

## **Public Awareness and Knowledge of Aphasia in Young Indian Adults**

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### **Abstract**

**Background:** It has been suggested that awareness and knowledge about aphasia can lead to appropriate diagnosis and enhanced intervention. Earlier studies showed that the knowledge about aphasia was very less compared to other medical conditions

**Aim:** To assess the awareness and knowledge of aphasia in young adults thereby developing a strategy to improve the responsiveness to the disorder

**Methods:** An aphasia awareness survey was administered to 189 young adults (19 – 40 years) in locations of large gatherings (youth meetings, club, and shopping malls). Questions regarding the knowledge of aphasia was administered, and the respondents to answered “yes”, “no” and not sure. Qualitative analyses of the obtained results were done.

**Results:** It was observed that females had better knowledge compared to males. Around 45 individuals (49.45 %) heard about aphasia during their work economy, 28 individuals (30.76%) through reading articles related to stroke and 18 of them(19.78%) known aphasia as their relatives having aphasia.

**Conclusion:** Though a small survey, the awareness and knowledge about aphasia in young adults, is higher in those who work in relation to it than those who do not with females getting an overall higher score. The knowledge that aphasia can affect all language modalities is limited with uncertainties about it impact on mental health, thinking and cognition.

**Key words:** Survey, Aphasia awareness, Young adults, Kerala

## **Introduction**

Stroke is a global health problem and a leading cause of adult disability worldwide. (Donnan, Fisher, Macleod & Davis, 2008). It is the fourth major cause of death in India, the rate being 0.6/ 1000. (Strong, Mathers & Bonita, 2007). Stroke in young adults (15 – 45 years) is becoming an important cause of morbidity and mortality throughout the world (Park, 2013).

India, a South Asian country has a population of over 1.311 billion people. Out of this general population 15% - 30% of all stroke patients in India constitutes of young adults (Nayak, Nair, Radhakrishnan & Sarma, 1997). Atrial fibrillation is identified as an independent risk factor of stroke in the young population. Compared with stroke in elderly alcohol use, smoking, hyperlipidemia, and cardiac diseases, which are known risk factors, are higher in young stroke (Subha, Pillai, Athira & Nujum, 2015).

Aphasia a most common effect of stroke is a multi-modal language disorder that affect reading, writing, auditory comprehension and expression. According to National Aphasia Association, Approximately 25 – 40% of strokes result in aphasia (as cited in Chazhikat, 2011).

Awareness of treatment strategies for stroke and related disorders is limited. A hospital based study revealed that more than 2/3rds of the subjects were not aware of treatment programs available for stroke (Das, Mondal, Dutta, Mukherjee & Mukherjee, 2007). Awareness of warning symptoms and risk factors of stroke in the general population and in survivors stroke. The aim of the present study was to assess the awareness and knowledge of aphasia in young adults thereby developing a strategy to improve the responsiveness to the disorder.

## **Methods**

### **Respondents**

An aphasia awareness survey (Appendix A) used in a previous study by Simmons – Mackie and colleagues (2002) was administered to 189 young adults (19 – 40 years ) in locations

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of large gatherings ( youth meetings , clubs , shopping malls). The survey was terminated if the person indicated that she/ he had not heard of the term aphasia.

### **Assessing Knowledge of Aphasia**

Questions regarding the knowledge of aphasia were formulated from the study done by Whitaker and colleagues (Whitaker, Marie and Mevshall & Carl, 2011). Eight questions of the Aphasia Awareness Survey (Appendix A) pertained to the symptoms and causes of aphasia (questions 4a – 6a to e). As with the study done by Whitaker and colleagues, the respondents answered these questions “yes”, “no” or “not sure”. An appropriate decision was made to consider any “not sure” answers from respondents as wrong answers.

### **Scoring**

Answers of respondents to the aphasia knowledge quiz were scored right or wrong. For each participant, the number of correct responses was computed. The percentage of correct responses on a question by question basis was also computed.

