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PARENTS' ATTITUDE TOWARDS THEIR CHILDREN SUFFERING FROM BETA THALASSEMIA MAJOR

Paediatrics

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ABSTRACT

Thalassemia is a chronic condition caused due to genetic abnormality which affects a child's normal physiological functioning. Thalassemia challenges every individual as well as their family members at physical, emotional, cognitive level and disrupts their quality of life. Hence the study "Parents' attitude towards their children suffering from beta thalassemia major" was undertaken at Thalassemia and sickle cell center Nagpur. A total of 50 study subjects were selected randomly. Parents having children with Thalassemia had severe financial stress (74% including medium and high issues). The problem oriented with Government benefits was 94% (high and medium issues) of the parents. The financial burdens on the family members cause major stress in the parents. The irregular availability of chelator's scared parents as it is life threatening for their child. Lack of knowledge about the disorder was significant in low socio economical families.

KEYWORDS

Parents attitude questionnaire, counselling, management

INTRODUCTION:

Thalassemia is an inherited blood disorder caused when the body doesn't make enough of a protein chain present in hemoglobin, an important part of red blood cells. When there isn't enough hemoglobin, the body's red blood cells don't function properly and they last shorter periods of time, so there are fewer healthy red blood cells traveling in the bloodstream.

Thalassemia is a disease which needs lifelong therapy. Thalassemia therapy includes regular blood transfusion, administration of several medications such as iron chelating agents and other medications. There is no definitive cure for this disease, the majority exclusively depends on blood transfusions as a treatment option that creates a burden not only on health system but also on the affected families, who are vulnerable to, social, and psychological problems. Although optional medical management has reduced the difficulties faced by Thalassemic children and their families, still the psychosocial impact on the development of the sick children and family is a continuous process throughout life. Children with Thalassemia have to regularly attend hospital for blood transfusion and chelation therapy. Parents suffer from psychosocial burden because of expenses, stress and fear of death.1 The cost of therapy in these patients as well as any other disease does not only cover medication cost. These extra costs include the cost of medical consultation, laboratory tests, diagnostic tests, cost of preventative or treatments of side effects of therapies and many other indirect costs. The disease and its consequences force the parents to generate and spend more money to meet the cost of treatment, adversely affecting the economic condition of the family. Families with low income are unable to sustain the monthly expenditure, and resort to loans.

It's possible that uneducated, poor and socially maladjusted parents are more affected in comparison to those who are educated, economically sound and socially well adjusted. The psychosocial burden can affect the quality of life of the families.

The various reasons of depression in parents identified are lack of awareness, limited resources, financial burden, regular availability of blood and chelators, lack of access to available facilities and anxiety about health of their child.

THE AIMS OF THE RESEARCH WERE:

- To demonstrate more explicitly the psychological burden that many families with beta thalassemia experience;
- To support, as far as possible, some of the families;
- To bring into the attention the lack of government services with leads to worsening of the child's condition.

HYPOTHESIS:

Parents feel sad and worried about the neglect of health and social issues and agitated about the less government involvement for such type of children.

MATERIALS AND METHODS

The total sample of this study will be 50 children whom were selected randomly via simple sampling procedure from clientele children who were identified and diagnosed in NKPSIMS and Lata Mangeshkar Hospital Nagpur. The research conducted during April 2018 to June 2018 (3 Months)

2. SUBJECTS AND METHODS

Cross sectional study design was utilized

INCLUSION CRITERIA - children with beta Thalassemia major, children's age ranged from 2-5 years, and from both genders.

EXCLUSION CRITERIA- children with alpha thalassemia and eta thalassemia minor and those who were not willing.

STATISTICAL TECHNIQUES USED:

The obtained data will be statistically analyzed by applying descriptive Average, percentile. We will enter all data and further Statistical Analysis will be done with the help of IBM- SPSS-25 software.

