

## Dietary Practice and Physical Activity in Children with Down Syndrome and Their Siblings in Saudi Arabia

Badreldin A Mohamed<sup>1\*</sup>, Adel A Alhamdan<sup>1</sup>, Manal M Samarkandy<sup>2</sup>

<sup>1</sup>Department of Community Health Sciences, College of Applied Medical Sciences, King Saud University, Riyadh, Saudi Arabia. <sup>2</sup> Manal M. Samarkandy, Senior Dietitian, Sultan Bin Abdulaziz Humanitarian City, Riyadh, Kingdom of Saudi Arabia.

\*Corresponding Author: Dr. Badreldin A Mohamed. Email: bmohamed@ksu.edu.sa

### ABSTRACT

**Background:** Feeding difficulties and inappropriate nutrition are common problems among children with Down Syndrome (DS). **Objective:** The aim of this study is to investigate the dietary practice and physical activity among children with DS. **Methodology:** The study groups were pre-pubertal DS boys and girls, aged 5 to 12 years clinically and cytogenetically proven to be suffering from DS. Healthy siblings, closest in age to the DS children were used as a control group. Breast feeding, eating difficulties, fast food intake, and physical activity were measured for both groups. **Results:** During infancy period, 36.4% of the DS children were bottle fed, compared to only 5.5% of the normal siblings. Nearly half of the breast-fed DS children were fed for duration of less than 6 months. The percentage of the DS children experiencing dietary difficulties is significantly higher compared to the siblings. Concerning physical activity, 73.1% of DS children did not exercise as compared to 44.2% of the control siblings. **Conclusion:** Controlling feeding practices and encouraging Down syndrome children to participate in physical activity either through support from parents or through designing special programs and facilities and are two avenues that can be used for obesity prevention.

**Key words:** *Down Syndrome, Feeding Difficulties, Obesity.*

Mohamed BA, Alhamdan AA, Samarkandy MM. Dietary Practice and Physical Activity in Children with Down Syndrome and their Siblings in Saudi Arabia. *Canad J Clin Nutr* 2013; 1(1): 35-46.

DOI: <http://dx.doi.org/10.14206/canad.j.clin.nutr.2013.01.05>

### INTRODUCTION

Down's syndrome (DS) is characterized by mental and growth retardation associated with genetic anomalies. DS is affecting approximately 1 in 800 live births without predilection for race or socioeconomic class (1). In Kingdom of Saudi Arabia (KSA), the incidence of DS births is around 1.8 for every 1000 babies born alive (2). In Arab countries it ranges from 1.93–3.5/1000 live birth (2). Overall, the incidence worldwide ranges from 1.25–1.67/1000 live birth (3). Feeding difficulties and inappropriate nutrition are common problems among children with Down's syndrome (4, 5). Little is known about the causes of feeding problems in infants with DS. These may be associated with low muscle tone, which also affects the strength, mobility and range of motion of the oral muscles and can result in weak sucking, swallowing, lip closure, and tongue protrusion, and gastroesophageal reflux (5, 6). The combination of reduced oral space and low muscle tone can result in tongue protrusion (5). True macroglossia can sometimes occur in infants with Down syndrome, which results in

additional problems with breathing, chewing and later on with speech development. Narrowed nasal passages and increased respiratory secretions interfere with nasal breathing and oral feeding in infants with Down syndrome. As a result of the early feeding problems in infants with Down syndrome, and the emotional responses of parents to the often unexpected diagnosis of Down syndrome, early mother-infant attachment may be disrupted and breast feeding is often not possible (7).

Feeding disorders in children with Down syndrome may have important long-term health consequences, including growth deficits and decreased performance on tests of academic and cognitive performance. Some studies estimate that up to 80% of children with DS have difficulties related to food or feeding (7-9). The attainment of feeding milestones in DS is also delayed by 10–35% depending on the age of assessment (10). Furthermore, a delay in the age of achievement of motor milestones and the poor gross motor performance of children with DS may limit physical activity during infancy and childhood and may further decrease physical activity levels during childhood (4, 11, 12). The feeding practice and physical activity for children with DS is not well defined particularly in Saudi Arabia. To the best of our knowledge this is the first study to assess the feeding problems and physical activity in DS children of Saudi Arabia.

