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### Cover Page Footnote

We express our sincere gratitude to the hospital authorities for their support, and sincere appreciation goes to the caregivers of children with Thalassemia for their kind co-operation

# Stress factors among caregivers of children with Thalassemia

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## Abstract

**Introduction:** Thalassemia is one of the most common genetic diseases known to mankind. Children with Thalassemia require medical, surgical and nursing care. Family members and caregivers of the affected children play a vital role during treatment. Moreover, they also undergo abundant stress and emotional changes concerning their children's lives. **Objective:** To identify factors associated with stress and to correlate the factors with selected demographic variables in caregivers of children with Thalassemia. **Materials and Methods:** A descriptive survey was conducted among sixty caregivers of children with Thalassemia, admitted in the Thalassemia ward of a selected hospital in Bangalore. Demographic data of the subjects, and the perceived stress were assessed using structured interview questionnaire. Data were analyzed using descriptive and inferential statistics. **Results:** Results showed that caregivers experienced significant stress on the following domains: daily care stress (DM1) with a score of  $2.82 \pm 1.14$  (mean $\pm$ sd), family emotional stress (DM2)  $24.43 \pm 9.65$ , social stress (DM3)  $3.30 \pm 1.59$ , financial stress (DM4)  $0.90 \pm 0.30$  and personal development stress (DM5)  $3.77 \pm 1.73$ . Results indicated a significant positive correlation between the stress domains and age, ( $r=0.64$ ,  $p<0.05$ ) family size ( $r=0.58$ ,  $p<0.05$ ) and duration of contact ( $r=0.70$ ,  $p<0.05$ ) of the caregiver with the child. **Conclusion:** The study shows that stress among caregivers is significant in the domain of 'family emotional stress', indicating that family members certainly experience more burden in providing care to children with Thalassemia.

**Key words:** Stress, caregivers, children with Thalassemia

## INTRODUCTION

Increasing number of children are admitted to hospitals, with treatment regimens requiring constant vigilance by family members and supportive caregivers. Serious illness and disability often have a devastating impact on caregivers and family members (Hussain and Juyal, 2007). 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. The carrier rate for  $\beta$ -Thalassemia varies from 1-17 % in India with an average of 3.2 %, which means that on an average one in every 25 Indians is a carrier of Thalassemia. One among 204 children born in a year are affected with Thalassemia (Indian Organisation of Thalessemia, 2014). 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 offsprings. They perceive themselves to be responsible, guilty and hopeless, as well as worried about the health and future of the affected children

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(Gyan and Mudra, 2012). Thus, it is important for the nursing staff to identify the stress related domains of caregivers of children with Thalassemia. The present study was carried out to identify factors associated with stress, and to correlate the stress-associated factors in caregivers of children having Thalassemia with selected demographic variables.

## MATERIALS AND METHODS

A descriptive survey approach, with descriptive research design, was used for the study. Convenient sampling technique was used to collect data from 60 caregivers of children with Thalassemia. The responses were collected from the Thalassemia ward of Vanivilas Hospital, Bangalore. Based on review of literature, the demographic proforma and structured interview having five domains such as daily care stress (DM1) with 04 items, family emotional stress (DM2) with 44 items, social stress (DM3) with 05 items, financial stress (DM4) with one item, and personal development stress (DM5) with 06 items, were developed to assess the stress factors among caregivers of children with Thalassemia. Five experts, two psychiatric nurses, two child health nurses and one statistician, validated the tool.

Test and re-test method was used to establish reliability of the tool and correlation co-efficient was computed. For this purpose, the tool was administered to 10 caregivers of children with Thalassemia and the same tool was re-administered after 10 days to the same subjects. Pre and post-test scores were computed using McNemar test. The 'r' value was found to be 0.8. The scoring of items were done by assigning score of 1 for agree, 2 for disagree and 3 for no response item. Data collection was carried out after obtaining permission and ethical clearance from the concerned authorities, and written informed consent was obtained from the subjects. The collected data were coded and analysed using SPSS v.16.0. The obtained data were organized according to the objectives of the study using descriptive and inferential statistics.

