

## Third party disability in ICF framework: A study of Aphasics family

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### Abstract

Participation restrictions imposed on members of the family due to disability among one of them has neither been studied nor addressed sufficiently to promote health of the stake holders. 'Third-party disability' is defined as the disability and functioning of family members due to the health condition of their significant others and was identified as a direction for future development by the WHO (2001). The International Classification of Functioning, Disability and Health (ICF) is the WHO's frame work for measuring health, functioning & disability at both individual & population levels.

For successful rehabilitation, it is essential for the professional to determine the support, motivation, attitude and functioning of significant others, as they are an important team member in the rehabilitation process of individuals with health related conditions including communication disorders. Sufficient data is not available on third party disability imposed on significant others for families of persons with speech & language disorders. Hence the study has been undertaken in order to delineate the third party disability in ICF framework of family members with persons having aphasia.

Problem areas faced by the receptive and expressive aphasics as reflected in ICF domains and core-sets were identified. The effect of these problem areas on the aphasic's family members (third party disability) in terms of activity limitations and participation restrictions (AL/PR) were then assessed through a questionnaire developed based on the ICF framework. Non-parametric (NPar) and group statistical tests were administered for data analysis & reliability check.

A total of 5 domains related to activity & participation and 1 domain under environmental factors have been found appropriate to assess the profile of aphasics. Through this study, activities limitation and more so participation restrictions in ICF could be linked to domains viz. domestic life, self-care, interpersonal interactions & relationship, social & community life, and communication whereas considering component of environmental factors includes attitude & emotions of the family members with persons having aphasia. All the problems faced by the family members of aphasics could be quantified easily through the ICF based scoring system which yielded maximum falling in severe & complete problem group

The study shows the existence of 'third party disability' in family members of individuals with aphasia. This is seen as, severely affecting the participation restrictions and activity limitations of family members of persons with aphasia.

**Keywords:** ICF framework, Aphasics family

### Introduction

According to the National Institute of Health (NIH), stroke is the third leading cause of death in the United States and the most common cause of adult disability (Zivin & Choi, 1991). For atleast 40% of those who survive, stroke is a seriously crippling disease- physically and often communicatively. Within a matter of minutes, the lives of stroke/aphasia victims change completely. They become prisoners in their own bodies, prisoners in their own minds. Stroke victims are often condemned to live as pariahs, are met with outright public rejections, and are shunned, ostracized and isolated by all but those most devoted to them. Aphasia patients may be unable to do the jobs they were trained for and be forced to retire, a further assault, on their egos that typically adds to feelings of isolation, frustration, and worthlessness (Brody, *et al.* 1992). The negative impact of Aphasia on the individuals' functioning, personal and quality of life (QoL) is well known & understood. It has been shown that there is lower QoL in

participants with aphasia wherein communication & Socialization domains were the most affected areas of functioning on 'The Stroke and Aphasia Quality of Life-Scale-39' (SAQOL) and ASHA's 'Quality of Communication Life Scale' (QCL) (Paul *et al.*, 2004, Bose A., *et al.* 2009) [5]. But the appreciation of the negative impact of individual's aphasia on their family members is limited.

The World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) (2001) is a well-established conceptual framework which describes the consequences of a health condition on a person in the context of their environment. The International Classification of Functioning, Disability and Health (ICF) is the WHO's frame work for measuring health, functioning & disability at both individual & population levels (Rangasayee *et al.*, 2010) [3].

As a classification tool, the ICF defines functioning from the perspective of the body, the individual and society in two

parts: (1) functioning and disability; and (2) contextual factors. Each part has two components. Functioning and disability consists of body structures and functions, and activities and participation. The contextual factors part consists of environmental factors and personal factors. Each component contains a number of domains, and within these domains are categories which are used to describe an individual's health and health-related states using the appropriate category code. (Scarinci N, *et al.*, 2009) [2, 4].

The application of ICF to clients with hearing impairment and other speech – language disorders has been well appreciated, but there has been limited application of the ICF to the client's family and significant others. The effect on others is known as a 'Third-Party Disability' and was initially proposed by the WHO as an area for future development and application of the ICF (WHO, 2001).

