VOLUME - 11, ISSUE - 02, FEBRUARY - 2022 • PRINT ISSN No. 2277 - 8160 • DOI : 10.36106/gjra

Original Research Paper

Nursing

ASSESS THE QUALITY OF LIFE AND COPING STRATEGIES OF PARENTS OF THALASSEMIC CHILDREN.

Ms. Archana P. Suraskar*

M.Sc. Nsg In Child Health Nursing , Singhgad College of Nursing, Narhe , Pune , 411041 Maharashtra,India. *Corresponding Author

ABSTRACT

AIMS: The aim of present study were to assess the quality of life and coping strategies of parents of thalassemic children.

MATERIAL AND METHODS: The sampling technique used in this study Non-probability purposive sampling technique to select the sample. Quantitative research approach. Non- experimental descriptive design was used .The data was collected during the month of December among parents of thalassemic children in selected hospitals. using Self reported likert scale and coping strategies rating scale of parents of thalassemic children. **RESULTS:** A number of sample being selected in the study. 60 parents of thalassemic children selected for study. Assessment of the Quality of life among parents of thalassemic children was 35.16, Assessment of the Coping Strategies among parents of thalassemic children was 22.18, association with quality of life of parents and gender of parents p-value are higher than 0.05, the demographic variables found not significant association with quality of life of parents. association with Coping Strategies of parents and gender of parents p-value are higher than 0.05, the demographic variables found not significant association with Coping Strategies

CONCLUSIONS: The assess quality of life and coping strategies of parents of thalassemic children was very important to know there quality of life and coping strategies of parents of thalassemic children.

KEYWORDS : assess, quality of life, Coping strategies , Thalassemic children, Parents

INTRODUCTION:

Thalassemia is inherited blood disorder characterized by defect in globin chain synthesis in red blood cell. It is a chronic disease that presents a range of serious clinical and psychological challenges. Long and undesirable treatment of thalassemia affects different aspects of patient's life. Thalassemia affects patients' health-related quality of life (HRQOL). Children with thalassemia major have to undergo blood transfusion at least once a month, depending on the severity of the disease[1].

Thalassemia have to regularly attend hospital for blood transfusion Parents suffer from psychosocial burden, stress and fear of death[2].

Background Of The Study:

Haemoglobin comprises four globin chains fetal haemoglobin (Hb F) has two α and two gamma chains and adult haemoglobin (Hb A) has two α and two β chains . Genes in the α-globin and β-globin gene clusters (on chromosomes 16 and 11) control globin-chain production. Due to spontaneous mutation, haemoglobin gene variants are present at low prevalence (carriers 1–1.5/1000) in all sizeable populations.[3] They fall into two broad groups – structural variants that change the amino acid sequence and produce an unusual haemoglobin.[4] and thalassaemias that lower or abolish production of globin chains.[5] Most haemoglobin gene variants are rare and many are harmless, but some are common because carriers are less likely than others to die from falciparum malaria. The most common such variant, α plus (α+) thalassaemia, is usually harmless. However, people who inherit combinations of haemoglobins S, C, E, D Punjab, β thalassaemia, or α zero (α0) thalassaemia may have a serious haemoglobin disorder. In populations in which malaria is endemic, 3 to 40% of individuals carry one of these significant variants, and the prevalence of haemoglobin disorders ranges from 0.3 to 25 per 1000 live births.[6]

Need For The Study:

Thalassemia syndromes are a heterogeneous group of single gene disorders, Worldwide 15 million people have clinically apparent thalassemic disorders. Reportedly, there are about 240 million carriers of β-thalassemia worldwide, and in India alone, the number is approximately 30 million with a mean prevalence of 3.3%.[8,9]

Parents of thalassemic patients not only have concerns regarding their children's goal, expectation and standard of life but, also the impact of diagnosis and treatment on family stability and family dynamics. The disease related concerns of parents are regarding the appearance of their child, bone deformities, short stature,poor self-image, frequent hospital visits for transfusion, delayed or absent sexual development and impaired fertility and other associated complications such as heart disease, bone disease, diabetes, infections etc. On parent's perspective it is a frightening and worrisome experience in which they have to cope up with the psychosocial aspects of thalassemia along with their regular visits to the thalassemic centers for blood tests and blood transfusion with iron chelation therapy and their determination to fulfill the treatment. Parents of β-thalassemic patients undergo a significant psychological impact, causing emotional burden, hopelessness, and difficulty with social integration. They experience negative thoughts about their life, guilt, increased anxiety and low self-esteem. They have severe psychosocial problems due to their inability to cope up with painful situation which leads to worseninnig of relationship amongst family members, increased marginalization and isolation. The present study focuses on psychological well being of parents of thalassemic patients. The parents of thalassemic patients elaborate a painful perception of the disease and show impairment in domains involved in physical health, psychological health, quality of life.[10]

Objective Of The Study:

1. To assess quality of life of parents of thalassemic children.
2. To assess coping strategies of parents of thalassemic children.
3. To determine the association between the study finding with selected demographic variables of thalassemic children.

