



Knowledge and Attitude Towards Down Syndrome Among People in Jeddah, Saudi Arabia

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ABSTRACT

Introduction: The knowledge and attitude of the people in a society about intellectual disabilities has a significant impact on the social functioning of afflicted individuals. Therefore, understanding deficiencies in this knowledge and attitude about Down Syndrome (DS) can help us raise awareness among the masses about the genetic disorder, in turn facilitating social insertion of individuals with DS. **Aims and Objectives:** In this study, we assess the knowledge and attitude towards DS among population of Jeddah, Saudi Arabia. **Place and Duration of Study:** The study was conducted in Jeddah in the month of March 2014. **Materials and Methods:** Adults were randomly surveyed at a shopping center, using a questionnaire that included 7 knowledge-related questions and 7 attitude-related questions. **Results:** Of the 1253 participants, 19% thought that DS is diagnosed based on ultrasound and blood test and 33.6% thought that it is curable. When asked if children with DS can understand speech, 38.3% thought that people with DS do not understand speech and 69% believed that they could not get employment. The knowledge and attitude towards DS was significantly deficient among females and participants younger than 35 years. Overall, deficiency was more pronounced in domain of attitude (47%) as compared to knowledge (37%). Only 59.5% expressed their willingness to support DS people in living a normal life. Further, we found a significant correlation between knowledge and attitude, even after adjustment for gender and age. **Conclusion:** There are important deficits in the general knowledge about DS leading to unfavorable attitude towards people with DS, which results in a certain overestimation of their handicap. Efficient awareness and educational campaigns require an understanding of conscious and subconscious social obstacles for the integration of people with DS at both the familial and social levels.

Key words: Knowledge, Attitude and Down Syndrome.

INTRODUCTION

The social insertion of people with disabilities is an integral part of their wellbeing. However, their social adjustment depends on society's attitude, which varies between acceptance and stigmatization, as a function of the adjacent culture and value system, and also as a function of popular knowledge and attitude towards the condition of disabled people.¹

Down syndrome (DS) is one of the most common genetic disorders leading to intellectual disabilities effecting around 1-2.2 of every 1000 live births according to statistics on prenatal statistics.² It is associated with characteristic dysmorphic features, as well as related health problems.² Between 1980 and 1999, the proportion of births to mothers of 35 years of age and over increased quite dramatically from 8 to 14% for the European Union as a whole.³ A study done in Riyadh, Saudia in the time period of 1982-1991 showed the incidence of 1.8 per 1,000 live births for DS.⁴ The number of

births with DS has been increasing, with the rise in maternal age, reaching up to two folds in some countries. This is observed even in countries where elective termination of pregnancy is legalized and is being increasingly practiced³ since the widespread use of antenatal diagnostic methods.⁵

The termination of a pregnancy because of prenatally diagnosed DS reflects a socially pre-integrated rejection of DS. This contradicts the modern concepts of acceptance of different people and fight against discriminations, especially in societies where these values coexist with the legalization of elective abortion.⁶ Antenatal diagnosis provides the option of keeping the “person” back from becoming a part of one’s life. Being part of the society, the parents and their apprehension about having a child with DS is intimately conditioned by the negative socially shared knowledge and attitude regarding taking on a child with special needs and stigmatizing physical traits. On the other hand, the real-life experience of parents who have children with DS surprisingly more optimistic, as the majority of these parents report that their children with DS are a source of love, pride and happiness.⁷ Of the 2,044 parents, 99% reported that they love their son or daughter; 97% were proud of them; 79% felt their outlook on life was more positive because of them. The parents also report that 95% of their sons or daughters without Down syndrome have good relationships with their siblings with Down syndrome. This denotes the adaptation of these families to the chronic condition of their children and maturation of their perceptions about what the life with such a child represents.¹ Similarly, almost all people with DS report having satisfactory familial and friendly relationships and happy lives, and they encourage healthcare professionals to improve their social image.⁷

In Saudi Arabia, elective abortion is still controversial, and consanguineous marriages are very common, which results in a high incidence of birth defects.⁸ Therefore, good social integration is the sole option for correct management of people with DS. Furthermore, the Islamic belief system promotes charity and beneficence towards the weak and encourages parents to be resilient and accept their child with DS, as a part of their destiny. However, there has been, to date, no published literature addressing the attitude of Saudi society towards DS and individuals with DS.

