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Assessment of Knowledge, Attitude and Practice toward Down Syndrome in Jeddah City, Saudi Arabia 2016

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ABSTRACT

Background: Down syndrome (DS) is a chromosomal disorder that results in intellectual disability and growth problems. The worldwide incidence of this syndrome is 1 in 1000 births and increases exponentially with the maternal age. People with DS usually have reduced life expectancy and suffer from mental retardation, heart problems, Alzheimer's disease among other complications. However, the severity of the disease differs from patient to patient. Perceptions of the disease and the public attitudes towards people with Down syndrome are very important in the inclusion of these people in the community and the supporting families. **Objectives:** to assess the level of awareness, attitude and practice toward Down syndrome in Jeddah city to identify barriers. **Methods:** a cross-sectional analytical questionnaire-based study among the general population of Jeddah city.

Results: a total of 360 subjects answered the questionnaires. The mean age was 36 years, it ranged from 16 to 70, with 45.2% females and 43.7% male respondents. Of these, 67% had attended college, 5% had a postgraduate degree, 23.5% had completed high school, and 3.1% had basic school. The majority of participants had a high level of monthly income (38%). The majority of subjects included in the research were (59.6%) married and (51.3%) were unemployed.

Most subjects (338) had poor knowledge about Down syndrome and there was no association between the knowledge and demographics of participants except for education at the higher levels of education, the more significant association with good knowledge.

Conclusion: The results of the present study reveal that the knowledge about the Down syndrome was poor among the studied population. Also, education significantly impacts the knowledge of Down syndrome, thus there is a need for providing the population and patients with the necessary information to improve their Down syndrome awareness.

Key words: Down syndrome; awareness spreading.

INTRODUCTION

Down syndrome (DS) is a chromosomal disorder that results in intellectual disability and growth problems [1]. The worldwide incidence of this syndrome is 1 in 1000 births and increases exponentially with the maternal age. People with DS usually have reduced life expectancy and suffer from mental retardation, heart problems, Alzheimer's disease among other complications. However, the severity of the disease differs from patient to patient [2]. Perceptions of the disease and the public attitudes towards people with Down syndrome are very important in the inclusion of these people in the community and the supporting families [3], and early interventions can improve their quality of lives [4]. Several surveys have been carried out to explore the understanding and the attitudes of people towards people with DS and their inclusion in the community**.**

Other studies that included different groups of people has found that the United States communities still hold negative opinions towards people with DS [5]. Another study found that European communities also still hold negative attitudes towards people with Down syndrome [6].

Our study was designed to examine health beliefs and the assessment level of awareness toward Down syndrome among the population in Jeddah city, Saudi Arabia and apply the health belief model to determine barriers.

Rationale

Down syndrome (DS) is a chromosomal disorder that results in intellectual disability and growth problems [1]. The worldwide incidence of this syndrome is 1 in 1000 births and increases exponentially with the maternal age. People with DS usually have reduced life expectancy

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and suffer from mental retardation, heart problems, Alzheimer's disease among other complications. However, the severity of the disease differs from patient to patient [2]. Perceptions of the disease and the public attitudes towards people with Down syndrome are very important in the inclusion of these people in the community and the supporting families [3], and early interventions can improve their quality of lives[4].

Objectives

General objectives

To assess the level of awareness of Down syndrome among the population in Jeddah city to identify barriers.

The goal of this study was to examine community health beliefs regarding Down syndrome, the perceptions related to it and evaluate the role of demographic factors in shaping beliefs about Down syndrome and assess possible associations between demographic characteristics with the preventive behavior of interest.

SUBJECTS AND METHODS

Study design: cross-sectional study.

Setting and data collection

This survey analysis was conducted among the community population in Jeddah city. A preformed self-administered questionnaire was distributed among the community population.

Sample

Subjects were chosen according to geographical and sex distribution. The sample size was calculated based on web-site calculator [7] taking the total size of Jeddah population (2,800,000), the confidence level (95%) and margin error (5%) to be 285. Additional 20 % was added to cover the missing data. The total sample obtained was 360.

Study population

The study population included was both males and females in Jeddah city.

Study tool

Preformed Self-administered questionnaire that requires information about:

1- Demographic characteristics: age, gender, education level, monthly income, marital status, and employment.
2- Knowledge assessment including 7 questions about risk factor of Down syndrome. A score of 1 was given to yes and 0 otherwise. For each subject, a maximum score of 7 was calculated. A scoring system was applied to measure the respondents' knowledge towards Down syndrome impacts. The Down syndrome knowledge score was calculated as a continuous variable by summing the participant's number of yes answers to the questions. One point was awarded for each yes, and zero for each no or don't know, with a maximum obtainable correct score of 7 for each respondent. The knowledge score was categorized into two levels indicated by poor (0–4.5), and good (5-7).

