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Research Article

**AWARENESS AND ATTITUDE TOWARDS PEOPLE WITH
DOWN SYNDROME – A COMMUNITY BASED STUDY IN
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Abstract:

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. So a cross-sectional study based on a questionnaire distributed to the participants which are the parents who are living in Almajmaah city and surrounding villages, and agreed to fill the questionnaire. The objective of this study was to assess the level of awareness of Down syndrome among the general population in Majmaah city in 2018/19. Through studying the level of knowledge and awareness about Down syndrome, assessing the attitude towards associated risk factor, and Studying the practice of primary prevention among the participants. The study showed that 44% of male respondents and 21% of female respondents know about DS. Moreover, 16% of participants know about Counseling of married couples who are at risk (10% for males and 5% for females). There were subtle but insignificant differences in the proportion of correct answers by genders. Concerning people's attitude towards DS patients, around 34% thought that think people with DS need special schools. Moreover, around 65% thought that mixing students with DS in public schools affects other students, while around 35% believed not. Around half respondents supported offering jobs to people with DS.

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INTRODUCTION:

Down syndrome (DS) is defined as congenital disorder arising from a chromosome defect, causing intellectual impairment and physical abnormalities including short stature and a broad facial profile. It arises from a defect involving chromosome 21, usually an extra copy (trisomy-21), DS is a chromosomal disorder that results in intellectual disability and growth problems. And was so-named after the British doctor John Langdon Down, who was the first to identify the disease in 1862 [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 worldwide according to statistics on prenatal statistics [2]. 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 [3].

Researchers have said that DS is often due to many factors, the most important factor is marriage among blood relatives. Such marriages have reached levels of 66.7 % in Saudi Arabia, 56.3 % in Oman, and 22% in Qatar and 54% in Kuwait. Other factors relating to the causes behind the disease include high birth rates and the absence of tests to reveal the disease early. Moreover, 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 between 1980 and 1999 [4].

A study was implemented at the period of 1982-1991 in Riyadh City, showed that 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 practiced since the widespread use of antenatal diagnostic methods [4, 5].

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 [6], and early interventions can improve their quality of lives [7]. 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 [8]. Another study found that European communities also still hold negative attitudes towards people with Down syndrome [9]. 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.

Therefore, there should be a general awareness about Down syndrome and those who have this disorder. It is generally seen that children and adults with Down syndrome are more prone to peer rejection and social isolation. Accurate knowledge and positive, but realistic, expectations are important for enhancing the acceptance of individuals with disabilities within their schools and communities.

However, there are very few literatures on awareness study in Saudi Arabia and particularly in Majmaah. This study will assess the awareness and attitude of the general population towards those affected with Down syndrome.

So, the study amid to assess the level of awareness of Down syndrome among the general population in Majmaah city, Saudi Arabia, 2018 - 2019. As 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 worldwide.

PATIENTS AND METHODS:

A cross-sectional study based on a questionnaire distributed to the participants which are the parents who are living in Almajmaah city and surrounding villages, and agreed to fill the questionnaire. This study will be conducted in Majmaah city in Sudair area in the north of Riyadh region, which includes "Hawtah Sudair, Rawdat Sudair, and surrounding villages. Sudair is located in the middle of Najed heights. Almajmaah city which is an area of 30,000 km² and has a population of 133 thousand people. It is the capital city of the province. The study will concern on Majmaah University in Majmaah city. It serves different city in the region like, Majmaah, Zulfi, Hawtah Sudair, Ghat, and Rumah. Total number of students is 24288, and for medical college is 206 (180 male, 26 female).^[10]

The questionnaire contained many different questions, in which all of them were close-ended questions. No personal, social or private questions were involved. It consisted of two main parts: the first part is concerned with the demographics (i.e. gender, age, marital status, and education level), the previous experience with people with Down's syndrome and whether the responders had a family member with Down's syndrome.

The second part consisted of six questions which were designed to measure 3 aspects of personal

opinions and attitudes towards inclusion of people with Down's syndrome. These were from educational, community, and personal perspectives. Some questions were adapted from previous surveys [11, 12].

- Question 1: Do you think people with DS need special schools?
- Question 2: Do you think mixing students with DS in public schools affects other students?
- Question 3: Do you support offering jobs to people with DS?
- Question 4: Do you think people with DS can be integrated into the community?
- Question 5: If you were a teacher, would you be able to teach people with DS?
- Question 6: Can you be a friend with anyone with DS?

