

## THE DIVERSITY OF BURDEN FOR SIGNIFICANT OTHERS OF PERSON WITH APHASIA

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### Abstract

*When a person suffers from a stroke and aphasia, life not only changes for him or her, but also for significant others (SO). Standardized and valid measures are available to identify severity and diversity of burden reported by SO of person with aphasia (PWA). The present aimed to investigate the extent of post stroke changes in experiences of SO of PWA in terms of daily situation and during conversation with PWA of different age groups. To describe changes in SO experiences in terms of educational status, family type, aphasia type and severity of PWA. Twenty five participants were rated on questionnaire related to extent of changes, interactional competence (IC), language and communication related activities (LCA), communication effectiveness (CE) and their own perspectives about PWA. 56% PWA were of 40-60 years of age, 40% were graduates, 56% had anterior aphasia, 48% had moderate severity and 52% were staying in nuclear families. Paired t-test indicated significant mean difference between pre and post stroke experiences of SO at 0.001 level. Majority of the SO perceived their conversations with the PWA as being less stimulating and enjoyable than conversation before stroke onset. The communicative responsibilities of the SO were perceived to have increased consequentially; interaction competence and communication effectiveness of population has decreased significantly. Chi square result suggests highly significant ( $p < .001$ ) association of education, type, severity and IC, CE and LCA of PWA. On the other hand, relation between competencies of PWA and type of family had border-line association ( $p \leq 0.046$ ). Denial or unawareness about the perceptions of burden was found particularly in nuclear families. Post stroke aphasia leads to emergence of negative psychosocial consequences and apportionment of communicative burdens to SO. Future direction: To design and conduct family oriented intervention that includes communication partner training and to investigate its outcome combination of impairment based language intervention.*

**Key words:** *Interactional competence, communication effectiveness, language and communication related activities.*

### Introduction

Communication burden may be defined as the share of responsibility of each participant in a conversation must bear to ensure the adequate transfer of information. Mostly communication burden is vast on significant others (SO) of person with aphasia (PWA). In this paper, the term "significant other (SO)" is used instead of "caregiver" in order to include family members, friends and other persons important to the person with aphasia. "Caregiver" could be perceived to imply a nursing role that may not be present, and "family" is too narrow a term.

Previous research about SO of stroke survivors has found evidence of negative impact on relationship with (PWA), when the possibilities of having conversations decrease or even cease altogether. The impaired communicative and physical ability caused by aphasia is a major problem of its own because of misunderstandings that cause irritation and frustration to both PWA) and their SO. These frequent misunderstanding, guessing about communication intent of PWA could create interpersonal problems and increase communication burden on SO. Blom (2012)

found that 43% of SO spent less time on conversations compared with before the onset of aphasia, but almost 30% of SO spent more time than before speaking with each other. Draper, Bowring, Thompson, Heyst, Conroy, (2007) used General Health Questionnaire (GHQ) and Relatives stress Scale to measure caregiver's stress and burden on 31 subjects and planned four session weekly caregiver programme that included element of education, support and communication skills conducted by a speech pathologist, social worker and clinical psychologist. After three-month follow-up, it was revealed that these programmes have no significant effects on communication skills or on caregiver burden. So, it was suggested to have ongoing involvement of all strategies in daily situation to maintain long term effect of these programmes. Thus, there is a need to understand as to how significant others of PWA perceive the extent of changes about their family member. What characteristic of difficulty they are facing in daily situation related to either physically, mentally, socially and economically? It would be of great importance to develop or adapt a SO oriented evaluation and intervention plan to provide complete rehabilitation and to reduce

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risks of negative psychosocial consequences and burden for significant others.

**Aims and objectives**

1. To investigate the experiences of significant others (SO) of persons with aphasia (PWA) in terms of extent of post stroke changes in daily situation.
2. To explore experiences of significant others (SO) during conversations with person with aphasia (PWA) of different age groups.
3. To compare the significant others (SO) experiences in terms of educational status, family type, aphasia type and its severity of person with aphasia (PWA).

