

# Perception of Saudi Mothers of Their Children with Down Syndrome in Al-Khobar City, Saudi Arabia

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## Abstract

**Purpose:** To evaluate the perception (awareness, feeling, belief and intention of attribute, characteristics and behaviors) of Saudi mothers of their children with DS and to identify the possible factors that affect their perception.

**Materials and Methods:** A cross sectional survey was conducted in Al-Khobar city, Saudi Arabia (SA), in 2015 involving all Saudi mothers of children with DS in special education schools in the private sector (n=100). Data were collected using a self-administered questionnaire. Al-Khobar city, Saudi Arabia (SA), in 2014 involving all Saudi mothers of children with DS in special education schools in the private sector (n=100). Data were collected using a self-administered questionnaire. A Spss 21 was used for statistical analysis.

**Results:** The response rate was 73%. The study found that 53.4% had a positive perception of their children with DS while 46.6 % perceived their children negatively. It is concluded that this positive perception of Saudi mothers of their children with DS related to: the burden (effect) imposed by the children with DS on the family and society, causal attribution of DS, education of children with DS, social integration and discrimination as well as health, treatment and care of the children with DS. The negative perception related to acceptance and joy with DS children, the quality of life of DS children, over-protection and dependence of these children as well as an embarrassment and disappointment of having children with DS.

Accordingly, it is recommended that educational programs be designed form others with children with DS, and for the community to improve mothers' disposition toward their children.

**Keywords:** perception, mothers, children and Down's syndrome.

## 1. Introduction

Down Syndrome (DS), the most common chromosomal abnormality among live born infant is the most frequently recognized genetic cause of Intellectual and physical disability (David, 2000; Patterson & Costa, 2005). The mother caring for children with DS are more likely to experience increased stress than the mother of normally developing children. The successful adaption and raising of children with DS depends on as how the mother perceive. Perception is a critical component of adapting and coping. Families are different in their perception of disability. Some mothers perceive disability as an irreversible condition, which may influence their perception of the severity of the disability, leaving them with subsequent feelings of helplessness and shame. On the other hand, a positive perception of disability enhances the ability of a mother to accept the diagnosis and to provide positive support for the child (Shira & Louise, 2002).

Perceptions and Attitudes toward disabled persons sometimes are influenced by the label affixed to the disability.

Even mothers' perceptions of their disabled children can be influenced by labels (Susan, 2014). Mothers may also be influenced by the attitudes of their family and community (Maloni et al., 2010; Green, 2003). Although social attitudes toward individuals with DS have become more positive, many children with DS and their families are stigmatized by friends, relatives, and the wider community (Herbert & Carpenter, 1994; Van Riper et al., 1992). Furthermore, the birth of a child with DS has been described as a worthwhile but stressful experience, resulting in a sense of imbalance in the family system (Priya et al., 2010) with a numbers of negative effects (Beckman, 1995; Dyson, 1991). It seems that the mothers bear the brunt of most of the negative effects of having a child with DS because mothers rather than fathers for various reasons normally stay at home and take greater responsibility for the overall child when a child has special needs (Hedov, 2002; McLinden, 1990; Sara Ashencaen Crabtree, 2007).

Perception of children with disabilities is influenced by the knowledge and understanding of the disability, capabilities, life experiences, religious beliefs and socio cultural background (Shira & Louise, 2002). Perception of children's disabilities also varies according to severity, preferences for treatment and by what is known from a medical and scientific standpoint (Aranda & Knight, 1997). In addition, parents' perception of the child's disability will be influenced by the family's attitudes towards disabled persons in general and their belief system (Shira & Louise, 2002).

In the Kingdom of Saudi Arabia, the incidence of DS is about 1.8 per 1,000 live births (Niazi et al., 1995), a rate similar to that reported in other countries (Iselius & Lindsten, 1986; Bittles et al., 2007; Antonarakis et al., 2004; Canfield et al., 2006).

This study was conducted in the year 2014, to evaluate the perception of Saudi mothers of their children with DS in the special education schools in the private sector in Al-Khobar city of Saudi Arabia. A thorough literature review revealed that only a few studies cite them have been conducted on mothers' perception of their children with DS, and to date, no study has investigated the Saudi mothers' perception of their children with DS. This lack of data lay behind the decision to conduct the study. This study was done with the hypothesis that Saudi mothers have a negative perception of their children with DS.

