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# Stress and Coping among Parents of Children Having Thalassemia

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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 to "assess the level of stress and coping among parents of children having thalassemia" was undertaken at St. John's Medical College Hospital (SJMCH), Bangalore. A total of 100 study subjects were selected using purposive sampling technique. Parents having children with Thalassemia had severe financial stress (74%). The problem oriented coping mechanisms were used effectively by 57% of the parents. There was no significant relationship found between overall stress and coping. The financial burdens on the family members cause major stress in the parents. The use of coping mechanisms was significant in those living in nuclear families and residing in urban areas which clearly emphasize that the parents are more exposed to the disease and taking more steps in knowing about the disease and also those parents who have not received counseling find difficulty in coping with the disease.***

**Keywords:** Stress, Coping, Children, Thalassemia, Parents.

## 1. Introduction

Thalassemia is the most common single gene disorder. It mainly affects infants on birth, affecting their ability to survive due to chronic anemia resulting from the inherited hemoglobin disorder.[4]

Thalassemia results in frequent hospitalization of patients because its management requires lifelong regular blood transfusions, together with Iron Chelation Therapy. Thus emotional distress, anxiety, fear, difficulties in dealing with feelings and the ensuing effects on normal family functioning are common problems in families with children who have Thalassemia. Hence the families of patients with Thalassemia must learn to deal with frequent hospital visits, resulting in a psychosocial burden.[13]

Studies have shown that parents who cope and adapt less successfully to the child's chronic illness tend to have a more negative and fatalistic attitude toward the child's illness.[5]

Thalassemia is on a rise and affects the psychological status of parents causing fear, despair, and helplessness. Psychological support for the caregivers is therefore particularly important and is a vital part of comprehensive medical treatment. In a month, nearly 100 patients having Thalassemia visit St. John's hospital for frequent blood transfusions. 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 stress and coping of parents of children with Thalassemia attending pediatric services.

### Objectives

- To assess the stress and coping among parents of children having Thalassemia.
- To find the correlation between stress and coping among parents of children having Thalassemia.
- To find the association between:-
  a) Stress and selected baseline variables.
  b) Coping and selected baseline variables

## 2. Review of literature

### 1) Studies related to prevalence of Thalassemia.

An extensive review study was done on literature of Indian tribes over the last 20 years. The results showed that Thalassemia and other hemoglobinopathies are highly prevalent (0.028-18%) among the communities. The high frequencies of these mutant alleles are maintained by the tribal populations probably due to consanguinity and endogamous mating for a long period of time, along with ignorance, lack of awareness and conveyance, low income status and high cost of treatment make them vulnerable.[14]

To study the occurrence of common mutations in certain high risk communities in the population of Gujarat, a total of 375 cases were screened for Beta Thalassemia mutation. A retrospective study design was used. The prevalence with respect to communities highlight that the Sindhi's are at higher risk with 25%, Rajputs (11.7%), SC/ST/OBC (9.67%), Patel (9.67%) and Lohana (8.86%).[16]

According to the United States Census Bureau, the number of Asians having Thalassemia increased significantly to a total of 6.9 million in the census count in 1990.[8] Reports reveal that no appropriate screening and counseling was offered to the parents who had children with severe alpha or beta Thalassemia.[6]

The life expectancy of patients having Thalassemia has significantly increased in recent years. However, complications are still frequent and affect the patient's quality of life. In a recent study from UK, it was found that 50% of patients had died before the age of 35 years. At that age, 65% of the patient's from an Italian long term study were still alive. Heart disease was responsible for more than half of the deaths. The prevalence of complications in Italian patient's born after 1970 included heart failure in 7%, Hypogonadism in 55%, Hypothyroidism in 11% and Diabetes in 6%. Hepatitis C virus antibodies were present in 85% of multi-transfused Italian patients, 23% of patients in the UK, and 35% in the US, 34% in France and 21% in India.[9]

### 2) Studies related to stress and coping among parents of children with Thalassemia.

A cross sectional study undertaken by the National Institute of Mental Health and Neuroscience, Bangalore on 44 caregivers to assess the contributions of psychiatric problems and concerns regarding the illness to quality of life in caregivers demonstrated that the caregivers psychiatric problems and concerns related to Thalassemia contributed to impaired quality of life. The commonest diagnosis was depressive disorder (n=19, 43%); dysthymia 11(25%); 4(9%) each mild / moderate depressive episodes; 3(7%) each-brief depressive reaction and alcohol dependence. The quality of life was adversely affected in 50% (n=22/44), the most commonly affected were pain / discomfort (n=19, 45%) followed by mobility (n=7, 17%).[15]

