

Assessment of Awareness Level toward Down Syndrome in Riyadh, Saudi Arabia

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Abstract

Background: Down syndrome is a genetic disorder that affects physical and mental development. It's the most prevalent chromosomal disorder. The worldwide incidence of this syndrome is 1 in 1000 births and increases exponentially with the maternal age. This study aims to assess the awareness level toward Down syndrome among females attending to the primary health care centers. As perceptions of the disease and the public attitudes towards people with Down syndrome are very important in the community.

Methods: A descriptive cross-sectional study was conducted among 402 female in primary health care centers. data was collected by using cluster sampling method and self-administrated pre-tested questionnaire from 2018 to 2019.

Results: Among total of 402 females who answered the questionnaires, the mean age was 35 years found that the awareness of Down syndrome was moderate with 61.4%. However, about the third of the females had low awareness 38.1%. Whilst, only 0.5% of them had high awareness score about Down syndrome. Of 402 participant's education level, 20% were attended college, 5% with postgraduate degree, 70% completed high school, and 5% with primary school.

Conclusion: This study indicated that awareness of Down syndrome among female was moderate. Furthermore, there is Significant association between education and awareness, and there is no significant association between age and awareness.

Keywords: Down Syndrome; Awareness; Saudi Arabia

Introduction

Down syndrome (DS) or Trisomy 21 is the most common chromosomal abnormality. but also the most compatible with survival of all autosomal trisomies. People With Down syndrome were referred to be mongolism or being Mongols. Children with Down syndrome are found in all ethnic groups. This is due to chromosomal disjunction during the process of meiosis and is more common with older

parents [1]. Affecting around 1 - 2.2 of every 1000 live births according to statistics on prenatal statistics [2]. Since the meiotic error rate increases nearly exponentially after a certain age, it's contribution to the overall incidence of aneuploidy may mask the contribution of other processes. The increase is particularly marked from 35 years [3]. 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 [4] since the widespread use of antenatal diagnostic methods [5]. There is a wide range of Down syndrome screening (DSS) tests, with rates of prediction obtained either with a single test or combinations of several, thus offering multiple options. The latest technological advancement is non-invasive prenatal test, an investigation based on the analysis of free circulating fetal DNA in the maternal blood. It has a high predictability potential, that recommends it as a next in line screening in case of a positive traditional DSS, in order to avoid invasive methods [6,7]. The influence of maternal age on Down syndrome is well approved but little is known about the genetic effect of advanced paternal age. Older fathers may add just as much as older mothers to the dramatic increment in Down syndrome risk faced by babies born to older couples. Yet, the impact of maternal age is needed for the presence of Down syndrome [8,9]. In Bosnia and Herzegovina, on average, each year 33 Down syndrome individuals were born and 13 Down syndrome fetuses were diagnosed prenatally. The live-birth prevalence Of Down syndrome was 9.6 per 10,000 births and the total prevalence of Down syndrome was 19.1. The total Down syndrome prevalence increases exponentially with the advanced maternal age [10]. During last two generations, a remarkably significant change in survival of people with Down syndrome has occurred, with life expectancy estimate increasing from 12 to nearly 60 years of age. With four life stages of Down syndrome were identified: prenatal, childhood, adulthood and senescence. Pneumonia and other viral infections were the commonest cause of death across the entire lifespan of individuals with Down syndrome [11,12]. There is no available standard medication to treat Down syndrome, but other measures for rehabilitation as physiotherapy, psychological as well as phonoaudiological special techniques that plays an important role in those with severe mental limitations. The goal of rehabilitation of individuals with Down syndrome is to help them integrate with the society [13]. This study is aimed to assess the level of general knowledge and risk factors awareness of Down syndrome, identify the source of information about Down syndrome, and to determine the impact of educational level and age on the awareness level of Down syndrome among female attending to primary health care centers in Riyadh district.

Methodology

Study design

It was done descriptive cross-sectional study conducted during the period of Aug 2018-Feb 2019 to estimate the awareness of Down syndrome among females attending to primary health care centers in Riyadh district. The target population was all in primary care centers in Riyadh district. who was available during the study period that we inducted in this study. The list of primary health care centers was provided by The Ministry of Health office in Riyadh district. The sample size required is 340 females, we added 18% (62) as drop out to the sample size to avoid any missing among females during data collection, so the sample size was increased to 402 females. The sample was selected by cluster sampling method as the following; we determined the total number of primary health care centers in Riyadh district which was 25 primary health care centers. The Ministry of Health office allowed us 12 primary health care centers in Riyadh district. We randomly selected 9 or the 12 permitted primary health care centers in Riyadh district using lottery method as shown in table 1. The females who participated in each selected primary health care centre were chosen by simple random sampling. Note, Prior permission was taken from administrations or relevant centers.

