

Surveying the ALS Population of Columbus and Dayton Over Their Thoughts of the Possible Placement of a Comprehensive ALS Center in Central Ohio

Madison McClain*

OhioHealth Westerville

Department of Biology, The Ohio State University

The study focused on surveying the ALS community (patients, family members to patients, and caregivers) on their thoughts about the possible placement of a comprehensive ALS center in central Ohio. The study design created an original survey that was distributed online through the ALS Association Central & Southern Ohio chapter's monthly newsletter (April) and in-person at two Columbus support group meetings and one Dayton support group meeting. Data from the survey was compiled and analyzed in pie charts to determine various trends in the responses. Overall, the ALS community supported the creation of an ALS center and felt it would be beneficial to them. It is recommended that a fiscally responsible, lightly staffed ALS center be created to meet the needs of the ALS patients of central Ohio.



Madison McClain is a freshman at The Ohio State University majoring in biology and minoring in neuroscience. Next year, Madison plans to continue her education at The Ohio State University.

Introduction

ALS, amyotrophic lateral sclerosis (also known as Lou Gehrig's disease), is a progressive neurodegenerative disease that affects the nerve cells (neurons) in the spinal cord and into the brain (What Is ALS?, 2010). The motor neurons (nerve cells that control movement in the body) that connect the brain to the spinal cord to muscles throughout the body progressively degenerate, waste away, and die (What Is ALS?, 2010). As the neurons die, they are no longer able to send signals from the brain to move muscles in the body and the patient loses voluntary control over muscle movement (Dugdale, Hoch, & Zieve, 2010). Patients with ALS slowly experience weakening of the muscles, twitching, atrophy, and eventually paralysis (What Is ALS?, 2010). Early symptoms include: weakness, speech issues, troubles breathing,

and troubles swallowing (What Is ALS?, 2010).

There is no known cure for ALS although some medications (such as riluzole) can be prescribed to slow the progression of the disease and prolong the patient's life (Dugdale, Hoch, & Zieve, 2010). As the muscles throughout the body become paralyzed and stop working, many complications ensue for the ALS patient (Mayo Clinic staff, 2010). Complications include: trouble breathing, eating problems, issues when moving around, and developing dementia (Mayo Clinic staff, 2010).

As ALS eventually paralyzes the muscles in the chest area, it becomes extremely difficult or impossible for the patient to breathe on their own (Dugdale, Hoch, & Zieve, 2010). Breathing devices, such as the CPAP mask (continuous positive airway pressure mask, used by many sleep apnea patients), may be

Question No. 3

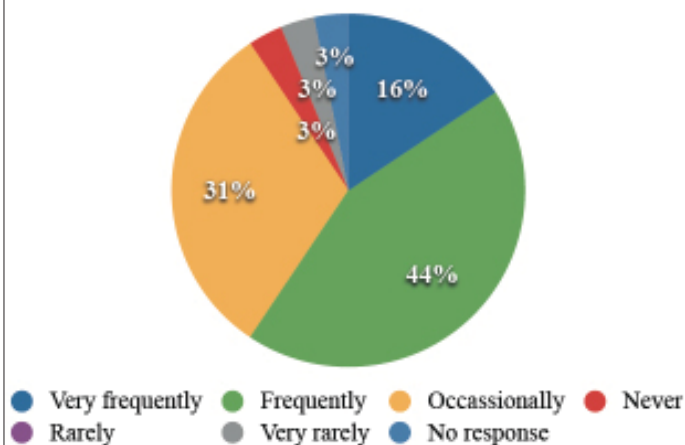


FIGURE 2. Survey Question No. 3:
How often do you find yourself seeking advice, support, tools, and resources beyond what is offered/available in your doctor's office?
(All respondents data)

used by ALS patient's to assist breathing (Mayo Clinic staff, 2010). In latter stages of ALS, some patients choose to undergo a procedure called a "tracheostomy" (Mayo Clinic staff, 2010). A tracheostomy is a surgical procedure where a tube is inserted through an incision in the front of the neck into the trachea (windpipe) so that a respirator can inflate and deflate the patient's lungs (Lindman & Morgan, 2011). Respiratory failure is one of the most common causes of death in ALS patients, often occurring within three to five years after onset of symptoms (Mayo Clinic staff, 2010).