### **Results**

The survey was administered to young adults between the ages of 19 to 40 years with average of 30.0 (sd = 5.54) years, which is shown in the table 1.

**Table: 1- Age group**

Maximum	40 years
Minimum	19 years
Average	30.0 years
SD	5.54

The number of correct responses on the aphasia knowledge quiz for the 91 participants who has heard of aphasia ranged from 2 – 13. The mean number of correct responses was 7.15

(sd =6.33). The tables 2 illustrate distribution of scores across the respondents. Percentage of correct responses for the respondents on a question by question basis is shown in the table 3.

**Table: 2- Distribution of scores**

No of correct responses	No of respondents
1	0
2	1
3	1
4	1
5	4
6	3
7	6
8	17
9	17
10	7
11	10
12	16
13	10

**Table: 3-Mean percentage of correct responses for participants on the aphasia knowledge quiz**

Statement	Percentage correct
1	78.02%
2	71.42%
3	69.23%
4	35.16%
5	52.74%
6	64.83%
7	64.83%
8	90.10%
9	94.50%
10	75.82%
11	74.72%
12	78.02%
13	94.50%

Computing the gender wise basis of knowledge of aphasia, it was observed that females had better knowledge compared to males. Among the 13 questions, only 9 in 59 females (15.25%) and only 1 person in 32 males (3.12%) scored better among the 91 participants.

The distributions of gender between samples were more of females compared to males, and may reflect the probability that greater number of females participated in socio curricular activities.

### Survey Participants' Profile

**Table: 4- Gender**

Gender	Number of Respondents	Percentage
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Male	32	35.16%
Female	59	64.83%

The individuals in the current study gained knowledge about aphasia mainly through their works and by reading articles related to stroke and also some of them know aphasia because some of them have relatives who is suffering from aphasia. Around 45 individuals (49.45 %) heard about aphasia during their work economy, 28 individuals (30.76%) through reading articles related to stroke and 18 of them(19.78%) known aphasia as their relatives having aphasia.

**Table: 5 - Awareness and knowledge of aphasia through different channels**

Different channels	Number of respondents	Percentage
Work	44	48.35%
Relative has Aphasia	18	19.78%
Articles	28	30.76%
TV	0	0
Doctor	1	1.09%

These data shows that more than 90% of the respondents who took the Aphasia knowledge quiz knew that aphasia is a disorder which affects communication ( question 8) caused by brain damage (question 9) and stroke (question 13). More than 70% correctly identified that aphasia affected oral communication (question 1 and 2) and was not caused by impaired intelligence, emotional or mental problems. (Questions 11, 10, 12).

Respondents, though, were uncertain whether persons with aphasia had problems with general intelligence, with only 35% answering correctly to question 4. Although nearly half the number of respondents were aware about aphasia through their work ( n = 44) , percentage of correct responses indicating whether aphasia affected all language modalities was less than 65%. (Question 6 = 64.83%. question 7 = 64.83). Finally, only half the respondents (52.74%) were aware that persons with aphasia did not have ‘mental health’ problems.

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## **Discussions**

This study assessed the awareness and knowledge of aphasia among young adults in Kerala there by implementing strategies to create better responsiveness to the disorder.

Among the 189 respondents' who were surveyed, it was disheartening to know that only 48.14% of the young adults had heard of the term aphasia. This low awareness of the disorder was corroborated with the study done by Chazhikat, in 2011 indicating that there is a limited awareness and understanding of the nature of aphasia among the general population in Kerala.

The distributions of gender between samples were more of females compared to males, and may reflect the probability that greater number of females participated in socio curricular activities as postulated by Gender differences in the knowledge of aphasia was figured indicating that females had better knowledge of aphasia compared to males, with similar results attained by Code and colleagues in the study of "The public awareness of aphasia: an international survey (Code et al., 2001).

