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ORIGINAL RESEARCH

Differences in Societal Participation Across Diagnostic Groups: Secondary Analyses of 8 Studies Using the Utrecht Scale for Evaluation of Rehabilitation-Participation

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Abstract

Objective: To determine differences in participation problems between diagnostic groups and to examine diagnosis as a determinant of participation with and without statistically accounting for confounders.

Design: Secondary analyses of data from 8 studies.

Setting: Community, the Netherlands.

Participants: Participants (N=1735) in diagnostic groups: stroke (n=534), subarachnoid hemorrhage (n=104), other acquired brain injury (n=163), progressive neurologic diseases (n=112), acute coronary syndrome (n=536), and spinal cord injury (n=286).

Interventions: Not applicable.

Main Outcome Measures: Participation was measured with the Utrecht Scale for Evaluation of Rehabilitation-Participation. This measure has 3 scales: Restrictions, Satisfaction, and Frequency. In this study, scores were also computed for 3 domains across these scales: Productivity, Leisure, and Social. Scores ranged from 0 (worst) up to 100 (best). Possible confounders were age, sex, level of education, marital status, and time since onset of the condition.

Results: Significant differences were found in levels of participation between diagnostic groups. Individuals with acute coronary syndrome showed better participation scores in all scales and domains compared with most or all other diagnostic groups, except for the Social domain. Individuals with progressive neurologic diseases showed the lowest (worst) Restriction and Satisfaction scores, whereas those with stroke showed the lowest Frequency scores. After correcting for confounders, diagnosis explained significant proportions of the variance of participation (Frequency, 6.4%; Restrictions, 15.1%; Satisfaction, 5.1%; Productivity, 13.2%; Leisure, 13.8%; Social, 6.9%).

Conclusions: Participation problems occurred in all 6 diagnostic groups within this study. Differences were found in participation between diagnostic groups, demonstrating diagnosis-specific participation profiles, including after correcting for confounders.

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Participation is defined as an individual's involvement in life situations in the International Classification of Functioning, Disability and Health (ICF). Participation is considered a human right and has evolved as one of the core outcomes of rehabilitation services.[1-3] Although supporting participation is embedded in rehabilitation practices, levels of participation are relatively low among individuals with a chronic illness or disability.[3] Previous studies on participation problems among individuals with spinal cord injury (SCI), stroke, subarachnoid hemorrhage (SAH), and spinal muscular atrophy (SMA) identified problems in participation domains such as mobility, education, work, recreation, leisure, sports, and partner relationships.[4-9] This makes it of great importance for rehabilitation practices to understand the key determinants of participation.[2]

According to the ICF, participation is influenced by the interaction between the health condition, impairments, activities, and personal and environmental factors.[10,11] Facilitators of participation in all settings were mostly found in social support and assistive technical devices, whereas barriers were often found in factors such as transportation modalities.[2,4] In the rehabilitation setting, positive associations were found between factors such as increased mobility, social relations and support, transportation, and good communication with increased levels of participation.[12-15] Furthermore, health condition-related factors associated with participation are age at diagnosis, comorbidity, level of activity after diagnosis, severity of diagnosis, and time since onset.[3,7] Lastly, according the ICF, personal factors also influence participation.[10] Age was found to be a predictor for participation levels after stroke.[16]

Little is known about the effect of diagnosis on participation. Studies which have evaluated participation after rehabilitation usually focused on one specific diagnosis or diagnostic group. Very few studies[17-19] were found in which levels of participation restrictions and satisfaction were compared across diagnostic groups. Therefore, it is not known whether participation problems are similar across diagnostic groups or if specific problems occur in diagnostic groups. Such knowledge could be useful for formulating specific rehabilitation goals for each diagnostic group.

Therefore, the aim of this study was to determine associations between diagnostic groups and participation patterns in terms of key domains. Demographic factors can be confounders of the association between type of condition and participation. Because differences in demographic factors were found across the diagnostic groups, analyses were done with and without statistically accounting for the available confounders of age, sex, level of education, marital status, and time since diagnosis.

List of abbreviations:

ABI	**acquired brain injury**
ACS	**acute coronary syndrome**
ANOVA	**analysis of variance**
ICF	**International Classification of Functioning, Disability and Health**
NEU	**neurologic and neuromuscular diseases**
SAH	**subarachnoid hemorrhage**
SCI	**spinal cord injury**
USER-Participation	**Utrecht Scale of Evaluation of Rehabilitation for Participation**

Methods

This study was a secondary analysis of studies that used the Utrecht Scale Evaluation Rehabilitation for Participation (USER-Participation).

