



A Study to Assess the Level of Stress among Care Givers of Thalassemia Attending Thalassemia Clinics of H.S.K Hospital and Research Centre, Bagalkot

Mrs. Treesa Joseph¹, Dr. Deelip S Natekar², Mr. Somashekar K³, Mr. Basavaraj K³, Mr. Sangamesh K³, Miss. Viraksha K³, Miss. Renuka M³, Mr. Shivappa³, Mr. Shrikanth³, Miss. Simran³, Miss. Shankamma³, Mr. Sharat³

¹Assistant Professor, Dept. of Psychiatric Nursing, BVVS Sajjalashree institute of nursing sciences, Navanagar, Bagalkot. – 587102, Karnataka, India.

²Principal, BVVS Sajjalashree institute of nursing sciences, Navanagar, Bagalkot. – 587102, Karnataka, India.

³BSc Nursing IV yr, BVVS Sajjalashree institute of nursing sciences, Navanagar, Bagalkot. – 587102, Karnataka, India.

ABSTRACT:

Background: Thalassemia affects approximately 4.4 out of every 10,000 live births throughout the world. This condition causes both males and females to inherit the relevant gene mutations equally because it follows an autosomal pattern of inheritance with no preference for gender. Approximately 5% of the worldwide population has a variation in the alpha or beta part of the hemoglobin molecule, although not all of these are symptomatic and some are known as silent carriers.¹

Objective: Find the level of stress among care givers of Thalassemia attending Thalassemia clinics.

Methods: Descriptive survey research design has been adopted with the sample of 50 care givers of thalassemia attending Thalassemia clinics of H.S.K Hospital and Research Centre, Bagalkot. Data were collected using self report method and Hospital's records. Tools used for data collection were; socio-demographic questionnaire, The Perceived Stress Scale (PSS) to assess the stress among care givers of thalassemia.

Results: Findings related to assessment of level of stress among care givers of thalassemia shows that, highest percent 66 % of care givers were mild stressed, 34 percent of them were have moderate stress. There is a significant association was found between level of stress and sex of care givers ($\chi^2=0.0254$; $P<0.05$). And no significant association was found between level of stress among care givers of thalassemia and their other socio demographic variables.

Conclusion: The overall findings of the study revealed that, care givers thalassemia was had mild and moderate level of stress. There is a significant association was found between level of stress and sex of care givers.

KEY WORDS: Care givers, Stress and Socio-demographic variable, Thalassemia.

INTRODUCTION

Thalassemia is a haemoglobinopathy and specifically an autosomal recessive disorder. The word thalassemia is derived from the Greek word thalassa which means "sea", and Latin word - emia (from Greek haema) meaning "blood". Thalassemia syndromes are a group of disorders resulting from inherited mutations which lead to decrease synthesis of either α or β globin chains. These α and β globin chains along with iron containing heme group form the structure of adult hemoglobin HbA ($\alpha_2\beta_2$). Because of the imbalance in synthesis of globin chain effects like anemia, hemolysis of red blood cells and tissue hypoxia are observed².

Thalassemia, affecting children, is one such condition, which requires a family vigilance approach throughout the life of the child. Globally, 15 million people are estimated to suffer from Thalassemia. In India, approximately 30 million people are affected; and 10,000 Thalassemia major children are born every year. Every hour one child is born with Thalassemia. Children with Thalassemia need monthly blood transfusion, regular iron chelation therapy and in some cases, bone marrow transplantation. Thus, parents of these children are exposed to repeated emotional suffering for their off springs³.

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. Although optional medical management has reduced the



difficulties faced by Thalassaemic children and their families, still the psychosocial impact on the development of the sick children and family is a continuous process throughout life. The psychosocial burden can affect the quality of life of the families. Less work has been done regarding the stress level of parents who are giving care and love to these chronically ill children⁴.

Stress in thalassemia patients and their parents can be attributed to a number of reasons like frequent treatment procedures and hospital visits, decreased life expectancy, expected complications from disease or treatment procedures and the monetary burden on parents/guardian. Also the long painful treatment sessions, such as to remove iron (iron overload being a complication of frequent blood transfusions) an eight hour long painful procedure (injecting chelators by chelation pump) is carried out, add to the stress factor².

