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PUBLIC AWARENESS OF APHASIA

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“Language is the armory of the human mind, and at once contains the trophies of its past and the weapons of its future conquests.”

-Samuel Taylor Coleridge

PUBLIC AWARENESS OF APHASIA

SARAH JANE JENKINS

ABSTRACT

Aphasia is an acquired communication disorder that affects portions of the brain responsible for language processing and production. It is a disorder that occurs secondary to strokes and other traumatic brain injuries. It is estimated that almost 1 million people in the United States have aphasia. However, there has been very little research regarding public awareness of aphasia, particularly among service-industry workers.

The purpose of this study was to analyze the level of public awareness of aphasia in Cleveland, Ohio. This study investigated 100 individuals' knowledge of aphasia by way of a questionnaire, with a focus on respondents who were employed within the public-service sector. Participants were recruited from public areas in Cleveland, Ohio, and filled out a 6-item survey. The responses were then analyzed using quantitative procedures and compared to other existing studies on aphasia awareness. Several categorical variables and their relationship to aphasia awareness were examined to determine if any statistically significant findings existed.

Out of the individuals surveyed, 19% had heard of aphasia. The results indicated there was a statistically significant relationship between the age of respondents and aphasia awareness. The education level of respondents also had an impact of aphasia awareness. Occupation, income level, and gender did not appear to have an impact on aphasia awareness. Respondents aged 36-55 years had the highest aphasia awareness rates, and adults ages 56-65 years had the lowest rates of aphasia awareness. Since stroke and aphasia are so closely linked, it is critical to improve public awareness among all age

groups, particularly older populations. This can be achieved through education, advocacy and job training.

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CHAPTER I

LITERATURE REVIEW

Aphasia is an acquired communication impairment that affects an individual's ability to process language. It is generally defined as a language impairment affecting one or more of the four language modalities: speaking, understanding language, reading and writing. Aphasia usually occurs secondary to a stroke, along with other brain injuries that affect the language areas of the brain. According to the National Aphasia Association (NAA), aphasia affects about one million Americans, or one in two hundred and fifty people, and is more common than Parkinson's disease, cerebral palsy or muscular dystrophy (NAA, 2010). More than 100,000 Americans acquire this disorder each year. Despite its prevalence, research exploring public awareness of aphasia has historically been under-reported.

A review of pertinent literature has failed to reveal any significant research in this area. Little has been done in educating populations who may frequently come into contact with people with aphasia, such as service industry workers. Given the high incidence of aphasia, particularly secondary to stroke, the lack of research on public awareness of aphasia and its related deficits demonstrates that a need for advocacy and education

exists, particularly for workers within the public service sector. With proper training and education about aphasia and its related deficits, these workers have the potential to facilitate the rehabilitation efforts of individuals with aphasia. In order to increase public advocacy of aphasia, policy leaders, educators, and the general community need to understand how social reintegration and active community involvement are key factors in psychosocial approaches to therapy and rehabilitation for individuals with aphasia.

Communication is intrinsically woven into the fabric of relationships, personal development, identity, and social interactions (Brown, McGahan, Alkhaledi, Seah, Howe, Worrall, 2006). When communication is impaired, people with aphasia may feel excluded from a realm that was once very much a part of their lives, such as work, church, and social interactions with others. People's emotional health, language functioning, and functional communication abilities are largely predictive of their quality of life, which may affect rehabilitation (Cruice, Worrall, Hickson & Murison, 2003). Quality of life (QOL) is described as physical, social, mental health, and psychological well-being (Cruice et al). In order for people with aphasia to have meaningful, public interactions, it is important to advocate for the unique obstacles they face and to train public service sector employees so they may be better equipped to interact with individuals recovering from aphasia on a more personal, effective level.

In addition to mental and physical impairments, the contextual nature of QOL measurements can make determining specific factors that contribute to rehabilitation elusive. Faced with a limited amount of research, rehabilitation of people with aphasia continues to be client-driven, with less emphasis on empirical evidence and research (Code & Herrmann, 2003). Additionally, little research has been conducted into the

relationship between emotional and psychosocial factors and communication problems in this wide range of conditions (Code & Herrmann, 2003).

In an attempt to define QOL factors in relation to aphasia, Cruice et al. (2003) based their study of QOL on the World Health Organization's (WHO) framework for identifying the domains in which aphasia can be applied, using the *International Classification of Functioning, Disability, and Health* (ICFD). Using the guidelines set forth by the WHO and the ICFD, these authors created a conceptual and operational model for determining the impact on aphasia rehabilitation and QOL. Under this framework, the term "disability" is defined as "impairments, activity limitations and participation restrictions" (WHO, 2001). It denoted the negative aspects of the interaction between an individual with a health condition and the individual's contextual factors, such as environmental and personal factors (WHO, 2001). Using the term "aphasia" as a guideline, the characteristics of aphasia may typically fall into the ICFD's domains of disability definitions of activity, which is the execution of a task or action by an individual. Limitations are stated as difficulties an individual may have when performing that specific activity. Participation is defined as involvement in life situations, with limitations and problems an individual may experience while participating. Environmental factors consist of the physical, social, and attitudinal environment in which people live (WHO, 2001).

Cruice et al. (2003) recruited 30 participants with mild to moderate aphasia in order to gauge the relationship between various physical and mental impairments in relation to their overall well-being. The authors of this study used several measurements and assessments to analyze participants' QOL, including an abbreviated form of the

geriatric depression scale (GDS), the Short-Form-36 Health Survey (SF-36), the Dartmouth COOP Charts, and the “How I Feel About Myself” well-being scale. The results revealed that the QOL of people with aphasia encompassed several factors, including emotional health, language functioning, and functional communication. Additionally, it was noted that social participation played a powerful part in QOL and may impact improvement outcomes in therapy. (Cruice et al., 2003). Because social participation is such a major component in aphasia rehabilitation, it is important to advocate for people with aphasia by creating effective environments that facilitate participation and communication. Educating the public, in particular public service sector employees, about aphasia and its related deficits should be an important part of this effort.

