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DRAFT

**The Italian Aphasia Awareness Survey (IAAS): an online questionnaire  
about the public knowledge of aphasia in Italy, informative findings**

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DRAFT

# **The Italian Aphasia Awareness Survey (IAAS): an online questionnaire about the public knowledge of aphasia in Italy, informative findings**

*Background.* According to surveys conducted in several countries, public awareness and knowledge of aphasia are inadequately low. Persons with aphasia appoint this fact as a relevant environmental barrier.

*Aims.* The present inquiry aims at analyzing the status of awareness and knowledge about aphasia in Italy.

*Methods & Procedures.* An original questionnaire was distributed online through a snowball sampling method on the Italian adult population. Respondents were asked if they had heard of the term “aphasia” and subsequently tested on its definition and clinical characteristics. Similar questions regarding “celiac disease” and “Down syndrome” were asked for comparison.

Demographic data and information about the source of knowledge were also recorded.

*Outcomes & Results.* Considering 2172 respondents, 62.4% had heard of aphasia, 58.2% showed definition knowledge, while 4.6% a complete general knowledge. These rates were lower than those for the other medical conditions. Older age, female gender, higher education, and being a health professional were significantly associated with awareness. The questionnaire highlighted poor knowledge about the social and functional consequences of aphasia.

*Conclusions.* Overall, the rates of aphasia awareness and knowledge were low. Although health professionals performed better, the level of general knowledge was poor also among these respondents. These preliminary data set the need for further inquiries, undertaking appropriate methodological ameliorations.

**KEYWORDS** Aphasia; survey; public awareness; public knowledge; Italy.

**WORD COUNT:** 5509 words.

## Introduction

Aphasia is a disorder of verbal communication characterized by the loss or impairment in the use of language, caused by brain damage. It impairs the ability “to translate thought into speech and speech into thought” (Vignolo, 1973). This is a condition that strongly affects the interpersonal relationships, the social participation and the quality of life of individuals and their families, as it can affect both receptive and expressive linguistic skills to various degrees (Hilari et al., 2003; Grohn et al., 2014).

Considering cerebrovascular accidents, which represent the most frequent cause of this condition, between 21% and 38% of post-stroke patients present aphasia, both in subacute (Mitchell et al. 2020) and chronic population (Laska et al., 2001; Engleter et al., 2006). For the Italian population, it was estimated that approximately 213.000 persons live with aphasia, with a number of new cases per year that varies from 22.000 to 99.000 (Basso et al., 2011). Although aphasia is one of the most common acquired language disorders and its impact on people’s life is usually severe, this condition and its main characteristics are little-known to most people. From 2000 to 2019, in several countries the question arose about the consideration of this clinical state in general and/or in specific populations. Simmons-Mackie and colleagues (2020) recently presented a review of international surveys about aphasia public awareness and knowledge levels, and discussed the results in view of awareness campaigns and possible future interventions. **Table 1** and **Table 2** show a summary of the main results according to the previous surveys.

Focusing on the methodological approach, many studies (Code et al., 2001; Kent & Wallace, 2006; Simmons-Mackie et al., 2006; Chazhikat, 2011; McCann et al., 2013; Patterson et al., 2015 ; Code et al., 2016; Vuković et al., 2017; Henriksson et al., 2019; Hill et al., 2019)

adopted a face-to-face semi-structured interview, as proposed by Code and colleagues (2001), collecting a convenience sample in public areas, such as malls, parks, squares (**Table 1**).

Other studies adopted the same procedures but focused on specific populations such as hospitality students (Guinan & Carroll, 2019) and hospital workers and visitors (Guo & Lim, 2018) (**Table 1**). In these surveys, aphasia awareness was defined as the positive answer to the question “Have you ever heard the term ‘aphasia’?”, while the notion of “basic knowledge” was qualified as the ability to describe aphasia as a speech, language and/or communication problem caused by a brain damage. [*Table 1 near here*]

Other researchers investigated these topics in general population through a telephone interview (“Speakability” project, cited in Code et al., 2001), or an online survey (National Aphasia Association, 2016, 2020). In these cases, the authors identified the rates of respondents who showed aphasia awareness, according to the abovementioned requirement, and who were able to define aphasia as a language disorder (**Table 2**). Other inquiries (Ni Dhonnabhàin, 2003; Maviş, 2007; Flynn et al., 2009; Mahima et al., 2016) administered questionnaires to specific populations (e.g., college students, health workers, carers) with heterogeneous outcome measures (for details see **Table 2**). [*Table 2 near here*]

Considering altogether the presented surveys, although not completely comparable, Simmons-Mackie and colleagues (2020) highlighted that, despite the benchmark for knowledge was set as very basic, there was a general agreement in qualifying the levels of aphasia awareness and knowledge as inadequately low. The number of participants that had heard the term “aphasia” varied between 10.3% and 66%, while the percentage of people who showed a basic knowledge ranged between 1% and 17% (**Table 1** and **Table 2**).

Demographic factors such as older age (Simmons-Mackie et al., 2002; Patterson et al., 2015; Code et al., 2016; Henriksson et al., 2019), female gender (Simmons-Mackie et al., 2002; Maviş, 2007; Patterson et al., 2015; Code et al., 2016; Vuković et al., 2017), higher education

(Maviş, 2007) and working in health (McCann et al., 2013; Patterson et al., 2015; Code et al., 2016) or in education (Code et al., 2001; Simmons-Mackie et al., 2002; Code et al., 2016) seemed to be associated with better aphasia awareness and knowledge. A few studies (Ni Dhonnabhàin, 2003; Flynn et al., 2009; McCann et al., 2013) further investigated the awareness of aphasia in comparison with that of other neurological condition (i.e., Parkinson Disease, Multiple Sclerosis, and stroke) through similar questionnaires, highlighting that aphasia was significantly less known.