When ALS causes muscles in the throat that control swallowing to become paralyzed, many patients develop eating problems, including poor nutrition and dehydration (Mayo Clinic staff, 2010). ALS patients are also at a greater risk of accidentally inhaling foods or liquids into their lungs, which can easily cause pneumonia (Mayo Clinic staff, 2010). If desired, patients can use feeding tubes to reduce these aforementioned risks (Mayo Clinic staff, 2010).

Due to all these various complications associated with amyotrophic lateral sclerosis, ALS patients have to visit many different types of physicians. ALS patients may need to visit a wide range of doctors, including but not limited to: neurologists, speech-language therapists, nutritionists, occupational therapists, physical therapists, respiratory therapists, pulmonologists, and gastroenterologists (ALS Team, n.d.). Often, there is no one ALS center where patients can go and meet with all of their physicians in the same place on the same day. This is the case in central Ohio where there is no

comprehensive ALS center for central Ohio patients to visit. This study aims to determine if ALS patients, family members, and caregivers would support the placement of a comprehensive ALS center at an OhioHealth hospital in central Ohio and whether they feel it would benefit them. These hypothetical benefits would not purely be based on extending the patient's life expectancy with the disease, but improving the patient's outlook on life and lessening the stress on the patient and his or her family, friends, and caregivers.

Methods

A survey was created using the program Google Docs and was administered online (through a link in the ALS Association Central & Southern Ohio Chapter's monthly newsletter) and in person at ALS support group meetings in Columbus and Dayton. The survey contained questions regarding whether or not the ALS patients, caregivers, and family members felt they would use a comprehensive ALS center in an OhioHealth hospital, how often they would use it, and how far they would be willing to travel to get to a comprehensive center. To determine what questions to ask in the survey, a series of possible questions was proposed to Mrs. Halpin, director of operations at OhioHealth Westerville, for review. The best questions were selected after the review.

The survey consisted of six multiple choice questions (five of which had an open-ended "additional comments" section) and one open-response question (located in appendix, Fig. 1). The survey also included an incentive in an attempt to gain more respondents. At the end of the survey, there was an optional section to write in contact in-

Question No. 4

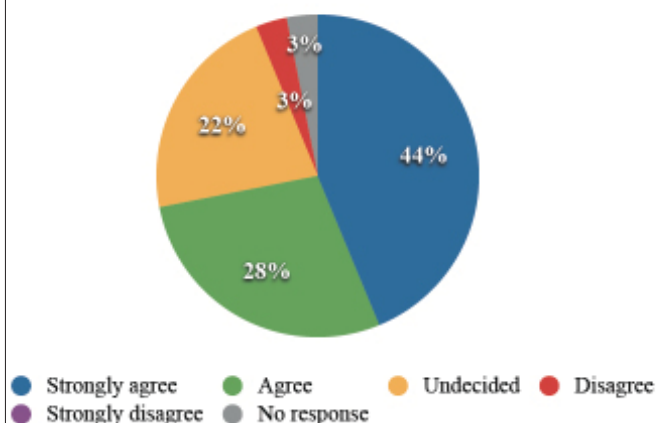


FIGURE 3. Survey Question No. 4:
Would you utilize a comprehensive ALS center if one was located in the central Ohio area?
(All respondents data)

formation if the survey-taker wished to be entered into a raffle to win one of three available \$25.00 BP gas cards.

After undergoing an approval process through the ALS Association Central & Southern Ohio Chapter, a link to the survey was placed in the April newsletter. I attended two support group meetings in Columbus and one meeting in Dayton to hand out surveys in-person.

Six surveys were completed and returned through Google Docs online and twenty-six surveys were collected through the support group meetings, thirty-two surveys were collected in total. Of the thirty-two surveys collected, sixteen were completed by patients and sixteen were completed by ALS caregivers/family members to ALS patients, making the distribution exactly 50-50. The data gathered from the surveys was synthesized into tables and then analyzed. The data was analyzed with all respondents together and was also broken up into two subgroups; ALS patients and ALS caregivers/family members to ALS patients. When the data was analyzed within the subgroups, there were no significant points to be found. The data was made into pie charts based on all respondent's results.