## SUBJECTS AND METHODS

Al-Nahda Schools for DS and the DS Charitable Association are the only two schools for DS children in Riyadh city, Saudi Arabia. The DS children in these schools are distributed in class rooms according to their chronological ages. The approval to conduct the study was obtained from the school board of these two schools. One hundred and eight families were enrolled in the study. Consent of all families was obtained, and the study objective was fully explained to them. The study group included pre pubertal DS boys and girls (n=108) clinically and/or cytogenetically proven to be ailing with DS. Healthy siblings, closest in age to the DS children were used as a control group (n =113). Some of the siblings were twins. The reason for using siblings as controls in the study was to ensure quite similar environmental backgrounds. All the DS children included in our samples were living with their parents and had at least one sibling; all siblings of DS children were living in the same house. The study was conducted during the period of February-May 2011.

Thirteen illiterate mothers and 10 mothers with elementary education that were not able to fill the questionnaire and were personally interviewed by the observer in the school class rooms. The history of infant feeding among DS children and the siblings was obtained including type of feeding and duration of breast feeding. Nutrition feeding problems were recorded for the DS children and the siblings, such as difficulties in using utensils, chewing and swallowing difficulties, food rejection and refusal. Physical activity status for the DS children and matched siblings were collected from their parents. Food frequency questionnaire was used to evaluate dietary habits. The parents were interviewed for daily details of food consumed by their children.

Data entry and analysis was carried out using SPSS 18. Results were presented in number (n) and in percentage (%), and were presented as mean values  $\pm$  standard deviation (SD). For testing statistical difference between the DS children and siblings, and Chi-Square test were used. *P*-value less than 0.05 ( $P < 0.05$ ) was considered statistically significant.

## RESULTS

Table 1 illustrates that the mean age is comparable between DS children and their siblings. DS children were significantly shorter and had a higher BMI than their siblings. The DS children weight less than their siblings, but the difference did not reach the significant level. Table 2 shows history of infant feeding of DS children and their siblings. The main interesting results were that during infancy period, 36.4% of DS children were bottle fed compared to only 5.5% of siblings. Almost half of the breast-fed DS children were fed for duration of less than 6 months compared to 36.5% of the breast-fed siblings. The percentage of DS cases that were not encouraged by the hospital to be breast fed (35.4%) was greater than the siblings (15.8%). The delay in introducing solid foods was markedly higher in the DS children compared to the siblings.

The percentage of DS children experiencing difficulties in using utensils and chewing/swallowing was almost ten times higher than the control siblings (Table 3). The percentage of DS children who experienced food rejection was almost twice the percentage of those siblings and the percentage of DS children who experienced vomiting after meals was almost three times higher than the siblings. About one third of DS children did not eat with their families as compared to only 15% of siblings.

Table 4 represents, the percentage of mothers preparing meals for DS children was lower compared to the siblings, but the difference did not reach the significant level. The frequency of eating fast food was lower in the DS compared to the siblings. The barrier for conducting physical activity among DS children were (dislike of parents to physical activity, weather condition, lack of facilities or space, lack of time, and embarrassment), and it was reported that 73% of the DS children did not exercise as compared to 44.2% of siblings, and in the group of children who exercised, only 13.8% of the DS children spent more than 30 minutes in exercising as compared to 79.4% of siblings.

Table 5 shows the frequency of consumption of some food items for the DS children and siblings. The main interesting result was that the weekly consumption of meat was lower in the DS cases as compared with the siblings. Also fruits and vegetables consumption was lower in the DS children compared with the siblings. In respect to the consumption of dairy products, the consumption of whole milk was lower in the DS children compared to the siblings, while the consumption of low fat or skimmed milk was higher in the DS children as compared with the siblings. No significant difference was detected between DS children and their siblings for 1-3 times consumption for all items ( $\chi^2 = 7.66$ ,  $P = 0.57$ ), for 4-6 times consumption ( $\chi^2 = 31.83$ ,  $P = 0.0002$ ) and rarely ( $\chi^2 = 67.09$ ,  $P = 0.0001$ ), a significant difference was observed between DS children and their siblings.

