Comparing participation outcome over time across international stroke cohorts

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ORIGINAL RESEARCH

Comparing Participation Outcome Over Time Across International Stroke Cohorts: Outcomes and Methods

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Abstract

Objective: To enable a direct comparison of participation levels in the first year post-stroke, assessed by different outcome measures internationally.

Design: Two prospective stroke cohort studies following persons from stroke onset to 12 months post-stroke.

Setting: Community.

Participants: Persons with stroke (N=495), not living at a nursing home, from Australia STroke imAging pRevention and Treatment-Prediction and Prevention to Achieve optimal Recovery Endpoints after stroke (START-PrePARE; n=100) and the Netherlands (Restore4stroke; n=395).

Interventions: Not applicable.

Main Outcome Measures: Activity Card Sort-Australia and Utrecht Scale for Evaluation of Rehabilitation-Participation. Activity domains were matched across measures to find common denominators and original scoring methods were recoded, hereby enabling a direct comparison of retained activities.

Results: Ninety-one (START-PrePARE) and 218 (Restore4stroke) persons with stroke were included for analyses. No major differences in background characteristics were observed between the cohorts; the Dutch cohort suffered from slightly more severe stroke. A higher level of participation was observed (radar charts) in the first months post-stroke for the Australian cohort than in the Dutch cohort, especially for unpaid work ($P<.003$). At 12 months post-stroke, participation levels were similar, without significant differences in retained activities using the defined common denominators ($P>.003$).

Conclusions: An international comparison of actual activities that persons re-engage in in the first year post-stroke was achieved using a new method and recoding of data. High levels of participation were observed in both cohorts. Unpaid work showed different frequencies at 2-3 months, contributing to different trajectories over time across cultures. Important insights were gained. Although valuable information is inevitably lost with recoding, the approach may assist future studies on the harmonization of data across cohorts, particularly for 1 of the key outcomes of stroke: participation.

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Stroke has a global and ongoing effect on society and on the person over time. Stroke can cause people to experience a wide array of long-term problems (ie, physical, cognitive, emotional, social)¹⁻⁵ that contribute to decreased levels of participation.⁶⁻¹¹ Meanwhile, participation in daily and social activities is valued as a key outcome by persons with stroke, rehabilitation specialists, and the World Health Organization.¹²⁻¹⁶

Participation is defined as involvement in a life situation which closely relates to activities, defined as the execution of a task or action.⁶ Many different interchangeable terms are used for participation such as engagement, involvement in a life situation or social participation. However, measuring the level of participation post-stroke is not straightforward. Several features of engagement in activities need to be considered: the domain (eg, household, social, vocational); status (previously done or new), and the aspect (eg, frequency, experienced restrictions, satisfaction with engagement).

Numerous outcome measures are used, all measuring different features of participation (eg, mobility, self-care, community life).¹⁷ Additionally, none of the outcome measures covered the description of participation and activities by the International Classification of Functioning, Disability and Health (ICF) model entirely.^{6,16} The Activity Card Sort (ACS)¹⁸⁻²¹ test was one of the most comprehensive measures of participation, along with the Stroke Impact Scale²² and the assessment of Life-Habits Measure-Shortened Version.²³ Since Tse et al¹⁷ published their systematic review, other participation measures aligning with the ICF model have been developed and used, such as the Utrecht Scale of Evaluation of Rehabilitation-Participation (USER-P).²⁴ It includes the frequency of actual performed activities and also focuses on the subjective part of participation (ie, experienced restrictions and satisfaction with participation).

Currently, there is no consensus on which participation measure to use. Further, the range in measures used impedes a direct comparison of outcomes across (international) populations. Cultural diversity also plays a role as measures are adapted to fit more cultural-specific activities such as indoor bowling (ie, popular in the United Kingdom) or riding a bike (ie, the Netherlands).

Currently, there is no consensus on 1 outcome measure on participation. To overcome the different features of engagement in life activities and cultural diversity is to identify common denominators across measures. The potential now exists to define common denominators, which enables a better characterization of participation outcomes of stroke cohorts and to compare the type and distribution of activities that persons with stroke engage in after a stroke; across countries and over time. We believe that the ICF domain of participation shares common aspects and categories across cultures, and thus the framework can contribute to

the cross-cultural understanding of chronic disability and participation.²⁵ Measures, such as the ACS and USER-P, are available to quantitatively and comprehensively measure actual activities engaged in. Therefore, we were interested to explore whether common denominators of participation could be identified from the 2 outcome measures aligning with the ICF framework: the ACS and the USER-P.

