Population-based survey of childhood disability in Eastern Jeddah using the ten questions tool

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Abstract

Purpose: To identify the prevalence of handicapping disabilities among children up to 15 years of age and their epidemiological pattern in the eastern part of Jeddah.

Methods: In a population-based cross-sectional household survey in the eastern Jeddah area, Saudi Arabia, a multistage sampling method was applied to screen children in 875 houses using the ten questions survey tool for identification of disabilities. Further information collected for detected disabilities included possible risk factors, cause of the disability as perceived by the family and services previously provided to the child.

Results: A total of 137 cases of disability were detected giving a point prevalence rate of 36.7 per 1000 children. Twenty-nine children (21.2%) were discovered for the first time during the survey. The majority of cases were male (57.7%) and the mean age for all cases was 10 years (SD = 5.5) with no case detected under one year of age. Disabled children were in the fourth or fifth birth order among their brothers and sisters and 47 (34%) of them were recorded as a second or third disability in the same family. Number of disabilities in the same child varied widely: 59% of cases had a single disability, 22% had two conditions and 19% had three or more conditions. Speech, motor and mental disabilities ranked top of the disabilities detected by the ten-question tool. The commonest cause of these disabilities as perceived by the family was hereditary diseases followed by childhood illnesses. Significant risk factors associated to these conditions included larger number of children in the family, older age of either parent, histories of handicapping conditions in the original families of either of the parents and presence of handicapping condition in the mothers. Families reported lack of services provided to their disabled children in the community.

Conclusions: The survey tool managed to document, successfully, a prevalence rate of childhood disabilities in the community with a general picture of their types and suspected causes which is quite comparable to that found in Saudi Arabia. It also reported a low service delivery for these disabilities and identified some risk factors related to their occurrence. It is recommended to apply this survey method with certain modifications to suit the local culture in Saudi Arabia. Improvement of the services rendered to handicapped children in Jeddah is also recommended.

Introduction

Handicapping disabilities in both developing and developed countries are important public health issues. Basic data on their frequencies, underlying risk factors and associations are necessary in order to plan health programs and to provide social services for them. Screening in community surveys is a good strategy for providing a quick insight for this problem among children. Many community surveys have been conducted for handicapped children in various parts of the world.[1–3] The ten-questions survey tool was proposed for this purpose and has been validated for its sensitivity and specificity in many developing countries.[4] This paper is reporting a field survey in Jeddah, Saudi Arabia in which a population-based study has applied the ten-questions tool to estimate the prevalence of handicapping disabilities among children up to 15 years of age and describe the epidemiological pattern of disabilities in the eastern part of the city. The study was part of the training field survey for male medical students in the Medical College.

Methodology

THE AREA AND POPULATION

Jeddah, the second largest city in Saudi Arabia, is divided geographically into four sections. The eastern part of Jeddah is composed of nine large crowded

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communities with a population that exceeds 100 000 inhabitants of whom 40–45% are in the age group 15 years and below. Three large governmental primary health care centres and a number of private ones serve this community. The socio-economical status of the population is low to moderate.

The ten questions survey instrument with their probes[5] was translated into Arabic and reviewed for common language use. The instrument was pilot tested on a group of households from another area of Jeddah and results of the test were used to modify the wording of questions in order to maximize their easy understandability and clear explanation of disabling conditions in the Arabic culture. Another questionnaire was prepared to collect detailed information about children with detected disabilities concerning the ages of children, types of the disabilities, risk factors, underlying cause as perceived by the family and any previous services delivered to the disabled child.

SURVEY DESIGN AND SAMPLING

In a multistage sampling frame, a cross sectional survey was conducted over a two week period in April 1999 to include a representative sample of households in the eastern Jeddah area. Using the estimated national figure of disabilities of 37.1/1000,[6] the sample size estimated for this prevalence study was calculated by the Epi-Info programme to reach 3500 children. With an expected number of 4 children per house in the age group in this crowded area, a total of 875 houses were needed to reach the sample size. The number of houses from each of the catchment areas of the three health centres was determined using the proportional allocation method according to the population density of each area. Selection of houses in each catchment area was done using the cluster sampling approach. The standard WHO clusters survey technique was followed.[7] In the absence of area maps, the systemic sampling approach was considered to be the most appropriate considering the housing pattern of the area. The interval of seven was the reasonable dividing figure judging from the gross estimation of number of houses in the districts. The search team used to start from the central mosque located in the centre of the district and randomly choose the first house to visit in the district from houses which are most adjacent to the mosque, using 1–7 number tossing. This is followed by systematic visits to every seventh house in each direction until they completed the required number of houses from the designated district.

