



AWARENESS AND UNDERSTANDING OF AMYOTROPHIC LATERAL SCLEROSIS (ALS) IN NEWLY DIAGNOSED PATIENTS, FAMILY, AND FRIENDS

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Introduction: Amyotrophic lateral sclerosis (ALS) is a rare disease, and may be referred to by a number of names, including motor neuron disease (MND) or Lou Gehrig's disease. ALS is a rare neuromuscular disorder that causes progressive degeneration of motor neurons that affects voluntary muscle control. Most people who develop ALS are between the ages of 40 and 70, with an average age of 55 at the time of diagnosis. Ninety percent of cases are known as sporadic, meaning no family history, the other 10% have a family history which is known as familial ALS. The average length of survival is “2 to 4 years from symptom onset; this means that 50 percent of patients will live longer than this. The survival curve has a “long tail” and some patients have survived 10 years or more.” (Bromberg, 2017)

Individuals diagnosed with ALS may or may not be familiar with the disease. The Ice Bucket Challenge in 2014 was, in part, a social media campaign, focused on increasing awareness of ALS. However, there remains a lack of understanding of ALS, and in particular, how the diagnosis impacts a patient and family. An article produced by the faculty at Edge Hill University in Ormskirk England stated: “The diagnostic journey is not straightforward. Within primary care, GPs infrequently encounter ALS/MND and often lack insight into the condition (18), resulting in failure to appreciate the significance of symptoms, leading to inappropriate non-neurological referrals. Increased awareness of ALS/MND is required among non-neurologists (18); recognizing the need for a neurological referral may be one of the most significant factors in reducing diagnostic delays (32). Although the medical curriculum is overburdened, there is clear need for further education to improve ALS/MND care.”

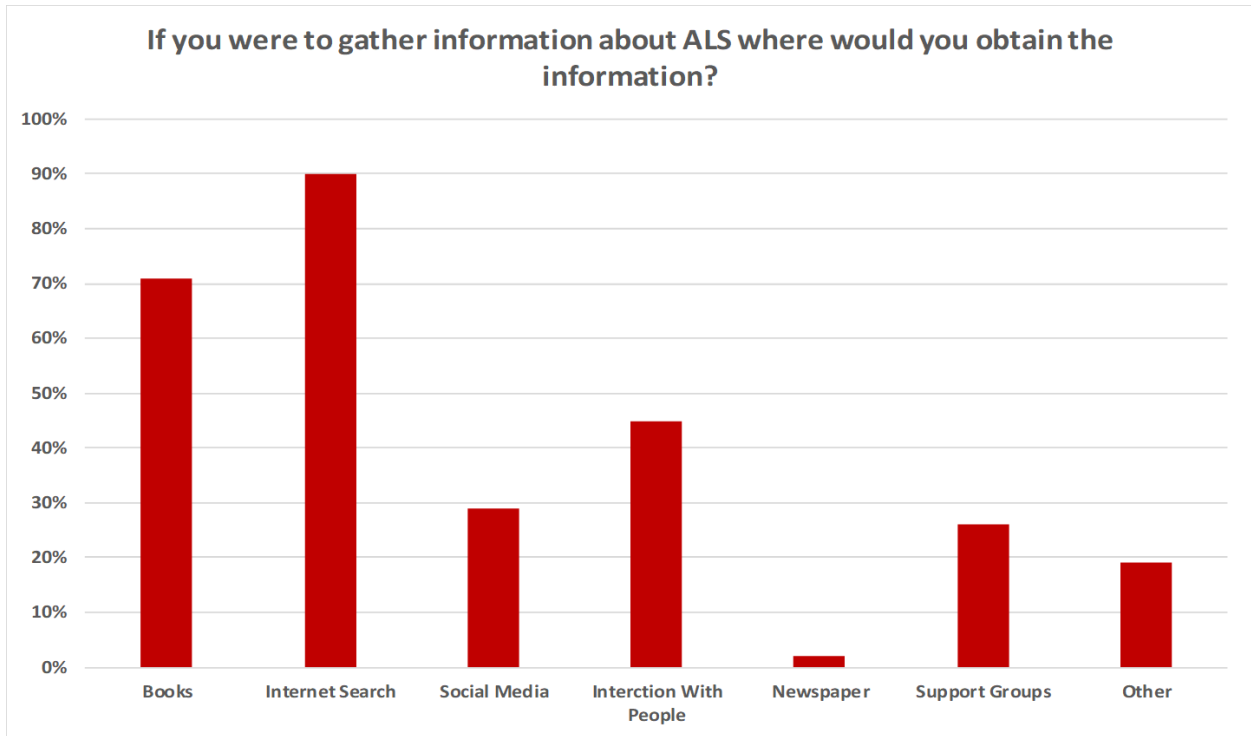
Purpose: This cross-sectional, descriptive study assessed the awareness of and the understanding of ALS in newly diagnosed patients, family, and friends. During the time period of 2017 to 2018.

