

Aphasia: Do We Understand its Impact?

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ABSTRACT

Objective: To establish the extent of Trinity College Dublin students' awareness of aphasia in comparison to multiple sclerosis, a disorder with lower prevalence. **Methods:** Three-hundred students from all six faculties in Trinity College Dublin were surveyed: Arts Humanities; Arts Letters; Business, Economics and Social Studies (BESS); Engineering and System Sciences; Health Sciences; and Science. The survey enquired if the students had "heard of aphasia", 'heard of multiple sclerosis', along with further questioning which allowed for the elaboration of their knowledge of each disorder. The scale ranked the students' knowledge as good, basic, or no knowledge. **Results:** Of the 300 students surveyed, 40 said they had heard of aphasia (13.3%), with 28 of these students (9.3%) meeting the criteria for "basic knowledge of aphasia". In comparison, 267 of the students surveyed (89%) said they had heard about multiple sclerosis, with 223 (74.3%) of these meeting the criteria for 'basic knowledge of multiple sclerosis'. These findings lend support to the notion that the students lack awareness and understanding of aphasia, and that there is an imbalance between the level of awareness and understanding between aphasia and multiple sclerosis.

INTRODUCTION

Aphasia is an acquired language disorder caused by injury to the left half of the brain, which

affects the generation and content of speech and its understanding.¹ It can affect all four modalities of language - reading, writing, comprehension and expression - to varying degrees. Some people with aphasia have problems primarily with expressive language (how they speak) while others have their major problems with receptive language (how they understand). Language is affected not only in its oral form of talking and understanding but also in its written form of reading and writing. Typically, reading and writing are more impaired than oral communication. The nature of the problems varies from person to person depending on many

factors but most importantly on the amount and location of the damage to the brain.² The impairment can be so subtle that it only manifests when the patient is put into unfamiliar surroundings and the language consists of "low frequency" words that he would be unlikely to come across in everyday life. Thus, aphasia is often called an 'invisible' disorder. There is little understanding of aphasia in both the general population and the medical community. Unfamiliarity with the disease has serious ramifications - less funding for services and research and less

empathy for those who suffer from aphasia.³

In this study, subjects' levels of aphasia awareness to their knowledge of multiple sclerosis (MS) were compared. There is little research done on peoples' knowledge of aphasia, yet it is a prevalent disorder. MS was chosen for comparison because it is less prevalent according to the

National MS Society and the National Aphasia Association in the United States.^{4,5} In Ireland, it is not certain which disorder is more prevalent due to lack of research into the number of people with aphasia, however the number of people with MS represents 0.13% of the population (Table

1).⁶ It was also chosen for similarities. MS confers physical as well as communication abnormalities. Aphasia will cause communicative and often physical abnormalities due to the nature of acquiring aphasia, for example a stroke.

Table 1. Prevalence of aphasia and multiple sclerosis

	Aphasia		Multiple Sclerosis	
	Number	%	Number	%
Ireland	Unknown	Unknown	4,735	0.13%
USA	1,000,000	0.35%	250,000 - 350,000	0.09% - 0.12%

It was predicted that awareness levels of aphasia would be lower in Ireland than in America or Britain, due to more advocacy groups and aphasia centres being available to the public in America and Britain. A previous international survey conducted in Australia, the UK and the USA

showed awareness levels are highest in populations near aphasia centres or advocacy groups.⁷ The role of society is to ease the reintegration of people with aphasia by promoting the understanding of their experience in order to create a physical and social environment which will

be most conducive for communication.⁷ However, if awareness of aphasia is lacking, how can society be expected to assume this role?

The opening statement of the 1988 National Aphasia Association's (NAA) survey says, "So many people don't even know the word aphasia, much less what it does to you." Ninety percent of those with aphasia who participated in this survey felt the public's awareness of this disability is

minimal.⁹ The company Speakability held a telephone survey in Great Britain in 2000, and found that only 3% of the participants could give an accurate definition of aphasia. The same study revealed that only 5.4% of the participants in the study had basic knowledge of aphasia in the UK,

the USA and Australia.⁴

Aphasia can be an extremely frightening experience, exacerbated by an absence of compassion due to ignorance or miscomprehension on the part of health professionals in treating these patients. Parr et al. (1997) highlight the view of a patient with aphasia from a stroke with regards to the nursing staff:

I was furious with the nurses because...well two nurses came on one and another side of me and they...they... they discussed me...over...never...never thought of me at all. Never. I couldn't help...you know I wasn't able to speak very well at that time. I was furious with, you know – I'm

usually the person to do the speaking.¹⁰

This lack of understanding within the health service sector also negatively affects information the patient and his family receive concerning services from which they may benefit.

METHODS AND RESULTS

A questionnaire was given to 300 students from the third and fourth years in Trinity College Dublin (TCD). Table 2 shows 13.3% of students had heard of aphasia by name as opposed to 89% of the students who recognised MS.

Table 2. Number of students who recognise the terms aphasia and MS.

