A Comprehensive Assessment of Dysphagia among Individuals with Intellectual Disabilities in Al-Baha region, Saudi Arabia

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ABSTRACT

To assess dysphagia and nutritional status among adults with intellectual disabilities living in an institutional care facility in Al Baha, Saudi ArabiaA cross-sectional study was conducted from May to October 2024 among 89 residents of special care homes. Demographics, the Decayed Missed Filled Teeth (DMFT) index, Dysphagia Handicap Index (DHI), and Eating Assessment Tool-10 (EAT-10) were recorded. Statistical analysis was performed using SPSS version 27, with p-values < 0.05 considered significant. The mean age of participants was 30.11 years (SD = 4.39). The mean Total DHI score was 50.36 (SD = 20.64), with functional, physical, and emotional domain scores of 18.06 (SD = 9.10), 17.84 (SD = 7.18), and 14.44 (SD = 6.08), respectively. The mean EAT-10 score was 22.34 (SD = 3.48). No significant differences were found across the severity of intellectual disabilities. A significant correlation was observed between DMFT and DHI (r = 0.635), DMFT and EAT-10 (r = 0.703), and DHI and EAT-10 (r = 0.585). Dysphagia is a significant concern for adults with intellectual disabilities, affecting nutrition and quality of life. Effective management strategies, including mealtime support and dietary modifications, are essential to enhance well-being in this population. Further research is warranted to explore comprehensive care approaches.

KEYWORDS: Dysphagia, Intellectual Disabilities, Quality of Life, Eating Assessment Tool-10 (EAT-10), Dysphagia Handicap Index (DHI)

INTRODUCTION

Individuals with severe to profound Intellectual and Developmental Disabilities (IDD) often require dedicated supervision in social settings and significant assistance with self-care activities. These individuals frequently face communication challenges and physical limitations, further impacting their daily lives. Among the fundamental activities essential for survival and well-being, feeding, swallowing, and breathing play a critical role, underscoring their importance in maintaining health and quality of life[1,2]. When these activities are impaired, they can lead to increased morbidity and mortality rates. The feeding process involves various stages, from food selection to oral insertion, chewing, and swallowing. Individuals with physical or mental disabilities may deviate from this process, potentially affecting their feeding patterns[3,4].

People with intellectual disabilities may experience challenges with feeding, such as difficulties with chewing or latching to the nipple. They may also have issues with oral sensory processing, self-feeding, engaging in mealtimes, and displaying maladaptive behaviors during meals. Swallowing is a crucial function for humans, and while it may seem simple, it is a highly intricate and dynamic process. The structures and systems involved in swallowing are similar to those involved in breathing, making it extremely important for overall nutrition[5,6].

Dysphagia, also known as difficulty in eating, drinking, and swallowing, can be categorized into oropharyngeal and esophageal. Individuals with intellectual disabilities may experience profound implications from dysphagia, including discomfort, poor nutritional status, dehydration, aspiration, and choking. Swallowing difficulties can manifest in the oral, pharyngeal, or esophageal phase of swallowing. The impacts of dysphagia can be considerable and may be associated with other symptoms such as regurgitation, tracheobronchial aspiration, retrosternal pain, heartburn, hoarseness, hiccups, and painful swallowing, affecting the clinical, nutritional, and social aspects of the individual[7-10].

If dysphagia is not treated for extended periods in older individuals, it can lead to severe issues such as malnutrition, dehydration, weight loss, aspiration pneumonia, and suffocation. In addition, symptoms of dysphagia, such as coughing, throat clearing, or choking during or after eating, may result in fear of eating and drinking, as well as prolonged mealtime duration, ultimately reducing the quality of life.

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Consequently, timely identification of dysphagia risk can significantly reduce the likelihood of experiencing various physical or psychological complications[11].

