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The public awareness and knowledge of aphasia in Saudi Arabia

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ABSTRACT

Background: Public awareness of aphasia is essential to ensure that people with aphasia receive the support and understanding they need. Previous studies in non-Arabic speaking countries have found a universally low level of aphasia awareness and knowledge. Aims: For the first time, the public awareness and knowledge of aphasia in Saudi Arabia was examined in this study. Additionally, the influence of demographic factors (i.e., age, gender, education, socio-economic status, and city of residency) on the levels of aphasia awareness and knowledge were investigated.

Methods: The target sample size was estimated a priori using power analysis, and thus the current study had the largest sample size compared to other public aphasia awareness studies published to date. A total of 1631 members of the public completed an online survey using an adapted version of the public awareness of aphasia questionnaire.

Results: 20.48% of the respondents had heard of aphasia, of whom only 4.79% had correct basic knowledge of aphasia in relation to its features and causes. Aphasia awareness was influenced by demographic factors, including age, level of education, and socioeconomic status, whilst demographic factors did not have an influence on aphasia knowledge. Interestingly, there was a prevalent belief that aphasia can improve, with Speech-Language Therapy being the most frequently chosen treatment option, followed by psychotherapy.

Conclusions: Although aphasia awareness in Saudi Arabia was slightly higher than has been observed in some non-Arab countries, aphasia awareness and knowledge remain low despite several aphasia awareness campaigns carried out across multiple countries over the past two decades. These results highlight the need to develop action plans not only to raise public awareness of aphasia. but to educate the public on the nature of aphasia. This could be accomplished through international collaborations to raise aphasia awareness and knowledge. Future initiatives must be directed towards providing adequate aphasia education to families and the general public by healthcare providers.

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Introduction

Despite the efforts of several organisations to raise awareness of aphasia, many people are not aware of what aphasia is, and what impact it can have on individuals and their families. Although this information is well known to clinicians, researchers, and scientists interested in aphasia, public levels of aphasia awareness and knowledge are very low. This has been documented universally across different countries. To date, aphasia awareness and knowledge have been examined in several non-Arabic speaking countries, including Australia, United Kingdom, United States of America (Code et al., 2001), New Zealand (McCann et al., 2013), Canada (Ontario) (Patterson et al., 2015), Norway, Croatia, Greece, Slovenia, Argentina (Code et al., 2016), Serbia, Montenegro (Vuković et al., 2017), Sweden (Henriksson et al., 2019), Ireland (Guinan & Carroll, 2019), India (Kerala) (Chazhikat, 2014), and Italy (Viganò et al., 2022). Only one aphasia awareness study has been conducted in an Arabic-speaking country in the Middle East (Kuwait) (Aljenaie & Simmons-Mackie, 2022), but the extent to which these results generalise to other Arabic countries with much larger populations than Kuwait, such as Saudi Arabia, is unclear. This is a gap in the literature that was addressed in this study.

The first published study that investigated aphasia awareness was by Code and colleagues (Code et al., 2001). They reported awareness levels between 10% and 18%, and knowledge rates between 1.5% and 7.6% in Exeter (England), Louisiana (United States of America), and Sydney (Australia). Subsequent international studies revealed similar figures, with public awareness of aphasia between 9.67% and 16.4%, and basic knowledge of aphasia between 1.5% and 11.5% (Chazhikat, 2014; McCann et al., 2013; McMenamin et al., 2021; Patterson et al., 2015; Vuković et al., 2017). The level of aphasia awareness was higher in certain European countries: 57.4% in Norway (Code et al., 2016), 66% in Sweden (Henriksson et al., 2019), 46% in Greece (Code et al., 2016), as well as in Canada (31.8%), and New Zealand (30%) (Code et al., 2016; Patterson et al., 2015). To date, only one aphasia awareness study has been conducted in an Arab country (Kuwait) to examine changes in public awareness of aphasia over a four-year period using a face-to-face survey carried out in one shopping mall in the capital city of Kuwait (Aljenaie & Simmons-Mackie, 2022). Their results revealed that aphasia awareness differed based on the time of data collection: 14.2% in 2013 and dropped to 9.1% in 2017 (Aljenaie & Simmons-Mackie, 2022). Most previous aphasia awareness studies collected data using face-to-face surveys and recruited between 85 and 400 participants mainly from shopping malls. One exception is a recent study conducted in Italy using an internet survey, which had the largest sample size compared to other studies (Viganò et al., 2022). On the other hand, UK-based charities have conducted telephone surveys and managed to recruit larger samples (of around 1000 respondents) than studies that employed face-toface surveys, but they revealed comparably low levels of aphasia awareness: 3% (Speakability, 2000) and less than 10% (The Aphasia Alliance, 2008). These compelling results from different studies highlight huge variability aphasia awareness (between 11% and 60%) and knowledge (between 3.2% and 7%) across different countries. This could be due to different educational levels, economic circumstances, spoken languages, or cultural attitudes towards disability. Results from the existing literature highlight the importance of examining levels of aphasia awareness and knowledge in different countries.

