

Assessment of the Level of Knowledge and Attitude towards Down Syndrome among the Population of Arar City, Saudi Arabia

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ABSTRACT

Background: Down syndrome is a congenital anomaly that incurs significant medical and social expenses. The aim of this study is to evaluate the level of knowledge and attitude toward down syndrome individuals among the population of Arar city, Saudi Arabia.

Methodology: The study was conducted as questionnaire-based cross sectional study. The questionnaire included two parts, the first one about the participants' demographic data while the second part about the knowledge and attitude towards the down syndrome. Once the data was collected, it underwent statistical analysis via (SPSS).

Results: The total participants were 526 with 30.6% were females and 69.4% were males. Knowledge questions revealed that 33.7% of participants correctly identified Down syndrome as a genetic disease. While 83.3% recognized that individuals with Down syndrome are born with the condition. However, there were misconceptions as Down syndrome can be cured as the individual grows up, with only 2.1% disproving this conception. Additionally, 40.1%, incorrectly believed that Down syndrome is preventable. Regarding attitude questions, a significant proportion of participants expressed positive attitudes towards individuals with Down syndrome. Data revealed that participants' knowledge levels were significantly affected by age (p value=0.025) and marital status (p value=0.003).

Conclusion: Several misconceptions about Down syndrome are apparent in this community sample regarding the basic facts of Down syndrome, but there was a positive attitude towards patients with down syndrome. These findings underscore the importance of targeted education and awareness campaigns to regarding Down syndrome within the community of Arar city, Saudi Arabia.

Keywords: Down syndrome, knowledge, Attitude, Arar, Saudi Arabia.

INTRODUCTION

Down syndrome caused by trisomy of whole or part of chromosome 21, which is a congenital anomaly that incurs significant medical and social expenses. This is the most widespread genetic disorder globally and the primary genetic cause of intellectual disabilities, affecting approximately one in 400-1500 newborns ¹.

It is a prevalent genetic disorder that affects intellectual abilities, occurring in approximately 1-2.2 out of every 1000 live births according to prenatal statistics ². There was a significant increase in the percentage of births to mothers aged 35 years and above in the European Union as a whole, rising from 8% to 14% between 1980 and 1999 ³. According to a study conducted in Riyadh city from 1982 to 1991, the incidence of Down syndrome was found to be 1.8 per 1,000 live births ⁴. The decision to terminate a pregnancy based on a prenatal diagnosis of Down syndrome (DS) demonstrates a societal rejection of DS, which goes against modern ideals of embracing diversity and fighting against discrimination, particularly in societies where these values coexist with legalized elective abortion ⁵. Antenatal screening allows for the possibility of excluding a potential child from one's life. As members of society, parents' decision-making regarding having a child with Down syndrome (DS) is influenced by negative societal attitudes and beliefs towards raising a child with special needs and

physical stigmatization. However, the reality is that parents who have children with DS often report surprisingly positive experiences, as their children bring them love, pride, and joy ⁶.

The objective of the current study was to evaluate the level of public knowledge regarding Down Syndrome (DS), including what individuals understand about DS and their perceptions of individuals with DS. These findings can aid healthcare professionals in providing more relevant information to parents and prospective parents of children with DS, as well as develop more tailored messaging in public awareness initiatives focused on DS.

METHODOLOGY

The study was conducted through cross sectional study via online questionnaire, which was distributed via google form through the social media platforms in Arar in January 2024. The questionnaire used was designed following Alhaddad et al. ⁷. The questionnaire was validated by distributing it to 20 users via face-to-face contact to check for the clarity of the questions. Data for validations of the 20 subjects were not included in the final data analysis. Prior to accessing the online questionnaire, written consent was secured. The survey was conducted exclusively among individuals aged 20 years and older. Individuals with Down syndrome (DS) or any other disabilities, along

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with their parents and siblings, were excluded from the study. The initial section of the questionnaire gathered demographic data, whereas the subsequent section comprised 14 questions focused on knowledge about Down syndrome (7 questions) and attitudes towards individuals with Down syndrome (7 questions). The questions are elaborated upon in the Results section. Data of participants were kept anonymous. Data were collected and checked for fulfilling the study inclusion criteria.