A qualitative study explored the lived experiences of fifteen mothers of children with Thalassemia major in Thailand. A semi structured interview schedule was used. Six themes were found namely, lack of knowledge about Thalassemia, psychosocial problems, concerns for the future, affected social support systems, financial difficulty and non-effectiveness of health care services. These findings suggested that a holistic, culturally sensitive nursing approach should be considered when caring for children with Thalassemia.[10]

Another prospective study undertaken in KEM hospital, Mumbai in order to evaluate psychopathology and coping mechanisms in parents of children with chronic illness, 30 parents whose children had Thalassemia were selected. The findings showed that parents had high psychopathology, depression having the maximum elevation. A measure of general distress was extremely high in about 86.66% of the parents. Most parents were fatalistic in their approach towards the illness. Avoidant coping strategies were used in various dimensions by the same group.[11]

The authors in West Bengal tried to explore the experiences of adolescent Thalassemic patient respondents (ATPRs) in view of addressing the question of whether Thalassemia can be considered a disability, 36 patients were interviewed. The findings showed that culture and education played a major role in illness experience. The consequence of Thalassemia is extremely stressful and patients' face a variety of physical, psychological and social problems. Considering these experiences, the study concluded that Thalassemia might be officially considered as a disability in India, requiring a multiple theoretical as well as a prolonged intervention method to tackle it.[12]

Many causes including the chronicity of disease, burden of treatment modalities, morbidities and the expectation of early death resulting from the disease complications may lead to psychosocial burden in Thalassemia major (TM). To understand the psychosocial implications, a total of 38 patients with TM and their mothers were recruited. The study focused on the evaluation of psychosocial burden as well as to disclose whether the psychological status of patients contribute to the compliance with the therapy or to the contrary.

Symptom Distress Checklist 90 (SCL-90) scale was administered to all mothers for evaluating their psychopathology. The scores indicated that mothers who had a child with good adherence to Desferal Therapy had higher scale scores than the mothers with a poor adherent child. The increase risk of psychosocial and behavioral problems in Thalassemics and their parents indicated the importance of a lifelong psychosocial support for the prevention of mental health issues. The patients and parents who were more conscious of the illness were more worried but more compliant with the therapy and needed stronger psychiatric support.[1]

## 3. Methodology

Survey approach and descriptive design was adopted for the study. The study was conducted in the day care ward of SJMCH. The population comprised of parents of children having Thalassemia and attending the Pediatric services of SJMCH, Bangalore. A total of 100 study subjects were selected using purposive sampling technique guided by the inclusion criteria.

Stress and coping scale was used and modified from the instruments developed and tested by the other researchers ie, Chronicity Impact and Coping Instrument: Parent Questionnaire (CICI: PQ) - developed by Debra P. Hymovich (1984) to measure the stress; Hemodialysis Stressors Scale- developed by Baldree (1982) to measure stress among Hemodialysis patients; and Coping checklist – developed by Jalowiec Coping Scale, suitable for Indian setting.

The study tool was validated and reliability was established using split half method, the 'r' value for stress scale was 0.71 ($r^1$=0.83) and for coping scale was 0.9 ($r^1$=0.95). The tool was found to be reliable. Pilot study using the validated tool was conducted and the findings showed that the study was feasible and practicable.

Data for the main study was collected using structured interview schedule comprising of stress and coping scale. Collected data was organized and analyzed using descriptive and inferential statistics.

## 4. Results

**Baseline Data**

Distribution of parents according to their age group showed that all the parents belonged to the age group between 20-50 years and the mean age was 34.1 with the deviation of ±6.8. Among them, 58% of the samples were females and 42% of them were males.

The data also showed that all the children having Thalassemia, belonged to the age group between the range of 0.7-15 years and the mean age group was 7.7 with the deviation of +4.1. Majority of the children having Thalassemia (57%) were males and 43% of them were females.

All the children were first hospitalized between the age group of 0.08 to 5 years of age and the mean being 1.01 with deviation of + 1.01. Among all, 35% of the children had the illness duration of 6-10 years, 34% of them were between 1-5 years and 24% between 11-15 years where as 7% of them were below 1 year of age. The ranges of illness were 0.4-14.0 and mean duration being 6.5 (SD-4.1).

Majority (46%) of the parents had completed high school education, 22% of them were graduates, 14% of them had completed higher secondary education and 9%, 6% and 3% were illiterate, primary and post graduates respectively. The mean value was 10.3 (range being 0-17) and deviation of + 4.3.

Most of them ie, 63% of the parents were semiskilled workers, 19% of them were skilled and 18% of them were unskilled workers. 65% of them had a monthly income between Rs.1,001-5,000; 18% of them had between Rs.5,001-10,000; 7% between Rs.10,001-15,000 and Rs.15,001-20,000 each and 3% of them had income above Rs.20,000. In the data finding, 53% of the parents belonged to extended family and 47% of them belonged to the nuclear family and 55% of the population belonged to urban area and 45% of them were from rural area. The findings showed that majority (75%) of the samples was from Hindu background, 21% of them were Muslims and 4% of them were Christians.