Study selection

Studies were identified from the literature between October 2018 and January 2019. There was no timeframe for included studies; the first validation study was published in 2011. Criteria for inclusion were that the study was an original research study in which participation was measured with the USER-Participation in a health care setting and that the study was performed in the Netherlands. Twelve studies were identified. The corresponding authors were invited to make their dataset available. Two datasets were not available.[20,21] Another study analyzed data from partners of patients with stroke and was excluded for that reason.[22] Nine datasets were sent through a secured data transfer to the first author and warehoused in a secured digital environment.

Selection of participants

Five datasets consisted of longitudinal data. For those, the last follow-up measurement was used because that measurement reflected the chronic situation the best. Included datasets were merged into a single dataset (N=2432). Participants with similar diagnoses were merged into homogenous diagnostic groups. Participants were eliminated if USER-Participation scale scores could not be computed owing to missing item scores (n=476), if the participant's diagnosis was not evident (n=128), or if it was not possible to form a homogenous diagnostic group of reasonable size (chronic pain, n=64;[23] visual impairment, n=29[24]). A total of 1735 participants from 8 different studies were included. Included studies are displayed in appendix 1 and table 1.[8,9,23,25-29]

Instrument

The USER-Participation is a measure with 3 scales: Frequency of Participation, Participation Restrictions, and Satisfaction with Participation. Reproducibility of the 3 scales was moderate to good.[30] The USER-Participation showed good concurrent validity and responsiveness in a prospective study.[23] Scores on all scales did not show strong intercorrelations, which demonstrates the usefulness of the separate scales.[31] The Restriction and Satisfaction scales fitted the Rasch model after minor adjustments. For the Frequency scale, Rasch analysis was considered not applicable.[32]

The Frequency scale consists of 11 questions on the frequency of performance of activities such as housekeeping, visiting friends, or work. Four items are scored in hours per week "as usual" and the remaining 7 items are scored in frequency of performance in the previous 4 weeks. Scores are rated with a 6-point scale from 0 (none/never) to 5 (≥36h or ≥19 times). The Restriction scale consists of 11 items similar to those in the Frequency scale but asks questions on experienced Restrictions rated with a 4-point scale from 0 (not possible) to 3 (without difficulty). The Satisfaction scale consists of 10 items related to how satisfied one is with the activities scored above, rated with a 5-point scale from 0 (very dissatisfied) to 4 (very satisfied). For each scale, a total score is computed with a theoretical range from 0 (very poor participation)

Table 1 Diagnostic groups created from 8 included datasets

Original Study Diagnosis	Participants in Selected Studies, n*	Current Study Diagnostic Group	Participants Per Diagnostic Group, n
Brain tumor	135[26]	ABI†	163
Other brain injury (traumatic brain injury, meningitis, and other)	28[23]		
Stroke	324[28]	Stroke‡	534
	105[29]		
	105[23]		
SMA	62[8]	Progressive NEU	120
Progressive NEU	50[23]		
SAH	104[9]	SAH	104
ACS	536[27]	ACS	536
SCI	267[25]	SCI	286
	19[23]		
Total			1735

* Number of participants after removing participants without follow-up, participants with an unclear diagnosis, and diagnostic groups that were too small (<100).
† Without stroke and SAH.
‡ Without SAH.

to 100 (excellent participation). Despite this equal range, scores are not directly comparable across scales because it is easier to reach the maximum score on the Restrictions scale (indicating no restrictions) compared with the Frequency scale (indicating the maximum frequency for all activities, which is impossible).

To analyze differences with respect to participation domains, we grouped all similar items into 3 new domains: (1) Productivity, including paid work, unpaid work, education, and housekeeping; (2) Leisure, including transportation, physical exercise, going out, outdoor activities, and leisure indoors; and (3) Social, including relationships with partner, family, and friends. Such a distinction is theoretically founded in the ICF (chapters 7, 8, and 9),[2,33] respectively, and has been confirmed in empirical research.[34,35] For each domain, a total score was computed that ranged from 0 to 100. This novel structure of the USER-Participation is shown in figure 1.

Possible confounders included age, sex, marital status, level of education, and time since onset. Marital status was recoded as single (never married, divorced, or widowed) or partnered (married, cohabitating, or in a relationship). Level of education was coded as low or high, with high indicating that the participant completed high school, college, or university.

