

A NON-COMPARATIVE DESCRIPTIVE STUDY OF THE RISK FACTORS FOR CHILDHOOD DISABILITY, AND THE REHABILITATION SERVICES IN JEDDAH, SAUDI ARABIA

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أهداف البحث: إبراز عوامل الخطورة الكامنة في مجتمعنا التي يمكن أن تؤدي إلى ولادة طفل معاق و الإلمام بالخدمات التأهيلية المتاحة للأطفال ذوي الاحتياجات الخاصة.

طريقة البحث: تم جمع البيانات من ستة مراكز تأهيل للإعاقات السمعية و البصرية و العقلية في مدينة جدة خلال شهر إبريل (نيسان) 1999، و قد تم نقل البيانات عن المؤشرات الاجتماعية و الديموغرافية و الصحية من الملفات بمراكز التأهيل، بالإضافة إلى المقابلة الشخصية مع الأطفال المعاقين للتعرف على الخدمات المقدمة لهم من قبل المراكز.

نتائج البحث: مازالت بعض عوامل الخطورة التي يمكن تصحيحها و التي تزيد من نسبة فرص ولادة طفل معاق قائمة في مجتمعنا مثل الزواج و الإنجاب في سن مبكرة أو في سن متقدمة للجنسين، كذلك الأمية و البطالة و كثرة الإنجاب و زواج الأقارب. كما تم رصد ارتفاع في نسبة الأطفال المعاقين للأباء بوظائف عسكرية و الأمهات العاملات. كما تم ارتفاع في نسبة الإعاقة لدى الأطفال بنسب عن الحالة الصحية للأم و الطفل أثناء الحمل و الولادة و ما بعد الولادة. كما وجد أن مختلف الخدمات التأهيلية متاحة للأطفال المعاقين بمراكز التأهيل.

الخلاصة: الحاجة إلى تدخل صحي على محورين، الأول هو الوقاية المستقبلية من حالات الإعاقة لدى الأطفال من خلال البحث المستمر لإثبات و تجنب مؤشرات الخطورة الضارة بالصحة و تحسين العناية بالأم و الطفل. و الثاني هو تعضيد الخدمات التأهيلية المتاحة من أجل تحسين الخدمات المقدمة لهم بشكل يعينهم على الحياة بشكل أفضل مع تخفيف معاناتهم.

الكلمات المرجعية: الإعاقة، مؤشرات الخطورة، العناية بالأم و الطفل، السعودية

Objectives: Identify the possible risk factors in our community that may influence having a disabled child, and identify the rehabilitation services available to disabled children.

Methods: Data were collected from six rehabilitation institutes for auditory, visual and mental disabilities in Jeddah City during April 1999. Complete data available on sociodemographic and medical risk factors were extracted from the institutes' files. Personal interviews with the disabled were conducted to confirm information on the services offered to them.

Results: Certain modifiable risk factors affecting child health, such as early and late marriages and childbearing, illiteracy, unemployment, high parity and

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consanguineous marriages still exist in our community. Occupational hazards were also detected among military workers and working women. Disabilities related to perinatal health with antenatal, natal and postnatal components were also observed. According to resources available, various rehabilitation services are offered to disabled children.

Conclusion: *The need for intervention in two areas of health is crucial. The first is the prevention of future disabilities through continuous research, modification of unfavorable habits and the strengthening of the quality of perinatal care. The second is the improvement of rehabilitation services in order to raise the quality of life of the handicapped.*

Key words: *Childhood disability, handicapped, risk factors, consanguineous marriage, perinatal care, Saudi Arabia.*

INTRODUCTION

It has been estimated that over three-quarters of the world's disabled children under 15 years of age live in developing countries¹. The burden of childhood disability as a public health problem and the services offered to this category of patients in developing countries remain relatively unrecognized. There is a major information gap in the Third World concerning the magnitude of the problem and the needs, in terms of prevention, rehabilitation, medical and social requirements, to combat this problem.²⁻⁴