To the public, aphasia is relatively unknown. This sentiment is further enforced by analyzing the data from several surveys that focused on individuals’ knowledge of aphasia. A survey conducted by Whitaker and Marshall (2011) studied the results of respondents who live in the “stroke belt,” a region in the southern portion of the United States of America. This area is usually defined to include the eight southern states of North Carolina, South Carolina, Georgia, Tennessee, Mississippi, Alabama, Louisiana, and Arkansas (American Heart Association, 2011). The state of Louisiana scored the lowest in regards to regional awareness, despite being designated as a “stroke belt” state (National Stroke Association, 2000). Out of 223 respondents, about half indicated they had heard of aphasia. Additionally, the survey explored respondents’ view of what causes aphasia, including stroke, impaired intelligence, and emotional and mental problems (Whitaker and Marshall, 2011). The results of this survey reflect the dire need for public

awareness of aphasia, especially in areas where strokes are prevalent. Another survey by Mackie, Code, Armstrong, Stiegler, & Elman (2002) gave 978 individuals a brief survey on whether the respondents had heard of aphasia, and if they had, to describe the condition. While 14% indicated they had heard of aphasia, only 5% were able to accurately describe the symptoms.

A disconnect between people with aphasia and the individuals close to them was explored by Mavis (2007). This study surveyed 196 participants consisting of people without aphasia and caregivers who were visiting the neurology unit of Osmangazi University Hospital in Eskisehir, Turkey. The results showed that epilepsy is the most commonly known disorder, followed by dementia, and stroke. Conversely, only one third of respondents had heard of aphasia. Unlike the American population, most Turkish people receive the majority of their health information from doctors, with radio and television taking second and third place. This study was unique in that it was one of the first in Turkey to explore the public's attitudes and awareness levels of neurologically-based disorders, including aphasia.

To date, limited studies have investigated awareness of aphasia among service industry workers. A survey by Brown, McGahan, Alkhaledi, Seah, Howe, and Worrall (2007) identified several key components noted by service workers that support and hinder community participation for people with aphasia. The participants were employed by a wide variety of industries, such as restaurant workers, retail associates, and bank tellers. Many respondents had never heard of aphasia until participating in the study. Despite their lack of familiarity with aphasia, all of the respondents expressed a desire to create awareness among their community. Many noted the need for community

awareness, staff training, and implementing adaptive measures, such as increased visual imagery in shopping centers and utilizing technology in the form of touch-screen menu systems. This study found that public service workers are willing to work with people with aphasia, and have a keen understanding of potential barriers and facilitators essential for community integration (Brown et al., 2006). Perhaps most importantly, the findings of this study noted that a lack of awareness about aphasia was the most commonly cited barrier to community participation for people with aphasia (Brown et al., 2006). Proper training in aphasia awareness for public service employees is a valuable link between the rehabilitation efforts of individuals of aphasia and their quality of life. It is also important to note that as of this writing, no other research studies focusing on aphasia awareness within the public service sector have been conducted in North America.

Why is there a lack of aphasia awareness among the public? Several studies have attributed this lack of public knowledge of aphasia to a variety of factors. Unfortunately, a major obstacle in promoting awareness lies within the term “aphasia” itself. Elman, Ogar, & Elman (2000) noted that while individuals with AIDS, cancer and heart disease are able to create a vocal and public persona for their disorder in order to secure funding and better services, people with aphasia do not have that option since their disorder affects language so profoundly. Because the term ‘aphasia’ is unfamiliar to the majority of the public, it is difficult to attach conditions and symptoms to a term that is largely unrecognizable to society. Without public awareness, there is less funding for research, less money for services, and less empathy and understanding for people with aphasia who are trying to reintegrate themselves into the community (Elman, Ogar, & Elman, 2000). Public awareness of aphasia and funding for research and services are closely

intertwined. In order to increase public awareness and advocacy of aphasia, it is critical to provide adequate funding for services and organizations that will create aggressive media campaigns needed to educate the public on aphasia, its related characteristics, and its causes.

Another reason for a lack of awareness of aphasia among the public can be attributed to incorrect or inadequate knowledge about the characteristics of aphasia. A survey conducted by Simmons-Mackie (2002) indicated that less than 6% of respondents who reported they had heard of aphasia met the criterion of having a basic knowledge of aphasia. This information demonstrates that knowledge of aphasia encompasses a variety of symptoms, many of which the public are not aware.

Increasing the public's knowledge of aphasia becomes even more critical to address when considering the link between stroke and aphasia. According to the National Aphasia Association, about 25-45% of stroke survivors acquire aphasia. Stroke is the third leading cause of death in the United States. Approximately 800,000 people suffer a stroke, with 600,000 people suffering a first-time stroke. (American Heart Association, 2012). This number is even greater among minority populations. Strokes affect African Americans twice as often as Caucasians, and Hispanics of Mexican origin have a higher incidence of intracerebral hemorrhage and subarachnoid hemorrhages than non-Hispanic whites (AHA, 2012). With stroke incidence increasing among minorities, it is critical to address aphasia awareness. A review of published studies and data from clinical trials found that hospital admissions for intracerebral hemorrhage have increased by 18% in the past 10 years (AHA, 2012). There are more than 6 million stroke survivors living in the United States. Men make up about 2,500,000 of survivors and women make up

3,900,000. About one-third have mild impairments, one-third are moderately impaired, and the remainder have severe impairments. (ASA, 2012). Increasing cerebral hemorrhage rates, paired with over half a million stroke survivors illustrate why the need for aphasia awareness and advocacy is critical. In order to adequately treat these individuals and prepare for the increase in strokes, the public needs to possess the necessary knowledge of aphasia to ensure that each individual is aware that aphasia is a significant and common aspect of stroke.

Emerging research has pointed to the benefits of psychosocial rehabilitation in regards to aphasia recovery. Rehabilitation that focuses on reintegrating individuals is largely dependent on the public's knowledge of aphasia. A study by Code (2003) noted the positive outcomes of raising the public's awareness level of aphasia. His study suggested the potential benefits of targeting public awareness, education, and the training of service providers who work in areas most frequented by people with aphasia. Code argued that these measures would help reduce the communication barriers individuals with aphasia frequently face outside of their homes and promote effective communication. In order to lead a fulfilling and meaningful life that complements a QOL service model and focuses on the psychosocial aspects of aphasia, it is crucial for individuals with aphasia to be reintegrated into society. This transition can be facilitated by educating the public about aphasia, particularly public service workers. A study by Code found that a large portion of people with chronic aphasia spent a significant amount of time at retail outlets and community facilities with family and friends. Further, Code noted that socially oriented approaches focused on social interactions in shops,

restaurants, pubs, and other commercial premises were important benefits related to a psychosocial approach for aphasia therapy.

