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Prevalence of dysphagia symptoms in Cretan children and adolescents with neurological disorders

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المخلص

أهداف البحث: يعرف عسر البلع بأنه أي خلل في التغذية أو البلع في مرحلة واحدة أو أكثر. هدفت هذه الدراسة إلى معرفة مدى انتشار أعراض عسر البلع لدى الأطفال والمراهقين المصابين باضطرابات عصبية، وعلاقتها بالخصائص المحددة للأطفال والمراهقين.

طرق البحث: باستخدام زيارات المستشفى العام/قسم طب الأطفال في هيراكليون، مدينة كريت، اليونان، تم تصميم دراسة مقطعية وتنفيذها على مدى ٧ أشهر (2017-2018) وتم اجلاب ما مجموعه ٢٦٨ طفلاً ومراهقاً. تم تسجيل بياناتهم الديموغرافية وملفهم الطبي، مع التركيز على السمات الأكثر وضوحاً وغالباً السريرية التي تصف اضطرابات التغذية والبلع لكل مرحلة (الفم، البلعوم، والمريء).

النتائج: ٥٤,٩٪ كانوا ذكورا، وكان متوسط العمر للجميع ٥,٩ سنوات، بينما كانت الاضطرابات النفسية والسلوكية الأكثر انتشاراً (٣٧,٣٪) في التصنيف الإحصائي الدولي للأمراض والمشكلات الصحية ذات الصلة. كان انتشار أعراض عسر البلع ٢٤,٣٪ في الفم و ١٨,٣٪ في البلعوم و ٢٠,١٪ في المرء. تم العثور على عرض واحد على الأقل في الفم وفي البلعوم وفي المرء أو عسر البلع في ٤٢,٥٪. يبدو أن وجود عسر البلع مرتبط بعمر أقل، ارتفاع الأمراض المرافقة للتصنيف الإحصائي الدولي للأمراض والمشكلات الصحية ذات الصلة أو استخدام الدواء.

الاستنتاجات: وجدت الدراسة انتشار عسر البلع في الأطفال والمراهقين الذين يعانون من اضطرابات عصبية، في حين أن الأعمار المنخفضة والأمراض المرافقة واستخدام الأدوية ظهرت هي العوامل التي تتطلب إدارة أفضل.

الكلمات المفتاحية: عسر البلع؛ اضطرابات البلع؛ خلل البلع؛ البلع؛ اضطرابات التغذية.

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Abstract

Objectives: Dysphagia is defined as any feeding or swallowing dysfunction at one or more stages of digestion. This study aims to investigate the prevalence of dysphagia symptoms in children and adolescents with neurological disorders and its relationship with the specific characteristics of the subjects.

Methods: Using data from general hospital/paediatric department visits in Heraklion, Crete, Greece, a cross-sectional study design was implemented over a seven-month period (2017–18), and a total of 268 children and adolescents were recruited. Demographic data and medical profiles were recorded, focusing on the most obvious and frequent clinical features of feeding and swallowing disorders per stage (oral-OS, pharyngeal-PS, and oesophageal-ES).

Results: In the sample, 54.9% were boys and the mean age was 5.9 years; the most prevalent International Statistical Classification of Diseases and Related Health Problems (ICD-10) disorder was mental and behavioural disorders (37.3%). The prevalence of dysphagia symptoms was 24.3% during the OS (95% CI: 19.0–29.9), 18.3% in the PS (95% CI: 14.0–23.2), and 20.1% in the ES (95% CI: 15.7–25.4). At least one symptom of dysphagia was observed during the OS, PS, and ES in 42.5% (95% CI: 36.7–48.5) of the sample. The presence of dysphagia seems to be related to lower age (Odds Ratio [OR] = 0.45, $p < 0.001$), higher ICD-10 comorbidity (OR = 1.89, $p < 0.05$), or medication use (OR = 2.31, $p < 0.05$).