Saudi Arabia has undergone rapid economic development in the last few decades. This is consequently reflected in improved health care services and the decrease in infant mortality.⁵ Overtly disabled children are now more likely to survive in greater numbers and pose a major drain on the health and social services. Many studies on the subject have been done in the Kingdom, each focusing on a single type of child disability. Definitions in these studies have not been uniform, neither have the data been published. A recent national survey in the Kingdom reported the prevalence of major disabilities as approximately 4.0% of the population.⁶ Epidemiologic studies tackling the potential risk factors specific to our

community are still lacking. Overall evaluation of perinatal care and programs directed at disabled children are mostly hospital-based. Nevertheless, there are government and private rehabilitation institutes all over the Kingdom that offer various services to this category of the population.

An analysis of the problem of disability in the Kingdom would give an indication of the situation in the Middle East and emphasize potential risk factors specific to the traditions in the region. Basic data from the specialized rehabilitation institutes are of enormous importance as they constitute data banks suitable for an evaluation of the problem as well as the development of relevant local prevention programs and health interventions directed at improving the quality of life. Consequently, the study was initiated with basic data from rehabilitation institutes for disabled children to give some insight into (a) the potential risk factors and (b) the services available for disabled children.

MATERIAL AND METHODS

Study Population

Data were collected from the major governmental rehabilitation institutes in Jeddah

that specialize in single disability care. There are three specialized governmental institutes for boys and three twin institutes for girls. The Al-Amal Rehabilitation Institute, established in 1970, provides special education for the auditory disabled (deaf-mutes) with an IQ of at least 70. The Al-Noor Rehabilitation Institute, established in 1983, offers special education for visually disabled children with visual acuity not exceeding 6/60 and IQ of at least 70. The Al-Tarbyia Al-Fikrayia Rehabilitation Institute, established in 1975, is for the education of mentally disabled children with minimum IQ of 50.

Data collection

Data were collected during April 1999 on all children in the six governmental rehabilitation institutes in Jeddah. Only the complete files of children present in the institutes during the data collection period were considered. Basic data on socio-demographic status and the potential risk factors were extracted by trained medical students under the direct supervision of medical staff, from the institutes' social, psychological and medical files. Trained medical students interviewed the disabled children to confirm the data collected on services provided.

Data and statistical analysis

Data entry and analysis were done using SPSS for Windows (Version 9.05). Three cohorts were defined: the auditory disabled (deaf-mutes), the visually disabled, and the mentally disabled children. Parity was defined as the mother's parity at childbirth including the index child. Multiparity was defined as having at least 5 children, including the index-disabled child. Spontaneous abortion, fetal death and/or infant mortality were defined as having had at least one experience during the mother's

reproductive life preceding the birth of the index disabled child. All conditions of maternal and disabled child's health considered were those diagnosed by physicians and recorded in the medical files. Chi-square test was used to detect significant differences in the proportions among the three cohorts.

RESULTS

A total of 421 auditory disabled, 178 visually disabled, and 666 mentally disabled children were enrolled in the study. Their ages ranged from 6 to 20 years with mean \pm SD of 13.7 ± 3.1 . Of the total, 53.3% were boys and 46.7% girls. The majority were of Saudi nationality (85.8%) and residents in Jeddah (80.6%). Table 1 shows the sociodemographic characteristics of the disabled children in Jeddah City.

Fathers' current ages ranged from 22 to 70 years (mean \pm SD of 44.9 ± 9.7). Fathers' extreme age marriages (Table 2) were observed, with 16.9% of the fathers below the age of 20 years at the time of marriage, and 9.6% in this age group at the time of birth of their children. At the other extreme, 8.0% of the fathers married at the age of at least 50 years and 9.6% of them had children. Young fathers (<20 years) were more associated with having an auditory disabled child while older fathers (50+ years) were more likely to have a mentally disabled child ($P < 0.001$). Around 27.9% of the fathers had never attended school and the highest proportion were among the parents of auditory disabled children, but results were not of statistical significance.

