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.

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).

Method

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,” “dysphagia,” “Quality of life,” “dysphagia.”

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

Results

Table 1. SWAL-QOL Group Mean Scores

<table>
<thead>
<tr>
<th>Study #</th>
<th>Spinal/</th>
<th>Month(s)</th>
<th>Desire for eating</th>
<th>Comm.</th>
<th>Sleep</th>
<th>Fatigue</th>
<th>Mental health</th>
<th>Social concerns</th>
<th>Food selection</th>
<th>Fear related to eating</th>
<th>Burden of dysphagia</th>
<th>Eating duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Did not specify</td>
<td>21.2 months</td>
<td>82.1</td>
<td>67.9</td>
<td>69.8</td>
<td>59.5</td>
<td>77.1</td>
<td>70.8</td>
<td>81.8</td>
<td>75.7</td>
<td>81.6</td>
<td>67.7</td>
</tr>
<tr>
<td>2</td>
<td>Spinal</td>
<td>22 months</td>
<td>78.4</td>
<td>55.8</td>
<td>60</td>
<td>63.2</td>
<td>76.4</td>
<td>46.6</td>
<td>81.6</td>
<td>58.4</td>
<td>75.7</td>
<td>40.4</td>
</tr>
<tr>
<td>3</td>
<td>Did not specify</td>
<td>6 months</td>
<td>49</td>
<td>49</td>
<td>49</td>
<td>49</td>
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<td>49</td>
<td>49</td>
<td>49</td>
<td>49</td>
<td>49</td>
</tr>
<tr>
<td>4</td>
<td>Spinal</td>
<td>22.25 months</td>
<td>62</td>
<td>37.25</td>
<td>65.5</td>
<td>89.5</td>
<td>66.25</td>
<td>66.25</td>
<td>62.5</td>
<td>56</td>
<td>25</td>
<td></td>
</tr>
</tbody>
</table>


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.

References