation after Stroke Compared to Normal Aging. Journal of Rehabilitation Medicine 2005;37(6):353-7.
72. Bentsen L, Christensen L, Christensen A, Christensen H. Outcome and risk factors presented in old patients above 80 years of age versus younger patients after ischemic stroke. J Stroke Cerebrovasc Dis 2014;23(7):1944-8.
73. Dehlendorff C, Andersen KK, Olsen TS. Sex Disparities in Stroke: Women Have More Severe Strokes but Better Survival Than Men. Journal of the American Heart Association 2015;4(7).
74. Verhoeven CLM, Post MWM, Schiemanck SK, van Zandvoort MJE, Vrancken PH, van Heugten CM. Is cognitive functioning 1 year poststroke related to quality of life domain? Journal Of Stroke And Cerebrovascular Diseases: The Official Journal Of National Stroke Association 2011;20(5):450-8.
75. Stummer C, Verheyden G, Putman K, Jenni W, Schupp W, De Wit L. Predicting sickness impact profile at six months after stroke: further results from the European multi-center CERISE study. Disability and rehabilitation 2015;37(11):942-50.
76. Mallinson T, Hammel J. Measurement of participation: Intersecting person, task, and environment. Archives of Physical Medicine and Rehabilitation 2010;91(9 SUPPL.):S29--S33.
77. Duncan F, Wu S, Mead GE. Frequency and natural history of fatigue after stroke: a systematic review of longitudinal studies. Journal of psychosomatic research 2012;73(1):18-27.
78. Whiteneck GG. Issues affecting the selection of participation measurement in outcomes research and clinical trials. Arch Phys Med Rehabil 2010;91(9 Suppl):S54-9.
79. Eyssen IC, Steultjens MP, Dekker J, Terwee CB. A Systematic Review of Instruments Assessing Participation: Challenges in Defining Participation. Archives of Physical Medicine and Rehabilitation 2011;92(6):983-97.
80. Salter K, Campbell N, Richardson M, Mehta S, Jutai J, Zettler L et al. Outcome Measures in Stroke Rehabiliation. Canada: Evidence Based Review of Stroke Rehabilitation.; 2013.
81. Salinas J, Sprinkhuizen SM, Ackerson T, Bernhardt J, Davie C, George MG et al. An International Standard Set of Patient-Centered Outcome Measures After Stroke. 2016.
82. Woodman P, Riazi A, Pereira C, Jones F. Social participation post stroke: a meta-ethnographic review of the experiences and views of community-dwelling stroke survivors. Disability and rehabilitation 2014;36(24):2031-43.