Statistical analyses

In 2 studies,[9,23] the preliminary version of the USER-Participation was used. A standard recoding procedure for this situation was applied to convert the scores into scores from the final version of the USER-Participation, as shown in appendix 2.[36] Analyses were performed using IBM SPSS Statistics, version 25.[a]

Descriptive analyses were used to describe characteristics of the participants and the distributions of the participation scores in the various diagnostic groups. One-way analysis of variance (ANOVA) was used to determine whether there were statistical differences between the levels of participation, in both scales and domains, between the diagnostic groups. Pairwise comparisons between diagnostic groups were performed using the Bonferroni correction. Differences were considered statistically significant in case of P values <.05. Finally, multiple regression analyses were used to determine whether diagnostic groups still explained variance in levels of participation after correcting for confounders. The variable diagnostic group was entered as a series of dummy variables and added in a separate block from the confounders. In the first model, possible confounders were added. In model 2, all dummy diagnostic groups were added with stroke as the reference category.

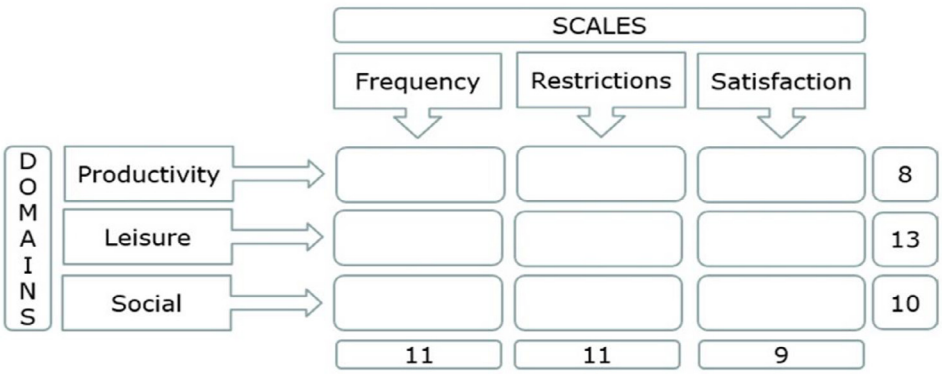


Fig 1 USER-Participation: the 31 questions divided over the scales and domains.

Table 2 Characteristics of included patients

Characteristics No. of Participants	Total (N=1735)	Stroke (n=534)	SCI (n=286)	SAH (n=104)	ABI (n=163)	NEU (n=112)	ACS (n=536)
Sex, %							
Male	64	62.9	72.7	34.6	28.8	42	81.3
Female	36	37.1	27.3	65.4	71.2	58	18.7
Educational level, %							
Low	56.6	67.8	30.4	69.2	54	50	59.1
High	37.5	29	68.9	27.9	39.9	45.5	28.7
Missing	5.9	3.2	.7	2.9	6.1	4.5	12.1
Marital status, %							
Single	24.1	25.8	38.1	14.4	28.2	31.3	14.2
Partnered	69.6	73.6	61.9	52.9	69.3	66.1	73.7
Missing	6.3	.6	0	32.7	2.5	2.7	2.1
Age, mean ± SD, y	57.6±12.8	63±12.8	47.9±9.2	55.6±11.8	57.1±13.4	46.6±15.6	60.3±8.9
Inclusion source, %							
Hospital	70.6	72.7	0	100	82.8	55.4	100
Rehabilitation center	29.4	27.3	100	0	17.2	44.6	0
Time since onset of condition, mean ± SD, y	6.7±11	1.9±1.2	22.7±10.2	.9±.3	2.9±1.7	22.1±20.1	1.8±.5

Results

The stroke (n=534) and acute coronary syndrome (ACS) (n=536) groups included the highest number of participants, and the SAH group included the lowest number (n=104). Participants with SCI had a higher level of education compared with the other diagnostic groups. In the SCI and ACS groups, most participants were men, whereas the acquired brain injury (ABI) group consisted mainly of women. Furthermore, differences were present in the time between onset of condition and the study. Individuals with SCI and progressive neurologic and neuromuscular diseases (NEU) showed a long time since diagnosis compared with the other groups, especially SAH, with less than 1 year since diagnosis. Information on characteristics of the participants can be found in table 2.

Total sample

The Frequency scale showed a mean score ± SD of 32±11.6. The highest score on the Frequency scale was 68 (out of a possible score of 100). The Restrictions scale showed a mean score of 80.6±22.3, and 33.3% (n=561) of the participants had the maximum score of 100. The mean score on the Satisfaction scale was 69±18.2, and 2.8% (n=47) of the participants showed the maximum score of 100.

