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The silent struggle: Swallowing impairment affects quality of life in dysphagia

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Abstract
Introduction: Dysphagia or swallowing impairment involves inadequate consumption of foods/liquids. This inadequate oral intake affects their quality of life. The impact on quality of life includes mental health, physical health, activities of daily living and social interaction etc.
Aim: To examine the effects of dysphagia on quality of life of individuals based on FOIS levels.
Methods: This study was conducted among 15 individuals with dysphagia. SWAL-QOL (Swallowing quality of life) questionnaire was administered among the individuals with swallowing impairment and compared the SWAL-QOL scores with Functional Oral Intake Scale (FOIS).
Results: The SWAL-QOL scores and FOIS level comparison reveals a significant correlation.
Discussion and Conclusion: Dysphagia includes decreased oral intake, prolonged tube feeding and weight loss and risk of essential changes to the eating pattern and social lives, thereby leading to poor quality of life. Understanding of impact of swallowing impairment is necessary for clinicians to provide management for both psychological and physical aspects of condition. To improve quality of life individuals with dysphagia patients require clinical nutritionalist counselling, psychologist counselling, speech and swallowing therapy.

Keywords: Deglutition, dysphagia, dysarthria, oral intake, quality of life

Introduction

Swallowing is a complex neuromuscular function involving structures in the oral cavity, pharynx, larynx and oesophagus, requiring coordinated activity of muscles in these regions.
Swallowing or deglutition involves the passage of liquid or a food bolus from the oral cavity to the stomach through the pharynx and oesophagus, over the Entrance to the laryngeal vestibule. During deglutition, the valves in the oral cavity and pharynx are adjusted to direct the flow of food efficiently and safely. The occurrence of pain while swallowing reduces the overall oral intake of food in these individuals. Dysphagia is defined as an abnormal delay in the movement of a food bolus from oropharynx to the stomach. It can be caused by cerebro-vascular accidents, head and neck cancers, traumatic brain injuries, cranial nerve palsy, de-myelinating diseases, neurological conditions, etc. Dysphagia affects all aspects of life, by reducing individual's dignity, self-esteem, security, work, capacity, exercise, leisure and the regard of others. Treatment of dysphagia follows some general principles. Identifying the cause, the components of the deficit, and the relevant patient factors has prime importance. Modifying oral intake in terms of quantity and consistency is often required due to the difficulty to tolerate foods like earlier. Dysphagia can destroy the social opportunities and pleasures of meal times, affect the quality of the individual's relationship with his or her caregiver and family which can further undermine health as well as their confidence. This induces a feeling of constant need for oral stimulation by food in the oral cavity and the want to return to normal feeding adversely impacts their life.
Dysphagia can significantly impact an individual's quality of life, affecting nutrition, independence, and social interactions. Assessing the severity and functional impact of dysphagia is crucial for understanding its effect on daily living. The functional oral intake scale (FOIS) provides a standardized method to evaluate a patient's ability to consume food and liquids, offering valuable insights into their functional oral intake by correlating FOIS with quality of life; this study aims to highlight real world challenges faced by individuals with varying degrees of dysphagia patients. The findings can help the professionals better understand the limitations posed by dysphagia and improve management strategies to enhance patient well being.

Aim

1. To evaluate the levels of functional oral intake and quality of life in individuals with dysphagia using FOIS and SWAL-QOL
2. To analyse the correlation between FOIS and SWAL-QOL questionnaire to understand impact of dysphagia on overall wellbeing

Methods

Participants

This study was conducted in 15 individuals (12-male, 3-female) randomly selected with Tamil as their native language, who were referred to our institute and diagnosed as dysphagia. The mean age of the participants is 55.6 years, ranging from 25 - 77 years.

Materials

The SWAL-QOL (160 items) was used, consisting of 12 domains. The patients were asked to respond to each item based on their experiences during the past month. The 12 domains of the SWAL-QOL are: burden, food selection, symptom, eating, fear, fatigue, sleep, communication, mental health, social, information and quality. The responses to each SWAL-QOL item are provided on a 5-point Likert scale (5-strongly approve 4-approve, 3-undecided, 2-disapprove, 1-strongly disapprove). The items within each QOL domain were averaged and transformed to a score of 0 to 100, with higher score indicating greater impairment. Functional Oral Intake Scale (FOIS) which consists of a 7-point Likert scale where scores 1-3 related to different grades of non-oral feeding and 4-7 related to different grades of oral feeding.