The study may be used as a base-line national study for future applications to improve social and health services, and as a guide in preparing the health education programs for DS children.

## 2. Methods and Materials

This was a cross-sectional study. The field work was conducted from November 2013 to March 2014. The special education schools in the private sector in Al-Khobar city, of Saudi Arabia, were chosen for the study. All Saudi mothers of children with DS registered in these special education schools were the study population. Sequence of points For ethical reason codes (A, B, C, D, E) were given for each school instead of its name. A pilot study was conducted before starting the real study in which 10 mothers were involved and school A was involved.

Official approval to conduct the study was obtained from the Research Committee, Joint Program and Family Medicine Specialty of the Eastern Province. Telephone calls, official letters, and meetings were then held with the directors of the private special education schools to get their permission and cooperation for the study, and to determine the total number of Saudi mothers of children with DS.

Most mothers were personally contacted (face-to-face or by telephone) to get their permission for participation in the study, after its purpose had been clearly explained. All mothers who had participated in the pilot study were excluded from the list of participants in the actual study. Based on that, a total of 100 mothers were identified.

Table 1. Distribution of Saudi mothers of children with Down syndrome among the five special education schools in the private sector in Al-Khobar city, Saudi Arabia

Special education school (Code)	Number of Saudi mothers of children with Down's syndrome
A	31
B	25
C	24
D	12
E	8

Mother's perception was defined as awareness, feeling, belief and intention of attribute, characteristics and

behaviors (MD.Social perception, 2013; Psychology Dictionary Social perception, 2013), in mothers toward their children with DS. This included causal attribution, acceptance and joy from children with DS, embarrassment and disappointment of having children with DS, over-protection and dependence of children with DS, burden on family and society imposed by children with DS, Social integration and discrimination, education of children with DS, health, treatment and care of children with DS and Quality of life of children with DS.

Mothers' socio-demographic characteristics were documented on age, marital status, and level of education, occupation and number of children. The socio-demographic characteristics of children with DS consisted of age, sex, birth order and age at diagnosis. Fathers' socio demographic characteristics included age, level of education and occupation. Apart from this, family income and socio-economic class were the expanded socio demographic characteristics.

Socio-economic class was defined as the classification of family into upper, middle and lower socioeconomic class according to a composite of the following criteria: father's education, father's occupation and family income (ranking scores = 7, 3, and 1, for the three categories of each item respectively); as follows:

1- Father's education (item A):

University or secondary, preparatory or primary and illiterate.

2- Father's occupation (item B):

Professional or commercial, semi-professional, and low-income type of job or unemployed.

3- Family income in Saudi Riyals [SR] per month (item C):

≥ 10,000, (5,000 – <10,000) and < 5,000. Equivalent to Max 3500 US \$ and Min 1500 US\$.

Based on the above criteria, the families were considered to be in the upper, middle or lower class if the total scores of the three items together, A+B+C = 21, 9–20, 3–8 respectively.

The data were collected through a specially designed self-administered questionnaire "*perception of mothers of their children with Down's syndrome*". The questionnaire was designed by the investigator to achieve the study objectives. Content areas were identified after an extensive literature review, discussions with the supervisor, and a number of consultations with experts in the field of Family and Community Medicine Education. The experts, who were from Dammam University, SA, had been asked to evaluate the study and validate the questionnaire. The translation of the questionnaire into Arabic language was done by the investigator. The re-translation by two independent bi-lingual experts and was found to agree with the pre-translation version keeping with the back translation. Consequently, a self-administered, pre-coded, ten-page questionnaire was used. All the questions were close ended with 2–8 options for ease of responding to the questions, to reduce the time required to complete the questionnaire, and to avoid end questionnaire exhaustion.

The questionnaire was composed of two sections. Section 'A' dealt with socio-demographic characteristics of parents and their children with DS, and section B measured the mothers' perception of their children with DS.

Section 'A' consisted of four parts. Part one was made up of 5-items dealing with mother's socio-demographic characteristics (focusing on age, marital status, highest educational level attained occupation and the total number of normal children other than the DS child). Part two dealt with socio-demographic characteristics of children with DS with a 4-item data sheet (focusing on age, sex, birth order and age at diagnosis with DS). Part three comprised of 4-items that dealt with father's socio-demographic characteristics (focusing on age, highest educational level attained and occupation). Part four, had just 1-item on the expanded socio-demographic characteristics that dealt with the total monthly family income.