The Study targeted to interview all Saudi males and females who are 2. Working in the Majmaah University, which means that the study sample contained adult males and females their age is above 21 years who agreed to be involved in the study and filled the questionnaire. Moreover, the study excluded all expatriate population, People not employed in Majmaah University, and people under age of 21 years old.

Finally, a sample of 189 participants was successfully interviewed. The size and sampling technique for the study is considered convenience, since we only interviewed participants within this pre-designated period, also the mode of sampling is considered convenience sampling. However it was designed that the sample would cover 500 males and females by using a random sampling of 250 males and 250 females of Saudi origin within the Majmaah University would be done after dividing the total sample of males and females with the total colleges within the University.

A structured data sheet was created to aid in data collection as a study tool, in addition, data was entered into the data sheet then into an Excel document, and this process was repeated for all variables. The duration of the data collection process was not exceeding four weeks.

After raw data was processed in accordance with the best practice for raw data management to identify any inaccuracies in advance to the statistical analysis. And in order to achieve that task, implausible values were flagged. A similar process was applied to categorical variables to identify any potential anomalies. All identified anomalies were discussed with biostatistics team and were corrected prior to

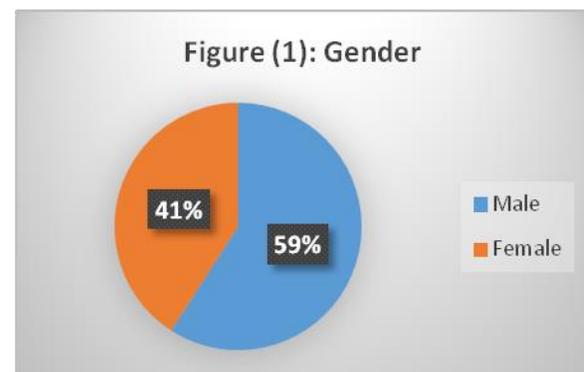
initiation statistical analysis. Data was filled into appropriately designed excel sheet. Statistical analysis was done using SPSS V22. Descriptive statistics will be presented as number, percentages, means and standard deviation in that report. All statistical tests was declared significant at a P value of 0.05.

The ethical approval was obtained from the ethical committee of the Basic Health Research Centre of Majmaah University. Informed consent was obtained from the participants. The data was planned to be collected and was used for research purpose only and access to this data was for the principle investigator. Name and personal information of participants was not obtained as an ethical consideration.

RESULTS:

As mentioned before a sample of 189 participants was successfully interviewed. Since, the objective of this study was to assess the level of awareness of Down syndrome among the general population in Majmaah city in 2018/19. Through studying the level of knowledge and awareness about Down syndrome, assessing the attitude towards associated risk factor, and Studying the practice of primary prevention among the participants.

Almost all participants in the study have ever been married (94%), while only 6% were still single. Among those who were married, 94% were having children, while only 6% haven't got any children yet. All respondents agreed to participate in the study were Saudi (100%). Furthermore, data shown in figure (1) shows that the sample contained male participants more than females (which is 59% and 41%, respectively).



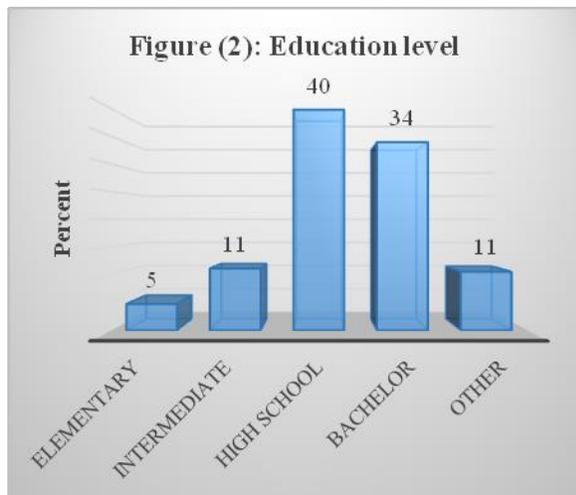
Participants were distributed among Majmaah city as follows; 49% were living in Al-Majmaah, 15% were in Hawtah Sudair, and 14% were in Rawdat Sudair, while 22% of the participants were living in surrounding villages around Majmaah city.

Concerning the age distribution of the sample in table (1) shows that around half participants (50.8%) of the sample was aged 21-31 years old, also around 34% of the respondents were aged 31 years old or more. While only 15% of respondents were under age of 21 years old.