Conclusions: A high prevalence of dysphagia was found in children and adolescents with neurological disorders, while lower age, comorbidity, and medication use emerged as factors that required better management.

Keywords: Dysphagia; Feeding disorders; Swallowing disorders; Swallowing dysfunction

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Introduction

Swallowing is a complex function that involves a vast number of anatomical structures to process and transport food and liquid from the oral region to the stomach in a well-coordinated manner. This process can be divided into four main stages: preparatory, oral, pharyngeal, and oesophageal.^{1,2} Rudolph and Thompson³ (2002) described feeding disorders in detail in five stages.³ In the first stage, the individual (more specifically the child) expresses the desire for feeding by communicating with the environment (e.g., the parents). The second stage is referred to as the oral stage, the third stage as the pharyngeal stage, the fourth as the oesophageal stage, and the fifth as the gastrointestinal stage, which refers to the process of transferring food from the stomach to the small and large intestine. Feeding and/or swallowing disorders, or dysphagia, are defined as any feeding or swallowing dysfunction occurring during one or more stages in a wide age range of patients, from premature infants to adults.² Reilly and Ward⁴ (2005) described it as “Dysphagia is not a single disease but a cluster of symptoms that occur as a result of an underlying disorder”.⁴ The main reported pathological causes of these disorders are 1) neurological deficits, 2) anatomical or structural abnormalities, 3) systemic or other health-related conditions, 4) psychological or psychiatric conditions, and 5) complex medical cases/conditions. More specific neurological disorders include genetic and metabolic disorders, degenerative neurological disorders, prematurity, autism spectrum disorders, and acquired brain injury.⁵

Assessment of feeding and swallowing disorders is performed by an interdisciplinary team of specialists, including a speech therapist, a doctor (Otolaryngologist, paediatrician, neurologist, pulmonologist, etc.), an occupational therapist, a nutritionist, a physiotherapist, and a psychologist.^{6,7} The process of assessing dysphagia consists of two main components: clinical and laboratory/instrumental evaluation, such as a videofluoroscopic swallow study or a flexible endoscopic evaluation of swallowing. Clinical evaluation involves obtaining a detailed history of the patient's health, daily life, and family environment, such as complaints about feeding and swallowing, and if necessary, observing the patient's dietary intake of different consistencies.^{8,9} In Greece, there are no recorded methods

or standardised indicators for the evaluation of feeding and swallowing disorders (for any stage) of the paediatric clinical evaluation. This study highlights the urgency for health professionals to integrate, into their daily practice, the use of valid tools for the early recognition of dysphagia symptoms in childhood in order to intervene and reduce its impact on child development.

This study aims to investigate the prevalence of dysphagia symptoms in children and adolescents with neurological disorders and its relationship with the specific characteristics of the subjects.

Materials and Methods

A cross-sectional study was designed using purposive sampling from October 2017 to April 2018 at the Venizelio General Hospital of Heraklion, Crete, Greece.

Participants

The study population consisted of children and adolescents aged 0–17 years living in South Aegean, Greece, who visited the outpatient paediatric neurology clinic and paediatric clinic of the Venizelio General Hospital of Heraklion, Crete. A purposive sampling method was used. The total sample consisted of 268 children and adolescents. The sample is representative; all the children who visited the two clinics over a period of six months had the same characteristics as the accessible population in this hospital, and consequently, as the total reference population—most paediatric patients with a neurological background, such as nervous system diseases and mental and behavioural disorders, visit this hospital. Venizelio General Hospital of Heraklion, Crete, is the reference hospital for the South Aegean regional units.