The current study provides an evidence-based appraisal of the integrated notions and misconceptions about DS in Saudi society. We answer the questions “what do people know about DS” and “how do they perceive persons with DS.” Such data will help healthcare professionals provide more pertinent information to the parents and future parents of children with DS, as well as communicate more targeted messages in public awareness campaigns on DS.

MATERIAL AND METHODS

This population-based study was conducted in Jeddah, in western Saudi Arabia, in March 2014. Before conducting the study, the research proposal was submitted to the Ethics Review Board of the King Abdulaziz University and a formal approval was obtained. We randomly surveyed people (male and female) attending one of the biggest shopping malls in Jeddah, over three consecutive days (including a weekend), with a team of 100 interviewers, all of whom were medical students. Written consent was obtained before filling of the questionnaires. Only individuals aged 21 years and above were surveyed. We excluded persons with DS or any other disability, as well as the parents and siblings of persons with DS.

The questionnaire included 14 questions related to¹ knowledge about DS (7 questions) and² attitude towards people with DS (7 questions). The questions are detailed in the Results. The basic demographic data was collected and the responses were kept anonymous. During the three days, we systematically verified that each individual was interviewed only once.

Statistical Analysis:

All the statistical analyses were performed using Statistical Package for Social Sciences version 22.0 for Windows (SPSS Inc., Chicago, IL, USA). Descriptive statistics were used to determine the frequencies of each answer. To assess the level of knowledge and attitude, we computed a score based on the number of correct responses from each section (knowledge and attitude). Adequate knowledge and attitude were assumed if >5 out of 7 responses were correct for each of them. Thus, we calculated the frequency and percentage of people who have adequate knowledge and who have favorable attitude. Correlations between categorical

variables were analyzed using Pearson's chi-square and Mantel-Haenszel chi-square. The significance level was set at $p < 0.05$.

RESULTS

Total of 1253 participants were administered the questionnaire after taking their informed consent. All the filled-in questionnaires were included, and any incompletely filled questionnaires were excluded at the initial stage of analysis. Around 62% of participants were male. More than 35% of the sample was in the age group of 35 to 50 years followed by those below 35 years of age (33%) and above 50 years (32%).

Analysis of the knowledge questionnaire showed that around 81% thought that DS is diagnosed based on appearance and/or genetic test, and only 19% thought it was based on ultrasound tests or simple blood test. With regard to the causative factors, 77% thought that DS is a genetic disease. Moreover, 87% believed that DS was a congenital disease; around 33% thought that it is alleviated with age; and another 33% believed that it could be cured. There were subtle but insignificant differences in the proportion of correct answers in both genders as well as the age categories. The responses are shown in Table-1.

With regard to people's attitude towards DS patients, around 62% thought that children with DS understand speech. Moreover, 47% thought that adults with DS can get married and have children, while around 89% believed that children with DS could attend mainstream school. Around 92% recommended special help or health services for DS people. Additionally, 69% said that as employers, they will give jobs to them and 74.5% remarked that they will like to play their role in improving the quality of life of people with DS. The responses are shown in Table-1.

In the analysis of the response in relation to age and gender, no significant difference was found between the different categories (Table-2 and Table-3) Based on their scores, the subjects were categorized as those with adequate or inadequate knowledge and those with favorable or non-favorable attitude towards DS. A cutoff of 70% correct answers, which corresponds to 5 correct answers out of 7 each for the knowledge-related and attitude-related questions, was considered to indicate adequacy. Overall, we found that 37% of

the interviewees had inadequate knowledge, and 47% had inadequate attitude (Figure-1).

Comparative analysis showed that the knowledge and attitude were significantly deficient among females (Table-4). Around 56.5% women could not answer more than 4 questions correctly for knowledge as well as attitude questions ($p = 0.001$). While in men, around 51% had both inadequate knowledge as well as non-favorable attitude ($p = 0.07$). Among age categories, there was significant gap in knowledge as well as attitude in those younger than 35 years (Table-4) in which 57.5% of participants showed inadequate knowledge as well as non-favorable attitude ($p = 0.004$).