Third party disability refers to the 'study of disability and functioning of family members due to the health condition of significant others'. That is, although the family member does not have a health condition, they may experience impairments, activity limitations and participation restrictions as a result of the health condition of their significant other. Further, their disability and functioning may be influenced by environmental and personal factors.

In 1991, Stephens and He' tu proposed an extension of the original WHO definition of handicap to include a reference to the handicap experienced by significant others, including making a distinction between 'primary' and 'secondary handicaps'. Secondary

handicaps were defined as the 'handicap resulting from the cost of adapting to a disability', a concept particularly relevant to the study of third-party hearing disability because of the number of adaptations spouses make as a result of their partner's hearing disability.

Scarinci N, Worrall L, Hickson L. (2009) [2, 4] conducted a study using ICF as a tool to describe the third party disability among 10 spouses of hearing impaired individuals who were above 60 years of age. They emerged with a total of 18 themes & 50 sub-themes in which the functioning was affected in spouses of the hearing impaired individuals. So a third-party disability was relevant in their study.

So the participation restrictions imposed on members of the family due to disability among one of them has neither been studied nor addressed sufficiently to promote health of the stake holders.

### **Need for the study & specific aims of the study**

For successful rehabilitation, it is essential for the professional to determine the support, motivation, attitude and functioning of significant others (family members) as they are an important team member in the rehabilitation process of individuals with health related conditions including communication disorders.

Sufficient data is not available on third party disability imposed on significant others for families of persons with speech & language disorders. Hence the study has been undertaken in order to delineate the third party disability in ICF framework of family members with persons having aphasia.

The Aims of the Study were:

1. To identify the core-sets & domains in terms of activity limitations and participation restrictions (AL/PR) in ICF

for the third party disability of family members of the aphasic individuals.

2. To quantify the third party disability of family members of the aphasics through ICF framework.
3. To determine whether any significant difference exists in third party disability of family members of the receptive versus expressive aphasics respectively.

### **Methodology**

#### **Procedure**

##### **Questionnaire Development**

First, the problems faced by expressive and receptive aphasics were identified. It was then reflected in ICF domains and core-sets. These domains were related to activities & participation and environmental factors. The core-sets in the activities & participation domain were mainly connected to domestic life, self-care, interpersonal interactions & relationship, social & community life and communication whereas attitudes & emotions were identified in the environmental factor domain. These areas were identified as problem or effects to the aphasics' family members referred to as third party disability. So, the third party disability on the aphasics' family members were assessed through a questionnaire developed on the ICF framework i.e. on problem areas identified in ICF domains & core-sets.

Initially 37 questions were made i.e. 37 problem areas for aphasics' family members were identified at preliminary basis.

#### **Validation & Pilot Study**

The questionnaire was validated by subject experts who had eminently worked in the research area of disability and known the use of ICF efficiently.

After the validation by subject experts and pilot study done on 5 aphasics' family members a total of 27 questions were selected in the questionnaire which included core-sets and domains from ICF related to activity & participation and functioning of the family members pertaining to issues of health, self-care, domestic life, recreation, social networking, attitudes, emotions, communication and interpersonal interactions & relationships.

#### **Subjects**

The subjects targeted in the study were family members of individuals with expressive or receptive aphasia who has been undergoing regular intervention / rehabilitation since atleast 3 months so that the effect on family members could be started to be felt.

A total of 6 confirmed cases with expressive aphasia and 5 cases with receptive aphasia were selected. The questionnaire was administered on their family members who were the primary caretakers. The family members who participated in the study were all spouses of the aphasic individuals who have been married for more than 14 years.

All participants had known to read & write English / Hindi / Marathi efficiently.

#### **Statistical Analysis**

Data was analyzed through various Non-parametric (NPar) and group statistical tests. Data was also subjected to reliability check.