Understanding the public awareness of aphasia is critical because it encourages researchers, clinicians, and patient advocates to take actions to raise awareness (Code, 2020). Raising awareness of aphasia has a potential positive impact by increasing financial support for aphasia

services and research. It has been reported that reduced aphasia awareness has limited access to information and resources by people with aphasia (Hinckley et al., 2013), and that financial funds depend, at least partially, on the recognition of the disorder by funders and policymakers (Elman et al., 2000; Simmons-Mackie et al., 2002). Raising awareness of aphasia can guide policymakers and funding bodies towards supporting aphasia research, and services provided to people with aphasia. Additionally, it has the potential to prompt the provision of a broader range of aphasia services (Elman et al., 2000). This is because knowledge of a disorder can influences referrals and the availability of healthcare services (Elman et al., 2000).

The aim of this study was to extend the existing literature and expand our understanding on the public awareness and knowledge of aphasia using a large sample size, estimated through an a priori power analysis, which was recruited from a country with a large population size of 36 million (Saudi Arabia). In Saudi Arabia, aphasia awareness has not been investigated to date. An additional aim was to examine the influence of different demographic factors (age, gender, educational level, socioeconomic status, and city of residency) on levels of aphasia awareness and knowledge.

Methods

This study received ethical approval from King Fahad Medical City Institutional Review Board (IRB No. 21-114).

Questionnaire

An Online Arabic questionnaire was developed by the author to gather responses on the public awareness and knowledge of aphasia (available in the Supplementary Materials). The design of this questionnaire was influenced by previous aphasia awareness questionnaires (Code et al., 2001; Simmons-Mackie et al., 2002). All components of the questionnaire were presented in the Arabic language. The first part of the questionnaire was designed to collect demographic information similar to those in the original questionnaire, including age, gender, and occupation. To account for the geographical size of Saudi Arabia, a new demographic question was introduced on the city of residency. To examine the potential influence of education on aphasia awareness and knowledge, the education level of the respondent was also collected. These were presented as forced-choice lists (available in Table 1). A standard socio-economic classification system was used to classify occupations according to the UK Office of Population Censuses and Surveys classification system (Office of Population Censuses and Surveys (OPCS), 1980), as was used in previous studies (Code et al., 2016; Simmons-Mackie et al., 2002). This system includes five categories: (I) highearning professions, such as lawyers, physicians, and academics; (II) intermediate professions, such as therapists, administrators, and teachers; (III-N) non-manual skilled jobs, such as secretaries; (III-M) manual skilled jobs, such as electricians, and cooks; (IV) semi-skilled workers, such as postmen; and (V) unskilled manual workers, such as cleaners. Category VI was added to represent the unemployed and students.

The second part of the questionnaire assessed aphasia awareness and knowledge. It started with a question on whether the respondents had heard of aphasia and/or the Arabic term for aphasia (?lħabsa ?lkala:mjiah), to account for linguistic differences between Arabic and other languages. Those who responded with yes to either term