Section B; perception of the mothers of their children with DS was assessed with a total of 56-items. For the degree of perception, mothers were asked to indicate their responses using a 3-point Likert scale ranging from 1 to 3 where 1 represented "disagree" in case of positive sentence and "agree" in case of negative sentence.

A covering letter of the questionnaire was designed to clarify the purpose of the study, the importance and benefits of the responses, as well as the assurance of strict confidentiality. Data were collected from the five special education schools with help of one pre-trained data collector for each school using pre tested and pre-coded questionnaire (Table 2). The data collectors were trained for one week for the method of data collection and communication skills with the mothers, and how to facilitate reminders to complete the questionnaire.

A two follow-up telephone contacts were made after two and four weeks by the data collectors to remind participants who had not responded in order to increase the response rate.

Table 2. Methods of data collection from the five special education schools

Special education school (Code)	Methods of data collection
A	Hand-delivery of the questionnaire
B	Google doc was used as a tool for dispatch and receipt of the questionnaire
C	Hand-delivery of the questionnaire/Telephone call/Direct personal contact
D	Telephone call
E	Hand-delivery of the questionnaire

### 2.1 Data Coding and Entry

The completed questionnaires were collected, checked for completeness, and verified for inconsistency. Data was entered by the investigator into a personal computer and analyzed using Statistical Package for the Social Sciences (SPSS) software version 21. All variables of the questionnaire were coded before entry, checked for accuracy and scrutinized before analysis. Frequency distribution tables were constructed with the mean and standard deviation (SD). After testing the sample homogeneity, Chi-square ( $\chi^2$ ) and Fisher's exact tests (FET) were used to examine the association between each independent variable and each outcome measure. Significant level was set at less than 0.05, throughout the analysis. Multiple Logistic regression analysis was performed to determine significant predictors of the study outcome.

A cut-off point was taken after calculating the mean of total perception score. The calculated mean score of the total perception was "135". Accordingly, those who scored  $\geq 135$  were considered to have positive perception while those who scored  $< 135$  were considered to have negative perception.

For each different aspect of perception, the total score was divided into two categories (negative and positive) according to the mean score i.e. those who scored above the mean were considered as positive score and those scoring below the mean were considered as negative score as follows:

- Causal attribution (mean was 17): positive for those who scored  $\geq 17$  and negative for those who scored  $< 17$
- Acceptance and joy with children with DS (mean was 26): positive for those who scored  $\geq 26$  and negative for those who scored  $< 26$ .
- Embarrassment and disappointment of having children with DS (mean was 13): positive for those who scored  $\geq 13$  and negative for those who scored  $< 13$ .
- Over-protection and dependence of children with DS (mean was 17): positive for those who scored  $\geq 17$  and negative for those who scored  $< 17$ .
- Burden on family and society imposed by children with DS (mean was 13): positive for those who scored  $\geq 13$  and negative for those who scored  $< 13$ .
- Social integration and discrimination (mean was 14): positive for those who scored  $\geq 14$  and negative for those who scored  $< 14$ .
- Education of children with DS (mean was 6): positive for those who scored  $\geq 6$  and negative for those who scored  $< 6$ .
- Health, treatment and care of children with DS (mean was 27): positive for those who scored  $\geq 27$  and negative for those who scored  $< 27$ .
- Quality of life of children with DS (mean was 6): positive for those who scored  $\geq 6$  and negative for those who scored  $< 6$ .

For analytical purposes, the continuous variables were categorized as follows:

- Mother's age in years was subdivided into four groups as follows:  $< 30$ , 30 to  $< 40$ , 40 to  $< 50$  and  $\geq 50$ .
- Number of normal children other than the child with DS was subdivided into four groups as follows:  $< 3$ , 3 to 5, 6 to 8 and  $\geq 9$ .
- Child's age in years was subdivided into the following four groups:  $< 5$ , 5 to  $< 9$ , 9 to  $< 13$  and  $\geq 13$ .
- Child's birth order was subdivided into the following three groups:  $< 5$ , 5 to 8,  $\geq 9$ .