**Method**

**Participants**

*Inclusion Criteria:* Significant other of PWA (n=25)

- Experiences of dealing with person with aphasia for at least 3 months on a regular basis (pre and post stroke)
- 18 years or older
- Understand and write Hindi or English in written or verbal mode

Person with Aphasia (n=25)

- Post stroke aphasia of all types and severity of 3 months or longer duration.
- 18 years or older
- Only left hemisphere lesion
- Should be awake and communicable (give eye contact, try to communicate, and have an ability to express him-/herself beyond a pain reaction)

*Exclusion Criteria:* Significant other of PWA (n=25)

- Significant hearing or vision problems
- Diagnosed dementia or any other known significant cognitive impairment

Person with Aphasia (n=25)

- Diagnosed dementia or any other known significant cognitive impairment
- Significant hearing or vision problems
- Known alcohol or drug abuse

**Test Material**

Questionnaires were developed in both Hindi and English to assess all aspects of Communication

and language related burden in following subheadings: (i) communication effectiveness, (ii) interaction competence and (iii) language and communication related activities. Pilot study was done to assess the ease of administration of questionnaire i.e. whether the terms and phrases in the questionnaire are comprehensive to SO of PWA or not. Five questionnaires were used, among which two were based on SO's self-experiences and three, on SO's experiences with their PWA about communication abilities.

*Table 1: Description of Questionnaire.*

Sl. no.	Domains to be assessed	No. of Questions	Purpose	Scale to be used
1	Extent of changes in experience (physical, cognition) of SO with Person with aphasia (PWA).	7 pair	To assess changes in experiences of SO related to changes in communication and personal activity after stroke.	Likert's scale (7 point rating scale) SA- Strongly agree SD- Strongly disagree
2	Language and Communication related activity(LCA)	11	To assess language and communication related activity of PWA.	5 point rating scale
3	Interaction competence (IC)	7	To assess level participation of PWA in terms of communication with others.	7 point rating scale
4	Communication effectiveness(CE)	8	To estimate communication ability of PWA in different communicative situations (i.e Basic needs, Social needs, life skills)	5 Point Rating scale
5	Significant others oriented	7	To investigate mental status of SO of PWA.	5 point rating scale

**Procedure**

Twenty five consecutive SO of PWA were interrogated through semi structured interview after written informed consent. Demographic data, clinical history, change in experience of SO with PWA and extent of problem of both (PWA and SO) were documented. All five questionnaire were given to SO for rating about their experiences/responses towards PWA after instruction i.e., How to rate?

**Results and Discussion**

Twenty five PWA with mean age 48.6 years (21yrs- 77yrs) and mean time since stroke onset of 5yrs (4mths-8yrs) were included in this study.

*Table 2: Description of Participants (PWA).*

Sl. no	Age	Sex	Educational status	Family status	Type of relationship	Aphasia type	Aphasia severity	Time of onset	Physical limitation
1	20-40 (6)	Male (19)	Illiterate (4)	Nuclear (13)	Cohabitant (spouse) (9)	Anterior (13)	Mild (7)	>3mth-2yr (13)	Normal (5)
2	40-60 (14)	Female (6)	High school (5)	Joint family (11)	Siblings/progeny/ Parents (15)	Posterior (3)	Moderate (11)	2-4yr (9)	Minimal (5)
3	≥60 (5)		Higher secondary (5)	Alone (1)	Others (e.g. Friends/ caregivers ) (1)	Global (4)	Severe (7)	>4yr (3)	Mild (6)
4			Graduate (10)			Anomia (5)			Moderate (7)
5			Post graduate (1)						Severe (2)

40% of the PWA was graduates and 56% were in the age range of 40-60yr. 48% had moderate severity and 56% had anterior type of aphasia. 52% PWA with 3mths to 2yr post stroke history had mild to moderate physical limitation. 48% were taken care by spouse whereas 40% by siblings/parents/progeny.

*Aim 1 :* Changes in experience of SO of PWA in terms of Social, Activities of daily living (ADL), Economical and Personal or Professional aspects suggest significant changes in pre and post stroke experience of SO. Paired t-test suggested that mean difference between pre and post stroke experiences of SO in this study is highly

significant at the 0.001 level for all cases (p<0.001 at 24 degrees of freedom).

*Aim 2:* With respect to conversation between SO and PWA, the small talk had the least, whereas deeper and more detailed conversations had decreased or ceased altogether. The conversations were perceived to be less enjoyable and meaningful compared with those before stroke. It was found that interaction competence and communication effectiveness of PWA had decreased significantly. In turn, the communicative responsibility of the significant others were perceived to have increased during language and communication related function.

