The Relationship Between Dysphagia and Quality of Life in Adults with Amyotrophic Lateral Sclerosis

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Introduction

- Amyotrophic Lateral Sclerosis (ALS; also called “Lou Gehrig's disease”) is a progressive neuromuscular disease of the upper and lower motor neurons (1,3).
- The primary motor symptoms of ALS are dysphagia, dysarthria, respiratory problems, and weak limb musculature (9).
  - Dysphagia is one of the primary symptoms that leads to decreased quality of life (QOL) in individuals with ALS.
  - Symptoms of dysphagia may be experienced differently for each individual with ALS.
- Non-motor symptoms observed in ALS include social isolation, depression, and fear (2,7,9).
- This literature review addresses two questions
  - Whether there is a significant cross-sectional relationship between dysphagia and QOL
  - Whether clinical intervention of dysphagia improves QOL.

Methods

Databases searched for evidence:

- *Pubmed, Web of Science*

Search Terms:

- A search was conducted using a combination of different search terms such as “amyotrophic lateral sclerosis,” “quality of life,” “deglutition disorders,” and “dysphagia.”

Final Search Results:

- The search resulted in 18 articles in which 6 studies met the criteria to answer the research questions.

Results

Cross Sectional Relationship Between Dysphagia and QOL

- The Swallowing QOL questionnaire (SWAL-QOL) is a 44-item tool, assessing 10 domains of QOL related to swallowing including (5):
  - Desire for eating
  - Communication
  - Sleep,
  - Fatigue
  - Mental health
  - Social concerns related to swallowing
  - Food selection
  - Fear related to eating
  - Burden of dysphagia
  - Eating duration.
- 4 studies used the SWAL-QOL to assess QOL related to dysphagia secondary to ALS.
  - Group mean scores reported in Table 1.

QOL Response to Intervention

- Per-oral image guided gastrostomy (PIG) and percutaneous-endoscopic gastrostomy (PEG) reduced anxiety from long effortful meals, stabilized weight, and prolonged survival (3,8).

Sample questions from the SWAL-QOL (6)

Burden	Food Selection	Symptom Frequency /Bother	Eating	Fear
Dealing with my SP is very difficult	Figuring out what I can eat is a problem	Choking when eating food	Takes me longer to eat than others	Fear choking when I eat
Given up important things because of SP	It is difficult to find foods I both like and can eat	Drooling	SP takes pleasure out of eating out	Concerned about losing weight
SP is a major distraction in my life	Don’t have enough information about what I can eat	Coughing	Don’t care if I eat or not	Afraid to take liquids
Can’t do everything I want because of my SP	Figuring out what I can eat is trial and error	Food sticking in your throat	Embarrassing to finish meals	Worry about infections

Fatigue	Sleep	Comm.	Mental Health
Feel lacking in energy	Have trouble falling asleep	Difficult for me to talk	My SP is a big worry
Feel exhausted	Wake up feeling tired	People can’t understand me	Feel others see me as different due to my SP
Feel weak	Have trouble staying awake	My voice is weak	My SP depresses me
Need to rest more	Have trouble staying asleep	Difficult for me to speak clearly	Get impatient dealing with my SP

Table 1. SWAL-QOL Group Mean Scores

Study #	Spinal/ Bulbar	Months w/ symptoms	SWAL-QOL Domains									
			Desire for eating	Comm.	Sleep	Fatigue	Mental health	Social concerns	Food selection	Fear related to eating	Burden of dysphagia	Eating duration
1	Did not specify	21.2 months	82.1	**67.9**	**69.8**	**59.5**	77.1	79.8	81.8	75.7	81.6	**67.7**
2	Spinal	22 months	78.4	**55.8**	**60**	**63.2**	76.4	**46.6**	81.6	**58.4**	75.7	**40.4**
3	Did not specify	6 months	**<49**	**<49**	Not reported	Not reported	**<49**	**<49**	**<49**	**<49**	**<49**	**<49**
4	3 spinal, 1 bulbar	22.25 months	**62**	**37.25**	**65.5**	89.5	**66.25**	**66.25**	**65.25**	**62.5**	**56**	**25**

1. Tabor et al. (2016), 2. da Costa Franceschini & Mourao (2015), 3. Paris et al. (2013), 4. Luchesi & Silveira (2018)
Bold= moderate-severe impact on swallowing QOL, as reported by the authors
Dark blue= severe, Medium blue= moderate, Lightest blue= mild

Discussion & Conclusion

- The QOL domains most affected by ALS-related dysphagia were social concerns related to eating, communication, sleep, fear related to eating, and eating duration.
  - Individuals with ALS may take a longer time to eat because their swallowing muscles are weakening (2).
  - The swallowing muscles are the same muscles as the muscles used to speak, so communication becomes difficult as the muscles weaken.
  - These individuals may also avoid eating in a group setting because of embarrassment caused by altered food consistencies and/or a feeding tube (2).
- When the patient is still able to intake nutrition orally, an SLP may suggest adaptive feeding utensils, provide altered food consistencies, and work in a multidisciplinary team (e.g., physical and occupational therapists) to help the patient with all aspects of feeding (9).
- Feeding tubes (PEG and PIG) have shown to improve QOL in these individuals with ALS by prolonging survival and stabilizing weight (3,8).
- It is important for the SLP to recognize the desire and meaning of food to the individual and plan treatment around their views on QOL (4).

Limitations

- Limited research- only 6 studies that addressed the two questions
- Inclusion criteria was not specific to spinal- vs. bulbar-onset ALS, age of symptoms onset

Future directions

- More research needs to be conducted on QOL in individuals with ALS and dysphagia.
- More research is needed to learn if and how compensatory strategies (e.g., chin tuck, effortful swallow) can be implemented during the early stages of dysphagia.

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