



City Research Online

City St George's, University of London

Citation: Ivanszky, Z., Cocks, N. & Dipper, L. (2015). A pilot study exploring public awareness and knowledge of right hemisphere communication disorder compared with aphasia and stroke in Northwest London, UK. *Aphasiology*, 30(9), pp. 1058-1070. doi: 10.1080/02687038.2015.1081141

This is the accepted version of the paper.

This version of the publication may differ from the final published version. To cite this item please consult the publisher's version.

Permanent repository link: <https://city-ref-test.eprints-hosting.org/id/eprint/14212/>

Link to published version: <https://doi.org/10.1080/02687038.2015.1081141>

Copyright and Reuse: Copyright and Moral Rights remain with the author(s) and/or copyright holders. Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge, unless otherwise indicated, provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way. For full details of reuse please refer to [City Research Online policy](#).

AUTHOR COPY

A pilot study exploring public awareness and knowledge of right hemisphere communication disorder compared with aphasia and stroke in Northwest London, UK.

Abstract

Background: No previously published research has investigated public awareness and knowledge of *Right Hemisphere Communication Disorders* (RHCD). In comparison, there are a handful of published studies that have investigated public awareness and knowledge of aphasia. The results of these studies indicate that awareness and knowledge is low but has marginally increased in recent years, due to international efforts to raise the public profile of the disorder.

Aims: The current study investigated public awareness and knowledge of RHCD and compared it to that of aphasia. Information regarding awareness and knowledge of stroke was also determined for those participants who did not have awareness of RHCD or aphasia.

Methods & Procedures: A face-to-face survey of 87 members of the public was undertaken in North-West London, United Kingdom.

Outcomes and Results: Of the 87 survey respondents, only 9.2% reported having heard of RHCD and 4.6% met the criteria for having basic knowledge of this disorder. In comparison, 32.2% of participants had heard of aphasia and 24% had basic knowledge about it. While the results show that fewer people were aware and had knowledge of RHCD compared to aphasia, this difference was not significant. Of those participants who had heard of neither disorder, all had heard of and the majority had knowledge of stroke.

Conclusions: The findings suggested that awareness of RHCD amongst members of the public is low. It is suggested that in order to improve quality of services, funding and social re-integration following a right hemisphere stroke, raising public awareness and knowledge is necessary.

Keywords: Right hemisphere communication disorder, aphasia, public awareness, public knowledge.

MAIN TEXT

Public awareness and knowledge of a communication disorder has significant implications for the lives of people with that disorder. The belief that one has a condition that no one else has can lead to social isolation and subsequently to anxiety and depression (Code et al., 2001). Furthermore limited media presence of a communication disorder, for example aphasia, is often associated with insufficient public support for people with that disorder (Elman, Ogar, & Elman, 2000). In contrast, high levels of awareness are positively associated with a) improved health, social and public services that are provided for a condition; b) improved psychosocial wellbeing and social inclusion for the people with the condition; c) increased research funds invested in the condition; and d) increased monetary intake of charitable organisations (Elman, et al., 2000). It follows that there is a significant need to determine what public awareness and knowledge is of a specific communication disorder. If the level is low, then it is important to take active steps to increase knowledge and awareness of that disorder.

Right Hemisphere Communication Disorder (RHCD) is a communication difficulty most commonly caused by a right hemisphere stroke (Myers, 2001). The evidence base suggests that left hemisphere strokes tend to be slightly more common than those affecting the right hemisphere (see, for example, Foerch, Misselwitz, Berger, Steinmetz & Neumann-Haefelin, 2005), however a significant proportion (around 44%) of strokes result in damage to the right hemisphere. In their review of deficit patterns in right hemisphere stroke, Blake, Duffy, Myers & Tompkins. (2002) found that 20%-83% of people who experience damage to the right hemisphere present with some or all of the impairments that characterize RHCD. These characteristics include cognitive deficits; difficulties with understanding and using social and pragmatic language; impaired insight and awareness; problems with focus, orientation and memory resulting in emotional and behavioural difficulties; impulsiveness; difficulties interpreting information; and difficulties with social communication and speech (Myers, 2001). These difficulties have a substantial impact on the person's ability to return to work and to successfully engage in social activities (Koch, Egbert, Coeling, & Ayers, 2005).

