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a research agenda in aphasia awareness

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Beyond the statistics: a research agenda in aphasia awareness

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Raising awareness of aphasia has been a high priority of aphasia organizations, people living with aphasia and professionals who work with aphasia. Multiple publications have urged professionals and consumers to improve public recognition of aphasia (e.g. Code, Papathanasiou, Rubio-Bruno, de la Paz Cabana, Villanueva, Haaland-Johansen, et al. 2016; Patterson, Robert, Berry, Cain, Iqbal, Code, Rochon & Leonard, 2015; Simmons-Mackie, Code, Armstrong, Stiegler, & Elman, 2002). An inter-organizational effort to improve aphasia awareness was a key recommendation proposed in a comprehensive white paper on the “state of aphasia” (Simmons-Mackie, 2018). It is believed that a lack of public and political knowledge of aphasia has major consequences. For example, it has been suggested that financial support depends, at least in part, on recognition of a disorder by policy makers and funders (Bojorquez, 1998; Simmons-Mackie et al. 2002). Knowledge of a disability or disorder impacts referral and availability of services (NAMI, 1995), public acceptance (Elman, Ogar & Elman, 2000), ease of community reintegration (Elman, Ogar & Elman., 2000) and access to information and resources by people living with aphasia (Hinckley, Hasselkus & Ganzfried, 2013). The literature is rife with reports by people with aphasia of negative experiences due to public misunderstanding of aphasia such as the following: “I think that’s been the hardest part…being in public. We had one occasion when someone snickered and someone made the comment “we don’t have all night for you to finish saying what you have to say.” They think his mental ability is impaired…there’s nothing wrong with his mental ability. He’s the same Reis that he was before” (Video http://www.aphasiawtx.org/our-stories/reispaula quoted in Simmons-Mackie, 2018)
In an effort to raise public awareness of aphasia, organizations have spent considerable time and effort on public awareness campaigns (e.g., National Aphasia Association and Aphaisa Access funded a campaign including poster art, printing and mailing to hundreds of people in North America, https://www.aphasiaaccess.org/aam2016; In Australia, the Australian Aphasia Association organized an event to educate Queensland Parliamentarians about aphasia; The stroke association of the UK has created postcards to distribute to shops and health centers to raise awareness of aphasia communication, https://stroke.org.uk/what-is-aphasia/aphasia-awareness), but is progress being made? We propose that efforts to raise aphasia awareness have not resulted in appreciable changes in public knowledge of aphasia. Other campaigns have been more successful. For example, to raise awareness of Motor Neuron Disease (MND) the “Ice Bucket Challenge” resulted in $220 million dollars raised worldwide to fund MND research (Newhouse, 2015). This paper examines efforts to raise public awareness of aphasia and proposes a strategic agenda to move awareness building forward.

The Statistics

Studies have reported results of public awareness surveys in various countries around the world (e.g. Code et. al., 2001, 2016; Chazhikat, 2011; Flynn, Cumberland, & Marshall, 2009; Guinan & Carroll, 2019; Guo & Lim, 2018; Henriksson et al., 2018; Hill, Blevins & Code, 2018; Mahima et al. 2016; Mavis, 2007; McCann, Tunicliffe & Anderson, 2013; National Aphasia Association, 2016; Patterson et al., 2015; Simmons-Mackie, Code, Armstrong, Stiegler & Elman, 2002; Vukovic, Matic, Kovac, Vukovic & Code, 2017) and for various sectors of populations (Mavis, 2007 – hospital patients and families; McCann, Tunicliffe & Anderson, 2013 – health care; Guinan & Carroll, 2019 – hospitality industry students). Most
of these studies utilized similar methods of surveying the public about levels of awareness and basic knowledge of aphasia; thus, results can be compared across many countries or regions.

In most studies awareness of aphasia has been defined as “having heard the word aphasia” (Simmons-Mackie et al. 2002). Basic knowledge has been defined as identifying or providing rudimentary information such as: aphasia involves speech, language and/or communication problems and aphasia is caused by brain damage. In other words, the benchmark for basic knowledge has been very low. The result: studies have invariably reported low levels of aphasia awareness and basic knowledge.