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		#	06	Heard of	Correct basic	Somo knowledge
Variable	Category	" Respondents	Respondents	(%)	aphasia (%)	of aphasia (%)
Gender	Male	715	43.84	22.1	2.3	38.9
	Female	916	56.16	18.5	5.9	49.5
Age range	18-24	151	9.26	20.5	3.2	67.7
(years)	25-30	192	11.77	25.5 4.1		59.2
	31-35	222	13.61	27	10.2	42.4
	36-40	241	14.78	16.2	7.7	56.4
	41-45	196	12.02	21.4	2.4	28.6
	46-50	185	11.34	25.4	2.1	34
	51-55	178	10.91	16.3	3.4	34.5
	56-60	122	7.48	11.5	0	35.7
	61-65	98	6.01	15.3	0	53.3
	66-70	28	1.72	10.7	0	66.7
	71-75	13	0.80	30.8	0	25
	>76	5	0.31	20	0	0
City of	Central (Najd)	1120	68.67	21.2	5.5	46.2
Residency	Northern	82	5.03	25.6	0	76.2
	Southern	115	7.05	18.3	0	42.9
	Eastern	121	7.42	15.7	0	36.8
	Western (Hejaz)	193	11.83	18.7	5.6	27.8
Education	No formal	75	4.60	10.7	0	87.5
	education	57	2.42	16.07	•	22.2
	Primary or	56	3.43	16.07	0	22.2
	School					
	High School	245	15.02	13.9	0	64 7
	Diploma	154	9 4 4	17.5	37	37
	Graduate	841	51.56	20.9	3.4	44.6
	degree	011	51150	2002	511	1 110
	Postgraduate	260	15.94	30.8	10	40
	dearee					
Socio-	l: high-earning	194	11.89	33.5	5.5	39.6
economic	professions					
status	II: intermediate	698	42.80	21.2	5	43.2
	professions					
	III: skilled jobs	208	12.75	14.9	0	35.7
	IV: semi-skilled	20	1.23	10	0	0
	workers					
	V: unskilled	7	0.43	0	3.4	56.8
	manual workers					
	VI: unemployed	504	30.90	17.5	4.5	45.3
	and students					

Table 1. Respondents'	demographic	profile	(N =	1631)	and	levels	of	aphasia	awareness	and
knowledge.										

continued to answer further aphasia knowledge questions regarding the features and causes of aphasia, possible treatment options for people with aphasia, and how they had heard of aphasia. Each question included a list of options. The present study used more options than the original questionnaire (these are illustrated in Figure 1 and 2). For instance, social media platforms were included as a source of how aphasia had been heard of, because these platforms are widely used in the current era. Moreover, the possible treatment options for aphasia were adjusted to reflect Arab culture and society (e.g., family support). Respondents were able to select more than one option in all questions. The questionnaire also included two yes/no questions: can aphasia improve, which was only answered by those who had heard of aphasia; and another question answered by all respondents asking them if they had heard of Speech-Language Therapists/Pathologists.

Participants and Recruitment Process

The inclusion criteria involved adults living in Saudi Arabia. Participants were recruited through snowball-sampling, and voluntarily participated in this survey. Power analysis was applied to determine the required sample size using the quantitative research sample size calculation method for survey studies based on the size of the target population: 36 million in Saudi Arabia (39% in Najad region, 12% in the Northern region, 4.5% in the Southern region, 9.5% in the Eastern region, and 35% in the Hejaz region). An a priori power analysis revealed that sufficient statistical power with a margin of error of \pm 0.05% and 99% confidence interval, and an expected sample proportion of 0.5, would be gained with 666 respondents.

Online informed consent was obtained from each participant before participation in this study; this included reading the online information sheet with details on their right to withdraw, confidentiality, and anonymity of their responses. The online questionnaire was disseminated electronically using Google Forms via social media platforms (e.g., Twitter [or X as it has been renamed recently], LinkedIn) and through direct messaging (e.g., SMS, WhatsApp, email). To avoid sampling bias, I did not use specific sources, databases, or events to recruit participants; instead, the questionnaire was disseminated at a national level.