While no previous research has been conducted investigating public awareness and knowledge of RHCD, a handful of researchers around the world have investigated public

awareness and knowledge of aphasia (Code, Katz, Petheram, T., & Granzfried, 2013; Code, et al., 2001; Flynn, Cumberland, & Marshall, 2009; Kent & Wallace, 2006; Mavis, 2007; McCann, Tunnicliffe, & Anderson, 2013; Patterson et al., 2015; Simmons-Mackie, Code, Armstrong, Stiegler, & Elman, 2002). In most of these studies members of the public were considered to have an awareness of aphasia if they indicated that they had heard of the term, and they were considered to have knowledge of the disorder if they were able to correctly answer a series of questions about the disorder. These questions usually required the participant to select from a list of causes and characteristics that were most commonly associated with aphasia. It is important to distinguish between awareness and knowledge since they are not the same, as can be seen from the scores in these aphasia surveys where people's awareness of a condition was routinely higher than their knowledge (Code, et al., 2001; Flynn, et al., 2009; Mavis, 2007; McCann, et al., 2013; Patterson, et al., 2015; Simmons-Mackie, et al., 2002).

A number of studies have explored public awareness and knowledge of aphasia of participants who were recruited from shopping malls and public spaces in the USA (Hawaii, Louisiana and California), UK (Exeter), Canada (Ontario) and Australia (Sydney) (Code, et al., 2001; Kent & Wallace, 2006; Patterson, et al., 2015; Simmons-Mackie, et al., 2002). Awareness was low in all studies (Range: 13.6%- 31.8%). Knowledge of aphasia was also low in all studies (Range: 5.07% -5.7%).

Mavis (2007) explored public awareness and knowledge of aphasia in Turkey. Participants were 196 visitors of patients or patients in a neurology ward in Turkey. Awareness of aphasia was determined by simply asking participants if they had heard of aphasia. Despite participants being recruited from a neurology ward, only 34.2% of participants were aware of aphasia. Knowledge was determined by asking participants to select from a series of choices what the cause of aphasia was (choice of six), who was affected (choice of five), which symptoms related to aphasia (choice of eight, six of which were associated with aphasia, one was 'all of them' and one was 'no opinion'), and who would help in the rehabilitation process (choice of six). Sixty percent selected 'no opinion' in relation to the cause of aphasia, 55.6% selected 'no opinion' in relation to the symptoms, 59% selected 'no opinion' in relation to who

were affected by aphasia and 39% selected 'no opinion' in relation to the professionals who would help in the rehabilitation process. It is important to note, that knowledge scores for this study may have been inflated due to the nature of the questions. For example, for the question relating to symptoms, all symptoms listed were related to aphasia. Thus, the only way in which a participant could demonstrate 'no knowledge' of symptoms was to select 'no opinion'. Both awareness and knowledge would be expected to be higher in this study than in those surveying people in public spaces, given that the participants were either visitors or patients in a neurology ward.

Finally, Flynn et al. (2009) and McCann et al. (2013) compared public awareness of aphasia with Parkinson's disease. Flynn et al. explored the awareness in 100 people recruited in high streets in London, UK and 26 carers of people with aphasia. Awareness was determined by asking participants if they had heard of aphasia and then whether they had heard of Parkinson's disease. If they had heard of either condition, then they were asked to identify the *cause* from five options of which only one was correct for aphasia and only one was correct for Parkinson's Disease. They were then asked to identify which were *symptoms* for each of the conditions, of which there were 11 options: three of the symptoms were relevant to aphasia and three to Parkinson's disease. They were also asked about how they heard about each of the conditions. They obtained a score out of twelve for each condition. Awareness and knowledge were not considered separately in the analysis. Participants scored higher in the questions relating to Parkinson's disease than aphasia. Participants indicated that they most commonly obtained their information about Parkinson's disease from the media or a personal connection.

