

## Environment and the Daily Functioning of Jordanian Patients with Stroke: An Exploratory Study

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### Abstract

**Purpose:** Environment as described in the ICF can significantly affect the daily functioning of patients with long-term disabilities such as stroke. The purpose of this study is to explore barriers in the environment surrounding Jordanian patients with stroke.

**Methods:** A sample of 116 patients with stroke was recruited. A questionnaire listing the environmental factors as described in the ICF was used to explore patients' perception on the level of hinderness each factor imposes on their daily functioning. Patients were also asked to report the availability of necessary services they need in rehabilitation. Additionally, correlations were explored between patients' demographic and illness-related characteristics.

**Results:** External environmental factors such as sidewalks, other drivers, and noise in public places were perceived by the patients as hindering to daily functioning. Psychological services were reported to be provided the least in rehabilitation. Moderate but significant correlations were found between patients' perceived level of independence and patient's level of participation ( $r=0.56$ ,  $p<0.000$ ), as well as use of assistive devices ( $r=0.51$ ,  $p<0.000$ ).

**Conclusions:** Exploring the effect of environmental factors on the daily functioning of patients with stroke is important when planning intervention. Special attention must be given to the effect of external environmental factors where patients have minimal control over the surroundings.

**Keywords:** ICF; Contextual factors; Daily functioning; Stroke; Environmental Factors

### Introduction

Stroke is a global-health care concern and one of the main causes of acquired long-term adult-disability. Despite impressive developments that have been achieved in stroke management, its incidence rates are increasing rapidly [1] and stroke burden remains greater in low-income countries than it is in high-income countries [2]. While a majority of stroke survivors are expected to recover their independence in terms of self-care and walking competence – albeit at reduced velocity [3], many of them will have to live with limited participation in daily functioning and social roles [4-6]. Therefore, the disabling effects of stroke are profound and cannot be understood adequately from a single approach or point of view [7]. Instead, multidimensional factors that affect a person's experience of disablement have been identified [8], and disability was proposed as an interaction between the individual and the environment [9,10].

In this regard, the World Health Organization developed and endorsed the International Classification of Functioning, Disability and Health (ICF) model as a universal language between different health professions, researchers, policy makers and patients, to measure

bio-psychosocial outcomes related to chronic diseases such as stroke [11]. The ICF has not only been promoted as a conceptual framework for post stroke rehabilitation [12-14] but also as a valuable framework for illustrating the impacts of stroke [15]. This framework also considers the complex interaction between the individual and the environment of that individual [16]. In so doing, the ICF suggests that the environmental factors associated with the individuals' current circumstances affect their participation and general health condition [17].

The ICF defines environmental factors as “the physical, social and attitudinal environments in which people live and conduct their lives” [18]. In this regard, the environment interacts with the impairment to either facilitate or inhibits an individual's function, activities and participation [19]. The application of the environmental factors component of the ICF to particular disabilities has been increasingly advocated in research and clinical practice [19]. Social and physical barriers within the environment have been suggested to hinder daily activities and limit participation for individuals returning to community living after stroke [20,21]. Following a stroke, for example, it has been shown that the ability to resume valued activities was influenced, at least partially, by environmental factors [22]. In addition to barriers, potential facilitators within the environment have been

identified. For example, social support has been associated with improved functional outcomes after stroke [23].

However, the role of the environment as a domain of intervention after stroke has not yet been effectively emphasized [24]. This reflects the lack of complete understanding of the environment, its facilitating and inhibiting features and the way in which it affects activities and participation for people with stroke related disabilities [25,26]. Understanding environmental factors is, therefore, essential for health care planning and resource allocation. Moreover, while physical, social and attitudinal environmental factors have been identified, studies that explored environmental factors were mainly conducted in developed countries [27-29] and little is known about these barriers in developing countries [30]. Therefore, the aim of this exploratory study is to identify environmental barriers experienced by patients with chronic stroke in Jordan. Knowledge of environmental factors as facilitators or barriers is necessary and could assist in the advocacy for services in developing countries that are effective and appropriate.