Regarding Impact of knowledge on attitude, those having better knowledge about DS showed more favorable attitude towards children with DS (Table-4). Significant positive association between knowledge and attitude was observed adjusted for gender (OR 1.502 CI 1.193 – 1.891, P-value=0.001). There is 1.502 times more favorable attitude in those who have adequate knowledge. Similarly, a significant association was observed between knowledge and attitude when adjusted for age (OR 1.504 CI 1.194 – 1.895, P-value=0.001). There is 1.504 times more favorable attitude in those who have adequate knowledge.

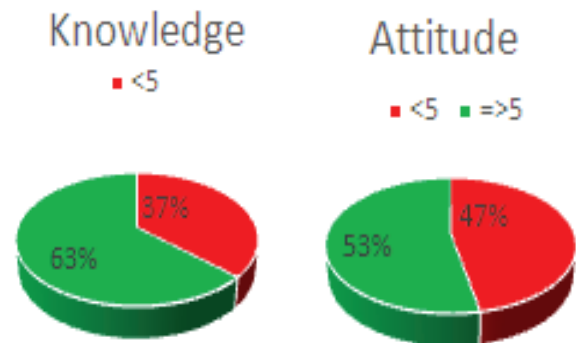


Figure-1: Assessment of Knowledge and attitude about Down syndrome in Saudi population

		Count	%	
Knowledge	In your opinion how Down syndrome in children is diagnosed? (appearance, genetic test)	Incorrect	237	18.9
		Correct	1016	81.1
	Is Down syndrome a genetic disease? (Yes)	Incorrect	280	22.3
		Correct	973	77.7
	Are they born with it? (Yes)	Incorrect	163	13.0
		Correct	1090	87.0
	Does it go away when he/she grows up? (No)	Incorrect	418	33.4
		Correct	835	66.6
	Do their other brothers or sisters always have Down syndrome? (No)	Incorrect	125	10.0
		Correct	1128	90.0
	Can Down syndrome be cured? (No)	Incorrect	421	33.6
		Correct	832	66.4
	Can Down syndrome be prevented? (Yes)	Incorrect	712	56.8
		Correct	541	43.2
Attitude	Is it possible that down's children understand when we talk to them?	Non Favourable	480	38.3
		Favourable(Yes)	773	61.7
	Is it possible for adults with Down syndrome to get married and have babies?	Non Favourable	662	52.8
		Favourable (Yes)	591	47.2
	Will you recommend for them special help/ health services?	Non Favourable	98	7.8
		Favourable (Yes)	1155	92.2
	As an administrator of a regular school, will you let them study in your school?	Non Favourable	140	11.2
		Favourable (Yes)	1113	88.8
	As an employer, will you consider giving them job?	Non Favourable	866	69.1
		Favourable (Yes)	387	30.9
	Will you like to play your role in improving the quality of life of people with Down syndrome?	Non Favourable	320	25.5
		Favourable (Yes)	933	74.5
	Will you support the Down syndrome people in living a normal life?	Non Favourable	507	40.5
		Favourable (Yes)	746	59.5