McCann et al. compared 200 members of the public with 100 health professional's awareness of aphasia and Parkinson's disease in New Zealand. Awareness was once again determined by asking participants if they had heard of aphasia and then whether they had heard of Parkinson's disease. They were also asked if they had heard of stroke. Participants were then asked to give a definition of each of the conditions, in their own words. They were deemed to have knowledge of Parkinson's diseases if they used the words "brain", "tremor" or a variation of these. Knowledge of aphasia was determined in a different way to Parkinson's

disease but in the same way as in the study by Simmons-Mackie (2002), in that participants selected symptoms from a list of eight. Unlike Simmons-Mackie (2002), McCann (2013) specified a clearer scoring method in which each participant would be given one point for a correct response and lose one point for each incorrect response. “Adequate knowledge” was determined if 50% of the symptoms were identified. When all participants were considered, awareness of Parkinson’s disease (96%) and stroke (99.3%) was higher than awareness of aphasia (30%). When the health professionals were removed awareness of Parkinson’s disease (95.5%) and stroke (99%) were still significantly higher than aphasia (11%). Knowledge of aphasia (8%) was also lower than knowledge of Parkinson’s disease (31.3%) and this remained the case when the health professionals were removed from the analyses (knowledge of aphasia 1.5% and knowledge of Parkinson’s disease 27%). However, it is important to note that in McCann et al. knowledge of aphasia was determined using different methodologies to knowledge of Parkinson’s disease, and thus different scoring mechanisms were used for each. The difference in knowledge of the two conditions could then have been an artefact of the difference in scoring.

While previous research has made an important contribution to the literature highlighting poor public awareness of one of the communication disorders commonly associated with stroke, there is a dearth in the literature regarding the level of public awareness of one of the other communication disorders commonly associated with stroke, RHCD. The current study compared public awareness and knowledge of RHCD with that of aphasia. It was predicted that the results of this study would reveal a low public awareness and knowledge of RHCD; and moreover, that public awareness and knowledge of RHCD would be lower than that of aphasia. It was further hypothesised that the majority of participants who had no awareness of either RHCD or aphasia, would have awareness and knowledge of stroke.

Method

Participants and sampling

For the purpose of this study, over 200 people from the general public were approached on various streets of North West London, within the boundaries of the borough of Westminster. Sampling mainly took place on weekdays between 8am and 5pm, with one session occurring

on Sunday afternoon between 1 pm and 4 pm. Sampling occurred over four consecutive weeks between January and February 2013.

Participants were approached in the street and asked if they would be happy to take part in a survey. If they agreed it was explained that they would first be asked some questions and then have the purpose of the study explained to them at the end so as to avoid bias. Eighty-seven people (59 female) agreed to participate. At the end of the questionnaire, participants were told that the research aim was to explore levels of public awareness and knowledge of RHCD. In line with the population distribution of Westminster, the majority of the participants in the study were 18-29 years old, were White British and had a university degree (City of Westminster economic report, August 2011). See Table 1 for details of participants' ages, highest level of education and ethnicity.

-----Insert Table 1 about here-----

Questionnaire

The questionnaire, which was used to interview the participants of the study, was administered face to face. All questionnaires were administered by the first author. Questions were asked verbally and the researcher recorded the answers verbatim on the questionnaire sheet. The content and structure of the questionnaire was partially based on those used in the studies by Flynn et al. (2009), Simmons-Mackie et al. (2002) and McCann et al. (2012). Unlike McCann et al. (2012) the same methodology for determining knowledge was used for both RHCD and aphasia.

The questionnaire consisted of four sections (see Appendix A). Three of the sections were identical but focused on different conditions, RHCD, aphasia and stroke. These sections contained 5 questions. Question 1 was "Have you heard of RHCD/aphasia/stroke?". If participants replied with "Yes", the following question asked the participants to describe in their own words what the condition was. If participants had not heard of the condition, the remaining questions in the section were discontinued. Participants who had indicated an awareness of the relevant condition were then asked to identify the cause of the condition

from a choice of five. Following this, participants were asked to identify which of the 12 symptoms were and were not associated with the specific condition. Participants were then asked to indicate from a choice of answers how they had gained awareness and knowledge about each of the conditions. The section concerned with awareness and knowledge of stroke was only completed if the participant indicated that they were not aware of either aphasia or RHCD. The final section of the questionnaire collected demographic information about the participants.

