

## Awareness of Aphasia and Aphasia Services in South India: Public Health Implications

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**Abstract:**

Aphasia is a language disorder resulting from brain damage. People who acquire aphasia need rehabilitation to maximize functional recovery. Assessing public awareness of aphasia is critical for development of and access to aphasia-related services. The current study addresses levels of public awareness of aphasia and access to aphasia-related services in an urban area of the State of Kerala, India, a region with potentially high incidence and prevalence of aphasia. Results of an aphasia-awareness survey of 114 urban Kerala residents suggest poor public awareness of aphasia in the population. Less than 10% of those surveyed met criteria for having basic knowledge of aphasia. Semi-structured interviews of two Kerala-based neurologists support the findings of the survey and further suggest that aphasia-related services in the region may be limited. Findings hold implications for development of aphasia services and improvement of the psychosocial life of people who have aphasia.

## Introduction

Aphasia is an acquired disorder of language that is caused by damage to the regions of the brain in the cerebral left hemisphere, which are responsible for language production and comprehension. The most common cause of aphasia is stroke, and approximately 25 to 40% of strokes result in aphasia (National Aphasia Association, 2012). Aphasia can also result from head injury, brain tumor or other neurological disorders. Aphasia is most common among adults, especially older adults who are at greater risk of stroke than are relatively younger adults. For most people who have aphasia, a complete recovery is unlikely, but rehabilitation services are essential and effective in restoring everyday communicative functionality (Chapey, 2008; Salter et al., 2012). One may assume that aphasia rehabilitation services may be more readily accessed when levels of public awareness of aphasia are high and when aphasia rehabilitation services are available; access to services for health disorders may depend on a sufficient level of public awareness of the disorder (Das & Banerjee, 2008).

The current study addressed: (1) public awareness of aphasia in an urban area of the southern Indian state of Kerala; and (2) the services and support structures available for individuals from Kerala who have aphasia. This research contributes to a recent worldwide effort to assess public awareness of aphasia, motivated by a desire to improve access to needed aphasia rehabilitation services for people who have aphasia (Simmons-Mackie et al., 2002). The ultimate motivation behind this research is to improve aphasia-related services in Kerala. The first step toward building awareness of aphasia is to assess what the current level of understanding is. In this study, levels of public awareness of aphasia were assessed using a public survey, as well as interviews of local clinicians.

### *Kerala Demographics*

Kerala ranks first in India in literacy and health services. (Institute of Applied Manpower Research, 2011). Thus, one would expect Kerala residents to be exposed to news, publications and other printed materials, including those related to health care. In particular, one might expect relatively good awareness of aphasia among members of this population and already-established health services for people who have aphasia.

### *Estimated prevalence of aphasia in Kerala*

The estimated population of Kerala is 33,387,677 (Directorate of Census Operations in Kerala, 2011), and the estimated prevalence of stroke survivors in southern regions of India near Kerala is 55.6 stroke per 100,000 people across all age groups (Dalal, 2007). This would suggest the number of Kerala residents who are survivors of stroke may be as high as 18,500 people. If one assumes that as many as 40% of stroke survivors will also have aphasia (National Aphasia Association, 2012), then an estimated 7500 people who live in Kerala may have aphasia

Furthermore, the incidence of stroke in India may be on the increase. The Indian National Commission on Macroeconomics and Health estimated an increase in the number of strokes from 1,081,480 cases in 2000 to 1,667,372 in 2015 (Shah & Mathur, 2006). Therefore, if cases of stroke are high within the population, one might expect a high number of cases of aphasia as well, since aphasia typically results from stroke.

The average life expectancy of Kerala residents is 74 years, (Institute of Applied Manpower Research, 2011). This high life expectancy rate is comparable to other developed countries around the world (Institute of Applied Manpower Research, 2011). Because aphasia is most common among the older population it would lead to the conclusion that a significant segment of the population of elderly adults in Kerala may be in need of aphasia rehabilitation

services.

### *Lack of Awareness of Aphasia*

Lack of awareness of a disease or disorder may affect general accesses to services for that disorder. For example, Das & Banerjee (2008) demonstrate that a lack of awareness of warning symptoms of stroke is associated with a delay in receiving medical care from local doctors and a delay in hospitalization, thus negatively impacting patient access to proper treatment. Likewise, lack of awareness of aphasia and its symptoms may negatively impact access to aphasia services for the people who need them.

