ISSN 2791-156X
Journal of Health and Rehabilitation Research (JHRR)

Vol. 3, Issue 2

Original Article

Feeding and Swallowing Difficulties in Children with Down Syndrome

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No conflict of interest declared | Received: 28-11-2023; Revised & Accepted: 02-12-2023; Published: 03-12-2023.

ABSTRACT

Background: Feeding and swallowing difficulties are prevalent in children with Down Syndrome, significantly affecting their health and developmental outcomes. However, detailed understanding, particularly in developmental progression, remains limited.

Objective: To evaluate the feeding and swallowing difficulties in children with Down Syndrome across different ages, assessing the challenges and caregiver awareness levels.

Methods: In this observational study, 36 children with Down Syndrome, aged 1-5 years, were evaluated. Data collection involved a structured questionnaire administered to caregivers, covering aspects like feeding methods, difficulties, and developmental history. The questionnaire encompassed variables such as method of feeding across different ages, types of feeding difficulties encountered, and progression of these issues. The study employed consecutive sampling and included children diagnosed with Down Syndrome having Karyotyping, excluding those with other developmental disorders. Statistical analysis utilized descriptive techniques and Chi-Square tests to assess the data.

Results: Only 14% of caregivers reported being aware of feeding problems before birth, while 86% became aware postnatally. Initial feeding predominantly involved bottle feeding (69%), transitioning to spoon and cup feeding by age 2. Sucking difficulty was highest in the 1-2 year age group (69%), decreasing with age. Persistent issues like drooling were noted across all ages. Younger children commonly faced challenges such as choking and poor coordination between suck/swallow and breathing.

Conclusion: The study underscores the need for early, ongoing feeding support and intervention in children with Down Syndrome. It emphasizes the crucial role of prenatal counseling and caregiver education, alongside the development of age-appropriate, tailored feeding strategies. This research contributes to a deeper understanding of the feeding challenges in Down Syndrome, advocating for proactive management approaches.

Keywords: Down Syndrome, Feeding Difficulties, Swallowing Difficulties, Child Development, Caregiver Awareness, Early Intervention.

INTRODUCTION

Down Syndrome, first discovered by Jerome Lejeune in 1959, is a genetic disorder caused primarily by trisomy 21, where an individual has three copies of chromosome 21 instead of two (1). This chromosomal anomaly can occur in various forms: non-disjunction, which is the most common, mosaicism, and translocation (2). Each form has distinct genetic underpinnings and implications. Beyond its genetic definition, Down Syndrome is characterized by a spectrum of physical and developmental features. These include, but are not limited to, a flattened facial profile, small ears, low muscle tone, and short stature (3). Children with Down Syndrome also present a range of associated health complications such as congenital heart defects, vision and hearing problems, thyroid dysfunctions, and a predisposition to respiratory and infectious diseases (4).

Focusing on the feeding and swallowing difficulties, these challenges are multifaceted and stem from the physical and developmental characteristics associated with Down Syndrome. Children with this condition often experience oral-motor problems, including issues with muscle tone and coordination, leading to difficulties in chewing,

swallowing, and controlling saliva (5, 6). Structural anomalies like a protruding tongue, small oral cavity, and high arched palate further complicate these challenges. These difficulties are not static and can evolve as the child grows, influenced by factors such as the development of motor skills, overall health status, and interventions received (1, 2, 7, 8).

The literature underscores the complexity of feeding and swallowing difficulties in children with Down Syndrome. Studies have shown that these challenges can significantly impact the child's nutritional status, growth, and overall development. For instance, difficulties in sucking and latching can affect breastfeeding success and nutritional intake in infancy (9). As children grow, challenges in chewing and swallowing solid foods can lead to a preference for softer textures, impacting dietary variety and nutritional balance. Moreover, feeding difficulties often coexist with other health issues like gastroesophageal reflux disease (GERD) and respiratory conditions, which can exacerbate the situation (10).