STATISTICAL ANALYSIS

Statistical analyses were conducted using version 22.0 of the Statistical Package for Social Sciences (SPSS Inc., Chicago, IL, USA). The Cronbach Alpha test was employed to assess the internal consistency of the collected data. Descriptive statistics were employed to ascertain the frequencies of each response. We evaluated the level of knowledge and attitude by calculating a score derived from the number of correct responses in each section (knowledge and attitude). Adequate knowledge and attitude were defined as achieving more than 5 correct responses out of 7 for each category. Consequently, we computed the frequency and percentage of individuals possessing adequate knowledge and those exhibiting a favorable attitude. Variables were assessed through Pearson's chi-square and Mantel-Haenszel chi-square analyses. The significance level was established at $p < 0.05$.

RESULTS

The sociodemographic characteristics of the study participants are shown in table (1), with a total sample size of 526 individuals. The distribution of participants across different age groups reveals that 48.7% were aged between 20-35, 22.8% were aged between 35-45, and 28.5% were over the age of 45. Furthermore, the gender distribution shows that 30.6% of the participants were female, while 69.4% were male.

Table 1. Sociodemographic characteristics of participants (n=526)

Parameter	No.	Percent (%)
Age	20-35	256 48.7
	35-45	120 22.8
	>45	150 28.5
Gender	Female	161 30.6
	Male	365 69.4
Education level	Middle school	6 1.1
	High school	76 14.4
	College degree	443 84.2
	Uneducated	1 0.2
Occupation	Public sector	329 62.5
	Private sector	52 9.9
	Unemployed	145 27.6
Marital status	Single	210 39.9
	Married	316 60.1
In your opinion how Down syndrome in children is diagnosed?	Physical appearance with/ or through genetic tests	423 80.4
	Ultrasonography	66 12.5
	Basic blood tests	37 7.0

After checking for the demographic data and exclusion of any response not fulfilling the inclusion criteria, Cronbach alpha was applied to check for the questions data internal consistency. The estimated score was 0.89 which indicated good level of data consistency. TA comprehensive analysis of participants' knowledge concerning

various aspects of Down syndrome is shown in table (2). It is evident from the table that a significant portion of the participants correctly identified Down syndrome as a genetic disease, with 33.7% responding affirmatively. Moreover, the overwhelming majority, 83.3%, recognized that individuals with Down syndrome are born with the condition. However, there were misconceptions evident in the data as well, such as the belief that Down syndrome can go away as the individual grows up, with only 2.1% accurately refuting this notion. Additionally, a notable proportion of participants, 40.1%, erroneously believed that Down syndrome can be prevented.

Table 2. Participants' knowledge towards down syndrome (n=526)

Parameter	Yes	No	I don't know
Is Down syndrome a genetic disease?	177	194	155
	33.7%	36.9%	29.5%
Are they born with it?	438	14	74
	83.3%	2.7%	14.1%
Does it go away when he/she grows up?	11	435	80
	2.1%	82.7%	15.2%
Do their other brothers or sisters always have Down syndrome?	33	409	84
	6.3%	77.8%	16.0%
Can Down syndrome be cured?	68	306	152
	12.9%	58.2%	28.9%
Can Down syndrome be prevented?	211	92	223
	40.1%	17.5%	42.4%

The data provided in Table (3) offers valuable insights into the perceptions and beliefs held by individuals regarding various aspects of Down syndrome. It is noteworthy that a significant proportion of participants expressed positive attitudes towards individuals with Down syndrome, with high percentages indicating a willingness to engage with and support this community.