Results

Fig. 2 (located on the following page) is a compilation of the data collected from all respondents without being broken into subgroups. The question, "How often do you find yourself seeking advice, support, tools, and resources beyond what is offered/available in your doctor's office?" had six multiple choice options along with an "additional comments" section. 44% of the total respondents to the survey question selected that they frequently find themselves seeking

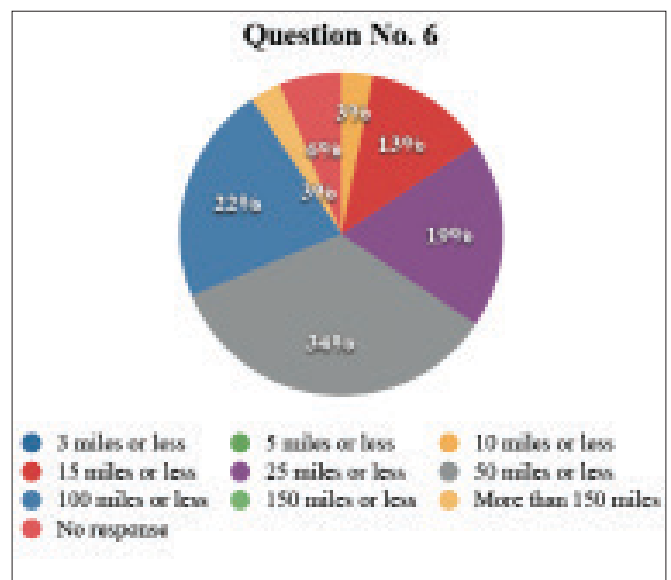


Figure 5: Survey question no. 6: How far would you be willing to travel to visit a comprehensive ALS center? (All respondents data)

services beyond what is provided by their own doctor, 31% of the total respondents selected that they occasionally find themselves seeking additional services, and 16% responded very frequently. The options of never and very rarely each received 3%, as did a neglected response. In the "additional comments" section following this question, some notable responses included; "We were lucky that we were in a city where we had an ALS clinic and it was invaluable. It would be great for all patients and caregivers to have that advantage" and "[I] got tired of teaching doctors and paying them for it... I get more information online and from [my] support group." Many respondents also stated that they supplement the lack of resources from their doctors through the information they receive from their respective support groups.

Fig. 3 (located on the following page) is a compilation of the data collected from all respondents without being broken into subgroups. The question, "Would you utilize a comprehensive ALS center if one was located in the central Ohio area?" had five multiple choice options along with an "additional comments" section. 44% of the total respondents to the survey question selected that they strongly agree that they would use a comprehensive ALS center, 28% responded that they agree they would use a center, and 22% were undecided if they would use a comprehensive ALS center. The option of disagree received 3%, as did a neglected response. It is important to note that the ALS patient that responded that they would not use a ALS center stated under the "additional com-

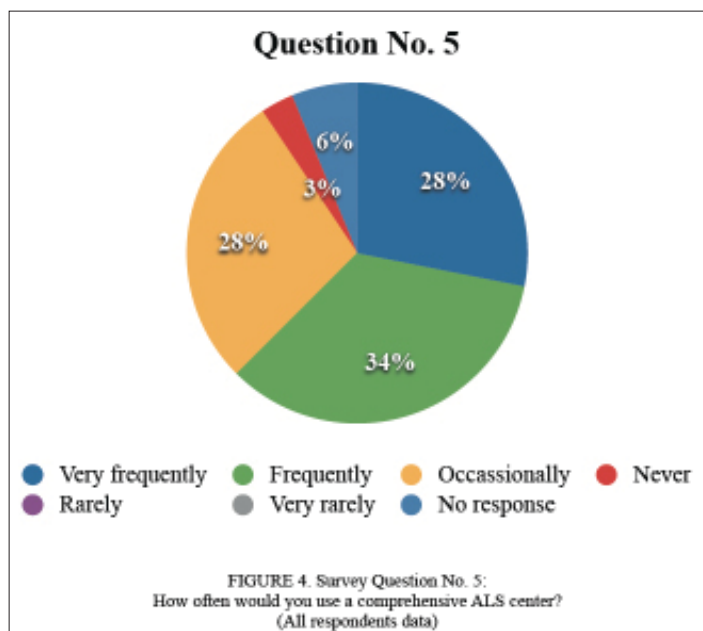
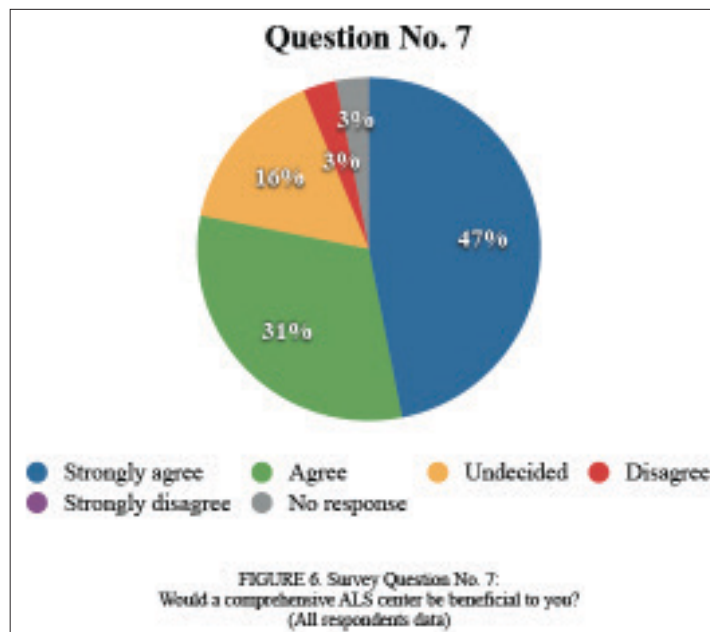