Research tools

The data were personally collected by the researchers using a short survey form, prepared specifically for this study. The form was designed according to the international literature and consists of two parts.^{10,11} The first part collected the demographic and medical data of the patient (diagnosis/possible diagnosis, insurance company, medication, body weight loss, and heritability of neurological disorders). The second part of the questionnaire used dichotomous questions (Yes/No) to focus on the most obvious and frequent clinical features that describe feeding and swallowing disorders per stage (oral, pharyngeal, and oesophageal). To reduce submission time, the oral stage includes questions representing the preparatory stage.⁸

In the pharyngeal stage, according to Morgan et al. (2010), Parkes et al. (2010), and Benfer et al. (2015),^{10,12,13} the presence or absence of salivation, coughing and/or choking, nasal escape, and reduced chewing ability are observed, as are residues in the oral cavity and pharynx, wet voice, inability to push bolus from the oral cavity to

the pharynx, respiratory infections, difficulty in coordinating, and lack of mobility of oral structures (jaw, tongue, and lips). Regarding the oesophageal stage, Rommel et al. (2003) reported the presence of gastroesophageal reflux disease (GERD) and oesophageal pathology (such as achalasia) in dysphagia.⁷ Additionally, according to Benfer et al. (2015), alternative feeding (nasogastric tube, etc.) is a consequence of feeding and swallowing disorders.¹⁰

The tenth revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10 English Version 2015) was the second tool in the study, used to classify and code all diagnoses or possible diagnoses given by physicians.

Data collection

Before the examination of each patient by the paediatric neurologist, the researchers interviewed the children's parents/escorts for less than 10 minutes. The researcher asked the questions from the questionnaire and recorded the data on the printed form, and then observed the examination, which included a (bedside) swallowing assessment, searching for the features listed above, and comparing the data received with the doctor's observations—the researcher filled the form where necessary.

Statistical analysis

Data were analysed using SPSS software (IBM SPSS Statistics for Windows, version 26.0. Armonk, NY: IBM Corp). Distributions of descriptive characteristics of the 268 children and adolescents with neurological disorders were estimated. In the assessment of the frequency of presence (prevalence) of different symptoms of dysphagia, 95% confidence intervals (95% CIs) were estimated. In addition to the observed (O) prevalence, the expected (E) prevalence of individual and stage clusters was assessed in order to estimate O/E ratios and provide the most frequent combinations of the three stages. To estimate the relationship between dysphagia and any of the characteristics of the children and adolescents, multiple logistic regression analysis was performed and odds ratio (OR) indices were graphically illustrated. The critical value was set to 0.05.

Results

Of the 268 children and adolescents with neurological disorders in the present study, 54.9% were boys, while the mean age was 5.9 years (median: 4.9), and 14.2% were aged 12+ years (Table 1). Of the patients, 68.3% had siblings, while 19.8% reported an inherited neurological disorder. No weight loss was observed in 98.5% of patients, and in 83.2% of patients, no medication for neurological disorders was reported. Further, 4.1% were uninsured, and 33.6% were accompanied by their mothers.

Table 1: Characteristics of 268 children & adolescents with neurological disorders.

		n	%
Gender	<i>boys</i>	147	54.9
	<i>girls</i>	121	45.1
Age, years	<i><1.0</i>	45	16.8
	<i>1.0–3.0</i>	61	22.8
	<i>3.1–6.0</i>	45	16.7
	<i>6.1–11.9</i>	79	29.5
	<i>12.0–17.0</i>	38	14.2
	<i>mean age</i> <i>(stand. dev.)</i> <i>[median]</i>	5.90 (4.80) [4.90]	
Siblings	<i>no</i>	85	31.7
	<i>yes</i>	183	68.3
Heritability (of neurological disorder)	<i>no</i>	215	80.2
	<i>yes</i>	53	19.8
Body weight loss	<i>no</i>	264	98.5
	<i>yes</i>	4	1.50
Drugs	<i>no</i>	223	83.2
	<i>yes</i>	45	16.8
Health insurance	<i>no</i>	11	4.10
	<i>yes</i>	257	95.9
Escort's relationship to patient	<i>mother</i>	90	33.6
	<i>father</i>	36	13.4
	<i>grandmother,</i> <i>aunt</i>	3	1.10
	<i>not stated</i>	139	51.9

Table 2: ICD-10 codes and frequencies of further diagnosis of the 268 children and adolescents in the present study.