- Age of child at time of diagnosis with DS in days was subdivided into five groups as follows: <8, 8 to <15, 15 to <22, 22 to <28 and  $\geq 28$ .
- Father's age in years was subdivided into four groups as follows: <40, 40 to <60, 60 to <80 and  $\geq 80$ .

Reliability of the questionnaire which was 0.77 using Cronbach's alpha statistic, was considered good.

### 3. Results

The total number of Saudi mothers of children with DS who were registered in the five special education schools was 100. Seventy three mothers completed the study questionnaire yielding an overall response rate of 73%.

#### 3.1 Mothers' Socio-Demographic Characteristics

As shown in (table 3), the mean age of all mothers was  $42.99 \pm 6.7$  (Range 29yrs – 55yrs). More than one-quarter of the mothers (27.4%) were below the age of 40 years, while more than half of the mothers (54.8%) were between age 40-<50, and only 13 (17.8%) were aged 50 years and over. The majority of the mothers were married (97.3%), while only 2 (2.7%) were divorced. More than one third of the mothers (38.4%) had college or university education, followed by less than one-third (31.5%) and less than one-quarter of the mothers (17.8%) who had high school and secondary school education respectively. Only 4 (5.5%) of the mothers were illiterate and 3 (4.1%) had post graduate degree. Two mothers (2.7%) had only the primary school education (Table 3). The details of the demographic characteristics are shown in Table 3.

Table 3. Socio-demographic characteristics of Saudi mothers of children with Down syndrome

Characteristics	Total ( n=73 )	
	No.	%
<b>Age (years)</b>		
< 30	2	2.7
30 – < 40	18	24.7
40 – < 50	40	54.8
$\geq 50$	13	17.8
Mean $\pm$ SD (42.99 $\pm$ 6.7)		
<b>Marital Status</b>		
Married	71	97.3
Divorced	2	2.7
<b>Educational Level</b>		
Illiterate	4	5.5
Primary school	2	2.7
Secondary school	13	17.8
High school	23	31.5
College/University	28	38.4
Post graduate degree	3	4.1
<b>Occupation</b>		
Government employee	14	19.2
Non-government employee	6	8.2
Self-employed	1	1.4
Student	2	2.7
House wife	44	60.3
Retired	4	5.5
Unemployed	2	2.7

Number of normal children		
<3	23	31.5
3-5	40	54.8
6-8	9	12.3
≥ 9	1	1.4
Mean±SD (4.77±2.54)		

### 3.2 Fathers' Demographic Characteristics

The mean age of all fathers was 50.6±9.49 years (Range 29 yrs-87 years). Most of the fathers (87.6%) were below the age of 60 years, while eight of the fathers (11%) were between age 60-<80, and only one (1.4%) was more than 80 years old (Table 4).

More than one third of the fathers (38.4%) had completed high school, followed by 23 (31.5%) and 11 (15.1%) who had college or university and secondary school education respectively. Six fathers (8.2%) had post-graduate degrees, two (2.7%) had primary school education and similar percentage has started primary school but had not finished. Only one father (1.4%) was an illiterate. Concerning the fathers' occupation, most of the fathers 32 (43.8%) were government employees while twenty-one fathers (28.8%) were non-government employees. Sixteen fathers (21.9%) were retired and four (5.5%) were self-employed (Table 4).

Table 4. Socio-demographic characteristics of the fathers of children with Down syndrome

Characteristics	Total ( n=73 )	
	No.	%
<b>Age (years)</b>		
<40	9	12.3
40 – < 60	55	75.3
60 – < 80	8	11.0
≥ 80	1	1.4
Mean±SD (50.60±9.49)		
<b>Educational Level</b>		
Illiterate	1	1.4
Less than primary school	2	2.7
Primary school	2	2.7
Secondary school	11	15.1
High school	28	38.4
College/University	23	31.5
Post graduate degree	6	8.2
<b>Occupation</b>		
Government employee	32	43.8
Non-government employee	21	28.8
Self-employed	4	5.5
Retired	16	21.9

### 3.2 Expanded Socio-Demographic Characteristics of the Study Sample

Nearly two-thirds of the mothers (63%) had a family income of 10,000 Saudi Riyal (S.R) or more per month, followed by almost one-quarter (24.7%) with a family income between 5,000-10,000 Saudi Riyal (S.R) (equivalent to between 1300 US\$ -2600 US\$) per month, and only nine mothers (12.3%) with a family income of

less than 5,000 S.R per month (Table 5).