Unemployed fathers (11.5%) were more likely to have a visually and mentally disabled child. Also, 42.8% of the fathers had a military assignment and were prone to having children belonging to the mentally disabled cohorts.

Table 1: Sociodemographic characteristics of disabled children in governmental rehabilitation institutes of Jeddah

Variables	Auditory (n=421)	Visual (n=178)	Mental (n=666)
	No. (%)	No. (%)	No. (%)
Age:			
< 10	50 (11.9)	36 (20.2)	125 (18.8)
10-14	131 (31.1)	80 (44.9)	352 (52.9)
15+	240 (57.0)	62 (34.8)	189 (28.4)
Sex:			
Boy	113 (26.8)	78 (43.8)	483 (72.5)
Girl	308 (73.2)	100 (56.2)	183 (27.5)
Nationality:			
Saudi	345 (81.9)	148 (83.1)	592 (88.9)
Non-Saudi	76 (18.1)	30 (16.9)	74 (11.1)
Residence:			
Jeddah	306 (72.7)	142 (79.8)	572 (85.9)
Outside	115 (27.3)	36 (20.2)	94 (14.1)
Education:			
Preschool	38 (9.0)	4 (2.2)	109 (16.4)
Primary	206 (48.9)	128 (71.9)	542 (81.4)
Intermediate	95 (22.6)	24 (13.5)	15 (2.3)
Secondary	82 (19.5)	22 (12.4)	0 (0.0)

Table 2: Father's risk factors among mothers of children in Jeddah city by type of disability

Father's risk factors	Auditory (n=421)	Visual (n=178)	Mental (n=666)
	No. (%)	No. (%)	No. (%)
Marital age:*			
<20 years	107 (25.4)	36 (20.2)	71 (10.7)
20-29 years	190 (45.1)	86 (48.3)	237 (35.6)
30-39 years	79 (18.8)	29 (16.3)	188 (28.2)
40-49 years	23 (5.5)	18 (10.1)	100 (15.0)
50+ years	22 (5.2)	9 (5.1)	70 (10.5)
Childbirth age:*			
<20 years	61 (14.5)	24 (13.5)	37 (5.6)
20-29 years	229 (54.4)	92 (51.7)	234 (35.1)
30-39 years	79 (18.8)	30 (16.9)	206 (30.9)
40-49 years	30 (7.1)	22 (12.4)	104 (15.6)
50+ years	22 (5.2)	10 (5.6)	85 (12.8)
Education:			
Never	131 (31.1)	47 (26.4)	175 (26.3)
Primary	87 (20.7)	45 (25.3)	155 (23.3)
Intermediate	58 (13.8)	24 (13.5)	82 (12.3)
Secondary	99 (23.5)	34 (19.1)	155 (23.3)
University and +	46 (10.9)	28 (15.7)	99 (14.9)
Occupation: †			
Unemployed	28 (6.7)	24 (13.5)	94 (14.1)
Skilled laborer	43 (10.2)	19 (10.7)	54 (8.1)
Private	64 (15.2)	34 (19.1)	107 (16.1)
Government	91 (21.6)	37 (20.8)	129 (19.4)
Military	195 (46.3)	64 (36.0)	282 (42.3)

* p<0.001, † p<0.05

Table 3: Mother's risk factors among disabled children in governmental rehabilitation institutes in Jeddah