In the treatment of patients with dysphagia, the quality of life (QoL) has recently become increasingly important. According to the World Health Organization (WHO), quality of life is defined as an individual's perception of their position within the culture and value systems in which they live and about their goals, expectations, standards, and concerns[12]. self-assessments using patient-centered measures have gained significance as they may not necessarily align with clinician-driven tools. Several questionnaires have been developed to evaluate the QoL of patients with dysphagia. The Dysphagia Handicap Index (DHI) is a self-assessment questionnaire that focuses on the quality of life-related to and resulting from the ability to swallow. The Eating Assessment Tool-10 (EAT-10) is a self-administered survey instrument used for the subjective assessment of dysphagia[13].

Dysphagia is a significant issue for individuals with intellectual disabilities. Research indicates that dysphagia negatively impacts various aspects of a person's life, such as employment, recreation, and social interactions. Due to the limited abilities of the individuals, caregivers have a restricted understanding of their conditions, leading to the worsening of existing and ongoing health problems[14]. This study aimed to assess dysphagia and nutritional status of adults with intellectual disabilities residing in an institutional care center at Al Baha, Kingdom of Saudi Arabia.

MATERIALS AND METHODS

A cross-sectional study was conducted among patients resided in the special care home in Al-Baha, Saudi Arabia. The study was conducted during May 2024 to October 2024 with approval of institutional ethical committee. The special care home authorities reviewed and granted permission to conduct the study. Informed consent was obtained from the guardians or parents of the participants.

Study Population: The study included individuals diagnosed with intellectual disabilities, based on the medical records of the special care center. The severity of their conditions was categorized as mild, moderate, or severe according to the International Classification of Diseases, 10th Revision (ICD-10). Each participant had undergone a comprehensive assessment at a qualified hospital, and the results were carefully documented to ensure accurate classification. Participants were adults aged 18 years and older, representing both genders, who were receiving care for intellectual disabilities. Efforts were made to include all eligible individuals; however, those who chose not to participate or did not provide consent were respectfully excluded from the study.

Sample size calculation: Based on the pilot study, the prevalence of periodontal disease among adults was 94% using the formula four $p*q/d^2$. The final sample size estimated was 87 individuals, 80% power, and a 5 % precision level. A comprehensive dental assessment was conducted using a specialized form that included a Structured Interview covering related age, gender, medication schedule, and comorbidity; the Clinical Examination evaluated assessed caries status using the DMFT index developed by Henry Klein, Carole E Palmer, and Knutson JW[15]. Additionally, DHI and EAT-10 were recorded.

Dental examination: Before the study began, two examiners were trained in the Department of Public Health Dentistry. The inter-examiner variability was assessed, resulting in a weighted kappa statistic of 0.91. With sufficient natural lighting, a clinical oral examination of Type III was conducted using a mouth mirror and community periodontal index probe.

Questionnare: The DHI is a self-evaluation survey regarding the impact of swallowing ability on quality of life. It comprises 25 statements, and patients use a three-point Likert scale to rate their answers (0 for "never," 2 for "sometimes," and 4 for "always"). These statements cover three aspects of swallowing disability: functional elements (9 self-assessment questions: 6, 7, 9, 10, 14, 15, 16, 22, 23), physical condition (9 self-assessment questions: 1, 2, 3, 4, 5, 11, 20, 24, 25), and emotional state (7 self-assessment questions: 8, 12, 13, 17, 18, 19, 21). Participants can score a maximum of 100 points. A score of 0 indicates complete satisfaction with swallowing ability. A higher DHI value signifies greater dissatisfaction with swallowing quality and ability. According to Sobol et al., the normative DHI score for a healthy individual is 4, and a score above 4 suggests self-perceived dysphagia symptoms[16].The Eating Assessment Tool-10 (EAT-10) was created in 2008 by Belafsky et al. as a screening tool for dysphagia. It consists of 10 self-assessment questions, each with five levels of difficulty. Patients rate their experience from "no problem" to "serious problem," with a total score ranging from 0 to 40. This tool helps to identify individuals at high risk of swallowing disorders and can be completed quickly[17].