Table 5. Expanded socio-demographic characteristics of the study sample

Characteristics	Total ( n=73 )	
	No.	%
Family income (S.R* per month)		
<5,000	9	12.3
5,000 – < 10,000	18	24.7
≥ 10,000	46	63.0
Socio – economic class		
Upper	35	47.9
Middle	35	47.9
Lower	3	4.2

\*S.R= Saudi Riyals.

### 3.3 Demographic Characteristics of the Children with DS of the Parents

The mean age of all children with DS was  $7.51 \pm 3.29$  years (Range 1 year-15 years). More than one-third of the children (41.1%) were between the ages of 5 - <9 years, followed by nearly another third (30.1%) between the ages of 9 - <13 and a quarter of the children (20.6%) were aged below 5 years. Only six (8.2%) were aged 13 years and more. Of the 73 children, 42 (57.5%) were male, and 31 (42.5%) were female (Table 6).

The age of the children at the time of diagnosis with D.S and children's birth order are shown in (Table 6). The mean age of the children at the time of diagnosis with D.S was  $12.7 \pm 35.74$  days (range 1 day -180 days).

The mean birth order of children with DS was  $4.99 \pm 2.58$ , with a maximum birth order of eleventh and a minimum of first. The birth order of thirty-three children (45.2%) was between 5<sup>th</sup>–8<sup>th</sup>. Thirty-two children (43.8%) were before the 5<sup>th</sup>, and eight children (11%) were the 9<sup>th</sup> or later in birth order (Table 6).

Table 6. Socio-demographic characteristics of children with Down syndrome

Characteristics	Total ( n=73 )	
	No.	%
Age (years)		
<5	15	20.6
5 – < 9	30	41.1
9 – < 13	22	30.1
≥ 13	6	8.2
Mean±SD (7.51±3.29)		
Sex		
Male	42	57.5
Female	31	42.5
Child's birth order		
<5	32	43.8
5 – 8	33	45.2
≥ 9	8	11.0
Mean±SD (4.99±2.58)		

Age at the time of diagnosis with D.S(days)		
<8	61	83.6
8 - < 15	2	2.7
15 - < 22	1	1.4
22 - < 28	2	2.7
≥ 28	7	9.6
Mean±SD (12.7±35.74)		

### 3.4 Mothers' Perception of Their Children with Down Syndrome

#### 3.4.1 Total Perception of Mothers

The total mean perception score of Saudi mothers of their children with DS was  $134.26 \pm 9.76$ , with a range of 114 to 154. Of 73 mothers, 39 (53.4%) had a positive perception of their children with DS, while 34 mothers (46.6%) were negative in their perception of their children with DS, as shown in (Figure 3).

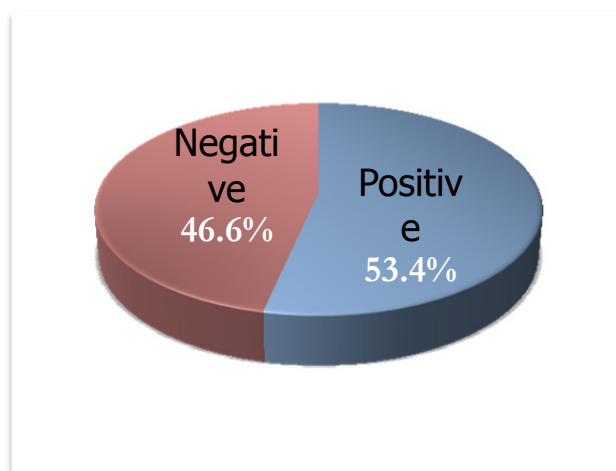


Figure 3. Distribution of Saudi mothers according to their level of perception of their children with Down syndrome

Mothers' perception of their children with DS was assessed in nine different aspects. Regarding positive perception, the highest proportion of positive perception was observed in relation to five aspects as follows: perception of burden (effect) on family and society imposed by children with DS and causal attribution of DS (67.1% and 65.8%, respectively), followed by perception of education of children with DS, social integration and discrimination; and health, treatment and care of children with DS (58.9%, 54.8% and 53.4%, respectively), as shown in (Table 7).