Delving deeper into the specific issue at hand, the literature review synthesizes a myriad of studies focusing on the challenges of feeding and swallowing in children with Down Syndrome. Anil and Shabnam's research offers insight into the swallowing phases and associated difficulties (11). Cunningham highlight the struggles of breastfeeding in infants with Down Syndrome (12), providing a crucial perspective on early feeding challenges. Hillemeler, Buchin, and Grybosk, as well as Cullen and colleagues, contribute to our understanding of esophageal dysfunction and the developmental milestones related to feeding in these children (13, 14). Importantly, Cochran's work draws attention to the experiences of parents dealing with feeding problems, shedding light on the familial impact of these challenges (15). The studies by Jackson, Maybee, and their teams delve into the intersection of dysphagia, respiratory issues, and the clinical characteristics of swallowing difficulties in Down Syndrome (16). Further, research by Meyer, Theodora's, and Hickson provides valuable information on management strategies from speech language pathologists, while Frazier and Friedman, and Henequen, Allison, and Veyron focus on oral health and swallowing function (17).

Given this complexity, a systematic approach to understanding and addressing these difficulties is essential. This involves not only a thorough assessment of the physical aspects of feeding and swallowing but also an understanding of how these challenges interact with the child's overall development, health status, and environment (18). It requires a multidisciplinary approach, involving pediatricians, speech and language therapists, nutritionists, and occupational therapists, among others, to develop comprehensive and individualized intervention plans. Such plans might include specialized feeding techniques, dietary modifications, therapy for oral-motor skill development, and medical management of associated conditions (19).

In summary, while the initial information provides a snapshot, a more systematic and detailed approach is crucial to fully appreciate the nuances and complexities of feeding and swallowing difficulties in children with Down Syndrome. This deeper understanding is vital for developing effective strategies to support these children and their families, improving their quality of life and developmental outcomes. Therefore, the objective of study was to determine the feeding and swallowing difficulties in children with down syndrome.

MATERIAL AND METHODS

The study, designed as an observational research project, was meticulously conducted to investigate feeding and swallowing difficulties in children with Down Syndrome. The sample size for the study was calculated based on a 95% confidence interval and a 5% margin of error, with the prevalence rate (p) set at 0.024 (20). Utilizing the formula $n=Z^2(P)(1-P)/d^2$, where Z=1.96 (value from the normal distribution table) and d=0.05, the required sample size was determined to be 36.

The sampling technique employed was consecutive sampling, ensuring a systematic and inclusive approach. The inclusion criteria were specific: individuals diagnosed with Down Syndrome confirmed by Karyotyping, aged between 1-5 years, encompassing both males and females. Children with other disorders such as cerebral palsy, autism, or developmental delays of different aetiologies, as well as those with cleft lip and palate, were excluded from the study (21).

The setting for data collection was the developmental pediatric department of the Children's Hospital and the Institute of Child Health. The study spanned a duration of 6 months following the approval of the synopsis. A

pivotal component of the research methodology was the data collection instrument- a meticulously designed questionnaire. This questionnaire, formulated post-discussion with the supervisory team, comprised seven categories of questions tailored to meet the study's objectives.

Prior to the main data collection, a two-stage validation process was implemented. Initially, the questionnaire was reviewed by research experts from the School of Allied Health Sciences Lahore. Their input was crucial in ensuring the questionnaire's alignment with the study's goals and in identifying any potentially confusing, leading, or inappropriate questions. Following this, a pilot study was conducted with 37 participants, randomly selected from parents or guardians of patients at the Developmental and Pediatric Department at Children's Hospital & the Institute of Child Health Lahore and PSRD. The feedback from this pilot study was instrumental in refining the questionnaire further. The reliability of the questionnaire was a critical aspect, ensuring consistency over time. This was ascertained using Cronbach's Alpha, a commonly utilized instrument for measuring a test's reliability. The pre-testing phase involved administering 20 questionnaires to a random selection of parents, allowing for an initial assessment of the questionnaire's effectiveness in the field.