Caregivers are the persons who provide care at the time of distress or illness. In the case of chronic diseases like thalassemia, their role becomes more evident. They face many challenges in providing high-quality care for their children. By definition, caregiver burden refers to a high level of stress or strain one experience while caring for another person (usually a family member) with some illness. Caregivers of thalassaemic children face many stress and strain to provide the best possible medical care for their children. Their quality of life, especially care-related quality of life is expected to be poor and dependent on QoL of their ward and other attributes (i.e., sociodemographic, clinico-therapeutic, perception related, financial)⁵.

The burden on parents is not assessed related to child's disease condition. Considering this, the researcher felt it as a strong need to study the level of stress among care givers of thalassemia attending pediatric services.

METHODS

It was a Descriptive survey research design has been adopted with the sample of 50 care givers of thalassemia attending Thalassaemia clinics of H.S.K Hospital and Research Centre, Bagalkot. A sample was selected by Purposive sampling technique The final Sample size was determined with the help of power analysis using data from pilot study. As the number of determinants included in the study is 10 and 2-3 patients and care givers of thalassemia attending Thalassaemia clinics of H.S.K Hospital and Research Centre, Bagalkot everyday considering this in order to improve the credibility of predictor analysis sample size for the present study was 50.

Study participants: The study participants were care givers of thalassemia attending thalassemia clinics of H.S.K Hospital and Research Centre, Bagalkot. The sampling criteria included care givers of thalassemia, who can able to understand Kannada, available at the time of data collection and willing to participate in the study. Care givers who are not physically fit at the time of data collection, who cannot able to cooperate throughout the period of study, those who are concerned with assessment or management of level of stress instability were excluded from enrolment in study sample.

Sample size calculation: The final Sample size was determined with the help of power analysis. The sample size was calculated considering the following criteria, $Z = 1.96$ (95% confidence level), margin of error (e) =5% (0.05), Population proportion (P) = 0.5. The population of patients with ESRD in Karnataka was considered around 3-4%. The calculated sample size was 100. The researcher enrolled 60 subjects and data was obtained from 50 subjects.

Setting of the study: The study was conducted at the thalassemia clinics of H.S.K Hospital and Research Centre, Bagalkot. The researcher enrolled 50 care givers of thalassemia.

Data collection Instrument: The data regarding level of stress is to assess the stress among care givers of thalassemia. The Perceived Stress Scale (PSS-10) is a 10-item questionnaire originally developed by **Cohen Sheldon (1983)**. **Validity, reliability and translation of data collection instruments:** Perceived Stress Scale has been widely used in many Indian languages including Kannada with very high reliability (Chronbach's α 0.907). Reliability for the Kannada translated tool in the present study was established by Test-retest method. In Test-retest method, the 7 days gap was given between the tests and correlation between the scores was calculated by using Cronbach's alpha value is 0.731, suggesting the tool was reliable for data collection.

Ethical clearance: Ethical clearance certificate was obtained from Institutional ethical clearance committee, B.V.V.S Sajjalashree Institute of Nursing sciences, Bagalkot (ref No. BVVSSIONS-IEC/2021/22/74. Dt: 12/07/2021) Written consent of participation was obtained from participants before data collection.



Statistical analysis: The data was analysed using SPSS version 25. The obtained data was entered in MS excel sheet. The data was edited for accuracy and completeness. The categorical responses were coded with numerical codes. The data was presented with frequency and percentage distribution tables and diagrams. Frequency and percentage distribution were used for analysis of socio demographic and clinical characteristics. The description of data was presented with mean, standard deviation and mean percentage of level of stress among care givers of thalassemia. Chi-square test is used to assess the association between level of stress scores of care givers of thalassemia with their socio demographic variables.

Data collection Procedure: The data was collected study was conducted from 01-10-2021 to 20-10-2021 among care givers of thalassemia. Prior formal administrative approval from the Principal of Sajjalashree institute of nursing science, Bagalkot. Obtained approval from institutional ethical clearance committee. Obtained administrative approval from concerned authorities of thalassemia clinics of H.S.K Hospital and Research Centre, Bagalkot. All the participants were explained about the purpose of study and that the data or information provided from them will be kept confidential and their identity will not be revealed. The written consent from care givers of thalassemia. Assessment of the level of stress was done with the Perceived Stress Scale (PSS) among care givers of thalassemia. The instruments were given according to their preferred language (English or Kannada). Instructions were given regarding content of data collection instruments. The researcher attained and clarified the doubts of participants during data collection. The filled tools were collected from the participants. On an average adolescents took 10 to 15 minutes to fill the tools and the whole process was completed in half an hour. Researcher thanked all the participants.