For the section of the questionnaire that was concerned with knowledge and awareness of RHCD, Lehman Blake et al.'s (2003) study was used as a reference in order to determine the most common causes and symptoms associated with RHCD. Symptoms associated with aphasia, were based on the symptoms used in the studies by Flynn et al. (2009), McCann et al. (2012) and Simmons-Mackie et al. (2002).

An earlier version of the questionnaire was piloted with 11 Speech and Language Therapists (SLTs). They were sent a group email containing a link to an online version of the original questionnaire, which they were asked to complete. They were also asked to give feedback, via email, on the phrasing and content of the questionnaire. Following the pilot, various adjustments were made to the phrasing of the questions in order to make them less ambiguous. These adjustments then led to the final version of the questionnaire, which was used in the actual study.

Awareness

In the present study, the method for measuring awareness used in previous research on awareness of aphasia was followed. Participants were considered to have “an awareness” of a condition if they replied with “Yes, heard of the condition” in question 1.

Knowledge

Participants only gained points for knowledge for the questions regarding cause and symptoms for each of the conditions. For the former question, respondents received one point for identifying the correct cause of the condition. For the latter question, participants obtained

one point for each correctly identified symptom and one point for correctly identifying that a symptom was not associated with the specified condition. Incorrect responses, “don’t know” and “not sure” replies received no points. Participants obtained a score out of 13 for each of the conditions. This approach was based on McCann et al. (2012), in which participants were considered to have “knowledge” of the condition if they scored 50% or greater on questions 3 and 4. It was possible for a participant to be scored as ‘having knowledge’ even if they did not know the cause of the condition

Results

Analysis

Awareness

Most participants (63.2%, 55 participants) indicated that they had not heard of either aphasia or RHCD. Few (27.6%, 24 participants) participants had heard of aphasia but not RHCD and even fewer (4.6%, 4 participants) had heard of both. The same percentage (4.6%, 4 participants) had heard of RHCD but not aphasia. Overall, fewer participants had heard of RHCD (9.2%, 8 participants) than aphasia (32.2%, 28 participants). A Fisher’s exact test indicated that there was not a significant relationship between awareness of aphasia and awareness of RHCD ($p=0.26$). Of those participants who had heard of neither aphasia nor RHCD (55 participants), all had heard of stroke.

Knowledge

24.1% of all participants (21 participants) in the study had knowledge of aphasia (i.e. scored greater than 50% in questions 3 and 4), 4.6% had knowledge of RHCD (4 participants) and 1.1% (1 participant) had knowledge of both. A Fisher’s exact test indicated that there was not a significant relationship between knowledge of aphasia and knowledge of RHCD ($p=1$). Aphasia knowledge scores were compared to RHCD knowledge scores using a Wilcoxon signed rank test. There was not a statistically significant difference between aphasia knowledge scores and RHCD knowledge scores ($Z= -.54$, $p= .59$). Of those participants who had heard of neither aphasia nor RHCD, 69.1% (38 participants) had knowledge of stroke.

Sources of Knowledge and Awareness

Finally the sources of information for participants' awareness of each of the conditions were examined (see Figure 1). In terms of sources of information, participants were able to choose multiple answers. The most common source of information for RHCD was 'other'. Two of the participants who selected 'other' indicated that they studied university subjects in which this topic was covered. The remaining participant who selected 'other' did not indicate the source of information regarding RHCD. The most common source of information regarding aphasia was the media and "other". Specifically five participants reported to have seen the UK television program, "The Undateables", which had included a young woman with aphasia resulting from stroke. Participants who selected "other" with regards to aphasia indicated that they worked with people with aphasia or were aware of an awareness-raising campaign. The most commonly chosen source of information for stroke was the "media" followed by "knowing someone who had a stroke" and "other". Participants, who selected "other", reported that they were aware of the "FAST" NHS awareness campaigns. The FAST campaign encouraged the public to act 'fast' when a person has a stroke and to identify the symptoms of a stroke (Face, Arms, Speech, Time).