I) SWAL QOL questionnaire: Appendix 1.1
ii) FOIS: Table 1.1

Table 1: FOIS (Functional Oral Intake Scale)

Fois Level	Comment
Level 1	Nothing by mouth.
Level 2	Tube dependent with minimal attempts of food or liquid.
Level 3	Tube dependent with consistent oral intake of food or liquid.
Level 4	Total oral diet of a single consistency.
Level 5	Total oral diet with multiple consistencies, but requiring special preparation or compensation.
Level 6	Total oral diet with multiple consistencies without special preparation, but with specific food limitations.
Level 7	Total oral diet with no restrictions.

Procedure and Data Analysis

Data was collected through direct interview in individuals with dysphagia. SWAL-QOL was administered in the participants who were explained to listen the instruction carefully. Each participant was asked about the difficulties caused by dysphagia in different aspects of life and give adequate responses by choosing one of the options provided. Higher scores indicate more impact on the caregiver's quality of life. Statements were re-read to participants, if required, but not rephrased.

The response for each question was recorded by the examiner. To score a SWAL-QOL, we calculated a total score by summing up the scores from each individual domain within the questionnaire and averaged score was rated on a 5-point Liker scale, and then transforming the raw score to a 0-100 scale, with a lower score indicating greater swallowing impairment. High score (near 100): Suggests significant impairment in quality of life due to swallowing issues. Low score (near 0): Indicates minimal impact of swallowing difficulties on daily life. Functional Oral Intake Scale (FOIS) was rated for each of the individuals with dysphagia depending on the mode of nutritional intake on assessment.

Results

The subdivision of SWAL- QOL scores are represented in table 1.2, The individuals with FOIS level 1 (nothing by mouth) experienced the highest SWAL- QOL score whereas the individual with FOIS level 7 (total oral diet with no restrictions) experienced the lowest SWAL-QOL score. This shows there is a significant correlation between FOIS level and SWAL- QOL total score is presented in table 1.3.

Spearman's correlation analysis revealed a strong negative correlation between Functional Oral Intake Scale (FOIS) levels and Swallowing Quality of Life (SWAL-QOL) scores ($\rho = -0.879$, $p < 0.001$). This indicates that as FOIS levels increase (better oral intake), SWAL-QOL scores decrease, suggesting an inverse relationship between functional oral intake and perceived swallowing-related quality of life. The scatter plot in fig 1.1 further supports this finding, showing a downward trend in SWAL-QOL scores with higher FOIS levels.

Table 2: Overall scores in each subdivision of SWAL -QOL

S. No	Age	Subdivision of Swal -QOL											
		Burden	Food selection	Symptoms	Eating	Fear	Fatigue	Sleep	Communication	Mental health	Social	Information	Quality
1.	52 years/Male	19	20	55	57	30	53	12	44	107	80	36	130
2.	50 years/Male	12	17	41	39	27	24	16	41	95	62	45	130
3.	70 years/Male	4	5	43	55	28	35	11	46	24	19	47	130
4.	54 years/Male	20	21	39	66	36	35	27	46	100	73	35	130
5.	62 years/Male	14	9	51	50	27	35	20	62	70	47	75	130
6.	25 years/Female	17	17	61	81	32	28	33	43	98	73	75	130
7.	52 years/Male	15	13	30	53	17	10	17	40	100	75	60	130
8.	70 years/Male	16	14	34	52	16	7	19	42	96	73	59	130
9.	77 years/Male	20	25	58	88	40	35	30	46	110	81	50	130
10.	72 years/Male	20	22	60	92	40	35	32	43	111	85	59	130
11.	48 years/Male	20	25	79	100	40	35	31	50	118	95	60	130
12.	49 years/Female	20	25	42	65	40	35	25	37	116	63	47	130
13.	58 years/Female	16	20	38	59	28	7	19	21	80	56	55	130
14.	50 years/Male	9	12	38	54	8	7	7	10	72	38	75	130
15.	45 years/Male	12	15	19	44	16	14	14	20	48	38	73	130