With respect to the participation domains, levels of participation were highest in the Social domain. The lowest scores were found in the Productivity domain. In all domains, a maximum score of 100 was reported by .1% or .2% (n = 1 or 2) of the participants.

Differences between diagnostic groups without correction for confounders

The range between the lowest and the highest mean Frequency scores per diagnostic group was <1 SD. This range was much wider for the Restriction and Satisfaction scales, which indicates that diagnostic groups score more similar on Frequency. With respect to the participation domains, within the Productivity and Leisure domains, the range between the lowest and highest scores was almost 2 SDs. In the Social domain, this range was <1 SD, which indicates that diagnostic groups score more similarly in the Social domain. An overview of all scores can be found in table 3 and figures 2 and 3.

The one-way ANOVA analyses indicated significant differences between diagnostic groups in all scales and domains. Individuals with NEU and ACS showed the most significant differences with other diagnostic groups, with the ACS group scoring higher and the NEU group scoring lower than the other diagnostic groups. These differences were not consistent across all scales. For example, participants with ABI and SAH showed similar scores on the Frequency and Satisfaction scales, but participants with ABI showed much higher scores on the Restrictions scale compared with individuals with SAH. Furthermore, participants with ABI showed similar scores in Satisfaction compared with individuals with SCI, whereas participants with SCI scored much lower on the Restrictions scale and the Productivity and Leisure domains than participants with ABI. All outcomes are displayed in table 3.

Differences in levels of participation between diagnostic groups with correction for confounders

After correcting for the confounders age, sex, educational level, marital status, and time since onset, diagnosis still explained significant proportions of the variance in participation scores. Diagnosis explained the most variance (15.1%) of the Restriction scale scores and the least variance (5.1%) of the Satisfaction scale scores (table 4).

Discussion

In this study, we found differences in levels of participation between individuals with different diagnoses, thereby showing diagnosis-specific participation profiles. We found that participants with ACS showed the highest levels of participation and

Table 3 Total participation scores within the diagnostic groups

Scales	Total (N=1735)	Stroke (n=534)	SCI (n=286)	SAH (n=104)	ABI (n=163)	NEU (n=112)	ACS (n=536)
Frequency, mean ± SD	32.7±11.6	29.4±12.3^{Sc,A,H}	33.4±10.4^{H,St}	30.1±11.4^{H}	32.8±10.9^{St,H}	30.4±12^{H}	36.3±10^{St,Sc,Sa,A,N}
N	1702	532	286	87	163	99	535
Restrictions, mean ± SD	80.6±22.3	77.5±22^{Sa,N,H}	76.4±19^{N,H}	68.5±24.6^{A,N,H}	81.1±21.1^{Sa,N,H}	52.2±25.1$^{St,Sc,Sa,A,\ H}$	94.6±11.5^{St,Sc,Sa,A,N}
N	1699	527	284	101	159	112	516
Satisfaction, mean ± SD	69.0±18.2	66.7±18.5^{N,H}	68.8±15.6^{N,H}	65.5±22.8^{N,H}	68±20.5$^{N,\ H}$	56.3±18.8^{St,Sc,Sa,A,H}	74.6±15.4^{St,Sc,Sa,A,N}
N	1696	511	283	96	152	110	526
Domains							
Productivity, mean ± SD	53±18.3	49.2±18.4^{N,H}	47.2±17^{A,N,H}	42.1±20.9^{A,H}	53.6±18.8^{Sc,Sa,N,H}	38±17.4^{St,Sc,A,H}	64.1±11.7^{St,Sc,Sa,A,N}
N	1494	459	279	69	137	81	469
Leisure, mean ± SD	63.2±17.2	60.7±17.5^{Sa,N,H}	60.3±13.9^{Sa,N,H}	50.9±20.7^{St,Sc,A,H}	62.4±18.2^{Sa,N,H}	44.2±18^{St,Sc,A,H}	72.7±11.3^{St,Sc,Sa,A,N}
N	1529	465	273	61	146	95	489
Social, mean ± SD	71.2±12.5	69.6±13.8^{Sc,N,H}	73.6±11.1$^{St,\ N}$	71.7±12^{N}	72.3±13.9^{N}	61.9±15.2$^{St,Sc,Sa,\ A,H}$	72.9±9.6^{St,N}
N	1597	493	280	78	148	99	499