Other researchers underlined how a lack of public awareness and knowledge negatively influenced the social participation, the feeling of isolation and the quality of life of people with aphasia (PWA) and their caregivers (Hinckley et al., 2013; Wallace et al., 2016; Lanyon et al., 2019). Considering that the 2003 Canadian Stroke Network consensus conference identified community reintegration as the first priority of stroke rehabilitation and research, the poor awareness of aphasia and of its impact on PWA appears even more dramatic (Bayley et al., 2007).

The Italian Aphasia Association, A.IT.A. (both at national and regional level), and similar international groups of patients, caregivers and concerned clinicians, try to address these issues delivering advocacy campaigns, providing services tailored for PWA and organizing recreational activities for enhancing their social life. As some of the authors of this paper service as volunteers in A.IT.A. Lombardy, during meetings and conversation groups with PWA, these persons directly reinforced the idea that the public knowledge of their condition is vital for their daily living and for feeling understood. The present research has been undertaken incorporating this need and these feelings.

To the best of our knowledge, no study about aphasia awareness and knowledge with the Italian population has been published yet. As previously shown, the heterogeneity in the level of aphasia awareness and knowledge in different countries sets the need for an inquiry to



analyze the same constructs and to uncover national peculiarities in Italy. For this reason, the present study describes the results of a preliminary survey focused on the following questions:

- Which proportion of a sample from an Italian population is aware of the term “aphasia” and of its definition?
- Which are the demographic factors associated with differences in aphasia awareness and definition knowledge within the sample, if any?
- Are there any differences between the awareness of aphasia and that of other medical conditions within the sample?
- Which features and functional consequences of aphasia are better known within the recruited population?

## **Methods**

A panel of clinicians who regularly work with PWA, composed by three speech therapists (DC, MS, and MV), three neuropsychologists (FF, GG, and AM), a phoniatician (MG), a neurologist (MC) and a sociologist (RD), realized a simple questionnaire about aphasia awareness and knowledge. The tool was original and included suggestions arisen from the discussion with PWA, but the international survey proposed by Code et al. (2001) and the National Aphasia Association Survey (2016) were taken into account as references, too. The questionnaire was then optimized for online distribution with Google Forms app.

The inquiry was conducted in 2019 between 1<sup>st</sup> October and 31<sup>st</sup> December with a snowball sampling method. The URL of the online form was, thus, distributed by direct messaging (e.g., e-mail, SMS, WhatsApp, Telegram, Facebook Messenger, Instagram DM), social

network posting (e.g., Facebook, Instagram, LinkedIn, Twitter), leafleting and face-to-face meetings during special events (e.g., meetings of the Italian Aphasia Association A.IT.A., university lessons). Although snowball sampling is a non-random method and does not guarantee the representativeness of the sample, it was chosen because of the exploratory nature of this study. This strategy was indeed identified as an efficient way to reach a great number of people, so to provide broad preliminary results, and to test the clarity of the questionnaire, evaluating possible outcomes from respondents' answers. Only the complete records with reliable data filled by adults (>18 years of age) were considered for the final sample. The participation was voluntary; respondents were informed and received no compensation. Reports were anonymous and data were aggregated before being analyzed. The survey (full version in **Appendix A**) was structured in three parts: Demographics, Awareness and Definition, and General Knowledge of Aphasia.

### ***Demographics***

In the Demographics section, the following data were collected:

- Access to the survey: direct messaging system, social network, leaflet, face-to-face meeting.
- Age: choice among the following ranges: <18, 18-24, 25-34, 35-44, 45-54, 55-64, ≥65.
- Gender: male, female.
- Geographical location: region and town of residence (or residence abroad), to be further analyzed under two aspects – the Nomenclature of Territorial Units for Statistics (NUTS1) in Italy, and the dimension of the town/city of residence (whether province capitals or smaller).
- Occupation: student, worker, unemployed, homemaker, retired person.
- Education: education level according to the Italian school system (None, Primary school, Middle school, High school, Bachelor or Master degree, PhD or medical specialization), and,

for graduates, the degree subject, which was categorized in four fields (Health Sciences, Non-medical Sciences, Humanities, Economics/Law and Society).

- Link with healthcare: being a Health Professional (HP: physician, psychologist, nurse, allied health professional), having a professional link with the healthcare system (subsidiary health worker, care assistant, hospital administrative or technical worker, volunteer), no link.

### *Awareness and Definition*

In this section, the respondent was asked if she/he had heard of the three terms “aphasia”, “celiac disease” and “Down syndrome”, to assess and compare the awareness of these medical conditions. For each of these, it was then asked to select the correct definition of the term among seven alternatives (“I don’t know” option included). Although the comparison between aphasia, which is the clinical manifestation of a substrate pathology, and other disease entities might be controversial (see Hucklenbroich, 2014 for a discussion about the definition of “disease entity”), this operation was conducted by previous studies (Ni Dhonnabhàin, 2003; Flynn et al., 2009; McCann et al., 2013) and could provide interesting findings. Moreover, the pathological condition of aphasia identifies a group of people who face comparable issues and leagues in specific patients’ associations, as for other illnesses (e.g., Italian Aphasia Association A.IT.A., Italian Celiac disease Association A.I.C., Italian National Coordination of Associations of Persons with Down Syndrome COORDOWN). The celiac disease was included for comparison because its prevalence in Italy is esteemed to be similar of that of aphasia (Volta et al., 2001). Instead, Down syndrome was chosen because it is a rare condition (Lanzoni et al., 2019), unlike aphasia, and it can involve communicative disturbances (Abbeduto et al., 2007), including aphasia. Furthermore, the respondents, who reported to have heard of aphasia, were asked about the source of such information.