Table 3: Correlation between FOIS and SWAL-QOL

S. No	Age/Sex	Diagnosis based on Speech, Language and Swallowing Evaluation	Etiology	FOIS (Level)	SWAL QOL Score
1.	52 years/Male	Oropharyngeal dysphagia	Carcinoma left floor of mouth. Left composite resection with PMMC flap reconstruction	2	53.58
2.	50 years/Male	Pharyngeal dysphagia	Skull base osteomyelitis with Multiple cranial nerve palsy	6	45.75
3.	70 years/Male	Oropharyngeal dysphagia	Progressive bulbar palsy associated with motor neuron disease	7	35.5
4.	54 years/Male	Oropharyngeal dysphagia	Left inferior maxillectomy specimen and maxilla- facial surgery in Lower jaw.	2	52.33
5.	62 years/Male	Oropharyngeal dysphagia	Carcinoma in tongue. Right hemiglossectomy	5	49.16
6.	25 years/Male	Oropharyngeal dysphagia	Gillian barre syndrome. Acute onset of quadriparesis with bulbar involvement	1	57.33
7.	52 years/Male	Oropharyngeal dysphagia	Carcinoma in tongue. Left wide local excision and extended supraomohyoid neck	5	46.6
8.	70 years/Male	Oropharyngeal dysphagia	Carcinoma in Larynx. Total laryngectomy and tracheosophageal puncture done	5	46.5
9.	77 years/Male	Oropharyngeal dysphagia	Carcinoma in Lateral tongue, Post OP PT2N0 Left hemiglossectomy nasolabial flap reconstruction	2	59.41
10.	72 years/Male	Oropharyngeal dysphagia	Carcinoma Right Lower alveolus. Right composite resection and tongue flap	1	60.75
11.	48 years/Male	Oropharyngeal dysphagia	Acute ischemic stroke	1	65.25
12.	49 years/Female	Oropharyngeal dysphagia	Acute ischemic stroke	2	53.75
13.	58 years/Female	Oropharyngeal dysphagia	Acute ischemic stroke	3	44.08
14.	50 years/Male	Oropharyngeal dysphagia	Acute ischemic stroke	4	38.33
15.	45 years/Male	Oropharyngeal dysphagia	Acute ischemic stroke	6	36.91

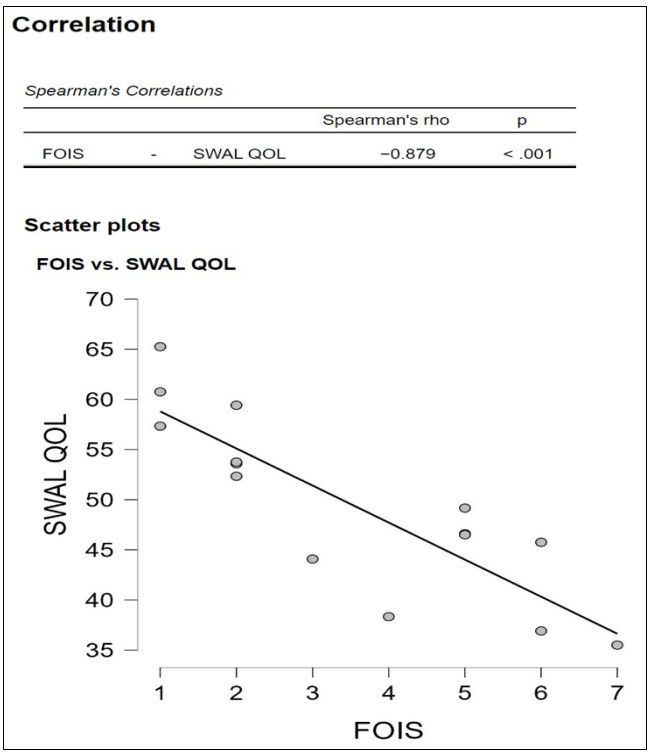

Fig 1: Spearman's Correlation between SWAL-QOL and FOIS

Discussion

Patient with dysphagia can present with various problems which include both physical and psychosocial. The physical problems consist of hoarse voice, nasopharyngeal regurgitation and coughing on swallowing. If not managed properly, dysphagia can lead to dehydration; malnutrition, respiratory infections and death some individuals dealing with swallowing problem suffer and gave up important things because of their swallowing impairment. They take more time to have their meal and some of them lose their interest in eating and also other family members and friends has to wait while the individual with dysphagia eat. They have fear of choking during intake of liquids and experience fatigue, weakness, tiredness due to improper intake of foods/liquids. They faced difficulty in communication (not able to speak clearly, worse voice quality).

The individuals with dysphagia become more emotionally driven, discouraged, ashamed, unhappy, depressed because of tube dependent intake of foods/liquids and social gathering aren't enjoyable, refused to eat out alone and with their family and friends. Anxiety can clinically present with increased physical arousal, sleep disturbance, inattention, impaired decision-making, agitation and anger. These can affect the patient's activities of daily living as well as the relationship with the family.