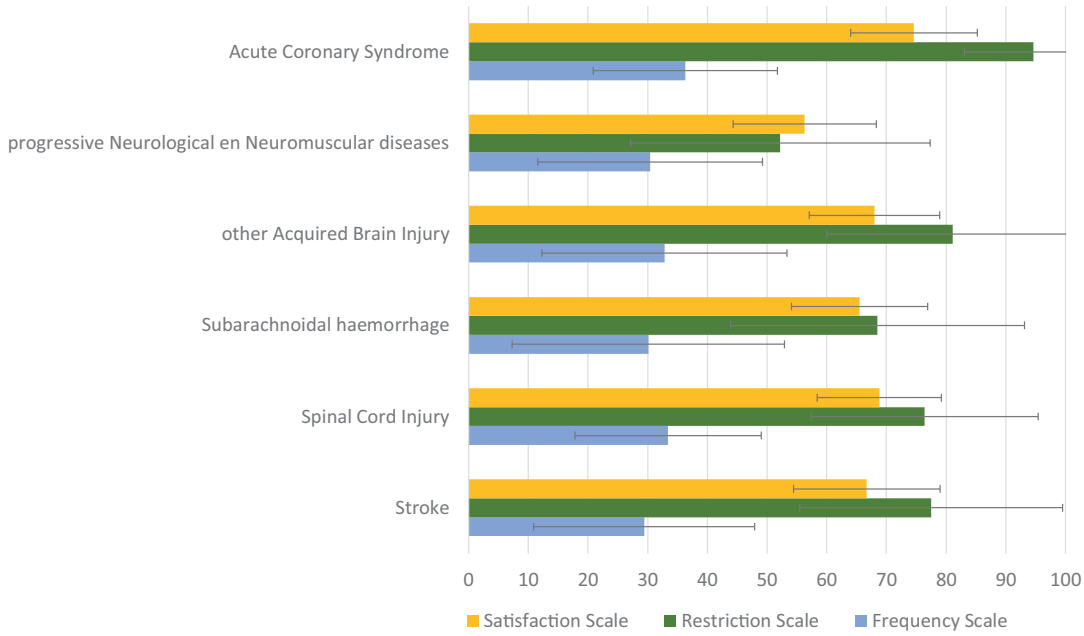
NOTE. Groups were compared with the 1-way ANOVA test. All significant differences are identified with: A (ABI), H (ACS), N (NEU), Sa (SAH), Sc (SCI), and St (stroke). All scores ranged from 0 (worst) to 100 (best).

participants with NEU the lowest. Overall, the most participation problems occurred in the Productivity domain and the least in the Social domain. Individuals with ACS showed a contradictory profile, with high scores in all participation domains, compared with more fluctuation in the scoring in other diagnostic groups. After correcting for confounders, diagnosis still explained significant proportions of the variance of participation.

Differences between diagnostic groups

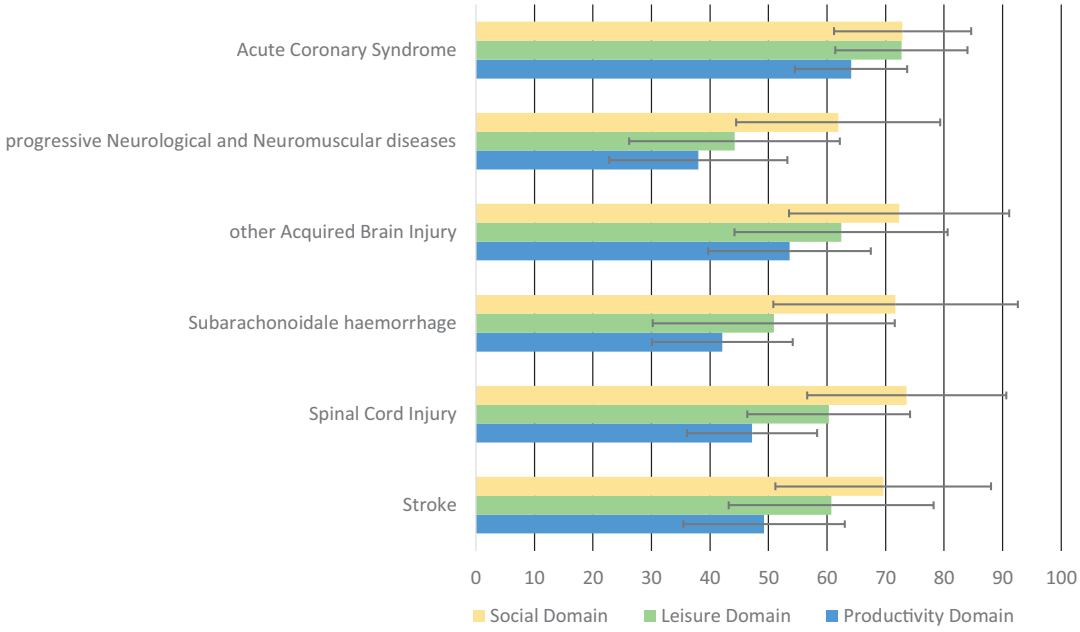
Only a few studies were found in which comparisons between diagnostic groups were made concerning participation levels. In contrast with our results, 1 study using the Impact on Participation and Autonomy scale found more participation problems among participants with stroke compared with individuals with SCI or neuromuscular diseases.[17] This variance could possibly be explained by a difference in sampling frames; patients in that study were recruited through rehabilitation hospitals[18] vs recruitment through acute hospitals in our study. Also, the diagnostic groups in the other study were small (21-31 participants each),[18] which increases the risk of type 1 error.

