

Knowledge of genetic counselling.

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ABSTRACT:

The study was conducted to find out the knowledge of genetic counselling among significant others of mentally retarded children. Thirty significant others from selected mentally retarded home were part of the study. The findings suggested that the awareness should be increased in caring for the mentally retarded children significant others by reaching out to the community and focussing on topics such as genetic counselling, and also on the preventive measure aspects.

KEY WORDS: significant others, genetic counselling

INTRODUCTION

A mentally retarded child in a family is usually a serious stress factor for the parents. It often requires a reorientation and re-evaluation of family goals, responsibilities and relationships. In India, the majority of persons with mental retardation have traditionally been cared for by their families. The parents of mentally challenged requires lifelong adjustment. Hence the parents need guidance and counselling which is an important aspect of management. By doing so the parents will understand and accept the child's problem and make necessary plans. The parents should be taught to tackle and adjust with the child's actual problems. They should accept the child as he is and at the same time avoid feeling of guilt, depression.

NEED OF THE STUDY:

At least 2% of India's population is said to be suffering from some kind of mental disability. Overall rates of mental disability in India & other middle and low income countries range from 6% to 15%. Genetic counselling can be helpful intervention for many life issues like adjustment or acceptance of given disability, management in terms of training, adaptive or vocational guidance and can help in finding employment and living independently. The counsellor can provide emotional support and understanding during what can be a very difficult times, If there are decisions to be made about the pregnancy, care of a child, having more children, or about the family to cope with on-going problems, the parents can make informed choices with the facts in hand. Luckily the prevention of genetic disorder has got a big boost as

genetic testing has become more advanced and we recognize that the knowledge regarding the human genetics and prevention of genetic disorders through genetic counselling is very important. As significant others are always with close contact of mentally retarded child it is important that they are aware of genetic counselling for better care of them.

STATEMENT OF THE PROBLEM:

A study to assess the knowledge regarding genetic counselling among significant others of mentally retarded children in selected areas of Mumbai

SPECIFIC OBJECTIVES:

1. To assess the level of knowledge regarding genetic counselling among significant others of mentally retarded children.
2. To associate the level of knowledge regarding genetic counselling among significant others of mentally retarded children with their selected demographic variables.

METHODOLOGY:

RESEARCH APPROACH

Quantitative Descriptive approach

RESEARCH DESIGN

Descriptive

SETTING

The study was conducted in selected areas in Mumbai.

POPULATION:

Significant others of mentally retarded children

SAMPLE

Significant others of mentally retarded children in selected areas of Mumbai

SAMPLE SIZE

30 significant others of mentally retarded children

SAMPLING TECHNIQUE

Non Probability Purposive sampling was used to obtain participants in the study.

TOOLS

Structured interview schedule

TECHNIQUE

Interviewing

INCLUSION CRITERIA

1. Significant others who stay with the mentally retarded child for more than 12 hours
2. Significant others who are willing to participate in study.

FINDINGS RELATED TO DEMOGRAPHIC VARIABLES OF SIGNIFICANT OTHERS:

In all 30 significant others of mentally retarded children were included in this study. Among the samples 78% belonged to the age group of 20 to 40 years significant others were homemakers, 73% had undergone primary education.

FINDINGS RELATED TO DEMOGRAPHIC VARIABLES OF MENTALLY RETARDED CHILDREN:

In all 54% of the mentally retarded children's parents had consanguineous marriage, 71% of the mentally retarded children had one brother or sister. Regarding siblings of mentally retarded children 93% had normal physical and mental health.

FINDINGS RELATED TO KNOWLEDGE ABOUT GENETIC COUNSELLING IN SIGNIFICANT OTHERS:

Almost 57% of the significant others of mentally retarded children had awareness about genetic counselling. Majority of the samples i.e. 81% had heard about it from their physician, 47% of significant others opinion regarding mental retardation was that it is curable, 64% had felt difficulty in taking care of this children.

FINDINGS RELATED TO OVERALL KNOWLEDGE SCORES ABOUT GENETIC COUNSELLING IN SIGNIFICANT OTHERS:

Overall distribution of knowledge scores of significant others of mentally retarded children showed that 53% scored between 0 - 6 which revealed that they had inadequate knowledge on genetic counselling. In all 37% scored between 7 -13 which showed that they had moderately adequate knowledge and 10% scored between 14 - 12 which revealed that they had adequate knowledge on genetic counselling.

FINDINGS RELATED TO ASSOCIATION BETWEEN LEVEL OF KNOWLEDGE AND SELECTED DEMOGRAPHIC VARIABLES OF SIGNIFICANT OTHERS:

There was no association between the level of knowledge and their significant demographic variables i.e. age, sex, education at $P < 0.05$ level.

CONCLUSION:

Health care is always changing so it is important that regular screening can be arranged by community nurse to detect mentally retarded children and prevent further complications. Health educations can be given in school, community regarding genetic counselling. Further research should be conducted focussing on impact of stigma among significant others and various interventions required to handle mentally retarded children

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