With respect to negative perception, the highest proportion of negative perception was observed in relation to four aspects as follows: perception of acceptance and joy with children with DS, and quality of life of children with DS (58.9% and 56.2%, respectively) followed by perception of embarrassment and disappointment of having children with DS, and over-protection and dependence of children with DS (53.4% each), as shown in (Table 7).



Table 7. Perception of Saudi mothers of different aspects of their children with Down syndrome

Perception	Total (n=73)			
	Positive		Negative	
	No.	%	No.	%
Causal attribution of Down syndrome	48	65.8	25	34.2
Acceptance and joy with child with Down syndrome	30	41.1	43	58.9
Embarrassment and disappointment of having child with Down syndrome	34	46.6	39	53.4
Over-protection and dependence of child with Down syndrome.	34	46.6	39	53.4
Burden (effect) on family and society imposed by child with Down syndrome	49	67.1	24	32.9
Social integration of and discrimination against child with Down syndrome	40	54.8	33	45.2
Education of child with Down syndrome	43	58.9	30	41.1
Health, treatment and care of child with Down syndrome	39	53.4	34	46.6
Quality of life of child with Down syndrome	32	43.8	41	56.2

3.5 Factors Affecting Mothers' Perception of Their Children with Down Syndrome

Table 8 shows the mothers' perception of their children with DS. Of the mothers who positively perceived their children with DS, 97.4% were married, 48.7% were aged between (40-<50 years), 53.7% were house-wives, 43.6% had the college or university education and 64.1% had normal children between 3-5 yrs other than the child with DS.

It was found that the mothers aged between 40-<50 years had a significantly more positive perception of their children with DS than their counterparts (p < 0.05). However, no significant difference was found between married and divorced mothers in their perception of their children with DS. Also, no significant association was found between mothers' perception and other socio-demographic characteristics (level of educational, occupation and number of normal other children) (Table 8).

Table 8. Association between the perception of Saudi mothers of their children with Down syndrome and their socio-demographic characteristics

Characteristics	Positive (n= 39)		Negative (n= 34)		Test of significance (p-value)
	No.	%	No.	%	
Age (years)					
< 30	0	0	2	5.9	$\chi^2 = 8.03$ (P < 0.05)
30 – < 40	9	23.1	9	26.5	
40 – < 50	19	48.7	21	61.7	
≥ 50	11	28.2	2	5.9	
Marital Status					
Married	38	97.4	33	97.1	FET* = 0.01 (P > 0.05)
Divorced	1	2.6	1	2.9	
Educational Level					
Illiterate	2	5.1	2	5.9	$\chi^2 = 8.03$ (P > 0.05)
Primary school	2	5.1	0	0	
Secondary school	8	20.5	5	14.7	
High school	9	23.1	14	41.2	
College/University	17	43.6	11	32.3	
Post graduate degree	1	2.6	2	5.9	

Occupation					
Government employee	9	23.1	5	14.8	$\chi^2 = 3.58$ (P > 0.05)
Non-government employee	4	10.3	2	5.9	
Self-employed	0	0	1	2.9	
Student	1	2.6	1	2.9	
House wife	21	53.7	23	67.7	
Retired	3	7.7	1	2.9	
Unemployed	1	2.6	1	2.9	
Number of normal children					
<3	10	25.6	13	38.2	$\chi^2 = 3.68$ (P > 0.05)
3-5	25	64.1	15	44.2	
6-8	4	10.3	5	14.7	
≥ 9	0	0	1	2.9	

\*FET= Fisher’s Exact Test.

### 3.5.1 Mothers’ Perception and Fathers’ Socio-demographic Characteristics

As revealed in (Table 9), the characteristics of fathers whose children with DS were positively perceived by their mothers were as follows: 76.9% aged between 40-<60 years, 41.0% had college or university education and 43.6% were government employees. There was no significant association between mothers’ perception of their children with DS and the fathers’ socio-demographic characteristics (age, level of education and occupation).