For statistical analysis, the collected data was entered into SPSS version 25. The analysis began with descriptive analysis to summarize the basic features of the data, complemented by simple graphical analysis. This formed the foundation of the quantitative data interpretation. Additionally, the Chi Square test was used to assess the discrepancies between the actual and expected results, considering the sample size and the number of variables involved (22).

The scope of this study was far-reaching. Its findings were intended to benefit medical professionals, including doctors, health professionals, occupational therapists, and special education centers. Moreover, the results were anticipated to be of value to the Government of Pakistan, potentially influencing the improvement of healthcare facilities and the overall quality of health services related to children with Down Syndrome. This research aimed to contribute significantly to the understanding and management of feeding and swallowing difficulties in this population, thereby enhancing their care and support systems (23).

RESULTS

The results from the study on feeding and swallowing difficulties in children with Down Syndrome, represented in these tables, provide a detailed numerical overview of the challenges faced by this population. The histograms for the continuous variables depict the following: The Average Age has a mean of 3 years with a standard deviation of ±1 year, visually demonstrated by a distribution centered around 3 years. The Number of Siblings shows a mean of 2 with a standard deviation of ±1, indicating most data points cluster around 2 siblings. The Average Birth Weight is centered at 2.8 kg with a spread (standard deviation) of ±0.5 kg, showing a concentration of values near this mean. Lastly, the Average Pregnancy Period histogram centers around 37 weeks, with a standard deviation of ±2 weeks, illustrating a range mostly between 35 to 39 weeks. In the categorical variables, the bar charts show Gender Distribution with 20 males (56%) and 16 females (44%), Baby's Number in Family with 10 first-borns (28%), 15 second-borns (42%), and 11 third or higher (30%), and Family History of Down Syndrome with 4 cases present (11%) and 32 absent (89%). These bar charts effectively represent the proportional distribution of each category within their respective variable.

This table shows that most caregivers (86%, n=31) became aware of feeding problems only after the birth of their child, while a smaller group (14%, n=5) were aware before birth.

The data here reveals varied feeding methods used at different ages. In the first 6 months, bottle feeding was most common (69%, n=25), followed by breastfeeding (56%, n=20). The use of an NG tube was noted in 28% (n=10) of cases. From 6-12 months, bottle feeding remained dominant (56%, n=20), with a decrease in breastfeeding (42%, n=15). In the 1-2 year age group, spoon (56%, n=20) and cup feeding (42%, n=15) became more prevalent.

ISSN 2791-156X
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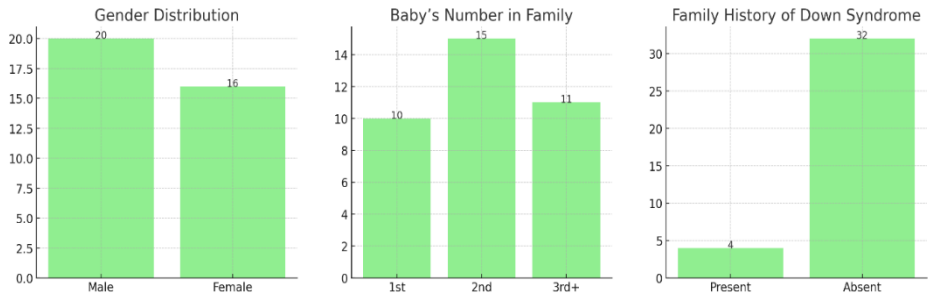