In agreement with our results, a study using the World Health Organization Disability Assessment Schedule 2.0 showed lower levels of participation for individuals with neurologic diseases compared with individuals with circulatory diseases.[18,19] However, it is unclear whether the group of circulatory diseases included both patients with stroke and patients with ACS. Furthermore, in our study, the neurologic diseases category consisted of individuals with progressive NEU. In the comparison study, the neurologic diseases category included individuals with spina bifida, Parkinson disease, and Guillain Barre syndrome.[18,19]



*Higher scores mean better levels of participation.

Fig 2 Total participation scores in the scales for the different diagnostic groups.



*Higher scores mean better levels of participation.

Fig 3 Total participation scores in the domains for the different diagnostic groups.

Differences in levels of participation between diagnostic groups will, to a large degree, be attributable to differences in physical, cognitive, and behavioral impairments resulting from the respective conditions.[37,38] For example, high independence in activities of daily living was associated with higher levels of participation,[29] whereas cognitive limitations were associated with lower levels of participation.[23] Lower motor skills and higher levels of depression for individuals with SMA also resulted in lower levels of participation.[26] Lastly, individuals with paraplegia showed higher levels of participation in most participation

Table 4 Influence of diagnosis on participation scales and domains after correcting for confounders, with stroke as reference category

Scales	Model 1 R^2	Model 2 R Change	*P* Value	Diagnosis With Significant B	B	95% Confidence Interval
Frequency	.066	.064	<.001	ACS (<.001)	6.7	5.3-8.1
Restrictions	.145	.151	<.001	SCI (.048)	4.3	.03-8.5
				SAH (.001)	−8.1	−12.8 to −3.4
				ABI (.003)	5.3	1.8-8.9
				NEU (<.001)	−19.7	−24.9 to −14.6
				ACS (<.001)	15.9	13.5-18.3
Satisfaction	.026	.051	<.001	SCI (.024)	4.6	.6-8.5
				NEU (.002)	−7.6	−12.4 to −2.8
				ACS (<.001)	7.8	5.6-10.1
Domains						
Productivity	.106	.132	<.001	SAH (<.001)	−8.7	−13.4 to −4.1
				ABI (.002)	5.2	1.9-8.5
				NEU (<.001)	−11.5	−16.4 to −6.7
				ACS (<.001)	13.5	11.4-15.7
Leisure	.088	.138	<.001	SAH (<.001)	−11.2	−16.1 to −6.4
				NEU (<.001)	−14	−18.3 to −9.7
				ACS (<.001)	11.7	9.6-13.7
Social	.016	.069	<.001	SCI (<.001)	8.6	5.8-11.4
				NEU (.004)	-4.9	−8.3 to −1.5
				ACS (<.001)	3.9	2.3-5.5

NOTE. Assesed with linear multiple regression analyses. Two models were added, the first with the confounders of age, sex, level of education, marital status, and time since injury. The second block was all diagnostic groups as dummy variables and with stroke as a reference category. Outcome categories were the 3 participation scales and the 3 participation domains.

domains compared with individuals with tetraplegia.[28] A Swiss study also showed associations between severity of the SCI and lower levels of participation.[39] We could not take these physical, cognitive, and behavioral factors into account in the current study, however, because these were measured with different scales in the included studies.