Table-1: Overall Knowledge and Attitude

		Gender				P-Value	
		Female		Male			
		n	%	n	%		
Knowledge	In your opinion how Down syndrome in children is diagnosed? (appearance, genetic test)	Incorrect	96	40.5	141	59.5	.528
		Correct	389	38.3	627	61.7	
	Is Down syndrome a genetic disease? (Yes)	Incorrect	116	41.4	164	58.6	.289
		Correct	369	37.9	604	62.1	
	Are they born with it? (Yes)	Incorrect	60	36.8	103	63.2	.594
		Correct	425	39.0	665	61.0	
	Does it go away when he/she grows up? (No)	Incorrect	167	40.0	251	60.0	.522
		Correct	318	38.1	517	61.9	
	Do their other brothers or sisters always have Down syndrome? (No)	Incorrect	53	42.4	72	57.6	.372
		Correct	432	38.3	696	61.7	
	Can Down syndrome be cured? (No)	Incorrect	170	40.4	251	59.6	.387
		Correct	315	37.9	517	62.1	
	Can Down syndrome be prevented? (Yes)	Incorrect	271	38.1	441	61.9	.591
		Correct	214	39.6	327	60.4	
Attitude	Is it possible that down's children understand when we talk to them?	Non Favourable	193	40.2	287	59.8	0.390
		Favourable (Yes)	292	37.8	481	62.2	
	Is it possible for adults with Down syndrome to get married and have babies?	Non Favourable	249	37.6	413	62.4	0.400
		Favourable (Yes)	236	39.9	355	60.1	
	Will you recommend for them special help/ health services?	Non Favourable	36	36.7	62	63.3	0.676
		Favourable (Yes)	449	38.9	706	61.1	
	As an administrator of a regular school, will you let them study in your school?	Non Favourable	53	37.9	87	62.1	0.827
		Favourable (Yes)	432	38.8	681	61.2	
	As an employer, will you consider giving them job?	Non Favourable	340	39.3	526	60.7	0.547
		Favourable (Yes)	145	37.5	242	62.5	
	Will you like to play your role in improving the quality of life of people with Down syndrome?	Non Favourable	113	35.3	207	64.7	0.149
		Favourable (Yes)	372	39.9	561	60.1	
	Will you support the Down syndrome people in living a normal life?	Non Favourable	190	37.5	317	62.5	0.461
		Favourable (Yes)	295	39.5	451	60.5	

Table-2: Knowledge and attitude by Gender

		Age in Years						P-Value	
		<35		35-50		>50			
		n	%	n	%	n	%		
Knowledge	How Down syndrome is diagnosed? (appearance, genetic test)	Incorrect	83	35.0	92	38.8	62	26.2	0.109
		Correct	330	32.5	349	34.4	337	33.2	
	Is Down syndrome a genetic disease? (Yes)	Incorrect	80	28.6	112	40.0	88	31.4	0.106
		Correct	333	34.2	329	33.8	311	32.0	
	Are they born with it? (Yes)	Incorrect	62	38.0	60	36.8	41	25.2	0.120
		Correct	351	32.2	381	35.0	358	32.8	
	Does it go away when he/she grows up? (No)	Incorrect	139	33.3	150	35.9	129	30.9	0.865
		Correct	274	32.8	291	34.9	270	32.3	
	Do their other brothers or sisters always have Down syndrome? (No)	Incorrect	40	32.0	37	29.6	48	38.4	0.207
		Correct	373	33.1	404	35.8	351	31.1	
Can Down syndrome be cured? (No)	Incorrect	143	34.0	145	34.4	133	31.6	0.857	
	Correct	270	32.5	296	35.6	266	32.0		
Can Down syndrome be prevented? (Yes)	Incorrect	231	32.4	254	35.7	227	31.9	0.886	
	Correct	182	33.6	187	34.6	172	31.8		
Attitude	Is it possible that down's children understand when we talk to them?	Non Favourable	156	32.5	156	32.5	168	35.0	0.129
		Favourable (Yes)	257	33.2	285	36.9	231	29.9	
	Is it possible for adults with Down syndrome to get married and have babies?	Non Favourable	228	34.4	234	35.3	200	30.2	0.347
		Favourable(Yes)	185	31.3	207	35.0	199	33.7	
	Will you recommend for them special help/ health services?	Non Favourable	30	30.6	38	38.8	30	30.6	0.735
		Favourable(Yes)	383	33.2	403	34.9	369	31.9	
	As an administrator of a regular school, will you let them study in your school?	Non Favourable	53	37.9	44	31.4	43	30.7	0.398
		Favourable(Yes)	360	32.3	397	35.7	356	32.0	
	As an employer, will you consider giving them job?	Non Favourable	291	33.6	311	35.9	264	30.5	0.303
		Favourable(Yes)	122	31.5	130	33.6	135	34.9	
	Will you like to play your role in improving the quality of life of people with Down syndrome?	Non Favourable	114	35.6	107	33.4	99	30.9	0.493
		Favourable(Yes)	299	32.0	334	35.8	300	32.2	
	Will you support the Down syndrome people in living a normal life?	Non Favourable	172	33.9	169	33.3	166	32.7	0.523
		Favourable(Yes)	241	32.3	272	36.5	233	31.2	

