



# Development of Checklist to Assess Caregivers Perspectives and Preparatory Knowledge about Aphasia

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## Abstract

Aphasia has a devastating effect on both the patient and the caregiver. As the onset of this condition is sudden it doesn't offer time for the caregiver to gain preparatory knowledge about aphasia. If the preparatory knowledge is poor, then the empathy and mutuality would get affected. In order to carry out his/her role effectively a caregiver must have preparatory knowledge about aphasia, its impact on speech and language abilities of a person, co morbid conditions associated, rehabilitation services need for the patient to overcome the constraints induced by aphasia. The study aimed at assessing preparatory knowledge about aphasia in the caregivers. It had three parts part (a) concentrated on questions about impact of aphasia, part (b) tested the knowledge of caregivers questionnaire about the rehabilitation service while the last part, part (c) concentrated on testing their knowledge about the responsibilities to be taken up. The questionnaire was circulated among four Caregivers (females) of four patients with aphasia, who were in acute phases. It was found that the caregivers had limited knowledge about the impact of aphasia. They knew that it would take time for the person with aphasia to recover and also the roles to assumed during this phase

**Keywords:** Impact; Burden; Preparation; Dilemma; Shock

## Abbreviations

UMAP: University of Michigan Aphasia Program.

## Introduction

Stroke tends to change lives; the effect of stroke is more devastating if it is associated with language deficits i.e. aphasia. Though apparently aphasia is viewed as a language deficit affecting the domains of language in a broader view it tends to affect the activities related to daily living. As daily living of persons with aphasia gets affected, the lives

of caregivers also undergo a change. Aphasia is found to be more dreadful to caregivers compared to other conditions such as dementia and other neuro degenerative conditions as the onset in aphasia is sudden and the caregivers have to cope up with its consequence with no prior mindset about the deficit.

Some persons with aphasia may be the bread earners for their families, when aphasia strikes their lives the caregivers may have to take up the role and responsibilities [1]. The caregivers also experience feelings of anger and guilt [2]. Aphasia is often viewed in perspective to the stroke survivor

or victim in this particular paper. The caregivers of persons with aphasia are sometimes called as informal caregivers.

An informal caregiver is defined as an unpaid person, who is most closely involved in taking care of persons with aphasia [3]. The caregivers also may find it difficult to cope with the emotional consequences such as depression, loneliness associated with aphasia. These factors are not paid much attention in service delivery model for persons with aphasia.

The caregivers in western context are introduced to enablers and barriers affecting communications [4].

A stroke survivor would be discharged after a period of 3 months by this duration sufficient preparatory knowledge would be induced in the caregivers of stroke survivors and thus this factor would be an enabler in western context but here it would be a barrier. The caregivers of persons with aphasia in western context would be acclimatized about the usage of gadgets and apps, which would enable them to use such gadgets and apps specially designed for the betterment of stroke survivors. This factor again is enabler in western context and barrier in here again.

The other barriers include geographical constraint, affordability for therapy etc, these factors may be counteracted but the most important barrier in these contexts would be lack of preparatory knowledge.

Fewer studies have focused on the caregiver's perspective about aphasia, their knowledge, their level of preparation in coping up the cognitive, emotional, and behavioral problems associated with aphasia.

Ostwald SK, et al. [5] developed a scale for determining the stress levels in caregivers and named it as perceived stress scale. This was circulated among the caregivers of persons with aphasia at a duration of 3, 6 and 9 months from the onset of aphasia and he reported that coping behaviors were poor at the onset and progressively improved with time. In a study Hinckley JJ [6] two core behaviors (preparation and mutuality) were investigated in caregivers with aphasia. Preparation refers to knowledge, perception and the mindset of the caregivers, while mutuality refers to the ability of the caregiver to take up responsibility and share activities with the person with aphasia. Preparation and mutuality was poor in all the caregivers initially and improved eventually.

The concept of preparation and mutuality led to the concept of care giver education as the preparation and mutuality is poor in the caregivers of persons with aphasia. Many aphasiologists and aphasia programs have employed this concept of care giver education. Yalom ID,

et al. [7] advocated caregiver education. In this program direct imparting of education, advice, imitative behaviors to increase the empathy and corrective recapitalization to change the mind set of caregivers was followed. University of Michigan Aphasia Program (UMAP) also implemented an awareness program to the caregivers where the caregivers were given education about aphasia its circumstances and the measures to increase the readiness of the caregivers to work with persons with aphasia. In Indian perspective no such awareness programs have been inducted.

**Need for the study-** It is a well-established fact that the caregivers with aphasia may not be mentally prepared to cope with communicative, cognitive and behavioral changes seen secondary to aphasia, they may have limited knowledge about the rehabilitation services needed for persons with aphasia. This limited knowledge may impede the progress of aphasia. Moreover the preparation knowledge is dependent on several other factors like basic education, socio economic class, age of the caregiver and client and so on. Hence there is a need to develop a questionnaire which assess for preparation knowledge, if preparation knowledge is low then it would imply that informal education to increase the readiness and preparatory knowledge has to be imparted for the caregiver to successfully cope up with aphasia. Questionnaires to assess the burden in caregivers of aphasia have already been developed but questionnaires to assess the preparatory knowledge exclusively have not been developed in the past.