Scoring and Data Analyses

Respondents were considered to have awareness of aphasia if they had heard of the term aphasia (i.e., either the original term or the Arabic term). Three classifications were used to categorise respondent's knowledge of aphasia based on the options they selected in relation to features and causes of aphasia. First: as was done in previous studies (Code et al., 2001; Code et al., 2016; Hill et al., 2019; Patterson et al., 2015; Simmons-Mackie et al., 2002; Vuković et al., 2017), respondents were considered to have correct basic knowledge of aphasia if they met two criteria. The first criterion was to identify 'language problems' and/or 'communication problems' as feature(s) of aphasia without selecting incorrect features (e.g., muscular weakness, psychological or cognitive problems). Respondents could also choose problems with 'reading', 'writing' and 'understanding' as features of aphasia, but choosing one or all of these three features was insufficient on its own to classify a respondent as having correct basic knowledge of aphasia. The second criterion was to identify 'brain damage' (stroke, brain injury or brain surgery) as potential cause(s) of aphasia, without identifying any of the other incorrect conditions (e.g., developmental delay, mental health problems, or impaired intelligence). Second, respondents were considered to have some knowledge of aphasia if they identified at least one correct feature of aphasia (i.e., language problems, communication problems, problems with understanding) together with at least one correct cause of aphasia (i.e., stroke, brain injury or brain surgery). It was acceptable to select incorrect features or causes of aphasia, in addition to a correct feature and cause of aphasia, to be classified as having some knowledge of aphasia. Third, respondents were considered to have incorrect knowledge of aphasia if they did not select any correct feature of aphasia (i.e., language problems, communication problems, problems with understating), and did not select any correct cause of aphasia (i.e., stroke, brain injury, or brain surgery), and if all selected options were not related to aphasia (e.g., developmental delay, psychological or cognitive problems, impaired intelligence, and/or sensory problems).

Data were exported from Google Forms to Microsoft Excel (version 2301) and analysed using SPSS version 29. Descriptive statistics were displayed as frequencies and percentages to summarise participant demographics and to determine the level of awareness and knowledge of aphasia. Relationships between the level of aphasia awareness (two dichotomous parameters: presence/absence of aphasia awareness), or the level of knowledge (three categorical parameters: correct basic knowledge, some knowledge, incorrect knowledge), and demographic variables (age, gender, educational level, socio-economic status, and city of residency) were examined using Pearson's chi-square tests, because the data were categorical, in that all variables consist of two or more ordinal (e.g., gender), or nominal (e.g., education) independent groups. A Bonferroni correction for multiple comparisons was applied to the p-value required for statistical significance (i.e., $p \le 0.01$).

RESULTS

Respondents

A total of 1631 adults completed the questionnaire. Demographic information of the respondents is presented in Table 1. There was an approximately even gender balance with 56.16% of respondents being female. The sample of respondents represented all age ranges, all educational levels, all socio-economic status levels, and all regions of Saudi Arabia. Most respondents were school teachers (13.6%), administrators (19.1%), and unemployed (23.72%). Only 1.9% of the respondents were physicians, 4.4% were health-care workers from specialties that are not related to Speech-Language Therapy/Pathology, and only 0.49% were healthcare workers within rehabilitation specialties. 7.2% of the respondents were university/college students. The remainder of the respondents (28.7%) were from other backgrounds, including finances, architecture, law, business, military, armed-force, security, art, public relations, and media. Only 3.2% of the total respondents knew someone with aphasia.

Awareness of aphasia

Of the 1631 respondents, 20.48% (n = 334) reported that they had heard of aphasia. Of these 334 respondents, only 7.48% of the total sample (n = 122) had heard of the term 'aphasia', and the remaining 13% (n = 212) had heard of the Arabic term for aphasia '2lħabsa '2lħala:mjia'. Of the 334 respondents who had heard of aphasia, the source of aphasia awareness for 22.16% was through a family member or a friend; whereas 15.87% knew someone with aphasia; 18.59% had heard about aphasia at work; 15.42% had heard about it through formal education (i.e., lectures); 14.06% had read about aphasia; 18.59% had heard about aphasia through Twitter); and 5.67% had heard about it from TV or radio.

Knowledge of aphasia

Of the 334 respondents who had heard of aphasia, only 4.79% (n = 16) were deemed to have correct basic knowledge of aphasia in relation to its features and causes. 45.21% (n = 151) were deemed to have some knowledge of aphasia, and 50% (n = 167) had incorrect knowledge of aphasia. 40.42% of the respondents who had heard of aphasia correctly identified 'language problems' as an aphasia feature, while 72.75% of the respondents identified 'speech problems' as a feature of aphasia, but with confusion between aphasia and stuttering. Figure 1 illustrates responses in relation to aphasia features. 57.49% of the respondents identified 'brain injury' as a potential cause of aphasia, and 41% identified 'stroke' as a potential cause. Figure 2 illustrates responses to the potential causes of aphasia.