-----Insert Figure 1 about here-----

Discussion

This study explored the public's awareness and knowledge of RHCD, aphasia and stroke in Westminster, a borough of North West London in the UK. Public awareness and knowledge of both RHCD and aphasia was low, and there was no relationship between awareness of RHCD and aphasia. While the results indicated that fewer people were aware and had knowledge of RHCD compared to aphasia, this difference was not significant. A possible reason this difference was not significant was the small sample size of this study and this should therefore be explored in a larger study on this topic. For those participants who had heard of neither RHCD nor aphasia, the majority had heard of and had knowledge of stroke.

The percentage of participants who had an awareness of aphasia in the current study however, was similar to the most recent study conducted on public awareness of aphasia (31.8% in Patterson et al., 2015) and higher than previously published public awareness

levels of aphasia in which participants were recruited in a similar way (11% McCann et al., 2013; 16.5% in Kent and Wallace, 2006, 13.6% in Simmons-Mackie, 2002; 13.7% in Code et al., 2001). The level of awareness was however, lower than the public awareness levels in the study conducted in Turkey by Mavis (2007). This difference may have been due to the fact that Mavis's participants were patients and visitors at a neurology ward and so were more likely to have exposure.

It is unclear why the level of public awareness of aphasia was higher in this study than the earlier studies on public awareness of aphasia, other than the more recent Patterson et al., (2015) study. It could be due to the demographic profile of the participants in the current study. Both the Simmons-Mackie et al. (2002) and the Patterson et al. (2015) studies found that females were more likely to have an awareness of aphasia and the majority of the participants in the current study were female. However, both the Simmons-Mackie et al. and the Patterson et al. studies found that the average age of participants more likely to have an awareness of aphasia was in their mid-40s (46.5 in Simmons-Mackie et al. study and 45.4 in the Patterson et al. study) and the majority of the participants in the current study were under the age of 39. Participants in the current study were not asked what their profession was and so it was not possible to determine whether they were intermediate professionals, healthcare professionals or worked in the science field, i.e., the participants who were more likely to have an awareness of aphasia in the Simmons-Mackie et al. and Patterson et al. studies.

Unfortunately due to the smaller sample size in the current study, exploration of the participant profile most likely to have an awareness of aphasia and/or RHCD was not possible. Future research should explore this question.

Similar to the awareness results, the percentage of participants who had knowledge of aphasia was higher (as indicated by a score of 50% or above) than previously published studies (Patterson et al., 5.7%, McCann et al. 2012: 1.5%; Simmons-Mackie et al. 2002: 5.4%; Code et al. 2001: 5%). Comparisons of knowledge levels could not be made with the current study and the study by Mavis (2007) or Flynn et al., (2009) as, while knowledge was explored in these studies, an overall knowledge score was not calculated. The scoring methods were not specified in the study by Code et al., and used a different scoring method

to Simmons-Mackie et al. so this may have been the reasons for the difference in result. However, more direct comparisons could be made with McCann et al., as in both studies used the same knowledge scoring system. It is not clear why higher levels of awareness were found in the current study than the previously published studies and why the level of knowledge was higher than that of the participants in the study by McCann et al. Once again, the demographic profile of the participants in the current study does not paint a clear picture as to why their knowledge was higher and the study was not large enough to explore which participants were more likely to have knowledge of aphasia and/or RHCD. This question should also be explored in future research.

In comparison to aphasia, very few participants in the current study had heard of or had knowledge of RHCD. Simmons Mackie et al. (Simmons-Mackie, et al., 2002) encouraged health professionals and health professional students to use the term aphasia with patients and families and to advocate for the condition. Similarly with RHCD, health professionals should be promoting the existence of RHCD both amongst themselves and with the general public by using the term “Right Hemisphere Communication Disorder” with patients and families. Contributing to the lack of recognition of RHCD may be the limited support services specifically targeted for those with RHCD. As Sharon Kissler from the American Parkinson’s Disease association notes, “If the disorder doesn’t have a name, how will it ever be understood?” and “Name recognition is imperative” (cited in Elman et al., 2000 page 456). The name of RHCD has only recently been agreed upon and there are no disorder-specific associations or organisations to support those with the condition or to lobby for more recognition of it in the UK. Given this situation it would be useful for future research to complement the findings reported here with a survey of the knowledge and awareness of RHCD amongst UK Health professionals

In contrast, the term aphasia has been used for over a century (Wallesch, 2004) and the associations and organizations that support people with aphasia and lobby for more recognition are numerous in the UK (for example in the UK: Aphasia Now; British Aphasiology Society; Connect; The Communication Disability Network; Dyscover; North East Trust for Aphasia; Speakability; Speakeasy; TALK; The Tavistock Trust for Aphasia). Despite this there

is still limited public awareness of aphasia. So perhaps having support groups and organisations specific for people living with RHCD is not the only pathway to improving public awareness and knowledge.