We assessed which activity domains were congruent across measures and redefined their scoring procedures to achieve common denominators. Herewith, we aimed to enable a direct comparison of the outcome measures across countries and to provide a proof-of-principle of methods. This method may assist in future projects in order to harmonize 1 of the key outcomes of stroke rehabilitation and to better characterize participation across cohorts, toward a common score of participation.

Methods

Design and procedure

The current study includes data from persons with stroke from 2 prospective cohort studies: the Australian cohort from the STroke imAging pRevention and Treatment-Prediction and Prevention to Achieve optimal Recovery Endpoints after stroke (START-PrePARE) study^{26,27} and the Dutch cohort from the Restore4stroke study.²⁸ Both cohorts are part of multicenter longitudinal studies, which have been described in more detail elsewhere.^{11,26,28}

In the START-PrePARE cohort, persons with stroke were recruited from 5 hospitals with stroke units in Melbourne, Australia. Once eligibility criteria were met, informed consent was obtained and persons were followed up to 12 months. The cohort consisted of 3 main assessment timepoints: first week post-stroke and at 3 and 12 months post-stroke. The Restore4stroke cohort recruited persons with stroke from 6 general hospitals in the Netherlands. Once eligibility criteria were met and informed consent was obtained, they were monitored up to 24 months post-stroke. The cohort consisted of 5 assessments: in the first week post-stroke and at 2, 6, 12, and 24 months post-stroke.

Corresponding assessment timepoints of the 2 cohorts were used as means of comparison: the first week post-stroke (T1); 2 (T2) or 3 months (T3); and 12 months (T12) post-stroke. Retrospective data on premorbid levels (T0) of the USER-P were gathered in the first week post-stroke for the Netherlands cohort. As the ACS is assessed with reference to activities engaged in prior to stroke, a T0 time point was also available for the Australian cohort. For both studies the institutional medical ethics committees gave their approval. Ethical standards were followed and both studies comply with the declaration of Helsinki. Raw data analyses were performed separately in each country and results were then pooled.

Participants

Inclusion criteria for the START-PrePARE cohort were: a confirmed diagnosis of ischemic stroke suffered within the past 3 days; 18 years or older; English speaking; and no significant premorbid disability (modified Ranking Scale; mRS <2). The criterion for inclusion in the Restore4stroke cohort was a confirmed diagnosis of stroke (ischemic or intracerebral hemorrhagic lesion) suffered within the past 7 days. Exclusion criteria

List of abbreviations:

ACS	Activity Card Sort
ADL	activities of daily living
BI	Barthel Index
ICF	International Classification of Functioning, Disability and Health
IQR	interquartile range
mRS	modified Ranking Scale
USER-P	Utrecht Scale of Evaluation of Rehabilitation-Participation
START-PrePARE	STroke imAging pRevention and Treatment-Prediction and Prevention to Achieve optimal Recovery Endpoints after stroke

Fig 1 Schematic overview of the recoding steps to achieve the aim of a direct comparison of retained participation levels across the outcome measures: ACS and the USER-P.

for this Dutch cohort concerned a comorbid condition (eg, neuromuscular diseases) which was anticipated to interfere with study outcome; premorbid dependency in activities of daily living (ADL; Barthel Index²⁹ ≤17); insufficient command of the Dutch language to understand and complete questionnaires (on clinical judgement); and premorbid cognitive decline (Hetero-anamnesis List Cognition³⁰ ≥1).

Two additional exclusion criteria were set for this study: (1) incomplete data on 1 of the domain scores of the ACS or USER-P at any of the time points; 2) persons who lived at a nursing home at 1 year post-stroke. The second criterion was set because of the focus on community-dwelling persons.

Measures

The ACS-Australia recovering version is a reliable and valid self-report measure of activity participation.^{19,31} This version incorporates the level of activity relative to the injury. It consists of 82 cards that depict photographs of older people doing different activities. Four cards were additionally included (86 in total) based on the second edition of the original United States version.³² Participants sort these cards into 5 categories: not done prior to the injury (ie, not applicable); continued to do after the injury (score = 1); given up to do due to the injury (score = 0); beginning to do again (score = 5); and new activity since the injury (score = 1). The categories add up to total scores reflective of premorbid, current, and retained activity participation. Retained score is calculated as current activity level (sum of continued to do, new activity, and beginning to do again) divided by previous activity level (sum of continued to do, given up, and beginning to do again) multiplied by 100. Higher domain scores are indicative of more activity participation in those domains.

