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ORIGINAL ARTICLE

PARENTS' PERCEPTIONS OF MORBIDITIES AND SOME FUNCTIONAL ABILITIES IN PEOPLE WITH DOWN SYNDROME IN MOROCCO

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ABSTRACT

Objective. This study aimed to assess parental perceptions of morbidity and certain functional abilities in people with Down syndrome (DS) and their variability according to age and sex in Morocco.

Material and Methods. A retrospective and analytical survey was conducted between May 2014 and November 2017, and addressed to the parents of 279 individuals with DS, including 161 boys (57.7%) aged 1-40 years. The sample was subdivised to tree age groups, children under 10 years old, adolescents aged 10-18 years and adults aged ≥ 18 years. Information about the identity of parents, age and sex of people with DS, their morbidity during the two years preceding the survey, and some functional abilities was collected. Data were entered and analyzed using the statistical program SPSS statistics software for Windows (version 20.0). Chi-square ($\chi 2$) test was used for testing statistical significance. Differences were considered significant when the p-value <0.05. The multivariate analysis were used to identify the causes of morbidies independently associated with age and sex of child. Associations were measured in Odds ratio (OR) with 95% confidence intervals (95% Cl).

Results. The most common factors of morbidity registered in the study sample with DS, included respiratory infections, visual disturbances, oral pathologies, and cardiac problems (75.4%, 72.1%, 59.3%, and 44.9%, respectively). The hearing deficit, cardiac problems, respiratory infections, and oral pathologies showed statistically significant differences among the three age groups. According to the participants parents' perceptions, half of them (50%) were able to walk at 30 months, talk at 72 months, sit at 16 months, crawl at 16 months and eat alone at 48 months old.

Conclusion. People with DS at different ages present a set of potentially treatable diseases that require multidisciplinary medical monitoring. They also need early paramedical care to improve their functional abilities.

Key words: *Down syndrome, morbidity, functional abilities, Morocco*

INTRODUCTION

The life expectancy of people with Down syndrome (DS) has increased considerably over the past few decades. Since the 1980s, the improvement in the survival of children with DS has led to a spectacular improvement in the life expectancy of this population. The median age at death for American adults with DS passed from 25 years in 1983 to 49 years in 1997 [1], reaching the seventh decade of life in developed countries for many older adults with DS [2]. This increase in life expectancy has been linked to significant medical developments in recent decades, such as improvements in cardiac surgery, prevention of childhood infections, wider access to standard care, and better global psychosocial support for the population with DS [2].

Children with DS have an increased risk of birth defects and a wide range of treatable medical problems with 40-60% of DS babies having congenital heart disease. This make of importance to establish a cardiac malformation assessment for all babies with DS before the age of 6 weeks [3]. There is also a significant risk of hearing loss (75%), acute otitis

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media (50%-70%) [4], visual disturbances (60-70%) [3, 4], and thyroid disease (4% –18%) [5, 6, 7, 8]. In children under 19 years of age with DS, respiratory infections are the second leading cause of death (after heart diseases) and the respiratory problems are the leading cause of hospitalization and extended stays [3]. On the other hand, people with DS are at an increased risk of developing infectious oral diseases such as periodontitis and caries lesions with more serious consequences than those observed in the general population [9]. As dental caries can appear as soon as teeth appear, initiating rigorous daily dental hygiene after tooth eruption, as well as dental visits after 18 to 24 months are reported to be important in this category [10]. In addition, there is generally a delay of psychomotor development in children with DS compared to their counterparts in the general population. Indeed it is reported that children with DS can roll around 6 months (51%), sit around 12 months (78%), crawl around 18 months (34%), walk around 24 months (40%), run, walk up the stairs, and jump around 5 years (45% to 52%) [11]. Also, about 75% of people with SD can eat alone with their fingers at the age of 20 to 22 months and eat alone with a fork around 5.5 to 7.5 years [12].

To our knowledge, no data highlighting the characteristics of the clinical profile and functional abilities of people with DS are available in Morocco. Therefore, the present study aimed to describe the main causes of morbidities in people with DS and to analyze their differences according to age group, sex and psychomotor development.