*Table 3: The most common experiences of SO's during conversations with PWA in terms of their Language and Communication related functions, Interactional competence and communication effectiveness.*

Language and communication related activities	<ul style="list-style-type: none"> <li>• 28% frequently try to communicate ideas but rarely able to make others understand.</li> <li>• 28% couldn't express without any assistance.</li> <li>• 32% rarely gives attention to others communication.</li> <li>• 36% rarely initiate communication but frequently ask others to repeat/repairs.</li> <li>• 40% rarely talk about their spoken abilities (verbally/nonverbally).</li> </ul>
Interactional Competence	<ul style="list-style-type: none"> <li>• 20% sometimes interact during conversation.</li> <li>• 20% never uses different ways (gesture, written mode, picture or others) to get his/her message across.</li> <li>• 28% are having overall less interactional competence.</li> <li>• 40% are sometimes uses communication function and gets his/her message across by actively participating in interactive communication.</li> </ul>
Communication effectiveness	<ul style="list-style-type: none"> <li>• 24% frequently understand written content whereas 24% understand rarely.</li> <li>• 32% frequently participate in conversation with strangers whereas 32% involve rarely.</li> <li>• 36% sometimes acknowledge person's name involved in conversation</li> <li>• 44% express their emotions (by different mode).</li> <li>• 52% frequently involve in group conversation and use to answer in yes/no always (verbal/non verbal mode).</li> <li>• 56% can respond to pain and other physical need.</li> </ul>

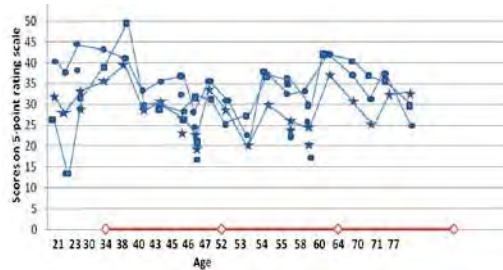


Figure 1: Responses of SO about perceived abilities of PWA in relation to their age on language and communication related function, max score= 55 communication effectiveness, max score=49 Interaction competence of PWA, max score= 35) 5-Point rating scale.

This figure depicts relationship between age of PWA with language and communication related function (LCRF), communication effectiveness (CE) and Interaction competence (IC) of PWA from SO's perspective. Younger group i.e. below 40 yr of age group has better LCRF, CE and IC than other age group. Ferro (1988) studied 254 young adults with stroke and found that cardiac embolism was the most common cause of stroke in patients younger than 40, while atherosclerosis was the most frequent etiology among those aged 41-50 years. Kertesz (1981) found that in comparison to older aphasic population, young patients had significantly more non-fluent aphasia and fewer comprehension deficits. In fact, aphasia types characterized by impairment of comprehension, whether non-fluent (global) or fluent (wernicke's, transcortical sensory), were less frequent in young patients. This finding indicates that comprehension deficits are either less prevalent or have a superior recovery in young adults. Consequently, less comprehension deficits lead to fewer burdens to SO of PWA in terms of interactional competence, communication effectiveness and language and communication related activities.

Aim 3: Chi square data analysis has shown highly significant ( $p < .001$ ) association of education, severity, type of aphasia and interaction competence, communication effectiveness and language- communication related activities of PWA. On the other hand, relation between competence of PWA with type of family (i.e. joint family, nuclear family and alone) is border-line acceptable ( $p \leq 0.046$ ).

The figure reveals that those having education up to higher secondary (37.5%) and graduation (35%), always use language and communication related activities effectively with a good interactional competence as reported by SO. Consequently, it reduces the dependency of PWA on their SO and decreases the burden of SO.

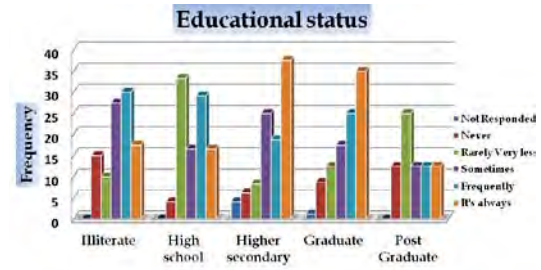


Figure 2: Representing responses of SO towards PWA in terms of educational status of PWA.

Printz-Feederson (1990) also found that advanced education, high income and moderate physical disabilities were related to reduce feeling of burden. On the other hand, Reis (2003) has stated that studies about the influence of educational level and literacy (or illiteracy) on aphasia severity have yielded conflicting results.

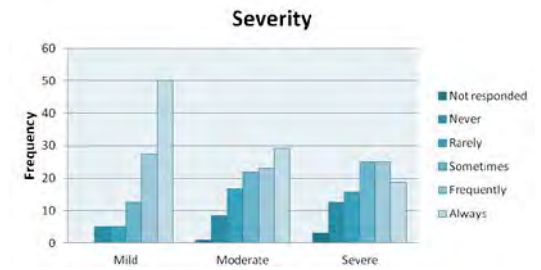


Figure 3: Representing responses of SO towards PWA in terms of severity of aphasia.