There is no cure for aphasia. However, with frequent and intense therapy, aphasia and its related deficits can be managed. This present study is part of a larger study initiated by Code (2002) that seeks to establish global public awareness of aphasia. The purpose of this study is to demonstrate a need for aphasia awareness, both within the general public and among people who work in public-service industries. The results of this survey will serve as the catalyst for implementing public awareness of aphasia at the local and national levels. Along with promoting aphasia awareness, this survey analyzes the responses of individuals who work in the public service sector. When these employees are familiar with the symptoms of aphasia, social rehabilitation efforts are strengthened. These workers will be able to use communication strategies that facilitate better understanding between people with aphasia and service industry workers. By promoting increased public exposure to aphasia and its related deficits, aphasia awareness advocates, health professionals, relatives, and friends of people with aphasia will be able to lobby for the funds needed to provide programs to increase public knowledge of aphasia. Increased advocacy and awareness efforts from speech language pathologists, medical professionals, and others familiar with aphasia will also benefit the community by providing a voice for those who have been silenced by aphasia.

CHAPTER II

METHODS

Participants

One hundred participants from Northeast Ohio were administered a face-to-face survey on aphasia awareness. The ages of the participants ranged from 18-68 years of age. ($X=37.8$; $SD=11.6$). The six-section survey took approximately 3 to 5 minutes for respondents to complete, and the surveys were administered to participants from September 2011 to March 2012. The participants were recruited from a variety of public places by the surveyor, including restaurants, shopping plazas, public parks, and retail establishments. The surveys were administered on-site to willing participants. Institutional Research Board (IRB) approval was obtained from Cleveland State University to conduct this study. All participants received an informed consent form and checked a box that indicated he or she was willing to participate in the survey. This form also stated that all information provided was completely anonymous and confidential, and no names or identifying details were required to participate in this study

(See Appendix B).

The criterion for participating was determined by past and present occupation history. All participants were screened by the examiner prior to administration of the survey. This employment information is critical for ensuring that each participant meets the participation standards for this survey. In order to participate in this survey, each respondent must have worked or currently work in a public service-dominated industry. For the purposes of this study, a service-dominated industry is defined as any occupation where the primary job duties involve interaction with the public. Examples of service-oriented occupations include restaurant workers, civil-service employees, teachers, hair stylists, retail clerks, social workers, and service-industry managers.

Using this service-industry definition as a guideline, the surveyor then questioned each potential respondent about his or her current or past occupation. If the individual was employed in a service-oriented industry as determined by this definition, then he or she was asked to participate. Because the survey focused on service-related occupations and individuals who are currently employed in these industries, unemployed individuals were not included in this study. Similarly, if an individual's occupation did not fit the definition of a service-oriented industry, they were thanked for their time, and the surveyor gave a brief explanation of aphasia and the purpose of the study.

Procedures

The questions for this current survey were modeled after a similar questionnaire developed by Mackie, Code, Armstrong, Stiegler & Elman (2002). Since the original survey was developed using British English, this survey was revised to reflect Standard American English. In addition, the survey omitted details regarding how busy these public areas were during data collection, as well as a British aphasia organization. These

omissions were done to better reflect the population and demographics for this particular survey, which was conducted throughout Cuyahoga County in Northeast Ohio. For this study, a convenience sample method was utilized. The participants were interviewed in restaurants, shopping plazas, public parks, and retail establishments. Targeting areas where individuals with aphasia are likely to spend time outside of their home increases the likelihood of a service worker potentially coming into contact with a person with aphasia (Code, 2002).

This survey was comprised of six sections. The first section supplied demographic information such as gender, age, education level, occupation, and annual income. These questions were asked in order to determine if there was a correlation between these descriptors and an individual's knowledge of aphasia. The second section asked participants whether they had heard of aphasia. The participants who had not heard of aphasia were asked to define the term "stroke," along with whether they were aware of any communication problems following a stroke. For individuals who had not heard of aphasia, the survey was concluded after answering this question. If the respondent indicated that he or she had heard of aphasia, they then answered a series of questions in section three that assessed their knowledge of aphasia. Participants had the option of choosing "yes" "no" or "don't know" when answering questions on the characteristics of aphasia (speech problems, problems using and understanding language, reading, writing, and communication problems). Section four contained questions that measured the respondent's knowledge of what causes aphasia (brain damage, emotional problems, impaired intelligence, and mental problems). For these questions respondents could choose "yes," "no," or "don't know" when answering. In section five, participants were

asked to list how they had heard of aphasia (a relative or friend has aphasia, on the television or radio, a newspaper or magazine, or through work). Section six asked respondents whether or not anything could be done to help an individual with aphasia. Participants had the option of choosing “yes” or “no” to this question, in addition to filling out specific ideas for helping individuals with aphasia. (See Appendix A).

CHAPTER III

ANALYSIS

Descriptive data were compiled for the gender, age, and occupation for each survey respondent. Out of the hundred respondents, 50% were female, and 50% were male. The age range of the respondents was 18-68 years, and the mean age of the respondents was 37.8. This number matches closely to the average age of Cuyahoga county residents (40.2), the largest county in Northeast Ohio (U.S. Census, 2012). For this survey, 84% of the respondents were Caucasian, 6% were African American, 4% were Asian, and 4% identified as non-white Hispanic. Two percent of respondents identified as 'other,' listing two or more races on the survey. The racial analysis of the respondents is also representative of the 2010 census data on Cuyahoga County. In 2010, 62.6% of residents were Caucasian, 29.7% were African American, 4.8% were Hispanic, 2.6% were Asian, and 2.1% were two or more races (See figure 1).