Hypothesis

- H0 -There may be alter quality of life and coping strategies of Parents of thalassemic children.
- H1- There may not be alter quality of life and coping strategies of parents of thalassemic children.

Research Question

Is there any alter between quality of life and coping strategies of parents of thalassemic children

Ethical aspect

- Problem statement and objectives will be discussed and due permission will be obtained from the authorities

before conducting the study.

- The written permission will be taken from concerned authority.
- The written inform consent will be taken from all the subject.
- Prior to data collection maintain the confidentiality during the data collection.

Sampling Criteria:

Inclusion Criteria

- Parents who are willing to participate in the study.
- Only parents of major thalassemic children
- Parents of thalassemic children those who know Marathi, English language.
- Sample who are from age group of 20years and above.

Exclusion Criteria

- Parents those children are not suffering from thalassemia.
- Parents those children are suffering from minor thalassemia.
- Parents who are not willing to participate.

METHODOLOGY:

The sampling technique used in this study Non-probability purposive sampling technique to select the sample. Quantitative research approach. Non- experimental descriptive design was used. The data was collected during the month of December 2016 among parents of thalassemic children in selected hospitals. After obtaining consent from the subjects 60 parents of thalassemic children number being selected in the study. Self reported likert scale for quality of life and coping strategies rating scale of parents of thalassemic children was used for data collected.

TOOLS:.

Investigator had development the tool with his own experience, practical knowledge and guidance from the experts along with the few help from review of literature for developing the necessary tool for the present study.

Self reported likert scale and rating scale was developed for the study.

Self reported likert scale and coping strategies rating scale of parents of thalassemic children prepared in such a way that it will consist of as follow,

Appendix A: Consent Form

Section I: it consists of eight points of demographic data
Section II: it consists of five points of quality of life scale.
Section III: it consists of five points of coping strategies.

Description of the tool

Section I – Demographic data

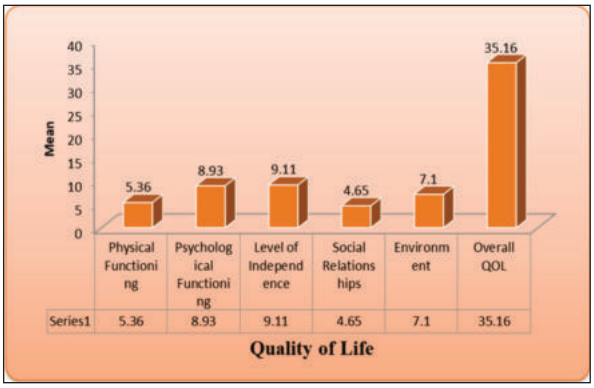
It includes age of parents, gender of parents, education of parents, occupation of parents, age of child, gender of child, number of blood transfusion per month, number of children affected by thalassemia in the family,

Section II – Assessment scale of the Quality of life among parents of thalassemic children

Total 6 scoring of the statement included on likert scale.

Scoring technique

Quality of Life	Mean	SD	Mean Percentage
Physical Functioning	5.36	2.26	53.6
Psychological Functioning	8.93	2.07	59.53
Level of Independence	9.11	2.24	60.73
Social Relationships	4.65	1.83	46.5
Environment	7.10	1.77	71.0
Overall QOL	35.16	7.19	58.61

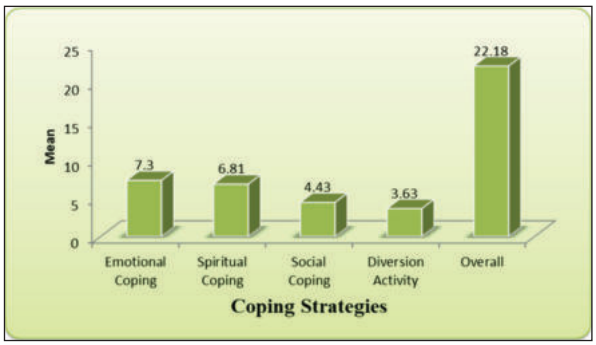


Section III – Assessment scale of the Coping Strategies among parents of thalassemic children.

Total 4 coping statergies points are included on three point rating scale.