Maternal risk factors	Auditory (n=421)	Visual (n=178)	Mental (n=666)
	No. (%)	No. (%)	No. (%)
Marital age:*			
<16 years	65 (15.4)	20 (11.2)	51 (7.7)
16-19 years	126 (29.9)	62 (34.8)	167 (25.1)
20-29 years	188 (44.7)	72 (40.4)	317 (47.6)
30-39 years	33 (7.8)	18 (10.1)	116 (17.4)
40+ years	9 (2.1)	6 (3.4)	15 (2.3)
Childbirth age*			
<16 years	24 (5.7)	6 (3.4)	8 (1.2)
16-19 years	88 (20.9)	36 (20.2)	88 (13.2)
20-29 years	217 (51.5)	90 (50.6)	352 (52.9)
30-39 years	75 (17.8)	36 (20.2)	161 (24.2)
40+ years	17 (4.0)	10 (5.6)	57 (8.6)
Education*			
Never	268 (63.7)	80 (44.9)	327 (49.1)
Primary	68 (16.2)	33 (18.5)	129 (19.4)
Intermediate	48 (11.4)	31 (17.4)	102 (15.3)
Secondary	26 (6.2)	19 (10.7)	65 (9.8)
University and +	11 (2.6)	15 (8.4)	43 (6.5)
Working status*			
Housewife	416 (98.8)	159 (89.3)	638 (95.8)
Working	5 (1.2)	19 (10.7)	28 (4.2)
Parity			
Primi	95 (22.6)	41 (23.0)	136 (20.4)
Para 1	78 (18.5)	38 (21.3)	127 (19.1)
Para 2	63 (15.0)	25 (14.0)	109 (16.4)
Para 3	65 (15.4)	16 (9.0)	83 (12.5)
Para 4+	120 (28.5)	58 (32.6)	211 (31.7)
Consanguinity*			
No	179 (40.4)	98 (55.1)	348 (52.3)
First degree	199 (47.3)	62 (34.8)	230 (34.5)
Others	52 (12.4)	18 (10.1)	88 (13.2)

*p<0.001

The current mother's age ranged from 21 to 60 years (mean \pm SD: 39.4 \pm 8.1 years). As shown in Table 3, mothers who married before their 16th birthday accounted for 10.8% and those who gave birth before that age accounted for 3.0%. At the other extreme, mothers who married at 40 years or over accounted for 2.4% while those in this age group who gave birth accounted for 6.6%. Young maternal marital and childbearing ages were mainly observed among auditory disabled children while late marriages and childbearing were mainly

associated with visual and mental disability (p < 0.001). Approximately, 53.4% of the mothers had never attended school and 95.9% did not work. Maternal illiteracy and unemployment were more marked among the auditory and mentally disabled cohorts (p<0.001). Multiparity at childbirth accounted for 30.8% and was marked among the visually and mentally disabled, but the results did not reach statistical significance. Consanguineous marriages were reported in approximately 51.3% of the cases, 75.7% of these were among first degree relatives.

Table 4: Mother's past history and perinatal risk factors among disabled children attending governmental rehabilitation institutes in Jeddah

Maternal risk factors	Auditory (n=421)	Visual (n=178)	Mental (n=666)
	No. (%)	No. (%)	No. (%)
Mother's past history			
Spontaneous abortion*	24 (5.7)	3 (1.7)	14 (2.1)
Fetal death &/or infant mortality	9 (2.1)	5 (2.8)	7 (1.1)
Previous disabled child†	102 (24.2)	51 (28.7)	104 (15.6)
Perinatal risk factors			
German measles	28 (6.7)	4 (2.2)	2 (0.3)
Threatened abortion†	7 (1.7)	15 (8.4)	13 (2.0)
Pre-eclampsia†	5 (1.2)	16 (9.0)	10 (1.5)
Natal & Postnatal risk factors			
Caesarian/assisted labor†	15 (3.6)	7 (3.9)	48 (7.2)
Prematurity (<28 weeks) †	13 (3.1)	18 (10.1)	25 (3.8)
Very low birthweight (<1500 gm)	7 (1.7)	11 (6.2)	121 (18.2)
Jaundice†	17 (4.0)	4 (2.2)	62 (9.3)
Oxygen therapy‡	10 (2.4)	8 (4.5)	48 (7.2)
Admission to Neonatal Intensive Care Unit†	14 (3.3)	8 (4.5)	92 (13.8)