Translation: In the translation process, the original English version of the DHI and EAT-10 was translated along with the principles of good practice carried out for the translation and cultural adaptation process for patient-reported outcome measures as defined by the International Society for Pharmacoeconomics and Outcome Research[18]. A speech-language expert proficient in Arabic translated the original questionnaire, and the translation was reviewed collaboratively with an experienced researcher fluent in the language. The items were then back-translated into English and compared with the original questionnaire to ensure accuracy and equivalence. The authors thoroughly reviewed the back-translation to finalize the adaptation process. Internal consistency of the translated questionnaire was assessed using Cronbach's alpha coefficient, yielding high reliability scores of 0.904 and 0.891 for the two questionnaires. Similarly, the Cronbach's alpha coefficients for the Dysphagia Handicap Index (DHI) subscales—physical (0.890), functional (0.899), and emotional (0.921)—were also robust. These findings indicate strong internal consistency, suggesting that all items effectively measure the same underlying construct.

Statistical Analysis: Statistical analysis was performed using SPSS for Windows, version 27, with a two-tailed p-value of less than 0.05 considered statistically significant. The reliability of the Dysphagia Handicap Index (DHI) and the Eating Assessment Tool-10 (EAT-10) was assessed through internal consistency and test-retest reliability. Cronbach's alpha was calculated to evaluate the internal consistency of the total DHI and its physical, functional, and emotional subscales. The normality of quantitative variables was assessed using the Shapiro–Wilk test, while test-retest reproducibility was analyzed using Spearman's rank correlation coefficient (r-Spearman). Comparative analysis was conducted using the Kruskal–Wallis test to evaluate DHI and EAT-10 scores across subgroups. For multiple comparisons, the Mann-Whitney U test was applied to identify significant differences between pairs. All results were interpreted with a statistical significance threshold set at $p < 0.05$, ensuring robust and reliable findings.

RESULTS

The study involves 89 adults, all of whom have intellectual disabilities. The average age of the participants was 30.11 years, with a standard deviation of 4.39, and their average duration of residence in the facility was 26.49 years, with a standard deviation of 4.66. Most of

the participants (58.4%) were female. The participants were divided based on the severity of their disabilities, with 43.8% classified as mild, 29.2% as moderate, and 26.9% as severe. Some participants also had physical disabilities in addition to their intellectual disabilities. Approximately 44.9% of the participants had malocclusion, and all of them were taking medication.[Table 1].

Table 1. Demographic Characteristics of Study Participants

	N	%
Age		
18-25	1	1.1
26-30	58	65.2
31-35	21	23.6
36	9	10.1
Gender		
Female	37	41.6
Male	52	58.4
Intellectual disability		
Mild	39	43.8
Moderate	26	29.2
Severe	24	26.9
Disability Types		
None	45	50.6
Physical	39	43.8
Hearing	4	4.5
Visual	1	1.12
Medication		
Yes	89	100
No	0	0
Comorbidity		
Yes	59	66.3
No	30	33.7

For the study participants, the mean Total DHI score was 50.36 (20.64), the mean Functional aspect domain score was 18.06 (9.10),), the mean physical condition domain score was 17.84 (7.18), the mean emotional state domain score was 14.44 (6.08). There was no significant difference seen across the domains and Total DHI score when they were compared across the severity of Intellectual Disabilities. Also, the mean EAT -10 score for the participants was 22.34 (3.48), which was found to be comparable across various severity of Intellectual Disabilities [Table 2]

The mean DHI index scores were compared across the patients concerning additional disability. The mean scores of 31.02(6.02) were found in patients with no disability, in comparison to 66.00 (11.43) for patients having a hearing disability. These findings in comparison shows significant findings. For functional aspect and physical condition domains, significantly lower scores were seen among patients having no disability in comparison to patients having a hearing disability. However, For emotional state domains, significant differences in scores were seen among patients having no disability and patients having a visual disability. The Eat-10 scores were also significantly lower among patients having no disability as compared to patients having a visual disability. [Table 3]