Table-3: Knowledge and attitude by age

				Attitude				P-Value	Odds Ratio	Adjusted
				<5		≥5				
				n	%	n	%			
Gender	Female	Knowledge	<5	104	56.5%	80	43.5%	0.001	1.856	OR=1.502
			≥5	124	41.2%	177	58.8%			
	Male	Knowledge	<5	142	51.1%	136	48.9%	0.070	1.314	P-Value=0.001
			≥5	217	44.3%	273	55.7%			
Age in Years	<35	Knowledge	<5	88	57.5%	65	42.5%	0.004	1.817	OR=1.504
			≥5	111	42.7%	149	57.3%			
	35-50	Knowledge	<5	86	50.6%	84	49.4%	0.110	1.368	P-value=0.001
			≥5	116	42.8%	155	57.2%			
	>50	Knowledge	<5	72	51.8%	67	48.2%	0.129	1.376	
			≥5	114	43.8%	146	56.2%			

^a Mantel-Haenszel adjustment

Table-4: Adequacy of knowledge and attitude

DISCUSSION

This population-based study investigated people’s knowledge about DS and their attitude towards individuals with DS in Saudi Arabia. Based on a scoring system, our analytical model aimed to verify the correlation between knowledge and attitude, in an attempt to contribute to the understanding and prevention of the social rejection of people with DS. The findings support the existence of important gaps in knowledge about DS that result in many social misconceptions about people with DS, which are an obstacle to their social integration.²

Half the interviewees believed that DS is diagnosed by appearance. Of the five choices proposed, this was the most frequently given answer, which is most probably related to the conspicuous physical traits associated with the syndrome. Physical stigmatization constitutes one of the major obstacles to the social integration of people with DS, especially for those who have more typical facies of DS.² It is evidenced that implicit cognition about a category of people unconsciously fashions social behavior towards individuals in this category.⁹

On the other hand, only a minority of interviewees replied that DS can be detected by blood tests (6.4%) or by ultrasound examination (4.5%), both of which are screening methods for DS, while a third of them replied that it is diagnosed by genetic tests. Recently, the focus of antenatal screening of DS has been on the first trimester of pregnancy, during which period ultrasound examination is used to measure nuchal translucency and a double biomarker test is used to measure the

serum level of free β-HCG and pregnancy-associated plasma protein A (PAPP-A). These maternal serum tests are noninvasive and have high sensitivity for detecting pregnancies with a high risk of DS.^{10,11} However, the definitive prenatal diagnosis relies on genetic tests, which require the use of more invasive methods, such as amniocentesis or chorionic villus sampling, which is associated with a high risk of fetal loss.^{10,12}

Antenatal screening for DS is now a well-established practice in many countries. Future parents are informed about the benefits and risks of screening¹³ and the termination of pregnancy is offered as a therapeutic solution if DS is diagnosed.¹⁴ Many authors have reported that a majority of women make an uninformed choice regarding antenatal screening for DS and a big proportion of them ignore its possible complications.¹³ Other authors stipulated that such programs provide focused information about the screening tests, while parents expressed the need for more information about what it means to live with a child with DS.¹⁵

In Saudi Arabia, there is no established national prenatal screening strategy for DS¹¹ although different studies surveying Saudi parents reported a generally positive attitude in both mothers and fathers towards prenatal diagnosis of congenital abnormalities in children.¹⁶ Conversely, the same studies reported a less positive attitude of Saudi parents towards termination of pregnancy (TOP), which is probably related to the Islamic values, in comparison with parents from other cultural backgrounds.¹⁶ A comparable disparity in the attitude towards TOP was observed between women from different ethnic groups in the USA.¹⁷

This could be seen as the pre-acceptance of having a child with disabilities, as part of a conscious and coherent cognitive sense in expectant parents.