### *Aphasia Services in India*

There are several institutions outside of Kerala which provide medical services for people affected with aphasia. National Institute of Mental Health and Neuro Sciences (NIMHANS) is a multidisciplinary institute in Bangalore which offers rehabilitative services for patients with aphasia (National Institute of Mental Health and Neuro Sciences, 2012). Sanjay Speech Hearing and Rehabilitation Center is a private clinic that offers aphasia rehabilitative services in Bangalore, India- (Kumar, 2012). Aphasia services are available in other major urban areas. The current study was designed to explore aphasia services are available in urban areas of the state of Kerala.

### *Questions:*

Motivated by the desire to develop aphasia rehabilitative services in Kerala, the current study addressed the following questions:

1. What are the levels of public awareness of aphasia in the urban areas of the state of Kerala, India?
2. What are perspectives of physicians in urban Kerala, on the following topics:

- a) public awareness of aphasia in Kerala
- b) the role of clinicians in treating people from Kerala who have aphasia
- c) services available to people from Kerala who have aphasia

## Methods

### *Public Survey in Urban Areas of Kerala*

A survey tool was used to assess the level of public awareness of aphasia. The survey used for this study was one designed specifically to assess public awareness of aphasia, and has been used at multiple locations worldwide (Simmons-Mackie et al., 2002). To date, this survey has been conducted in multiple locations in North America, Europe and Australia, although the survey has not yet been conducted in India. Of 978 individuals surveyed to date worldwide, 133 (13.6%) said that they had heard of aphasia, but only 53 (5.4%) met the criteria for having “basic knowledge of aphasia” (Simmons-Mackie et al., 2002). For the current Kerala-based administration of this survey, the survey questions were translated into Malayalam, which is the native language of Kerala. Back-translation of the survey was conducted to assure translation accuracy. IRB approval was obtained prior to conducting the study and the approved method was followed in data collection. Surveyors were fluent speakers of Malayalam pursuing degrees in speech and hearing sciences, one of whom is the first author of this study (Chazhikat).

### *Survey Participants*

A convenience sample of participants was gathered in a local busy shopping complex in the town of Kottayam. Following the survey procedure of Simmons-Mackie et al (2002), Surveyors asked potential respondents if they would answer a few questions, then asked basic demographic information consisting of age, gender, and occupation. Participants were then asked

if they had even heard of aphasia. From those participants who answered positively, knowledge of aphasia was tested by asking them to define aphasia. Each participant was asked to identify characteristics associated with aphasia by choosing “yes” or “no” or “not sure” from a list of characteristics such as “problem with speech”, “intelligence problem” or “communication problem.” They were also asked what cause aphasia and where they had heard of aphasia.

#### *Semi-structured Ethnographic Interviews of Clinicians*

A semi-structured interview of clinicians was used to assess the level of public awareness of aphasia; the questions addressed areas such as: medical practice with patients with aphasia, diagnosis and treatment of aphasia and public awareness of aphasia and aphasia resources in South India.

Face-to-face semi-structured interviews were conducted with neurologist in Kerala to solicit their perceptions of the level of public awareness of aphasia, and to gather information about the services and support structure available to individuals with aphasia in India, with a concentration on the state of Kerala. The interviews were structured in a semi-structure format to that allows new questions to be addressed while targeting all the areas that need to be concentrated on. Semi- structured interviews allow for reliable qualitative data to be collected.

Two physicians who provide care to patients affected with neurological disorders and who have experience serving patients who have aphasia were interviewed. The clinicians were selected through a Member of Legislative Assembly (MLA) for the state of Kerala. This person was chosen as the referral source for this study because he possessed the most complete knowledge available of the variety of health care services and health care providers in the state of Kerala. Research team phoned and e-mailed the MLA to provide him with an information sheet about the study to give to the potential participants.



The MLA anonymously contacted potential participants and provided them with an information sheet which contained the basic information of the. Potential participants who were interested to learn more about the study then directly contacted the Key Personnel to indicate their interest in study participation. Once this contact was made by the potential participant, they were provided with written Informed Consent and the opportunity to ask questions about the study.