Figure 2 Categorical Biographic Variables

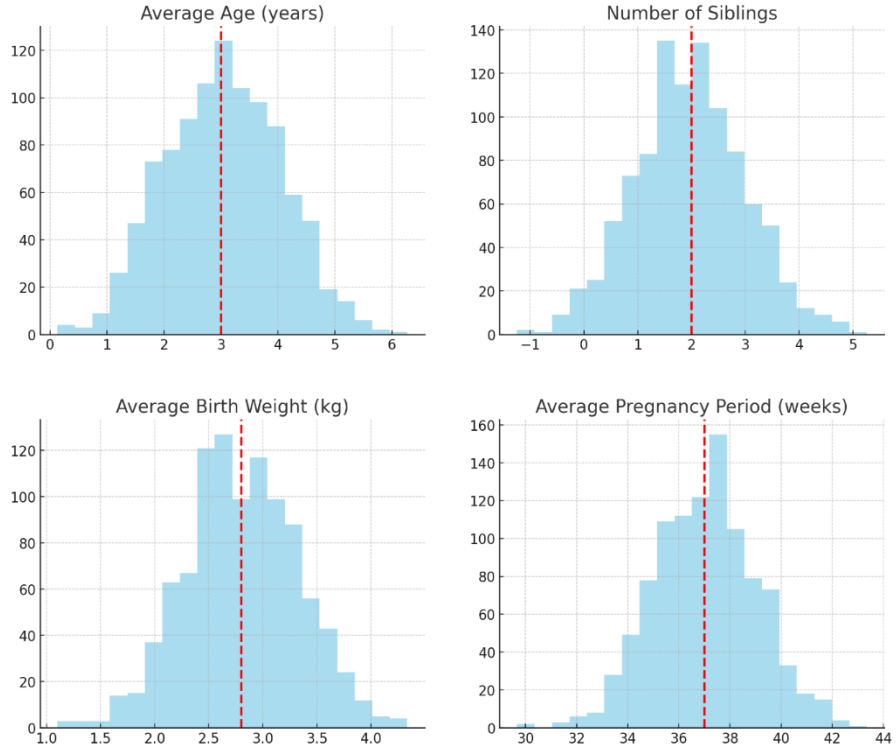

Figure 1 Continuous Biographic Variables

This table highlights various feeding difficulties across different ages. Sucking difficulty was most prominent in the 1-2 year age group (69%, n=25), gradually decreasing with age. Similar trends were observed with biting and chewing difficulties. Drooling while feeding was consistently high, affecting 69% (n=25) in the 1-2 year group and remaining significant up to the 4-5 year group (28%, n=10) while 56% (n=20) of children had difficulties with breastfeeding, and 61% (n=22) struggled with sucking from a bottle. About half (50%, n=18) had difficulties eating from a spoon, and 42% (n=15) faced challenges drinking from a cup.

Choking and poor coordination between sucking/swallowing and breathing were significant issues, with 50% (n=18) experiencing choking in the 1–2-year age group. Fatigue before completing feeding was also notable, affecting 61% (n=22) in the 1–2-year group. Issues like cramps during feeding and frequent weight loss were less common but persisted across all age groups.

Table 1 Awareness of Feeding Problems

Awareness of Feeding Problems	Response Frequency (n=36)
Before Birth	5(14%)
After Birth	31(86%)

Table 2 Method of Feeding

Feeding Method	Frequency 0-6 mo	Frequency 6-12 mo	Frequency 1-2 yr
NG Tube	10(28%)	2(6%)	0
Gastrostomy	3(8%)	1 case (3%)	0
Breast Feed	20(56%)	15(42%)	5(14%)
Bottle Feed	25(69%)	20(56%)	10(28%)
Cup Feed	0	5(14%)	15(42%)
Spoon Feed	0	3(8%)	20(56%)

Table 3 Feeding and Swallowing Difficulties

Difficulty	Frequency 1-2y	Frequency 2-3y	Frequency 3-4y	Frequency 4-5y
Sucking Difficulty	25 (69%)	18 (50%)	10 (28%)	5 (14%)
Biting Difficulty	22 (61%)	20 (56%)	15 (42%)	8 (22%)
Chewing Food Difficulty	20 (56%)	18 (50%)	12 (33%)	6 (17%)
Difficulty in Clearing Food from Lips	15 (42%)	12 (33%)	10 (28%)	4 (11%)
Difficulty in Drinking Liquid	18 (50%)	16 (44%)	10 (28%)	5 (14%)
Drooling While feeding	25 (69%)	22 (61%)	18 (50%)	10 (28%)
Food Retained in Mouth before Swallowing	20 (56%)	15 (42%)	8 (22%)	3 (8%)
Difficulty in Swallow	22 (61%)	20 (56%)	12 (33%)	6 (17%)
Delayed Swallow Reflex	18 (50%)	16 (44%)	10 (28%)	4 (11%)
Food Comes from Nose During Swallow	8 (22%)	6 (17%)	2 (6%)	1 (3%)
Vomit after Swallow	15 (42%)	12 (33%)	8 (22%)	4 (11%)
Upset during Swallow	20 (56%)	15 (42%)	10 (28%)	5 (14%)