## Methods

### Participants

A consecutive sample of Jordanian patients with stroke was collected over a period of 4 months. Patients were recruited from two general hospitals after a referral from their physicians and a confirmation of diagnosis. The two hospitals received patients from different rural and urban areas in the Kingdom and therefore were selected for patient recruitment to represent the different environmental background. Inclusion criteria were patients who had: a confirmed diagnosis of cerebrovascular accident for at least 4-6 months (a reasonable time frame for patients to start adapting to the new functional limitations), the ability to understand spoken and written Arabic language, and been living in Jordan for at least 10 years. Exclusion criteria were patients with: acute stroke (less than 4 months), resolved transient ischemic attack, mental illness that affects patient's insight, comorbidity of major medical conditions (e.g., arthritis) perceptible or expressive aphasia, and hearing impairment. The study was ethically approved by the Scientific Research Committee at the Faculty of Rehabilitation Sciences and the Deanship for Academic Research at The University of the authors. All participants gave their informed consent to participate in the study according to the latest version of the Declaration of Helsinki.

### Data Collection

Information on demographic variables and medical history were collected from all patients. Also, the Arabic version of the Mayo-

Portland Adaptability Inventory (MP) was used to collect information on patients' overall outcomes after the illness [31]. The MP is a valid and reliable assessment tools designed for patients with acquired brain injury [32]. Using the MP allows therapist, caregiver or patients themselves to determine limitations in 36 items concerning physical, cognitive, behavioural, and social impairments. The Items are classified into three subscales of Ability, Adaptability, and Participation. The Ability subscale collects information about specific impairments in body function and structures post stroke (e.g., balance, hand function...etc.). The Adaptability subscale gathers information about behavioural difficulties post stroke (e.g., anxiety, aggression... etc.). The Participation subscale identifies limitations in the patient's involvement in daily tasks and obligations (e.g., employment, social activities...etc.). An overall scale will then indicate the overall outcomes based on the predetermined difficulties in all three subscales. Raw scores from all three subscales are transformed into a standardized score provided in the MP manual based on standardized norms. The standardized overall score is then situated within a functional category as follows: >30=good outcomes; 30-40=mild limitations; 40-50=mild to moderate; 50-60=moderate to severe; >60=severe limitations.

### Environmental Factors

A questionnaire was constructed to explore perceptions of Jordanian patients with stroke on environmental factors affecting their daily functioning. The ICF Environmental Factors chapter and its subsections were used to identify relevant factors. A panel of local experts in multidisciplinary rehabilitations (the authors) formed the panel to define the relevant factors. The questionnaire included items relevant to the Jordanian culture classified into items under: Products and technology (Chapter 1 in the ICF) which described factors in the surrounding environment that may be hindering to the patients functioning (e.g., furniture, electrical appliances, stairs...etc.); Natural environment and human-made changes to environment (Chapter 2) which described natural and geographical factors (e.g., air quality, climate); Support and relationships (Chapter 3) which described relationships in patients' lives (e.g., family, friends); Attitudes (Chapter 4) which described personal attitudes by people surrounding the patient (e.g., attitudes of relatives) and Services, systems, and policies (Chapter 5) which described general supportive services provided to patients with stroke (e.g., social security services). Table 1 outlines the environmental factors identified and used in the questionnaire.

Environmental factors	Items asked about in the survey [ICF code]
Chapter 1:	Home (furniture, stairs, kitchen, toilet) [e1150]
Products and technology	Computers [e1300]
	Electrical Appliances (fridge, washer) [e1150]
	Phones [e1250]
	Cars [e1200]
	Books/ magazines [e1300]

	Public restrooms [e1500]
	Pools and gym [e1500]
	Recreational places (parks, clubs) [e1500]
	Malls [e1400, e1500]
	Restaurants /cafes [e1400, e1500]
	Streets/sidewalks [e1601]
	Driving laws/behaviours [e1209, e5501]
Chapter 2:	Hilly nature city (check wording) [e2100]
Natural environment and human-made changes to environment	Crowdedness/traffic [e2151]
	Plants and pets [e2200, e2201]
	Climate (Middle Eastern :dry and warm) [e2250, e2251, e2255]
	Glare/daylight (strong lighting during the day [e2400]
	Day/night time [e2450]
	Voices and sounds [e2500, e2501]
	Air quality [e2601]
	Noise [e2501]
Chapter 3:	Relationships with:
Support and relationships	Immediate family [e310]
	Relatives [e315]
	Friends [e320]
	Acquaintances and neighbours [e325]
	Managers [e330]
	Colleagues [e325]
	Caregivers [e340]
	Strangers [e345]
	Healthcare professionals [e355]
	Specialist (e.g., lawyers, social workers) [e360]
Chapter 4:	Attitudes and opinions of the following on your illness and life choices
Attitudes	Family [e410]
	Relatives [e415]
	Friends [e420]
	Acquaintances and neighbours[e425]
	Managers [e430]
	Colleagues [e425]
	Caregivers [e440]
	Strangers [e445]