The most common sources of information regarding RHCD was 'other' indicating that those who do know about RHCD have learnt it through varied means. Two of the participants with knowledge of RHCD who selected other had learnt about it at university. In contrast the most common source of information regarding aphasia and stroke was the media. Interestingly, a specific programme ("The Undateables") was mentioned by a number of participants. This gives some indication of the impact that simply including a single person with a communication disorder in a single television programme can have. The media was also identified as one of the most common sources of knowledge of Parkinson's disease in Flynn et al. (2009). This highlights the power of the media industry and the need to include more people with communication disorders and more specifically those with aphasia and RHCD, in their productions.

This study found that there was a low level of public awareness and knowledge of RHCD and aphasia. Although one effect of this lack would be on the monetary intake of charitable organisations that provide support to people living with RHCD, the consequences extend much further. Evidence from aphasia (Elman et al., 2000; Simmon-Mackie et al., 2002) suggests that rectifying this situation would increase public support for people with RHCD, and could lead to an increase in the health, social and public services that are provided for RHCD. Simmons-Mackie et al. (2002) also emphasise that increased awareness and support would impact on levels of acceptance of people with aphasia which affect re-integration into communities and workplaces, as well as psychosocial adjustment. These same linked issues of awareness, support and acceptance apply to people with RHCD who have social communication difficulties, and are arguably even more important given that this condition can also impinge on insight, awareness, emotion and impulsivity.

Although this was an exploratory study, limited to 87 participants in a single borough in London, our results highlight the significant need to raise awareness and knowledge of both

RHCD and aphasia. In their 2002 study, Simmons-Mackie and colleagues conclude with seven suggestions for increasing awareness of aphasia which would work equally well with RHCD. These include using the words 'aphasia' (or 'right hemisphere communication disorder') to describe the condition, and encouraging and supporting people with these conditions, as well as their friends and family members, to raise public awareness where they can. These authors also advocate using the media and public spaces to provide information wherever possible, and encourage people to try to influence public policy and political action.

Simmons Mackie et al. (2002, page 847) concluded their study with the following statement: "through international efforts and the combined voices affected by aphasia and professionals interested in aphasia, the public will learn what aphasia is and that people with aphasia have much to offer for society". A similar statement can be made for people affected by RHCD because it is important that both the public and health professionals learn that people with RHCD have much to offer to society. Recently, a website hosted by the Centre for Clinical Neuropsychological Research (CCNR) site at the University of Exeter in the UK (Code, 2014) has been created to provide extensive data on international levels of public awareness of aphasia in a range of countries. The information provided was prepared to be accessible by people with aphasia and their families, health care professionals and, importantly, the media and also provides advice and tips on raising awareness. A similar site could and should be created for RHCD.

In conclusion, this exploratory study indicates low levels of awareness and knowledge of right hemisphere communication disorder in a small cohort of people in a single London borough, and suggests that further research involving much larger numbers from a more representative sample should be carried out. If, as the results presented here suggest, there is a considerable lack of awareness then this will affect funding, services, and the quality of life of those living with right hemisphere communication disorder.

References

Blake, M. L., Duffy, J. R., Myers, P. S., & Tompkins, C. A. (2002). Prevalence and patterns of right hemisphere cognitive/communicative deficits: Retrospective data from an inpatient rehabilitation unit. *Aphasiology*, 16(4-6), 537-547.