ICD-10 codes	Description	n	%
II.C	Neoplasms	1	0.40
III.D	Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	2	0.70
IV.E	Endocrine, nutritional, and metabolic diseases	4	1.50
V.F	Mental and behavioural disorders	100	37.3
VI.G	Diseases of the nervous system	98	36.6
VII.H	Diseases of the eye and adnexa	6	2.20
IX.I	Diseases of the circulatory system	4	1.50
XIII.M	Diseases of the musculoskeletal system and connective tissue	2	0.70
XV.O	Pregnancy, childbirth, and the puerperium	38	14.2
XV.P	Certain conditions originating in the perinatal period	13	4.90
XVII.Q	Congenital malformations, deformations, and chromosomal abnormalities	8	3.00
XVIII.R	Symptoms, signs, and abnormal clinical and laboratory findings, not elsewhere classified	47	17.5
XIX.S	Injury, poisoning, and certain other consequences of external causes	1	0.40
XXI.Z	Factors influencing health status and contact with health services	1	0.40

Table 3: Prevalence of dysphagia symptoms during the Oral (OS), Pharyngeal (PS), and Oesophageal Stage (ES) in 268 children & adolescents.

Symptoms	n	%	95% CIs
Difficulty chewing	44	16.4	11.9, 20.9
Difficulties in processing bolus (movement coordination – lips/tongue/cheeks)	52	19.4	14.6, 24.3
Increased duration of bolus processing	46	17.2	12.7, 22.4
Salivation	24	9.00	5.6, 12.7
Residues in oral cavity	22	8.20	5.2, 11.9
At least one symptom during OS	65	24.3	19.0, 29.9
Nasal escape	2	0.70	0.1, 1.9
Nasal speech	1	0.40	0.1, 1.1
Coughing while feeding	47	17.5	13.3, 22.4
Liquids (e.g., water)	35	13.1	9.4, 16.9
Semi-liquids (e.g., yoghurt)	8	3.00	1.1, 5.2
Solids (e.g., biscuit)	17	6.40	3.7, 9.0
Choking while feeding	42	15.7	11.7, 20.4
Wet voice during and after feeding	2	0.70	0.2, 2.4
Frequent respiratory infections	4	1.50	0.4, 3.4
At least one symptom during PS	49	18.3	14.0, 23.2
History of GERD	52	19.4	14.9, 24.3
History of oesophageal pathology (e.g., achalasia, upper or lower oesophageal sphincter dysfunction)	0		
Alternative feeding (e.g., nasogastric tube)	2	0.70	0.1, 1.9
At least one symptom during ES	54	20.1	15.7, 25.4
At least one symptom during OS, PS, and ES or presence of dysphagia	114	42.5	36.7, 48.5

95% CIs, 95 confidence intervals; OS, Oral Stage; PS, Pharyngeal Stage; ES, Oesophageal Stage.

According to the ICD-10 codes, the most common disorders occurring in the present study were *mental and behavioural disorders* (F) (37.3%), followed by *diseases of the nervous system* (G) (36.6%), and *symptoms, signs, and abnormal clinical and laboratory findings, not elsewhere classified* (R) (17.5%); the last category included dysphagia under code R13 (Table 2). Of the 68 different ICD-10 diagnoses, the highest percentage of the examined children presented with autism spectrum disorder (14.2%) and premature birth (14.2%) (results not shown in table). The following diagnoses were followed in descending percentages: mild mental retardation (12.3%), focal symptomatic epilepsy and epileptic syndromes with complex focal seizures (9.30%), generalised idiopathic epilepsy and epileptic

syndromes (7.00%), cerebral palsy (7.00%), headaches (6.30%), and seizures and fainting (4.10%).