The USER-P is also a valid and reliable self-report measure of participation^{24,33} that consists of 3 scales: frequency of participation (total, Part A and Part B); experienced participation restrictions; and satisfaction with participation. Part A of the frequency scale consists of 4 items on vocational activities (eg, [un]paid work and household activities) which are rated on hours per week from none at all (score = 0) to ≥36 hours (score = 5). Part B consists of 7 items on social or leisure activities (eg, going out, day trips) which are rated on frequency in the past 4 weeks from none at all (score = 0) to ≥19 times (score = 5). The restrictions scale consists of 11 items concerning vocational and social or leisure activities rated by the severity of experienced restrictions in the particular activity, from not possible to perform (score = 0) to performed without difficulty (score = 3). If one does not perform that particular activity, not applicable can be recorded. The satisfaction scale consists of 10 items on vocational and social or leisure activities which can be rated from score very dissatisfied (score = 0) to very satisfied (score = 4). Not applicable can be recorded on 2 items: if one does not have paid work or does not have a partner. All the scales convert to a 0-100 scale, where higher scores are indicative of, respectively, more participation, less experienced restrictions and higher satisfaction.

Measures used to describe the clinical characteristics of the cohorts were the National Institute of Health Stroke Scale³⁴ for stroke severity; the modified Ranking Scale (mRS)³⁵ or the Barthel Index²⁹ for the level of independence in ADL; the Montreal Cognitive Assessment (MoCA)³⁶ for level of cognitive functioning; and the Montgomery-Asberg Depression Rating Scale-interview³⁷ or the Hospital Anxiety and Depression Scale³⁸ for the level of experienced depressive symptoms (clinical interview vs self-report, respectively). Demographic information was also obtained.

Table 1 The categorization of the ACS cards according to USER-P items

USER-P Frequency Scale Items	ACS	
Paid work. All forms of paid work, including work for your own business.	- Paid work	
Unpaid work. Volunteering for a society, community center, at school or any voluntary activities.	- Volunteer work	
Education. Only training courses taken in the context of your paid work to help you obtain paid work.	Not applicable	
Household duties. Such as cooking, cleaning, shopping, caring for or supervising children, do-it-yourself, gardening etc.	- Home maintenance - Light household chores - Heavy household chores - Storytelling with children - Preparing meals - Yard maintenance - Gardening and growing flowers - Shopping for groceries - Child care	- Laundry - Dishes - Taking out the rubbish - Paying bills - Money management - Mending clothes - Getting petrol - Care-giving - Shopping in store
Sports or other physical exercise. Such as tennis, cycling, gym, long walks. Please note: do not include, eg, cycling to work.	- Exercising - Walking - Golfing - Bowling	- Swimming - Fishing - Yoga, tai chi, Pilates - Lawn bowls
Going out. Such as eating out, visiting a café, cinema, concert, alone or together with others.	- Going to the theatre - Attending concerts - Going out for a meal or drinks - Interest group or club - Going to the library	- Going to the post-office - Parties, picnics, barbeque - Using public transport - Going to art or craft classes or groups
Day trips and other outdoor activities. Such as shopping, attending events, going to the beach, church, or mosque.	- Going to the beach - Going to a place of worship - Recreational shopping - Going to park or garden	- Taking a day trip - Preparing for outing or trip - Traveling
Leisure activities at home. Such as crafts, needlework, reading, puzzles, playing computer games.	- Watching television - Computer (email or games) - Reading newspaper - Reading magazines or books - Listening to radio - Resting - Listening to music - Sitting and thinking - Playing a musical instrument or singing - Cooking as a hobby - Looking at color slides or photos - Photography - Puzzles - Sewing	- Bingo - Collecting - Researching family history - Gambling - Knitting or crocheting - Hand crafts - Crosswords and word games - Health-related activities - Taking care of a pet - Beauty or barbershop - Having morning or arvo cupa - Spectator sport - Cards - Table games
Going to visit family or friends and family or friends coming to visit at your home.*	- Visiting with friends - Family gatherings - Going to (grand) children's activities	- Visiting friends who are ill - Talking with family and neighbors - Doing favors or helping out.
Contacting others by phone or computer. Such as talking on the phone, texting, e-mailing.	- Talking on the phone - Letter writing	- Internet (locating info, surfing)

NOTE. Not all cards of the ACS are comparable to the items of the USER-P and therefore; also not included in this table of common denominators (these cards include marriage and relationships, community and civic activities, driving, entertaining at home or club, watching movies at theatre or home).