FIGURE 4. Survey Question No. 5:
How often would you use a comprehensive ALS center?
(All respondents data)

ments” that it would be too late to benefit them and that they would be starting hospice soon. Many of the respondents who selected undecided stated under the “additional comments” that it would depend what the center offered and how far they would have to travel in order to utilize the services provided.

Fig. 4 (located on the following page) is a compilation of the data collected from all respondents without being broken into subgroups. The question, “How often would you use a comprehensive ALS center?” had six multiple choice options along with an “additional comments” section. 34% of the total respondents to the survey question selected that they would frequently use a comprehensive ALS center, 28% responded that they would very frequently use a comprehensive center, and another 28% were undecided on whether they would use a center or not. Neglected response received 6% and the option of never using a comprehensive ALS center received 3%. Once again, it is important to note that the patient who selected that he or she would never use a comprehensive ALS center did state that they were too far along in the disease for a center to be of use to them. Again, many of the respondents who stated under the “additional comments” that how often they would use a center would depend what it offered and how far they would have to travel.

Fig. 5 (below) is a compilation of the data collected from all respondents without being broken into subgroups. The question, “How far would you be willing to travel to visit a comprehensive ALS center?” had nine multiple choice options along with an “additional comments” section. 34% of the total respondents to the survey question selected they would be willing to travel 50 miles or less to visit a comprehensive ALS center, 22% responded that they would travel 100 miles or less, 19% responded they would travel 25 miles or less, and 13% responded they would travel 15 miles or less to visit a center. The options of 10 miles or less and more than 150 miles of traveling each received 3% and a neglected response gained 6%. Fig. 6 (below) is a compilation of the data collected from all respondents without being broken into subgroups. The question, “Would a comprehensive ALS center be beneficial to you?” had five multiple choice options along with an “additional comments” section. 47% of the total respondents to the survey question selected they strongly agree that a comprehensive ALS center would be beneficial to them, 31% responded that they agree a center would be beneficial, and 16% of the respondents were undecided. The option of disagree received 3%, as did a neglected response. Again, the ALS patient that responded that they disagree a comprehensive center would be beneficial



to them stated under the “additional comments” that it would be too late to benefit them in the progression of the disease.

Discussion

Because of the limited sample size, it is difficult to analyze any of the results in depth, however, suggestions and recommendations can be made off the data collected to inform OhioHealth what the ALS patients, caregivers, and family members in the area think about the possible placement of a comprehensive ALS center. Under the open-response question “As a patient with ALS, what do you feel are the main challenges you face to your ongoing ALS care?” (or “As an ALS caregiver or family member, what do you feel are the main challenges you face caring for a patient with ALS?” depending on if the respondent selected they were a patient or a caregiver/family member), besides the obvious health problems associated with the disease, many respondents listed things such as “no central location” and “not enough resources” as their main challenges. This indicates an obvious gap in ALS care and treatment in central Ohio. Results of the data collected from all respondents showed some clear trends to based recommendations on. As expected, the results were over-all in favor of the placement of a comprehensive ALS center. For example, in Fig. 2, the majority of respondents said they frequently or occasionally seek resources beyond what is available with their doctor’s office. Fig. 3 shows the majority of respondents strongly agree and agree that they would utilize a comprehensive ALS center. In Fig. 4, the majority of those responding would frequent-

ly or occasionally use a hypothetical center. Fig. 6 shows the majority of respondents strongly agree or agree that a comprehensive ALS center would be beneficial to them.