Table 3 presents the prevalence of dysphagia symptoms during the oral (OS), pharyngeal (PS), and oesophageal stages (ES) in 268 children and adolescents. In the oral stage, 24.3% of the participants (95% CI: 19.0–29.9) showed at least one symptom, with 19.4% (95% CI: 14.6–24.3) experiencing difficulties in processing bolus, 17.2% (95% CI: 12.7–22.4) showing increased duration of bolus processing, and 16.4% (95% CI: 11.9–20.9) having difficulty in chewing. During the pharyngeal stage, 18.3% (95% CI: 14.0–23.2) showed symptoms of dysphagia, with 17.5% (95% CI: 13.3–22.4) coughing during feeding, especially with fluids. In the oesophageal stage, 20.1% (95% CI: 15.7–25.4) showed at least one symptom of dysphagia, with 19.4% having a history of gastroesophageal reflux (95% CI: 14.9–24.3). At least one symptom during OS, PS, and ES, or the presence of dysphagia, was found in 42.5% (95% CI: 36.7–48.5) of the subjects. Overall, 11.2% had symptoms in both OS and PS, 7.10% in OS and ES, and 7.10% in PS and ES (Figure 1), while 5.20% showed symptoms in all three stages (OS, PS, and ES) (Table 4). The combination of all three stages had the highest degree of clustering, as the observed frequency was 584% higher than expected ($\chi^2/E = 5.84$), while PS was significantly lower than expected ($O/E = 0.47$; 95% CI: 0.07–0.88).

Finally, the multiple logistic regression analysis of dysphagia presence in relation to different characteristics of the 268 subjects, and the odds ratio (OR) indices (Figure 2), showed that dysphagia seems to be significantly related to lower age (OR = 0.45, $p < 0.001$), increased comorbidity according to ICD-10 (OR = 1.89, $p = 0.043$), or medication use (OR = 2.31, $p = 0.034$).

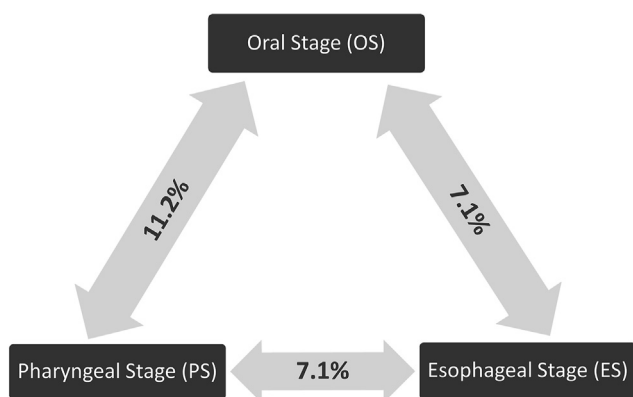


Figure 1: Prevalence of combined presence of dysphagia symptoms during Oral Stage (OS), Pharyngeal Stage (PS), and Oesophageal Stage (ES) in 268 children & adolescents.

Table 4: Clustering of dysphagia stages (Oral Stage – OS, Pharyngeal Stage – PS, and Oesophageal Stage – ES) individually or in combination in 268 children & adolescents.

Clustering	OS	PS	ES	n	O (%)	E (%)	O ÷ E	95% Confidence Intervals	
none	–	–	–	154	57.5	49.4	1.16	0.86	1.46
1	+	–	–	30	11.2	15.9	0.71	0.29	1.12
1	–	+	–	14	5.2	11.1	0.47	0.07	0.88
1	–	–	+	30	11.2	12.4	0.90	0.37	1.43
2	+	+	–	16	6.0	3.6	1.68	0.33	3.03
2	+	–	+	5	1.9	4.0	0.47	0.01	1.14
2	–	+	+	5	1.9	2.8	0.67	0.01	1.63
3	+	+	+	14	5.2	0.9	5.84	0.83	10.86

+: presence of stage.

Observed (O) & Expected (E) combination frequencies of Stages.