Interviews were carried out at the physicians' respective office places in person and interview data was collected using hand written notes which were expanded and typed immediately after the interview from memory. IRB approval was obtained for these interviews and the approved method was followed in data collection.

#### *Data Analysis*

Analyses related to Question 1 on public awareness of aphasia: Distributions of age, gender and occupation of the survey participants was tallied. The number of people had heard or not heard of aphasia was tallied. Of those who had heard of aphasia, the number of those who had "basic knowledge" of aphasia was tallied; participants were classified as having basic knowledge of aphasia if their responses met the criteria of having chosen "speech", "language" and/or "communication problem" and if they also identified the cause of aphasia to be brain damage and/or stroke. Data was compared between the responses of those who were aware of aphasia and those who were not.

#### **Results**

##### **Survey results**

Survey respondents consisted of a convenience sample of 114 adults. Similar proportions of males and female were surveyed. Responses of survey participants were compared across

demographic groups. The age of respondents ranged from 27 to 62 years, with an average age of 47 years. Of the 114 respondents, 69 (60.5 %) were in professions which do not require higher education and 45 (39.4 %) were in professions which typically required higher education(See Table 1).Thirteen participants (11.4% respondents) said they had heard of aphasia. Of those, only 10 (8.7% respondents) had “basic knowledge of aphasia”; participants had basic knowledge of aphasia if all four conditions below are met:

- “yes” to Is aphasia associated with: “speech problems”, “language problems” and/or “communication problems”
- “yes” to the cause is brain damage
- “no” to “psychological problems” and “problems with intelligence” are not symptoms
- “no “ to “emotional problems”, “impaired intelligence” and “mental problems” are not causes

Table 2 shows comparison between the occupation of the participants and their knowledge of aphasia. In demonstrating their knowledge of aphasia, a number of participants offered varying definitions of the word “stroke”. Respondents who had heard of aphasia and demonstrated basic knowledge of aphasia were evaluated by occupation and gender. Analysis of the occupations among the participants who had “basic knowledge” of aphasia showed that those who worked in hospital or school settings had more knowledge of aphasia than those of other occupations and work settings.

Table 3 shows the responses of the participants to the various questions concerning aphasia. The responses from this table show a better understand of the participants’ familiarity with aphasia and area related to aphasia. Table 4 shows high awareness among the population of stroke compared to the lack of awareness of aphasia. This was an important finding during this

study. Almost all the participants had heard of stroke and 105 participants answered correctly what stroke was. This shows that there is an awareness and well-informed understanding of stroke among this population.

The clinicians report that there is an evident lack of awareness of aphasia, even among the patients who have had a stroke and have acquired aphasia. Clinician A sees patients who come from middle class socio-economic group, mainly consisting of Hindu and Christian patients. He reports that he sees about 2-3 patients with aphasia a week, and that the aphasia severity level of these patients ranges from mild to severe. The general patients and their families are often not aware of aphasia. Clinician B works with patients who come from the lower socio-economic group. His patients come from varying religious backgrounds including: Hindu, Christian and Muslim and have no formal education to college education. He sees on average 2-3 patients with aphasia per month and sees cases of aphasia that are mild to severe.

Both interviewees report that there are no assessments or interventions for aphasia in the facilities where they work. Both clinicians expressed that they feel there is no cultural barrier such as religious customs or beliefs that prevents patients from seeking care. Although both clinicians expressed that it may be difficult to change this lack of awareness they feel can be done with proper planning. This might be accomplished by encouraging medical professionals to engage in public education about aphasia through printed materials and the media.

### Discussion

Both the public survey results and the results of the semi-structured interviews are consistent in their suggestion that there is limited awareness of and understanding of the nature of aphasia among the population who live in Kerala. However, one would expect that a socio-political region like Kerala that boasts a high literacy rate and relatively high levels of general

education would be a prime location for development of public knowledge of aphasia and improved access to services. This would suggest that perhaps the general public is not being informed by medical professionals and other resources about aphasia.

The overall proportions of survey participants who have heard of aphasia, and proportions of those who possess basic knowledge of aphasia, are comparable to those found in other regions of the world. Thus, Kerala may not be unique with respect to other world regions in its generally poor levels of public awareness of aphasia.