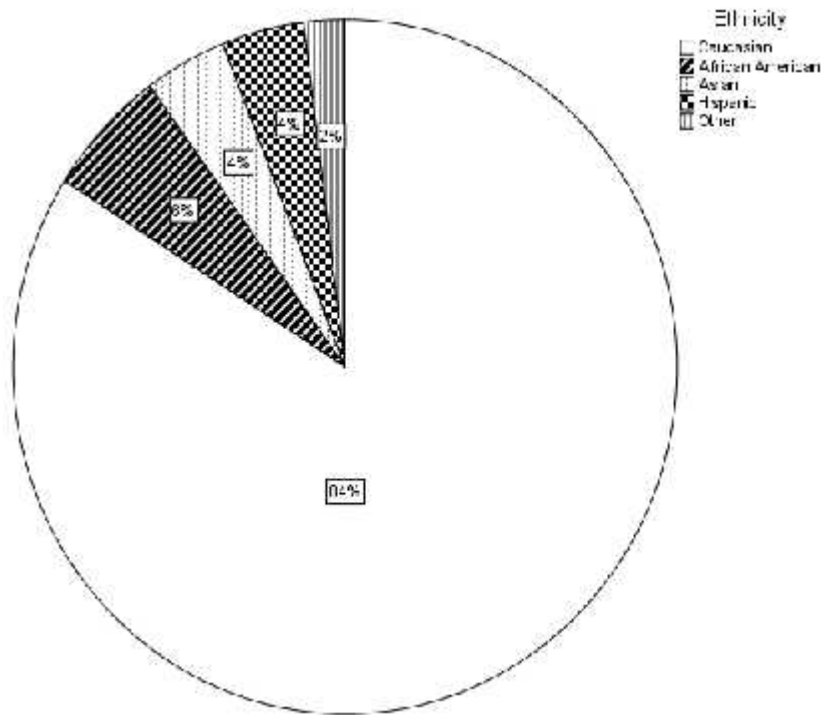


Figure 1. Ethnic profile of survey respondents

Occupations listed by the respondents were arranged into 10 categories: food/restaurant industry, civil service employees, educators, salon services, social workers, banking/financial services, managers/business owners, retail sales, healthcare, and other. The ‘other’ group included service-oriented occupations that had less than two respondents representing a particular occupation category. Three percent of the respondents were retired from service-related industries, while the remaining respondents were employed (See table 1).

Industry Breakdown	Have you heard of Aphasia?		Total
	Yes	No	
Total			
Food Industry	4%	22%	26%
Civil Service	3%	7%	10%
Education	5%	4%	9%
Salon/Hair Services	1%	5%	6%
Social Workers	2%	5%	7%
Bank/Financial Services	0%	3%	3%
Managers/Business Owners	0%	14%	14%
Retail/Sales	3%	12%	15%
Healthcare	0%	5%	5%
Other	1%	4%	5%
	19%	81%	100%

Table 1. Industry breakdown of survey respondents

Of the 10 industry categories represented in this survey, 26% of the respondents worked in the food/restaurant industry, 15% worked in retail or sales, 14% were business owners or managers, 10% were civil servants, 9% were educators, 7% were social workers, 6% were employed by salons or worked as barbers, 3% worked in banking or finance, 5% worked in healthcare, and 5% were categorized as ‘other’ service occupations, respectively (See figure 2).

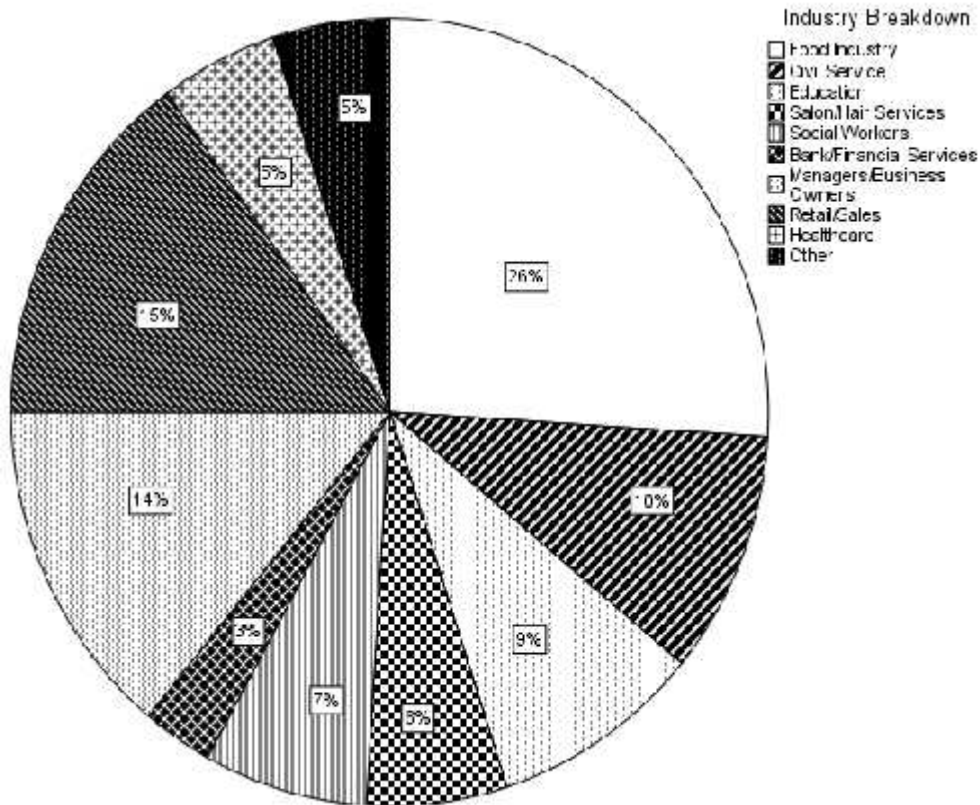


Figure 2. Industry breakdown of survey respondents

The education levels of survey respondents were widely represented, with 34% of participants indicating a high school degree as their highest education level. Respondents who earned a bachelor’s degree accounted for 24% of the sample population, and 16% had associate’s degrees. Nine percent had earned a master’s degree and received vocational training, respectively, and 6% had attended school until the eighth grade. Two percent of survey respondents had earned a doctorate degree. Education levels represented in this survey directly reflect the statistics gathered for the 2010 Census. In Cuyahoga County, Ohio, 28% of residents had earned a bachelor’s degree, and 86% had completed high school. Additionally, 11% of Cuyahoga county residents had earned a master’s degree or higher (U.S. Census, 2010) (See figure 3).