* These 2 items of the USER-P are collapsed into Family visit as the ACS cannot make a differentiation between these 2 items.

Analyses

Characteristics of both cohorts were firstly described on demographic and stroke-related factors. Secondly, outcomes from the ACS and the USER-P were described according to their

original domains. Paired *t* tests were used to compare T0 with T2 or T3 participation levels per cohort.

As the ACS includes a percentage of activities retained post-stroke, the USER-P data was recoded for direct comparison. Figure 1 depicts the recoding procedure. Step 1, matching and

Table 2 Characteristics of included persons in the START-PrePARE cohort (n=91) and Restore4stroke cohort (n=218)

Characteristics	START-PrePARE			Restore4stroke		
	n Total	Mean $\pm$ SD	n (%) or Median* (IQR [†])	n Total	Mean $\pm$ SD	n (%) or Median* (IQR [†])
Age (y)	91	65.5 $\pm$ 13.0	66.0 (15.1)	218	64.8 $\pm$ 11.4	65.1 (16.9)
Sex (male)	91		68 (74.7)	218		145 (66.5)
Partner (yes)	91		66 (72.5)	218		165 (75.7)
High education level [‡]	91		18 (19.8)	217		59 (27.2)
Stroke recurrence	91			218		29 (13.3)
3/2 mo post-stroke (T3 or T2)			1 (1.0)			NA
12 mo post-stroke (T12)			0 (.0)			NA
Ischemic stroke	91		91 (100.0)	218		204 (93.6)
Site of index stroke	91			216		
Left hemisphere			36 (39.6)			86 (39.8)
Right hemisphere			38 (41.8)			88 (40.7)
Both hemispheres			3 (3.3)			
Cerebellum or brainstem			7 (7.7)			42 (19.4)
Unclear			9 (9.9)			
Stroke severity (NIHSS)				218		
4/3 d post-stroke (T1)	90	1.9 $\pm$ 2.4	1.0 (3.0)		2.3 $\pm$ 2.5	2.0 (2.0)
3/2 mo post-stroke (T3 or T2)	91	0.7 $\pm$ 1.2	.0 (1.0)		NA	NA
12 mo post-stroke (T12)	88	0.6 $\pm$ 1.5	.0 (1.0)		NA	NA
Disability in daily living (mRS)	91			217		
3/2 mo post-stroke (T3 or T2)		1.1 $\pm$ 1.0	1.1 (2.0)		NA	NA
6 mo post-stroke (T6)		NA	NA		1.1 $\pm$.9	1.0 (2.0)
12 mo post-stroke (T12)		0.9 $\pm$ 1.0	1.0 (1.0)		NA	NA
Cognitive functioning (MoCA)						
3-7 d post-stroke (T1)	91	24.0 $\pm$ 5.2	25.0 (5.0)		NA	NA
Impaired ($\leq$ 23)			37 (40.2)			
3/2 mo post-stroke (T3 or T2)	90	26.3 $\pm$ 3.7	27.0 (4.0)	217	24.1 $\pm$ 3.5	24.0 (5.0)
Impaired			16 (17.6)			85 (39.2)
6 mo post-stroke (T6)		NA	NA	215	25.2 $\pm$ 3.1	26.0 (4.0)
Impaired						58 (27.0)
12 mo post-stroke (T12)	83	25.8 $\pm$ 4.2	27.0 (3.0)		NA	NA
Impaired			17 (20.2)			
Aphasia (NIHSS item 9)						
3-4 d post-stroke (T1)	90		8 (8.9)	217		24 (11.1)
3/2 mo post-stroke (T3 or T2)	91		6 (6.6)	217		16 (7.3)
12 mo post-stroke(T12)	88		3 (3.4)			NA
ADL assessed with the BI						
4/3 d post-stroke (T1)		NA	NA	218	88.7 $\pm$ 19.1	100.0 (15.0)
3/2 mo post-stroke (T2)	91	93.2 $\pm$ 22.3	100.0 (.0)	218	98.1 $\pm$ 5.5	100.0 (.0)
6 mo post-stroke (T3)		NA	NA	217	98.1 $\pm$ 5.4	100.0 (.0)
12 mo post-stroke (T12)	89	97.8 $\pm$ 7.6	100.0 (.0)		NA	NA
Living situation at T3 or T2	91			218		
Home			89 (97.8)			198 (90.8)
Rehabilitation center			-			13 (6.0)
Supported accommodation or retirement village			2 (2.2)			-
Nursing home			-			7 (3.2)
Living situation at T12	91			218		
Home			89 (97.8)			218 (100.0)
Rehabilitation center			-			0 (.0)
Supported accommodation or retirement village			2 (2.2)			-
Depressive symptoms (MADRS [§] vs HADS)						
3-7 d post-stroke (T1)	90	6.1 $\pm$ 6.0	4.0 (8.3)		NA	NA
Mild depressive symptoms			32 (35.2)			
3/2 mo post-stroke (T3 or T2)	91	6.8 $\pm$ 7.2	4.0 (10.0)	218	4.4 $\pm$ 3.8	3.0 (6.0)
Mild depressive symptoms			37 (40.7)			44 (20.2)