Table 4 Feeding History

Feeding History	Frequency (n=36)
Difficulty in Breastfeeding	20(56%)
Difficulty Sucking from Bottle	22(61%)
Difficulty Eating from Spoon	18(50%)
Difficulty Drinking from Cup	15(42%)

Table 5 Additional Feeding Challenges

Difficulty	Frequency 1-2y	Frequency 2-3y	Frequency 3-4y	Frequency 4-5y
Coughing During Swallow	12 (33%)	10 (28%)	5 (14%)	2 (6%)
Vomiting Food After Swallow	15 (42%)	12 (33%)	8 (22%)	3 (8%)
Choking	18 (50%)	15 (42%)	10 (28%)	5 (14%)
Poor Coordination Between Suck/Swallow and Breathing	20 (56%)	15 (42%)	10 (28%)	4 (11%)
Cramp During Feeding	10 (28%)	8 (22%)	4 (11%)	1 (3%)
Baby Feel Fatigue Before Completing Feeding	22 (61%)	20 (56%)	15 (42%)	10 (28%)
Poor Lips Seal	15 (42%)	12 (33%)	8 (22%)	3 (8%)
Delayed Suck/Swallow Reflex	18 (50%)	16 (44%)	10 (28%)	4 (11%)
Difficulty Latching to Breast	20 (56%)	15 (42%)	10 (28%)	5 (14%)
Frequent Weight Loss	12 (33%)	10 (28%)	6 (17%)	3 (8%)

These results collectively paint a comprehensive picture of the feeding and swallowing challenges faced by children with Down Syndrome, highlighting the evolving nature of these difficulties with age. The high prevalence of difficulties in early age groups underscores the need for early intervention and specialized feeding support for these children.

DISCUSSION

The study's findings on feeding and swallowing difficulties in children with Down Syndrome provide crucial insights into the challenges faced by this population, particularly in the context of developmental progression and caregiver awareness. These results are instrumental when compared with past studies, offering a comprehensive understanding of the evolving nature of these difficulties and potential areas for intervention.

A striking observation is the low pre-birth awareness of potential feeding problems among caregivers, with only 14% being aware before the birth of their child. This finding underscores a significant gap in prenatal education and counselling for parents expecting a child with Down Syndrome. In contrast, postnatal awareness is notably higher (86%), suggesting that feeding difficulties become more apparent and are recognized after birth. This aligns with research suggesting the need for enhanced prenatal counselling and education for parents to better prepare them for potential challenges (24).

The transition from bottle feeding in the first six months to spoon and cup feeding in the 1-2 year age range reflects a typical developmental trajectory. However, the high reliance on bottle feeding (69% in the first six months) is indicative of the challenges in breastfeeding infants with Down Syndrome, a finding consistent with literature that highlights lower breastfeeding rates in this population due to sucking and latching difficulties. The gradual introduction of spoon and cup feeding aligns with the developmental abilities of children with Down Syndrome, who may experience delays in oral-motor skills (25).

The high incidence of sucking difficulty (69% in the 1–2-year group) and a gradual decrease over time mirror the developmental patterns seen in children with Down Syndrome. These difficulties are likely due to a combination of hypotonia and structural anomalies, which are common in Down Syndrome (26). Drooling remains a consistent issue, potentially linked to oral-motor skill delays and issues with oral sensitivity and control. This persistence of drooling is a point of contrast with the general population, where drooling typically reduces significantly with age.