Only a third of the participants replied that the diagnosis of DS is based on genetic tests, which seems inconsistent with the fact that the majority of them think that DS is a genetic and congenital disease (responses to questions 2 and 3). This inconsistency is probably due to imprecise knowledge, but an in-depth analysis of answers to the other questions (questions 6 and 7) show that the genetic/congenital origin of DS is vaguely but generally more assimilated than other scientific questions, such as prevention, diagnosis and treatments, where there are smaller percentages of correct answers. In particular, consanguineous marriage, which is very frequent in Saudi Arabia¹⁸ is a controversial risk factor associated with DS.⁸

With regards to the attitude about individuals with DS, a little over one-third of the interviewees thought that people with DS do not understand speech. The language skills of people with DS are characterized by impaired expressiveness but more conserved receptiveness. In other terms, most of them have no or little difficulty in understanding verbal communication, but almost half of them find it difficult to make themselves understood.¹⁹ People with DS have more difficulty in syntax but have stronger vocabulary skills; this means that they integrate simple words and understand simple phrases, but have difficulty in leading elaborate conversations. In addition, recurrent episodes of otitis media (in relation with associated anatomical abnormalities) frequently lead to transitory or definitive hearing loss, impacting language acquisition in many children with DS.²⁰ Despite these shortcomings, many individuals with DS can achieve a certain level of literacy.²⁰

The issue of language skills leads us to the educational aspect. The majority of the interviewees think that children with DS can be integrated in regular school. For a long time, students with disabilities, including DS, had limited access to school. However, many countries encouraged the inclusion of DS children in mainstream schools. The example of Italy is remarkable, where special educational centers for children with disabilities have been abolished since the 70s. Since then, children with DS have been enrolled in the common educational system, with the view of their complete insertion in society.¹⁹ In other countries such as

Netherlands, the number of children with DS attending regular school has increased from 2% to 37% in the two last decades.²¹ In Saudi Arabia, the authorities support the education of children with disabilities by facilitating the creation of specialized centers, including those equipped with technology-assisted programs.²² Nevertheless, some surveyed personnel report insufficient training for teachers and lack of adapted material, especially programs in the local language, which highlights the need for a deeper and harmonized national strategy of education.²³

Integrating children with DS in mainstream schools is a very advantageous strategy, as it helps to improve their communication and cognitive skills²⁴ involves them in regular activity¹⁹ and enhances their socialization process. Children with DS who grow up in natural social environments are able to develop friendships more easily than those living in specialized centers or group homes.⁷ Children with DS have relatively conserved emotional skills, in comparison with other disabilities²⁵ which helps them forge human relationships. In contrast with the question about attending regular school, the majority of participants replied that persons with DS cannot get employment. Studies suggest that a small but significant proportion (up to 30%) of people with DS could be employed with a regular contract, while the employment rate seems to depend on the age category and academic achievement.^{17,19} We were unable to obtain data about the employment of people with DS in Saudi Arabia.

With regard to the last item of our questionnaire, around three in every four of the participants think that they want to help improve the quality of life of people with DS as they feel they are neglected by the society. This reflects that there is an obvious gap between the perception of society about DS and the self-perception of people with DS⁷ as well as shared experience of their parents⁷. On a social scale where “normal” people form the majority and people with DS form the minority, such misconceptions raise many ethical questions, especially if they are largely present in the collective unconscious.

Despite the limitations of this model and the subjectivity of some parts of the questionnaire, our results strongly indicate that knowledge about the disorder influences the attitude towards DS individuals. People with DS conform themselves as

normal persons and request to be valued as any other member of the society.

The relevance of public awareness campaigns lies not in attempting to transform a marginal issue like DS into a social priority, but in understanding the conscious and subconscious factors related to the stigmatization of people with DS in adjacent society, and in disseminating targeted information to tackle these factors at both the familial and social levels.

Our study has borne very important findings which can greatly impact the social lives of people with DS. We recommend that similar studies should be carried out on large scale to determine the deficiencies in the knowledge and attitude of people, in order to deliver targeted messages to the communities through educational campaigns.

CONCLUSION

The results of this population-based study indicate the existence of important deficits in the general knowledge about DS in Saudi society, resulting in unfavorable attitude towards people with DS with a certain overestimation of their handicap. Successful insertion of this category of people relies on a deep understanding of the conscious and subconscious social factors related to stigmatization and the dissemination of targeted information in public awareness campaigns. Moreover, resourceful education of people with DS and their families should be in accordance with the commonly shared beliefs and value systems, especially in a society such as Saudi Arabia where family and religious values prevail.

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