

## RESEARCH ARTICLE

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### Living with stroke in Northern Cyprus: Which ICF-Based Biopsychosocial Factors are Related to Community Participation?

Kurtaran et al. Community Participation of People Living with Stroke

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#### Abstract

**BACKGROUND/AIMS:** Improved treatment and rehabilitation care opportunities are resulting in increased numbers of stroke survivors. Accordingly, well-preserved community participation of stroke survivors is becoming more important to maintain a person's psychological and social status to improve their quality of life. This study aimed to investigate the relationships among sociodemographic characteristics, clinical characteristics, International Classification of Functioning, Disability and Health (ICF)-based biopsychosocial factors, and community participation of stroke survivors living in Northern Cyprus.

**MATERIALS AND METHODS:** This cross-sectional study recruited 43 participants. The sociodemographic and clinical characteristics of the participants were recorded. Functional Independence Measure (FIM), Stroke Impact Scale 3.0 (SIS), Fall Efficacy Scale (FES), Fatigue Severity Scale (FSS), Beck Depression Inventory (BDI), Measure of Quality of the Environment-Short Form (MQE-SF), and the Community Integration Questionnaire (CIQ) were used to collect data.

**RESULTS:** The participants who did not use assistive devices had higher community participation ( $p < 0.05$ ). On the other hand, sex, lesion type, and affected body side did not have relationship with community participation ( $p > 0.05$ ). As the Brunnstrom stages (Upper extremity:  $r: 0.455$ ,  $p: 0.002$ ; Lower extremity:  $r: 0.608$ ,  $p: 0.000$ ) of the participants and their scores in FIM ( $r: 0.809$ ,  $p: 0.000$ ), SIS ( $r: 0.766$ ,  $p: 0.000$ ), and MQE-SF ( $r: 0.467$ ,  $p: 0.002$ ) increased, their CIQ scores increased ( $p < 0.05$ ). However, as the age of the participants ( $r: -0.413$ ,  $p: 0.006$ ) and their FES ( $r: -0.752$ ,  $p: 0.000$ ), FSS ( $r: -0.479$ ,  $p: 0.001$ ), and BDI ( $r: -0.783$ ,  $p: 0.000$ ) scores increased, their CIQ scores decreased ( $p < 0.05$ ).

**CONCLUSION:** To increase their community participation, stroke survivors need to be assessed holistically by considering all factors of the ICF model and including multidisciplinary rehabilitation, which will lead to better rehabilitation outcomes. Community participation level of stroke survivors living in Northern Cyprus were related to the factors of the ICF base biopsychosocial level

**Keywords:** Stroke, community participation, ICF

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## INTRODUCTION

Disease-related limitations in the biological system affect the psychological and social aspects negatively, which in turn limits community participation among stroke survivors. Recently improved treatment and rehabilitation care opportunities are resulting in increased numbers of stroke survivors.<sup>1</sup> Therefore, it is therefore important for this population not to be isolated from society, so that they continue to participate actively in the community, as their activity and participation levels are related to their quality of life.<sup>2</sup>

The International Classification of Functioning, Disability and Health (ICF) is a classification system that is based on biopsychosocial factors and aims to improve health-related issues.<sup>3</sup> It examines body structure, functions, activity, and participation, the capacity of individuals to perform their functions, and their communication with the environment.<sup>4</sup> As described by the ICF, environmental factors constitute the physical and social context in which people live and maintain their lives. Personal factors include those in an individual's life that are not a part of their health status. Contextual factors can have a positive or negative effect on an individual's bodily functions and physiology, behaviours or capacity to perform tasks, and community participation.<sup>5</sup> Therefore, it is important to understand the community participation levels of stroke survivors to increase their quality of life.

Studies on community participation in stroke survivors have mostly been conducted in developed countries such as the United States, Northern Ireland, and Australia.<sup>6,7,8,9</sup> It is important to identify the ICF-based biopsychosocial factors that are related to the community participation of stroke survivors in a socioeconomically diverse country such as Northern Cyprus.

### Aims

It is aimed to determine the amount of relation of sociodemographic and ICF-based biopsychosocial factors with the community participation of stroke survivors living in Northern Cyprus. The results of this study will shed light on the development of appropriate strategies for participation and introduction of mechanisms to facilitate the community participation of this population. This research will also help to understand if this concept of the ICF is also relevant for the stroke survivors who lives in North Cyprus to understand if culture has any impact that ICF-based biopsychosocial factors are related to the community participation of stroke survivors in Northern Cyprus.