**Method-** The aim of the present study was to develop a questionnaire for assessing preparatory knowledge in persons with aphasia. The study was carried out in two phases. In the first phase, a questionnaire was developed. The questionnaire in turn was divided into three parts part A had questions related to 15 questions on communicative, cognitive and behavioral problems related to aphasia. Part B included 15 questions related to treatment (like the different rehabilitation services needed and its knowledge about the approximate duration etc). Part C had 10 questions to elicit details on their knowledge about their role in rehabilitation. All the questions were close ended (Table 1).

Parts	Domains	Number of questions
Part 1	Core and Co-morbid conditions associated with aphasia	15 questions
Part 2	Need for Rehabilitation services	15 questions
Part 3	Role of self (caregiver) in rehabilitation	15 questions

**Table 1:** Details of the Three Parts of the Questionnaire.

The developed questions were subjected to a goodness rating from 3 experienced SLP's and the questions shortlisted as apt were only used. In the second phase the questionnaire was administered on 5 care takers of patients with aphasia. All the persons with aphasia were in acute phase and were diagnosed to have global aphasia. All the care takers were females in the age range of 45-55. The education of the caretakers varied from SSLC to Degree see Table 2. They were asked to fill the questionnaire by using Yes/No and the results on the three parts were analyzed. Each correct response was given a score of 1.

The maximum score was 15 for each domain.

Sl No	Age/Gender	Qualification	Place
1	51/F	PUC	Urban
2	53/F	Degree	Urban
3	47/F	Degree	Urban
4	45/F	SSLC	Sub-Urban
5	55/F	Part-Degree	Urban

**Table 2:** Details of Caregivers.

## Results

The responses of the caregivers on the three domains were compared. Table 3 provides comparison of scores on the three domains. Higher score was obtained for domain 3, followed by domain 2 and domain 1. The data not subjected to test of normality as the sample size was less. Invariably Non-parametric test was used. For within group analysis, Friedmann's test was carried out and the  $\chi^2$  obtained was 2.34 showing that there was significant difference between the three domains. Further Wilcoxon's signed rank test was carried out and the Z score obtained on comparing domain 1 vs domain 2, domain 1 versus domain 3 and domain 2 vs domain 3 was 2.34, 2.55 and 1.69 respectively and the corresponding p values showed significant difference for the first two domains, when domain 1 was compared with the other domain significant difference was seen

Domain 1	Domain 2	Domain 3
7	11	12

**Table 3:** Comparison Across Domains.

Descriptive analysis was carried out to analyze the data. On the first domain of questionnaire, all the caregivers except one had limited knowledge. Most of the caregivers viewed aphasia as a linguistic deficit and they had limited knowledge about the co morbid problems in aphasia mainly. One of the five participants had sound knowledge about aphasia, the linguistic, behavioral, and cognitive deficits

associated with aphasia as she had goggled about aphasia. On part B the caregivers believed that considerable amount of recovery would take through spontaneous recovery and also felt that speech and language therapy was needed for the person to revert to normalcy. However the knowledge about approximate duration required for therapy was not there in the caregivers and the four out of five caretakers were not much about allied therapy services needed for persons with aphasia. On part C all the caregivers were aware of their responsibilities and knew that it would take time for their spouses to take up responsibilities.

## Discussion

The study aimed at developing a questionnaire with the intent of assessing preparatory knowledge of persons with aphasia. The basic premise for developing such a questionnaire is that the preparatory knowledge would be less in the caregivers. The preparatory knowledge in turn would depend on certain other factors like gender of the caregiver. It is often assumed that the preparatory knowledge would be more in males as caregivers compared to females. However all the caregivers considered for the study were females and hence this variable would not be unveiled from the inputs of the current study. Another factor which would affect/alter the preparatory knowledge is the education of the participants. This factor proved to be an important variable affecting the preparatory knowledge even in this study. The participants with better educational status would empathize the conditions better and also understand the need of rehabilitation services in a better way.

The three parts of the questionnaire addressed at three different domains concerning the preparatory knowledge of the participants. The first part focused on assessing the caregiver's knowledge on the core and co morbid conditions associated with aphasia. Knowledge about this aspect was limited especially in older caregivers as the participants recruited for this study. Few participants showed enthusiasm to understand about aphasia through web sources but there were myths and areas which had lack of understanding. This aspect would be one salient aspect to be considered during the process of intensive counseling.

The second part of the questionnaire addressed on understanding the need of rehabilitation services. Most of the caregivers would understand the need for such services and did not assume that betterment could be induced through spontaneous recovery only and most of the caregivers depended on the suggestions of the physicians or neurologist to understand the importance of therapy. The caregivers had relatively better knowledge about their role at home and also knew that it would take time for their spouse to take up their responsibilities after stroke. The overall administration of

the checklist showed that caregivers especially house wives and people with comparatively lesser education had limited knowledge about the core and co morbid deficits involved in aphasia and also about speech language and allied services required for betterment and the duration required for the same was limited. All the caregivers knew that their spouses could not take up the responsibilities and there mutuality was good in the caregivers apparently.

### Conclusion

The onset of aphasia is sudden. It gives a minimum time for the caregivers to gain preparatory knowledge about aphasia. With advancement of technology the caregivers and relatives may browse and know about the impact of aphasia and line of treatment; however certain people may be deprived of such preparatory knowledge. If the preparatory knowledge is poor, then the empathy and mutuality would get affected. The questionnaire developed through this study was developed with the motive of assessing preparatory knowledge and by administering the questionnaire the areas or domains which the caretakers are deprived of can be identified and training the caretakers on these domains will enable them to empathize in a better way and develop mutuality. The limitation of the study was that it was administered on a smaller group and such questionnaires must be administered on a heterogeneous knowledge for better utility.

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