Table 1 summarizes the results across 20 surveys of public awareness of aphasia between over an 18 year period (2000 to 2018). Variability across countries/studies is notable with basic awareness (simply having heard the word aphasia) ranging from a low of 3% in the UK (Speakability 2000) to a high of 66% of the general public in Sweden (Henriksson et al. 2018). However, it is questionable whether having heard the word aphasia actually furthers the aphasia cause. For example, respondents who recognize the word often provide incorrect descriptions of aphasia such as “a type of skin disorder” (Simmons-Mackie et al. 2002; Aphasia Institute, 2012), “a half a facial,” “a mystical creature” (Aphasia Institute, 2012), “a fruit” (NAA, 2016), or “an oriental insect problem affecting people throughout Asia” (Simmons-Mackie et al. 2002, p. 840).

The more meaningful survey responses are associated with the number of people who have a rudimentary knowledge of aphasia. The general public’s basic knowledge of aphasia was
tested in 17 countries and ranged from a low of 1% in Argentina (Code et al. 2016) to a high of 78.6% in Singapore (Guo & Lim, 2018). Despite a few “outliers,” the overwhelming finding was an abysmally low understanding of aphasia among the general public; for example, 75% (12/16) of surveys that tested basic knowledge found it to be below 10%, and 94% (15/16) of surveys found basic knowledge below 20% of those who had heard of aphasia.

To gain insight into public awareness over time, a survey was repeated after 16 years in the UK (Table 2). The authors concluded that after 16 years: “while awareness of aphasia has improved (…) the public level of knowledge has not advanced at all” (Hill, Blevins & Code, 2018, p. 8). Again it is noteworthy that having heard the word aphasia (awareness) is not a helpful outcome of aphasia awareness campaigns or for people living with aphasia.

In the USA two surveys were conducted 14 years apart (National Aphasia Association, 2016; Simmons-Mackie et al. 2002). These 2 studies employed different methodology. The National Aphasia Association (2016) conducted a telephone survey, while the Simmons-Mackie et al. (2002) survey was a face-to-face survey in public spaces. Despite these methodological differences it appears that awareness and basic knowledge over time were not markedly different in the USA (Table 3). Despite campaigns such as “aphasia awareness month” it appears that basic knowledge remains below 10% of those who have heard of aphasia in both the USA and UK.
In addition to surveying the proportions of people who know about aphasia, researchers have attempted to identify variables associated with higher or lower aphasia awareness and knowledge. Although it is difficult to draw conclusions about variables contributing to awareness and knowledge of aphasia due to marked variability in findings across studies, Hill et al. (2018) concluded that awareness and basic knowledge tend to be higher among females, higher as age increases, and higher for professionals such as teachers and health professionals. Hill and colleagues also noted that even among health care professionals basic knowledge of aphasia was very low.

Surveys of specific population sectors have also been conducted (Table 4). These include surveys of hospital patients and their families (Mavis, 2007), health care providers (McCann, Tunnicliffe & Anderson, 2013) and hospitality industry students (Guinan & Carroll, 2019). As might be expected there was a slightly higher level of awareness and basic knowledge among those associated with health care.

In summary, a plethora of surveys around the world and over time continue to report low aphasia awareness and basic knowledge. This remains consistent despite initiatives to increase aphasia awareness taking place over/across this time period. It appears logical that a different approach is needed if we are to increase the public’s knowledge of aphasia and reduce the negative impact of public ignorance on people living with aphasia.

What is aphasia awareness?
Perhaps the first issue to address is the definition of awareness. As noted, surveys tend to
differentiate name recognition from knowledge of aphasia. However, name recognition does
not advance understanding of aphasia. We would like to propose a merger of definitions from
the literature such that aphasia awareness includes a basic understanding of the disability of
aphasia. Furthermore, it is probable that the level of knowledge or understanding considered
sufficient will vary depending on the target audience. For example, improved knowledge or
behavior change by the general public might be defined less stringently than health care
provider knowledge. In fact, awareness building should be targeted to identified segments of
the population. While this paper concentrates largely on awareness by the general public,
campaigns should define specific target groups such as young people, health care providers,
government workers or service providers in order to create relevant messages.