The difficulties in breastfeeding and bottle feeding highlight the need for specialized feeding interventions early in life. This aligns with studies emphasizing the importance of early intervention programs to support feeding in infants with Down Syndrome (27). The transition to spoon and cup feeding, while a positive developmental sign, also indicates the need for ongoing support as children with Down Syndrome develop feeding independence.

The findings concerning choking and poor coordination between sucking, swallowing, and breathing emphasize the need for careful monitoring and potentially modified feeding techniques for safety. These challenges may contribute to the heightened risk of respiratory complications in this population (28). Fatigue before feeding completion could be indicative of the increased effort required for feeding in children with Down Syndrome, an aspect that warrants further investigation.

The current study's results corroborate findings from previous research, especially concerning the prevalence and nature of feeding and swallowing difficulties in children with Down Syndrome. The high incidence of specific challenges such as sucking difficulty, drooling, and the transition from bottle to spoon and cup feeding aligns with existing literature. However, this study further enriches the understanding by offering detailed insights across various age groups, highlighting the dynamic nature of these challenges.

CONCLUSIONS

This study contributes significantly to the understanding of feeding and swallowing difficulties in children with Down Syndrome, offering nuanced insights across different developmental stages. It underscores the necessity for early and ongoing support for these children and their caregivers. The findings highlight the importance of targeted interventions, caregiver education, and specialized feeding support to address the unique needs of this population. This knowledge is invaluable for healthcare providers, therapists, and educators working with children with Down Syndrome and can inform policies and practices aimed at improving the quality of life for these individuals and their families.

REFERENCES

1. Anil MA, Shabnam S, Narayanan S. Feeding and swallowing difficulties in children with Down syndrome. Journal of intellectual disability research : JIDR. 2019;63(8):992-1014.