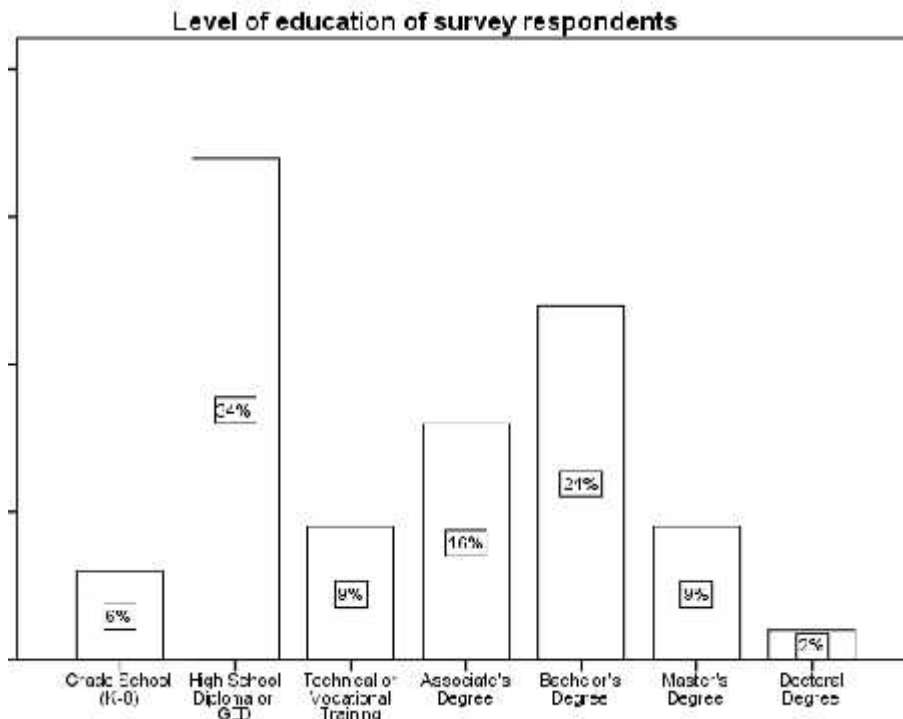


Figure 3. Education levels of survey respondents

Aphasia awareness analysis

For this survey, 19% of respondents indicated they had heard of aphasia (See Table 1). Out of the 19% of respondents who stated they had heard of aphasia, 58% of respondents were aware that aphasia causes problems understanding the speech of others, and 84% knew that aphasia contributed to language problems. Only 79% knew that aphasia was caused by brain damage, and 16% of respondents did not know what causes aphasia. Fifty seven percent of respondents stated that aphasia causes writing problems, and 47% knew that aphasia also causes deficits in reading (See table 2).

Aphasia Awareness Analysis						
Defining Aphasia Characteristics						
	Yes		No		Don't Know	
	Number	Percent	Number	Percent	Number	Percent
Problems using language	16	84%	1	5%	2	10%
Problems understanding the speech of others	11	58%	6	32%	2	10%
Does brain damage cause aphasia?	15	79%	1	5%	3	16%

Table 2. Defining aphasia characteristics used in this study

Thirty two percent of 36-45 year-olds and 46-55 year-olds indicated they had heard of aphasia. Eleven percent of 56-65 year-old respondents had heard of aphasia, and 26% percent of 26-35 year-old respondents had heard of aphasia. None of the respondents aged 18-25 indicated that they heard of aphasia (See figure 4).

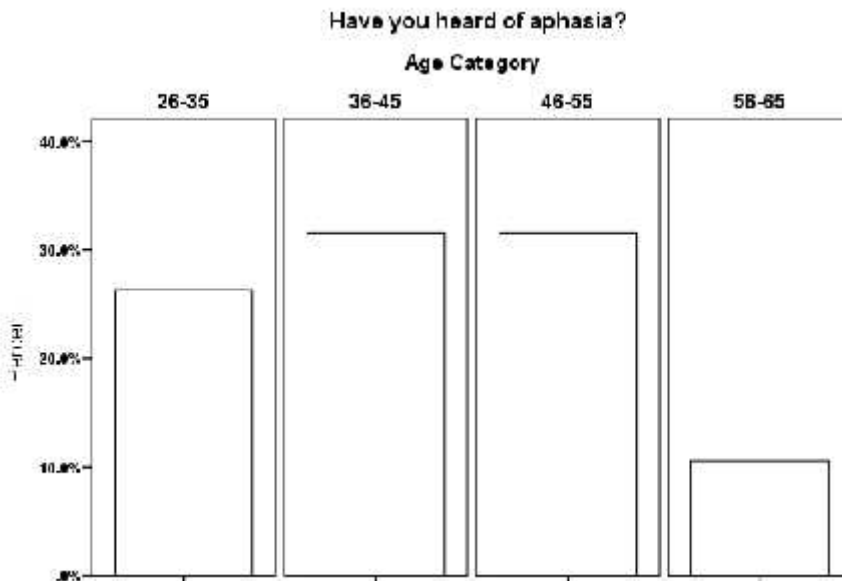


Figure 4. Age categories of survey respondents who have heard of aphasia

The education level of respondents who had heard of aphasia tended to be significantly higher than those who had not heard of aphasia. Higher educational attainment typically resulted in higher levels of aphasia awareness. Thirty-two percent of respondents who had heard of aphasia had earned a bachelor's degree, and 26% had earned a master's degree. Twenty-one percent of respondents with an associate's degree had heard of aphasia, and 11% of respondents with an associate's degree and a high school diploma or GED respectively had heard of aphasia (See figure 5).