MATERIAL AND METHODS

Participants

The data were collected using a retrospective survey, conducted between May 2014 and November 2017 on a sample of 277 parents of children, adolescents and adults with DS. The sample was recruited from 11 sites that are associations and health centers providing care and support for individuals with DS in 5 provinces, Marrakech, Safi, Chichaoua, El Kelâa of Sraghna**,** and Al Haouz belonguing to Marrakech-Safi region. The study was conducted based on an information note accompanying the questionnaire placed at the survey centers inviting for interview with the parents. The study objectives were explained to the representives responsible of all centers and associations. The eleven centers in which the study was conducted were those who accepted our request. Families with at least one child clinically and/or cytogenetically confirmed DS were included. Except for two couples who had two children with DS, all participants in this study were sporadic.

Procedures

The survey tool used is a standardized questionnaire to collect information on the identity of the parents, age and sex of people with DS, functional abilities and state of psychomotor development. Information on morbidity and certain medical conditions as well as and the age at which the child was able to sit, crawl, walk, talk and eat alone are also collected. The sample contains 279 people with DS, however the number of responses obtained varies depending on the questions. This number varies between 277 for ear problems and 115 for thyroid dysfunction.

Our study was designed in accordance with the Declaration of Helsinki. It was conducted in full respect of local ethical considerations, namely obtaining the prior authorization of the competent authorities of the university and the responsibles of the visited centers. We contacted the parents/guardians of people with DS to whom we presented the objectives of the investigation and enlightened them on their rights. The principle of voluntary participation and the confidentiality and anonymity of the questionnaire were respected. Written parental consent was obtained before participation in the study.

Statistical analysis

Statistical analysis was performed using the SPSS software for Windows (version 20.0). Nominal and ordinal qualitative variables were presented as percentages of the different modalities. For descriptive analysis of functional abilities and because of the small sample size, the median and interquartile ranges (IQR) (25th percentile and 75th percentile) were used. The differences between groups for these variables for age groups and sex were tested using the Pearson's *Chi*-square ($\chi 2$) test. Differences were considered significant when the *p*-value <0.05.

The multinomial logistic regression model and the binary logistic regression model which allows the elimination of confounding factors of the associated variables with age and sex of child in the bivariate analysis ($P<0.2$), were used to identify the causes of morbidies independently associated with age and sex of child. Associations were measured in Odds ratio (OR) with 95% confidence intervals (95% Cl).

RESULTS

Morbidity of people with Down's syndrome

Table 1 summarizes the main causes of morbidity in people with DS. Overall, 51.1% of the participants had ≥3 pathologies. Even though the age of the participants did not show a statistically significant difference in the total number of pathologies, it is clear from Table 1 that the incidence of ≥3 pathologies increases with age (45.9% in children under 10 years old, 55.3% in

Table 1. Differences between modalities of causes of morbidity of people with DS and age groups

Diseases	Modalities	Total n (%)	Age < 10 years n (%)	Age 10-18 years n (%)	Age ≥ 18 years n (%)	χ2 ; significance
Number of pathologies	<3	131 (48.9)	85 (54.1)	34 (44.7)	12 (34.3)	5.25 ; n.s
	≥3	137 (51.1)	72 (45.9)	42 (55.3)	23 (65.7)	
Visual disturbances	Yes	150 (72.1)	81 (73.0)	46 (68.7)	23 (76.7)	0.74 ; n.s
	No	58 (27.9)	30 (27.0)	21 (25.6)	7 (23.3)	
Hearing deficit	Yes	14 (9.9)	6 (8.3)	2 (3.9)	6 (31.6)	12.29 ; **
	No	128 (90.1)	66 (91.7)	49 (96.1)	13 (68.4)	
Ear problems	Yes	47 (17.0)	28 (17.4)	11 (13.8)	8 (22.2)	1.31 ; n.s
	No	230 (83.0)	133 (82.6)	69 (86.2)	28 (77.8)	
Cardiac problems	Yes	101 (44.9)	74 (54.8)	21 (31.8)	6 (25.0)	13.77 ; **
	No	124 (55.1)	61 (45.2)	45 (68.2)	18 (75.0)	
Respiratory infections	Yes	205 (75.4)	131 (81.9)	54 (69.2)	20 (58.8)	10.24 ; **
	No	67 (24.6)	29 (18.1)	24 (30.8)	14 (41.2)	
Thyroid dysfunction	Yes	23 (20.0)	16 (18.8)	6 (27.3)	1 (12.5)	1.08 ; ns
	No	92 (80.0)	69 (42.9)	16 (19.5)	7 (87.5)	
Oral pathology†	Yes	143 (59.3)	52 (40.9)	59 (74.7)	32 (91.4)	40.45 ; ***
	No	98 (40.7)	75 (59.1)	20 (25.3)	3 (8.6)	