50% mild aphasics and 29.6% moderate aphasics communicate effectively and have good interaction competence as shown in figure 3. On the other hand, SO of severe aphasic has reported limited competency and infrequent communication effectiveness of PWA. Since individuals with severe (global) aphasia often remain severely impaired, despite of some improvement in comprehension (Paolucci Antonucci, Pratesi, Trabalesi, Lubich, & Grasso, 1998), which in turn increases dependency and burden of PWA on their SO. Blake and Lincoln 2000) by using caregiver strain index (CSI) found that increased stroke severity causes poorer caregiver health and physical burden.

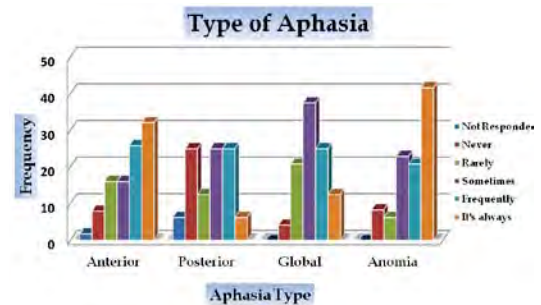


Figure 4: Representing responses of SO towards PWA in terms of types of aphasia.

As indicated in fig.4, 42% and 33% person with anomic and anterior aphasia respectively, have



more competencies and less burden on SO in comparison to posterior and global aphasia. Godefroy (2002) assessed syntactic comprehension of PWA through word and sentence-picture matching tasks and observed that Broca's aphasic has performed well than other types of aphasic and showed mild impairment on syntactic comprehension tasks. Murray & Chapey (2001) also stated that anterior and anomic aphasias have often good prognosis over time and relatively preserved comprehension than Wernicke's aphasia.

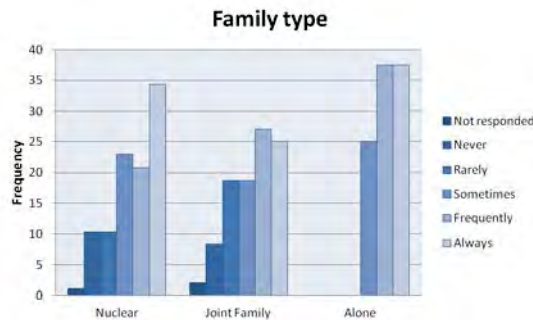


Figure 5: Representing responses of SO towards PWA in terms of types of family.

37% & 35% of PWA staying in either nuclear family or alone are having better communication effectiveness and competency in comparison to those residing in joint family. It could be due to the reason of appropriate demand and performance or due to usage of one to one communication (which is more facilitating) or more focused interaction with PWA residing in nuclear family and alone (with caregivers/others).

Mekala, Mioshi, Alladi, Fathima, Poodipeddi, & Kaul, (2012) studied SO of Person with dementia and found that Carer's burden is a multifaceted construct, which is not easily explained by severity, but atleast partly can be explained by carer anxiety, depression and stress. Thus, burden of SO were assessed on the basis of ratings on "Significant others' oriented questionnaire". Through questionnaire it was found that despite of long-term intensive effort, challenges and expensive intervention programme after Aphasia, they do not get impatient, annoyed with PWA during conversation. Even they do not find that intensive care of their relative lead to dearth of time and rest for themselves. Surprisingly, they were totally disagreed with the statements e.g. "Do you think your family member's illness is main cause of your poor economical status?", "Do you think intensive care of your family member (PWA) leads to feeling of burden". These apparent paradoxical results may be due to unawareness about self feelings or cultural factors. Since, SO's burden is a complex construct

that is likely to be modulated by cultural background. People may be in denial mode or did not properly express or do not know the exact status of their view about their relatives.

### Conclusion

Impaired communicative ability is an important factor for the emergence of negative psychosocial consequences (post stroke changes in social, physical, economical, personal and professional) and apportionment of communicative burdens to SO.

56% of aphasic can respond to pain and other basic physical needs whereas only 28% frequently tries to communicate ideas but rarely able to make other understand. So, SLP should provide services that especially facilitate operational and strategic competency of SO to achieve optimal communicative competence of PWA.

Burden of SO is difficult to study not only due to various dysfunction following stroke and other influencing factors such as educational status, family type, severity and type of aphasia but also due to the diversity about importance of communication in any society (especially for creating and maintaining relationships) and usage of communications strategies by SO.

### Future direction

Use/improve coping strategies through all modalities i.e., spoken, comprehension, reading, writing, pictorial representation and others to reduce communicative burden of SO.

Learn more about how to design and conduct family oriented interventions that include communication partner training.

To investigate outcome of combination of impairment based language intervention alongwith family oriented intervention.

To assess facilitating factors that increases the possibility of PWA for being an active participant in social life.

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