	Societal attitudes (understanding, acceptance, Interest, help, volunteer work [e460])
Chapter 5:	Policies and laws on:
Services, systems and policies	Labor and employment [e5900-e5902]
	Social security [e5700]
	Health services [e5800-e5802]
	Housing [e5250-e5252]
	Transportation [e5400-e5402]
	Human rights [e5550]
	Media [e5600]
	Economic services [e5650]
Note*=Adapted from Hamed et al., [31]; **=International Classification of Functioning, Disability, and Health. Bold items denote those items that are included in the Comprehensive ICF core set for stroke[33]	

**Table 1:** Relevant Environmental Factors as classified and coded in the ICF\*\*.

Patients were instructed to: “rate the level of hindering/difficulty each of the following items has on your daily functioning especially when considering the impairment and limitations associated with your illness”. Daily functioning was defined to participants as “Your daily performance of important activities to you such as moving inside the house, showering/bathing, dressing, feeding, meal preparation, cleaning the house, or other activities). A 5-point rating scale was used where “1=not hindering at all (i.e., hindering 0% of the time/activities)”; “2=mildly hindering (i.e., hindering<25 of the time/activities)”; “3=moderately hindering (i.e., hindering 25%-50% of the time/activities)”; “4=significantly hindering (i.e., hindering 50%-75% of the time/activities)”; “5=completely hindering (i.e., 75%-100% of the time/activities).

Moreover, patients were asked to rate their perception on the availability of supportive services to their daily functioning. Services included health-related (i.e., medical insurance), convenient transportation (i.e., accessible or disability-friendly buses), rehabilitation services (e.g., occupational therapy), financial support (i.e., social security) psychological services (i.e., counselling, support groups), and attitudes of community members (i.e., accepting, supporting, and volunteering in helping patients with stroke). A 4-point scale was used for this purpose where “1=unavailable”; “2=limitedly available”; “3=available”; “4=abundantly available”.

Only items rated by at least 50% of the patients to be mildly to entirely hindering (i.e., items with rating of 2-5) were considered of clinical significance and therefore reported in this study. Moreover, services rated by at least half of the participants as “unavailable” or “limitedly available (i.e., ratings 1 and 2) were reported in this study.

To explore how personal characteristics of patients may affect or be affected by the illness, a correlation analysis was conducted between the demographic variables and the MP subscale and overall scores as well as stroke-related characteristics (e.g., previous strokes, perceived level of independence, use of assistive aids). Spearman’s correlations were used for this purpose.

Data were collected by two trained and licensed occupational therapists and were analysed using Statistical Package for the Social Sciences (SPSS version 20.0 SPSS, Inc., Chicago IL, USA).

## Results

### Participants

A total of 116 Jordanian patients with stroke agreed to participate in the study with a mean age of the participants being 58.2 (SD+13.1). Most of the participants were males (60.3%), married (87.9%), living with a family (94.0%), unemployed (85.3%), and had a school-level education (46.6%). Moreover, a large number of the participants had the onset of illness for less than a year (51.7%), 61.2% had the affected side on the right, 99.1% have the right side as the dominant side, and 83.6% had no previous strokes. Finally, a large number of the participants reported that there were independent in at least 50% of their daily activities (59.6%) and most used an assistive device for mobility such as a cane or walker (55.7%). Table 2 describes other demographic characteristics of the participants.

The overall MP scores revealed that 15.5% had good outcomes, 29.3% had mild limitations, 41.4% had mild to moderate limitations, 10.3% had moderate to severe limitations, and 3.4% had severe limitations.

	n (valid percentages)
Mean age (SD)	58.2 (SD+3.1)
Gender (Male)	70 (60.9%)
Marital status	
Married	102 (87.9%)
Single	6 (5.2%)
Divorced	2 (1.7%)
Widowed	6 (5.2%)