## DISCUSSION

Improved medical care has played a role in improving health quality and longevity of DS children. In USA, the average age mortality has increased from 25 years in 1983 to 49 years in 1997, with approximately 44% surviving to age 60 years and 13% to age 68 years (13, 14). Longer life expectancy imposes the need to address dietary intake and feeding difficulties faced by DS cases. In this study, a high rate of bottle feeding in infancy was observed with 36.4% of DS children bottle fed compared to only 5.5% of the siblings. This may be attributed to the lack of breast feeding encouragement from hospitals which may have led to the result that DS children being more frequently bottle fed as compared to the siblings.

Furthermore, poorer motor function of the mouth and generalized muscular hypotonia can contribute to less breastfeeding (6, 15, 16). Decreased muscle tone is associated with problems starting sucking, a poor lip seal, slow sucking and swallowing reflex and uncoordinated suck/swallow/breathing pattern. These conditions may contribute to coughing, choking, aspiration, milk escaping through the nose which may result in incomplete feeding (17). Our results showed that DS children are breast fed on average in a less duration compared to the siblings. Breast feeding is initiated in less than 50 % of newborns with DS (18). DS infants have poor sucking ability which makes establishment of breast feeding more difficult, since they have muscles that are poorly developed, thus making it difficult to position the infant during breast feeding, which will require longer breastfeeding sessions. DS children may also have problems in their mouth, such as a too-large tongue or a flat palate, which can affect the depth of latch on the breasts (16, 18), this poor sucking will discourage the mother from breastfeeding as it takes a great deal of patience to teach the baby to suck properly (and strongly) to obtain a milk ejection reflex and to stimulate the milk (6). In our study, Down syndrome babies were less frequently breastfed (64.6%) compared with their siblings (84.2%) during hospital admission. Previous studies reported that the main reasons cited by mothers were infants' illness, frustration and depression. It was shown that the feeling of depression, grief, guilt or disbelief can make a new mother question whether she should keep the baby or let alone nurse him (19).

DS children in this study were introduced to solid foods at a much later stage compared to the siblings, which is in agreement with other findings (8, 9). Feeding difficulties like food rejection, chewing and swallowing are common in children with DS (22-24). In our study, more than half of DS children were having difficulties in using utensils, 33% had chewing problems and almost three fourth of them had some kind of food refusal. Some authors attributed this feeding difficulty to low muscle tone, reduced oral space, presence of heart defects, slow sucking reflex, slow swallowing reflex, low birth weight, choking, and narrowed nasal passage and increased respiratory secretion (2,4,5,9). It was reported that feeding problems in infants with Down syndrome change as they grow older (10). The infants may experience problems with transition from breast/bottle feeding to cup feeding, and from liquids to solids which can result in inadequate lip closure, poor chewing ability and choking. Regarding food frequency consumption, the main interesting results were that the daily consumption of meat like lamb, chicken and fish was lower in the DS children as compared to the siblings, and fruits, juices and vegetable daily consumption was lower in DS children compared to the siblings. This is in agreement with Hopman *et al.*, who reported that children with Down syndrome consume a substantial amount of products that requires less mastication (22). It was suggested that fruits and vegetables are rejected or not offered to DS children (10).

The present study showed that some parents were isolating their DS children from other family members, as it was found that the percentage of DS children not sharing meals with the family was significantly higher as compared with their siblings. Furthermore, the percentage of the mothers preparing meals for their DS children was lower compared to siblings. Several studies reported that DS mothers feel anxious, frightened, guilty, angry and in rare cases, suicidal (23 -26). Other major observation seen in DS children is less time exercising. International research has shown that one of the major influences on children with DS is parental involvement and support in physical activity (27, 28). Previous studies on physical activity in Saudi Arabia showed that inactivity prevalence was 97.3% in Riyadh,

with about 70% of preschool children, about 60% of elementary and 96.1% of married being physically inactive (29,30). Poor weather has been identified as an environmental barrier to being physically active. In Riyadh the weather is a typical desert climate, being very hot in summer and very cold in winter, beside apartments are small and inadequate areas are available to play at.