**Why focus on aphasia awareness?**

Christiano and Neimand (2017) argue that it is natural for any organization to want to raise
awareness of the cause they champion, whether it is a health condition, road safety or
environmental issue. It is based on a belief that if people knew about the issue, then they
would act appropriately. Hence, the public are bombarded with media messages about
“National Cancer Day” or reducing plastic in our oceans, or saving the koala. How can
aphasia campaigns make an impact? Does awareness of a condition change the behaviour of
the recipient? This section delves further into the concept of “awareness”, especially for the
field of aphasia.
At the level of an individual with aphasia, it is thought that if other people knew about aphasia, then there would be greater understanding of the condition when people with aphasia interact with others and reduced stigma associated with the condition. Individuals with aphasia may consider that communicative interactions will be easier because other people will be more skilled in communicating because of their understanding of the condition. Greater public awareness of similar “invisible” disabilities such as autism, Alzheimer’s or depression have resulted in the public empathy and created greater affinity with those who have the condition. Aphasia consumer organizations appear to want others to not only have knowledge about aphasia but also have the skill and attitude to communicate with them. A greater awareness of aphasia may help others recognize the significant impact it has on their lives thus raising the importance of knowing about aphasia. Word finding problems and language difficulties happen to everyone and if the public understands aphasia, then people with aphasia may not appear so “different.” Having a more well-known condition can normalize that condition. Being the same as others also promotes participation in mainstream activities.

At a broader organizational level, a higher profile of the condition may affect the level of funding that support organizations or research institutions receive because of the perceived importance of the condition. For example, Elman, Ogar and Elman (2000, p. 457) state: “We argue that because aphasia is largely unknown, it is extremely difficult to raise money either from foundations or individual donors.”

The aforementioned reasons why people with aphasia and their support organizations focus so much on aphasia awareness draw largely from supposition and anecdotal reports. There has been little research that reports why there is a perceived need for greater public awareness of
aphasia. There has been no research documenting what happens when the public does understand aphasia; does improved aphasia knowledge change behavior or attitudes?

**What do people living with aphasia want others to know?**

Researchers and practitioners are challenged to conduct research about disability in collaboration with service users (World Health Organization & The World Bank, 2011). Despite the fact that the communication disability literature reports a growing body of evidence documenting the aspirations of individuals with aphasia to make active contributions to research and civil society (Pound, 2011), people with aphasia are often excluded from research and development work because of their communication disability. To date, no research has explored what people with aphasia want included in aphasia awareness campaigns.

While no research has specifically explored the perspectives of people living with aphasia with regards to aphasia awareness, studies examining the goals and outcomes of these populations may provide a foundation for future research. Wallace and colleagues (2017) investigated the outcomes that were most important to people living with aphasia in Australia, USA, UK, Denmark, South Africa, and Hong Kong. In response to the question, “What would you most like to change about your communication and the way aphasia affects your life?” people with aphasia prioritized outcomes that related to increased awareness about aphasia and its impacts. Increased awareness was desired amongst the general public, but was also discussed in reference to specific contexts such as the workplace and in specific populations such as families, children, carers, and health professionals. Both people with aphasia and their family members connected the need for increased awareness with a desire for greater understanding and changed attitudes.
towards aphasia, e.g., “To enhance public awareness of aphasia, so that the general public will understand the communication needs of PWA (person with aphasia) as well as the pressure of PWA’s family members” (family member participant, Hong Kong, Wallace et al., 2017, p. 1373).

Manning et al. (2019) recently conducted a qualitative evidence synthesis of 31 articles in which the perspectives of 350 people with post-stroke aphasia towards concepts relating to Personal Recovery and Living Successfully (PR-LS) were explored. Five analytical themes about promoting PR-LS were identified including one entitled “The participation of PWA is facilitated by opportunities and supportive, enabling environments.” In this theme, PWA explained that improved public knowledge of the condition was important for removing barriers to their participation (Brown, Worrall, Davidson, & Howe, 2010; Howe, Worrall, & Hickson, 2008; Pearl, Sage, & Young, 2011; MacKenzie, Bennett & Cairney, 2011; Worrall et al., 2011). People with aphasia valued awareness, tolerance and understanding from others (Howe et al., 2008; Le Dorze, Salois-Bellerose, Alepins & Halle, 2014) and reported that increasing awareness of aphasia and communication strategies among service providers and the general public would help support participation (Manning, MacFarlane, Hickey & Franklin, 2019).

In this paper, we suggest that including the experiential knowledge of people living with aphasia will contribute new perspectives to aphasia awareness campaigns that will help to target population needs. However, it is essential to support the involvement of people with aphasia in this work from a position of equality with meaningful rather than tokenistic involvement (Pound, 2013; McMenamin, Tierney & MacFarlane, 2015; McMenamin & Pound 2019). Researchers and co-researchers with aphasia should work collaboratively to co-design and co-evaluate aphasia
awareness campaigns that will positively impact the lives of people living with aphasia around
the world.