Compensatory strategies are intended to improve the swallowing in an immediate but temporary manner. Usually, they do not involve the strengthening of the musculature. Most often, food is involved while carrying out these techniques and hence termed "direct." There are mainly three compensatory strategies: (1) postural modification, (2) diet modifications (texture and volume modifications), and (3) sensory enhancements. Postural modification is to eliminate or reduce patients' food or liquid aspiration as seen during evaluation. Also, postural modifications may be implemented during an instrumental assessment to bring about an immediate change in swallowing physiology and bolus flow. Changes in position of the head or body have been shown to eliminate aspiration. Diet modification includes texture and bolus volume. Sensory enhancement is useful when there is a delay in initiation of the swallow. Viscosity, the method of presentation (spoon vs. cup, anterior placement vs. posterior placement), carbonation, taste modification, and temperature modification.

The present study found a strong negative correlation (ρ = -0.879, p< 0.001) between Functional Oral Intake Scale (FOIS) levels and Swallowing Quality of Life (SWAL-QOL) scores, indicating that individuals with higher functional oral intake reported lower swallowing-related quality of life. These finding contrasts with the general

expectation that improved oral intake would enhance quality of life.

One possible explanation for this inverse relationship is that patients with higher FOIS levels may experience persistent swallowing difficulties despite better oral intake, leading to reduced quality of life due to fear of aspiration, dietary restrictions, or social discomfort while eating. Additionally, individuals with lower FOIS levels (who rely on non-oral feeding) may adapt to their condition over time, experiencing fewer meal-related anxieties and, consequently, reporting a better swallowing-related quality of life.

Previous studies have highlighted that dysphagia impacts multiple aspects of well-being, including emotional distress, physical discomfort, and social interactions. While improved oral intake may offer nutritional benefits, it does not necessarily alleviate psychosocial concerns associated with swallowing difficulties. This suggests that quality of life assessments should consider both physiological and psychological aspects of dysphagia.

Conclusion

As the FOIS level increases, SWAL-QOL score decreases. This shows reduced oral intake of foods/liquids has a negative impact on sleep, communication, mental health and social interaction. To improve quality of life and the individuals with dysphagia should increase their level of functional oral intake. Regularly attending speech and swallowing therapy will improve their functional oral intake. Due to inadequate functional oral intake of foods/liquids, they lack in nutritional status. The individuals with swallowing impairment should be referred to clinical nutritionalist for their proper diet. This will reduce the negative impact of quality of life in individuals with dysphagia.

Clinical Implications

The findings emphasize the need for comprehensive dysphagia management, focusing not just on improving oral intake but also on addressing psychosocial and emotional challenges. Clinicians should incorporate patient-centered interventions, including counselling, dietary modifications, and swallowing therapy tailored to individual needs.

Limitations and Future Research

This study is limited by sample size and does not account for other factors influencing quality of life, such as age, comorbidities, or duration of dysphagia. Future research should explore longitudinal studies to assess changes in swallowing-related quality of life over time and examine psychological coping mechanisms in dysphagia patients.

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Appendix 1.1

SWAL-QOL Questionnaire

Burden

1. Dealing with my SP is very difficult
2. Given up important things because of SP
3. SP is a major distraction in my life
4. Can’t do everything I want because of my SP

Food Selection

1. Figuring out what I can eat is a problem
2. It is difficult to find foods I both like and can eat
3. Don’t have enough information about what I can eat
4. Figuring out what I can eat is trial and error
5. I know what I can/can’t eat

Symptom Frequency/Bother

1. Coughing
2. Choking when eating food
3. Choking when taking liquids
4. Thick saliva
5. Thick phlegm
6. Dry mouth
7. Gagging
8. Excess saliva
9. Excess phlegm
10. Bad breath
11. Sore throat
12. Clearing your throat
13. Drooling
14. Problems chewing
15. Food sticking in your throat
16. Food sticking in your mouth
17. Food/liquid dribbling out your mouth
18. Food/liquid coming out your nose
19. Coughing food/liquid out your mouth when stuck

Eating

1. Takes me longer to eat than others
2. SP takes pleasure out of eating out
3. Don’t care if I eat or not
4. Embarrassing to finish meals last
5. Avoid a lot of foods
6. Miss going to restaurants
7. Don’t enjoy eating anymore
8. Prefer eating alone
9. Lost my connection with food
10. Rarely hungry anymore
11. Takes forever to eat