Table 4 compares Dysphagia Handicap Index (DHI) and Eating Assessment Tool-10 (EAT-10) scores based on the presence of comorbidities. No significant differences were found in DHI subdomains, total DHI scores, or EAT-10 scores between participants with comorbidities (mean total DHI = 52.95, EAT-10 = 22.19) and those without comorbidities (mean total DHI = 45.27, EAT-10 = 22.67). This indicates that comorbidities did not significantly impact swallowing or eating difficulties. A significant moderate positive correlation was observed between DHI and EAT-10 scores ($r = 0.585$, $p < 0.01$), indicating that higher perceived swallowing difficulties were associated with increased eating-related challenges. Similarly, a significant moderate positive correlation was found between DMFT

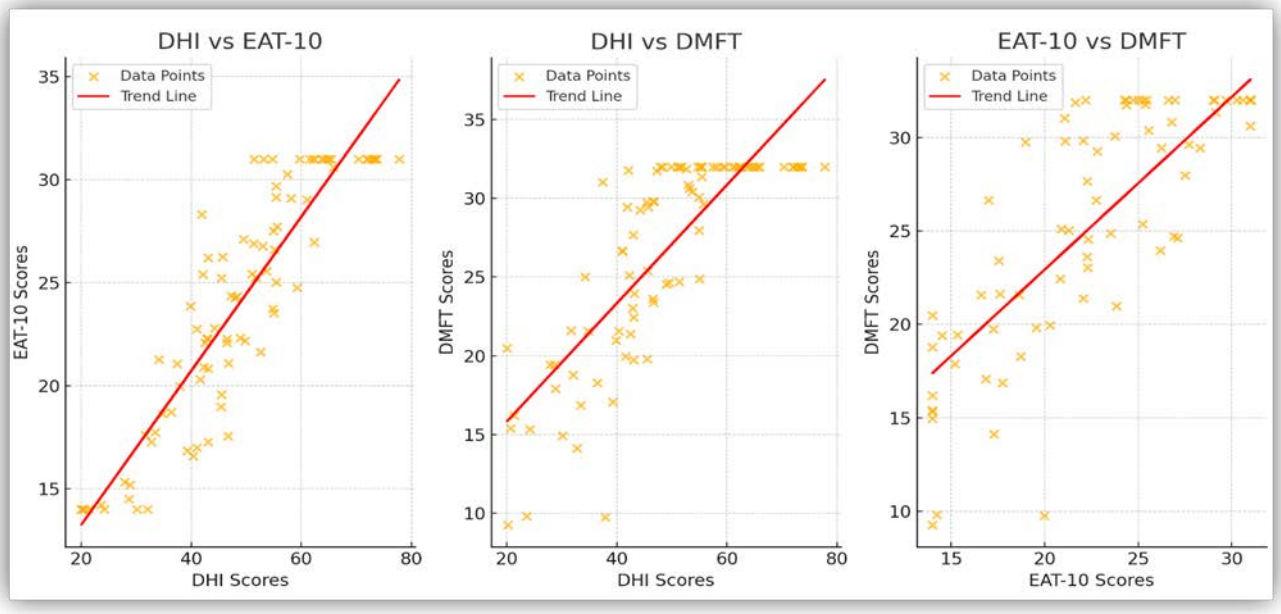

Figure 1. Relationships between Dysphagia Handicap (DHI), Eating Difficulties (EAT-10), and Dental Health (DMFT).

Table 2. Dysphagia Handicap Index (DHI) and Eating Assessment Tool-10 (EAT-10) Scores by Severity of Intellectual Disability.

	N	Mean	Std. Deviation	95% Confidence Interval for Mean		Minimum	Maximum	P value
				Lower Bound	Upper Bound			
Functional aspect								
Mild	39	17.5	9.6	14.4	20.6	0	34	
Moderate	26	16.2	8.4	12.8	19.6	6	30	0.157
Severe	24	21	8.6	17.4	24.6	4	34	
Total	89	18.1	9.1	16.1	20	0	34	
Physical condition								
Mild	39	18.5	6.8	16.3	20.7	8	32	
Moderate	26	15.2	7.4	12.2	18.2	6	28	0.07
Severe	24	19.7	7	16.7	22.6	6	28	
Total	89	17.8	7.2	16.3	19.4	6	32	
Emotional state								
Mild	39	14.9	6.5	12.8	17	4	26	
Moderate	26	12.6	5.8	10.3	14.9	4	24	0.169
Severe	24	15.7	5.5	13.4	18	4	22	
Total	89	14.4	6.1	13.2	15.7	4	26	
Total DHI								
Mild	39	50.9	21.2	44	57.8	22	86	
Moderate	26	44.1	19.7	36.1	52	20	74	0.108
Severe	24	56.3	19.6	48.1	64.6	22	80	
Total	89	50.4	20.6	46	54.7	20	86	
EAT -10								
Mild	39	22.7	3.4	21.6	23.8	16	31	
Moderate	26	21.4	3.2	20.1	22.7	15	28	0.242
Severe	24	22.9	3.7	21.3	24.5	14	29	
Total	89	22.3	3.5	21.6	23.1	14	31	