(continued on next page)

Table 2 (continued)

Characteristics	START-PrePARE			Restore4stroke		
	n Total	Mean $\pm$ SD	n (%) or Median* (IQR [†])	n Total	Mean $\pm$ SD	n (%) or Median* (IQR [†])
6 mo post-stroke (T6)		NA	NA	218	4.5 $\pm$ 3.8	4.0 (6.0)
Mild depressive symptoms						48 (22.0)
12 mo post-stroke (T12)	91	5.9 $\pm$ 6.0	4.0 (7.0)	217	4.5 $\pm$ 3.8	4.0 (6.0)
Mild depressive symptoms			28 (30.8)			48 (22.1)

NOTE. Values are percentages, mean $\pm$ SD, or median (IQR).

Abbreviations: BI, Barthel Index; HADS, Hospital Anxiety Depression Scale; MADRS, Montgomery-Asberg Depression Rating Scale-interview; MoCA, Montreal Cognitive Assessment; NIHSS, National Institutes of Health Stroke Scale; NA, not available.

* Medians are displayed.

[†] IQR=75% quartile (Q3)–25% quartile (Q1).

[‡] Participants completed higher professional education or have a university degree.

[§] Cut-off for the HADS is ≥ 8 ^{39,40} and for the MADRS ≥ 7 .^{39,41}

recoding of activity domains, was undertaken with the aim of a direct comparison of retained participation levels, as measured by the ACS and USER-P. Step 2 concerned the dichotomization of the USER-P frequency items into doing and not doing. The ACS followed its original scoring procedure in this step. In Step 3, retained activities were calculated for the USER-P in which item 9 (going to visit your friends) and item 10 (family or friends coming to visit at your home) of the USER-P were collapsed for comparability with the ACS. Only when both activities were retained, this collapsed item was recoded as retained. Newly performed activities post-stroke were also regarded as retained to align with the scoring definition used for the ACS. Inclusion of new activities in percentage retained can lead to a percentage greater than 100%. Step 4 concerned the direct comparison of the common denominators (table 1) and the comparison on domain level. The formula of the ACS (in fig 1) was used for the USER-P to calculate the retained percentages on domain level.

The ACS cards were grouped to align with the USER-P items, thereby defining common denominators and allowing for a direct comparison (see table 1). The distribution of retained scores of the ACS and the USER-P of the common denominators were compared visually using radar charts, followed by 2-sample *z* score calculations to compare proportions. A Bonferroni correction for multiple comparisons was applied (.05/20=.003 significance level).

Results

Cohort characteristics

Of the 100 participants in the Australian cohort, 91 met the inclusion criteria for this study (7 with incomplete data, 1 with outlier scores, and 1 living at a nursing home at T12 were excluded). Of the 395 participants in the Dutch cohort, 218 were included (168 with incomplete data and 9 living at a nursing home at T12 were excluded).

Table 2 shows the baseline characteristics of both cohorts. Australian participants suffered from less severe stroke (median=1.0, interquartile range [IQR]=3.0) and had higher cognitive functioning (median=27.0, IQR=4.0) than Dutch participants (median=2.0, IQR=1.0 and median=24.0, IQR=5.0, respectively). Nearly all participants were discharged home in both cohorts, 98% vs 91%, respectively.