RESULTS

The percentage wise distribution of sample according to their age, majority of care givers 46% were in the age group of 20- 25yrs, 58% of were females, 44% were with the income of 5000-10000Rs. Majority 28% of the care givers were no formal education, most of the care givers father occupation 34% are farmers, mother occupation 36% of them were labor, 50% of them were from joint family, 60% of them were had 2 children’s and 58% of them were from urban area.

Table 1: Frequency and percentage distribution of socio demographic characteristics of sample.

| SL. NO | Socio demographic variables. | Characters | F | % |
|--------|------------------------------|------------------------|----|-----|
| 1 | Age | 1. 20-25 years | 23 | 46% |
| | | 2. 26-30years | 10 | 20% |
| | | 3. 31-35years | 17 | 34% |
| 2 | Sex | 1. Male | 21 | 42% |
| | | 2. Female | 21 | 58% |
| 3 | Family monthly income | 1. 5000-10000 | 22 | 44% |
| | | 2. 10001-15000 | 12 | 24% |
| | | 3. 15001-20000 | 16 | 32% |
| 4 | Educational status | 1. No formal education | 14 | 28% |
| | | 2. Primary education | 12 | 24% |
| | | 3. Secondary education | 12 | 24% |
| | | 4. Degree | 12 | 24% |
| 5 | Father occupation | 1. Labor | 9 | 18% |
| | | 2. Agriculture | 17 | 34% |
| | | 3. Govt employee | 13 | 26% |
| | | 4. Self-employee | 11 | 22% |
| 6 | Mother occupation | 1. House wife | 15 | 30% |
| | | 2. Labor | 18 | 36% |
| | | 3. Self-employee | 15 | 30% |
| | | 4. Others | 2 | 4% |



| | | | | |
|----|--------------------|--|--------------------|-------------------------|
| 7 | Type of family | 1. Nuclear family 2. Joint family 3. Extended family | 19 25 6 | 38% 50% 12% |
| 8 | No of Childrens | 1. 1 2. 2 3. 3 4. 4& above | 8 30 11 1 | 16% 60% 22% 2% |
| 9 | Place of residence | 1. Rural 2. Urban | 21 29 | 42% 58% |
| 10 | Information | 1. Health officer 2. Friends & Social groups 3. Electronic media 4. Print media | 25 17 6 2 | 50% 34% 12% 4% |

Abbreviations: F: Frequency, %: Percentage

Part - II: Description of assessment of level of stress among care givers of thalassemia.

Distribution of sample according to their assessment of Level of stress among care givers of thalassemia shows that, highest percent 66 % of care givers were mild stressed, 34 percent of them were have moderate stress.

Assessment of mean, SD, and mean percentage of care givers of thalassemia reveals that, the total mean percentage of level of stress scores was 49.7 percent with mean and SD 19.88 +_1.3797.

Part III: Association between level of stress among care givers of thalassemia with their socio demographic variables.

Table 2: Association between level of stress scores of care givers of thalassemia with their socio demographic variables.

n = 50

| SL. No | Socio Demographic Variables | Df | Chi- Square Value | Table value | P' Value | Level of Significance |
|--------|-----------------------------|----|-------------------|-------------|----------|-----------------------|
| 1 | Age | 1 | 0.079 | 3.84 | 0.7783 | P>0.05, NS |
| 2 | Sex | 1 | 4.993 | 3.84 | 0.0254 | P<0.05, S |
| 3 | Family Monthly Income | 1 | 0.098 | 3.84 | 0.7545 | P>0.05, NS |
| 4 | Educational Status | 1 | 0.480 | 3.84 | 0.4882 | P>0.05, NS |
| 5 | Father Occupation | 1 | 0.038 | 3.84 | 0.8460 | P>0.05, NS |
| 6 | Mother Occupation | 1 | 1.532 | 3.84 | 0.2758 | P>0.05, NS |
| 7 | Type Of Family | 1 | 0.485 | 3.84 | 0.4861 | P>0.05, NS |
| 8 | No Of Children | 1 | 0.003 | 3.84 | 0.9554 | P>0.05, NS |
| 9 | Area of Residence | 1 | 1.860 | 3.84 | 0.1727 | P>0.05, NS |
| 10 | Source of Information | 1 | 0.802 | 3.84 | 0.3705 | P>0.05, NS |

NS- Not Significant

S- Significant

Df- Degree of Freedom

There is a significant association was found between level of stress and sex of care givers ($\chi^2=0.0254$; $P<0.05$). And no significant association was found between level of stress among care givers of thalassemia and their other socio demographic variables.