## *General Knowledge*

To assess the general knowledge of this condition, in the last section the panel of experts identified ten yes/no questions regarding aphasia. Three questions focused on etiology and epidemiology, four on clinical features, such as concurrent motor and cognitive deficits, and three of them on aphasia related outcomes. In particular, the respondents were asked about language recovery, driving permission and working reintegration. The list of the questions is available in **Appendix A**. The relevant topics were selected during A.IT.A. meetings and took into consideration PWA suggestions. They identified as particularly important the fact that aphasia by itself is not characterized by intelligence or memory impairment, and their difficulties in regaining a fully active social and working life. Due to the heterogeneity and variability of the A.IT.A. group, the conversation about these topics was informal and neither qualitative analysis nor documentation of this process is available.

## *Analysis*

All the variables were represented as categorical, so descriptive data were displayed as absolute number and frequency. To identify the demographic factors related with better understanding of aphasia the sample was grouped according to two dichotomous parameters: presence/absence of aphasia awareness (A+ vs. A-) and presence/absence of the knowledge of aphasia definition (D+ vs. D-). The Pearson's  $\chi^2$  test was used to assess possible significant differences between groups. Upon univariate analyses, the statistically significant variables of the univariate analyses were included in two logistic regression models, to identify the independent predictors respectively for aphasia awareness and for definition knowledge.

Adjusted odds ratios (OR) and 95% confidence intervals (CI 95%) were used as measures of effect. IBM SPSS Statistics® software (version 25.0) was used to perform all statistical analyses. The statistical significance was set at  $p < 0.05$ .

## Results

During a three-month period, 2181 records were collected. Four of them were excluded because the subjects were underage (<18 years of age), while the answers of five individuals were considered unreliable (awkward or unacceptable replies to the open questions regarding city or degree subject). Hence, a final sample of 2172 subjects was considered in the analysis. Direct messaging was the most frequent way to access the survey (89.5%), followed by social media (9.6%), while leafleting and face-to-face meeting strategies were much less common (0.5% and 0.4% respectively).

The majority of the participants were below 45 years of age with a peak in the range from 25 to 34 years (29.9%). The other age ranges were more homogeneous (14.7% for 18-24, 17.3% for 35-44, 16.4% for 45-54, 14.5% for 55-64), while the population over 65 years was less represented (7.3%). The female proportion in the sample was 73.3%. Regarding the geographical location, the majority of the respondents were resident in the North-West of the Country (61.3%), especially in Lombardy (42.4% of the overall sample), and 57.6% was resident in a province capital city. With respect to the occupation, 64.9% were workers, 16.3% were students, 8.7% were retired persons, 5.8% were homemakers, and 4.4% were unemployed. Most of the participants were graduates (54.6%), 36.6% completed high school, while lower education levels were less represented (<10%). Out of the overall sample, 1368

individuals (63.0%) had no relevant link with the healthcare system, 442 were HP (20.3%), and 362 were subsidiary, administrative or volunteer health workers (16.7%).

### *Awareness and Definition*

Within the overall sample, 1356 subjects (62.4%) declared to have heard of the term “aphasia” (A+), while 1264 identified the correct definition of aphasia among the alternatives (58.2% of D+).

The univariate analyses identified that all the considered demographic features significantly ( $p < 0.001$ ) differed between groups (A+ vs. A- and D+ vs. D-), as displayed in **Table 3**. In particular, in the groups that showed awareness and definition knowledge there was a significantly higher prevalence of people over 55 years of age or in the 25-34 range. Other factors more represented in A+ and D+ were female gender, university degree, link with healthcare system, and being HP. Moreover, health sciences graduates were significantly more likely to be A+ and D+, the humanities field subgroup did not differ from the overall distribution, while the graduates in economics, law or non-health sciences were more frequent in A- and D- groups. [Table 3 near here]

### *Sources of aphasia awareness*

Considering the 1356 A+ subjects, 49.7% reported that they had become aware of aphasia for work or study reasons, while 17.3% had a personal relationship with a PWA or a HP who worked with PWA. The remaining 33% affirmed to have heard of the term “aphasia” from the media (e.g., radio, television, written media, social networks) and, among these, the proportion of D+ was significantly lower in comparison with the other subgroups ( $\chi^2=67.020$ ;  $p < 0.001$ ).

### *Link with healthcare system*

Taking into account the sample without the HPs (n=1730), the proportions of A+ and D+ decreased to 53.1% and 47.9% respectively. Moreover, with such sample, the univariate analyses regarding the factors associated with aphasia awareness and definition knowledge, confirmed the results based on the overall sample ( $p < 0.001$ ; data not presented). However, analyzing the population of non-HP that declared to have heard the term “aphasia” (n=918), no significant difference regarding the knowledge of definition was found between those who had a link with healthcare system and those who did not ( $\chi^2=0.205$ ;  $p=0.651$ ).

### *Independent predictors of aphasia awareness and knowledge*

A few variables were not included in the logistic regression models, for specific reasons. In particular, the information regarding the geographical location was excluded due to the wide inhomogeneity of the overall distribution. Considering the high prevalence of graduates, only the dichotomous variable about university degree was considered as representative for education area. Finally, the variable regarding the university field was excluded, in order not to affect the entire sample. The logistic regression analyses (**Table 4**) identified age over 55 years, female gender, university degree, link with healthcare system and being HP as significant independent predictors for both A+ model and D+ model (all  $p < 0.001$ ). [*Table 4 near here*]

### *Comparison with other medical conditions*

About the awareness of the three considered medical conditions, the proportions of the overall sample were 97.9% for celiac disease, 99.5% for Down syndrome, and 62.4% for aphasia, as mentioned above. Considering the knowledge of the definition of these pathological conditions, the rates were 97.1%, 92.3%, and 58.2% respectively.