Examination of table 3 shows that among the 48.14 % who responded to the survey, 48.35% knew about aphasia through their work environment. These high levels of awareness in the results could be explained by the fact that a larger portion of the respondents consisted of students and professionals like social workers, physical therapists, nurses, teachers etc. Thus we can assume that awareness regarding aphasia increased with co – relation to the type of work one was associated. This is corroborated by a study done by Simmons- Mackie and colleagues (Simmons-Mackie, Code, Armstrong & Elman, 2002). Less than 20% had knowledge about aphasia through print or electronic media thereby highlighting the lack in promoting awareness about this debilitating disorder. Even among those who knew about aphasia through their work,

if a cut of 90% was used, regarding language modalities affected and presence of impaired health and mental health conditions, few of the respondents would get a passing score.

In conclusion, though a small survey, the results indicates some clear patterns. Among young adults, the awareness and knowledge about aphasia is higher in those who work in relation to it than those who do not with females getting an overall higher score. Majority of the participants are aware that brain damage through stroke is the primary causal factor for aphasia. The knowledge that aphasia can affect all language modalities is limited with uncertainties about its impact on mental health, thinking and cognition. The survey responses highlight the lack of awareness and hence poor responsiveness to the disorder thereby delaying the treatment strategies and overall prognostic value. With heightened awareness programs these drawbacks can be eradicated to ensure a beneficial outcome to the patients.

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## APPENDIX A

### Awareness of Aphasia Survey

Date of Survey: \_\_\_\_\_ Place of Survey: \_\_\_\_\_ Time of Day: \_\_\_\_\_

1. Age of respondent \_\_\_\_\_ Gender \_\_\_\_\_ Occupation \_\_\_\_\_

2. Have you ever heard of aphasia? Yes \_\_\_\_\_ No \_\_\_\_\_ Not sure \_\_\_\_\_

If no stop here

3. What is aphasia? Tell me in your own words.

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4. Would you say that people with aphasia
  - a. Have trouble with pronunciation of speech (yes, no, not sure)
  - b. Have trouble with language or putting their ideas into words? (Yes, no, not sure)
  - c. Have problems understanding what people say to them? (yes, no, not sure)
  - d. Have problems with thinking or general intelligence? (yes, no, not sure)
  - e. Have “mental health” problems? (yes, no, not sure)
  - f. Have reading problems? (yes, no, not sure)
  - g. Have writing problems? (yes, no, not sure)
  - h. Have communication problems? (yes, no, not sure)
5. What causes aphasia? Tell me in your own words. (Write verbatim)
6. Is aphasia caused by?
  - a. Brain damage (yes, no, not sure)
  - b. Emotional problems (yes, no, not sure)
  - c. Impaired intelligence (yes, no, not sure)
  - d. Mental problems (yes, no, not sure)
  - e. Stroke (yes, no, not sure)
7. Where did you hear about aphasia? (In what context did you hear about aphasia?)
  - a. Relative/friend has/had aphasia \_\_\_\_\_
  - b. On TV/radio \_\_\_\_\_
  - c. Newspapers/magazines \_\_\_\_\_
  - d. Doctor \_\_\_\_\_
  - e. Through my work \_\_\_\_\_
  - f. Other (specify) \_\_\_\_\_
8. What do you think can be done to help people with aphasia? (write verbatim)

**Aphasia Knowledge Quiz.** (Answer true or false)

1. PWA have trouble with pronunciation of speech
2. PWA have trouble with language or putting their ideas into words
3. PWA have problems understanding what people say to them
4. PWA have problems with thinking or general intelligence
5. PWA have “mental health” problems
6. PWA have reading problems
7. PWA have writing problems

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8. PWA have communication problems
  9. Aphasia is caused by brain damage
  10. Aphasia is caused by emotional problems
  11. Aphasia is caused by impaired intelligence
  12. Aphasia is caused by mental problems
  13. Aphasia is caused by stroke
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