Interviews at the selected houses were conducted primarily by gathering the basic socio-demographic information of the family from the head of the household, usually the father. Variables included in this part were family income, number of family members, age of the child, ages of parents, occupation of parents, education level of parents, history of disabilities in either families of the parents and consanguinity between parents. The ten questions tool with their probes was explained to the head of the household to detect any disabled member of the family in the age 15 or below. Houses with no children at the required age were skipped and replaced by the next one fulfilling the research criteria. The detailed questionnaire was filled for any child with a positive answer on one or more of the disability questions. As a service outcome from the survey, disabled children newly detected by the surveying team were referred to the pediatric consultant in the university hospital for detailed physical examination, preliminary assessment of the disability and further advice. Statistical analysis using the X^2 and student t-test was applied to compare various risk factors among families with and without disabled children. Significance level was determined at the 0.05 level.

Results

A total of 7397 Saudis were surveyed in 926 houses visited by the survey team in the three catchment areas of the health care centres. The number of people in these houses ranged between 3 and 22 with a mean of 8 persons per house. Mean age for the parents was 43.8 years for fathers and 34.9 for mothers. Family income in these houses was on the lower level in this part of Jeddah with 54.3% in the low income group (< 5000 SR) and 31.2% in the middle income group ($5000 < 1000$ SR). Table 1 details the demographic and socio-economic characteristics of the population.

Table 1 Demographic characteristics of families in eastern Jeddah area (N = 926)

Characteristic	Percentage	Number
Work of the father:		
Governmental employee	38.2%	354
Military work	24.8%	230
Self or private sector employed	14.7%	136
Working mothers	7.9%	73
Illiterate and low education mothers	68.9%	636
Illiterate and low education fathers	46.5%	429
Marriage with more than one wife	14.8%	136
First grade consanguinity of parents	44.4%	411
Second grade consanguinity	28.1%	260

Table 2 Age frequencies of all children and the disabled group

Age	Disabled group		All children		Rate per 1000	95% C.I.
	No	%	No	%		
< 1 year	0	–	164	4.4	0	0
1–< 2	4	2.9	321	8.6	12.5	0.3–24.7
2–< 6	33	24.1	914	24.5	36.1	24.0–48.2
6–< 12	58	42.3	1550	41.5	37.4	28.0–46.8
12–15	42	30.7	784	21.0	53.6	37.8–69.4
Total	137		3734		36.7	30.7–42.7

Table 3 Frequency of various types of disabling conditions in eastern Jeddah area

Condition	Previously diagnosed	Newly identified
Speech	46	7
Motor	45	4
Mental	32	4
Fits	26	6
Learning difficulty	23	3
Hearing	22	5
Vision	13	4
Emotional problem	11	2
Chronic or hereditary	10	–

NB: Conditions have not been totaled due to multiple disabilities in some cases.

Table 4 Causes of disabilities as perceived by parents

Suspected cause of disability	No	%
Hereditary causes	69	50.4
Non hereditary illnesses	20	14.6
Accidental/traumatic causes	5	3.6
Other causes	5	3.6
Unknown cause	38	27.8

Children up to 15 years of age in these families formed 50.5% of the population (3734) with males forming 54% of them. The mean number of children was 4 per household. Using the ten questions survey tool, the survey team detected 137 disability cases in the specified age group, with a point prevalence rate of 36.7 per 1000 children. Of these cases, 29 children (21.2%) had been undetected before the survey. The mean age for all disabled children was 10 years (SD = 5.5); 57.7% were males. Table 2 describes the age pattern for all children and the disabled.

Disabled children, on average, were in the fourth or fifth birth order among their brothers and sisters and 47 of them were counted as the second or third disability in the same family. The number of disabling conditions in the same child varied widely: 59% of cases had a single disability, 22% had two conditions and 19% had three or more conditions. These conditions were categorized according to the answers on the ten questions (table 3). Definite causes of the disabilities were difficult to determine from the families because there were no medical records at home and failure of accurate recall. Hence, only general descriptive terms were used in describing possible causes for these disabilities as perceived by the family. Nearly, one third (27.8%) of fathers did not know the cause of their child's disability.

Over 50% of them believed it might be due to hereditary causes (table 4). Fathers reported a low rate of services provided to these children in the community as only 36 (33.3%) of all previously diagnosed handicapped children were exposed to a rehabilitating health service for their conditions.

Possible risk factors associated to disabilities were compared among families with and with out disabled children. Table 5 describes mean and proportion difference of these risk factors among both groups of families with their significance levels.