### ***General Knowledge***

The questionnaire results about the general knowledge of aphasia and the identification of the right answers are reported in **Table 5**. More than 50% of the participants answered correctly the questions regarding: driving license withdrawal, recovery, memory deficits, aphasia not being a developmental disorder and aphasia prevalence. Among the respondents, 48.1% stated correctly that aphasia is not itself characterized by intelligence impairment and 39.4% identified stroke as the main cause of aphasia. Almost one in four subjects could place the higher incidence of aphasia after 50 years of age (25.5%) and identified correctly the common association between aphasia and motor impairment, i.e., hemiplegia (26.5%). Just one respondent in ten recognized that usually people with aphasia could not restore their previous occupational status (10.9%). [*Table 5 near here*]

Overall, 4.6% of the sample (100 subjects) answered correctly all ten questions in the questionnaire. Within this group, 73 respondents were HP, while the other 27 (1.2% of the global sample) were characterized as follow: equally distributed considering age, 16 women vs. 11 men, 14 graduates vs. 13 non-graduates; 12 with a link to healthcare system vs. 15 with no link.

### **Discussion**



This study presents the results of a preliminary survey about aphasia awareness and knowledge in Italy. The choice of delivering an online survey with a snowball sampling led to a vast sample of respondents who, however, cannot be considered representative of the Italian population. In particular, most of the participants were young adults, graduates and health workers. Nevertheless, interesting findings and hints for further inquiries emerged from the research. Moreover, the choice of an online distribution is coherent with the progressive public interest for online resources and it revealed to be an effective strategy for rapidly collecting a large amount of records.

Awareness campaigns regarding certain diseases or clinical conditions have allowed people who do not have direct knowledge of the issue, to be familiar with it. Unfortunately, the aphasic condition, although its incidence is higher than that of other disorders, is still too poorly known. In agreement with the previous literature, despite a different survey method, the levels of awareness and knowledge were found to be inadequately low. Aphasia awareness was present in 62.4% of the sample, the knowledge of its definition in 58.2%, while a complete general knowledge just in 4.6% (**Table 6**). These findings set the need for a revised survey on a systematic sample of the Italian population and for in-depth researches on specific categories of health workers. [*Table 6 near here*]

### ***Aphasia awareness and knowledge rates***

#### *Awareness*

In comparison with the previous international surveys, the result regarding the rate of aphasia awareness was comparable, although it placed Italy among the countries with a higher level of awareness, such as Sweden (Henriksson et al., 2019), Norway and Greece (Code et al., 2016). This finding seemed to be valid considering both the overall sample (62.4% of A+)

and the sample without the HPs (53.1%). As for the notion of “basic knowledge”, which is not always univocally described in the previous literature, in the present study it was split into the knowledge of the definition and a general knowledge, according to a 10-item questionnaire.

### *Knowledge of definition*

The knowledge of the definition of aphasia was found to be higher (58.2% of D+ in the overall sample; 47.9% in the sample without HPs) than in previous studies (Code et al., 2001; Simmons-Mackie et al., 2002; Chazhikat, 2011; Patterson et al., 2015; Vuković et al., 2017; Henriksson et al., 2019; Hill et al., 2019). However, unlike many other face-to-face surveys, the item regarding the definition in the present inquiry was not an open question but a multiple-choice one. This could have increased the chance of identifying the right answer for any respondent. A further possible explanation of this could rely on the snowball sampling method. In fact, such chain-distribution could have traced a community of people that share some information about this topic. Another reason for this common knowledge could be suggested by the fact that 91.2% of the sample had an education degree equivalent or superior to high school. In particular, in Italy the study of classical languages, such as Latin and Greek, is curricular in many high schools and university courses and it is therefore possible that the correct definition of “aphasia” could have been correctly identified through an etymological understanding of the term itself. It derives indeed from the Greek privative suffix “a-” and “-phásis” (speech), generally meaning “speechless” (Code, 2012). This argument about the etymology of “aphasia” has already been considered in a previous study (Code et al., 2016) to account for a higher knowledge rate in Greece.

### *General knowledge*

As for the level of general knowledge, the proportion of the sample that answered correctly all the questions of the proposed questionnaire was dramatically low: 4.6% of the overall population and 1.2% excluding the HPs. In comparison with the previous studies, the requirements of the present survey were more specific; however, proposing yes/no questions, the chance of receiving the right answers was higher. Furthermore, from the analysis of the results, the authors guess that a few questions might have been misinterpreted by some of the respondents, due to ambiguity or lack of details in their formulation. Looking at the information that was considered by the previous surveys as suggestive of a basic knowledge, i.e., etiology and concurrent cognitive impairments (Chazhikat, 2011; Henriksson et al., 2019), less than half of the respondents provided the correct answers. Although more than half of the respondents acknowledge that complete recovery is rare, even after the rehabilitation treatment (Basso & Marangolo, 2000), the question about this topic does not specify that it was intended to be focused on the rehabilitation in the post-acute phase. This ambiguity could have influenced the answers. Regarding the areas of knowledge in which the worst performances were registered, it should be highlighted that the majority of the sample did not recognize that aphasia is a condition that occurs more frequently in the late adulthood and that it is usually associated with motor deficits, i.e., hemiplegia. This lack of information could in particular imply negative consequences in terms of accessibility and physical/social barriers for PWA (Howe et al., 2008). However, since only 26.5% of the overall sample (including HPs) acknowledged the association between aphasia and motor impairment (Andelini et al., 2019), interpreting this question might be problematic because it could be unclear if it implies a causal or deterministic association between the two conditions. In that case the right answer would be the opposite. Moreover, just one in ten respondents acknowledged that PWA could not restore their previous occupational status, entailing a

severe misconception of this fragile community of people that might limit their social reintegration (Garcia et al., 2000).