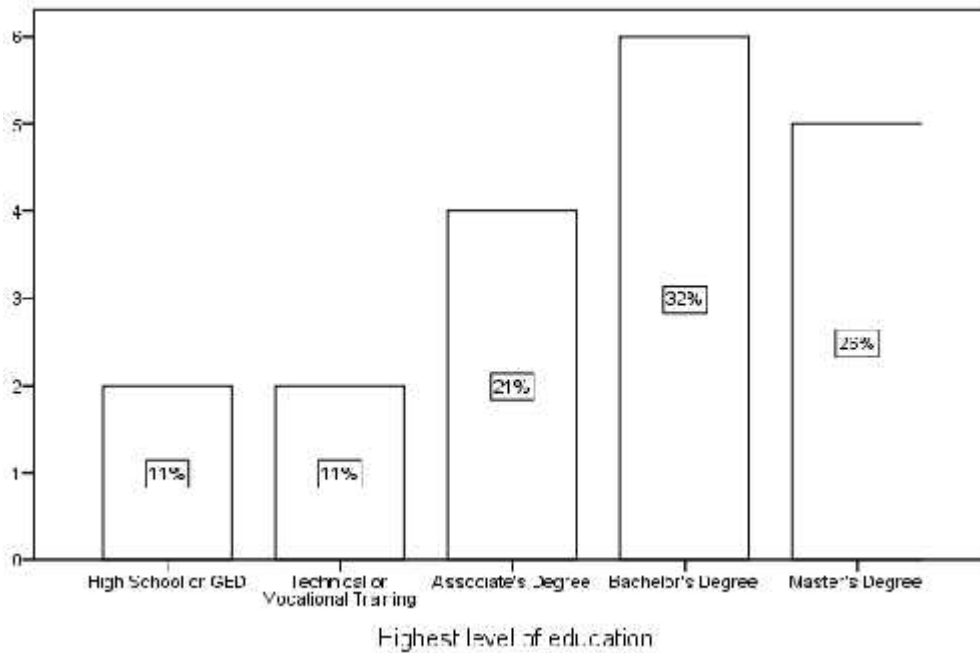


Figure 5. Highest educational level of respondents who had heard of aphasia

Of the respondents with an annual income level of \$45,000-55,000, 26% had heard of aphasia and 21% of the respondents with an income level of \$25,000-35,000 and \$35,000-45,000 had heard of aphasia. (See figure 6).

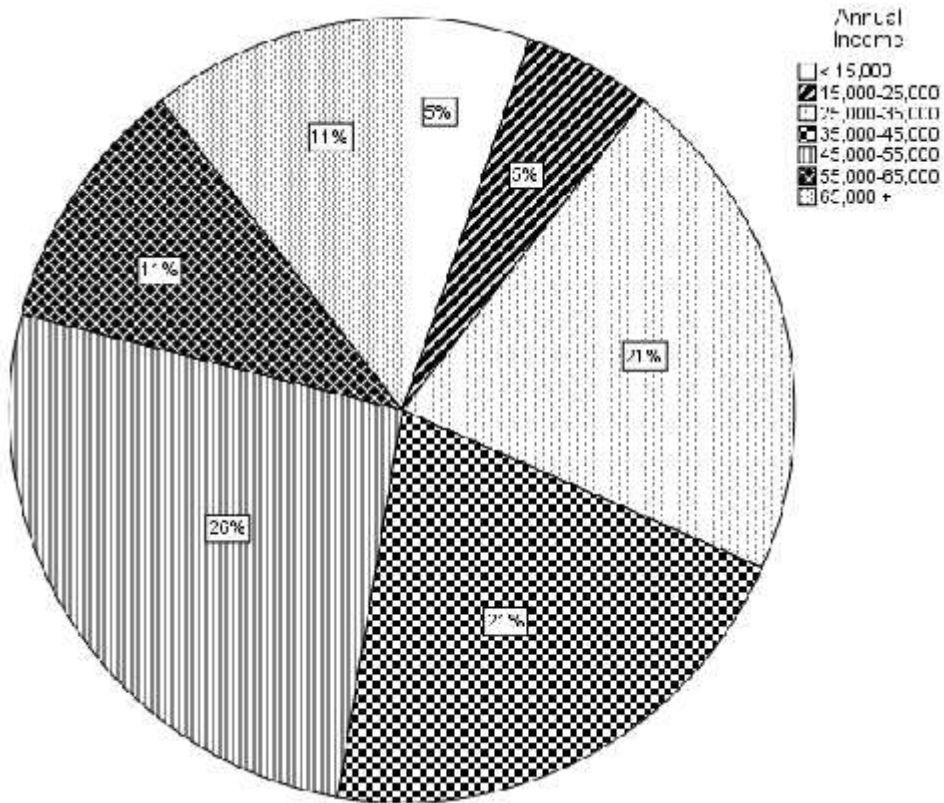


Figure 6. Income levels of survey respondents who have heard of aphasia

Chi-Square Analysis

Chi-square tests of independence were performed to examine the relationship between aphasia awareness and several categorical variables. Chi-square analysis revealed that the relationship between gender and aphasia awareness yielded no statistical significance, $X^2 (1, N = 100) = .58, p > .44$. Similarly, the correlation between occupation and aphasia awareness was not significant, $X^2 (77, N = 100) = .67.08, p > .78$. Income level also had no statistical significance on aphasia awareness, $X^2 (6, N = 100) = 6.50, p > .37$. However, chi-square analysis did demonstrate a statistical significance between the age of survey respondents and awareness of aphasia, $X^2 (37, N = 100) = 53.28, p < .04$.

There was also a significant relationship between education level and aphasia awareness,
 $\chi^2(6, N = 100) = 14.49, p < .02$.

CHAPTER IV

DISCUSSION

Results of this survey indicated that 19% of individuals had heard of aphasia (11% of females and 9% of males). While this percentage is slightly higher than previous surveys on aphasia awareness, only 79% of the respondents who heard of aphasia were also aware that aphasia is caused by brain damage. Additionally, just 58% of respondents knew people with aphasia had difficulty understanding the speech of others. Eighty-four percent of respondents who had heard of aphasia were aware that aphasia causes problems using language. (See table 2). In a survey conducted by Simmons-Mackie et al. (2002) 13.6% of respondents indicated they had heard of aphasia, but only 5.4% actually met the criterion for having a basic understanding of aphasia. The guidelines used by Simmons-Mackie to determine a respondent's basic knowledge of aphasia included correct responses for aphasia being a communication problem that affects speech and language, and also identifying the cause of aphasia as brain damage. However, when applying the guidelines set forth by Simmons-Mackie for this current survey, the percentage of respondents who indicated they had heard of aphasia was reduced. Eighty-four percent of respondents knew that aphasia causes problems using language, but only

58% were aware that aphasia also causes problems in understanding the speech of others. Just 79% of respondents were aware that brain damage causes aphasia, and 16% did not know what causes aphasia. (See table 2).