**What do speech-language pathologists (SLPs) want others to know?**

No research has explored speech-language pathology practice or perspectives related to
creating awareness of aphasia and what SLPs consider people with aphasia, their families, and
the broader community need to know about aphasia. Furthermore, whilst resources exist for
increasing community awareness of aphasia (e.g., http://www.aphasiapathway.com.au/?name=community-awareness), little is known about if
and how SLPs equip people with aphasia and their families to raise awareness of aphasia.
This said, some insight into what SLPs think is important may be gleaned from the aphasia
education literature. For example, in an Australian study with 130 SLPs, the majority (>70%)
reported that they provided information to both people with aphasia and their family members
about (1) the definition of aphasia, (2) characteristics of aphasia, (3) causes of aphasia, (4)
aphasia recovery, (5) strategies to assist communication, and (6) coping strategies (Rose et al.,
2018). In addition, all 132 SLPs (100%) in a Belgian study by Manders, Marien, and Janssen
(2011) reported that they considered it important to provide (1) positive information related to
aphasia, (2) information about how to improve communication, and (3) the best way to
communicate. However, we are aware of no research data on what SLPs want the public or
other audiences to know.

**What has been done to raise aphasia awareness?**
Aphasia awareness campaigns are not described in the research literature and therefore little is known about their effectiveness. Several of the survey studies mentioned above suggest that the documented low public awareness of aphasia should have implications for future campaigns (e.g., Code et al., 2001; McCann et al., 2013). For example, Simmons- Mackie et al. (2002) suggest public awareness might be improved by using the word “aphasia” instead of stroke, bombarding the media with human interest stories about aphasia, distributing educational materials and posters about aphasia in the community and promoting grassroots efforts by people living with aphasia to influence public policy. However, such suggestions are not based on evidence of what works or on theoretical models of what promotes behavior and attitude change.

There have been campaigns and other attempts to raise awareness at local and national levels (e.g. the “Giv tid” [English: give time] in Denmark by Hjernesagen, 2013). Aphasia Access and the National Aphasia Association (NAA) in North America have distributed informational posters in June during “Aphasia Awareness Month”. The Australian Aphasia Association (AAA) has promoted “Wednesday without Words” to raise awareness of the impact of aphasia. Some organizations combine fundraising with public awareness such as the “Walk, Talk and Roll” event conducted by the Aphasia Institute in Canada. In the recent past aphasia awareness campaigns have taken advantage of social media. For example, “Aphasia Awareness Month” has grown from a largely American and British event (e.g. Association Internationale Aphasia, 2019; American Stroke Association, n.d.) to an international phenomenon through platforms such as Twitter and Facebook. While a few organizations suggest that people participate in campaigns by reposting messages or using readymade graphics and messages to forward to others (e.g. National Aphasia Association, n.d.), most awareness campaigns are not coordinated
across organizations or groups. Regional differences in the timing of Aphasia Awareness Month (June, September, October) exemplify this lack of international coordination and represent a missed opportunity to increase the impact of awareness campaigns using international communication channels (e.g., social media).

Not only are awareness campaigns not conducted in a unified or coordinated manner across organizations and groups, but also the messages are highly variable. For example, a review of messages posted on Twitter in June, 2019 included numerous variations of the following content:

- What is aphasia? / definitions of aphasia
- Aphasia is a loss of language, not a loss of intelligence
- Incidence and prevalence of aphasia
- Tips to improve communication

Videos on You Tube and posts on Facebook show a similar variety of messages (e.g. Country Durham & Darlington NHS Foundation Trust, 2017). Also, similar messages are delivered in different formats and use different wording and graphics across campaigns. The lack of message redundancy, identifiable graphics and a memorable “tag line” are likely to reduce the effectiveness of campaigns.

Aphasia awareness campaigns appear to largely “preach to the choir.” That is, social media, print material and events typically target people who already know about aphasia – family, friends, professional colleagues and those on organization contact lists. Aphasia awareness campaigns do not appear to be based on tested marketing or health promotion principles. Nor
do these campaigns appear to draw from research on what the public should know or proven methods that will change public behaviour or attitudes. Finally, we found no published data on campaign evaluations, - that is, evidence that outcomes or impact of campaigns have been assessed.