Methods: A patient, family members, and friends attending their first visit to the MND/ALS multidisciplinary clinic were queried via written survey about 1) their awareness and 2) knowledge of ALS. Demographic information; age, gender, education level were captured for each individual, and the origin of the information. Awareness focused on familiarity with key terms, e.g. ALS, Lou Gehrig's, MND, Ice bucket challenge, and if they knew anyone with the disease. Awareness was scored using a 1-5 Likert scale from no awareness: 1 to being able to converse about the topic: 5. Knowledge of the disease queried which of 14 listed body part(s) would be impacted by ALS. (Respondents could choose as many body parts as indicated and the questions had some correct and incorrect responses.)

Results: Forty-two individuals completed surveys, which included 17 patients, and the 25 additional individuals who were spouses/caregivers (13) and family members (12). The age range for all respondents was 40-79 years, 18 indicated high school was the highest level of education (Figure 1), and the majority of individuals used the internet to gather their information. (Table 1) Less than 10% reported enough knowledge or awareness to carry on a conversation about the topic (ALS, Lou Gehrig’s, Ice Bucket Challenge, and Purpose of Ice Bucket Challenge). (Table 2) 55% of the individuals were aware of somebody else with ALS prior to their own diagnosis. Among the 14 options for areas of the body that can be affected by ALS, 93% of the individuals surveyed chose the correct options: (Lungs/Breathing, Mouth/Chewing, muscles/Nerves, and Strength/Mobility), however, 64% also chose incorrect areas of involvement. (Libido/Intimacy, Ears/Hearing, Stomach/Digestion, Brain/Thinking, Nose/Smelling, Eyes/Seeing, Control of Emotion, Bones/Joints, and Heart/Circulation.) (Table 3)

Relation	#	Sex	#	Highest Education Level Completed	#	Occupational Industry	#
Patient	17	Male	19	No High School Diploma/GED	4	Healthcare	5
Spouse/ Caregiver	13	Female	23	High School Graduate	18	Business	7
Family Member	12			College Graduate Associates Degree	2	Construction/ Labor	2
Friend	1			College Graduate Bachelors Degree	10	Food Industry	4
				Masters/ Graduate Program	8	Education	5
						Science	2
						Engineering	2
						Other	13
						Not Selected	2

(Figure 1)



(Table 1)