Inclusion criteria: All others in primary health care centers.

Exclusion criteria: There was not any exclusion criteria regarding our sample selection.

Study variables

Dependent variables: Awareness level of Down syndrome among females attending to primary health care centers in Riyadh district.

No.	Primary health care centre	No. of participants
1	Health Care Specialty Center	40 participants
2	King Abdulaziz City Housing	7 participants
3	National Guard Comprehensive Specialized Clinic	40 participants
4	King Saud City Housing	112 participants
5	Employee Health Clinic	57 participants
6	Prince Bader Residential City Clinic	42 participants
7	King Khalid Military Academy Clinic	34 participants
8	Headquarters Clinic	45 participants
9	Prince Bader Palace Clinic	25 participants
Total		402

Table 1: Number of participants in each primary health care centre in Riyadh.

Independent variables: Age and educational level (Primary and Secondary educated, collage and post- graduation degree).

Data collection

The data was collected by using self-administrated questionnaire which was involving; Personal data such as (age and educational level, level of general knowledge about Down syndrome, the awareness level about risk factors of Down syndrome, and the source of information. Note, we used link-workers complete questionnaire in those cases where the mother could not understand the questions.

Pilot study (pre-test): The pre-test questionnaire conducted among 20 recipients who were randomly selected from the females attending to primary health care centers. The sample or recipient which we used in this pre-test was not included in this study. The questionnaire, which was used in the pre-tested, aimed to determine the question sequence; identification of words and consistency of answers to the "check" questions.

Data analysis: The data was checked and analyzed by using Statistical Package using Social Science (SPSS version 20) software program. Descriptive statistics (mean, percentage and frequency) for continuous variables were calculated. Frequencies were determined for categorical variables. Data presented in tables and graphs by using computer applications Microsoft Office Word and Microsoft Office Excel. Awareness scale: The questionnaire was divided into categories. A true response was coded with a score of (1). a False response was along with do not know were coded with a score (0). The optimal total score was (10) (100%). Females awareness was measured by the number of correct responses on the questionnaire. Responses of the study sample members were calculated by summing then extracting the (percentage, mean and standard deviation) of the correct responses for each member of the sample on the questionnaire. If the correct responses of a particular sample member were above (mean + SD) their awareness about Down syndrome was considered (High); if it ranged between (mean \pm SD) their awareness about Down syndrome was considered (Moderate); and if it was below (mean -SD) their awareness about Down syndrome was considered (Low). Higher scores indicated a better awareness about Down syndrome and lower scores indicated a weaker awareness about Down syndrome.

Ethical consideration: An approval of our study was obtained from King Saud University College of Medicine, department of Community Medicine and Ministry of Health Office in Riyadh district. Objectives of our study were clarified participant and a variable consent was taken from them. We ensured that those who agreed to participate in our study and their information were kept in strict confidence used in the benefit of the community.

Result

Data from 402 females in primary health care centers were analyzed regarding age most of them were between 15-35 years old with about 77% and just 1.7% between 56 - 75 years old. About the level of education 5% and 70 % were had primary and secondary education while 25% were had collage or post-graduate degree.

As table 2 demonstrate the general awareness of Down syndrome, in which almost 80% of participants had heard about Down syndrome, but only 42.3% of the females heard about the tests availability. 47.3% of the participants were aware that the disabilities people Down syndrome include both physical and Mental. And 25.9% of the participant females reported that Down syndrome is caused by chromosomal mutation. The females agreed that people with Down syndrome confront difficulties learning accounting 47% of total participants. Regarding the effect of Down syndrome on the age of person our results showed that 28.6% of the females reported that Down syndrome leads to reduce person's life. When asked about treatment of Down syndrome 27.4% or the participants replied that there is no treatment.

