Aphasia: Be in the Know

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Disclosure Statement
We have no relevant financial or nonfinancial relationships to disclose.

Question: What is the value of aphasia awareness?

Hypothesis:
- decreases community participation of people living with aphasia
- deters people living with aphasia from seeking adequate health information and resources
- negatively impacts research funding and insurance coverage for aphasia

Background: Code et al. 2001
- Out of 929 people in 3 cities, only 13.7% had heard the term aphasia
- people who had basic knowledge about aphasia: Exeter-7.37% Sydney-7.54% Louisiana-1.54%
- Women more likely to know about aphasia
- Elderly people more likely to have heard of it
- of people who had heard of it, younger people were more likely to have basic knowledge about it
- Most people who have basic knowledge of aphasia learned about it through the media or at work

Background: Sherratt 2011
- Although media coverage of aphasia has increased between 1999 and 2009, quality of media coverage is low
- News stories of people living with aphasia are not representative of most people living with aphasia (usually they depict someone who has “recovered” from aphasia, or someone who has no language abilities whatsoever)
- Aphasia is often mentioned without a definition, and often of a definition is provided it is inaccurate (such as describing aphasia as a complete loss of all language abilities across all modalities)
- Inaccurate descriptions of people living with aphasia contributes to negative stereotypes towards aphasia

Results
Lack of awareness of aphasia is crucial to address because of the effects it has on individuals living with aphasia
- Environmental: Howe Worrall, and Hickson (2008) found that lack of awareness impacts community participation. It is difficult for someone with aphasia to explain their communication disorder; poor public awareness exacerbates this issue.
- Psychological: Parr (2007) identified three levels at which people with aphasia experience social isolation: infrastructurally, interpersonally, and personally.
  - Social inclusion seems to be rare; factors that lead to inclusion are: how others communicate and try to understand and how others approach somebody with aphasia
  - Study suggests that social exclusion could be addressed through training that promotes support for communication
Campaign Goals

- To make “aphasia” a household term
- To debunk misconceptions about aphasia in the general population
- To advocate on behalf of individuals with aphasia, so that our society can be more aphasia-friendly.

This will be accomplished via:

- Social media: facebook page and website
- Community involvement: outreach to medical professionals, community awareness events, posters in populated cities

References