Of the 334 respondents who had heard of aphasia, 95.21% (n = 318) reported that aphasia can be improved. 77.25% of the respondents identified Speech-Language Therapy/Pathology as a possible treatment option. However, other treatment options were also identified, including psychotherapy (51.80%), medications (24.25%), surgical intervention (9.58%), physical therapy (9.88%), and others (5.7%, e.g., alternative medicine, religious ritual, and learning another language). Moreover, other methods of support were also highlighted by the respondents, including family support (61.98%), community support (53.89%), and technological support (e.g., use of applications) (26.35%). 25.15% of respondents reported that helping a person with aphasia would require communicating with them in a different way, such as speaking slowly. Interestingly, of the 1631 respondents who completed the questionnaire, 87% (n = 1419) had heard of a Speech-Language Therapist/Pathologist.



Figure 1. Bar graph illustrating aphasia features that were identified by respondents with aphasia awareness. The bars represent the percentages of respondents (n = 334), as they can select more than one option.

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Figure 2. Bar graph illustrating causes of aphasia that were identified by respondents with aphasia awareness. The bars represent the percentages of the respondents (n = 334), as they can select more than one option.

Influence of gender and age on aphasia awareness and knowledge

Gender did not have a significant influence on either aphasia awareness or knowledge. Age, on the other hand, had a significant influence on aphasia awareness only, $\chi^2 = 26.56$, two-sided p = 0.005, in that awareness was highest amongst those aged between 71 and 75 years (30.8% of this age category were aware of aphasia). These results are summarised in Table 1.

Influence of education and socio-economic status on aphasia awareness and knowledge

Educational level had a significant influence on aphasia awareness, $\chi^2 = 30.08$, two-sided p < 0.001, but not knowledge. Awareness was highest amongst those who held a postgraduate qualification (30.8% of whom had aphasia awareness), while the lowest awareness was in those who had not received a formal education (only 10.7% in this category were aware of aphasia). Again, aphasia awareness, $\chi^2 = 30.38$, two-sided p < 0.001, but not knowledge, was significantly influenced by the socio-economic status of the respondents, in that 33.5% of high-earning professionals were aware of aphasia, compared to 0% of unskilled manual workers. These results are summarised in Table 1.

Influence of city of residency on aphasia awareness and knowledge

The geographical region of residency of the respondents did not have a significant effect on either aphasia awareness or knowledge. The results are also summarised in Table 1.

DISCUSSION

Public awareness of aphasia is essential to ensure that people with aphasia receive the support and understanding they need. This study examined the public awareness and knowledge of aphasia in Saudi Arabia. The current study included the largest sample size compared to similar international studies. The study reports several key findings: (1) out of 1631 respondents, 20.48% had heard of aphasia, but only 7.48% had heard of the term 'aphasia', whereas the remainder had heard of the Arabic term for aphasia '2lħabsa 2lkala:mjia'; (2) only 4.79% of those who had heard of aphasia had correct basic knowledge of aphasia related to its features and causes; (3) aphasia awareness was influenced by demographic factors, including age, level of education, and socio-economic status; (4) aphasia knowledge was not influenced by any demographic factors; (5) the highest source of aphasia awareness was hearing about it from another person; and (6) there is a high level of belief that aphasia can improve, with Speech-Language Therapy being the most frequently identified treatment option, followed by psychotherapy. These findings are discussed below.

Awareness and knowledge of aphasia

The level of aphasia awareness in Saudi Arabia is slightly higher than the reported awareness in most countries, including the United Kingdom, Australia, United States of America (Code et al., 2001), India (Chazhikat, 2014), Slovenia (Code et al., 2016), Serbia, Montenegro (Vuković et al., 2017), Ireland (Guinan & Carroll, 2019), and Kuwait (Aljenaie & Simmons-Mackie, 2022). It is unlikely that sampling bias contributed to the slightly higher level of aphasia awareness in the present study, since over one third of the sample had an educational level below college degree, including some individuals who were illiterate or unemployed. The larger and well powered sample size of the current study could account for the slight discrepancy. Another reason could be methodological differences, as the current study used an online survey, which might have allowed the survey to reach higher numbers of the general public than face-to-face surveys. Nevertheless, since participation in this online survey (as in all research studies) was voluntary, it might potentially encouraged participation from those who are interested in the research topic.