## MATERIALS AND METHODS

### Design

This is a cross-sectional analytical study conducted between January 2020 and May 2020 with stroke survivors in a private rehabilitation centre at the Northern Cyprus, after obtaining

the ethical approval numbered ÜEK/50/01.02/1920/10, date: 11.02.2020 from the University Ethics Committee of European University of Lefke. The population of the study included individuals who presented to the neurology inpatient clinics of a public hospital and a private hospital in the last five years. People who met the inclusion criteria were informed about the study, and written consent was obtained from those who agreed to participate.

### **Participants**

Fifty-three stroke survivors were invited to the study by systematic sampling method. Registration numbers at hospitals have been listed and sixth person is chosen randomly, followed by every subsequent sixth person. All chosen individuals have been invited. (n= 53) Some individuals (n=10) were not included because they either did not want to participate (n=8) or could not spare time to be evaluated (n=2). As a result, 43 participants were included.

### **Inclusion/Exclusion Criteria**

The inclusion criteria were living in Northern Cyprus who can speak and write in Turkish diagnosed with stroke for the first time by a neurologist, being 45-80 years old, having had a stroke at least three months ago, and being able to cooperate and agree to participate in the study (Mini mental test $\geq$ 24). The exclusion criterion was determined as having other neurological disorders or other diseases affecting the musculoskeletal system.

### **Data Collection Tools**

The sociodemographic and clinical characteristics of the participants were recorded on personal information and clinical information forms. The sociodemographic data of the participants included their age, sex, smoking status and alcohol intake, education status, while the clinical information form included affected side of the body, duration of stroke, walking aid usage status, and lesion type.

The data collection instruments included the Functional Independence Measure (FIM) to determine functional levels in activities, the Brunnstrom Stage Assessment to assess the stage of recovery, the Stroke Impact Scale (SIS) for assessing disease status and limitations in daily activities, the Falls Efficacy Scale (FES) to assess self-efficacy related to falls, the Fatigue Severity Scale (FSS) to determine fatigue levels, the Beck Depression Inventory (BDI) to assess depression, the Measure of Quality of the Environment-Short Form (MQE-SF) to determine environmental factors, and the Community Integration Questionnaire (CIQ) to assess community participation. Turkish language versions of all measures, which were validated, were used.

Data collection has been performed by the primary investigator, who works as a physiotherapist and each assessment took 45-50 minutes according to the participants. However, breaks for 10 minutes took place in between the assessment if requested by the participants.

### **Stage of Motor Recovery**

The Brunnstrom Stage Assessment was used to assess the stage of recovery for the upper and lower extremities. It is an approach developed by Signe Brunnstrom in 1960s that has six stages to understand how motor control can be restored to gain functionality after a stroke.<sup>10</sup> Higher scores mean better improvement. It is a valid, reliable, and responsive stroke-specific and commonly used tool that helps classify the motor level of stroke survivors after stroke.<sup>11-</sup>

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### **Functional Level in Activities**

The Functional Independence Measure (FIM) is an 18-item scale that evaluates both the physical (13 items) and cognitive (five items) functions of an individual to evaluate them in terms of personal care, sphincter control, transfer, mobility, communication, and social-cognitive status.<sup>14</sup> The validity and reliability study of the scale in Turkish was carried out by Ayşe Küçükdeveci.<sup>15</sup>

### **Community Participation**

The Community Integration Questionnaire (CIQ) consists of 18 items and evaluates three variables consisting of home participation, community participation, and productivity and work-school activity.<sup>16</sup> The validity and reliability of the scale in Turkish were tested by Akyürek et al.<sup>17</sup>

### **Limitations in Activities of Daily Living**

The Stroke Impact Scale Version 3 (SIS) was specifically developed for stroke survivors. It is a scale developed by Duncan et al. to evaluate the quality of life of people who experience loss of mental and physical function after a stroke, depending on the extent of the impact of stroke.<sup>18</sup> In this scale, which consists of eight domains and 59 items, each item is evaluated by scoring difficulties experienced in the last seven days on a 5-point Likert-type scale. The validity and reliability study of the scale with Turkish stroke survivors was performed by Hantal et al.<sup>19</sup>

### **Self-Efficacy Related to Falls**

The Fall Efficacy Scale (FES) was developed by Tinetti et al.<sup>20</sup> It aims to investigate the self-efficacy of stroke survivors regarding falls they experience while fulfilling activities of daily living. This scale consists of 10 items which determine their self-efficacy while performing activities, such as how confident they are that they can dress and undress without falling.<sup>20</sup> Higher scores indicate higher self-efficacy levels. The Turkish language validity and reliability study of the scale was conducted by Ulus et al.<sup>21</sup>