12. Don't like food anymore
13. Miss being able to eat
14. Have to plan ahead about eating
15. Able to eat anything
16. Lost interest in eating
17. Looking forward to eating normally
18. Can't taste food very well
19. Others have to wait while I eat
20. Long for certain foods
21. Eating is a chore
22. Feel rushed when I eat out

Fear
1. Fear choking when I eat
2. Concerned about losing weight
3. Worry about pneumonia
4. Anxious about eating
5. Afraid of choking when I drink
6. Worry about infections
7. Afraid to take liquids
8. Never know when I will choke

Fatigue
1. Feel lacking in energy
2. Feel exhausted
3. Feel weak
4. Feel tired
5. Feel weary
6. Need to rest more
7. Feel worn out

Sleep
1. Have trouble falling asleep
2. Wake up feeling tired
3. Getting enough sleep
4. Have trouble staying awake
5. Wake up feeling rested
6. Have trouble staying asleep
7. Awaken and can't fall back to sleep

Communication
1. Difficult for me to talk
2. People can't understand me
3. My voice is weak
4. Satisfied with my voice quality
5. Difficult for me to speak clearly
6. Not able to talk for very long
7. My speech quality has gotten worse
8. Difficult to make myself clear
9. Have to limit my talking
10. Hard for me to communicate

Mental Health
1. My SP is a big worry
2. My SP doesn't emotionally affect me
3. Feel others see me as different due to my SP
4. My SP depresses me
5. Get impatient dealing with my SP
6. Self-conscious due to my SP
7. Bothers me to have to drink/eat carefully
8. Feel despair over my SP
9. More emotional due to my SP
10. Feel lonely due to my SP
11. Embarrassed to be around others due to my SP
12. Not eating normally makes me mad
13. Not happy due to my SP
14. My SP frustrates me
15. Ashamed for people to know about my SP
16. Discouraged due to my SP
17. irritating to see others eat/drink normally
18. My SP has gotten me down
19. My self image is worse due to my SP
20. My SP makes me angry
21. Unhappy because I can't eat normally
22. Bitter because no one knows what I deal with
23. Not being able to eat depresses me
24. Don't like depending on others

Social/role
1. Don't eat out due to my SP
2. Depend on others more due to my SP
3. My SP makes my social life difficult
4. People treat me different due to my SP
5. Get enough social support for my SP
6. My work activities have changed due to my SP
7. My SP makes me want to stay home
8. Don't like to eat with others anymore
9. Have someone to help with my SP
10. My SP hasn't changed my social life
11. My family/friends reject me
12. Don't enjoy same activities anymore
13. Have someone help prepare my food
14. Social gatherings aren't enjoyable due to my SP
15. My friends/family is there when I need them
16. Less patient with family due to my SP
17. My role with family has changed due to my SP
18. My SP has brought me closer to others
19. People give me too much attention due to my SP

Information
1. Foods I should eat
2. Foods I should avoid
3. Liquids I should drink
4. Liquids I should avoid
5. Techniques to help get food down
6. Techniques to avoid choking
7. Imagine my swallowing in the future
8. Dealing with embarrassment
9. Progress to date
10. Contacting a swallowing clinician
11. Treatment options
12. What to do while choking
13. Effect my SP has on my lungs
14. Signs of not enough food/drink
15. Goals of my SP treatment

Quality
1. Clinicians provide useful information
2. Clinicians don't know my problems
3. Clinicians are experts at problems like mine
4. Clinicians listen to me
5. Clinicians don't know what an SP is like
6. Clinicians know what they're doing
7. Have confidence in my clinicians
8. Feel my clinicians could do more for me
9. Clinicians give clear answers to questions
10. Trust the clinician's judgement
11. Clinicians do everything possible for me

12. If a clinician tells me something, it's true
13. Clinicians are available when needed
14. Always try to follow clinician's advice
15. Clinicians don't communicate with others
16. Clinicians really care about me
17. Clinicians and I communicate well
18. Get conflicting advice from different clinicians
19. Clinicians explain everything about my treatment
20. Clinicians encourage my questions
21. Clinicians believe what I tell them about my SP
22. Clinicians spend enough time with me
23. Clinicians put my needs first
24. Clinicians take me seriously
25. Clinicians are considerate of my needs
26. Clinicians keep me informed of my progres