*p<0.05 †p<0.001 ‡p<0.01

Table 5: Rehabilitation services offered to disabled children attending governmental rehabilitation institutes in Jeddah

Services*	Auditory (n=421)	Visual (n=178)	Mental (n=666)
	No. (%)	No. (%)	No. (%)
Social services			
Grants	276 (65.6)	119 (66.9)	166 (24.9)
Meals	180 (42.8)	64 (36.0)	154 (23.1)
Boarding	145 (34.4)	64 (36.0)	94 (14.1)
Social support	227 (53.9)	39 (31.9)	120 (18.0)
Psychological	248 (58.4)	100 (56.2)	178 (26.7)
Medical services			
Physiotherapy	193 (45.8)	37 (20.8)	102 (15.3)
Medical	90 (21.4)	51 (28.7)	107 (16.1)
Dental care	288 (68.4)	100 (56.2)	140 (21.0)
Vaccination	268 (67.9)	106 (59.6)	190 (28.5)
Educational services			
Physical exercise	230 (54.6)	102 (57.3)	184 (27.6)
Manual work	139 (33.0)	68 (38.2)	103 (15.5)
Drawing	313 (74.3)	119 (66.9)	195 (29.3)
Cooking	209 (49.6)	70 (39.3)	59 (8.9)
Knitting	295 (70.1)	60 (37.3)	67 (10.1)

*p<0.001

Consanguinity occurred more among the parents of the auditory disabled children (p<0.001).

As shown in Table 4, past history of spontaneous abortion was mainly reported in the mothers of the auditory disabled (p<0.05), while fetal deaths and/or infant

mortality were mainly seen among mothers of the visually disabled cohorts, but results did not reach statistical significance. Conditions that affected the mother during pregnancy, such as German measles, were reported for the auditory disabled, but the results were not significant. Threatened abortions and pre-eclampsia were reported mainly for the mothers of the visually disabled cohort ($p < 0.001$). Severe prematurity (less than 28 weeks gestation) was observed more among the visually disabled children ($p < 0.001$). There were more caesarian section deliveries, very low birthweight (less than 1500g), jaundice, oxygen therapy at birth and admission to neonatal intensive care units among the mentally disabled cohort ($p < 0.01$).

Six institutes offer education to disabled children up to the secondary level, using specially adapted syllabi. In every institute, in addition to the teaching staff there are a social worker, psychologist and a medical doctor. In varying proportions social, psychological, medical, and other educational services are offered to these children (Table 5). The institutes which were best were those which cared for the auditory and the visual disabilities while those rated lowest were those institutes that cared for the mentally handicapped. In spite of the public information efforts of the rehabilitation institutes, most of the families of disabled children knew of these institutes only from their friends or neighbors; 99.2% of the auditory disabled, 73.2% of the visually disabled, and 92.3% of the mentally disabled children were taken to the institutes by their families, on their own. Those referred from primary health care units, school health and the private sectors were few and did not exceed 3.0%. Similarly, except for the visually disabled, who formed about 25.0% of those admitted to the institutes, those referred from the government hospitals were very few.

DISCUSSION

Childhood disability is a public health concern since it affects the health and economic status of nations. The disabled child is a result of multiple factors. Most of these factors are modifiable by controlling the risk factors known to influence infant health and rectifying the quality of health services provided in our society.

The results of our study open multiple areas for research and discussion. They also aid in formulating hypotheses on determinants of childhood disability that could be restricted to the Middle East, illustrated by the conditions in the Kingdom.