Table (1): Age groups

	Frequency	Percent
<21	29	15.3%
21-31	96	50.8%
≥31	64	33.9%
Total	189	100.0%

In addition, it was clear the most of sample were reasonable level of educated, where 34% of the participants had bachelor's degree from universities. And 40% of participants were secondary educated, while 11% of respondents were intermediate educated and 5% have elementary education. Figure (2) shows also that 11% of the respondents were having other education (above university education).

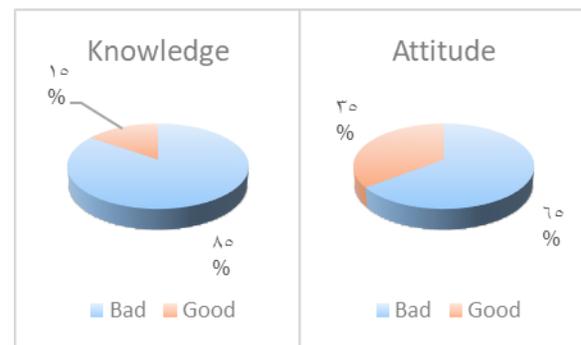


According to the aim of the study which is assessing the level of awareness of Down syndrome among the general population in Majmaah city, through studying the level of knowledge and awareness about Down syndrome. Data in table 2 shows that the level of knowledge and Attitude of people towards DS. Analysis of the knowledge questions showed that around 44% of male respondents and 21% of female respondents know about DS. Moreover, 16% of participants know about Counseling of married couples who are at risk (10% for males and 5% for females). There were subtle but insignificant differences in the proportion of correct answers by genders.

Concerning people's attitude towards DS patients, around 34% thought that think people with DS need special schools. Moreover, around 65% thought that mixing students with DS in public schools affects other students, while around 35% believed not. Around half respondents supported offering jobs to people with DS.

Moreover, around 40% said that people with DS can be integrated into the community. Additionally, there were no significant difference between participants in the attitude of teaching people with DS, since around 50% of participants were able to teach people with DS is case they were teachers, this percent did not show a significant difference between male respondents and female ones.

Figure (3): Assessment of Knowledge and attitude about Down syndrome in Saudi population



In the analysis of the response in relation to gender and education 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 good or bad knowledge and those with favorable or non-favorable attitude towards DS. A cutoff of 50% correct answers, which corresponds to 5 correct answers out of 11 each for the knowledge-related and attitude-related questions, was considered to indicate adequacy. Overall, we found that 85% of the interviewees had bad knowledge, and 65% had inadequate attitude (Figure-3).

Concerning levels of knowledge and attitude of people towards DS according to their level of education, it is clear that there were statistically significant in this direct relation, which means that as the level of education increase, the knowledge level of people towards DS will increase, this pattern was appeared with attitude of respondents towards people with DS.

Table (2): Knowledge and Attitudes of people towards DS by gender							
			Gender				P-value
			Males		Females		
			No.	%	No.	%	
Knowledge	Do you Know what down syndrome is?	Incorrect	68	36.0%	38	20.1%	0.056
		Correct	44	23.3%	39	20.6%	
	Do you know about Counseling of married couples who are at risk?	Incorrect	93	49.2%	67	35.4%	0.297
		Correct	19	10.1%	10	5.3%	
	Do you know about screening program for females at risk?	Incorrect	93	49.2%	67	35.4%	0.297
		Correct	19	10.1%	10	5.3%	
Attitudes	Do you think people with DS need special schools?	Non Favorable	82	43.4%	43	22.8%	0.010
		Favorable(Yes)	30	15.9%	34	18.0%	
	Do you think mixing students with DS in public schools affects other students?	Non Favorable	41	21.7%	26	13.8%	0.404
		Favorable(Yes)	71	37.6%	51	27.0%	
	Do you support offering jobs to people with DS?	Non Favorable	56	29.6%	42	22.2%	0.321
		Favorable(Yes)	56	29.6%	35	18.5%	
	Do you think people with DS can be integrated into the community?	Non Favorable	63	33.3%	51	27.0%	0.110
		Favorable(Yes)	49	25.9%	26	13.8%	
	If you were a teacher, would you be able to teach people with DS?	Non Favorable	57	30.2%	41	21.7%	0.433
		Favorable(Yes)	55	29.1%	36	19.0%	
Can you be a friend with anyone with DS?	Non Favorable	55	29.1%	46	24.3%	0.098	
	Favorable(Yes)	57	30.2%	31	16.4%		