This review of past public awareness campaigns suggests several potential problems:

1. Lack of a unified, clear and compelling message,
2. Lack of coordination across organizations and campaigns,
3. Targeting audiences that are already familiar with aphasia,
4. Failure to base campaigns on theory and research from disciplines such as marketing, health promotion and communication research,
5. Failure to involve people with aphasia, their families and health-care professionals in the co-design of campaigns,
5. No evidence that the impact of campaigns has been evaluated.

What can we learn from other disciplines?

According to public information specialists Christiano and Neimand (2017, p. 36),

“Too many organizations concentrate on raising awareness about an issue—such as the danger of eating disorders or loss of natural habitat—without knowing how to translate that awareness into action, by getting people to change their behaviour or act on their beliefs. (…) Because abundant research shows that people who are simply given more information are unlikely to change their beliefs or behaviour, it’s time for activists and
organizations seeking to drive change in the public interest to move beyond just raising awareness. It wastes a lot of time and money for important causes that can’t afford to sacrifice either. Instead, social change activists need to use behavioural science to craft campaigns that use messaging and concrete calls to action that get people to change how they feel, think, or act, and as a result create long-lasting change.”

However, developing campaigns to raise awareness of health conditions, including aphasia, is a complex process. Health mass media campaigns need to be targeted and well-executed to have even a small to medium effect on health knowledge and behaviour (Noar, 2006). In a meta-synthesis of US mass media campaign literature, health campaigns changed the behaviour of 8% of the population positively (Snyder & Hamilton, 2002). Adoption of new behaviours had more positive results than the cessation of negative ones, and greater reach and exposure led to better outcomes (Snyder & Hamilton, 2002).

According to Noar (2006), the key components and principles of health promotion campaigns firstly include six requirements. First, formative research is needed to help researchers understand the nature of the target campaign, the audience and target audience preferences. Second, the campaign should be underpinned by carefully selected theory, based on the focus of the campaign. The researcher needs to have established the purpose of the theory being used to provide a strategy for the intervention, and to help stratify the target audience because different theories have different implications (for example the Behaviour Change Wheel by Michie, Atkins & West, 2014 versus the transtheoretical model of change (Prochaska, Redding & Evers, 2015)). Third, researchers must segment the audience according to target
characteristics, including age, socioeconomic status and sex, to target the message approach for that specific group. For example, younger people may be more ‘at-risk’ of a targeted behaviour, such as drug use (e.g. Palmgreen et al. 2005)). Fourth, the message needs to be designed and targeted, which can also involve targeting people who may influence a population (e.g. doctors) (Naor, 2006). Fifth, the message should then be placed in channels often viewed by the target audience (e.g. print media or community-based activities). Multiple channels can be used to increase the exposure of the message; however, this can make it difficult to know which was the most effective (Derzon & Lipsey, 2002). Finally, there is a need to use sensitive evaluation design, to evaluate the process of the campaign and not just the outcome, as this can help to determine where the campaign may have potentially failed or where it could be developed (Moore et al. 2015).

Noar (2006, p. 22) describes a mass media campaign as an ‘intervention tool that potentially can address health attitude and behavioural change across numerous health problems’ and should have specified outcomes and affects. Therefore, it is timely to view aphasia awareness campaigns with the same lens. As researchers and clinicians in the field of aphasia we may need to look beyond our discipline and consider collaborating with others who have more expertise in this field, such as advertising or social marketing (e.g. Evans et al., 2002).

**Proposing an agenda for the future**

We propose an international effort and comprehensive research agenda to address aphasia awareness. Key elements of this agenda include the following features.
• Meaningful involvement of key stakeholders should occur at all levels of development. Concepts of co-design and co-evaluation, including participation of people living with aphasia, should pervade efforts to create successful campaigns.

• Campaigns should be based on evidence of what is needed according to key stakeholders.

• International campaigns across organizations should adopt unified messages and shared understanding of goals or expected outcomes.

• Campaign development should recruit disciplines that have expertise in marketing, health promotion, public communication or similar.

• Campaigns should be theoretically driven based on research into how to change knowledge, attitude and actions.

• Campaigns should identify the target audience and tailor the message accordingly.

• Evaluation of the impact of campaigns is imperative in order to insure understanding of strategies that work (or not) and revise approaches as needed. Elements of evaluation should be identified such as how many people were reached, changes in knowledge, attitude and/or behavior or changes on awareness surveys.