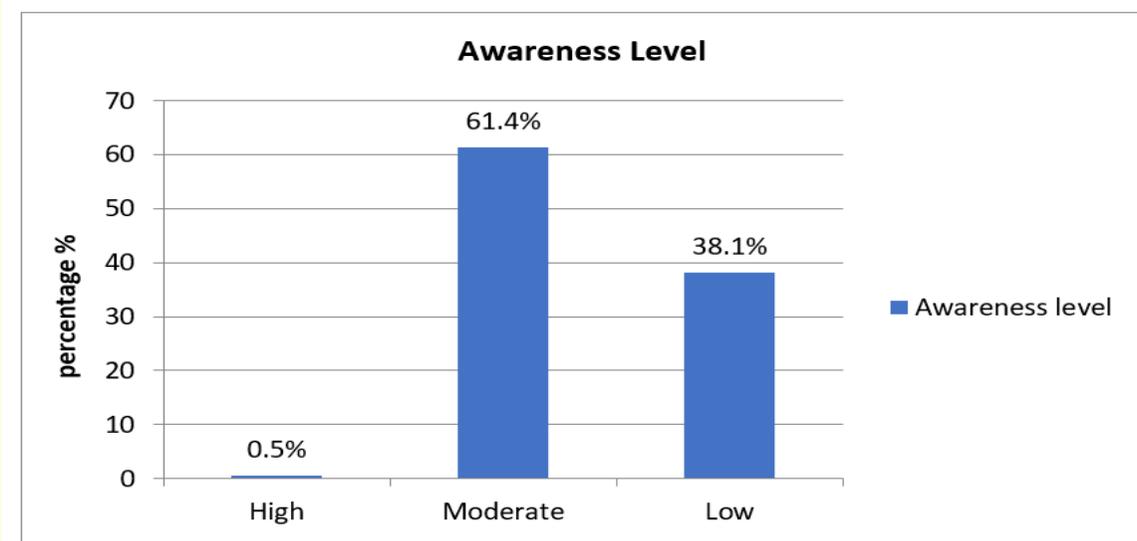
No.	Item	Frequency	Percentage
1	Heard about Down syndrome	321	79.9%
2	Heard about Down syndrome tests	170	42.3%
3	Type of disability in Down syndrome	190	47.3%
4	Causes Down syndrome	104	25.9%
5	Presence or difficulties in learning	189	74.0%
6	Effect of Down syndrome on life	115	28.6%
7	Availability of treatment	110	27.4%

Table 2: General awareness or Down syndrome.

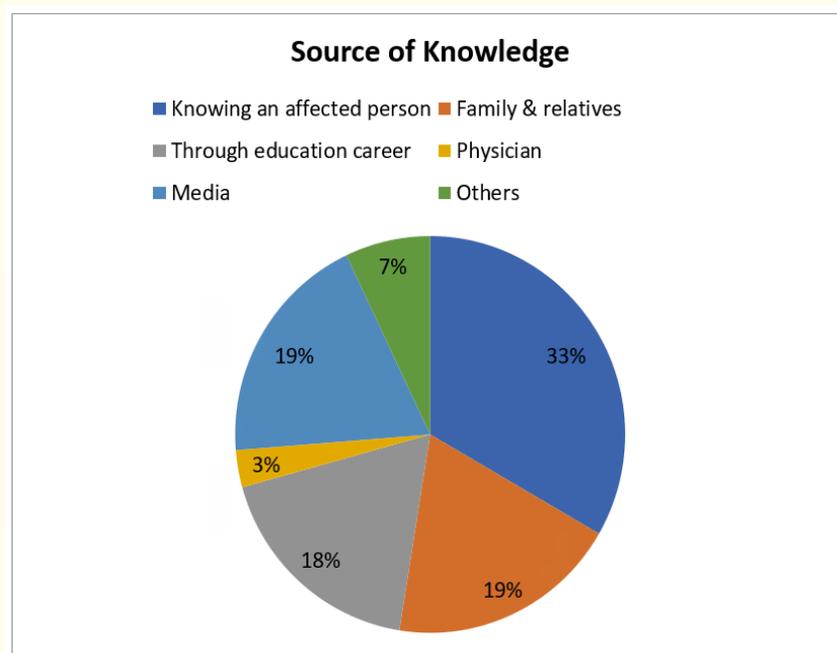
In about 22.6% of the females thought that old age or mothers could increase the risk of having a child affected by Down syndrome. On the other hand, 7.7% of the participants said that old age or fathers can increase the risk of having a child with Down syndrome. However, 11.2% or the participants believed that consanguineous mating does not associate with having a child with Down syndrome and 12.7% thought that drug intake during pregnancy does increase the risk of having a child affected by Down syndrome (Table 3). Level of general knowledge and risk factors awareness toward down syndrome illustrated in table 3 showed that more than the half of the participants (56.7%) had a moderate level of general knowledge about Down syndrome. while 36.3% of them had a low level of general knowledge, and the rest of them (7%) had a high level. Regarding the risk factors awareness, the majority of participants had a low awareness level. while 33.8% of the them had a moderate awareness level and almost no one had a high awareness level of the risk factors. Our results showed that 61.4% of the participants had a moderate awareness level about Down syndrome in general, while 38.1 % of them had a low awareness level (Graph 1 and 2). Regarding the association between awareness level and educational level or age of participants. we notice that education level had an impact on the awareness level of Down syndrome, while no significant association between the age of participants and their awareness level. The results indicates that 33.1% of the participants cited knowing an affected person as their source of information, family and media together were the second source of information with 19.5 others attributed educational career and physician as their source of knowledge.