Living Conditions	
With Family	109 (94.0%)
Elderly home	2 (1.7%)
Alone	5 (4.3%)
Educational level	
University	22 (19.1%)
2-year diploma	16 (13.9%)
School	54 (47.0%)
Illiterate	23 (20.0%)
Onset in years	
Less than a year	60 (52.2%)
1-2 years	31 (27.0%)
2.5-5 years	16 (13.9%)
5.5-10 years	7 (6.1%)
More than 10 years	1 (0.9%)
Income	
None	40 (37.0%)
Less than 100 JD**	1 (0.9%)
100-500 JD	41 (38.0%)
501-1000 JD	19 (17.6%)
More than 1000 JD	
Affected side	
Right	71 (61.7%)
Left	44 (38.3%)
Dominant side	
Right	114 (99.1%)
Left	1(0.9%)
Other illnesses	
Hypertension	47 (40.5%)
Diabetes	3(2.6%)
Cholesterol	3(2.6%)
Hypertension and Diabetes	23(19.8%)
Hypertension and Cholesterol	5 (4.3%)
All three	17(14.7%)
Perceived independence in ADL**	
Independent in 100% of ADL	17(14.9%)
Independent in 50-90% of ADL	51 (44.7%)
Independent in 10-50% of ADL	36(31.6%)

Dependent	10(8.8%)
Use of assistive device for mobility	
None	51 (44.3%)
Cane/crutch	29 (25.2%)
Walker	2 (1.7%)
Wheelchair	27 (23.5%)
Multiple devices	6 (5.2%)
Note: * Jordanian Dinar (1 USD=0.71 JD); **ADL= Activities of Daily Living)	

**Table 2:** Personal Characteristics of the Participants (n=116).

### Environmental Factors

The participants perceived the following factors as hindering to their daily functioning: violating driving rules by other drivers (63.2%), aggressive driving by others (60.5%), noise in public places (e.g., malls) (60.3%), and street and sidewalks (59.5%) under “Products and technology”; and loud noises (e.g., construction work and cars) under “Natural environment and human-made changes to environment”. All items under “Support and Relationships” and “Attitudes” were reported by less than 50% of the participants to be hindering to their daily functioning and therefore were not reported in this study.

### Services

The participants reported the following services to be unavailable or very limitedly available: psychological services (e.g., counselling) (90.4%); human rights (87.8%); volunteerism in stroke rehabilitation and support (85.1%); spiritual support (84.3%); media in stroke support and public awareness (82.8%); financial services (e.g., social security) (73.9%); religious support (57.4%); and community support and acceptance to patients with stroke (56.9%).

### Correlations

The correlational analysis showed low-to-moderate but significant associations between the stroke-related impairments (represented by MP scores) and the identified relevant environmental factors. The strongest correlations were found between the perceived level of independence and the MP participation subscale ( $r=0.56$ ,  $p<0.000$ ) as well as the use of assistive devices ( $r=0.51$ ,  $p<0.000$ ). Significant correlations showed in this analysis are presented in table 3.

	Ability	Adaptability	Participation	Overall
Highest level of education	-		0.294**	0.215*
Independent level in daily activities	0.200*	0.324**	0.561**	0.377**
Relevant environmental factors	-	-		
User stairs at home	0.302**	-	0.369**	0.311**
Kitchen and bath at home	-	-	0.361**	0.284**

Computer without any adaptive tools	0.236**	-	-	-
Car without any adaptive tools	0.268**	-	0.264**	0.269**
Any kind of book	0.312**	-	-	0.296**
Magazine and newspaper	0.349**	-	-	0.284**
Swimming pool and gym	0.281**	-	0.290**	0.261**
Places of entertainment	0.272**	-	0.260**	0.252**
Local climate	0.230**	-	-	-
Relationship with family at home	0.243**	0.359**		0.240**
Relationship with friends	0.305**	0.356**	0.285**	0.385**
Relationship with neighbors and others	0.226**	0.274**	0.232**	0.256**
Relationship with caregiver (e.g., driver, assistant)	0.283**	-	0.229**	0.235**
Relationship with strangers anywhere	-	0.226**	-	-
Relationship with health workers (doctors and therapist)	-	0.266**	-	0.252**
Relationship with professionals (Lawyers, engineers, social workers)	0.251**	-	-	-
Relative attitudes about you and your life		0.244**		0.288**
Friends attitudes about you and your life	0.302**	0.258**	0.223**	0.373**
Neighbors and other people attitudes about you and your life	0.227**	-	-	0.267**
Managers and work administrators attitudes about you and your life	0.223**	-	-	-
Colleagues at work or at a volunteer place attitudes about you and your life	0.225**	-	-	-
Strangers attitudes about you and your life	0.277**			0.271**
People accept CVA patient	-	-0.260**	-	-
Community attention to CVA patient	-	-0.210*	-	-
Community help to CVA patient	-	-0.210*	-	-
Fasting Help me to accept the disease	-		0.258**	0.295**
Read or hear the Koran or the Bible help me to accept the disease	-	-0.239**	-0.206*	-0.220**