Fig. 5 shows a large variation in how far those surveyed would be willing to travel in order to visit a comprehensive ALS center. Since the responses were spread across the board, it is recommended that a center would be placed anywhere from 15 to 100 miles away from these target areas.

It is important to note that oftentimes on questions where respondents selected undecided or neglected to answer all together, they stated in the “additional comments” that their answer would depend on where the center would be located and what services would be provided.

Based on the data gathered from the survey, we can recommend to OhioHealth that they should go forward with the creation of an ALS center, as the ALS community is overall in favor of it’s creation. Since the population of ALS patients in central Ohio isn’t extremely high, it is not recommended that a full-blown comprehensive center be created, as it would not

be fiscally worthwhile. However, it is recommended that a hybrid center be created, a center with a light staff to coordinate patient care that could be supplemented with various online resources. Perhaps a “virtual care center” could be created to help patients connect with the needed doctors and answer any questions that the patient or his or her family members may have.

Acknowledgments

Special thanks to Peggy Clary (RN, MHA, CCM), Care Coordinator for the ALS Association Central & Southern Ohio Chapter, for allowing a place for my survey in the April newsletter and for helping to connect me to the leaders of local support groups. An additional thank you to Wilma Beckner (RN), Care Service Coordinator and leader of the Dayton area support group, and Leigh Reed (RN), Care Service Coordinator and leader of the Columbus area support group, for allowing me time in their support group meetings to discuss my survey and ask for participants.

References

ALS. (n.d.). Retrieved January 1, 2012, from Henry Ford Health System website: <http://www.henryford.com/body.cfm?id=48875>

ALS clinics. (2011). Retrieved January 1, 2012, from ALS Association website: http://webcsoh.alsa.org/site/PageNavigator/CSOH_8_Clinics.html

ALS team. (n.d.). Retrieved January 1, 2012, from Henry Ford Health System website: <http://www.henryford.com/body.cfm?id=48961>

Bhatta, J. M., & Mitsumotoa, H. (2008, November 4). Amyotrophic Lateral Sclerosis (ALS). *Encyclopedia of Neurology*. doi: 10.1016/B978-008045046-9.00549-0

Clinical trials. (2011). Retrieved January 1, 2012, from ALS Association website: http://webcsoh.alsa.org/site/PageNavigator/CSOH_3_drugtable.html

Hoch, D. B., & Zieve, D. (2010, August 27). Amyotrophic lateral sclerosis. Retrieved January 1, 2012, from PubMed Health database.

For caregivers. (2011). Retrieved January 1, 2012, from ALS Association website: http://webcsoh.alsa.org/site/PageNavigator/CSOH_8b_caregivers.html

Lindman, J. P., & Morgan, C. E. (2011, May 19). Tracheostomy. Retrieved January 1, 2012, from Medscape website: <http://emedicine.medscape.com/article/865068-overview>

Mayo Clinic staff. (2010, December 2). Complications. Retrieved January 1, 2012, from Mayo Clinic website: <http://www.mayoclinic.com/health/amyotrophic-lateral-sclerosis/DS00359/DSEC->

TION=complications

Newly diagnosed. (2011). Retrieved January 1, 2012, from ALS Association website: http://webcsoh.alsa.org/site/PageNavigator/CSOH_8_diagnosed.html

Senior research project: Comprehensive ALS center. (2012, April). *The ALS Connection*, 5(4), 2. Retrieved from http://webcsoh.alsa.org/site/DocServer/The_ALS_Connection_April_2012.pdf?docID=85901

Support groups: The ALS association central & southern ohio chapter. (2011). Retrieved January 1, 2012, from ALS Association website: http://webcsoh.alsa.org/site/PageServer?pagename=CSOH_8_SG_listings

What is ALS? (2012). Retrieved January 1, 2012, from ALS Association website: <http://www.alsa.org/about-als/what-is-als.html>

What we do - the ALS Association. (2011, February). Retrieved December 6, 2011, from <http://www.alsa.org/about-us/what-we-do.html>

Who gets ALS? (2011). Retrieved January 1, 2012, from ALS Association website: http://webcsoh.alsa.org/site/PageServer?pagename=CSOH_1_WhoGets.html

To cite this article, please visit go.osu.edu/citations2012