- Code, C., Katz, R., Petheram, B., T., S., & Granzfried, E. (2013). Aphasia Awareness Research Summary. Retrieved 20th October, 2013, from <http://www.aphasia.org/content/aphasia-awareness-research>
- Code, C., Mackie, N. S., Armstrong, E., Stiegler, L., Armstrong, J., Bushby, E., . . . Webber, A. (2001). The public awareness of aphasia: An international survey. *International Journal of Language & Communication Disorders*, 36(S1), 1-6. doi: 10.3109/13682820109177849
- Elman, R. J., Ogar, J., & Elman, S. H. (2000). Aphasia: Awareness, advocacy, and activism. *Aphasiology*, 14(5-6), 455-459. doi: 10.1080/026870300401234
- Flynn, L., Cumberland, A., & Marshall, J. (2009). Public knowledge about aphasia: A survey with comparative data. *Aphasiology*, 23(3), 393-401. doi: 10.1080/02687030701828942
- Foerch, C., Misselwitz, B., Sitzler, M., Berger, K., Steinmetz, H., & Neumann-Haefelin, T. (2005). Difference in recognition of right and left hemispheric stroke. *The Lancet*, 366(9483), 392-393.
- Kent, B. P., & Wallace, G. L. (2006). Aphasia awareness among the Honolulu Chinese Population. *Hawai'i Medical Journal*, 65, 142-147.
- Koch, L., Egbert, N., Coeling, H., & Ayers, D. (2005). Returning to work after the onset of illness experiences of right hemisphere stroke survivors. . *Rehabilitation Counseling Bulletin*, 48(4), 209-218.
- Lehman Blake, M., Duffy, J., Tompkins, C., & Myers, P. (2003). Right hemisphere syndrome is in the eye of the beholder. *Aphasiology*, 17(5), 423-432. doi: 10.1080/02687030344000120
- Mavis, I. (2007). Perspectives on public awareness of stroke and aphasia among Turkish patients in a neurology unit. . *Clinical Linguistics & Phonetics*, 21, 55-70.
- McCann, C., Tunnicliffe, K., & Anderson, R. (2013). Public awareness of aphasia in New Zealand. *Aphasiology*, 27(5), 568-580. doi: 10.1080/02687038.2012.740553
- Myers, P. S. (2001). Towards a definition of RHD syndrome. *Aphasiology*, 15(10/11), 913-918.
- Patterson, R., Robert, A., Berry, R., Cain, M., Iqbal, M., Code, C., . . . Leonard, C. (2015). Raising public awareness of aphasia in southern Ontario, Canada: A survey. *International Journal of Speech-Language Pathology*, 17(2), 121-126.
- Simmons-Mackie, N., Code, C., Armstrong, E., Stiegler, L., & Elman, R. J. (2002). What is aphasia? Results of an international survey. *Aphasiology*, 16(8), 837-848. doi: 10.1080/02687030244000185
- Wallesch, C. W. (2004). History of aphasia: Freud as an aphasiologist. *Aphasiology*, 18(4), 389-399.

Table 1. Percentage of participants according to age, highest level of education and ethnicity

Demographic		% of participants
Age	18-29	44.8
	30-39	32.3
	40-49	9.2
	50-59	9.2
	60-69	3.4
	70-79	1.1
Highest level of Education	PhD	2.3
	Masters	20.7
	Post-graduate	3.4
	Bachelors	40.2
	Foundation Degree	1.1
	NVQ	3.4
	Higher National	2.3
	Certificate/Diploma	10.3
	AS/A levels	4.6
	GCSE	2.3
	High School	8
	Other	1.1
	No response	
Ethnicity	White British	59.8
	White Other	23
	African British	2.3
	African	0
	Other	1.1
	Asian British Asian	2.3
	Other	11.5
	Other (including mixed race)	

Appendix A

The questionnaire

Section I.

1) Have you heard of a right hemisphere communication disorder? (if the answer is “no” please go straight to section II)

2) What are right hemisphere communication disorders?