Finally, although a direct comparison between the results and the reference literature (Simmons-Mackie et al., 2020) would be improper, due to the above-mentioned reasons, it could be said that the general knowledge of aphasia in Italy is poor too.

### ***Methodological considerations and perspectives for future inquiries***

As mentioned above, the choice of an online survey with a snowball sampling was a cost-effective and rapid strategy to retrieve a fairly large amount of data. This strategy, however, prevents the generalization of the results for the Italian population and a straightforward comparison with the international surveys. In comparison with the previous online surveys (National Aphasia Association, 2016, 2020), the present research analyzed the demographic factors possibly associated with aphasia awareness and investigated aphasia knowledge more thoroughly. To verify the present findings on a representative sample, the present questionnaire could be administered online or by telephone with a random sampling through a dedicated research agency (as performed for National Aphasia Association, 2016, 2020). In the case of a further distribution of this questionnaire some amendments would need to be considered. In particular, an open answer to the questions regarding the definition of aphasia and the other medical conditions could induce more reliable information. Furthermore, a general reformulation of the ten questions about the general knowledge would need to be conducted. Adverbs of frequency should be avoided and general questions (e.g., on recovery or on associations of symptoms) should be clarified through specifications. Another option for investigating aphasia public awareness in Italy could be to perform an Italian adaptation of Code et al (2001), with a face-to-face interview in public places, as described for other

international inquiries (Simmons-Mackie et al., 2020). Moreover, the present findings highlight a poor level of awareness and knowledge, even within the significant sample of HPs, which suggests the advisability to test such constructs more thoroughly in the healthcare professional environment by means of specific future inquiries.

### ***Factors associated with aphasia awareness and knowledge***

In the present survey, possible demographical features associated with better aphasia awareness and knowledge were investigated. Since the distribution of the participants was not homogeneous to the national population, due to the sampling method, these results should be considered with caution. However, factors that emerged as significantly associated were in accordance with the reference literature. In particular, older age (Simmons-Mackie et al., 2002; Patterson et al., 2015; Code et al. 2016; Henriksson et al., 2019), female gender (Simmons-Mackie et al., 2002; Maviş, 2007; Patterson et al., 2015; Code et al. 2016; Vuković et al., 2017), higher education (Maviş, 2007) and being a health professional (McCann et al., 2013; Patterson et al., 2015; Code et al. 2016) were identified as independent predictors for being A+ and D+. Similarly to some differences found among countries in the previous studies, also within this Italian sample some regional discrepancies regarding the proportion of A+ and D+ were found. Interestingly, having a link with the healthcare system was also associated with a better awareness, however, excluding HPs (i.e., physicians, psychologists, nurses and allied health professionals), the subsidiary, administrative or volunteer health workers did not show a better knowledge of aphasia definition in comparison to those who did not have any link with the healthcare system. This alarming finding is coherent with previous works (Law et al., 2010; McCann et al., 2013; Guo & Lim, 2018; Anderle et al., 2019) and suggests that even among health and social care providers the

knowledge of aphasia is limited. Furthermore, the results of the ten-item questionnaire highlighted that these care workers may have little or no concept of the possible obstacles faced by someone who struggles with oral and written language and communication issues. These data seem to confirm the conclusions of a previous inquiry (Parr, 2007), conducted on a sample of twenty PWA through participants' observation and interviews, that underlined a lack of knowledge and competence among carers and welfare services. This issue appears even more burdensome considering that care assistants are commonly the daily medium for interpersonal interactions of PWA and elderly people. Moreover, in hospitals and other care facilities the assistance for the daily activities, including communication, is usually delegated to subsidiary health workers, which appear not to be adequately trained with regard to aphasia.

#### ***Possible implications for the healthcare system***

These findings ground the need for specific training programs for the above-mentioned categories of workers, in order to improve the standards of health and welfare services and to enhance the possibility and quality of participation for PWA. Such formal training might also increase the confidence, self-efficacy and communication competence of the recipients and, as a result, it would strengthen the involvement of PWA in their own healthcare decisions (Cameron et al., 2018). A number of studies attested optimistic results of education programs about aphasia with medical students (Forsgren et al., 2017) and emergency workers, such as police officers, fire fighters and paramedics (Baig, 2011; Ganzfried & Symbolik, 2011; Ranta, 2013; Togher et al., 2013).

#### ***Sources of aphasia awareness***

Reliable data regarding the source of information about aphasia are difficult to trace and their distribution is strictly related to the sample population. Therefore, a comparison with the reference literature (Code et al., 2016; Vuković et al., 2017; Henriksson et al., 2019) is poorly revealing, although the present results seem consistent with those reported by McCann and colleagues (McCann et al., 2013), identifying work and study as the main sources of awareness and knowledge. Considering the relationship between the source of information and the knowledge of aphasia definition, it should be highlighted that the proportion of D+ was significantly lower among those who have heard of the term “aphasia” from the media, in comparison with the other sources. Hence, it could seem that mass media, such as radio, television, newspaper and social networks, delivered defective and unreliable information about aphasia. This hint is in agreement with previous researches about the media coverage of aphasia (Elman et al., 2000; Sherratt et al., 2011). In particular, Sherratt (2011) showed how written media, published in English in 1999 and in 2009, lacked details about the characteristics, recovery, personal and social consequences of aphasia.