### **Level of Fatigue**

The Fatigue Severity Scale (FSS) was developed by Krupp et al.<sup>22</sup> It is a 7-point Likert-type scale (1=strongly disagree, 7=strongly agree) consisting of nine items, and the total score of the scale is found by averaging the scores of all nine items. Getting a score of four or higher indicates the presence of pathologic fatigue. The Turkish validity and reliability study of the scale was conducted by Armutlu et al.<sup>23</sup>

### **Level of Depression**

The Beck Depression Inventory (BDI) was developed by Beck et al.<sup>24</sup> The purpose of this scale is to objectively measure the level of depression symptoms possessed by an individual. It determines the behavioural pattern that is specific to depression and includes 21 evaluation statements with four options each. The Turkish validity and reliability study of the scale was conducted by Hisli.<sup>25</sup>

### **Environmental Factors**

The Measure of Quality of the Environment-Short Form (MQE-SF) was tested for reliability by Boschen.<sup>26</sup> The scale is a modified ICF format measure created specifically for people with different degrees and types of disability. The five dimensions of this scale include 26 items aiming to assess the impact of the environment on the success of a person's daily activities by considering their abilities and limitations. The respondent scores whether their daily activities are facilitated or obstructed by environmental factors. The validity study of MQE-SF in Turkish was conducted by Gökçen Akyürek.<sup>27</sup>

### **Statistical Analysis**

The Statistical Package for the Social Sciences (SPSS) 25.0 program was used for the statistical analyses of the collected data. Percentage, mean and standard deviation values were calculated for the sociodemographic and clinical data.

Based on the Shapiro-Wilk test that was conducted in the study, the FIM, CIQ, SIS, FES, FSS, BDI, and MQE-SF scores of the participants were not normally distributed.

Accordingly, Mann-Whitney U test was used to compare the CIQ scores of the participants based on their sex, use of walking aids, affected body side, and lesion type. The relationships between the participants' FIM, SIS, FES, FSS, BDI, and MQE-SF scores and their CIQ scores were examined with Spearman's correlation test. The degree of correlation was defined as

low if the coefficient was lower than 0.3, moderate if it was between 0.3 and 0.5, and strong if it was greater than 0.5. The level of statistical significance was determined as  $p < 0.05$ . As a result of the power analysis, the sample size was determined as 43 participants to provide 80% power in a 95% confidence interval.

## RESULTS

Forty-three individuals participated in the study (13 female, 30 male, mean age:  $70.67 \pm 8.22$ ). Table 1 shows the sociodemographic and clinical characteristics of the participants.

Descriptive statistics were calculated regarding the stroke-related scores of the participants and their scores in the Brunnstrom Stage Assessment (Upper/Lower extremity), FIM, SIS, FES, FSS, BDI, MQE-SF, and overall CIQ (Table 2).

A statistically significant difference was determined in the participants' CIQ scores based on their walking aid usage status ( $p < 0.05$ ). On the other hand, there was no statistically significant relationship between the CIQ scores of the participants and their affected body side or lesion type ( $p > 0.05$ ). The results of the comparisons between the participants' overall CIQ scores based on their sociodemographic and disease-related characteristics are presented in Table 3.

A statistically significant relationship was found between the participants' age, Brunnstrom stages, scores in FIM, SIS, FES, FSS, BDI, and MQE-SF and their CIQ scores ( $p < 0.05$ ).

Table 4 shows the correlations between the independent variables of the participants and their CIQ scores.

## DISCUSSION

Stroke results in physical and psychological impairments that have a negative relationship with the community participation of individuals. The qualifiers for activity and participation components are performance and capacity.<sup>5</sup> The performance qualifier is the qualitative and quantitative definition of the behaviour or abilities shown for the action performed while performing an activity in the environmental conditions of the individual. Capacity defines how much an individual can perform a task or an action. This construct argues that individuals perform an activity with the maximum efficiency while performing an action.<sup>5</sup> Therefore, this study aimed to determine the ICF-based biopsychosocial factors are more or less related to the community participation of stroke survivors living in Northern Cyprus. It was hypothesised that ICF-based biopsychosocial factors are correlated with the community lives of stroke survivors living in Northern Cyprus in different amounts, and the results of this study confirmed this hypothesis.