3) Right hemisphere communication disorders are caused by:

- a) Heart disease
- b) Loss of red blood cells
- c) Lung cancer
- d) Stroke
- e) Chemical imbalance in the brain

4) Which of the following are most commonly symptoms associated with right hemisphere communication disorders? (please choose either “yes”, “no” or “not sure” for each point)

- a) Difficulties with saying words
- b) Trouble with focusing and remembering things
- c) Disorientation
- d) Difficulties with saying socially appropriate things in social situations
- e) Difficulties with carrying out everyday tasks in the correct order e.g. making a cup of tea
- f) Difficulties with understanding written and spoken words
- g) Asthma
- h) Difficulty writing
- i) Arthritis

- j) Difficulties with understanding and using social aspects of language e.g. understanding jokes and hints
- k) Trouble with awareness and insight of own communication difficulties
- l) Monotone voice

5) How do you know about right hemisphere communication difficulties?

- a) I know someone who has right hemisphere communication disorders
- b) I have heard of someone who has right hemisphere communication disorders
- c) Through the media (newspaper, television, magazine etc.)
- d) I work with people who have right hemisphere communication disorders
- e) I have heard about right hemisphere communication disorders through awareness campaigns
- f) Other
- g) No response

Section II.

1) Have you heard of aphasia? (if the answer is “no” please go straight to section III)

2) What is aphasia?

3) Aphasia is caused by:

- a) Heart disease
- b) Loss of red blood cells
- c) Lung cancer
- d) Stroke
- e) Chemical imbalance in the brain

4) Which of the following are most commonly associated with aphasia? (please choose either “yes”, “no” or “not sure” for each point)

- a) Difficulties with saying words
- b) Trouble with focusing and remembering things
- c) Disorientation
- d) Difficulties with saying socially appropriate things in social situations
- e) Difficulties with carrying out everyday tasks in the correct order e.g. making a cup of tea
- f) Difficulties with understanding written and spoken words
- g) Asthma
- h) Difficulty writing
- i) Arthritis
- j) Difficulties with understanding and using social aspects of language e.g. understanding jokes and hints
- k) Trouble with awareness and insight of own communication difficulties
- l) Monotone voice

5) How do you know about aphasia?

- a) I know someone who has aphasia
- b) I have heard of someone who has aphasia
- c) Through the media (newspaper, television, magazine etc.)
- d) I work with people who have aphasia
- e) I have heard about aphasia through awareness campaigns
- f) Other
- g) No response

Section III.

1) Have you heard of stroke?

2) Do you know what a stroke is?

3) Stroke is caused by:

- a) Heart disease
- b) Loss of red blood cells
- c) Lung cancer
- d) Blood clot or burst blood vessel in the brain
- e) Chemical imbalance in the brain

4) Which of the following difficulties may be implications of a stroke? (please choose either “yes”, “no” or “not sure” for each point)

- a) Difficulties with saying words
- b) Trouble with focusing and remembering things
- c) Disorientation
- d) Difficulties with saying socially appropriate things in social situations
- e) Difficulties with carrying out everyday tasks in the correct order e.g. making a cup of tea
- f) Difficulties with understanding written and spoken words
- g) Asthma
- h) Difficulty writing
- i) Arthritis
- j) Difficulties with understanding and using social aspects of language e.g. understanding jokes and hints
- k) Trouble with awareness and insight of own communication difficulties
- l) Monotone voice

5) How do you know about stroke?

- a) I know someone who had a stroke
- b) I have heard of someone who had a stroke

- c) Through the media (newspaper, television, magazine etc.)
- d) I work with people who had a stroke
- e) I have heard about stroke through awareness campaigns
- f) Other
- g) No response

Section IV- Demographic details

1) Age

- a) 18-29
- b) 30-39
- c) 40-49
- d) 50-59
- e) 60-69
- f) 70-79
- g) 80+

2) Gender

- a) Male
- b) Female

3) Ethnicity

- a) White British
- b) White Other
- c) African British
- d) African Other
- e) Asian British
- f) Asian Other
- g) Other (including mixed race)

4) Please choose the highest level of your education:

- a) Primary School
- b) High School
- c) GCSEs
- d) AS and A levels
- e) Bachelors degrees
- f) Postgraduate degree
- g) Masters degree
- h) Phd
- i) Foundation degrees
- j) Higher National Certificates and Higher National Diplomas
- k) International Baccalaureate Diploma
- l) Key Skills qualifications
- m) NVQs
- n) Other (please specify)
- o) No response

The end

Thank you for your assistance