Participation by original scales

In the Australian cohort, all domains at T3 were significantly decreased relative to T0. Ninety percent of the total activities performed pre-morbidly were retained at T3 with relatively stable levels up to T12. Social or educational and household activities showed stable levels over time (at median=100%). Leisure

Table 3 Level of participation measured with the ACS, in the START-PrePARE cohort

Current Activity Participation	T0: Premorbid		T3: 3 mo Post-Stroke		T12: 12 mo Post-Stroke	
	Mean $\pm$ SD	Median (IQR)	Mean $\pm$ SD	Median (IQR)	Mean $\pm$ SD	Median (IQR)
Total activities	49.5 $\pm$ 9.2	50.0 (14.0)	47.9 $\pm$ 10.3*	48.0 (14.0)	47.9 $\pm$ 10.3	48.0 (14.0)
Leisure activities	25.6 $\pm$ 5.5	25.0 (8.0)	23.3 $\pm$ 5.9*	23.0 (9.0)	24.5 $\pm$ 5.8	24.5 (8.5)
Social and educational activities	14.6 $\pm$ 3.5	15.0 (5.0)	13.1 $\pm$ 3.9*	13.5 (4.5)	12.6 $\pm$ 3.7	13.0 (5.0)
Household activities	9.3 $\pm$ 2.0	10.0 (3.0)	8.5 $\pm$ 2.3*	9.0 (2.5)	8.8 $\pm$ 2.4	9.5 (3.0)
Percentage Retained Participation	Mean % $\pm$ SD	Median % (IQR)	Mean % $\pm$ SD	Median % (IQR)	Mean % $\pm$ SD	Median % (IQR)
Total	-	-	90.1 $\pm$ 16.0	97.0 (15.0)	94.6 $\pm$ 11.6	98.0 (8.0)
Leisure activities	-	-	91.2 $\pm$ 17.2	95.7 (17.3)	94.3 $\pm$ 11.7	98.0 (11.1)
Social and educational	-	-	89.8 $\pm$ 18.9	100.0 (17.9)	95.4 $\pm$ 18.3	100.0 (6.7)
Household activities	-	-	92.2 $\pm$ 17.1	100.0 (13.6)	93.2 $\pm$ 17.2	100.0 (9.1)

* $P \leq .001$.

Table 4 Level of participation measured with the USER-P, in the Restore4stroke cohort (n = 218)

	Premorbid			T2: 2 mo Post-Stroke			T6: 6 mo Post-Stroke			T12: 12 mo Post-Stroke			T24: 24 mo Post-Stroke		
	Mean ± SD	Median (IQR)		Mean ± SD	Median (IQR)		Mean ± SD	Median (IQR)		Mean ± SD	Median (IQR)		Mean ± SD	Median (IQR)	
Current Activity Participation															
Total frequency	34.7±10.5	34.1 (13.8)		28.5±10.7 [†]	28.4 (15.0)		29.9±10.3	29.8 (15.5)		30.6±10.7	29.6 (16.4)		30.0±11.4	30.4 (15.3)	
Vocational or household activities	21.8±12.5	20.0 (20.0)		13.0±10.1 [†]	10.0 (15.0)		14.5±9.9	15.0 (15.0)		16.3±11.7	15.0 (17.5)		17.2±11.5	15.0 (20.0)	
Leisure or social activities	47.7±15.9	48.6 (22.9)		44.0±16.8*	45.7 (25.7)		45.2±16.1	45.7 (23.6)		44.8±15.1	44.3 (20.7)		42.8±11.5	42.9 (22.9)	
Restrictions	NA	NA		73.5±22.1	75.0 (36.9)		81.2±18.7	85.7 (28.0)		83.0±18.6	88.9 (29.7)		82.8±21.0	92.6 (30.0)	
Satisfaction	NA	NA		64.4±17.0	65.6 (22.5)		67.7±17.7	69.4 (19.7)		70.2±17.6	72.5 (21.3)		69.1±17.9	72.2 (25.0)	
Percentage Retained Participation	Mean % ± SD	Median % (IQR)		Mean % ± SD	Median % (IQR)		Mean % ± SD	Median % (IQR)		Mean % ± SD	Median % (IQR)		Mean % ± SD	Median % (IQR)	
Total frequency	-	-		90.0±27.2	88.9 (22.2)		97.8±24.4	100 (12.5)		99.4±26.6	100 (23.6)		97.5±27.7	100 (22.8)	
Vocational or household activities	-	-		79.4±39.1	100 (50.0)		88.0±37.0	100 (33.3)		92.3±46.6	100 (33.3)		94.0±42.2	100 (33.3)	
Leisure or social activities	-	-		96.1±37.4	100 (16.7)		103.4±33.6	100 (14.3)		103.7±35.3	100 (31.0)		100.4±34.5	100 (31.0)	

* $P < .05$.† $P \leq .001$.

activities increased from median 96% (80%-100%) at T3, to a level of 98% (89%-100%) retained at T12 (table 3).