We analysed participation not only as an overall community integration score but also from the aspects of social, home and work-school participation. The community participation levels of our sample were low, where participation was highest in the social participation subscale. It was expected for the participants to report low in-home participation subscale scores, as they could have support from family members. It was also predicted for the participants to score low in work-school integration as many studies in the literature have supported this expectation.<sup>28,29</sup>

We found a significant relationship between the sociodemographic characteristics and community participation levels of stroke survivors. The participants who used walking aids had lower community participation than those who did not use walking aids. Tyson and Rogerson reported that walking aids are an environmental facilitator for stroke survivors, which may increase community participation, suggesting that supportive equipment can be beneficial to increase the participation of individuals who have had a stroke.<sup>30</sup> However, the results of our study did not agree with the study conducted by Tyson and Rogerson. This may be because of both physical infrastructure and psychological factors. As a physical infrastructure obstacle, the inadequacy of urban design in Northern Cyprus was identified as a limiting factor for participation.<sup>31</sup> At the same time, it was reported that depression seen in

individuals after stroke causes individuals to feel watched by their environment.<sup>32</sup> Therefore, besides urban accessibility barriers, the use of walking aids by the participants who had a stroke limited their participation, based on their perception of psychological pressure on them.

It is known that getting older restricts community participation due to physiological or biopsychosocial reasons.<sup>33,34,35</sup> Our results were similar to those in the literature because it was found that community participation decreased along with increasing age. Nevertheless, it was expected for our sample to have low community participation rates as 74.42% of the participants were 65 years old or older. On the other hand, duration of living with stroke was not found related to community participation, which was a parallel result to that reported by D'Alisa et al.<sup>29</sup> This may be because participants may learn how to live with their limitations and develop coping strategies. This shows that there is a need for further follow-up of stroke survivors to understand the degree of their limitations over time.

We found that each ICF factor including body structures, functions, activities, and participations, environmental, and personal factors, had a different relationship with the community participation levels of the participants. The functional independence levels of the participants were found to be the most significantly related factor to their community participation. "Function is a process, and the vector of change in function through time is, in part, determined by the unique interaction of an individual's genome with their environment, diet, and lifestyle".<sup>37</sup> A previous study revealed that functional disability is the most significant variable that explains restriction in the community participation rates of stroke survivors.<sup>29</sup> Moreover, it was found that the current level of activities of daily living (ADL) of the participants of this study and their mobility stages were moderately correlated with their community participation levels. Mikołajewska reported that especially the gait parameters, hand functions, and functional levels of stroke survivors were related to community participation among individuals with limited ADL.<sup>37</sup> Other than ADL limitations, psychological factors, and functional status, there are more factors that may have a negative impact on community participation among stroke survivors, such as comorbidities, coordination in exercise, family support, and the physical and social environment.<sup>38,39,40</sup> Many studies have investigated the factors affecting community participation and return to society after stroke.<sup>41,42</sup> In our study, which is in line with the literature, it was found that the community participation levels of stroke survivors were affected by not only physical function but also personal and environmental factors. Therefore, it is important to think holistically and consider all aspects that can affect obstacles to participation to improve the rehabilitation outcomes of stroke survivors.

Our results also showed that the community integration of our participants was moderately obstructed by environmental factors. Although the relationship of community participation with environmental factors are not evaluated as much as functionality, activity, or depression in the literature, it is known that environmental factors including social and attitudinal aspects of one's environment have a high impact on the community participation levels of stroke survivors.<sup>43</sup> A recent systematic review suggested the need for a core set of outcome measures to assess the long-term participation of stroke survivors in life situations due to the diversity of outcome measures in this area.<sup>41</sup> Although the tool that we used helps measure the quality of environment in different aspects, we think the use of a stroke-specific tool to measure the interaction between these variables and changes in community participation could give us a better view of the relationships of environmental factors.

Additionally, personal factors such as fatigue, depression, and self-efficacy related to falls were all found to have moderate relationships with community participation. Stroke survivors with functional limitations develop some compensatory movements while performing activities, and extra energy consumption was found to cause early fatigue and subsequent

development of withdrawal from activities.<sup>44</sup> Our participants' depression levels were at the borderline of clinical depression. This may be due to the possibility of the participants having difficulty in performing activities that they found easy before their stroke. It has also been documented that the attitudes of people around hemiplegic people result in anxiety, lack of respect and affect the social roles of stroke survivors, which have negative relationship with their community participation.<sup>44,45</sup> Stroke survivors with a history of falling are afraid of falling and lower self-efficacy related to falls,<sup>46</sup> and it has been reported that individuals with poor participation have more fears of falling.<sup>47,48</sup> Our results provided the conclusion that fear of falling in stroke survivors can be due to their belief that in the event of a possible fall, their health status may deteriorate, so they have avoided community participation. Our results highlighted that it is important to work with a multidisciplinary team in cases with long-term limitations as they are restricted in terms of different biopsychosocial factors.