Discussion

This study was conducted to explore the awareness level in general about Down syndrome among females attending primary health care centers in Riyadh district. The result of this study revealed that the level of awareness about Down syndrome in general was moderate along with the Australian [19], Thai [15] and Greek [16] studies, only the Dutch study [17], found that the majority of the participants



Graph 1: General awareness level of down syndrome.



Graph 2: Source of information of down syndrome.

Item No.	Item	Frequency	Percentage
1	Old age of mothers	91	22.6%
2	Old age of fathers	31	7.7%
3	Consanguineous mating	45	11.2%
4	Drug intake during pregnancy	51	12.7%
Characteristics			
Level of general knowledge	High	28	7%
	Moderate	228	56.7%
	Low	246	36.3%
Level of risk factor awareness	High	1	0.2%
	Moderate	136	33.8%
	Low	265	65.9%

Table 3: Awareness of risk factors and level of general knowledge of Down syndrome.

had sufficient knowledge about DSS. Comparing to a study conducted in Jeddah where the level of knowledge was low in the majority of responders [14]. This finding conflicting with that of other studies we found conducted in Australia and United Kingdom [18,19]. Which observed low level of awareness about the syndrome. We assumed that many factors helped in explaining the previous finding. The results revealed that female participated in our study heard about Down syndrome from different sources, knowing an affected person was the major source of their information. As well as most of the females in our sample educated which we think may explain the finding in our study. Regarding whether heard about Down syndrome, our findings showed that of the participants in our study heard about the syndrome by its scientific (Down syndrome) or its out of date familiar term (mongolism) which equaled 80% of the total population, which is closely similar to the finding of a study conducted in Australia. About type of disability affecting the children of Down syndrome, our study observed that 47.3% of the females stated that Down syndrome affects physical and intellectual abilities. In contrast with inconsistent finding of Australia study, which showed that 33% of women stated the syndrome associated with physical disability and 37% stated that it was associated with intellectual disability. With respect to the cause of Down syndrome, our results showed that 25.9% of the females who participated responded it was caused by chromosomal abnormality with slight similarity with our finding. A study conducted in Australia revealed that 30% of the sample also stated that the syndrome caused by chromosomal abnormality. When Addressing the issue or learning difficulties associated with Down syndrome, less than the half of the sample selected (47%) agreed that Down syndrome is associated with the presence of learning difficulties. We think that this finding can be explained by the approximate percentage of the participated females in our study with the previous percentage that stated Down syndrome is associated with physical and intellectual disability and also can be explained by the relativity of the two findings. According to life expectancy more than the quarter of the females thought that Down syndrome have less life expectancy than normal ones. Finding of Levis DM indicated that most of the participants were unsure about Down syndrome impact on life expectancy, while some of them stated that it causes shorter life expectancy comparing to normal individuals [20]. When asked about treatment of Down syndrome or if the syndrome is curable, around fourth of the participated females responded with no. In contrast with the rest two-fourth of females who also participated in the study responded incorrectly stating that there is an available treatment and that the syndrome is curable while others stated that they don't know if Down syndrome is curable or not. In a study conducted in the United States or America, the older maternal age was the most frequently mentioned as a risk for Down syndrome. With agreement to our finding which showed that maternal age too was the most risk factor of Down syndrome. Additionally, a few participated females correctly chose the advanced paternal age as a risk factor for Down syndrome. The influence of advanced maternal age on Down syndrome is understood but little is known about the effect

of increased paternal age on the relative syndrome which concluded in the study of Fisch H [9] a study noticed significant association between educational level with the awareness level or participated females. Higher educational level indicates better understanding of Down syndrome. Which might be justified by relating to the finding in our results which mentioned. Near the fifth of the Participated females chose through the educational career in responding to our self-administrated questionnaire as the source of information about the previously mentioned syndrome. Besides the results that there is no significant association between the age and the awareness level of Down syndrome. This finding is consistent together with the finding of the other study that conducted in Australia. Our study revealed that knowing an affected person was the most common source of information regarding down syndrome with 33.1%, followed by family and media as the second source with 19% for each, while in a study conducted in USA the primary source was the internet followed by TV as the second source [20]. In other study conducted in Australia, the participants cited the hospital information leaflet as their single most source of information, while family and friends were their second source. Those variations regarding the source of information concerning these studies could be due to different social lifestyle and cultures.

Conclusion

More than half of the females had moderate awareness about down syndrome. The vast majority of the females had moderate general knowledge toward down syndrome. Almost two thirds of the females had a low awareness level about the risk factors of down syndrome. There is significant association between educational level and awareness level about down syndrome. There is no significant association between age and awareness level. Knowing an affected person was the primary source of information.

Limitation of the Study

This study has some limitations, which do not represent the whole population of Jeddah city, therefore, the results cannot be generalized.

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