The combination of all three stages had the highest degree of clustering, as the observed frequency was 584% higher than expected ($O/E = 5.84$), while PS was significantly lower than expected ($O/E = 0.47$; 95% CI: 0.07–0.88).

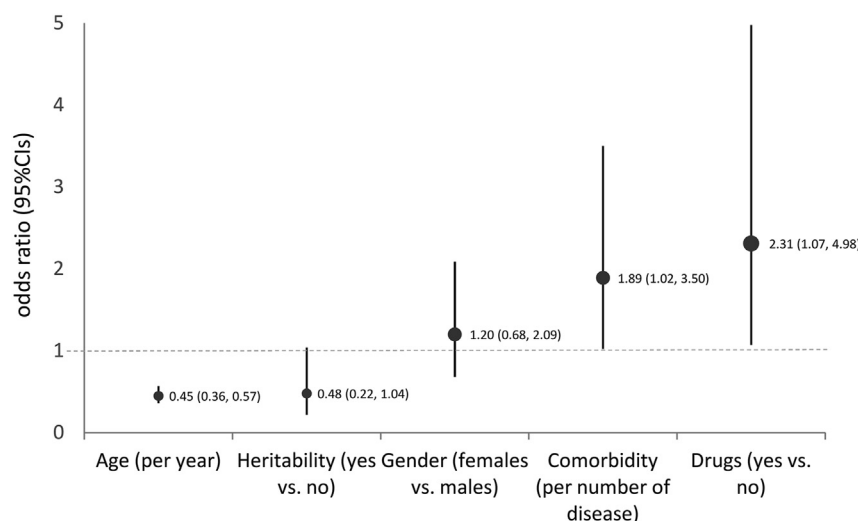


Figure 2: Odds ratio (OR) indices based on multiple logistic regression analysis of dysphagia presence (vs. absence) in relation to different characteristics in 268 children & adolescents.

Discussion

The key findings of this study were as follows. Most of the sample did not report any kind of inherited neurological disorder, weight loss, or medication for neurological disorders. A total of 68 different diagnoses were given, with the largest percentage of the examined children showing autism spectrum disorder and prematurity. The most frequent disorders were mental and behavioural disorders, followed by neurological disorders. In the oral stage, at least one symptom was observed—primarily, difficulties in processing bolus, followed by increased duration in processing bolus, and finally, difficulties in chewing. In the pharyngeal stage, symptoms such as coughing during feeding (mainly with fluids), were observed. In the oesophageal stage, at least one symptom of dysphagia was observed in children with a history of gastroesophageal reflux; no child had a history of oesophageal pathology. A significant number of children presented with dysphagia. An increased prevalence of dysphagia was observed in preterm infants and children with differing clinical and laboratory findings; the highest

percentage was observed in boys. The presence of dysphagia seems to be significantly related to lower age, increased comorbidity according to ICD-10 criteria, or medication use.^{14–16} The majority of the sample did not show any inherited neurological disorders. Hereditary neurological disorders are less common than other acquired diseases of the nervous system (e.g. cerebral palsy). They can occur anytime from the infancy to adulthood, which also makes early and valid diagnosis difficult.^{17–19} The majority of children did not experience weight loss and did not report medication for neurological disorders. In contrast, in various studies, such as that of Erasmus et al. (2012),²⁰ there is a correlation between dysphagia and medication, mainly with drugs that suppress voluntary movement (in some cases) and often increase salivation. Moreover, although many children with dysphagia do not lose weight, it is very common for them to have difficulty gaining weight, especially during the first two years of life.^{21,22}