According to our study, individuals with ACS showed the highest levels of participation in all scales and in 2 domains (Leisure and Productivity). Individuals with SCI showed the highest score in the Social domain. Those 2 diagnostic groups often express with only physical impairments. As for individuals in the NEU diagnostic group, our study showed lower levels of participation compared with other diagnostic groups. Progressive NEU often appear with physical, behavioral, and cognitive impairments, as well as a continuously changing health situation. This may explain the lower levels of participation in this group found in this study.[40-42] This same combination of impairments was found in a study with individuals with traumatic ABI. Almost half of the individuals in that study experienced physical problems in combination with cognitive, behavioral, and social problems or impairments. This combination of impairments could explain lower levels of participation for these diagnostic groups compared with individuals with SCI or ACS.[43]

Patterns in domain scores

Our analyses showed that diagnoses appear to have more influence on an individual's productivity level and leisure score and less on their social participation levels. To compare with other studies, 1 study also found differences in perceived restrictions in the social relations between diagnostic groups to be smaller compared with the perceived restrictions in the Autonomy Indoors, and Work and Education domains,[18] which are related to the Productivity and Leisure domains. A study on health-related quality of life demonstrated major differences in physical functioning between 4 diagnostic groups (SCI, ABI, NEU, chronic pain). That same study also evaluated social functioning of those diagnostic groups and found that outcome scores were closely related to each other.[44] A validation study of a measurement instrument for participation[38] was partially in agreement with our study results. Disease characteristics, wherein functional status showed a stronger correlation with the Productivity domain compared with the Social domain. In contradiction with our results was that they found that the Social, Functional, and Community domains were all influenced by an individual's functional status, which is often influenced by diagnosis.[38]

Apparently, the level of social participation is less influenced by only diagnosis compared with the other domains. Apparent from our study results is that individuals in all diagnostic groups do not experience many problems with social contacts or visits. A possible explanation for this could be that an individual does not have to leave their house for social contact. Another explanation for diagnosis having less influence on social participation is that other influences of personal and environmental factors, alongside the health condition itself,[45] are often underestimated.[46] It can be argued that this would influence the other domains of participation as well. A decrease in levels of social participation was correlated with the social role of a person,[17] instead of diagnosis or impairment. A study on individuals with stroke determined mood as the major predictor for social-based participation.[47] Lastly, social support is experienced as a facilitator for higher levels of participation.[2,5]

Implications

Our results showed that participation problems occur in all diagnostic groups and may support the statement that rehabilitation specialists must maintain a focus on a patient's participation and role in life (ie, being a mother) during the whole trajectory. Participation is a complex construct with multiple domains. For clinical practice, it would be recommended to measure different domains of participation to ensure that all aspects of an individual's participation are apparent. This means specified questions concerning all important domains.

Study limitations

The number of participants per diagnostic group differed. Small groups were less likely to show significant differences with other groups compared with larger groups, which could obscure differences between some of the diagnostic groups in this study. We were dependent on what data were collected, which differed between studies. We could not take levels of impairments and comorbidities into account, as well as a limited number of personal factors.

The USER-Participation is a validated tool used throughout Dutch health care. For this study, we did not add or omit any questions, but we did calculate 3 new domain scores: Productivity, Leisure, and Social. Such a distinction was theoretically founded in the ICF because these domains relate to ICF activities and participation (chapter 7, 8, and 9).[2,33] In addition, empirical evidence for this distinction has been found in other research on participation measures.[34,35] Nevertheless, validity and reliability are recommended to confirm this new scoring system concerning the Functional, Leisure, and Social domains. Lastly, only datasets of studies conducted in the Netherlands and of authors willing to share their datasets were used. This means that the outcomes of this study apply only to the Dutch situation. More research needs to be done to compare participation outcomes internationally through different domains.

Conclusions

In conclusion, the results of this study indicate clear differences in levels of participation between different diagnostic groups. Individuals with ACS reported higher levels of participation compared with other diagnostic groups. Individuals with NEU reported the lowest levels of participation. However, diagnosis appears to have less influence on social participation compared with productivity and leisure. The diagnosis-specific participation profiles described in this study could provide a context for rehabilitation professionals to set diagnosis-specific participation goals.

Supplier

a. IBM SPSS Statistics, version 25; IBM Corp.