Kruskal wallis test , mann whitney u test, level of significance set at $p < 0.05$.

Table 3. Comparison of Dysphagia Handicap Index (DHI) and Eating Assessment Tool-10 (EAT-10) Scores by Type of Additional Disability.

	N	Mean	Std. Deviation	95% Confidence Interval for Mean		Minimum	Maximum	P value
				Lower Bound	Upper Bound			
Functional aspect								
None	45	9.9	3.6	8.8	11	0	18	
Physical	39	26.3	3.9	25.1	27.6	16	34	0.001*
Hearing	4	27.5	3	22.7	32.3	26	32	
Visual	1	28				28	28	
Physical condition								
None	45	11.7	3.6	10.6	12.8	6	20	
Physical	39	24.5	3.3	23.4	25.6	16	32	0.001*
Hearing	4	21.5	4.4	14.4	28.6	16	26	
Visual	1	20				20	20	
Emotional state								
None	45	9.5	3.5	8.4	10.5	4	16	
Physical	39	19.7	2.9	18.8	20.7	14	26	0.001*
Hearing	4	17	5.3	8.6	25.4	10	22	
Visual	1	22				22	22	
Total DHI								
None	45	31	6	29.2	32.8	20	44	
Physical	39	70.6	6.1	68.6	72.5	52	86	0.001*
Hearing	4	66	11.4	47.8	84.2	52	78	
Visual	1	70				70	70	

Kruskal wallis test , mann whitney u test, level of significance set at $p < 0.05$.

Table 4. Dysphagia Handicap Index (DHI) and Eating Assessment Tool-10 (EAT-10) Scores by Presence of Comorbidities.

	N	Mean	Std. Deviation	95% Confidence Interval for Mean		Minimum	Maximum	P value
				Lower Bound	Upper Bound			
Functional aspect								
Yes	59	19.3	8.9	17	21.6	6	34	0.076
No	30	15.7	9.1	12.3	19.1	0	30	
Physical condition								
Yes	59	18.4	7.5	16.5	20.4	6	32	0.273
No	30	16.7	6.5	14.2	19.1	6	28	
Emotional state								
Yes	59	15.2	6.1	13.6	16.8	4	26	0.094
No	30	12.9	5.8	10.8	15.1	4	26	
Total DHI								
Yes	59	53	21	47.5	58.4	20	86	0.097
No	30	45.3	19.2	38.1	52.4	22	80	
EAT -10								
Yes	59	22.2	3.4	21.3	23.1	15	31	0.542
No	30	22.7	3.6	21.3	24	14	29	

Mann whitney u test, level of significance set at $p < 0.05$

and DHI scores ($r = 0.635$, $p < 0.01$), suggesting that poorer dental health was linked to greater dysphagia impact. Additionally, a strong positive correlation was identified between DMFT and EAT-10 scores ($r = 0.703$, $p < 0.01$), emphasizing the connection between dental health issues and eating difficulties.

DISCUSSION

Intellectual disability (ID) is a neurodevelopmental disorder characterized by inconsistentency with limitations in intellectual ability and adaptive functioning. There is a close relationship between motor disabilities (MD) and ID. Individuals with both the condition having systemic illness in compare to the general population[19-20].