† For the analysis of the prevalence of dental caries, we excluded children under 3 years of age.
χ2 – *Chi*-square test; n.s - not significant; ** p<0.01; *** p <0.0001.

Table 2. Result of Multinomial Logistic Regression Model. Analysis between age groups and morbidities studed

Age groups	Morbidities	Modalities	Adjusted OR	(Cl 95%)	p
< 10 years	Number of pathologies	<3	0.32	(0.04-2.50)	0.283
	Hearing deficit	Yes	0.08	(0.008-0.79)	0.031
	Cardiac problems	Yes	3.44	(0.50-23.77)	0.209
	Respiratory infections	Yes	9.57	(1.55-58.90)	0.015
	Oral pathologies	Yes	0.07	(0.01-0.51)	0.009
10-18 years	Number of pathologies	<3	0.67	(0.11-4.12)	0.669
	Hearing deficit	Yes	0.06	(0.007-0.65)	0.020
	Cardiac problems	Yes	2.52	(0.37-17.08)	0.344
	Respiratory infections	Yes	2.23	(0.47-10.45)	0.309
	Oral pathologies	Yes	0.72	(0.10-4.85)	0.744
The reference modality is age ≥ 18 years					

OR = odds ratio; p= significance; Cl= confidence limits

preadolescents and adolescents aged 10-18 years and 65.7% in adults aged ≥ 18 years). The most common groups of diseases in the whole sample were respiratory infections (75.4%), visual disturbances (72.1%), oral pathologies (59.3%), cardiac problems (44.9%), thyroid dysfunction (20.0%) and ear problems (17.0%). Visual disturbances were particularly prevalent in all age groups, ranging from 73.0% in children under 10 years, 68.7% in preadolescents and adolescents aged 10-18 years old to 76.7% in adults aged ≥ 18 years (χ2 = 0.74, p not significant).

The distribution of ear problems and thyroid dysfunction by age group in our sample also did not show significant differences among the three groups. The hearing deficit, cardiac problems, respiratory infections and oral pathologies showed statistically significant differences among the three groups. Oral pathologies was very common in adults (91.4%; p<0.0001). Respiratory infections and cardiac problems were significantly common in children under 10 years of age with rates of 81.9% and 54.8%, respectively.

Multinomial logistic regression model analysis between morbidities and age groups with age ≥ 18 years as reference modality showed statistically significant differences between age < 10 years and age ≥ 18 years in hearing deficit, respiratory infections and oral pathologies (OR= 0.08; 95%Cl: 0.008-0.79, OR= 9.57; 95%Cl: 1.55-58.90 and OR= 0.07; 95%Cl: 0.01-0.51, respectively). While the age group 10-18 years showed only one statically significant difference compared to the age ≥ 18 years in favor of hearing deficit (OR= 0.06; 95%Cl: 0.007-0.65).

The distribution of diseases studied by sex (Table 3) did not show any statistically significant difference in the morbidities studied eccept for thyroid dysfunction ($\chi 2$ =3.92 ; p = 0.048). To take into account and simultaneously all the variables selected in this study, we applied the binary logistic regression method (Table 4). The results obtained showed that none of the morbidities studied allowed the observation of statistically significant differences by sex.