### ***Comparison with other medical conditions***

These studies (Elman et al., 2000; Sherratt et al., 2011) suggested that aphasia was less represented in social media in comparison with other pathological conditions. Coherently, the present results showed that the rates for aphasia awareness and knowledge were lower than those for celiac disease, which has a comparable prevalence in Italy, and for Down syndrome, which is a rare condition. It can be suggested that the reason for these differences lies on a widespread representation of both celiac disease and Down syndrome, unlike aphasia. In particular, it has been reported that celiac disease has a broad social and traditional media

coverage and gluten-free products are strongly advertised (Niland & Cash, 2018). Also Down syndrome is described to be vastly acknowledged by general population, due to the diffusion of genetic screenings during pregnancy in many Counties (Wardell et al., 2014). Similar findings regarding a minor consideration of aphasia were reported in previous surveys (Ni Dhonnabhàin, 2003; Flynn et al., 2009; McCann et al., 2013), although they investigated the comparison with other medical conditions and on different population samples.

### ***Possible implications for the research agenda in aphasia awareness***

Even if the data regarding the source of information, the coverage of aphasia in mass media and the contrast with other clinical entities should be carefully weighted, the public representation of aphasia is a crucial element for supporting PWA social reintegration and for promoting aphasia advocacy (Elman et al., 2000; Simmons-Mackie et al., 2020). A greater visibility for this condition might lead to increase funding campaigns for patients' associations, community interventions and clinical research (Elman et al., 2000).

Approaching this topic from the patient perspective, it should be highlighted that it is much more difficult for PWA to advocate for themselves, in comparison with other minorities due to their communication impairment (Elman et al., 2000). Furthermore, Howe and colleagues (2008) reported that PWA identified aphasia awareness as the main environmental factor that could be barrier or facilitator in their community participation, within the International Classification of Functioning, Disability and Health (ICF) framework. In this inquiry, negative opinions and inadequate behaviors, driven by the lack of attention towards this condition, were themselves pointed out as barriers by PWA. They reported that many objects, such as timetables, Automated Teller/Ticket Machines, signals, supermarket shelves, are not designed in an accessible way for them (physical barriers). PWA also highlighted that the



majority of public services, policies and procedures are difficult to access for them, since often allowing limited time for interaction, requiring abilities in reading or writing, and being mediated by staff that is unprepared to adequately communicate with PWA (societal barriers).

In such context, the involvement of people living with aphasia and their associations (e.g., A.IT.A. in Italy) in research and in advocacy campaigns is crucial for targeting the population needs (Simmons-Mackie et al., 2020).

## **Conclusions**

This preliminary survey about aphasia awareness and knowledge in Italy highlighted that the proportion of the sample that have heard the term “aphasia” and shown basic knowledge of its definition and main characteristics, is comparable with previous literature and is inadequately low. In particular, poor recognition was found regarding the social consequences of aphasia. Concerning the demographical characteristics of the respondents, older age, female gender, higher education, and being a health professional seem to be positively associated with a better understanding of this condition. These results set the need for further inquiries on Italian population and for specific actions to improve aphasia awareness in support of PWA social participation. Consequently, the effects of information may improve indirectly the quality of life of PWA and their families, especially in the chronic phase.

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**Appendix A.** English translation of the Italian Aphasia Awareness Survey (IAAS) questionnaire.

Please take a few minutes to complete the following survey. All of the responses will be anonymous and they will be reported in aggregate form only. We kindly ask not to search for the correct answers while responding.

**Demographics section**

How did you find out about the present survey? *Direct messaging system / social network / leaflet / face-to-face meeting / other (please write)*

How old are you? *<18 (end of the survey) / 18-24 / 25-34 / 35-44 / 45-54 / 55-64 / ≥65*

Please select your gender. *Male / female*

Please select the region of your residence. *List of the Italian regions and “abroad” option*

Please write the name of your municipality of residence. *Open answer*

Please select your occupational status. *Student / worker / unemployed / homemaker / retired person / other (please write)*

Please select your education level. *None / Primary school / Middle school / High school / Bachelor or Master Degree / PhD or medical specialization*

(For graduates only) Please write your degree subject. *Open answer*

Do you have a professional link with the healthcare system? *Yes/No*

If yes: *I am a Health Professional (i.e., physician, psychologist, nurse, allied health professional) / I am a subsidiary health worker / I am a personal care assistant / I work in a hospital as an administrative or technical worker / I serve as a volunteer / other (please write)*

**Awareness and Definition section\***

Have you ever heard of the term “celiac disease”? *Yes/No*

If so, select the definition that seems more appropriate. *Immune-mediate food intolerance* / *Sight disease / Behavioral disorder / Motor speech disorder / Congenital skin condition / Balance disorder / I don't know*

Have you ever heard of the term “Down syndrome”? *Yes/No*

If so, select the definition that seems more appropriate. *Genetically determined intellectual disability* / *Motor neurone disease / Pervasive developmental disorder / Dementia / Postnatal brain damage / Inflammatory bowel disease / I don't know*

Have you ever heard of the term “aphasia”? *Yes/No*

If so, select the definition that seems more appropriate. *Acquired language disorder* / *Progressive sight loss / Respiratory illness / Systemic cardiovascular disease / Personality and mood disorder / Ear disorder / I don't know*

How did you come across the term “aphasia”? *Because of my work / Because of my education / Because I know a person with aphasia / Because I know a health professional who works with persons with aphasia / Because I heard it or read it in the media (television, radio, newspaper, social networks) / other (please write)*

\* The right answers are underlined. Multiple choice options were automatically randomized.

