

SYMPOSIUM “INTERNATIONAL PERSPECTIVES ON THE PUBLIC AWARENESS OF APHASIA”

THE PUBLIC AWARENESS OF APHASIA: AN INTERNATIONAL SURVEY IN BUENOS AIRES.

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This study was conducted by the Fundación Argentina de Afasia “Charlotte Swartz” as a part of a mayor study, with the aim of extending our understanding of the public awareness of aphasia, and exploring levels of awareness. We present the results of a survey of 800 shoppers selected randomly in several shopping centres in Buenos Aires, Argentina, using a standard questionnaire (Code et al, 2001), in order to assess the level of awareness of aphasia in people from different social groups. The percentage of people who had heard of aphasia was surprisingly high (20%) compared to the results in other countries, but when asked follow up questions about the condition, only 1% of the sample had some basic knowledge that aphasia is a an impairment of language, speech or communication caused by cerebral damage. Results will be discussed.

THE PUBLIC AWARENESS OF APHASIA IN CROATIA

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We surveyed 360 shoppers in different parts of Croatia (88% female, 12% male, aged 18 to 68 years). Results showed that 43% of respondents said they had heard of aphasia. Of these, 67% connected aphasia with speech problems, 62% with language problems, 38% with problems understanding others, 3% with problems of intelligence, 16% with psychological problems, 33% with reading problems, 31% with writing problems and 56% with communication problems. 68% presumed that brain damage causes aphasia, 11 % thought that emotional problems caused aphasia, 3% said that impaired intelligence caused aphasia, and 15% thought that ‘mental’ problems cause aphasia. 63% thought that something could be done for people with aphasia. We found surprisingly high levels of awareness that could be explained by the fact that a large proportion of our sample were students and professionals like social workers, physicians, nurses, teachers etc.

THE PUBLIC AWARENESS OF APHASIA IN GREECE

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It is important to raise public awareness and provide education about aphasia in order to improve access and reduce communicative barriers for people with aphasia. The purpose of this study was to determine what the Greek population knows about aphasia.

We surveyed 800 individuals (400 women and 400 men) equally distributed from four towns in Greece (Athens, Patras, Tripoli and Lamia) using a standard questionnaire (Code et al, 2001; Simmons Mackie et al, 2002) adapted to Greek.

Results revealed that 48% of the respondents reported that they have heard about aphasia, but only between 0.8% to 5% had some basic knowledge of aphasia. Knowledge about aphasia was higher in women and younger respondents. Most had heard about aphasia through the media and fewer through their work and discussion with friends. There were significant interactions also with social class: knowledge of aphasia was higher in people from higher socio-economic groups and retired people.

These finding should allow speech and language therapists to significantly improve the psychosocial life of people with aphasia, by improving access to the services they need through *targeting* awareness of aphasia in the general public, high street service providers, health, social and community professionals and providers and family and friends.

Code, C., Simmons-Mackie, N., Armstrong, E. et al. (2001). The public awareness of aphasia: an international survey. *International Journal of Language & Communication Disorders*, 36 (Suppl.), 1-6.

Simmons-Mackie, N., Code, N., Armstrong, E. Stiegler, L. & Elman, R.J. (2002). What is aphasia? Results of an international survey. *Aphasiology*, 16 (8), 837-848.

THE PUBLIC AWARENESS OF APHASIA IN NORWAY

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A survey was undertaken to explore public awareness of aphasia in Norway (Haaland-Johansen, 2004). Individuals (N=251) were surveyed in public places using the same approach (convenience sample) and survey method as Code and co-workers (Code et al., 2001; Simmons-Mackie, Code et al, 2002). The sample seemed comparable to earlier studies regarding variables like age, gender and socio-economic status. More than half of the Norwegian sample (57.4 %) reported to have heard about "aphasia", but only 13.9 % demonstrated basic knowledge of the term, main sources of information being the media or their work. The findings of the survey will be further analyzed and compared to newer data.

Media being a central information source, we studied how print media (N=14) portrays aphasia in Norway. Searches were conducted in 2004 and in 2010, each looking at the previous five years. The term aphasia is used infrequently in both samples, when compared to disorders with significantly lower incidence rate. When used, the term is rarely defined or found in a significant context (2004 sample). This is in line with earlier findings (Elman, Ogar & Elman, 2000). The context and contents of the aphasia stories (2010 sample) will be further analyzed.

References

- Code, C., Simmons-Mackie, N., Armstrong, E. et al. (2001). The public awareness of aphasia: an international survey. *International Journal of Language & Communication Disorders*, 36 (Suppl.), 1-6.
- Elman, R. J., Ogar, J. & Elman, S. H. (2000). Aphasia: Awareness, advocacy, and activism. *Aphasiology*, 14 (5-6), 455-459.
- Haaland-Johansen, L. (2004, July). The Public Awareness of Aphasia: A Norwegian Study. Poster presented at Aphasia: 11th International Rehabilitation Conference, Milos, Greece.
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THE PUBLIC AWARENESS OF APHASIA IN SLOVENIA

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Increasing awareness and knowledge of aphasia highlights the importance where to aim awareness, to whom and how. It can be used to help us to understand the impact of lack of public awareness on services, funding, and quality of life for people with aphasia and to plan effective action to improve awareness of aphasia. This study aimed to determine what the Slovene population knows about aphasia. A face-to-face survey was carried out in shopping areas in Ljubljana and in two other cities using a standard questionnaire (Code et al. 2001) adapted to the Slovene language. The presentation will report the results collected from 400 respondents. We shall compare results from different locations, different age and social groups and discuss the implications of the results

INTERNATIONAL PERSPECTIVES OF THE PUBLIC AWARENESS OF APHASIA

Chris Code, University of Exeter, England

Knowing the level of public awareness of aphasia, and where people have heard about aphasia, is vital for targeting awareness raising. Awareness of aphasia has been surveyed in convenience samples of shoppers in English-speaking countries (Simmons-Mackie et al, 2001), in Greece, Argentina, Norway (N=1851), and more recently in Croatia (N=360) and Slovenia (N=400), using translations of the same questionnaire (Code et al, 2001). This symposium will present new data on the levels of awareness in approximately 2,500 respondents from different countries and an overview presentation will examine levels of awareness between countries and previous surveys. Significant variability in knowledge of aphasia has been found between the countries surveyed and earlier surveys. This provides further evidence of differences in levels of awareness of aphasia in different cultures. The keynote overview will present a statistical analysis of these differences and patterns, with a special emphasis on where and how members of the public have heard about aphasia so that attempts to raise awareness can be targeted more successfully in the general public, high street service providers, health, social and community professionals and providers and family and friends..

- Code, C., Simmons-Mackie, N., Armstrong, E. et al. (2001). The public awareness of aphasia: an international survey. *International Journal of Language & Communication Disorders*, 36 (Suppl.), 1-6.
- Simmons-Mackie, N., Code, N., Armstrong, E. Stiegler, L. & Elman, R.J. (2002). What is aphasia? Results of an international survey. *Aphasiology*, 16 (8), 837-848.