Psychomotor development

Data analysis concerning the perceptions of parents surveyed, regarding the functional abilities of their children with DS is presented in percentiles in Table 5. In the sample of people with DS studied, the median age where they were able to walk was 2.5 years IQR (2.0-4.0), to speak was 6.0 years IQR (4.0-7.0), to sit was 16.0 months IQR (10.75-24.0), to crawl was 16.0 months IQR (12.0-24.0), and to eat alone was 4.0 years IQR (3.0-6.0).

DISCUSSION

The present study reports data on the types of certain morbidities and their incidence within a sample of people with DS in Morocco as well as the median age at which they were able to aquire certain functional abilities according to their parents' perception. The results show that more than half of the participants (51.1%) had ≥3 types of morbidities. This rate is lower than that recorded previously by de Asua et al in a group of Spanish adults who presented in average 5 ± 2 clinical problems [13]. The lower rate observed in the present study population could be related to the age difference between the two cohorts.

Contrary to the Pikora et al [14] study reporting age differences in rates of diseases in school-age children (5–17 years) and young adults (16–30 years), the distribution of the number of illnesses did not show any statistically significant difference by age group in the present study.

The most common diseases in the whole sample were respiratory infections in 75.4%, visual disturbances in

Table 3. Differences between modalities of causes of morbidities in people with DS and sex of child

Diseases	Modalities	Male n (%)	Female n (%)	$\chi 2$; significance
Number of pathologies	<3	69 (45.1)	62 (53.9)	2.04 ; n.s
	≥3	84 (54.9)	53 (46.1)	
Visual disturbances	Yes	82 (69.5)	68 (75.6)	0.93 ; n.s
	No	36 (30.5)	22 (24.4)	
Hearing deficit	Yes	7 (9.0)	7 (10.9)	0.15 ; n.s
	No	71 (91.0)	57 (89.1)	
Ear problems	Yes	33 (20.8)	14 (11.9)	3.80 ; n.s
	No	126 (79.2)	104 (88.1)	
Cardiac problems	Yes	52 (40.3)	49 (51.0)	2.56 ; n.s
	No	77 (59.7)	47 (49.0)	
Respiratory infections	Yes	120 (77.4)	85 (72.6)	0.81 ; n.s
	No	35 (22.6)	32 (27.4)	
Thyroid dysfunction	Yes	9 (13.6)	14 (28.6)	3.92 ; *
	No	57 (86.4)	35 (71.4)	
Oral pathologies†	Yes	90 (63.8)	53 (53.0)	2.84 ; n.s
	No	51 (36.2)	47 (47.0)	

† For the analysis of the prevalence of dental caries, we excluded children under 3 years of age; $\chi 2$ – *Chi*-square test; n.s - not significant; * p<0.05

Table 4. Result of Binary Logistic Regression Model. Analysis between sex of child and morbidities studed

Variables	Adjusted OR	(CL 95%)	p
Number of pathologies	0.29	(0.07-1.11)	0.07
Ear problems	2.18	(0.39-12.02)	0.37
Cardiac problems	0.88	(0.28-2.71)	0.82
Thyroid dysfunction	0.30	(0.08-1.16)	0.08
Oral pathologies	0.60	(0.19-1.89)	0.38

OR = odds ratio; p= significance; Cl= confidence limits

Table 5. Medians and interquartile ranges (IQR) of age (months) when functional abilities are well achieved

	Q25	Q50	Q75
Walking (n = 240)	24.00	30.0	48.00
Talk (n = 76)	48.00	72.00	84.00
Sit (n = 230)	10.75	16.00	24.00
Crawling (n = 157)	12.00	16.00	24.00
Eating alone (n = 206)	36.00	48.00	72.00

72.1%, oral pathologies prevalent in 59.3%, cardiac problems in 44.9%, thyroid dysfunction in 20.0% and ear problems in 17.0% of the study people. In comparison with the rates found by Pikora et al [14], the visual disturbances are the most frequent (73%) followed by the hearing problems (45%), respiratory problems (25%), and the cardiac problems (36%). Another study conducted in a group of school-aged children with DS by Leonard et al [15] showed that heart and bowel problems are prevalent in less than half of the children. More than half had ear problems and more than three-quarters had eye problems. Also, ear, nose and throat (ENT) professionals were the specialists the most frequently consulted.