	Multiple Sclerosis	Aphasia
Yes	89% (267)	13.3% (40)
No	11% (33)	86.7% (260)

In Table 3 shows the number of students who had heard of either illness. Knowledge of aphasia was predominantly through studying or reading about the illness. In contrast, knowledge of MS was largely through knowing someone or seeing campaigns. In addition, Table 3 highlights again the low percentage of students who have had contact in any way with aphasia.

In Table 4, students are categorised based upon their level of knowledge of aphasia. Group 1 involves students who have heard of aphasia (n=40) while Group 2 takes into account all participants (n=300) in the study, regardless. Table 5 elaborates on the levels of knowledge of each disease.

Table 3. Percentages of ways in which respondents have heard about aphasia and multiple sclerosis.

	Aphasia (n=300)		MS (n=300)	
	Number	%	Number	%
Know someone who suffers from it?	10	3.3%	93	31%
Heard of someone who suffers from it?	1	0.3%	41	13.6%
Work with / study it?	15	5%	37	12.3%
Know someone who works with / studies it?	6	2%	27	9%
Heard about it in the media?	3	1%	72	24%
Heard about it through awareness campaigns?	0	0%	68	22.6%
Read about it in books, journals, the internet etc.?	13	4.3%	46	15.3%
No Response	7	2.3%	0	0%

Table 4. Level of students' knowledge of aphasia.

	Understanding of Aphasia		
	Numbers	Group 1	Group 2, n=300
	Group 1 n=40	% of people who have heard about aphasia	% of overall participants in the study
Good Knowledge	9	22.5%	3%
Basic Knowledge	19	47.5%	6.3%
No Knowledge	12	30%	90.7%

Table 5. Classification of levels of knowledge of aphasia and multiple sclerosis.

	Aphasia	Multiple Sclerosis
Good Knowledge	A knowledge that aphasia is an impairment that can affect all four modalities of communication, and is caused by injury to the brain / stroke.	Knowledge that multiple sclerosis is a degenerative disease, caused by demyelination, that effects at least one of the following symptoms: fatigue, vision, co-ordination, strength, sensation, speech and swallowing, bladder control, sexual intimacy and cognitive function.
Basic Knowledge	A knowledge that at least one modality of communication can be affected by aphasia and /or that aphasia is caused by injury to the brain / stroke.	A knowledge that multiple sclerosis is associated with at least one of the following: <ul style="list-style-type: none"> • a degenerative disease • demyelination • one of the symptoms listed above.
No Knowledge	No knowledge of what aphasia affects, or how it is caused.	No knowledge of what multiple sclerosis is, how it is caused, or what its symptoms are.

DISCUSSION

There is some encouraging news to be found in this study. Of the 300 student sample population, 9.3% meet basic knowledge requirements, (with 3% of the participants considered to having good

knowledge), as compared with the 5.4% determined by the Simmons-Mackie survey.⁷ However, since subjects were pooled from the Health Science faculty, one would hope that these students have a higher level of familiarity.

Results from the study also indicate that there was a large imbalance between aphasia recognition and awareness of multiple sclerosis, despite the fact that aphasia occurs in up to 4

times as many people in the United States.^{4,5} There are a number of possible explanations for this. For example, multiple sclerosis generally affects a younger population than aphasia (although aphasia can strike at any age), so the sample population of college students who are generally a young population, might have been more likely to come into contact with MS patients. Of the total sample population, 31% indicated personal contact with someone affected by multiple sclerosis (MS), and a further 13.6% indirectly associated with an MS sufferer. Conversely, only 3.3% of the population knew someone with aphasia and 0.3% of them had heard of somebody who suffers from it. Only 1% of total respondents had heard of aphasia through the media compared with 24% concerning MS. A very disturbing finding was that 0% of the sample population have heard about aphasia through awareness campaigns in contrast to 22.6% with regards to MS. These disparities in differences of awareness of MS and aphasia due to contact with individuals or awareness campaigns are significant.

CONCLUSION

These results indicate there is not enough being done to promote knowledge of aphasia. Simmons-Mackie et al. (2002) state that the awareness of aphasia in the general public is lacking,

but one must address why this is so.⁷ The public's lack of awareness points to media apathy. From the period between 1985 to 2001, only eight articles were written in the Times and the Sunday Times (English) newspapers that mention the word 'aphasia'. Of these eight articles, five of them detailed that aphasia is caused by a stroke or brain injury, and only three articles explained the background to aphasia. In contrast, when observing the exposure these same papers gave MS,

163 articles discussing the condition appeared from the years 1998 to 2001.¹¹ Why is there such a contrast between media exposure of the two disorders?

The advocates of aphasia promotion must find a way to generate enough appeal so that it will be beneficial for reporters, newspapers and television stations to research and publicise this disorder. By its very nature, suffering from aphasia can cause difficulty for those afflicted to promote awareness, and it is therefore essential that active aphasia advocacy groups be set up in this country to elevate awareness of the disorder.

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