Keywords

Diagnosis; Patient Reported Outcome Measure; Rehabilitation; Social participation

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Appendix 1. Overview of All Included Studies

Study Name or Diagnostic Group	Main Inclusion Criteria	Sample Size and Demographic Characteristics	Measurement Moments and Time Point Used in the Current Study	Disease Characteristics
Restore4Stroke Cohort study[28]	Patients admitted to general hospitals with clinically confirmed stroke within the past 7 d; age ≥18 y	390 participants; mean age, 67.4 y; 71% were discharged to their home, 15.1% to a rehabilitation center, and 13.8% to a nursing home	T1: within 1 wk after stroke T2: 2 mo poststroke T3: 6 mo poststroke T4: 12 mo poststroke T5: 24 mo poststroke	Ischemic stroke: 93.2% Left hemisphere: 40.6% Median Barthel Index at 6 mo: 20 (range, 4-20 mo) Median MoCA at 6 mo: 25 (range, 9-30)
ALLRISC cross-sectional study[25]	Former patients of SCI rehabilitation centers, wheelchair users, >10 years post-SCI, and age ≥18 y	292 participants Mean age, 48.4 y 73.6% male	Cross-sectional study design Mean time ± SD: 24± 9 y post-SCI	Tetraplegia: 40.4% Motor complete SCI: 81.9%
Cerebral meningioma[26]	Patients who underwent operation at the University Medical Center Utrecht between 2007 and 2009, age ≥18 y	194 participants Mean age, 59.1 y 22% male	Cross-sectional study design Mean time ± SD: 32.6±10.6 mo postsurgery	WHO classification: Grade 1: 86% Grade 2: 17% Grade 3: 2% Complete resection: 71%
Restore4Stroke Self-Management[29]	Patients with symptomatic stroke and participation problems, age ≥18 y	113 participants Mean age, 57 y 52.2% male	T1: 1-2 y poststroke, at the end of the intervention T2: 3 mo after the end of the intervention T3: 9 mo after the end of the intervention (Mean time: 27.8 mo poststroke)	Infarction: 82.7% Right hemisphere: 45% Barthel Index: 18.7
Validation USER-Participation[23]	Multidiagnostic group of outpatient rehabilitation patients aged ≥18 y	395 participants Mean age, 52.1 y 53.4% male	T1: within the first 2 wk after rehabilitation T2: at the end of rehabilitation T3: 4 mo after rehabilitation (Mean time: 13.5 mo postdiagnosis)	Musculoskeletal: 17.5% Brain Injury: 34.9% Neurological diseases: 22% Chronic pain injury: 14.7% Heart failure: 9.9% Other: 1%
SAH[9]	Patients treated at the University Medical Center Utrecht, ADL independent, age ≥18 y	120 patients Mean age, 54.8 y 45.2% male	T1: 3 mo post-SAH T2: 6 mo post-SAH T3: 12 mo post-SAH (Mean time ± SD: 10.5±3.5 mo post-SAH)	WFNS score on admission: I: 58% II: 26% III-V: 14% Unknown: 2%
SMA[8]	Outpatients of the University Medical Center Utrecht, age ≥18 y	62 participants Mean age, 43 y 45% male	Cross-sectional (no timeframe available)	Type of SMA: Type 1: 6.5% Type 2: 33.8% Type 3a: 21% Type 3b: 32.3%

(*continued on next page*)

(*Continued*)

Study Name or Diagnostic Group	Main Inclusion Criteria	Sample Size and Demographic Characteristics	Measurement Moments and Time Point Used in the Current Study	Disease Characteristics
				Type 4: 6.4% MHFSE score median 3.5 (range, 0-66)
OPTICARE[27]	Patients with ACS referred for a cardiac rehabilitation program, age ≥18 y	740 participants Mean age, 57 y 81.1% male	T1: 3 mo after the start of the program T2: 12 mo after the start of the program (end of the program) T3: 18 mo after the start of the program (6 mo after the program)	Therapeutic intervention: No revascularization: 8% Percutaneous coronary intervention: 77.6% Coronary artery bypass graft: 14.5%

Abbreviations: ADL, activities of daily living; HFMSE, Expanded Hammersmith Functional Motor Scale; MoCA, Montreal Cognitive Assessment; SMA, spinal muscular atrophy; WHO, World Health Organization, WFNS, World Federation of Neurological Surgeons scales.

Appendix 2. Short Summary: Converting the Old Version of the USER-Participation to the New Version

- Items removed in the new version will not be calculated.
- Items added in the new version will be taken as missing.
- Items split into 2 items in the new version will be calculated 2 times.
- Items merged into 1 item in the new version will be calculated by the mean score of both.

Agreement between the old version and the new version

Scale	Difference in Scores, Mean ± SD	Effect Size	Intraclass Correlation Coefficient	*P* Value
Frequency scale	2.40±2.09	.22	.982	<.001
Restriction scale	0.29±1.37	.02	.997	<.001
Satisfaction scale	−2.82±4.83	.21	.947	<.001

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