DISCUSSION

A descriptive study was conducted to assess the level of stress among care givers of Thalassemia. Study conducted at Hanagal Shri Kumareswar Hospital and Research Centre, Bagalkot. The sociodemographic data and determinants were assessed by using a structured close ended questionnaire prepared by researcher. The percentage wise distribution of sample according to their age describes that most of the care givers of Thalassemia 46% were in the age group of 20- 25yrs. Findings of present study is supported with the study conducted by **Palit S, Bhuiyan RH, Aklima J, Emran TB, Dash R**, majority of care givers were in the age group of 21– 30 yrs⁶. 58% of were females. The results of the present study are in consistent with a study conducted by **Hisam A, Khan NUS, Tariq NA, Irfan H, Arif B, Noor M**. The Result of the study reveals that, the majority of care givers were 57 (65.8%) females⁷. 44% were with the income of 5000-10000Rs. The results of the present study are in contradictory with a study conducted by **Jamun K, Felen G, Zoy J**. The findings suggested that the majority 44% were with the income of 50000 and above⁸. Majority 28% of the care givers were no formal education. The present study is in consistent with a study conducted by **Vinnakota A, Rai M**, most of the care givers were have no formal education⁹. Most of the care givers father occupation 34% are farmers. The present study are in contradictory with a study conducted by **John k, Goerge T**, most of the care givers were Self employees¹⁰. Mother occupation 36% of them were labor. 50% of them were from joint family. The present study are in consistent with a study conducted by **Gooli C, Venkat M.**, most of the care givers were from joint family¹¹. 60% of them were had 2 children's. The results of the present study are in contradictory with a study conducted by **Reddy K, Venkatachalam N**. The results shown that, most of the care takers are had 3 children¹². 58% of them were from urban area. According to their source of Information reveals that majority 50% of them were receiving information from the health officer.

Findings related to assessment of level of stress among care givers of thalassemia shows that, highest percent 66 % of care givers were mild stressed, 34 percent of them were have moderate stress. The present study was in consistent with a cross sectional interview based study was conducted by **Inamdar S, Inamdar M, Gangrade A**, majority of the parents were under mild stress (60.6%)¹³. Similarly, a study was conducted by **Hisam A, Khan NUS, Tariq NA, Irfan H, Arif B, Noor M**. 10 (20.8%) were having mild stress⁷. Assessment of mean, SD, and mean percentage of care givers of thalassemia reveals that, the total mean percentage of level of stress scores was 49.7 percent with mean and SD 19.88 +₋1.3797. The present study was in consistent with a cross sectional interview based study was conducted by **Raj Y, Ganagal U, Hatti R**, caretakers had stress 46.8, with mean and SD 21.21 +₋1.5498¹⁴.

There is a significant association was found between level of stress and sex of care givers ($\chi^2=0.0254$; $P<0.05$). And no significant association was found between level of stress among care givers of thalassemia and their other socio demographic variables Thus the H_2 stated is accepted for the socio demographic variable that is sex of care givers and rejected for other variables.

LIMITATIONS OF THE STUDY

The present study is a preliminary study to assess the level of stress among care givers of thalassemia. The limitations of this study include; The sample size was limited to 50. This was only a small sample for generalization. Other variables like anxiety, depression could have been included. The study included the assessment of stress only. Long- term follow up could not be carried out due to time constraints.

CONCLUSION AND RECOMMENDATION

Findings related to assessment of level of stress among care givers of thalassemia shows that, highest percent 66 % of care givers were mild stressed, 34 percent of them were have moderate stress. On assessment of mean, SD, and mean percentage of care givers of thalassemia reveals that, the total mean percentage of level of stress scores was 49.7 percent with mean and SD 19.88 +₋1.3797. Association between level of stress scores of care givers of thalassemia with their socio demographic variables reveals that, there is a significant association was found between level of stress and sex of care givers ($\chi^2=0.0254$; $P<0.05$). And no significant association was found between level of stress among care givers of thalassemia and their other socio demographic variables. The study recommends that a similar study can be undertaken with a large stratified sample including care givers of thalassemia from different sections of society to generalize the findings. A study can be conducted to find out the prevalence of selected level of stress among care givers of thalassemia. A study can be carried out to evaluate the efficiency of various teaching strategies like SIM, pamphlets and computer-assisted instruction on stress on care givers of thalassemia.



