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Health, education, and attitude toward Down syndrome people in the Pashtun

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Abstract

Down syndrome (DS) is the most common genetic abnormality worldwide. This preliminary study aims to assess the attitude of society toward DS people and the understanding of their health and education status in the Pashtun population of Khyber Pakhtunkhwa (KP), Pakistan. The study sample was DS people (no. 108) and their parents/guardians (no. 108) belonging to different province areas. Information was collected on a predesigned questionnaire by trained professionals. P≤ 0.05 was considered significant. The overall response of the study population was positive (mean=4.066, SD=0.99). However, no significant difference appeared in the categorical analysis for sex, age group, location, and education level of the respondents. The result indicated that cardiovascular disease was the most common disease in DS people (7.4%). Further, 82.4% of the DS people were not enrolled in any school. Although the overall attitude toward DS people is very positive in the Pashtun population, the province's national social system cannot support disabled people appropriately. Policies should be made for these people on the provincial and national levels to reduce their dependency on the family.

Keywords: Intellectual disability, Attitude, Congenital disorders, Health status, Education.

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1. INTRODUCTION

Down syndrome (DS) is a frequently identified chromosomal abnormality with an incidence of 1 in 730 live births [1]. People with DS have a specific characteristic set of facial and physical features [2]. In addition to intellectual disabilities [3], other congenital abnormalities such as cardiovascular disease, hypotonia, and gastrointestinal diseases may also be associated with DS[2].

The complex phenotype of DS is the result of the dosage imbalance of those genes which are located on chromosome number 21. The long arm of chromosome 21 (21q) is 33.5MB [4], while the short arm (21p) is 5-15MB [5]. The initial sequencing of chromosome 21 showed a total of 225 genes [4]. Mostly DS arises due to an extra copy of chromosome 21 derived from the mother in about 88% of cases through chromosomal non-disjunction. This non-disjunction may arise during the first meiotic division (~65% maternal; ~3% paternal), second meiotic division (~23% maternal; ~5% paternal), or during cleavage (~3%) [6]. Partial trisomy occurs if only a segment of chromosome number 21 has three copies [7]. Also, if three copies of chromosome 21 are present in some cells while other cells have the normal number (two copies), such type of DS is called mosaicism (in ~1.3–5% of cases) [8]. Mosaicism is considered to have a milder phenotype [7].

Pakistan has a population of 197 million [9] and a higher level of kinship, [10,] which is a possible risk factor for DS [11]. Prenatal diagnosis is less common in the country; therefore, it has many people with genetic disorders [12]. An understanding of people's attitudes toward patients with cognitive disabilities is important for the successful integration of such people into society. In addition to personal abilities, the social integration of a person with an intellectual disability depends upon society's attitude toward people with intellectual disabilities[13].

Therefore, this preliminary study aims to investigate the health status of DS people and the attitude of DS people's close relatives/ parents toward children with DS in the Pashtun population of Khyber Pakhtunkhwa Province-Pakistan. To the extent of our knowledge, no literature is available on the attitude toward DS in any population in Pakistan.

2. MATERIALS AND METHODS

2.1 Samples collection

As no special registry system for DS patents is available in the province, for this pilot study, a door-to-door survey of the different areas in the province was conducted from June 2018 to March 2019. Different residential areas were selected randomly for the survey from five districts of Khyber Pakhtunkhwa provinces, including Peshawar, Mardan, Malakand Agency, Sawabi, and Sawat. Information was collected on a predesigned questionnaire by the trained health personnel. The study sample was the parents /guardians of DS patients. Written informed consent from the parents/guardians was obtained before the interview. No ethical issue is associated with this study as this is a survey-type study and involved no human experimentation

2.2 Analysis

A five-point response scale was used to assess the attitude of parents/ guardians of the DS people. The highest value, i.e., 5, indicates a more positive response than the lowest, i.e.1. The questionnaire contained questions regarding demographic characteristics, education, health status, and congenital disorders associated with DS. Also, questions regarding the behavior and approach of the relatives towards the DS were included in the questionnaire. A five-point response scale was used for the assessment of the attitude of society toward DS patients. Data were analyzed by SPSS version 20.

3. RESULTS AND DISCUSSIONS

DS patients, including 86 males and 22 females (Total 108) with ages ranging from 8 years to 45 years, with the majority of teenagers in their 20s, were included in this study. The single parents (mother or father)/guardians of these patients (Available at the time of the survey), including 93 males and 15 females with different ages, education levels, and localities, were interviewed.