In the Dutch cohort, all domains at T2 were significantly decreased relative to premorbid levels. Vocational activities increased, experienced restrictions with participation decreased (ie, scores on the USER-P increased), and satisfaction increased up to T12. At T2, a median of 89% (78%-100%) of the total activities were retained, which increased to 100% (88%-111%) at T12. Retained vocational and leisure or social activities both showed stable levels over time (at median = 100%) (table 4).

Retained activities using common denominators

Visual inspection of the radar charts at T3 and T2 showed that, overall, the Australian cohort covered more frequency area (had higher frequencies on 7 common denominators out of 9) than the Dutch cohort (fig 2). Significantly more persons in the Australian cohort retained unpaid work at T3 (82% vs 56%) than in the Dutch cohort at T2 ($P < .003$). Relatively large (but nonsignificant) differences were observed in retaining paid work (67% vs 50%) and going out (87% vs 72%) in the Australian cohort vs the Dutch cohort. At T12, the covered areas of the cohorts across the common denominators were relatively alike; no significant differences were observed ($P > .0025$) (see fig 2 and table 5).

Discussion

We compared participation of persons with stroke in Australia and the Netherlands during the first year post-stroke. The cohorts were comparable on demographic information and stroke-related information. The Dutch cohort suffered from slightly more severe stroke and had lower cognitive functioning than the Australian cohort. As expected, current participation levels were decreased at 2 or 3 months post-stroke in both cohorts, relative to premorbid levels. Retained participation levels were higher after 3 months in the Australian cohort which remained relatively stable up to 12 months, whereas participation levels increased over time in the Dutch cohort. Remarkably, leisure or social activities percentages increased to above 100% at 12 months, which is indicative of individuals adding new activities to retained activities post-stroke. The frequency of leisure or social activities (original scoring) remained relatively stable, which suggests that new activities were added at the expense of the frequency of retained activities.

Australian persons with stroke seemed to return to unpaid work earlier than the Dutch cohort as their levels were 26% higher at the first time point. A relatively larger number (17% more) also returned to paid work at this time, although the difference was not significant. The time point of 2 vs 3 months post-stroke may have contributed to the lower number of people returning to work in the Dutch cohort. Notably, at 12 months post-stroke, Dutch levels of paid work were higher, which could be explained by cultural differences, such as social expectations to return to work post-stroke. Factors associated with post-stroke participation could also provide more insight. Earlier identified factors were shown to be age, level of education, ADL dependency,¹¹ and depressive symptoms⁴² (from the cohorts in this study and a systematic review⁴³). However, the seeming cross-cultural differences in trajectories of unpaid and paid work levels should be examined in future research, possibly considering social expectations.

Fig 2 Radar charts displaying percentage retained activities for common denominator activity categories, at 3 or 2 months post-stroke (T3 for START-PrePARE and T2 for Restore4stroke; Part A) and at 12 months post-stroke (T12; Part B).

Method of comparison

In this study we introduced a method for comparing participation measures across international cohorts, making use of common denominators. This method could be repeated for other outcome measures on participation such as Life-Habits Measure-Shortened Version and Stroke Impact Scale being the 2 most used participation measures post-stroke,¹⁷ which can also lead to new insights. Methods for comparing the content of outcome measures already exists through linking them to the domains of the ICF model, in other words, using linking rules.⁴⁴⁻⁴⁶ Herewith, response options of different measures, such as frequency, limitations, or satisfaction can also be categorized according to what was assessed.^{46,47} Essentially the same procedure was followed as the previously described linking rules.⁴⁷ Common denominators in content and response options were defined across the measures. Recoding the response options added upon the categorization of

the linking rules. This specific method enabled a direct comparison of participation across cohorts.