Table (3): Knowledge and Attitudes of people towards DS by education level

			Gender										P-value
			Elementary		Intermediate		High school		Bachelor		Others		
			No.	%	No.	%	No.	%	No.	%	No.	%	
Knowledge	Do you Know what down syndrome is?	Incorrect	9	4.8%	17	9.0%	39	20.6%	26	13.8%	15	7.9%	0.000
		Correct	0	0.0%	4	2.1%	36	19.0%	38	20.1%	5	2.6%	
	Do you know about Counseling of married couples who are at risk?	Incorrect	9	4.8%	17	9.0%	71	37.6%	55	29.1%	8	4.2%	0.000
		Correct	0	0.0%	4	2.1%	4	2.1%	9	4.8%	12	6.3%	
	Do you know about screening program for females at risk?	Incorrect	9	4.8%	17	9.0%	71	37.6%	55	29.1%	8	4.2%	0.000
		Correct	0	0.0%	4	2.1%	4	2.1%	9	4.8%	12	6.3%	
Attitudes	Do you think people with DS need special schools?	Non Favorable	9	4.8%	15	7.9%	46	24.3%	45	23.8%	10	5.3%	0.076
		Favorable(Ye s)	0	0.0%	6	3.2%	29	15.3%	19	10.1%	10	5.3%	
	Do you think mixing students with DS in public schools affects other students?	Non Favorable	2	1.1%	17	9.0%	19	10.1%	17	9.0%	12	6.3%	0.000
		Favorable(Ye s)	7	3.7%	4	2.1%	56	29.6%	47	24.9%	8	4.2%	
	Do you support offering jobs to people with DS?	Non Favorable	7	3.7%	19	10.1%	37	19.6%	19	10.1%	16	8.5%	0.000
		Favorable(Ye s)	2	1.1%	2	1.1%	38	20.1%	45	23.8%	4	2.1%	
	Do you think people with DS can be integrated into the community?	Non Favorable	9	4.8%	15	7.9%	47	24.9%	33	17.5%	10	5.3%	0.039
		Favorable(Ye s)	0	0.0%	6	3.2%	28	14.8%	31	16.4%	10	5.3%	
	If you were a teacher, would you be able to teach people with DS?	Non Favorable	6	3.2%	17	9.0%	38	20.1%	27	14.3%	10	5.3%	0.035
		Favorable(Ye s)	3	1.6%	4	2.1%	37	19.6%	37	19.6%	10	5.3%	
	Can you be a friend with anyone with DS?	Non Favorable	9	4.8%	17	9.0%	40	21.2%	20	10.6%	15	7.9%	0.000
		Favorable(Ye s)	0	0.0%	4	2.1%	35	18.5%	44	23.3%	5	2.6%	

DISCUSSION AND CONCLUSION:

This cross-sectional study was undertaken to understand the level of knowledge and awareness towards people with Down Syndrome (DS) among population in Majmaah City. And to know the relations between, education and gender and the level of awareness about DS.

A self-administered questionnaire was randomly distributed to parents of both sexes. 189 people agreed to participate, answered the questionnaire and involved in the study.

As mentioned before 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 [6]

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 [7].

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. However, most of these studies focus on specific groups of people (e.g. students [11], teachers [12], and physicians [13])

Other studies that included different groups of people has found that United States communities still hold negative opinions towards people with DS[14]. Another study found that European communities also still hold negative attitudes towards people with Down's syndrome [14].

Community attitudes and knowledge of this condition are important for inclusion of people with DS into the community and improving their quality of lives. Results from surveys from the world showed that people still hold negative attitudes towards inclusion of people with DS [10].

Results from surveys from the world showed that people still hold negative attitudes towards inclusion of people with DS. Studies in the Arab world are sparse and there are no data exploring these attitudes in Majmaah city in the absence of formal awareness programs; hence, this study aim to provide analysis of the majmaah community attitudes towards people with Down syndrome.

Another recent study in 2018 showed that 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 [15].

In 2016, a study was conducted in Jeddah to discuss Assessment of Knowledge, Attitude and Practice toward Down syndrome. That study concluded 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 [16].

In conclusion, findings indicated low knowledge of the general population of parents in Majmaah city about Down syndrome. They also showed a reasonable attitude towards dealing with people with DS. In addition, data showed that there was no significant relation between gender of parents and his/her level of knowledge about DS. On the other hand, there was a relation between parents' level of education and his/her level of knowledge and attitude towards people with DS.

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