Work leaves no time for physical activity. Parents come late from work, work double shifts or have social and family obligations beside in Saudi culture; women are not allowed to go out unless she is accompanied by the husband or a very close relative. A very strong barrier is the presence of grief, even shame or embarrassment for having a DS child (25, 28).

## CONCLUSION

The presence of a sibling as a control group to the DS children decreases the potential for confounding by environmental and genetic factors, and also decreases the recruitment bias of using healthy controls. The results suggest that parents can play a key role in the participation of children with DS in physical activity as this may be one avenue for obesity prevention. Children with DS need specially designed program and facilities. Another avenue is controlling feeding practice. Mothers of DS children should be trained and given advice to make decision regarding feeding options. Attention should be given to the age at which solid food is introduced as late introduction can be harmful to oral-motor development and may be responsible for developing malnutrition.

## Conflicts of Interest

The authors indicated no potential or actual conflict of interest pertaining to this study.

## Authors' Contributions

All authors made full contribution to data acquisition, interpretation of results, drafting and revising the final manuscript. All authors read and approved the final manuscript.

## Study Limitations

Sample size number and the shortage in records regarding medical condition status for DS children were the major limitations.

## Acknowledgements

The authors deeply extended their appreciation to the parents of the enrolled children for dedicated effort to complete this study.

## REFERENCES

1. Susan NV, William IC. Clinical practice guidelines for children with Down syndrome from birth to 12 years. *J Pediatr Health Car* 2006; 20: 47-54.
2. Al-Sarheed M. Feeding habits of children with Down's syndrome living in Riyadh, Saudi Arabia. *J Trop Pediatr* 2006; 52:83-86.
3. Mohamed T A. Incidence of Down syndrome in Dubai, UAE. *Med Princ Pract* 2007; 16:25-28.
4. O'Neill KL, Shults J, Stallings VA, Stettler N. Child-feeding practices in children with down syndrome and their siblings. *J Pediatr*. 2005; 146:234-238.

5. Lewis E and Kritzinger A. Parental experiences of feeding problems in their infants with Down syndrome. *Down Syndrome Research and Practice* 2004; 9: 45-52.
6. Pisacane A, Toscano E, Pirri I, Continisio P, Andria G, Zoli B, Strisciuglio P, Concolino D, Piccione M, Lo Giudice C, Vicari S. Down syndrome and breastfeeding. *Acta Paediatr* 2003; 92: 1479– 1481.
7. Grammatikopoulou MG, Manai A, Tsigga M, Tsiligioglou-Fachantidou A, Galli-Tsinopoulou A, Zakas A. Nutrient intake and anthropometry in children and adolescents with Down syndrome--a preliminary study. *Dev Neurorehabil* 2008; 11:260-267.
8. Shabayek MM. Assessment of the nutritional status of children with special needs in Alexandria: I. Nutrient intake and food consumption. *J Egypt Public Health Assoc* 2004; 79:225-241
9. Hopman E, Csizmadia CG, Bastiani WF, Engels QM, de Graaf EA, le Cessie S, Mearin ML. Eating habits of young children with Down syndrome in The Netherlands: adequate nutrient intakes but delayed introduction of solid food. *J Am Diet Assoc* 1998; 98:790-794.
10. Pipes PL. Nutrition and children with Down syndrome. In: Van Dyke, Matthesis DC, Eberly SS, Williams. *A guide for parents*. Bethesda: Woodbine House 1995, pp. 327-344.
11. Sanyer ON. Down syndrome and sport participation. *Curr Sports Med Rep* 2006; 5:315-318.
12. Shields N, Dodd KJ, Ablitt C. Do children with Down syndrome perform sufficient physical activity to maintain good health? A pilot study. *Adapt Phys Activ Q* 2009; 26:307-320.
13. Glasson EJ, Sullivan SG, Hussain R, Petterson BA, Montgomery PD, Bittles AH. The changing survival profile of people with Down's syndrome: implications for genetic counselling. *Clin Genet* 2002; 62:390-393.
14. Yang Q, Rasmussen SA, Friedman JM. Mortality associated with Down's syndrome in the USA from 1983 to 1997: a population-based study. *Lancet* 2002; 23:1019-1025.
15. Colón E, Dávila-Torres RR, Parrilla-Rodríguez AM, Toledo A, Gorrín-Peralta JJ, Reyes-Ortiz VE. Exploratory study: barriers for initiation and/or discontinuation of breastfeeding in mothers of children with Down syndrome. *P R Health Sci J* 2009; 28:340-344.
16. Spender Q, Stein A, Dennis J. An exploration of feeding difficulties in children with Down syndrome. *Dev Med Child Neurol* 1996; 38: 681–694.
17. Cooper-Brown L, Copeland S, Dailey S, Downey D, Petersen MC, Stimson C, Van Dyke DC. Feeding and swallowing dysfunction in genetic syndromes. *Dev Disabil Res Rev* 2008; 14:147-157.