Table 9. Association between the perception of Saudi mothers of their children with Down syndrome and fathers’ socio-demographic characteristics

Characteristics	Positive (n= 39)		Negative (n= 34)		Test of significance (p-value)
	No.	%	No.	%	
<b>Age (years)</b>					
<40	4	10.3	5	14.7	$\chi^2 = 1.73$
40 – < 60	30	76.9	25	73.6	(P > 0.05)
60 – < 80	5	12.8	3	8.8	
≥ 80	0	0	1	2.9	
<b>Educational Level</b>					
Illiterate	0	0	1	2.9	$\chi^2 = 7.54$
Less than primary school	1	2.6	1	2.9	(P > 0.05)
Primary school	2	5.1	0	0	
Secondary school	6	15.4	5	14.7	
High school	12	30.8	16	47.1	
College/University	16	41.0	7	20.6	
Post graduate degree	2	5.1	4	11.8	
<b>Occupation</b>					
Government employee	17	43.6	15	44.1	$\chi^2 = 0.83$
Non-government employee	10	25.6	11	32.4	(P > 0.05)
Self-employed	2	5.1	2	5.9	
Retired	10	25.7	6	17.6	

### 3.5.2 Mothers' Perception and Their Expanded Socio-demographic Characteristics

Regarding the mothers who positively perceived their DS children, more than three-quarter (76.9%) had a family income  $\geq$  10000 S.R per month and more than half of them (53.8%) were in the upper socio-economic class. (Table 10)

Table 10. Association between the perception of Saudi mothers of their children with Down syndrome and the expanded socio-demographic characteristics

Characteristics	Positive (n= 39)		Negative(n= 34)		Test of significance (p-value)
	No.	%	No.	%	
Family income (S.R* per month)					
<5000	2	5.2	7	20.6	$\chi^2 = 7.62$
5000 – < 10000	7	17.9	11	32.3	(P < 0.05)
$\geq$ 10000	30	76.9	16	47.1	
Socio – economic class					
Upper	21	53.8	14	41.2	$\chi^2 = 1.43$
Middle	17	43.6	18	52.9	(P > 0.05)
Lower	1	2.6	2	5.9	

\*S.R= Saudi Riyals.

As shown in (Table 10), it was found that mothers with a family income of  $\geq$  10000 S.R per month were significantly more positive in the perception of their children with DS than their counterparts ( $p < 0.05$ ). However, no significant difference was found between mothers in upper socio-economic class and their counterparts with regard to their perception of their children with DS.

### 3.5.3 Mothers' Perception and the Socio-demographic Characteristics of their Children with Down Syndrome

The characteristics of children with DS who positively perceived by the mothers as were follows: 61.5% were male, 43.6% were aged between (5-<6 years), the birth order of 51.3% was between (5<sup>th</sup>-8<sup>th</sup>) and most (87.2%) were aged less than eight days or eight days at the time of diagnosis with DS.(Table 11)

As shown in Table 11, no significant association was found between mothers' perception of their children with DS and socio-demographic characteristics of children with DS (age, sex, child's birth order and age of the child at the time of diagnosis with DS).

Multiple logistic regression analysis test for different independent variables (socio-demographic characteristics of mothers, fathers and their children with DS; and the expanded socio-demographic characteristics) affecting the mothers' perception of their children with DS revealed that no statistically significant association between any of these variables and the mothers' perception.

Table 11. Association between the perception of Saudi mothers of their children with Down syndrome and socio-demographic characteristics of children with Down syndrome

Characteristics	Positive (n= 39)		Negative(n= 34)		Test of significance (p-value)
	No.	%	No.	%	
Age (years)					
<5	9	23.1	6	17.6	$\chi^2 = 2.20$
5 – < 9	17	43.6	13	38.2	(P > 0.05)
9 – < 13	9	23.1	13	38.2	
$\geq$ 13	4	10.2	2	6.0	
Sex					
Male	24	61.5	18	52.9	FET* = 0.55
Female	15	38.5	16	47.1	(P > 0.05)

Child's birth order					
<5	15	38.5	17	50.0	$\chi^2 = 1.27$
5 – 8	20	51.3	13	38.2	(P > 0.05)
≥ 9	4	10.2	4	11.8	
Age at the time of diagnosis with D.S(days)					
<8	34	87.2	27	79.4	$\chi^2 = 1.6$
8 - < 15	1	2.6	1	2.9	(P > 0.05)
15 - < 22	0	0	1	2.9	
22 - < 28	1	2.6	1	2.9	
≥ 28	3	7.6	4	11.8	

\*FET= Fisher's Exact Test.

#### 4. Discussion

The results of this study provide important information about the demographic characteristics of mothers and their children with DS, the mothers' perception of their children with DS and factors affecting that perception.