As a first step towards crafting effective aphasia awareness campaigns, we suggest the following research agenda:

1. **What outcomes do stakeholders want from aphasia awareness?**

In order to create meaningful messages, understanding of the desired outcome(s) across stakeholders is imperative. Stakeholders include people with aphasia, their family and friends, aphasia service providers, aphasia researchers, and aphasia consumer organizations. Each group may have different priorities for raising the awareness of aphasia, so understanding the
motivation of each group of stakeholders for raising awareness will help to target aphasia awareness campaigns and achieve the desired outcomes. Research should involve stakeholders in defining “what success would look like” for aphasia awareness campaigns. Well designed, rigorous investigations employing participatory involvement, qualitative interviews, focus groups and/or questionnaires might be appropriate to answer the question (not simply anecdotally solicited input).

2. What is/are the target audience(s)?

If campaigns are expected to change beliefs or behaviors, then they should be targeted to the needs of a specific audience. Identifying one or more target audiences and the associated behavior change goal is critical to a successful campaign (Christiano & Neimand, 2017). This question might be addressed along with question 1 above through qualitative and/or survey methods.

3. Gain consensus from an international interdisciplinary collaboration of stakeholders on fundamental concepts for an aphasia awareness campaign.

Once data are available regarding key target audiences and what messages stakeholders deem important, then consensus across organizations worldwide on a unified message and operationalized outcome goals is needed. Consistent messages and well defined, desirable outcomes will be an important component of any campaign. In addition, factors that affect success should be identified and appropriate consensus building methods implemented to create consistent, compelling messages that individuals, groups and organizations around the world utilize.
This paper serves as a call to action for those interested in increasing awareness and understanding of aphasia and ultimately improving the lives of those living with aphasia. It is time for more effective, targeted and collaborative aphasia awareness campaigns, or we risk the same disappointing aphasia awareness survey results over the next decade.
References


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Table 1.

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<tr>
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<td>Slovenia</td>
<td>Face-to-face</td>
<td>400</td>
<td>16%</td>
<td>4.5%</td>
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<tr>
<td>2016 Mahima et al.</td>
<td>India</td>
<td>Face-to-face</td>
<td>189</td>
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<tr>
<td>2016 National Aphasia Assoc.</td>
<td>USA</td>
<td>Phone</td>
<td>1142</td>
<td>15.5%</td>
<td>8.8%</td>
</tr>
<tr>
<td>Year</td>
<td>Authors</td>
<td>Country</td>
<td>Method</td>
<td>N</td>
<td>Acceptance 1</td>
</tr>
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<td>------</td>
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<td>2017</td>
<td>Vuković et al.</td>
<td>Serbia</td>
<td>Public – face to face</td>
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<td></td>
<td>Montenegro</td>
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<td>500</td>
<td>11%</td>
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<tr>
<td>2018</td>
<td>Hill et al.</td>
<td>UK</td>
<td>Public – face to face</td>
<td>167</td>
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<tr>
<td>2018</td>
<td>Henriksson et al.</td>
<td>Sweden</td>
<td>Public – face to face</td>
<td>372</td>
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<tr>
<td>2018</td>
<td>Guo &amp; Lim</td>
<td>Singapore</td>
<td>Public – face to face</td>
<td>100</td>
<td>14%</td>
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* Not available
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<tr>
<th>Year</th>
<th>Awareness</th>
<th>Basic Knowledge</th>
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<td>2001</td>
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<td>2018</td>
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<td>5%</td>
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Table 2
Table 3

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<tr>
<th></th>
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<th>Basic Knowledge</th>
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<tr>
<td><strong>2002</strong> (Simmons-Mackie et al.)</td>
<td>13.6%</td>
<td>5.4%</td>
</tr>
<tr>
<td><strong>2016</strong> (National Aphasia Association)</td>
<td>15.5%</td>
<td>8.8%</td>
</tr>
<tr>
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<td>Location</td>
<td>Sample Size</td>
</tr>
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<td>--------------------------------------------</td>
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<td>Mavis (2007)</td>
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<tr>
<td>Hospitalized patients/families</td>
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<td>McCann, Tunnicliffe &amp; Anderson (2013)</td>
<td>New Zealand</td>
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<td>Health care</td>
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<td>Guinan &amp; Carroll (2019)</td>
<td>Ireland</td>
<td>155</td>
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<td>Hospitality Industry students</td>
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* a different methodology was used for knowledge in Mavis, 2007