The level of aphasia knowledge in Saudi Arabia was either similar or lower than the reported knowledge in other countries. This is the first study to use three categories of aphasia knowledge, exploring not only whether knowledge of aphasia was correct or incorrect, but also if the respondents had some knowledge of aphasia (i.e., whether the respondent was able to identify correct aphasia features and causes amongst other unrelated features and causes). These findings indicate that although a very small number had correct basic knowledge of aphasia, nearly half of the respondents had some knowledge of aphasia, which is very promising. Is it interesting that around a third of the respondents described aphasia as 'speech/language delay', and around a quarter identified 'development delay' as a potential cause of aphasia. These findings suggest that the public have limited knowledge of acquired speech and/or language disorders compared to developmental disorders. This could be because more Speech-Language Therapy/ Pathology services are typically provided to paediatric rather than adult populations, or because certain development disorders (e.g., autism) receive more attention in social media and newspapers (Elman et al., 2000). This could also explain the high level of

awareness of Speech-Language Therapy/Pathology as a profession, which could also be attributed to recent increases in interest and demand for rehabilitation services in the region (Alanazi et al., 2023).

A possible reason for the low level of aphasia awareness and knowledge could be because professionals and the media tend to avoid use of the term 'aphasia' as people might not recognise it. Describing aphasia when talking about it without using the term 'aphasia' has the unintended negative consequence of decreasing levels of aphasia awareness and knowledge. Another possible reason might be because aphasia is underrepresented in the media (Elman et al., 2000). Simmons-Mackie et al. (2002) suggested that "Unless we use the word ourselves and encourage others to use the word, then aphasia will remain nonexistent to the public" (pp. 846).

Almost half of the respondents who had heard of aphasia thought that psychotherapy is a treatment option for aphasia. This is interesting given that only a quarter of these respondents selected 'psychological problem' as a feature of aphasia. This indicates that even those who know that aphasia is a language or communication problem thought that psychotherapy could help. However, only 20% of those who selected psychotherapy chose it without choosing Speech-Language Therapy, whereas the remainder chose psychotherapy alongside Speech-Language Therapy. The questionnaire used in this study did not allow free text to be added by the respondents, which could have provided further insight as to why psychotherapy was selected as a treatment option for aphasia. Additionally, these results cannot be directly compared to previous studies, as a multiplechoice response for treatment options has not been done in previous studies.

It is interesting that the main source of aphasia awareness in Saudi Arabia was hearing about aphasia from family members or friends, despite only 3.2% of the total respondents knowing someone with aphasia. This is different to previous studies in non-Arab countries which showed that 'work' was the highest source of aphasia awareness (Code et al., 2001; Code et al., 2016; Hill et al., 2019; Patterson et al., 2015). Interestingly, 'through family members or friends' were also the highest source of aphasia awareness in Kuwait (Aljenaie & Simmons-Mackie, 2022), despite several methodological differences between the two studies. Specifically, a national online survey was used here on a large sample that was determined through power analysis, as opposed to the face-to-face survey method recruiting public shoppers, which was used in Kuwait. Nevertheless, these are the only two studies that have explored aphasia awareness in an Arabic country. The similarity in their findings indicates that cultural differences might contribute to discrepancies in the source of aphasia awareness between studies conducted in Arab versus Western countries. Additionally, levels of aphasia awareness and knowledge were comparable between the current study on the general public of Saudi Arabia and the one conducted in Kuwait (Aljenaie & Simmons-Mackie, 2022), despite a huge difference in the population size of Saudi Arabia (36 million) compared to Kuwait (4.5 million). These findings might indicate that social, cultural, and economic similarities across different countries might contribute to the level of awareness of healthcare conditions.

Effect of demographic factors on public awareness and knowledge of aphasia

Interestingly, aphasia awareness was influenced by age, level of education, and socioeconomic status, whereas aphasia knowledge was not influenced by any demographic factor. Specifically, older people, those with postgraduate qualifications and high-earning professions were more likely to have heard of aphasia. However, these findings also suggest that having heard of aphasia among these groups does not necessarily mean having obtained correct knowledge of aphasia.