The high number of respondents who were aware of language production problems in individuals with aphasia may be attributed to associating similar language use in people with a stroke. The highest aphasia awareness rates for this survey in regards to age were the respondents in the 36-45 years and the 46-55 years age range. Sixty-four percent of respondents between these age brackets had heard of aphasia. This percentage is significant for this age group, since knowledge of aphasia will better prepare them for confronting age-related diseases, such as stroke and its related deficits, including aphasia. In addition, chi-square analysis revealed a statistically significant link between age and aphasia awareness. It is crucial to ensure that all individuals, particularly those within the 36-55 years age group, are able to differentiate between the symptoms of aphasia and other diseases common in older individuals. Being able to associate communication deficits with the term 'aphasia' may help to strengthen this relationship. In a study conducted by Elman, Ogar, & Elman (2000), the results of a Lexis-Nexis search of the top 50 U.S. newspapers revealed that the word 'aphasia' was used just 352 times in the past 5 years. Further, the term 'aphasia' was often used incorrectly or out of context, typically in association with Alzheimer's disease, AIDS, and brain tumors. While a small portion of the public is somewhat familiar with the link between stroke and communication deficits, more educational outreach is necessary, particularly in regards to aphasia. This current study, as well as the study conducted by Elman, Ogar, & Elman, demonstrates that this link is tenuous at best, and stronger efforts on behalf of health

professionals and educators are needed to establish a visible and concrete identity of aphasia among the public.

Although it is encouraging that a broad age range of individuals for this survey were aware of aphasia (19%), it is also interesting to note that while nearly three-quarters of strokes occur in people over 65 (NSA, 2011), the respondents in this age bracket had some of the lowest aphasia awareness rates in this survey. This again illustrates the need for increased public awareness and advocacy for aphasia, particularly among the 65 years and older population, where the incidence of stroke and aphasia occurs most frequently.

Incidentally, all of the respondents surveyed who had not heard of aphasia had heard of a stroke. Since aphasia always occurs as a result of brain damage, it is imperative that the link between stroke (a brain injury) and aphasia is better understood by the public, particularly in regards to how aphasia affects all language domains. This is especially true for individuals who work in the public service industry. These workers are likely to be some of the first people individuals with aphasia may encounter, outside of family and friends. Further, an increasing number of speech therapists are implementing psychosocial approaches to therapy, focusing on community re-engagement and functional independence. A 2006 survey of speech-language pathologists found that 97% of participants stated that psychosocial aspects were either important or very important to the overall management of their clients (Brumfitt, 2006). Properly educating these employees to communicate effectively with individuals with aphasia can improve self-esteem and promote independence, creating a positive effect on therapy outcomes.

Indeed, the education level of the respondents appeared to have had an impact on aphasia awareness, as evidenced by chi-square analysis. These results suggest that

education plays a role in aphasia awareness. The more education an individual has, the more likely it is that he or she has heard of aphasia. Results of this survey indicated that 31% of respondents with a bachelor's degree had heard of aphasia. Twenty-six percent of respondents with a master's degree had heard of aphasia, and 21% of respondents with an associate's degree had heard of aphasia. Ten percent of high school diploma holders and 10% of respondents with vocational training had heard of aphasia. (See figure 5).

Aside from formal education, this information also supports the belief that general education on aphasia supplied by health professionals and aphasia advocates is critical for promoting aphasia awareness among the public. Brown et al. noted that speech-language pathologists may play a pivotal role among service-industry workers by providing education and training to employees (2006). In addition, this can be achieved by offering seminars in communication deficits during employee training, providing literature on aphasia in physician's offices and other health clinics, and implementing aphasia classes and seminars for the public. It would be beneficial to offer these classes free of charge to the public, since individuals who had not heard of aphasia typically earned less annually than individuals who had heard of aphasia.

Although current research has established a connection between increased income level and higher educational attainment, (Cheeseman, Newburger, 2002), chi-square analysis determined that the income levels of survey respondents did not have an effect on aphasia awareness. Out of respondents earning \$45-55,000 annually, 26% had heard of aphasia. Twenty-one percent of respondents earning both \$35-45,000 a year and \$65,000 or more a year had heard of aphasia respectively (See figure 6). Despite the lack of statistical significance between income and aphasia awareness, free or reduced classes and training

would still benefit the public, particularly in low-income areas and stroke-belt states, where the incidence of strokes are high. In particular, training for service-industry employees could potentially lessen communication barriers and promote independence for individuals with aphasia.

Employment among survey respondents appeared to have a minimal effect on aphasia awareness. Chi-square analysis revealed no statistical significance between occupation and aphasia awareness. Respondents within the education sector had the highest level of aphasia awareness at 5%. Four percent of respondents employed within the food industry had heard of aphasia, and 3% of civil service employees and retail and sales workers had heard of aphasia. Since 26% of survey respondents were in the food industry, this higher number of aphasia awareness can be attributed to this occupation category representing one-fourth of survey respondents. Interestingly, individuals employed within the healthcare industry had no knowledge of aphasia. However, most individuals included in this service sector were primarily lab assistants and medical technologists, and therefore were not expected to possess any extensive knowledge of aphasia.

The race of respondents was not statistically analyzed due to the imbalanced representation of the survey sample. Although 94% of respondents who had heard of aphasia were Caucasian, the sample size for Caucasians was disproportionately larger than other racial groups, comprising 86% of the survey respondents. While the racial makeup of this study is similar to the region where the survey was conducted, the relatively small sample size and poor representation of other racial groups in this survey do not provide an accurate analysis of ethnicity and aphasia awareness. Future surveys

assessing the knowledge of aphasia would benefit from including a larger, more diverse sample population in order to fully explore the role race plays in aphasia awareness.