In the present study, 68 different diagnoses were made, with the highest percentage of the examined children showing autism spectrum disorder and prematurity. Mental disorders,

behavioural disorders, and nervous system disorders were also observed. In a study of 131 children with NMD in the Netherlands, 84 children (64%) showed symptoms of dysphagia.²³ According to Mari-Bauset et al. (2014), children with autism spectrum disorders have difficulty feeding as they make eating choices depending on characteristics such as colour, texture, shape, or taste.²⁴ Regarding premature births, numerous researchers have confirmed the difference in the ability to feed adequately, and consequently, in the experience and development of premature infants compared to full-term infants.^{24–27} A large, population-based cohort study found the prevalence of feeding problems in premature infants born at less than 37 weeks' gestation to be 10.5%, increasing to 24.5% among those born with a very low birth weight of less than 1500 g.²⁸ Calis et al. (2008) also reported that generalised severe cerebral palsy combined with mental retardation (IQ < 55) is associated with an increased risk of dysphagia.¹⁵ Other studies have reported an increased incidence of bolus management difficulty in the oral cavity and its transfer from the oral to the pharyngeal stage.^{29–31} Dodrill and Gosa (2015) pointed out the association between coughing, wet voice, and possible aspiration when swallowing thin liquids.²⁵ On the other hand, several studies indicated that disorders of the oesophageal stage, such as gastroesophageal reflux disease and food allergies, contribute significantly to the increased incidence of feeding and swallowing disorders.^{25,28,32,33}

In the present study, 114 children were diagnosed with dysphagia, with at least one of the 17 symptoms included in all stages of ingestion. Specifically, 38 children showed one symptom, 32 had three or even four symptoms, and 44 children presented with more than four symptoms. Relevant results were found in the study by Kooi-van Es et al. (2020); 90.0% had chewing problems, 43.0% had swallowing problems, and 33.3% had both chewing and swallowing problems.³⁴ Several studies reported an increased incidence of dysphagia in young children with neurological disorders.^{16,19} Costa et al. (2021) studied a sample of children with neurological disabilities, among others, and found a 75% prevalence of difficulty in chewing and swallowing.³⁵ More specifically, Schädler et al. (2007) identified a rate of 40.8% in children born prematurely and those with cerebral palsy.³⁶ Finally, Calis et al. (2008) reported a prevalence of 99% in children with cerebral palsy and mental retardation.¹⁵ Benfer et al. (2015) identified coughing as the most common symptom, according to parental reports, with an incidence rate of 30.5%, followed by gagging (31.3%), choking (18.8%), and multiple swallows (25.2%), as well as cases where some children had more than one symptom.¹⁰ Finally, according to Lefton-Greif (2008),³² approximately 37–40% of children assessed for feeding and swallowing difficulties are born prematurely and may have neurological, developmental, and/or respiratory problems in later life; similar results have been observed in many other studies.^{21,28,37}

The main limitation of the current study arises from the lack of a credible diagnostic tool (e.g., screening list). Furthermore, this study was conducted in a single region of the country; so, it is not representative of other regions of Greece. However, this is the first attempt in Greece to investigate the prevalence of feeding and swallowing disorders in children.

Conclusion

A high prevalence of dysphagia was found in children and adolescents with neurological disorders, while factors like lower age, increased comorbidity, and medication require proper management during feeding. Sufficient attention must be paid to these important factors to improve these children's quality of life. This study is the first to describe the prevalence of dysphagia using diagnostic tools in a large group of children with neurological disorders in Greece. We recommend further exploration of the underlying mechanisms of dysphagia in these populations to ensure timely diagnosis and treatment of these children.

Source of funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Conflict of interest

The authors have no conflict of interest to declare.

Ethical approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the Ethics Committee of the Hellenic Mediterranean University Research and Bioethics Committee (IRB; Venizelio General Hospital of Heraklion, Crete/UOC-13594/10 January 2018) and with the 1964 Helsinki declaration and its later amendments on comparable ethical standards. Informed consent was obtained from all participants included in the study.

Authors contributions

Conceptualisation: NR, GM; Methodology: NR, ML; Formal analysis and investigation: ML; TZ, CZ, MK, IT; Writing - original draft preparation: NR, ML; Writing - review and editing: NR, ML; Supervision: NR. All authors have critically reviewed and approved the final draft and are responsible for the content and similarity index of the manuscript.

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