The data also showed that 94% of the children affected did not have any other sibling with the same problem where as 6% of them had one sibling affected in the family. The majority of the children (56%) were first born in the family, 34% of them were second born, and 8% third born and only 2% of them were of the fourth birth order. Distribution of parents according to the frequency of visit of the children to the hospital shows that majority (65%) of them had to visit the hospital once a month, 21% of them visited once in less than a month and 14% of them visited once in more than a month. The data also revealed that 71% of the parents had not received any counseling and only 29% of them had received previous counseling and 94% of the samples did not have similar illness in the family background and only 6% had similar problems within the family relations.

### Stress and coping among parents having children with Thalassemia.

**Table 1:** Mean, mean percentage and standard deviation of the various aspects of stress among parents having children with Thalassemia. n=100

| Various aspects of stress | No of items | Max Score | Range | Mean | SD | Mean % |
|---|---|---|---|---|---|---|
| Physical stress | 5 | 25 | 5-19 | 10.94 | 3.74 | 43.75 |
| Emotional stress | 10 | 50 | 12-46 | 29.80 | 6.52 | 59.60 |
| Social stress | 7 | 35 | 7-29 | 17.01 | 5.33 | 48.60 |
| Financial stress | 5 | 25 | 5-25 | 20.50 | 4.77 | 82.00 |
| Total | 27 | 135 | 35-115 | 78.25 | 15.49 | 57.96 |

The data presented in table 1 show that 82% elicited financial stress, 59.60% had emotional stress, 48.60% experienced social stress and 43.75% had physical stress.

Similar findings have been found in the study conducted at NIMHANS were caregivers concerns were regarding the future (91%), illness (80%) and finances (73%).[15] Another study cited by Melnyk reported that finance is one of the factors which contribute to the stress of parents of young children admitted in hospitals.[7]

A similar finding was reported by Cimete. In his study parents undergoing hemodialysis reported that they were well aware that in case they did not have any insurance they wouldn't be able to afford the medical expenses and majority (93.55%) of parents reported that they were living in economic crisis.[3] The above study findings support the present study findings.

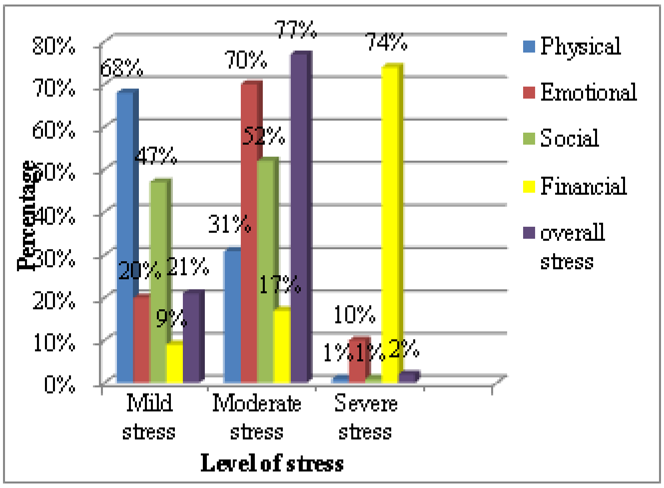

**Figure 1:** Levels of stress among parents having children with Thalassemia

The data presented in figure 1 shows that majority (77.30%) of the samples expressed moderate stress and 21% of them had mild stress. The most of the samples elicited severe financial stress (74%) and majority had moderate emotional stress (70%).

**Table 2:** Mean, mean percentage and standard deviation of the various aspects of coping among parents having children with Thalassemia. n=100

| Various aspects of coping | No of items | Max Score | Range | Mean | SD | Mean % |
|---|---|---|---|---|---|---|
| Problem oriented | 17 | 68 | 37-65 | 50.78 | 6.28 | 74.7 |
| Affective oriented | 43 | 172 | 77-115 | 92.89 | 6.42 | 54.1 |
| Total | 60 | 240 | 118-169 | 143.67 | 10.48 | 59.9 |

The data presented in table 2 shows that 74.7% used problem oriented coping mechanism and 54.1% used affective oriented coping mechanism.