### **Study Limitations**

Our study had some limitations. First, most of our participants were living close to the private centre where the study was conducted which are located in the central area of Northern Cyprus. This factor may affect the generalisation of the results. Second, the assessments were performed by the same physiotherapist who was not blinded to the community integration levels of the participants. Lastly, as this was a cross-sectional study, our results do not indicate a causal relationship. Further studies with different methodologies to explore causes of community participation are recommended.

### **CONCLUSION**

This study revealed that the community participation levels of stroke survivors living in Northern Cyprus were related to the factors of the ICF-based biopsychosocial model. Therefore, to be able to increase the community participation of stroke survivors, these individuals need to be assessed holistically by considering all factors of the ICF model, which will lead to better rehabilitation outcomes, and it is needed to include multidisciplinary rehabilitation approaches in this process.

### **MAIN POINTS**

- Holistic assessment is required to increase the community participation of stroke survivors.
- All factors of the ICF model have an impact on community participation of stroke survivors.
- A multidisciplinary rehabilitation will result better rehabilitation outcomes.

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### **ETHICS**

**Ethics Committee Approval:** This is a cross-sectional analytical study conducted between January 2020 and May 2020 with stroke survivors in a private rehabilitation centre at the Northern Cyprus, after obtaining the ethical approval numbered ÜEK/50/01.02/1920/10, date: 11.02.2020 from the University Ethics Committee of European University of Lefke.

**Informed Consent:** Written consent was obtained from those who agreed to participate.

**Conflict of Interest:** No conflict of interest was declared by the authors.

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**Table 1. Sociodemographic and clinical characteristics of the participants (n=43)**

	Frequency(n)	Mean ± SD
Age (years)	43	70.67±8.22
BMI (kg/m <sup>2</sup> )	43	25.69±4.18
Age (years)		Percentage (%)
55-64	11	25.58
65-74	14	32.56
75-84	18	41.86
Sex		
Male	30	69.77
Female	13	30.23
Smoking status		
Smoker	9	20.93
Non-smoker	34	79.07
Alcohol use status		
Does not drink	43	100.00
Drinks	0	0.00
Education status		
High school	30	69.77
University	13	30.23
Duration of stroke ( $\bar{x}$ =51.19±45.54 month)		
36 months or shorter	19	44.18
37-60 months	14	32.56
61 months or longer	10	23.26
Affected body side		
Right	22	51.16
Left	21	48.84
Status of using walking aids		
Using	22	51.16
Not using	21	48.84
Lesion type		
Haemorrhagic stroke	19	44.19
Ischemic stroke	24	55.81
BMI: Body mass index		

**Table 2. Results of the stroke-related tools examining the biopsychosocial dimension of the participants (n=43)**

	Mean ± SD	Min.	Max.
Brunnstrom stage (upper extremity)	5.37±0.87	3.00	6.00
Brunnstrom stage (lower extremity)	5.63±0.49	5.00	6.00

CIQ overall score	6.70±4.75	0.00	18.00
Home participation sub-score	1.05±1.46	0.00	7.00
Community participation sub-score	4.77±2.72	0.00	10.00
Work-school sub-score	0.88±1.33	0.00	5.00
FIM	93.30±17.08	45.00	118.00
SIS	195.81±36.23	107.00	281.00
FES	47.72±22.69	10.00	85.00
FSS	5.51±1.02	2.55	6.77
BDI	19.51±9.06	5.00	44.00
MQE-SF	41.12±5.83	30.00	54.00
CIQ: Community Integration Questionnaire, FIM: Functional Independence Measure, SIS: Stroke Impact Scale, FES: Falls Efficacy Scale, FSS: Fatigue Severity Scale, BDI: Beck Depression Inventory, MQE-SF: Measure of Quality of the Environment-Short Form			

**Table 3. Comparison of the clinical characteristics of the participants and their overall Community Integration Questionnaire scores (n=43)**

			Frequency (n)	Mean ± SD	p-value
Community Integration Questionnaire Overall Score	Lesion type	Haemorrhagic	19	6.47±5.10	0.623
		Ischemic	24	6.88±4.56	
	Walking aid	Using	22	4.09±3.19	0.000*
		Not using	21	9.43±4.63	
	Affected body side	Right	22	6.91±5.14	0.742
		Left	21	6.48±4.43	
	Sex	Male	30	7.33±4.52	0.108
		Female	13	5.23±5.13	