REFERENCES

1. Smith, Yolanda. (2021, May 22). Thalassemia Prevalence. News-Medical. Retrieved on October 06, 2021 from <https://www.news-medical.net/health/Thalassemia-Prevalence.aspx>.
2. Hisam A, Khan NUS, Tariq NA, Irfan H, Arif B, Noor M. Perceived stress and monetary burden among thalassemia patients and their caregivers. Pak J Med Sci. 2018; 34(4):901-906. doi:10.12669/pjms.344.15420
3. Valliammal S, Ramachandra. Stress factors among caregivers of children with Thalassemia. Department of Nursing National Institute of Mental Health and Neuro Sciences (Institute of National importance), Bangalore.
4. Shivansh I , Madhuri I , Anila G. Stress level among caregivers of thalassemia patients. Original Article pISSN 0976 3325 | eISSN 2229 6816 Open Access Article www.njcmindia.org
5. Biswas B, Naskar N N, Basu K, Dasgupta A, Basu R, Paul B. Care-Related Quality of Life of Caregivers of Beta-Thalassemia Major Children: An Epidemiological Study in Eastern India. J Epidemiol Glob Health. 2020; 10(2):168-177. doi:10.2991/jegh.k.200102.003
6. Palit S, Bhuiyan RH, Aklima J, Emran TB, Dash R. A study of the prevalence of thalassemia and its correlation with liver function test in different age and sex group in the Chittagong district of Bangladesh. J Basic Clin Pharm. 2012 Sep;3(4):352-7. doi: 10.4103/0976-0105.105339. PMID: 24826050; PMCID: PMC3979250.
7. Hisam A, Khan NUS, Tariq NA, Irfan H, Arif B, Noor M. Perceived stress and monetary burden among thalassemia patients and their caregivers. Pak J Med Sci. 2018;34(4):901-906. doi:10.12669/pjms.344.15420
8. Jamun K, Felen G, Zoy J. A comparative study of self esteem and level of stress among parents of thalassemic children living at Boston, US. American psychiatric association. vol. 5, no. 1, Jan.-June 2019, p. 50. Gale One File: Health and Medicine, link.gale.com/apps/doc/A666209232
9. Vinnakota A, Rai M. A study on prevalence of emotional problems among thalassemic children and care takers in Africa. 2017; 84(10):984-985. doi:10.1009/s12012-019-2697
10. John K, Goerge T. To assess the stress and anxiety level among caregivers of thalassemia patients a multicenter study in Malta. Volume 3 Number 2, June - August 2017 DOI: <http://dx.doi.org/10.21088/ijpen.2874.9126.6718.14>.
11. Gooli C, Venkat M. An epidemiological study on prevalence of stress and anxiety level among caregivers of thalassemia at Bangalore. Pak J Med Sci. 2017; 34(4):901-906.
12. Reddy K, Venkatachalam N. An exploratory study was conducted on level of stress and depression among caretakers of thalassemia. Health Care Systems Approach. BBB. 2016; 2 (3):491-515.
13. Inamdar S, Inamdar M, Gangrade A. Stress level among caregivers of thalassemia patients. Original article pISSN 0976 3325 | eISSN 2229 6816 Open Access Article www.njcmindia.org
14. Raj Y, Ganagal U, Hatti R. A study on Prevalence and associated factors of stress among care takers of hemoglobinopathies and thalassemia among children at multispecialty hospital, Gujarat. International Journal of Pediatric Nursing Volume 6 Number 1 May - August 2017. doi:10.4103/0973-6247.175424

Cite this Article: Mrs. Treesa Joseph, Dr. Deelip S Natekar, Mr. Somashekar K, Mr. Basavaraj K, Mr. Sangamesh K, Miss. Viraksha K, Miss. Renuka M, Mr. Shivappa, Mr. Shrikanth, Miss. Simran, Miss. Shankamma, Mr. Sharat (2023). A Study to Assess the Level of Stress among Care Givers of Thalassemia Attending Thalassemia Clinics of H.S.K Hospital and Research Centre, Bagalkot. International Journal of Current Science Research and Review, 6(12), 7843-7848