**Results & Discussion**

11 participants and all 11 being female i.e. wives of aphasic individuals participated in the study. Male participants were not available during the time of the research. All family members available for the study were spouses of aphasic individuals. The demographic details are shown in Table-I.

**Table 1:** Demographic Information of Participants (n = 11)

	Mean or Frequency	Range
Female	11	
Male	0	
Partner's AGE (years)	47	38 - 56
Length of Marriage (years)	23	14 - 32
Type of Marriage (First Marriage)	11	

The age of the subjects ranged from a youngest at 38 years to the oldest at 56 years of age. All were of first marriages and the lengths of the marriage were from 14 years to oldest of 32 years. All the aphasic individuals were the sole earner of the family except one who had his son earning.

The questionnaire was administered on spouses of aphasic individuals i.e. 5 Receptive & 6 Expressive aphasics respectively. These aphasic individuals were on therapeutic process since more than 3 months and maximally helped by their spouses on all caretaking.

**Identification of the domains in ICF for the third party disability of family members of the aphasic individuals**

A total of 5 domains related to activity & participation and 1

domain under environmental factors have been found appropriate to assess the profile of aphasics. Through this study, activities limitation and more so participation restrictions in ICF could be linked to domains viz. domestic life, self-care, interpersonal interactions & relationship, social & community life, and communication whereas considering component of environmental factors includes attitude & emotions of the family members with persons having aphasia. The effect of each component or problem areas i.e. third party disability of aphasic's family revealed that there were no significant differences statistically in between the receptive aphasic & expressive aphasic families. This indicated that both the family groups had equal amount of disability faced in each domain & in totality also due to their family members' aphasia. The statistical details amongst both groups within each ICF domain are shown in Table – II.

**Quantification of 'third party disability' of family members' of the aphasic through ICF framework.**

The ICF quantification system had categorization into 5 groups viz. No problem, Mild problem, Moderate problem, Severe problem & Complete problem which varied in percentage of 0-4%, 5-24%, 25-49%, 50-95% & 96-100% respectively. Family members of aphasics' had to fill in the ICF based questionnaire and report their difficulties faced according to the categories (i.e. percentage values) subjectively. Thus, all the problems faced by the family members of aphasics could be quantified easily through the ICF based scoring system which yielded maximum falling in severe & complete problem group i.e. 50-95% & 96-100%.

**Table 2:** Results obtained on group & independent sample t-test for each ICF domain between both receptive & expressive aphasia.

ICF DOMAINS	Category	n	Mean	S.D.	Std. Error Mean	t	df	Sig. (2-tailed)
Effect of Aphasia on family's everyday A/P in Domestic Life & Self-care	R. A.	5	45.60	6.504	2.909	.026	9	.980
	E. A.	6	45.50	6.221	2.540			
Effect of Aphasia on family's interpersonal Interactions & relationship	R. A.	5	4.20	1.643	.735	.208	9	.840
	E. A.	6	4.00	1.549	.632			
Effect of Aphasia on family's social and community life	R. A.	5	10.60	1.517	.678	.646	9	.535
	E. A.	6	10.00	1.549	.632			
Effect of Aphasia on family's communication	R. A.	5	10.80	1.304	.583	.576	9	.579
	E. A.	6	10.33	1.366	.558			
Effect of Aphasia on family's Attitudes and Emotions	R. A.	5	19.20	1.304	.583	.359	9	.728
	E. A.	6	18.83	1.941	.792			
Total Aphasia	R. A.	5	90.40	11.803	5.278	.243	9	.813
	E. A.	6	88.67	11.742	4.794			

(\*Receptive Aphasia = R.A.; \*Expressive Aphasia = E. A.)