This study has emphasized certain risk factors that still exist in our society. They include extreme age (early and late) of marriage and childbearing for both genders, as well as multiparity, illiteracy, unemployment and consanguineous marriages. Our results have shown that early marriage and childbearing, in both genders, have increased the risk of having an auditory disabled child. Arab countries as a whole are known to have a high rate of early marriages, a practice related to tradition and beliefs.⁷⁻⁹

It is true that early marriage and childbearing save the population from many health hazards but there should be a lower age limit for marriage and consequently childbearing, taking into account the biological maturity of both sexes. On the other hand, late childbearing maternal multiparity was also observed for both parents. In marriages that take place when the couples are old, child bearing in both genders tended to predispose to a mentally disabled child. Maternal multiparity predisposed to visually and mentally disability. Also, high parity, and thus pregnancies in old age, is typical for the Middle East region as documented in several studies.^{7,9,10-12} Studies on the distribution of paternal age and its relation to child health are still lacking.

Illiteracy and unemployment were very high among the parents, especially the mothers. Illiterate jobless mothers were at higher risk of having an auditory and mentally disabled child. Illiterate fathers were more prone to have an auditory disabled child, while jobless fathers were more likely to have a mentally and visually disabled child. Illiteracy and unemployment are other factors previously reported in the region.^{8,9}

A healthy occupational environment is a second factor to be considered. Fathers engaged in military jobs were at a higher risk of having auditory and mentally disabled children. This occupation should be investigated as a possible risk factor that may influence the health of offspring. Previous investigations have shown that even after adjustment for the economic condition, an infant whose mother is illiterate is more likely to die during the postneonatal period than one whose mother is literate.^{13,14}

Female education is a major advantage to future health. Education improves women's awareness, which is reflected in the quality of her life. The higher the level of the woman's education, the healthier she will be because she will have healthier active life style, nutritional habits, economic conditions and personal hygiene. Female education motivates women to continue their careers, discourages early marriage, and provides better marriage prospects, and in the event of consanguineous marriage, it also makes them aware of the importance of premarriage counseling and availability of health care services. Moreover, education strengthens mother's awareness of the quality of life of her offspring when she follows appropriate feeding practices, and childcare, early detection and better management of life threatening conditions. In short, female education makes mothers more efficient in raising their children.^{13,16}

The father's education and work affect the family's well-being through a similar mechanism. However, research on paternal risk factors is still insufficient.

Consanguineous marriage is the dominant marriage pattern in many Third World countries, particularly in the Arab World.^{7,9,10,17-20} Consanguinity is widespread in the Kingdom and is related to the culture. It was found in our data to be strikingly high, especially among first-degree relatives. This was more marked among parents of the auditory disabled.

Perinatal health is vital for child health and responsible for the pathogenesis of many health conditions.²¹⁻²³ Perinatal care is the best means for improving maternal and child health. Unfortunately, few maternal and child health conditions during the perinatal period were available for analysis. Maternal factors included threatened abortion and pre-eclampsia and were observed more among mothers of the visually disabled cohorts. Severe preterm (before 28 weeks gestation) and very low birth weight (<1500g) births are other indicators for antenatal care. Prematurity was mainly observed among the visually disabled cohort, while the very low birthweights were more among the mentally disabled. Caesarian section deliveries were reported mainly in the mentally disabled children. Such postnatal conditions as jaundice, oxygen therapy and admission into a neonatal intensive care unit at birth were more prevalent among mentally disabled children.

A wide variety of services, including special education, social, psychological, medical and rehabilitation services are offered to the disabled children. These services are available for both genders, Saudis as well as non-Saudis, and residents of Jeddah City and surrounding areas. The service that ranked the lowest were the institutes that cared for mentally disabled children. This could be explained by the fact

that these children are usually less capable than the other disabled, and were limited in what they would do and consequently overburdened the services offered to them. Nevertheless, participation of all professionals in the field is crucial in order to support the effort of the rehabilitation centers.

We conclude that much effort is required to reduce the incidence of future disability. This could be achieved through reducing the potential risk factors in our community and improving the quality of perinatal care and rehabilitation services in order to raise the quality of life for those infants who survive.

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