Go to the mosque or the church Help me to accept the disease	-	0.229**	0.287**	0.241**
Note. * =Correlation is significant at the 0.05 level (2-tailed); ** =Correlation is significant at the 0.01 level (2-tailed)				

**Table 3:** Results of significant nonparametric correlations (Spearman's rho) between MP scores, education level, activity level and relevant environmental factors

## Discussion

The purpose of this study was to explore the perceptions of Jordanian patients with stroke on the hindering effect of the surrounding environment on their daily functioning.

Generally, the results showed that outdoors factors were perceived as most hindering to the patient's functioning. That is, violating the driving rules, behaviours by other drivers, noise in public places and streets and sidewalks were all reported by over half of the participants to be hindering to daily functioning. All of which are external factors being outside the patient's home. While it was expected that factors within the immediate home environment to be most hindering (e.g., furniture, stairs), these results may be explained by the fact that most patients tend to adapt to the disability where they have control over the familiar home environment. Such environments allow patients to modify the surroundings as needed so as to facilitate functioning (e.g., redecorating furniture). On the other hand, when patients have less control over external factors such as sidewalks, the hindering effect of the environment becomes highlighted.

The ICF Core Set for stroke has been identified, following formal international consensus, which includes a comprehensive list of components including 33 categories from environmental factors [33]. This is among the largest of the environmental factors sets developed for the most burdensome neurological conditions (third to MS and TBI with 38 categories in each), reflecting the complex interaction between the environment and impairments and disability following stroke. Moreover, in our study we have included many new items that were not originally included in the ICF core set to meet the special consideration of the Jordanian community. However, this highlights the need for a local ICF core set definition.

The results about the availability of services were most interesting where patients reported that almost all needed services as unavailable. Psychological services and support system topped the list of needed yet unavailable services which was consistent with findings from previous studies in other countries [34,35]. Since this finding was reported by an overwhelming percentage of the patients to be hindering, the claimed "client-centered" approach by Jordanian rehabilitation therapists have to be reevaluated. In addition, this indicates that patients with stroke may actually need factors that rehabilitation therapists usually overlook or address seldom. For instance, most rehabilitation therapists tend to focus primarily on the physical and cognitive part of functioning [36] such as the functional mobility and independence in ADLs and spare the talk about patients' mental health and psychological well-being to other therapists (e.g., psychologists). The results indicate that psychological well-being may have to become a priority goal for rehabilitation sessions.

Important results were found under services where most participants reported spiritual and religious support to be very

limitedly available in the community. This finding comes interesting given that the Jordanian community is religion-oriented and people value giving and receiving religious support highly. Limited volunteerism and community support for stroke patients reflects the lack of public awareness on the suffering of patients with stroke which is amplified by the weak role of media perceived by the participants.

The correlation analysis showed that patients who actively participate in daily activities tend to be independent and more likely employed than patients who participate less actively. Also, patients who used assistive devices perceived themselves as independent in most daily activities. The results that education weakly associated with factors such as MP overall and participation scores and perceived independence may indicate that patients with better education have higher abilities to take care of themselves in the presence of a hindering environment.

### Clinical implications

The findings of this study have a number of clinical implications. First, it suggests that rehabilitation therapists have to extend their evaluation and possibly intervention to external factors that may be affecting or regressing the recovery and daily functioning of stroke patients. Second, the results indicate that Jordanian patients with stroke suffer most from the “invisible” aspect of the environment (e.g., lack of spiritual support) probably more than its physical aspect (e.g., clutter at home). Third, personal factors such as education and marital status may be important factors to consider when planning preventative interventions or public awareness.

### Limitations

The largest portion of the sample had illness for less than a year, which may have underestimated the effect of the environment of their daily functioning (e.g., attitudes of family) especially that families tend to be overprotective during the first year of illness. Hence, a larger sample of patients with a variety of onset durations maybe needed to confirm the results found in this study. Moreover, future qualitative research is needed to understand the underlining reasons of the patient’s perception on some of the factors.

In this study we have utilized the MP as a measure of participation. Although we have not considered other possible measures, there is no consensus on the ideal measure of participation after stroke and this requires further investigation considering specific environmental factors.

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