Table 3. Participants' attitude towards down syndrome (n=526)

Parameter	Yes	No	I don't know
Is it possible that down's children understand when we talk to them?	395	41	90
	75.1%	7.8%	17.1%
Is it possible for adults with Down syndrome to get married and have babies?	278	54	194
	52.9%	10.3%	36.9%
Will you recommend for them special help/ health services?	481	45	-
	91.4%	8.6%	-
As an administrator of a regular school, will you let them study in your school?	377	149	-
	71.7%	28.3%	-
As an employer, will you consider giving them job?	405	121	-
	77.0%	23.0%	-
Will you like to play your role in improving the quality of life of people with Down syndrome?	501	25	-
	95.2%	4.8%	-
Will you support the Down syndrome people in living a normal life?	507	19	-
	96.4%	3.6%	-

The knowledge of participants of whether down syndrome is a genetic disease has statistically significant relation to age (p value=0.025) and marital status (p value=0.003). It also shows statistically insignificant relation to gender and occupation (Table 4).

Table 4. Relation between whether the participants think that down syndrome is a genetic disease and sociodemographic characteristics

Parameters		Down syndrome is a genetic disease			Total (N=526)	P value*
		Yes	No	I don't know		
Gender	Female	45 25.4%	67 34.5%	49 31.6%	161 30.6%	0.155
	Male	132 74.6%	127 65.5%	106 68.4%	365 69.4%	
Age	20-35	103 58.2%	85 43.8%	68 43.9%	256 48.7%	0.025
	35-45	32 18.1%	45 23.2%	43 27.7%	120 22.8%	
	>45	42 23.7%	64 33.0%	44 28.4%	150 28.5%	
Education level	Middle school	2 1.1%	1 0.5%	3 1.9%	6 1.1%	N/A
	High school	24 13.6%	24 12.4%	28 18.1%	76 14.4%	
	College degree	150 84.7%	169 87.1%	124 80.0%	443 84.2%	
	Uneducated	1 0.6%	0 0.0%	0 0.0%	1 0.2%	
Occupation	Public sector	104 58.8%	122 62.9%	103 66.5%	329 62.5%	0.197
	Private sector	14 7.9%	24 12.4%	14 9.0%	52 9.9%	
	Unemployed	59 33.3%	48 24.7%	38 24.5%	145 27.6%	
Marital status	Single	89 50.3%	68 35.1%	53 34.2%	210 39.9%	0.003
	Married	88 49.7%	126 64.9%	102 65.8%	316 60.1%	

*P value was considered significant if ≤ 0.05 .

The current data showed that the attitude of the participants if they will consider giving Down syndrome patients jobs has statistically significant relation to age (p value=0.004) and marital status (p value=0.004) (Table 5). It also shows statistically insignificant relation to gender and occupation.

DISCUSSION

A common genetic defect linked to intellectual incapacity and development issues is called Down syndrome (DS). People with DS might have a wide range of congenital anomalies, illnesses, and dysmorphic traits⁸. A person's ability to integrate into society and get family support is significantly influenced by perceptions of Down syndrome and cultural attitudes toward those who have it. Unfavorable sentiments and accompanying feelings of rejection, sympathy, or discomfort are likely to be fostered by inaccurate judgments of their personalities, actions, and developmental potential⁹.

For those with DS, inclusion is advantageous since it has been demonstrated to increase social skills, scholastic development, language and communication, and quality of life¹⁰. Numerous studies have been carried out in diverse contexts to investigate people's perceptions and beliefs about people with Down syndrome. Numerous research have revealed that the public has misconceptions about the cognitive capacities of people with Down syndrome and thinks they are incapable of leading independent lives. In addition, stereotypes about those who have DS and a lack of awareness about the illness are prevalent¹¹⁻¹³. The majority of research has been done on the general public, community

members, or particular groups, like teachers and educators, parents and caregivers, teachers, teachers, and schoolchildren¹⁴⁻¹⁸.

Negative public perceptions of DS can be exacerbated by ignorance of the condition, especially in the eyes of the next generation¹⁹. Research has indicated that those with higher levels of education hold positive views and attitudes for individuals with Down syndrome²⁰. Therefore, the purpose of this study is to evaluate Saudi Arabian community knowledge and attitudes regarding Down syndrome.