The research on feeding pattern of patients with special needs is scanty. Dysphagia, or swallowing impairment, is a health risk threatening human dignity because swallowing is essential for sustaining an individual's life. It is documented that a significant percentage of children with chronic developmental issues, such as cerebral palsy (CP), Down syndrome, and others, experience or will experience difficulties with swallowing. These difficulties can lead to further health complications and impact their social adaptation. The motor challenges these children face may also affect their oral function, encompassing both motor and sensory aspects of the oral cavity and pharynx. In recent years it has been observed the interest in quality of life-related to swallowing and voice,there is a need for evaluation of QoL related to swallowing among adults with Intellectual Disabilities.

In the present study, the mean Total DHI score was 50.36 (20.64), the mean Functional aspect domain score was 18.06 (9.10), the mean physical condition domain score was 17.84 (7.18), the mean emotional state domain score was 14.44 (6.08). There was no significant difference seen across the domains and Total DHI score when they were compared across the severity of Intellectual Disabilities. The findings of Sielska-Badurek EM et al (2022) report that mean DHI was 55.7 ± 15.1 for group with neurological disorders (stroke, Alzheimer's, myasthenia gravis, mitochondrial myopathy)[23]. In the present study, the mean EAT -10 score for the participants was 22.34 (3.48), which was found to be comparable across various severity of Intellectual Disabilities. The higher score signifies the difficulty or barriers.

This high DHI and EAT-10 score found in the present study draws attention to the fact that participants couldn't communicate their pain or discomfort effectively and efficently. When the children showed signs of unusual restlessness, the caregivers were unsure about the condition. Though they observed abnormal signs in their children's mouths, they hesitated to take them to the clinic immediately. They were concerned that the children wouldn't understand the reasons or be able to handle the procedures.

A significant correlation was seen between DMFT scores and Total DHI scores (moderate: 0.635), DMFT scores and EAT -10 scores (high: 0.703), and also between total DHI and EAT -10 scores (moderate: 0.585). These findings highlight the fact that Children who experienced issues with chewing and swallowing tended to hold food in their mouths without swallowing. Patients' limited communication and cognitive skills posed a barriers with challenges. Caregivers were unaware about the children's symptoms which led to delay in scheduling dental visits. Caregivers were also hesitant to seek treatment due to previous negative experiences or concerns about rejection. Even when patients were able to receive treatment, they became frustrated by the children's resistance and distress during the procedures.

Also dental practitioners encounter challenges in conducting preoperative assessments, gauging the extent of issues, and conducting other appraisals, leading them to sometimes forgo commencing actual treatments. Identifying clinical indicators of dysphagia proactively can streamline case management and facilitate the referral for clinical and instrumental assessments and care. The appraisal of feeding difficulties by a diverse team (comprising caregivers, speech therapists, dietitians, and pediatricians) is essential[24].

Data Points: Individual participant scores for each variable pairing. Trend Line: Overall direction and strength of the relationship between paired variables. DHI (Dysphagia Handicap Index): A measure of dysphagia's impact on quality of life. EAT-10 (Eating Assessment Tool-10): A self-reported assessment of swallowing difficulties. DMFT (Decayed, Missing, Filled Teeth Index): An index assessing dental health.

This study was conducted at a single center with a relatively small sample size, which may limit the generalizability of the findings. Additionally, while dysphagia is often associated with conditions such as head and neck cancer, trauma, gastroesophageal reflux disease, and primary esophageal abnormalities, these conditions were not observed among the participants in this study.

CONCLUSION

Individuals with intellectual disabilities face significant challenges associated with dysphagia, which profoundly impacts their health, quality of life, and financial resources. Dysphagia often results in serious complications such as dehydration, malnutrition, and aspiration pneumonia, exacerbating the vulnerability of this population. Despite its critical implications, the quality of life for individuals with intellectual disabilities experiencing dysphagia has received limited attention in research. There is an urgent need for comprehensive studies focusing on effective management strategies, including mealtime assistance, proper positioning, dietary modifications, and their overall impact on health and well-being. Addressing these gaps is essential to improving care and outcomes for this underserved group.

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Competing Interest: None

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