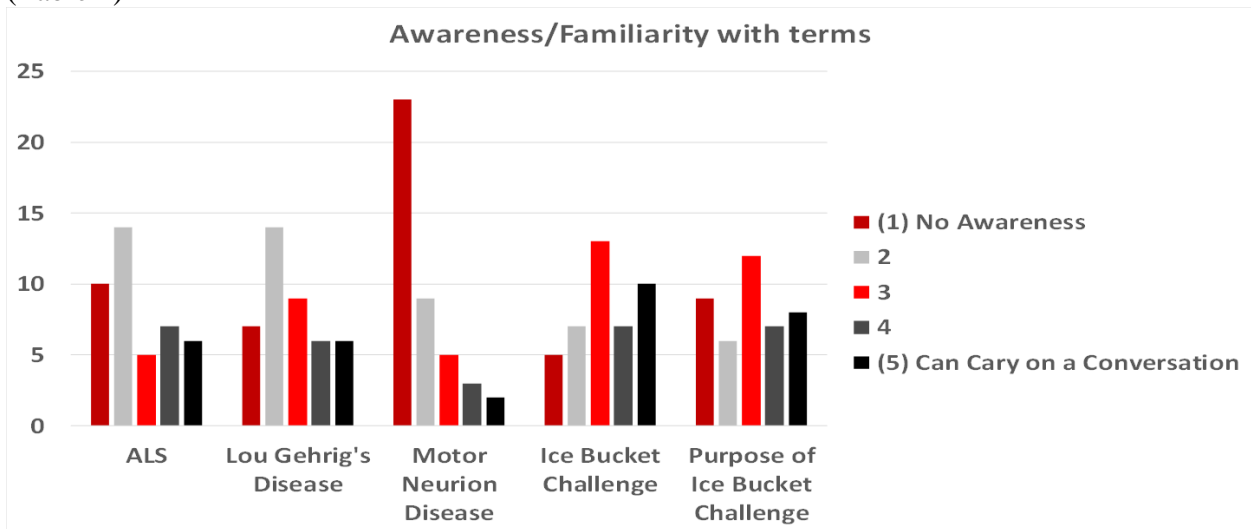


Table 1

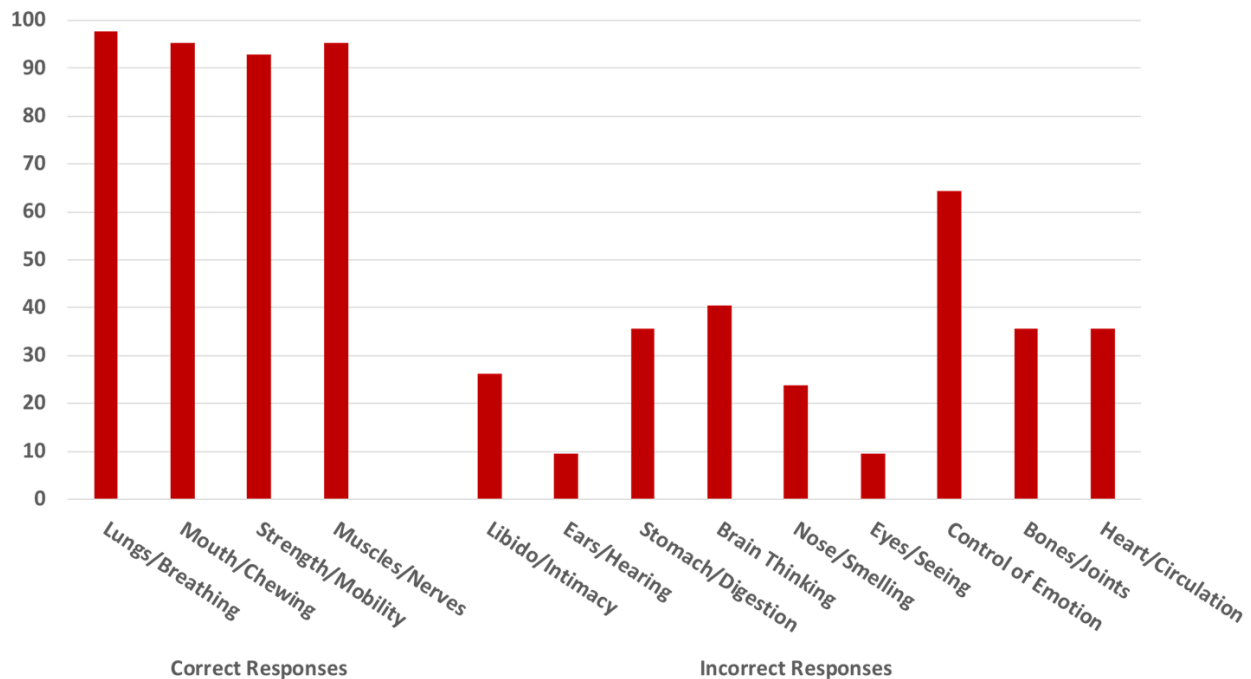


Table 2

Discussion: Although the respondents were patients, family, and friends who had already been given a diagnosis, the majority of the surveyed individuals demonstrated poor awareness prior to their first visit in the multidisciplinary clinic where the survey was completed of the key terms related to the disease, and were unaware of anybody with ALS. Despite the correct identification of the body areas that can be affected by ALS, the majority still chose incorrect options. This survey was conducted 3 years after the Ice Bucket Challenge & its associated information about ALS began/took place.

Conclusion: Despite the recent efforts of spreading public awareness and knowledge about ALS, it appears that there is still a gap in understanding and awareness of the disease. As mentioned early the article provided by Edge Hill University detailed some of the potential complications with limited awareness and knowledge, which leads to delayed diagnosis, treatment, and care of these individuals.

Literature Review section:

- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5065896/>
- <https://www.tandfonline.com/doi/full/10.3109/21678421.2014.984725>

- <https://www.als.org/understanding-als>

References:

Bromberg, M. B., & Bromberg, D. B. (2017). *Navigating Life with Amyotrophic Lateral Sclerosis*. Oxford University Press.

Mary R. O'Brien, Bridget Whitehead, Barbara A. Jack & John Douglas Mitchell (2011) From symptom onset to a diagnosis of amyotrophic lateral sclerosis/motor neuron disease (ALS/MND): Experiences of people with ALS/MND and family carers – a qualitative study, *Amyotrophic Lateral Sclerosis*, 12:2, 97-104, DOI: [10.3109/17482968.2010.546414](https://doi.org/10.3109/17482968.2010.546414)