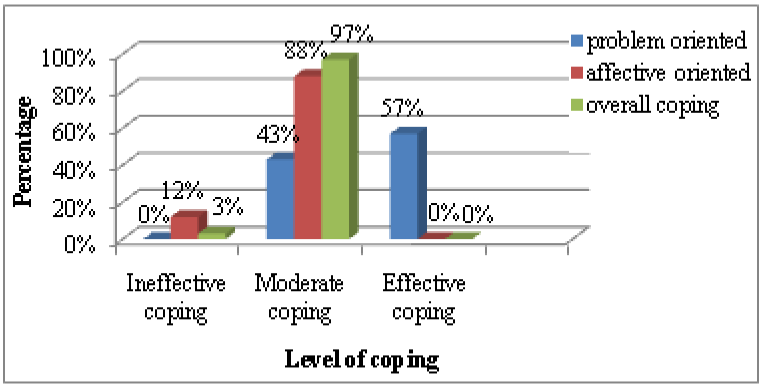

**Figure 2:** Levels of coping among parents having children with Thalassemia

Figure 2 represents the levels of coping where 97% of them used moderate coping and 3% of them used ineffective coping. The parents used effective coping in problem oriented coping (57%), and moderate coping in affective oriented coping (88%).

**Correlation between stress and coping among parents having children with Thalassemia.**

**Table 3:** Correlation between the stress and problem oriented coping, n=100

| Variables | Mean | SD | 'r' |
|---|---|---|---|
| Stress | 78.25 | 15.49 | -0.41** |
| Problem oriented coping | 50.78 | 6.28 | |

**p<0.001- highly significant

The findings reveal that there is a significant correlation (r=-0.41) between the stress score and problem oriented coping at p<0.001 level. This indicates that the parents using less problem oriented coping mechanisms are experiencing more stress.

**Table 4:** Correlation between the stress and affective oriented coping, n=100

| Variables | Mean | SD | 'r' |
|---|---|---|---|
| Stress | 78.25 | 15.49 | 0.16 |
| Affective oriented coping | 92.89 | 6.42 | |

coping where 'r' value shows negligible positive correlation (r=0.16).

**Table 5:** Correlation between the overall stress and coping, n=100

| Variables | Mean | SD | 'r' |
|---|---|---|---|
| Stress | 78.25 | 15.49 | -0.15 |
| Coping | 143.67 | 10.48 | |

The correlation value of 'r' shows negligible negative correlation (r=-0.15). Hence there is no significant relationship found between stress and coping used by the parents in this study. Studies have found that parents who use more problem solving coping strategies tend to be more actively involved in their child's care than parents who use emotion focused coping strategies. [2]

**Association between stress and coping among parents having children with Thalassemia and the selected baseline variables**

The obtained results from the study showed that there was association between the educational status and the stress at p< 0.01 level of significance. The obtained value of 'r' was -0.28, which indicates that lower the educational status, the greater the stress experienced by them.

Association was also found between the income and stress of the sample. The obtained 'r' value was -0.40 and is highly significant at p<0.001 level. This shows that the parents having less income experienced more stress.

The data clearly shows that there was a significant relationship between the stress scores and the birth order of the child (t value – 2.21) at p<0.01. This shows that higher the birth order; greateris the stress of parents. There was also a significant relationship found between the stress and the number of siblings affected (t= 2.41) at p<0.01. Parents having more than one child affected with Thalassemia experienced more stress. Association was found between the stress and previous counseling received (t= 2.81). The value was significant at p<0.01. The data shows that parents who did not receive previous counseling had more stress. There exists a strong association between coping and family type (t=2.30) at p<0.01 level of significance. Nuclear families were found to use better coping when compared to those living in joint families. A strong association also exists between coping and place of residence (t= 2.38) at p<0.01 level of significance. The parents belonging to the urban community are found to cope better than those living in rural areas.

## 5. Conclusion

The findings of the study clearly point out that Thalassemia is a stressful event faced by the parents and they are not using adequate coping mechanisms in order to deal with it. The problem oriented coping is used effectively rather than affective oriented which also suggests that positive attitude towards stress is present but needs to be better handled. This can be enforced by providing psychological support; more information about the disease condition, screening; and having counseling sessions in order to help them deal positively with the present condition or the illness of the child. The investigator suggests that all parents of children having Thalassemia should be given adequate counseling and psychological support in order to cope with the disease more effectively.

## 6. Limitations

1. The study was undertaken in the day care ward of St. John's Medical College Hospital which limits its generalization.
2. Purposive sampling technique was used for this study, which is not a representative of the population.

## 7. Recommendations

1. Qualitative study can be undertaken to analyze the effect of Thalassemia on parents as it helps in knowing the broad perspective of impact of the illness.
2. A similar study can be conducted by comparing impact of Thalassemia with other chronic illnesses.
3. A study can be conducted to assess the prevalence of Thalassemia in Bangalore.

## 8. Scope and Implications in Nursing

Nursing education should lay emphasis on preparing prospective nurses who are able to deal with the psychological aspects of illness through good communication and counseling. Nurses may influence the parents' perception of the child's illness by providing them with relevant information, reinforcing and encouraging them to express their feelings and concerns by providing individual and group counseling.

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