Ethical considerations

An informed consent was obtained from the participants included in this research before filling the questionnaire.

Statistical analysis

Data were entered into the Statistical Package for Social Sciences (SPSS, version 24, SPSS, Chicago, IL, U.S.A.) and descriptive analysis was conducted. The results were reported as a percentage (95% confidence interval).

The internal consistency was assessed using Cronbach's α test. The test results were for the7 statements of knowledge about Down syndrome was 0.422.

Association of respondents' characteristics with Down syndrome, was evaluated using univariate logistic regression. Results were reported showing odds ratio (OR) and 95% confidence interval. Statistical significance was accepted at $p < 0.05$. The dependent variables: knowledge of Down syndrome (1 = Poor knowledge and 0= good knowledge). The following independent variables were included: (1) age: ≤ 20 years, [21–30 years], [31–40 years],[41–50 years], > 50 years; (2) gender: males and females; (3) level of education: low, for those who completed secondary school or less, intermediate for those who finished college degree or have bachelor degree and high for those who had postgraduate degree; (4) monthly income: low [<3000Saudi Riyal (SR)], middle [3000–10000 SR] and high [>10000 SR];(5)marital status: single and married; (6) employment: unemployed and employed.

The study was done after approval of ethical board of king Abdulaziz university and an informed written consent was taken from each participant in the study.

RESULTS

Demographics of the studied subjects:

The socio-demographic characteristics were shown in Table. 1.

A total of 360 subjects were included in the study and answered the questionnaire. The

age ranged from 16 to 70 years. The mean age was 36 and about 8.6% of subjects were less than 20 years old, 29.7% of participants were from 21-30 years old, 13.3% were from 31-40% years old, 11.2% ranged from 41-50 years old, 15% were more than 51 years old and 22.3% of participants had missing data about age.

The gender distribution showed that 54.2% of participants were females, 43.7% were males and 2.1% had missing data about gender.

The study population represents a highly educated group of people, with 67% having attended university or college, 23.5% having completed high school, 5% having a post-graduate degree, 3.1% completed the basic school and 1.4% had missing data about education level.

The majority of participants had a high level of monthly income (38%) more than 10.000SR, followed by 21.4% of patients had a monthly income less than 3000 SR then 19% had income ranged from 7000-10.000 SR, 10.95% had an income that ranged from 3000-5000 SR and 8.1% had an income ranged from 5000-7000 SR.

The marital status showed that the majority of subjects included in the research were (59.6%) married and 40.1% were unmarried.

The most of the subjects were unemployed (51.3%), and 46.1% were employed, however only 2.6% had missing data.

Responses to questions of knowledge assessment questionnaire (Table. 2)

The response of participants to question 1 showed that 76.5% of population answered that they had good knowledge about the risks of Down syndrome, 58.4% of the subjects answered yes to question 2 as they have knowledge about the importance of genetic counseling of Down syndrome assessment by doctors.

As for question 3, 50.6% of participants had no knowledge about the complication of Down syndrome and 49.4% answered yes to this question.

Regarding Q 4, 95% of the subjects said yes to their knowledge about Down syndrome is a genetic disorder. Also, 76.2% of participants said that the majority of doctors underestimate informing patients about the risks and impacts of Down syndrome in Q 5.

57.2% of the subjects said that doctors don't give them enough information about the possible complication of Down syndrome and 42.8% had been given information about the possible complication of Down syndrome in question 6. In question [7] 78.9% of the population had knowledge about the complication that can lead to death in Down syndrome (Figure. 1).

Assessment of knowledge of participants regarding to the Down ***syndrome***

The mean knowledge score was 4.25 for all subjects (Table. 3).The overall mean knowledge score was 4.25 (Table. 3). So, it was found that the majority of 338(80.29%) subjects had poor knowledge and only 83 subjects had good knowledge about Down syndrome.

Association between knowledge and demographics of included participants

Univariate logistic regression to study the association between knowledge and participant's demographics showed that neither age nor other demographic variables showed significant association with being aware of Down syndrome (P >0.05). However, education level achieved statistical significance (p <0.0001) association with knowledge as higher education resulted in good levels (Table. 4). Interestingly, it was found that respondents who have completed their college degree have had a higher likelihood to have poor knowledge about Down syndrome with an OR (95%CI) of 8.07 when compared with those who get a higher post-graduate degree (Master or Ph.D.). Nearly the same difference was found in respondents, who have completed either high school or lower, with % of poor knowledge about (80.4%) when compared with individuals with high post-graduate degrees (Figure. 2).