18. Rendón-Macías ME, Castañeda-Muciño G, Cruz JJ, Mejía-Aranguré JM, Villasís-Keever MA. Breastfeeding among patients with congenital malformations. *Arch Med Res* 2002; 33:269-275.
19. Centers for Disease Control and Prevention (CDC). Breastfeeding-related maternity practices at hospitals and birth centers—United States, 2007. *MMWR Morb. Mortal. Wkly Rep* 2008; 57: 621–625.
20. Mazille MN, Woda A, Nicolas E, Peyron MA, Hennequin M. Effect of occlusal appliance wear on chewing in persons with Down syndrome. *Physiol Behav* 2008; 18:919-929.
21. Beaudry M, Dufour R, Marcoux S. Relation between infant feeding and infections during the first six months of life. *J Pediatr* 1995; 126:191-197.
22. Hopman E, Csizmadia CG, Bastiani WF, Engels QM, de Graaf EA, le Cessie S, Mearin ML. Eating habits of young children with Down syndrome in The Netherlands: adequate nutrient intakes but delayed introduction of solid food. *J Am Diet Assoc* 1998; 98:790-794.
23. Skotko B, Bedia RC. Postnatal support for mothers of children with Down syndrome. *Ment Retard* 2005; 43:196-212.
24. Yildirim A, Yildirim MS. Hopelessness of mothers who have children with Down syndrome. *Genet Couns* 2010; 21:375-380.
25. Bryant LD, Ahmed S, Ahmed M, Jafri H, Raashid Y. Understandings of Down syndrome and prenatal testing in Pakistan. *Soc Sci Med* 2011; 72:1393-399.
26. Norizan A, Shamsuddin K. Predictors of parenting stress among Malaysian mothers of children with Down syndrome. *J Intellect Disabil Res* 2010; 54: 992-1003.
27. Sayers MK. Parents' perceptions of health and physical activity needs of children with Down syndrome. *Downs Syndr Res Pract* 2007; 12(1):60-68.
28. Whitt-Glover MC, O'Neill KL, Stettler N. Physical activity patterns in children with and without Down syndrome. *Pediatr Rehabil* 2006; 9:158-164.
29. Hazza MA. Prevalence and trends in obesity and physical inactivity among Saudi children and adolescents: A growing public health challenge. *Int J of Pediatr Obes* 2009; 4: 6-14.
30. Al-Hazzaa H, Al-Rasheedi A. Adiposity and physical activity among preschool children in Jeddah, Saudi Arabia. *Saudi Med J* 28:766-773.

**Table 1: Age and anthropometric assessment of study subjects**

Parameter	DS children	Siblings	P- value
	Mean $\pm$ SD	Mean $\pm$ SD	
<b>Age (years)</b>			
Boys	8.2 $\pm$ 1.7	8.9 $\pm$ 1.4	0.115
Girls	7.9 $\pm$ 1.5	8.1 $\pm$ 1.6	0.523
<b>Weight (kg)</b>			
Boys	22.2 $\pm$ 7.7	26.1 $\pm$ 7.8	0.054
Girls	20.4 $\pm$ 6.3	21.5 $\pm$ 4.9	0.921
<b>Height (cm)</b>			
Boys	108 $\pm$ 9.9	124 $\pm$ 12.9	0.001
Girls	105.75 $\pm$ 8.3	115.1 $\pm$ 10.1	0.001
<b>BMI (kg/m<sup>2</sup>)</b>			
Boys	19.1 $\pm$ 4.1	16.9 $\pm$ 3.4	0.013
Girls	18.5 $\pm$ 3.1	16.3 $\pm$ 1.9	0.039