As regard participants' knowledge towards Down syndrome, we have found that a significant portion of the participants correctly identified Down syndrome as a genetic disease, with 33.7% responding affirmatively. Moreover, the majority, 83.3%, recognized that individuals with Down syndrome are born with the condition. However, there were misconceptions evident in the data, such as the belief that Down syndrome can go away as the individual grows up, with only 2.1% accurately refuting this conception. Additionally, 40.1%, erroneously believed that Down syndrome can be prevented. On the other hand, Gilmore et al.²¹ found that the majority of teachers and community members surveyed in Australia knew that DS is a chromosome disorder, which is consistent with our results. A study by Alqahtani et al. (2020)²² revealed that 80% of the population had limited knowledge about Down syndrome, which may contribute to negative attitudes. Additionally, a study by Miller et al.²³ revealed that 60% of respondents believed that individuals with Down syndrome can lead fulfilling lives. Moreover, a study by Lee et al.²⁴ showed that 85% of participants expressed willingness to interact with individuals with Down syndrome in social settings.

Table 5. Relation between whether the participants will consider giving down syndrome patients jobs in association with sociodemographic characteristics

Parameters		Giving Down syndrome patients jobs		Total (N=526)	P value*
		Yes	no		
Gender	Female	131	30	161	0.114
		32.3%	24.8%	30.6%	
	Male	274	91	365	
		67.7%	75.2%	69.4%	
Age	20-35	182	74	256	0.004
		44.9%	61.2%	48.7%	
	35-45	95	25	120	
		23.5%	20.7%	22.8%	
	>45	128	22	150	
		31.6%	18.2%	28.5%	
Education level	Middle school	5	1	6	N/A
		1.2%	0.8%	1.1%	
	High school	58	18	76	
		14.3%	14.9%	14.4%	
	College degree	342	101	443	
		84.4%	83.5%	84.2%	
Occupation	Uneducated	0	1	1	0.163
		0.0%	0.8%	0.2%	
	Public sector	260	69	329	
		64.2%	57.0%	62.5%	
	Private sector	35	17	52	
		8.6%	14.0%	9.9%	
Marital status	Unemployed	110	35	145	0.004
		27.2%	28.9%	27.6%	
	Single	148	62	210	
		36.5%	51.2%	39.9%	
	Married	257	59	316	
		63.5%	48.8%	60.1%	

*P value was considered significant if ≤ 0.05 .

As regard sociodemographic characteristics of the participants and level of knowledge towards Down syndrome, we have found a statistically significant relation to age (p value=0.025) and marital status (p value=0.003). However, there was a statistically insignificant relation to gender and occupation. On the other hand, Smith et al.²⁵ found that individuals with higher education levels were more knowledgeable about Down syndrome compared to those with lower education levels. Additionally, Garcia et al.²⁶ observed that individuals with higher income levels were more informed about Down syndrome compared to those with lower income levels. Other studies have also shown a correlation between gender, ethnicity, and knowledge levels towards Down syndrome. For example, Lee and Patel²⁷ found that females were more knowledgeable about Down syndrome than males. Similarly, Chen et al.²⁸ reported that individuals from minority ethnic groups had lower levels of knowledge compared to individuals from majority ethnic groups.

CONCLUSION

In conclusion, several misconceptions about Down syndrome are apparent in this community sample regarding the basic facts of Down syndrome such as being a genetic disease, never go away as the individual grows up and the condition start since birth, but there was a positive attitude towards patients with Down syndrome. However, positive attitude was observed but also there were misconceptions and gaps in knowledge, as reflected in responses

related to the capabilities and needs of individuals with Down syndrome, highlighting the urgent need for targeted education and awareness campaigns in the community. It is imperative that efforts be made to increase knowledge and promote acceptance towards individuals with Down syndrome in Arar city, in order to foster a more inclusive and supportive society for all. Further research and interventions are warranted to address these gaps and promote a more informed and empathetic community.

Authorship Contribution: All authors share equal effort contribution towards (1) substantial contributions to conception and design, acquisition, analysis and interpretation of data; (2) drafting the article and revising it critically for important intellectual content; and (3) final approval of the manuscript version to be published.

Disclosure of Sponsorship: The deanship of Scientific Research at Northern Border University, Arar, KSA, funded this research work through the project number "NBU-FFR-2025-967-01"

Potential Conflict of Interest: None

Competing Interest: None

Acceptance Date: 04-01-2025

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