RESULT:

Table No. 1 - Caregivers Attitude Towards Their Children Suffering From Thalassemia Prevalence By High, Medium And Low Issues

AREAS	HIGH ISSUES	MEDIUM ISSUES	LOW ISSUES
General Information	4%	70%	26%
Facilitation Interaction	0%	10%	90%

Child Management	0%	20%	80%
Services	0%	44%	56%
Vocational Planning	2%	12%	86%
Personal Emotion	0%	78%	22%
Personal Social	6%	22%	72%
Personal Financial	28%	46%	26%
Family Relationship	0%	6%	94%
Marriage	10%	36%	54%
Government Benefits	58%	36%	6%

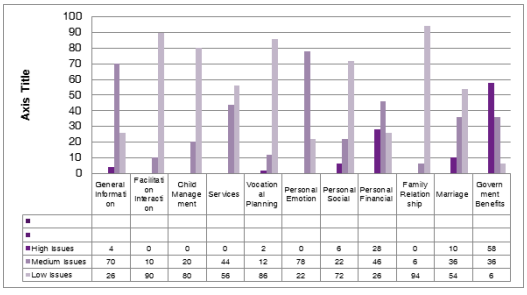
Around 4% of the parents were high issues or burden was found to be more about general information about child health (70%) are getting medium issues and (26%) are getting low issue about child health general information. High issues showed that they are not getting general information about their child health. In case of children with chronic disease, parents are considered as the primary caregivers and thus will face with many challenges to comply with multiple and complex problems and tasks resulted from the child's disease .[2]

Around 90% of the parents were low issues or burden about facilitation interaction between doctors and nurses, and 10% showed medium issues. About Child Management 80% parents showed low issues and 20% getting medium issues about child management and work. 56% parents reported low issues about services, multi- media are helping parents for searching services for their child ,44% showed medium issues for searching for services for their child. So, it is important that parents how deal with the critical situation which is occurred for their child as it shows their acceptance from their child condition and indicates how much ability they have to control and manage the situation of their sick child.[3]

About vocational planning and training 86% parents showed low issues and 12% parents showed medium issues but 2 % parents showed high issues about their child vocational and educational training. Personal emotion 22%parents reported low issues and 78% showed medium issues, 6% parents showed high issues in personal social skills , how child can adjust in social ,72% parents showed low issues ,and 22% parents showed medium issues about child personal social skills.

In this present study 28% parents showed high issues for financial issues, Thalassaemia is a chronic disorder requiring lifelong transfusions and medications causing emotional and financial burden to the family. 46% showed medium issues, 26% parents showed low issues. Parents suffer from weakness and disability of their ill child. They feel worried, frustrated, despaired and helpless. 2 Also they have numerous physical, psychosocial and financial sufferings. [4,5]Which are relatively connected to the chronic nature of the disease and strenuous treatments. Around 94% showed low issues in family relationship like communication, support, emotional bonding, 6% showed medium issues ,10% parents worried about child marriage, 54% showed low issues , 36% showed medium issues, and 58% parents showed high issues for not getting government benefits, 36% showed medium issues . The quality of life was affected adversely among 50% of caregivers of Thalassemia pateints at Banglore.[6] All the parents of Thalassemia children were found to have severe parental stress assessed by Parental Stress Scale (PSS) in Rawalpindi.[7]

Figure No.1- Caregivers Attitude Towards Their Children Suffering From Thalassemia Prevalence By High, Medium And Low Issues



CONCLUSION:

On comparing the areas expressed by parents of beta thalassemic children, parents reported significantly greater need for general information, services, personal emotion , personal financial and Government benefits which included especially the need to be provided with chelators that are most of the time not available to them and basic problems that their child might get due to thalassemia .

The level of concern and worry for the child was equally seen in both the parents. The need for psychosocial support of these families is imperative and it is necessary to provide a more comprehensive management of the child with thalassaemia that includes psycho-social aspects of the condition.

KEYNOTE:

- Awareness of disease should be ephasised by introducing the topic in school, use of media
- Few facilities are not provided to them by respective institutions like free chelators.
- Parents think that government benefits made available to them were given preference to sickle cell patients than thalassemic patients.
- For treating such children/ parents , it's a multidisciplinary approach which along with pediatrician includes psychological services & transfusion expert
- Screening of specific population where thalassemia is prevalent is to be done.

LIMITATION OF THE RESEARCH

- Limited sample size
- Areas based research

Future research is required to further delineate and characterize the prevalence, frequency, and psychosocial correlates related to the parents' attitude towards their children suffering from beta thalassemia major.

Future prospect study should be developed in cooperating large sample size and mass study with appropriate methodology to capture the frequency and prevalence of parents' attitude towards their children suffering from beta thalassemia major.

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CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

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