DISCUSSION

This study has some limitations, which do not represent the whole population of Jeddah city, therefore, the results cannot be generalized [1]. Also, Regardless of the sample size limitations, this study showed that there is a poor knowledge in the general population awareness about Down syndrome [2].

The response of participants to the questions showed that the majority had good knowledge about Down syndrome.

On the other hand, the majority of doctors don't give the patients adequate information about possible complications of Down syndrome.

It is also imperative that doctors should provide patients with the necessary information to increase their awareness towards risks and Down syndrome as it is a part of the responsibility of healthcare providers[3]. Also,

Down syndrome significantly affected the general knowledge of the included participants.

CONCLUSION

The knowledge about Down syndrome was poor, thus the awareness about risks and Down syndrome must be increased. This study showed a poor awareness about Down syndrome in the general population. Thus, many studies should be conducted to provide the necessary information in order to increase Down syndrome awareness of the population.

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Table 1. Socio-Demographic Characteristics of Respondents (n = 360)

	Frequency	Percentage (%)
<= 20.00	36	8.60%
21.00 - 30.00	125	29.70%
31.00 - 40.00	56	13.30%
41.00 - 50.00	47	11.20%
51.00+	63	15.0%
Missing	94	22.30%
Mean±SD	36±4	
Female	228	54.20%
Male	184	43.70%
Missing	9	2.10%
Basic school	13	3.10%
High School	99	23.50%
Collage degree	282	67.00%
Post-graduate	21	5.00%
Missing	6	1.40%
< 3000	90	21.40%
3000-5000	46	10.90%
5000-7000	34	8.10%
7000-10000	80	19.00%
>10000	160	38.00%
Missing	11	2.60%
Married	251	59.60%
Un Married	169	40.10%
Missing	1	0.20%
Employed	194	46.10%
Un Employed	216	51.30%
Missing	11	2.60%

Table 2. Responses to questions on assessment level of awareness towards Down syndrome

	No	Yes	Don't Know
Q1: Do you think that the Down syndrome has risks?	99(23.50%)	322(76.50%)	0 (0.0%)
Q2: Do you think that counseling assessment by doctors are important?	129 (30.60%)	246 (58.40%)	46(10.90%)
Q3: Do you have knowledge about the complication of Down syndrome?	213 (50.60%)	208 (49.40%)	0 (0.0%)
Q4: Do you think Down syndrome is a genetic disorder	21 (5.00%)	400 (95.00%)	0 (0.0%)
Q5: Do doctors clarify the impacts of Down syndrome?	321 (76.20%)	100 (23.80%)	0 (0.0%)
Q6: Do doctors provide adequate information for possible complication of Down syndrome?	241 (57.20%)	180 (42.80%)	0 (0.0%)
Q7: Do you think Down syndrome leads to severe complication can cause death?	89 (21.10%)	332 (78.90%)	0 (0.0%)

Table 3. Knowledge of awareness toward Down syndrome:

	Knowledge Score
Mean± SD	4.25±0.44
Min.- Max.	0-7
Good Knowledge (≥5.69)	83 (19.71%)
Poor knowledge (<5.69)	338 (80.29%)

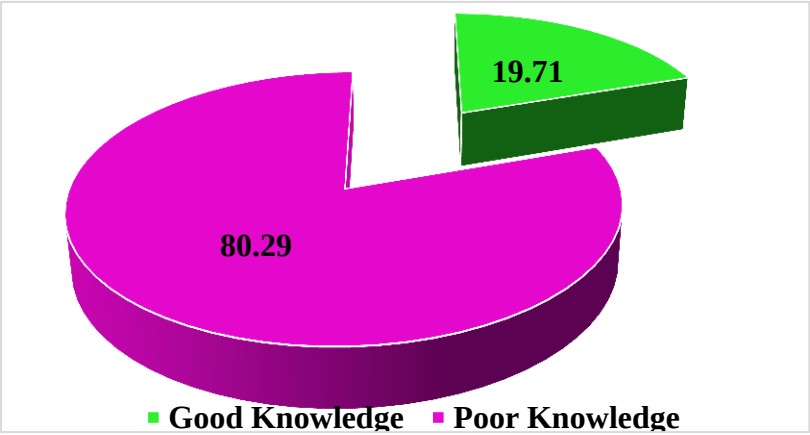

Figure 1. Respondent's Knowledge about Down **syndrome**

Table. 4: Univariate logistic regression model for the association between Down syndrome knowledge and socio-demographic variables:

	Good Knowledge (n=83)	Poor Knowledge (n=338)	OR (95%CI)	P-value
<= 20.00	5 (13.9%)	31 (86.1%)	1	0.434
21.00 - 30.00	30 (24.0%)	95 (76.0%)	0.51(0.18-1.43)	0.201
31.00 - 40.00	8 (14.3%)	48 (85.7%)	0.97 (0.29-3.23)	0.957
41.00 - 50.00	9 (19.1%)	38 (80.9%)	0.68 (0.21-2.24)	0.527
51.00+	10 (15.9%)	53 (84.1%)	0.86 (0.27-2.73)	0.791
Female	39(17.1%)	189 (82.9%)	1	0.115
Male	43(23.4%)	141(76.6%)	0.68 (0.42-1.1)	
High	14 (66.7%)	7 (33.3%)	1	< 0.0001
Intermediate	56 (19.9%)	226 (80.1%)	8.07 (3.11 - 20.94)	< 0.0001
Low	22 (19.6%)	90 (80.4%)	8.18 (2.95 -22.69)	< 0.0001
> 10,000 SR	31 (19.4%)	129 (80.6%)	1	0.68
3000-10000 SR	34 (21.3%)	126 (78.8%)	0.89 (0.52-1.54)	0.677
< 3000 SR	15 (16.7%)	75 (83.3%)	1.2 (0.61-2.37)	0.596
Married	51 (20.3%)	200 (79.7%)	1	0.727
Un Married	32 (18.9%)	137 (81.1%)	1.09 (0.67-1.79)	
Employed	42 (21.6%)	152 (78.4%)	1	0.429
Un Employed	40 (18.5%)	176 (81.5%)	1.22 (0.75-1.97)	

OR: Odds ratio, CI: Confidence Interval

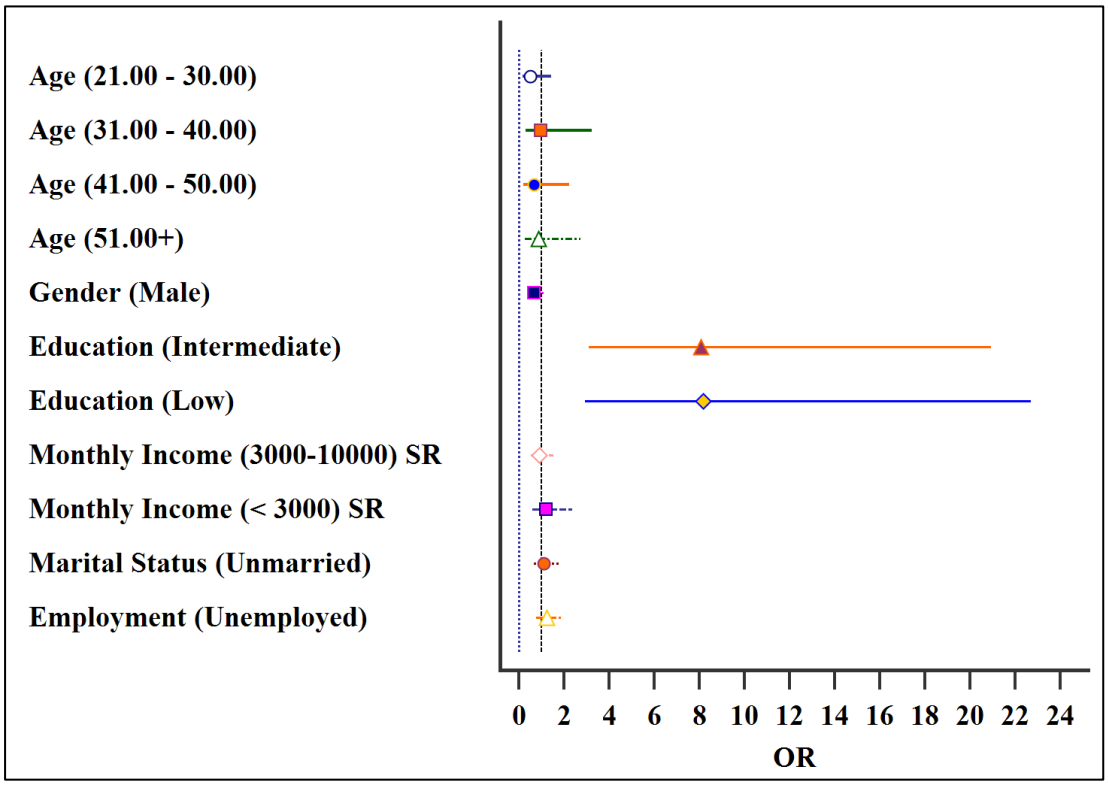

Figure 2. Forest plot illustrating the odd ratios with 95% confidence intervals of the different socio-demographic predictors for Respondent's Knowledge about Down **syndrome**