In Kerala, the survey respondents who had “basic knowledge” of aphasia worked in hospital or school settings and had more knowledge of aphasia than respondents who worked in private, non-medical or non-educational settings. This might also be the cases in other part of the world. Populations that are not in the health care setting may not have exposure to aphasia and may lack awareness of it.

Findings from the interviews with the neurologists suggest that aphasia-related services in the region may be limited in the urban area where they practice. This may be due to the poor awareness that the public have of aphasia. Since the population lack awareness of this issue, they will not have the tendency to seek care or treatment for aphasia or aphasia related symptoms.

Also, given the relatively high age of life expectancy in Kerala, public education about aphasia and development of additional aphasia intervention services would be particularly advantageous, since stroke-induced aphasia is typically associated with older cohorts of patients. A two-pronged approach to development of aphasia services would increase the public awareness of the nature of aphasia, and also the public awareness of the life benefits of aphasia intervention services and access to them. Models for both are provided by (Chapey, 2008). Models of aphasia advocacy efforts in Britain and the U.S., (Connect, 2012; Speakability, 2012 )

may be applicable in Kerala. Adapting the ideas and programs that these organizations provide for the public may serve as models for how to improve awareness of aphasia in Kerala and elsewhere. |

Global collaboration among aphasiologists and advocates for people who have aphasia will be essential to build an understanding of the demographic, historical and socio-cultural factors that will ultimately improve public awareness of aphasia and expand access to services and support, at the local level, for people who have aphasia. In these efforts, aphasia advocates may be inspired by Cole (1997, p. x) who states: “What models should be used for determining optimum health and life expectancy? Well, in my scientific Utopia, health objectives would be species specific rather than race specific. The only race for which health objectives would be established would be the human race.”

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## APPENDIX

### Semi-Structured Interview Questions (Core Questions)

#### **Personal Information and Education / Career Background:**

- Tell me about your education and training.
- Tell me about your work locations

**Medical Practice with patients with aphasia:**

- Could you describe the socio-economic background of the patients you see?
- Before your medical training/experience had you been familiar with aphasia?
- Tell me the nature of your contacts with people who have aphasia.
- On average how many people with aphasia do you see?
- What is the severity of the cases of aphasic patients you see?
- What are the backgrounds of the patients with aphasia that you see (education, age, gender, occupation, etc).

**Diagnosis and Treatment of Aphasia:**

- To your knowledge, what types of assessments or interventions are typically done for patients with aphasia in South India?
- Could you explain to me what therapeutic resources, clinics, hospitals there are that provide aphasia treatments in South India?
- Could you describe the role of doctors and clinicians with patients who have aphasia?
- What assessment tools and methods for aphasia are you aware of?

**Public awareness of aphasia and aphasia resources in South India**

- Tell me your perception of the public's awareness of aphasia in South India
- Is there a lack of awareness of aphasia?
- Do you perceive that there are any family/ cultural barriers that prevent people with aphasia from seeking treatment?

Table 1: *Survey Participants' Profile*

Gender		
	Male	58 (50.8%)
	Female	56 (49.1%)
Age		
	Max	62 years
	Min	27 years
	Average	47 years
	SD	7.5 years



Table 2  
*Basic Knowledge of Aphasia in relation to occupation*

	Basic knowledge of aphasia	
	Yes	No
All occupations	10 (9 %)	104 (91%)
Nurse	6	11
Engineer	1	6
Teacher	3	18
Non-degreed (e.g. farmer, housewife)	0	69

Table 3: *Survey Responses*

	Aphasia is speech problems?	Aphasia is a language problem	Aphasia is a understanding problem?	Aphasia is an intelligence problem?	Aphasia is a psychological problem?	Aphasia is a reading problem?	Aphasia is a writing problem?	Aphasia is a communicating problem?	Brain Damage is the cause?	Is emotional problems a cause?	Is ment problem a cause
Yes	23	23	22	3	3	5	2	13	37	0	0
No	58	38	49	60	64	68	70	55	77	80	100
Don't Know	33	53	43	51	47	41	42	46	0	34	14

Table 4: *Participants' Responses on Stroke and Aphasia*

Heard of aphasia - Y	Heard about stroke - Y	Answered Correctly what Stroke is:
13	113	105
Heard of aphasia - N	Heard of stroke- N	Answered Incorrectly what Stroke is:
101	1	9