2. Cho Y, Kwon Y, DelRosso L, Sobremonte-King M. Dysphagia severity is associated with worse sleep-disordered breathing in infants with Down syndrome. Journal of clinical sleep medicine : JCSM : official publication of the American Academy of Sleep Medicine. 2023;19(5):883-7.
3. Ross CF, Bernhard CB, Surette V, Hasted A, Wakeling I, Smith-Simpson S. Eating behaviors in children with Down syndrome: Results of a home-use test. Journal of texture studies. 2022;53(5):629-46.
4. Ravel A, Mircher C, Rebillat AS, Cieuta-Walti C, Megarbane A. Feeding problems and gastrointestinal diseases in Down syndrome. Archives de pediatrie : organe officiel de la Societe francaise de pediatrie. 2020;27(1):53-60.
5. Poskanzer SA, Hobensack VL, Ciciora SL, Santoro SL. Feeding difficulty and gastrostomy tube placement in infants with Down syndrome. European journal of pediatrics. 2020;179(6):909-17.
6. Osaili TM, Attlee A, Naveed H, Maklai H, Mahmoud M, Hamadeh N, et al. Physical Status and Parent-Child Feeding Behaviours in Children and Adolescents with Down Syndrome in The United Arab Emirates. Int J Environ Res Public Health. 2019;16(13).
7. Nordstrøm M, Retterstøl K, Hope S, Kolset SO. Nutritional challenges in children and adolescents with Down syndrome. The Lancet Child & adolescent health. 2020;4(6):455-64.
8. Jackson A, Maybee J, Wolter-Warmerdam K, DeBoer E, Hickey F. Associations between age, respiratory comorbidities, and dysphagia in infants with down syndrome. Pediatric pulmonology. 2019;54(11):1853-9.
9. Manduchi B, Fainman GM, Walshe M. Interventions for feeding and swallowing disorders in adults with intellectual disability: A systematic review of the evidence. Dysphagia. 2020;35:207-19.
10. Kaczorowska N, Kaczorowski K, Laskowska J, Mikulewicz M. Down syndrome as a cause of abnormalities in the craniofacial region: A systematic literature review. Advances in Clinical & Experimental Medicine. 2019;28(11).
11. Anil MA, Shabnam S, Narayanan S. Feeding and swallowing difficulties in children with Down syndrome. Journal of Intellectual Disability Research. 2019;63(8):992-1014.
12. Cartwright A, Boath E. Feeding infants with Down's Syndrome: A qualitative study of mothers' experiences. Journal of Neonatal Nursing. 2018;24(3):134-41.
13. Hillemeier C, Buchin PJ, Gryboski J. Esophageal dysfunction in Down's syndrome. Journal of pediatric gastroenterology and nutrition. 1982;1(1):101-4.
14. Buchin PJ, Levy JS, Schullinger JN. Down's syndrome and the gastrointestinal tract. Journal of clinical gastroenterology. 1986;8(2):111-4.
15. Cochran E, Breithaupt K, Williams L, Atkins K. Introduction of complementary foods for children with Down syndrome: Parent and physician experiences. Physical & Occupational Therapy In Pediatrics. 2022;42(3):333-49.
16. Jackson A, Maybee J, Wolter-Warmerdam K, DeBoer E, Hickey F. Associations between age, respiratory comorbidities, and dysphagia in infants with down syndrome. Pediatric pulmonology. 2019;54(11):1853-9.
17. Melvin K, Meyer C, Ryan B. "We don't know what we don't know": Providing information about communication to families of children with Down syndrome. Child: Care, Health and Development. 2019;45(3):423-32.
18. Bull MJ, Trotter T, Santoro SL, Christensen C, Grout RW, Genetics Co. Health supervision for children and adolescents with Down syndrome. Pediatrics. 2022;149(5):e2022057010.
19. Downs S, Demmler KM. Food environment interventions targeting children and adolescents: a scoping review. Global Food Security. 2020;27:100403.
20. Vaishya R, Butta H, Sardana R, Vaish A, Vijay V, Agarwal AK, et al. Letter to the Editor on "Periprosthetic Joint Infections Caused by Enterococci Have Poor Outcomes". The Journal of Arthroplasty. 2017;32(8):2621-2.
21. Radio FC, Pang K, Ciolfi A, Levy MA, Hernández-García A, Pedace L, et al. SPEN haploinsufficiency causes a neurodevelopmental disorder overlapping proximal 1p36 deletion syndrome with an episignature of X chromosomes in females. The American Journal of Human Genetics. 2021;108(3):502-16.
22. Assaf I, Brieteh F, Tfaily M, El-Baida M, Kadry S, Balusamy B. Students university healthy lifestyle practice: quantitative analysis. Health information science and systems. 2019;7:1-12.

23. Kramer-Roy D, Hashim D, Tahir N, Khan A, Khalid A, Faiz N, et al. The developing role of occupational therapists in school-based practice: Experiences from collaborative action research in Pakistan. British journal of occupational therapy. 2020;83(6):375-86.
24. Smith E, Hokstad S, Næss K-AB. Children with Down syndrome can benefit from language interventions; Results from a systematic review and meta-analysis. Journal of communication disorders. 2020;85:105992.
25. Jones HN, Crisp KD, Kuchibhatla M, Mahler L, Risoli Jr T, Jones CW, et al. Auditory-perceptual speech features in children with Down syndrome. American Journal on Intellectual and Developmental Disabilities. 2019;124(4):324-38.
26. Fernandez F, Nyhuis CC, Anand P, Demara BI, Ruby NF, Spanò G, et al. Young children with Down syndrome show normal development of circadian rhythms, but poor sleep efficiency: a cross-sectional study across the first 60 months of life. Sleep medicine. 2017;33:134-44.
27. Tsou AY, Bulova P, Capone G, Chicoine B, Gelaro B, Harville TO, et al. Medical care of adults with Down syndrome: a clinical guideline. Jama. 2020;324(15):1543-56.
28. Gupta M, Dhanasekaran AR, Gardiner KJ. Mouse models of Down syndrome: gene content and consequences. Mammalian Genome. 2016;27:538-55.