Scoring technique

Coping Strategies	Mean	SD	Mean Percentage
Emotional Coping	7.30	1.22	81.11
Spiritual Coping	6.81	1.25	75.66
Social Coping	4.43	1.09	73.83
Diversion Activity	3.63	0.91	60.5
Overall	22.18	2.65	73.93



RESULT

Findings related to quality of life of parents of thalassemic children.

- Physical function was 5.36, psychological function was 8.93, level of independence was 9.11, Social relationship was 4.65 and environment was 7.10. The Overall Quality of Life of parents of thalassemic children was 35.16. Hence it is interpreted that parents of thalassemic children was having Average Quality of Life.

Findings related to coping strategies of parents of thalassemic children

parents of thalassemic children uses 7.30 in emotional coping, 6.81 in spiritual coping, 4.43 in social coping, 3.63 in diversion activity. The overall coping strategies of parents of thalassemic children were 22.18. Hence it is interpreted that parents of thalassemic children was having Average coping strategies.

Findings related to association between the quality of life of parents with selected demographic variables of parents of thalassemic children.

Association of scores with age in years. The tabulated 'F' value was 3.44. Also the calculated 'p'=0.02 which was much lesser than the acceptable level of significance i.e. 'p'=0.05. Association of scores with gender. The tabulated 'f' values was 0.009 Also the calculated 'p'=0.92 which was much higher than the acceptable level of significance i.e. 'p'=0.05. Association of scores with education. The tabulated 'F' values was 5.56 Also the calculated 'p'=0.002 which was much lesser than the acceptable level of significance i.e. 'p'=0.05.

Association of scores with occupation. The tabulated 'F' value was 3.44. Also the calculated 'p'=0.023 which was much lesser than the acceptable level of significance i.e. 'p'=0.05

Findings related to association between the Coping Strategies of parents with selected demographic variables of parents of thalassemic children.

Association of scores with age in years. The tabulated 'F' value was 2.55. Also the calculated 'p'=0.02 which was much lesser than the acceptable level of significance i.e. 'p'=0.05. Association of scores with gender. The tabulated 'f' values was 0.56 Also the calculated 'p'=0.87 which was much higher than the acceptable level of significance i.e. 'p'=0.05. Association of scores with education. The tabulated 'F' values was 4.32 Also the calculated 'p'=0.023 which was much lesser than the acceptable level of significance i.e. 'p'=0.05. Association of scores with occupation. The tabulated 'F' value was 2.48. Also the calculated 'p'=0.063 which was much lesser than the acceptable level of significance i.e. 'p'=0.05

CONCLUSION

The assess quality of life and coping strategies of parents of thalassemic children is very important to know there quality of life and coping strategies of parents of thalassemic children.

REFERENCES

1. DR. S.S. RANDHAWA Anatomy and Physiology , 5th edn., new delhi: PV publication.
2. Sapountzi-Krepia D, Roupa Z, Gourni M, Mastorakou F, Vojiatzi E, Kouyioumtzi A et al. A Qualitative Study on the Experiences of Mothers Caring for Their Children With Thalassemia in Athens, Greece. Journal of Pediatric Nursing. 2006;21(2):142-152. Available from: https:// www. ncbi. nlm. nih. gov/ pubmed/ 16545674
3. Modell B, Darlison M, Birgens H, Cario H, Faustino P, Giordano P et al. Epidemiology of haemoglobin disorders in Europe: an overview. Scandinavian Journal of Clinical and Laboratory Investigation. 2007; 67(1): 39-70. Available from: https:// www. ncbi. nlm. nih. gov/ pubmed/ 17365984
4. Harkness D. A Review of "A Syllabus of Thalassemia Mutations ". Hemoglobin. 1998;22(1):95-96. Available from: http:// www. tandfonline. com/ doi/ abs/10.3109/03630269809071525
5. ANGASTINIOTIS MODELL B. Global Epidemiology of Hemoglobin Disorders. Annals of the New York Academy of Sciences. 1998;850(1 COOLEY'S ANEM):251-269.
6. Weatherall D, Clegg J, Gibbons R. The thalassaemia syndromes. 1st ed. Oxford [u.a.]: Blackwell Science; 2001. Available from: http:// www. ipcbee. com/ vol27/25-ICCGE2012T20004.pdf
7. Manglani M, Lokeshwar MR, Vani VG, Bhatia N, Mhaskar V. 'NESTROFT' an effective screening test for β-Thalassemia trait. Indian Pediatr. 1997; 703 - 708.
8. Thacker N. Indian Pediatric Prevention of Thalassemia in India 2007; 44(9):647-8. Available from: https://www.ncbi.nlm.nih.gov/pubmed/17921552
9. Sharma R. textbook of pediatric nursing ,India: Jaypee brother; 533