Discussion

Disabled children in developing countries are estimated to form 85% of the world's disabled children.[8] Accurate determination of the prevalence is hindered by a group of inherent problems in these countries including under reporting, late identification, poor registration and lack of infrastructure for their monitoring and service provision. To overcome these shortcomings, a variety of methods were tried in order to identify disabilities at the community level. These include the addition of questions to the national census and the interviewing of key informants in the community such as community leaders and teachers. The previous methods were found to produce serious faults of under-enumeration of handicapping conditions and under representation of children and women.[9–11] Researchers in developing countries have proposed the use of the ten question tool in a house survey to overcome these drawbacks. The questionnaire was validated in Bangladesh and Jamaica as a low cost

Table 5 Percentage (means) of risk factors among families with and without disabled children with their statistics and P values

Risk factor	Among disabled	Among non disabled	Statistic	P-value
Mean number of children in family	4.6	3.9	t = 2.78	0.05
Mean mother age	36.6	34.6	t = 2.39	0.017
Mean father age	45.9	43.5	t = 2.24	0.026
Handicap in mother's family	24.0%	10.6%	$X^2 = 10.6$	0.00001
Handicap in father's family	28.0%	14.7%	$X^2 = 20.6$	0.0003
Handicapping condition in mother	10.4%	2.6%	$X^2 = 4.6$	0.0001
Handicapping condition in father	18.5%	13.0%	$X^2 = 1.1$	0.29
Parents are relatives at any level	80.0%	71.4%	$X^2 = 3.6$	0.057
Low education of father	54.4	45.2	$X^2 = 3.3$	0.07
Low education of mother	80.8	67.0	$X^2 = 9.0$	0.003
Low family income	41.7	42.7	$X^2 = 0.008$	0.92

method with good yield for screening children with disabilities in community surveys.[12] It is composed of a set of interview questions to be administered by the health worker to one of the parents or any adult in the family who is familiar with the screened child. The questions are related to a variety of childhood disabilities including speech, visual, motor, fits, hearing, learning and emotional disabilities. They are designed to detect minor alterations from accepted normality as judged by the family. The questionnaire was also judged to be a powerful tool with perfect sensitivity for serious disabilities but with high rates of false positive cases.[13]

Application of this method in Jeddah has revealed many points worthy of discussion. Using this simple method of screening in a cross sectional survey, the tool has managed successfully and easily to reveal an estimation of the point prevalence rate for the disabilities on the community level which is quite comparable to the national rate of 37.3 per 1000 documented in the national study in Saudi Arabia.[6] The tool has also shown strength in detecting 29 cases of suspected disabilities which had not been detected before. This finding can be related to the questions content of the tool and its simplicity but it also indicates a low level of suspicion among these families of abnormality in their children early in life and points to under-diagnosis of disabled children in the community by the health services.

The suitability of the ten questions survey method in the Arabic culture, on the other hand, was indirectly tested in this survey. Due to the conservative nature of the society in Saudi Arabia, male interviewers were not

expected to question mothers in their homes. Hence, fathers or other adult males in the family were the only source of information on these children and their risk factors. This would be expected to reduce the validity of the answers related to the risk factors associated with the pregnancy and delivery of the child and information on the family history and personal history of the mother. This shortcoming could have been avoided if a female nurse or health worker was included in the search team. This was not feasible in this training survey.

This survey did not collect detailed information on the severity of the disabilities or the service needs, as it was not associated with physical examination or needs assessment of the detected case. We did not intend to provide a full profile of the severity of disabled cases or their rehabilitation needs in this screening process, but only to provide a prevalence estimate of these disabilities and a summary of their types.

In these disabilities, no case was detected in the first year of life and only 4 cases were detected in the 1–2 year's age group. This might be an indicator of low survival of disability cases in the young age group, but also can point to the late observation of the abnormalities in children by their families. Most of previously diagnosed cases had speech, motor and mental disabilities and this is in accordance with findings in another survey in Qassim area in Saudi Arabia.[14] These cases are easily recognized and detected by their families. Parents reported low service provision for their handicapped children as only one third of disabled children received it. Deficiency of rehabilitation programs is a shared prob-

lem among developing countries and Saudi Arabia is no exception.[6] This indicates the need for further research on availability of services for handicapped children and the area in which they need expansion.

In accordance with other studies in Saudi Arabia,[15, 16] consanguineous marriages were found to be highly prevalent in this part of the city. Although, consanguineous marriages were found to have only borderline significance with the presence of disability in the family in this study (P = 0.057), this does not undermine the well-established association of close relative marriages to many hereditary diseases. Disabilities in the child, on the other hand, were found to be significantly associated with history of handicapping conditions in parents' families. Moreover, half the families in this survey perceived that their children's disabilities were of hereditary origin. Hence, these findings may be quite constructive in discussing handicapping conditions in the Arabic culture. Peoples perception of the cause of disabilities and the known effect of close relative marriages can be used in health education campaigns in Saudi Arabia to describe the importance of premarital counselling and to promote premarital examinations in consanguineous marriages.

In conclusion, the survey managed successfully to document a comparable estimate of the prevalence rate for childhood disabilities in the community and provided a general picture of their types and suspected causes. It also reported a low service delivery for these disabilities and identified some risk factors related to their occurrence. Recommendation to apply this survey method in Saudi Arabia is justified in an extended field study with certain modifications to suit the local culture. This study also should be complemented with a second stage referral for follow up examination of detected cases of disabilities and evaluation of the disability and its required services.

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