Consistent with previous studies, older people are more likely to have heard of aphasia (Code et al., 2001; Code et al., 2016; Hill et al., 2019; Patterson et al., 2015; Simmons-Mackie et al., 2002). It is possible that older people may be more aware of aphasia due to the higher stroke rate among the elderly which might therefore make them more likely to know other individuals with aphasia compared to younger age groups in which the incidence of aphasia is lower (Simmons-Mackie et al., 2002). Aphasia awareness was higher among those with postgraduate gualifications followed by those with graduate gualifications. Aphasia awareness was highest among highearning professions (physicians, academics, lawyers) followed by intermediate professions (therapists, nurses, teachers, managers, and administrators). None of the unskilled manual workers had heard of aphasia, and only 10% of semi-skilled workers and those who did not receive formal education had heard of aphasia. This is different to previous reports which found that high-earning professions were not more likely to have heard of aphasia (Code et al., 2016; Hill et al., 2019; McMenamin et al., 2021; Simmons-Mackie et al., 2002). However, there was an unequal distribution of participants between occupation groups in such previous studies and authors of these publications acknowledged that respondents were drawn predominantly from socioeconomic groups of intermediate professions, which showed higher levels of awareness. The authors also indicated that their findings regarding the relationship between socio-economic status and aphasia awareness and knowledge should be interpreted with caution. Additionally, earlier studies utilised phone surveys or surveyed the public at a shopping mall (Code et al., 2001; Code et al., 2016; Hill et al., 2019; Simmons-Mackie et al., 2002), which might have limited their recruitment to certain age groups, socio-economic groups, and geographical regions, or to people who would normally shop at malls or would answer their phones. A high proportion of the population might use communication methods other than the phone or might shop online. The current study attempted to avoid these issues using a national level online survey, with the hope that this would obtain a more representative sample.

Conclusions and future directions

Levels of public awareness and knowledge of aphasia remain relatively low despite efforts over the past two decades to raise awareness of aphasia. We need to do more to ensure that people with aphasia receive the support and understanding they need. Raising awareness of aphasia and educating people about the nature of aphasia is not only important for individuals who have experienced a stroke or brain injury, but also for the general public. Raising awareness can help to promote a better understanding of aphasia and its consequences. By educating the general public of the signs and symptoms of aphasia, individuals who experience language difficulties following a stroke or brain injury can be identified earlier. Early intervention is crucial for maximising recovery and improving outcomes. This will also encourage individuals with aphasia to seek appropriate interventions and support. Moreover, increasing the awareness of aphasia might lead to better understanding between people with aphasia and their family, friends, and others. This can help to reduce frustration and improve quality of life for people with aphasia (Elman et al., 2000; Simmons-Mackie et al., 2002). Furthermore, raising awareness of aphasia can help to reduce stigma and negative attitudes towards people with communication difficulties. Greater awareness and understanding of aphasia can help to promote empathy and support (Elman et al., 2000; Simmons-Mackie et al., 2002). Raising awareness is also critical for promoting a more inclusive and supportive society, in which people with communication difficulties are better understood and supported. Finally, higher public awareness of aphasia can lead to increased funding and resources being made available for aphasia research, treatment, and support services. This can help to improve the availability and guality of services for people with aphasia and their families. Funding for healthcare services can be influenced by name recognition. For example, disorders with prevalence rates lower than aphasia (e.g., AIDS, and breast cancer) receive more widespread research funding in the United States, potentially because they have more vocal advocates (Elman et al., 2000).

Raising awareness and knowledge of aphasia should not be limited to a specific time or place. It should instead be an ongoing international collaborative effort. Healthcare providers, researchers, advocacy organisations, and community groups can work together to promote awareness through online resources, education campaigns, and public events. Finally, it is important to ensure that public awareness efforts are culturally sensitive and inclusive, considering the diverse needs and experiences of individuals with aphasia and their families. Healthcare workers are encouraged to use the term 'aphasia' and provide correct information about it. We should also encourage people with aphasia, their families and friends to self-advocate, to participate in public awareness campaigns, to educate others in the community, and to bombard the media with aphasiarelated stories. Future initiatives must be directed towards providing health workers and the general public with adequate aphasia knowledge. By working together, we can raise awareness of aphasia and improve health outcomes for people with aphasia.