The results of the study showed that the total mean perception score of Saudi mothers of their children with D.S was 134.26±9.76. The finding generally rejects the null hypothesis since it showed that less than half of the mothers (46.6 %) negatively perceived their children with D.S while 53.4% positively perceived their children with D.S.

This result was expected since in a Muslim community, such as ours, where there is a strong belief in God and adherence to Islamic teaching. People with disability are not treated the way they are in other societies where they are considered burdensome dependent elements in the society (Abdulkhak, 2012). This high level of positive perception could also be explained by the good knowledge and understanding of DS disability the mothers had, the positive social and cultural attitudes toward children with D.S, mothers' life experience, severity of DS disability and family attitude toward DS children. Furthermore, this positive perception toward children with D.S strengthens the ability of mothers and family to accept the diagnosis and provide support for their children (Aranda & Knight, 1997).

Surprisingly, more than two thirds of the mothers (67.1%) positively perceived the burden (effect) brought on by children with D.S on family and society. This finding is inconsistent with previous reports in which children with autism and DS were said to impose a financial burden on the family (Zuleyha Cidav et al., 2012). Interestingly, almost two thirds of the mothers (65.8%) positively perceived the causal attribution of D.S. This is a good sign which indicates that the mothers had good knowledge and understanding of the cause of DS. This result is supported by the findings of Linda Glimore et al. in Australia in 2003.

More than half of the mothers (58.9%) positively perceived the education of children with D.S, a finding which is consistent with the results of some investigators like Linda Glimore et al., 2003.

Surprisingly, 54.8% of the mothers positively perceived the social integration and no discrimination. This may indicate that the attitude toward children with D.S in our community was positive.

Interestingly, more than half of the mothers (53.4%) positively perceived the health, treatment and care of children with D.S. Studies indicate parents perceived their children with learning disabilities as having lower academic and social skills, less independent, and more relying on others people for assistance (Anna Niia et al., 2015). This supports our result in which more than half of the mothers (53.4%) had a negative perception of the over-protection and dependence of children with D.S.

As expected, more than half (53.4%) of the mothers negatively perceived the embarrassment and disappointment of having children with D.S. This finding is consistent with a previous report by Sara Ashencaen Crabtree in 2007 in which stigma towards children with disabilities was another issue of concern for parental care-givers.

Contrary to expectation, more than half of the mothers (56.2%) had a negative perception of the quality of life of their children with D.S, and most of the mothers (58.9%) also negatively perceived the acceptance and joy with children with D.S.

The results of the study showed that the mothers aged between (40-<50 years) were significantly more positive

about their children with D.S than their counterparts ( $p < 0.05$ ). It also showed that the mothers with a family income of  $\geq 10000$  S.R per month were significantly more positive toward their D.S children than their counterparts ( $p < 0.05$ ).

Contrary to expectation and based on multiple logistic regression analysis, our findings didn't show any statistically significant association between the perception of mothers toward of their children with D.S and any independent variables (socio-demographic of mothers, fathers and their children with D.S, and expanded characteristics).

Finally, it should be stated that sample sizes and methodologies adopted may have resulted in conflicting results on the perception among Saudi mothers of their children with D.S and the factors affecting that perception.

## 5. Conclusion

This study reported Saudi mothers' perception of their children with D.S in the special education schools in the private sector in Al-khobar city, Saudi Arabia. The findings, therefore, cannot be generalized to other mothers of children with D.S in the kingdom. However, the results are an important first step towards the understanding of Saudi mothers' perception of their children with D.S as their perception can affect their attitude towards their children.

Generally speaking, the positive perception of Saudi mothers of their children with D.S was most evident in relation to the burden (effect) that imposed by children with D.S on the family and society, causal attribution of DS, education of children with D.S, social integration and discrimination as well as and health, treatment and care that of children with D.S. While, the negative perception was observed in relation to the acceptance and joy they have with their children with D.S, quality of life, over-protection and dependence of their children with D.S as well as the embarrassment and the disappointment of having children with D.S.

The results of present study suggest that neither socio-demographics of mothers, fathers and children with DS nor the expanded socio-demographic characteristics had any association with the perception of Saudi mothers of their children with DS.

## Competing Interests Statement

The authors declare that there is no conflict of interests regarding the publication of this paper.

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