## General Knowledge section

1. Does aphasia determine the definitive driving license withdrawal? *Yes/No*
2. Is aphasia a rare disease? *Yes/No*
3. After six months of intensive rehabilitation, do people with aphasia display a full recovery of their premorbid linguistic proficiency? *Yes/No*
4. Is aphasia always associated with memory deficit? *Yes/No*
5. Is aphasia a developmental disorder? *Yes/No*
6. Does aphasia always determine an “intelligence impairment”? *Yes/No*
7. Is stroke the main cause of aphasia? *Yes/No*
8. Is aphasia usually associated with motor impairment? *Yes/No*
9. Is aphasia more frequent after 50 years of age? *Yes/No*
10. Is it difficult for people with aphasia to restore their previous occupational status? *Yes/No*

\* The right answers are underlined. The order of the questions was automatically randomized.

**Table 1.** Summary of the previous studies regarding aphasia public awareness and knowledge that used Code et al. (2001) questionnaire or an adapted version with a face-to-face interview on general population.

Study/Year	Location	Sample	Awareness (%)	Basic Knowledge* (%)
Code et al. 2001	UK (Exter)	378	18	7.7
	Australia (Sydney)	159	12	7.5
	US (Louisiana)	389	10.3	1.5
Simmons-Mackie et al. 2002	US (North California)	52	17.3	11.5
Kent et al. 2006	US (Honolulu)	85 <sup>a</sup>	16.4	3.5
Chazhikat et al. 2011	India (Kerala)	114	11.4	8.7
McCann et al. 2013	New Zealand	300 <sup>b</sup>	30	8
Patterson et al. 2015	Canada (Ontario)	831	31.8	5.7
Code et al. 2016	Norway	251	57.4	13.9
	Greece	800	46	10.6
	Croatia	400	60	7.0
	Slovenia	400	16	4.5
	Canada	831	31.8	5.7
	Argentina	800	20	1.0
Vukovic et al. 2017	Serbia	400	12	4
	Montenegro	500	11	3.2
Guo et al. 2018	Singapore	100 <sup>c</sup>	14	11
Guinan et al. 2019	Ireland	155 <sup>d</sup>	9.68	3.23
Henriksson et al. 2019	Sweden	372	66	17
Hill et al. 2019	UK (Exter)	167	34	5

\* Respondents were defined to possess “Basic Knowledge” if they reported that aphasia specifically involves speech, language, and/or communication problems and that aphasia is caused by a brain damage. <sup>a</sup>: Chinese speaking population. <sup>b</sup>: General population and Health workers recruited in hospitals. <sup>c</sup>: General population recruited in hospitals. <sup>d</sup>: Hospitality industry students (self-administered questionnaire).

**Table 2.** Summary of the previous studies regarding aphasia public awareness and knowledge that used different survey strategies.

Study/Year	Location	Sample	Awareness (%)	Knowledge/Definition (%)	Notes
Speakability 2000 (cit. in Code et al. 2001)	UK	1005	ne	3 <sup>a</sup>	General population (phone interview)
Ni Dhonnabhàin 2003	Ireland	300	13.3	9.3 <sup>b</sup>	College students (self-administered questionnaire)
Maviş 2007	Turkey	196	34.2	ne	General and hospital population (self-administered questionnaire)
Flynn et al. 2009	UK	126	ne <sup>c</sup>	ne <sup>c</sup>	General population and carers (face-to-face interview)
Mahima et al. 2016	India (Kerala)	189	48	ne	General youth population (face-to-face interview)
NAAS 2016	US	1142	15.5	8.8 <sup>a</sup>	General population (online survey)
NAAS 2020	US	1001	13.8	7.1 <sup>a</sup>	General population (online survey)

<sup>a</sup>: Respondents were defined to possess “Knowledge of definition” if they reported that aphasia is a language disorder. <sup>b</sup>: Respondents were defined to possess “Basic Knowledge” if they reported that aphasia specifically involves speech, language, and/or communication problems and that aphasia is caused by a brain damage. <sup>c</sup>: The results of the questionnaire were reported as scores, therefore it is not possible to presents rates for awareness and knowledge.

**Table 3.** Results of the univariate analyses regarding aphasia awareness (A- vs. A+) and definition knowledge (D- vs. D+). Data are presented as absolute frequency and percentage.