**Differences between 'third party disability of family members of the receptive versus expressive aphasics respectively**

On comparing inter – domains as per Mann-Whitney's Rank test, family members of individuals having receptive aphasia face slightly more problems in domains / areas of communication (6.60), and social & community life (6.60) followed by interpersonal interactions & relationships (6.40), then attitudes & emotions (6.30) and finally domestic life & self-care (6.00). Whereas the family members of individuals with expressive aphasia counterparts face most problems in domains / areas of domestic-life & self-care (6.00), followed by attitudes & emotions (5.75) then interpersonal relationships & interactions (5.67) and finally social & community life

(5.50), and communication (5.50), although the rank differences are marginal with an exact significance of 0.792 (total) on Non-Parametric tests. The total mean score of the problems faced by family members of receptive and expressive aphasics across all domains were 90.40 & 88.67 on independent group t-test (2-tailed) with a significance of 0.813 which indicated no significant difference amongst both the groups i.e. both the groups had similar affected domains. Table – III shows the results of rank correlations amongst inter-domains etc.

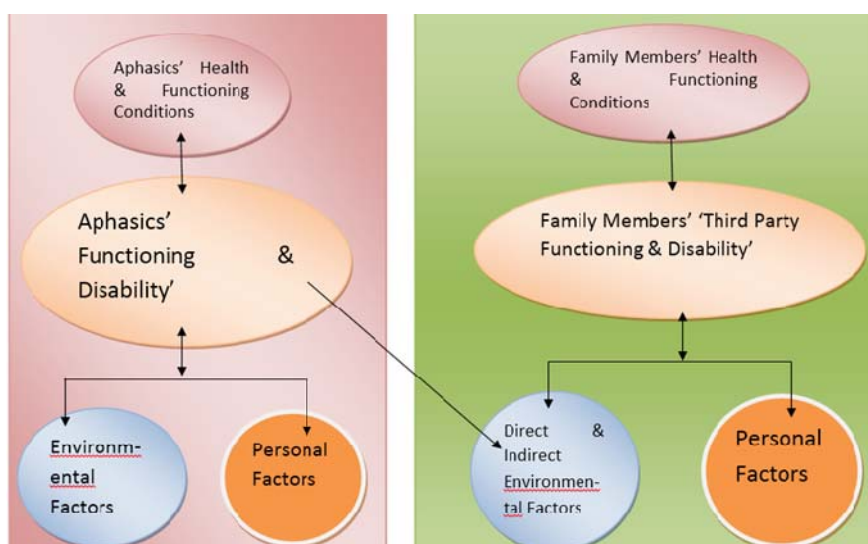
The ICF based questionnaire & the data tested well on Cronbach's Alpha reliability (0.982) and had good internal consistency on Guttman Split-half reliability (0.940).

**Table 3:** Results of rank correlation among the ICF Domains using Mann - Whitney Test & Npar Tests.

ICF DOMAINS	Category	n	Mean Rank	Sum of Ranks
Effect of Aphasia on family’s everyday A/P in Domestic Life & Self-care	R. A.	5	6.00	30.00
	E. A.	6	6.00	36.00
	Total	11		
Effect of Aphasia on family’s interpersonal interactions & relationship	R. A.	5	6.40	32.00
	E. A.	6	5.67	34.00
	Total	11		
Effect of Aphasia on family’s social and community life	R. A.	5	6.60	33.00
	E. A.	6	5.50	33.00
	Total	11		
Effect of Aphasia on family’s communication	R. A.	5	6.60	33.00
	E. A.	6	5.50	33.00
	Total	11		
Effect of Aphasia on family’s Attitudes and Emotions	R. A.	5	6.30	31.50
	E. A.	6	5.75	34.50
	Total	11		
Total Aphasia	R. A.	5	6.40	32.00
	E. A.	6	5.67	34.00
	Total	11		

The third party disability of family members with individuals having aphasia could be identified through the ICF framework and it is in agreement to Scarinci *et al.* (2009) [2, 4] who had identified third party disability in spouses of individuals with hearing impairment. All the problems faced by the family

members of aphasics could be quantified easily through the present ICF based questionnaire and scoring system which yielded maximum falling in severe & complete problem group.



**Fig. 1:** Application of ICF to ‘Third Party Disability’ in Aphasics’ Family Members

**Conclusion**

The study shows the existence of ‘third party disability’ in family members of individuals with aphasia, and which is seen as, severely affecting the participation restrictions and activity limitations of family members of persons with aphasia.

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