The respondents were satisfied with having their DS children (mean = 4.066, SD = 0.99). 37% were highly positive. About 9% of them were neither positive nor negative. However, about 6% of the respondents showed a negative attitude toward their DS children (Fig. 1).

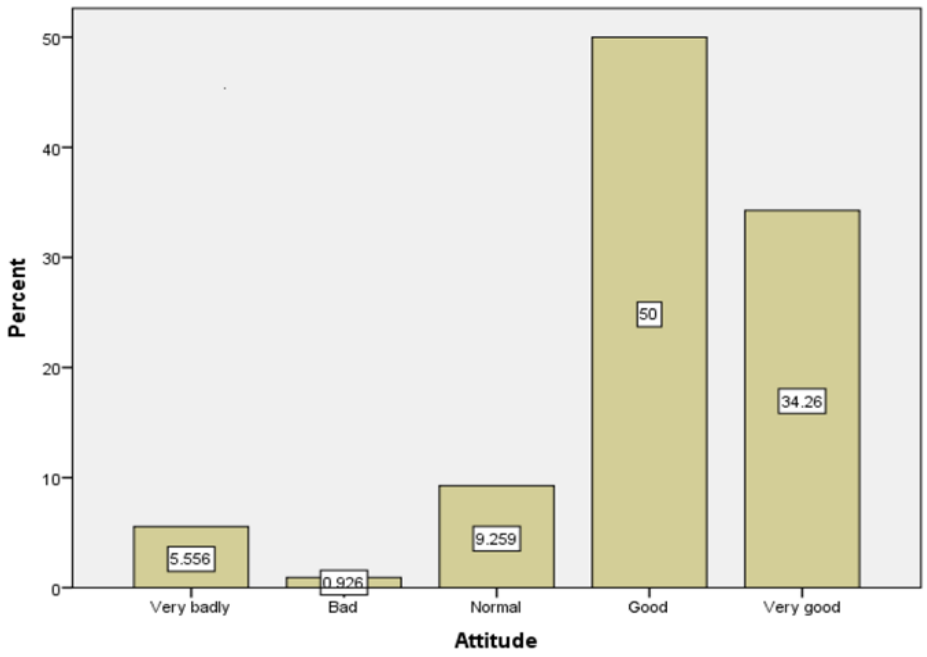

Fig. 1. Attitudes of people toward DS patients.

Table 1 presents the main result for the attitude toward DS by demographic characteristics of the respondents (Parents and guardians of the affected children). Although all respondents had a positive attitude about the DS children, no significant differences were obtained from comparing attitudes from different categories of sex, age, education level, and rural-urban location (P-value more than 0.05) (Table 1).

Table 1. Demographic characteristics of respondents and DS patients, KP province, 2018–19, No = 108

Demographic characteristics of respondents			
		Number	%
Sex	Male	93	86.1%
	Female	15	13.9%
Age (years)	≤ 25	7	6.5%
	≥ 26	101	93.55%
Education	Primary & below	75	69.4%
	Secondary	24	22.2%
	Graduate	9	8.3%
Location	Rural	67	62.0%
	Urban	41	38.8%

Demographic characteristics of DS patients (no. 108)

Age	≤ 20 years	65	60.2%
	21-39 years	36	33.3%
	≥ 40 years	7	6.5%
Sex	Male	86	79.6
	Female	22	20.4
Education	Yes	89	82.4%
	No	19	17.6%

In 73.1% of cases, no congenital abnormalities were associated with DS. In comparison, 8% were patients with cardiovascular disease, 6% with epilepsy, 6% with sensory problems (hearing and vision, etc.), while 9% had other abnormalities such as urinary, digestive, muscular, and respiratory (Fig. 2).