Independent variables	Awareness			Definition		
	A- 816 (37.6%)	A+ 1356 (62.4%)	Test	D- 908 (41.8%)	D+ 1264 (58.2%)	Test
Age			$\chi^2=22.204$ p<0.001			$\chi^2=21.101$ P=0.001
18-24	141 (44.2%)	178 (55.8%)		155 (48.6%)	164 (51.4%)	
25-34	220 (33.8%)	430 (66.2%)		244 (37.5%)	406 (62.5%)	
35-44	164 (43.7%)	211 (56.3%)		179 (47.7%)	196 (52.3%)	
45-54	139 (39.0%)	217 (61.0%)		155 (43.5%)	201 (56.5%)	
55-64	99 (31.5%)	215 (68.5%)		116 (36.9%)	198 (63.1%)	
+65	53 (33.5%)	105 (66.5%)		59 (37.3%)	99 (62.7%)	
Gender			$\chi^2=44.366$ p<0.001			$\chi^2=55.836$ p<0.001
Male	284 (49.1%)	295 (50.9%)		318 (54.9%)	261 (45.1%)	
Female	532 (33.4%)	1061 (66.6%)	590 (37.0%)	1003 (63.0%)		
NUTS1			$\chi^2=32.324$ p<0.001			$\chi^2=38.287$ p<0.001
North-West	464 (34.8%)	868 (65.2%)		520 (39.0%)	812 (61.0%)	
North-East	112 (35.6%)	203 (64.4%)		121 (38.4%)	194 (61.6%)	
Center	57 (35.6%)	103 (64.4%)		62 (38.8%)	98 (61.3%)	
South	127 (50.4%)	125 (49.6%)		142 (56.3%)	110 (43.7%)	
Islands	44 (46.3%)	51 (53.7%)		51 (53.7%)	44 (46.3%)	
Abroad	12 (66.7%)	6 (33.3%)		6 (33.3%)	12 (66.7%)	
Residence			$\chi^2=31.889$ p<0.001			$\chi^2=32.716$ p<0.001
Province capital	407 (32.5%)	844 (67.5%)		458 (36.6%)	793 (63.4%)	
Smaller town/city	409 (44.4%)	512 (55.6%)	450 (48.9%)	471 (51.1%)		
Education			$\chi^2=242.024$ p<0.001			$\chi^2=221.691$ p<0.001
None	1 (100.0%)	0 (0.0%)		1 (100.0%)	0 (0.0%)	
Primary school	7 (87.5%)	1 (12.5%)		7 (87.5%)	1 (12.5%)	
Middle school	126 (68.5%)	58 (31.5%)		132 (71.7%)	52 (28.3%)	
High School	398 (50.1%)	396 (49.9%)		427 (53.8%)	367 (46.2%)	
Bachelor/Master	266 (25.7%)	771 (74.3%)		321 (31.0%)	716 (69.0%)	
PhD	18 (12.2%)	130 (87.8%)		20 (13.5%)	128 (86.5%)	
Graduation			$\chi^2=205.726$ p<0.001			$\chi^2=181.941$ p<0.001
No	532 (53.9%)	455 (46.1%)		567 (57.4%)	420 (42.6%)	
Yes	284 (24.0%)	901 (76.0%)	341 (28.8%)	844 (71.2%)		
University Field*			$\chi^2=235.215$ p<0.001			$\chi^2=290.793$ p<0.001
Health Sciences	28 (4.9%)	539 (95.1%)		39 (6.9%)	528 (93.1%)	
Other Sciences	116 (49.2%)	120 (50.8%)		131 (55.5%)	105 (44.5%)	
Humanities	46 (25.3%)	136 (74.7%)		58 (31.9%)	124 (68.1%)	
Economics/Law	94 (47.0%)	106 (53.0%)	113 (56.5%)	87 (43.5%)		
Healthcare link			$\chi^2=310.556$ p<0.001			$\chi^2=325.045$ p<0.001
No	706 (51.6%)	662 (48.4%)		772 (56.4%)	596 (43.6%)	
Yes	110 (13.7%)	694 (86.3%)	136 (16.9%)	668 (83.1%)		
HP			$\chi^2=318.044$ p<0.001			$\chi^2=369.003$ p<0.001
No	812 (46.9%)	918 (53.1%)		901 (52.1%)	829 (47.9%)	
Yes	4 (0.9%)	438 (99.1%)	7 (1.6%)	435 (98.4%)		

\* Data available for the graduate participants (n=1185). NUTS1 = Nomenclature of Territorial Units for Statistics (groups of regions); HP = Health Professional.

**Table 4.** Results of the logistic regression models for aphasia awareness (Outcome A+) and for the knowledge of the definition (Outcome D+).

Predictor	Outcome A+			Outcome D+		
	OR	95% CI Lower-Upper	p	OR	95% CI Lower-Upper	p
Age						
18-24			0.000			0.000
25-34	0.78	0.56-1.09	0.145	0.85	0.61-1.18	0.323
35-44	0.79	0.56-1.12	0.194	0.82	0.58-1.15	0.248
45-54	1.25	0.88-1.76	0.216	1.22	0.86-1.72	0.262
55-64	2.30	1.60-3.30	0.000	2.08	1.46-2.96	0.000
+65	2.15	1.39-3.33	0.001	2.15	1.40-3.32	0.000
Gender						
Female/Male	1.50	1.21-1.87	0.000	1.65	1.33-2.06	0.000
University Degree						
Yes/No	2.70	2.15-3.38	0.000	2.17	1.74-2.70	0.000
Link with Healthcare						
Yes/No	2.85	2.19-3.72	0.000	2.51	1.95-3.22	0.000
HP						
Yes/No	27.64	9.95-76.76	0.000	23.48	10.66-51.70	0.000

The model for A+ yielded a Nagelkerke R-squared coefficient that explains the 34.1% of the variance, while the same coefficient for D+ model account for the 34.3%. OR = Odds Ratio; CI = Confidence Interval; HP = Health Professional.



**Table 5.** Results of the yes/no questionnaire about the general knowledge of aphasia. Questions are ordered according to the rate of right answers. Data are presented as absolute frequency and percentage.

<b>Question – Correct answer</b>	<b>Correct Answer (n=2172)</b>
Does aphasia determine the definitive driving license withdrawal? – <i>No</i>	1220 (56.2%)
Is aphasia a rare disease? – <i>No</i>	1218 (56.1%)
After six months of intensive rehabilitation, do people with aphasia display a full recovery of their premorbid linguistic proficiency? – <i>No</i>	1156 (53.2%)
Is aphasia always associated with memory deficit? – <i>No</i>	1148 (52.9%)
Is aphasia a developmental disorder? – <i>No</i>	1127 (51.9%)
Does aphasia always determine an “intelligence impairment”? – <i>No</i>	1053 (48.5%)
Is stroke the main cause of aphasia? – <i>Yes</i>	856 (39.4%)
Is aphasia usually associated with motor impairment? – <i>Yes</i>	575 (26.5%)
Is aphasia more frequent after 50 years of age? – <i>Yes</i>	553 (25.5%)
Is it difficult for people with aphasia to restore their previous occupational status? – <i>Yes</i>	236 (10.9%)

**Table 6.** Summary of the results of the present study.

<b>Sample</b>	<b>Overall sample (n=2172)</b>	<b>Sample without HP (n=1730)</b>
Awareness	62.4%	53.1%
Knowledge of definition	58.2%	47.9%
General Knowledge	4.6%	1.2%

\*HP: Health Professionals

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