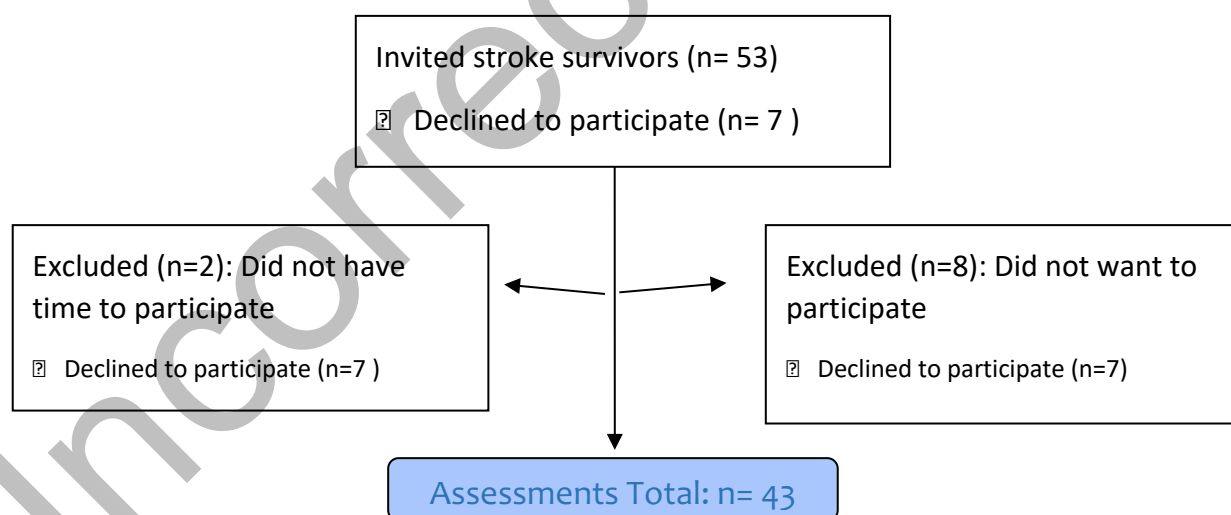
Statistically significant: \*p<0.05, Mann-Whitney U test

**Table 4. Correlations between age, duration of stroke, education status and stroke-related tools and the Community Integration Questionnaire scores of the participants (n=43)**

Variables		Community Integration Questionnaire Overall Score	Home participation	Society participation	Work-school
Age	r	-0.413	-0.354	-0.339	-0.317
	p	0.006*	0.020*	0.026*	0.038*
Duration of stroke	r	-0.170	-0.011	-0.175	-0.179
	p	0.275	0.942	0.261	0.251
Education status – (High school)	r	0.456	0.235	0.765	0.645
	p	0.227	0.975	0.199	0.083
Education Status – (University)	r	0.346	0.855	0.003	0.217
	p	0.446	0.434	0.256	0.134
Brunnstrom stage (Upper Extremity)	r	0.455	0.383	0.411	0.452
	p	0.002*	0.011*	0.006*	0.002*
Brunnstrom stage (Lower Extremity)	r	0.608	0.546	0.527	0.564

	p	0.000*	0.000*	0.000*	0.000*
FIM	r	0.809	0.747	0.743	0.660
	p	0.000*	0.000*	0.000*	0.000*
SIS	r	0.766	0.649	0.744	0.576
	p	0.000*	0.000*	0.000*	0.000*
FES	r	-0.752	-0.643	-0.714	-0.604
	p	0.000*	0.000*	0.000*	0.000*
FSS	r	-0.479	-0.433	-0.490	-0.344
	p	0.001*	0.004*	0.001*	0.024*
BDI	r	-0.783	-0.638	-0.798	-0.543
	p	0.000*	0.000*	0.000*	0.000*
MQE-SF	r	0.467	0.442	0.427	0.287
	p	0.002*	0.003*	0.004*	0.062

Statistically significant: \*p<0.05, Spearman's Correlation, FIM: Functional Independence Measure, SIS: Stroke Impact Scale, FES: Falls Efficacy Scale, FSS: Fatigue Severity Scale, BDI: Beck Depression Inventory, MQE-SF: Measure of Quality of the Environment-Short Form



**Flowchart Diagram of Recruitment of Participants**