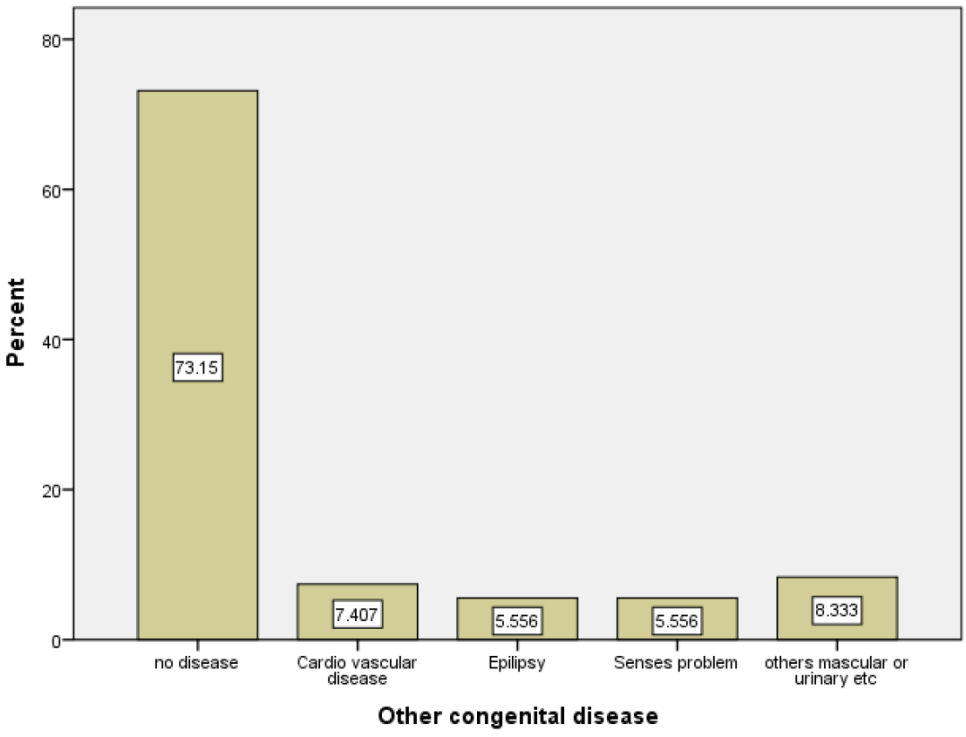

Fig. 2. Fig. 2. Percentage of other congenital diseases associated with DS.

According to the respondents, 82.4% of the sample patients were out of school; there were no special schools or organizations for the DS children in the region where they could send them for education. Only 17.6% of patients went to public or private schools for non-special children (Table 2).

Table 2. Attitude toward DS patients (Mean and standard deviation on a Likert scale)

Attitude toward DS		Mean[a]	(SD)	P-value
Sex	Male	4.06	0.99	0.93[b]
	Female	4.04	0.96	
Age (years)	≤ 25	4.12	0.69	0.88[b]
	≥ 26	4.05	1.01	
Education	Primary & below	4.21	0.8	0.09[c]
	Secondary	3.62	1.24	
	Graduate	4.0	1.22	
Location	Rural	4.01	1.02	0.51[b]
	Urban	4.14	0.98	

a Means based on a five-point scale, higher scores being more favorable.
b Mann–Whitney test.
c Kruskal–Wallis test

This study indicated an overall positive response from the respondents about their DS children. They attributed religious beliefs toward disability and considered the DS children gifts and blessings from God. Religion is one of the most influential value systems[14]. Globally, billions of people are not only receiving a code of life from the religion by which they live their lives, but also it provides them with social identity too[15]. The study indicated that no special school existed for the DS people in the study area. In Pakistan, some special education schools are available, but they are few and are in big cities. Common people cannot generally afford to send their special children to other cities for education. However, they prefer to place the students with DS in special schools to keep them away from violence and to facilitate their learning activities in the special environment. However, past studies in other regions of the world indicated that such children should be placed in schools with other children, i.e., in Rome, Italy, 100% of the DS children were enrolled in the public school system [15]. In contrast, in an American study, only 30% of the respondents supported special schools for DS children [16].

This study indicated that cardiovascular disease is the most common disease associated with DS in this population, followed by epilepsy and sensory problem. Previous studies showed similar results. About 64% of DS people have some congenital anomalies, with the most common being cardiac present in about 44% of individuals, followed by digestive, musculoskeletal, urinary, respiratory, ocular, and that nervous system abnormalities[17].

4. CONCLUSIONS

Despite the positive response toward DS people, the national social system of the province is unable to fully support these people. Awareness programmers for supporting intellectually disabled people, including people with DS should be initiated to develop their basic skills to reduce their dependency on their families.

Furthermore, the issues of the DS people should be publicized to allow better integration in society. Further studies with a larger sample size can give a clearer picture of the results.

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