In the present study, the visual disturbances were particularly prevalent in all age groups, ranging from 73.0% in children under 10 years of age, 68.7% in adolescents to 76.7% in adults aged ≥18 years ($\chi 2 = 0.74$, not significant). These rates were lower than those reported by de Asua et al [13].

The hearing deficit, respiratory infections and oral pathologies showed statistically significant differences between children under 10 years of age and adults aged ≥18 years. Whereas concerning pre-adolescents and adolescents aged 10-18 years old, only the hearing deficit which showed statistically significant differences compared to adults aged ≥18 years. As reported by Picciotti et al [16], hearing loss was common in adults with DS and increases gradually with age. The Stensson et al [17] study data on how the parents perceived the general and oral health of their children with DS, showed that 70% of parents climed that general health and 74% the oral health of their child's as good or very good.

In addition, the respiratory infections and cardiac problems were significantly common in children under 10 years of age with rates of 81.9% and 54.8%, respectively. Findings from Zachariah et al [18] study showed that the risk of being hospitalized with lower respiratory tract infection is significantly higher in children of less than 2 years old with DS than in those without DS. The literature has revealed also that congenital heart defects and respiratory problems are the main causes of death in people with DS [19]. Congenital heart disease is one of the main causes of morbidity and mortality in this population [20, 21, 22].

On the other hand, the distribution of ear problems and thyroid dysfunction by age group did not show significant differences among the three groups in this study population. The effect of age in thyroid dysfunction has been shown by some studies [23, 24] and has been banished by others [25]. Another factor examined is the effect of sex on the distribution of the diseases studied. This effect was not observed in the present study corroborating the results of several previous studies [13, 23].

Analysis of the present survey data regarding the parents' perceptions on their children functional abilities, showed that the median age of people with DS when they were able to walk was 2.5 years IQR (2.0-4.0), to talk was 6.0 years IQR (4.0-7.0), to sit was 16.0 months IQR (10, 75-24.0), to crawl was 16.0 months IQR (12.0-24.0) and to eat alone was 4.0 years IQR (3.0-6.0). Comparing these results to those found by *de Graaf* et al [26] in people with DS from the United States and the Netherlands, showed that people with DS were able to walk at 5 months earlier and speak reasonably well late at about 6 years, while they were able to maintain their hygiene by the age of 13 and to work independently by the age of 20 yrs old.

Limitations

This study has limits related to the sample size, which is insufficient for the particularity of the population studied and justified by the constraints of the limited number of centers that provide care and support to people with DS. The data on morbidity and functional abilities were those declared by the parents. Although these data are subjective and reflect only the perception of the parents, they remain important in so far as they allow the analysis and understanding of certain related aspects.

There may also have been a level of missing data due to the failure to perform the clinical examinations and biological analysis necessary to confirm the involvement of certain pathologies. This aspect may have contributed to missing data, which limited the interpretation of some results.

CONCLUSION

The results of the present study showed that the main causes of morbidities in Down Syndrome people surveyed are respiratory infections, oral pathologies, visual disturbances, cardiac problems, ear problems, and thyroid diseases. The data revealed an effect of age on morbidity with impact on the hearing deficit, cardiac problems, respiratory infections, and oral pathologies. This fact was clearely showen between age < 10 years and age ≥ 18 years.

However, the effect of sex factor on morbidity did not show any statistically significant difference. In addition, the data on functional abilities, showed that the majority of people with DS were able to achieve acceptable levels of mastery of certain functional abilities, according to their parents, at the usual age. The study draw attention on the necessary early medical and paramedical care, to avoid any complications related to congenital malformations and to help the child with DS to have a significant level of autonomy by acquiring certain functional abilities early.

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Disclosure conflict of interest

The authors declare that there is no conflict of interests.

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