When analyzing how respondents had heard of aphasia, 26% had heard of aphasia through a friend or a relative who has aphasia. An additional 26% had heard of aphasia through their occupation. This was particularly the case for civil service employees, who worked in emergency medical response professions, fire fighting, and police work. Ten percent of civil service employees indicated they frequently come into contact with people with aphasia through their work. Twenty-one percent of respondents had heard of aphasia through various media outlets, including radio, television, newspapers, and magazines. Another 17% had heard of aphasia through a variety of mediums, including a special population course on aging, academic coursework in psychology and nursing, and while attending occupational therapy. One respondent had heard of aphasia due to reading lots of “random information.”

While this study was small in scope, the results illustrate the need for additional public awareness and education, particularly in regards to how aphasia affects all language domains. It is especially critical for individuals employed in urgent medical response fields, such as paramedics, 911 dispatchers, and emergency room receptionists to be informed of aphasia and its related communication deficits. Providing effective communication strategies for employees who work in these occupations may help facilitate better response times during emergencies and also ease the communication barrier that is common when interacting with people with aphasia. In addition, promoting aphasia awareness among service industry employees will ensure that workers are familiar with aphasia and its associated deficits, thereby making communication easier

and more effective. Positive social interactions between service workers and individuals with aphasia creates much more than a time reduction at the cash register or speedier orders at restaurants—it also fosters a sense of self-worth and independence for individuals with aphasia, which is critical when considering the psychosocial aspects of rehabilitation. For service industry workers, effective communication provides satisfaction in assisting customers, and facilitates a better understanding of individuals with disabilities as a whole.

Future Research

The relatively small sample size of this survey was not conducive to obtaining an accurate analysis of the relationship between aphasia awareness and race. A larger study that includes more participants and diversity would be able to better address this relationship and provide additional data on underrepresented minorities, particularly African-Americans and Hispanics. The geographic focus for this study also limited the ability to analyze a wider population sample. While this study focused on individuals within the service-industry sector, a wider variety of occupations, including bankers, pharmacists, and grocery store employees will provide a wider perspective of aphasia awareness within these occupations. In addition, better education and publicity is needed to ensure that the public is aware of what the term ‘aphasia’ means. Associating the specific deficits that accompany aphasia will benefit public awareness of aphasia. It is also important to note that further studies focusing on how to incorporate aphasia awareness are still needed. Promoting public awareness of aphasia can be explored by collaborating with speech-language pathologists, as noted by Brown et al. (2006), and through media campaigns and advocacy (Elman, Ogar, & Elman, 2000).

Conclusion

In order for aphasia to become a common name among the public, it is crucial to address and promote more media presence in newspapers, magazines, radio announcements and television segments. Educating service-industry workers on aphasia, its related deficits, and what 'aphasia' means will provide self-confidence to individuals with aphasia and benefit psychosocial rehabilitation efforts. Community organizations, such as the YMCA and local hospitals, need to provide classes and training necessary for educating the public, family, and friends of individuals with aphasia. Additionally, improved advocacy from health professionals and other allied educators will also provide a voice for aphasia for those who are not able to speak for themselves.

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APPENDIX

Awareness of Aphasia Survey

Section 1

Date of Survey _____ Place of Survey _____ Time of
Day _____

English Speaker _____ Non-English Speaker _____

Rate how busy the shopping center is on the day you gathered this data

Very busy _____ Pretty busy _____ Fairly quiet _____ Quiet _____

Section 2

Age _____ Gender _____ Occupation _____ (provide detailed information for
nonspecific responses, i.e.,
salesman)

Where do you work? _____

If retired, previous occupation _____

If unemployed, previous occupation _____

Section 3

Have you ever heard of aphasia or dysphasia? Yes ___ (if YES, go to section 4)

No ___

If NO, have you ever heard of a stroke? Yes ___ No ___

If YES, can you tell me what a stroke is?

-

If NO, have you even known anyone who had communication or speech problems following a stroke, brain injury or head injury?

Yes _____

No _____ (if **NO**, give information on aphasia and end the interview)

Section 4

If **YES**, say, “So you have heard of aphasia/dysphasia. What is aphasia/dysphasia? Can it be:”

Speech problems Yes _____ No _____ Don’t know _____

Problems using language Yes _____ No _____ Don’t know _____

Problems understanding
the speech of others Yes _____ No _____ Don’t know _____

Problems with intelligence Yes _____ No _____ Don’t know _____

Psychological problems Yes _____ No _____ Don’t know _____

Reading problems Yes _____ No _____ Don’t know _____

Writing problems Yes _____ No _____ Don’t know _____

Communication problems Yes _____ No _____ Don’t know _____

Section 5

What causes aphasia/dysphasia?

Brain damage Yes _____ No _____ Don’t know _____

Emotional problems Yes _____ No _____ Don’t know _____

Impaired intelligence Yes _____ No _____ Don’t know _____

Mental problems Yes _____ No _____ Don’t know _____

Section 6

In what context have you heard of aphasia/dysphasia? How did you hear about aphasia/dysphasia, and where did you hear about aphasia/dysphasia?

a. relative/friend has aphasia _____

b. On the TV/radio _____

c. Newspaper/magazine _____

d. Through my work (specify how your work brings you into contact with aphasia)

e. Other (please specify)

Section 7

If you have heard about aphasia, can anything be done to help the person with aphasia?

Yes _____ No _____

If **YES**, what can be done?

INFORMED CONSENT FORM

I am a graduate student at **Cleveland State University**. I am gathering information about the public's awareness of aphasia. This will help me to provide information to the public in the future regarding health care.

I would like you to complete this 6-section questionnaire. Your participation is voluntary. I agree to protect your privacy by not sharing your information with others outside of this course. You do not have to sign your name in this document and your responses will in no way identify you. You do not have to participate in any tasks or talk about any topic that you do not want to pursue. You may stop at any time and withdraw from participation.

If you would like to know more about this project, please contact me at 419-677-1466 or my course instructor Dr. Violet Cox at (216) 687-6909. This project has been approved by Cleveland State University. If you have further questions you may contact the Cleveland State University's Institution Review Board at (216) 687-3630.

By checking the box you agree to participate in this project [].