A direct comparison of different outcome measures inevitably leads to loss of valuable information. Greater differences or incompatibility between measures will result in a greater loss of information. Here, information on specific activities using the ACS was lost due to the more general items of the USER-P. Likewise, information on the frequency of activities of the USER-P was lost. Translation to whether or not activities were performed (as assessed by the ACS) was possible but not vice versa. Further, participation consists of different features (domains, status, and aspects) which were examined for comparison across the measures. For example, the ACS holds information on whether an activity is beginning to be done again and the USER-P on whether an activity is performed with assistance or not. However, due to differences in the nature of the features (status vs aspects) and how this relates to premorbid levels for each of the

Table 5 Comparison of percentage of activities retained post-stroke according to the ACS and the USER-P using common denominators for activity categories

Common Denominators	ACS - START-PrePARE Cohort (n=91)				USER-P—Restore4stroke Cohort (n=218)			
	T3		T12		T2		T12	
	n*	% Retained	n*	% Retained	n*	% Retained	n*	% Retained
Paid work	91	66.7	91	69.2	96	50.0	99	76.8
Unpaid work	91	82.4 [†]	91	70.8	78	56.4 [†]	87	62.1
Education		NA		NA	19	5.3	24	37.5
Household duties	91	91.7	91	94.8	209	93.3	212	94.8
Sports or other physical exercise	91	84.1	91	87.6	198	84.8	195	92.8
Going out	91	87.0	91	90.5	173	72.3	182	80.2
Day trips and other outdoor activities	91	87.8	91	93.0	195	76.4	202	86.1
Leisure activities at home	91	91.9	91	94.4	206	89.8	206	94.7
Visiting or receiving friends at home	91	91.7	91	96.3	213	81.7	211	85.8
Contacting others by phone or computer	91	94.8	91	93.9	215	94.0	217	96.3

NOTE. Significance testing between cohorts was only performed between corresponding assessment times (eg, T12 vs T12).

Abbreviation: NA, not applicable.

* The number of participants for whom data is available on the particular item or common denominator.

[†] $P < .0025$.

activity categories, it was not possible to include a direct comparison on this level.

Ambiguous or potentially inaccurate interpretations may also be a consequence of the method of forming congruent concepts. The USER-P items were adapted to fit the concept of retained activities of the ACS, wherein new activities (which were not performed premorbid but were performed post-stroke) were regarded as retained. For example, with recoding, a person who added a new activity (eg, 8h/wk of voluntary work) in addition to retained participation in paid work (eg, 20h/wk), would appear to have an increased level of participation (score 1+1), compared to a person retaining paid work at premorbid levels (eg, 40h/wk) (score 1). In this case, the number of hours of paid work is not accounted for in the interpretation, labeling level of retained activities as more favorable for the first person. In comparison, original scoring of the USER-P would view the second person with more spend hours as having a higher level of participation.

We justified cultural diversity by including cultural-specific activities on item level (eg, lawn bowls as a card of the ACS) and the fact that we were able to couple 94% of the ACS cards with the USER-P item. This led to a high degree of comparability. However, collapsing all (cultural-rich) items to the higher level of specific domains could be considered culturally-flawed, as cultural-specific information is then lost.

An international collaboration was established in this study which led to integration of cross-cultural information on activity participation post-stroke; advancing the understanding and harmonization of this concept across countries. In addition, a proof-of-principle analysis was performed to compare outcome measures, which has led to insights and considerations for future studies aiming to execute similar procedures.

Study limitations

Next to concomitant considerations, this study had some limitations. The time at which the first assessment was conducted differed between the cohorts by 1 month. Ideally, this timepoint would be at the same time post-stroke. Only limited significance testing was possible due to ethical limits in pooling data. Pooled data allows for more advanced significance testing which strengthens conclusions. Future studies should weigh the effort of meeting ethical requirements against the benefits of pooling data.

Conclusions

In this study we proposed and performed a new method for comparing the actual activities that persons re-engage in during the first year post-stroke across international cohorts. High levels of retained activities were observed for both cohorts at 1 year post-stroke. Interestingly, unpaid work and to a lesser extent paid work, showed differences at similar times in the recovery trajectory across cultures. Execution of the recoding method showed to be feasible with the important side note that (valuable) information will inevitably be lost. However, this was a first and valuable proof-of-principle study which can be repeated on already existing datasets. Important insights were gained from this method which can assist in the harmonization of 1 of the key outcomes post-stroke in the future: participation.

Keywords

Comparative study; Cross-cultural comparison; Feasibility studies; Rehabilitation; Social participation; Stroke

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