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References

- Aljenaie, K., & Simmons-Mackie, N. (2022). Public awareness of aphasia in Kuwait. *Aphasiology*, *36* (10), 1149–1158. https://doi.org/10.1080/02687038.2021.1942773
- Chazhikat, E. (2014). Awareness of aphasia and aphasia services in south India: Public health implications. Online Manuscript. https://Digital.Library.Unt.Edu/Ark:/67531/Metadc86166/M2/1/ High_res_d/Chazhikat%20Emlynn.Pdf.
- Code, C. (2020). The implications of public awareness and knowledge of aphasia around the world. In Annals of Indian Academy of Neurology (Vol. 23, Issue 8, pp. S95–S101). Wolters Kluwer Medknow Publications. https://doi.org/10.4103/aian.AIAN_460_20
- Code, C., Mackie, N. S., Armstrong, E., Stiegler, L., Armstrong, J., Bushby, E., Carew-Price, P., Curtis, H., Haynes, P., McLeod, E., Muhleisen, V., Neate, J., Nikolas, A., Rolfe, D., Rubly, C., Simpson, R., & Webber, A. (2001). The public awareness of aphasia: An international survey. *International Journal* of Language and Communication Disorders, 36, 1–6. https://doi.org/10.3109/13682820109177849
- Code, C., Papathanasiou, I., Rubio-Bruno, S., De La Paz Cabana, M., Villanueva, M. M., Haaland-Johansen, L., Prizl-Jakovac, T., Leko, A., Zemva, N., Patterson, R., Berry, R., Rochon, E., Leonard, C., & Robert, A. (2016). International patterns of the public awareness of aphasia. *International Journal of Language & Communication Disorders*, 5(13), 276–284.
- Elman, R. J., Ogar, J., & Elman, S. H. (2000). Aphasia: Awareness, advocacy, and activism. *Aphasiology*, 14(5–6), 455–459. https://doi.org/10.1080/026870300401234
- Grohn, B., Worrall, L., Simmons-Mackie, N., & Hudson, K. (2014). Living successfully with aphasia during the first year post-stroke: A longitudinal qualitative study. *Aphasiology*, 28(12), 1405–1425.
- Guinan, N., & Carroll, C. (2019). An investigation of hospitality industry students' awareness and knowledge of aphasia. *Aphasiology*, 33(3), 337–351.
- Henriksson, I., Hjertén, A., Zackariasson, J., Davidsson, L., Damberg, A. A., Saldert, C., Ball, M. J., & Müller, N. (2019). Public awareness of aphasia–results of a Swedish sample. *Aphasiology*, 33(1), 94–104.
- Hill, A., Blevins, R., & Code, C. (2019). Revisiting the public awareness of aphasia in Exeter: 16 years on. International Journal of Speech-Language Pathology, 21(5), 504–512. https://doi.org/10.1080/ 17549507.2018.1485742
- Hinckley, J., Hasselkus, A., & Ganzfried, E. (2013). What people living with aphasia think about the availability of aphasia resources. *American Journal of Speech-Language Pathology*, 22, S310–S317.
- Maviş, I. (2007). Perspectives on public awareness of stroke and aphasia among Turkish patients in a neurology unit. *Clinical Linguistics and Phonetics*, 21(1), 55–70. https://doi.org/10.1080/02699200600903254
- McCann, C., Tunnicliffe, K., & Anderson, R. (2013). Public awareness of aphasia in New Zealand. *Aphasiology*, 27(5), 568–580. https://doi.org/10.1080/02687038.2012.740553
- McMenamin, R., Faherty, K., Larkin, M., & Loftus, L. (2021). An investigation of public awareness and knowledge of aphasia in the West of Ireland. *Aphasiology*, 35(11), 1415–1431. https://doi.org/10. 1080/02687038.2020.1812047
- Office of Population Censuses and Surveys (OPCS). (1980). Classification of Occupations. HMSO.
- Patterson, R., Robert, A., Berry, R., Cain, M., Iqbal, M., Code, C., Rochon, E., & Leonard, C. (2015). Raising public awareness of aphasia in southern Ontario, Canada: A survey. *International Journal of Speech-Language Pathology*, 17(2), 121–126. https://doi.org/10.3109/17549507.2014.927923
- 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. https://doi.org/10.1080/ 02687030244000185
- Viganò, M., Gilardone, G., Cassinelli, D., Fumagalli, F. M., Scialla, M., Gilardone, M., Dameno, R., Corbo, M., & Monti, A. (2022). The Italian Aphasia Awareness Survey (IAAS): an online questionnaire about the public knowledge of aphasia in Italy, informative findings. *Aphasiology*, 36(5), 599–617. https://doi.org/10.1080/02687038.2021.1897078
- Vuković, M., Matić, D., Kovač, A., Vuković, I., & Code, C. (2017). Extending knowledge of the public awareness of aphasia in the Balkans: Serbia and Montenegro. *Disability and Rehabilitation*, 39(23), 2381–2386. https://doi.org/10.1080/09638288.2016.1226410