**Table 2: Prenatal nutrition of study subjects**

Prenatal Nutrition	DS Children		Siblings		P - Value
	N	%	N	%	
<b>History of infant feeding</b>					
Only breast feeding	23	21.5	42	38.2	0.0001
Breast fed + Formula milk	45	42.1	62	56.4	
Bottle feeding	39	36.4	6	5.5	
<b>Duration of breast feeding</b>					
Less than 6 months	33	48.5	38	36.5	0.02
6 – 12 months	22	32.4	33	31.7	
More than 12 months	13	19.1	33	31.7	
<b>Hospital encouragement of breast feeding</b>					
No	35	35.4	16	15.8	0.002
Yes	64	64.6	85	84.2	
<b>Age of introduction of solid food</b>					
4 months	11	11.5	56	53.3	0.0001
5 months	25	26	34	32.4	
6 months	19	19.8	12	11.4	
7 months or more	41	42.7	3	2.9	

**Table 3: Difficulties associated with eating meals and food refusal of study subjects**

Eating Meals Practice	DS Children		Siblings		<i>P</i> –Value
	n	%	n	%	
<b>Difficulties in using Utensils</b>					
No	62	57.4	108	95.6	0.0001
Yes	46	42.6	5	4.4	
<b>Vomiting after meals</b>					
No	81	75	104	92	0.0006
Yes	27	25	9	8	
<b>Chewing/swallowing difficulties</b>					
No	72	67	110	97.3	0.0001
Yes	36	33	3	2.7	
<b>Food rejection</b>					
No	30	28	73	65	0.0001
Yes	74	72	40	35	

**Table 4: Trends of eating and physical activity of the study subjects**

Trends of Eating and Physical Activity	DS Children		Siblings		P-Value
	N	%	n	%	
<b>Eating meals with the family</b>					
No	38	35	17	15	0.0005
Yes	70	64.8	96	85	
<b>Meal preparation</b>					
Mothers	65	60	76	67	0.275
Others	43	40	37	33	
<b>Times/week of eating fast food</b>					
1	64	59.3	51	45.1	0.006
≥ 2	44	40.7	62	54.9	
<b>Physical exercise</b>					
No	79	73.1	50	44.2	0.001
Yes	29	26.9	63	55.8	
<b>Duration (minutes)</b>					
< 30	25	86.2	13	20.6	0.001
≥ 30	4	13.8	50	79.4	

**Table 5: Weekly consumption of selected food items of study subjects**

Food Items	Frequency of consumption					
	DS			Siblings		
	1 - 3	4 - 6	Rarely	1 - 3	4 - 6	Rarely
<b>Meat</b>	55 (51)	2 (1.8)	51 (47.2)	70 (61.9)	33(29.2)	10 (0.09)
<b>Chicken</b>	93 (86.1)	13 (12)	2 (1.9)	81 (71.7)	15 (13.3)	1 (0.9)
<b>Fish</b>	93 (86.1)	1 (0.9)	14 (13)	94 (83.2)	1 (0.9)	8 (7.1)
<b>Egg</b>	92 (85.2)	11 (10.2)	5 (4.6)	95 (84.1)	15 (13.3)	3 (2.7)
<b>Whole milk</b>	62 (57.4)	15 (13.9)	31 (28.7)	75 (66.4)	31 (27.4)	7 (6.2)
<b>Low fat milk/skimmed</b>	47 (43.6)	44 (40.7)	17 (15.7)	31 (27.4)	32 (28.3)	50 (44.2)
<b>Cheese</b>	86 (79.6)	19 (17.6)	3 (2.8)	94 (83.2)	18 (15.9)	1 (0.9)
<b>Rice/macaroni</b>	96 (88.9)	11 (10.2)	1 (0.9)	95 (84.1)	17 (15)	1 (0.9)
<b>Fresh vegetables</b>	68 (62.9)	18 (16.7)	22 (20.4)	73 (64.6)	31 (27.4)	9 (8)
<b>Fresh fruits</b>	75 (69.5)	16(14.8)	17 (15.7)	81 (71.7)	32 (28.3)	0