## RESULTS

**Table 1:** Frequency distribution of subjects according to demographic variables of the caregivers (N=60)

| Demographic Variables                                     | Frequency (f) | Percentage (%) |
|---|---------------|----------------|
| <b>Gender</b>   |               |                |
| Male  | 31            | 51.70          |
| Female  | 29            | 48.30          |
| <b>Age (in years)</b>                                     |               |                |
| 18-30   | 26            | 43.30          |
| 31-42   | 31            | 51.70          |
| 43-54   | 03            | 05.00          |
| <b>Religion</b>   |               |                |
| Hindu   | 40            | 66.67          |
| Muslim  | 18            | 30.00          |
| Christian   | 02            | 03.33          |
| <b>Educational Qualification</b>                          |               |                |
| Illiterate  | 03            | 05.00          |
| School education  | 39            | 65.10          |
| Graduates   | 16            | 21.70          |
| Others  | 05            | 8.30           |
| <b>Occupation (caregiver)</b>                             |               |                |
| House wife  | 25            | 41.70          |
| Business  | 07            | 11.70          |
| Labour  | 11            | 18.30          |
| Student   | 01            | 01.70          |
| Any others  | 16            | 26.60          |
| <b>Marital Status</b>                                     |               |                |
| Unmarried   | 01            | 01.70          |
| Married   | 59            | 93.30          |
| <b>Family Size (no. of members)</b>                       |               |                |
| 3-7   | 50            | 83.30          |
| 8-12  | 07            | 11.70          |
| 13-17   | 03            | 05.00          |
| <b>Monthly Income (rupees)</b>                            |               |                |
| <1000   | 07            | 11.70          |
| 1001-7000   | 37            | 61.70          |
| 7001-11000  | 16            | 26.70          |
| >11000  | 03            | 05.00          |
| <b>Nature of relation of the Caregiver with the child</b> |               |                |
| Father  | 28            | 46.70          |
| Mother  | 29            | 43.30          |
| Brother   | 01            | 01.70          |
| Sister  | 02            | 03.30          |
| Any Others  | 03            | 05.00          |
| <b>Duration of contact of the Caregiver (in years)</b>    |               |                |
| 3-6   | 25            | 41.70          |
| 7-10  | 23            | 38.30          |
| 11-14   | 09            | 15.00          |
| 15-18   | 03            | 05.00          |

Table 1 shows that the gender distribution observed was almost equal, in terms of numbers, in this study- 31(51.7%) were males and 29(48.3%) were females. Majority (51.7%) of caregivers were in the age group of 31-42years. Majority (66.7%) of the

respondents were Hindus. More than half (65.1%) of the respondents had completed their school education. In terms of their occupation, majority (41.7%) were housewives, and it is interesting to note that one (01.7%) caregiver was a student. Regarding marital status, majority (98.3%) of the caregivers were married. More than, three fourth of the caregivers (83.3%) were living in a family of three to seven members.

More than half of the subjects had a monthly income of INR 1001–7000. As for the relationship of caregivers with the children, 46.7% were fathers and 43.4% were mothers, compared to other relationships providing care to children with Thalassemia. Majority of the contact-years by caregivers with the children were three to six years (41.7%).

**Table 2:** Domain-wise distribution of stress among the caregivers (N=60)

| Domain                              | Percentage (%) | Mean  | SD    |
|-------------------------------------|----------------|-------|-------|
| Daily care stress (DM1)             | 06.6           | 2.82  | 01.14 |
| Family emotional stress (DM2)       | 73.3           | 24.43 | 09.65 |
| Social stress (DM3)                 | 8.3            | 3.30  | 01.59 |
| Financial stress (DM4)              | 16.6           | 0.90  | 0.30  |
| Personal developmental stress (DM5) | 10             | 3.77  | 01.73 |
| Total Score                         | 60             | 35.22 | 14.40 |

Results in Table 2 shows that stress faced by caregivers was more in the domain of family emotional stress (24.43 ±9.65). This shows that family members certainly experienced more burden (73.3%) in providing care to children with Thalassemia

**Table 3:** Correlation between stress and selected demographic variables of caregivers (N=60)

| Selected Variables  | Coefficient Correlation ('r' value) | Level of Significance (p<0.05) |
|---------------------|-------------------------------------|--------------------------------|
| Age                 | 0.64                                | significant                    |
| Family size         | 0.58                                | significant                    |
| Duration of contact | 0.70                                | significant                    |

Table 3 shows significant positive correlation between the family emotional stress (DM2) and the selected demographic variables such as age (r=0.64, p<0.05), family size (r=0.58, p<0.05) and duration of contact (r=0.70, p<0.05) of the caregiver with the child.

## DISCUSSION

The study revealed that caregivers of children with Thalassemia were affected by stress in different domains, and the domain wise analysis revealed that the percentage of stress affecting each domain were - daily care stress (DM1)6.6%, family emotional stress (DM2) 73.3%, social stress (DM3)8.3%, financial stress (DM4) 16.6% and personal developmental stress (DM5) 10%. Moreover, the findings also showed that the caregiver stress was more in the domain of the 'family emotional stress', indicating more burden on the family members of children with Thalassemia. These findings are similar to an earlier study conducted by Raptip et al., (2012) to assess the major stress factors affecting caregivers of children with Thalassemia, and the study results showed that 90% of caregiver stress was related to family emotion (Raptip, York, and Weisle, 2012). Another study conducted by Torchus, Brown & Nash (2011) to assess the level of depression and stress among caregivers of inpatient children with Thalassemia found that caregiver stress was high (78%) with regard to stressed family relationships.

The results of the present study indicate a significant positive correlation between stress domains and age (r=0.64, p<0.05), family size (r=0.58, p<0.05) and duration of contact (r=0.70, p<0.05) of the caregiver with the child. The findings showed that the stress felt by caregivers is less as their age increases, which shows that the adults are more mature in handling a stressful situation. The family with less number of members experienced reduced stress due to their minimized focus on all family needs, and the caregivers staying for a longer duration with the child experienced increased level of stress as it becomes a burden to them after a prolonged duration.

The results of the present study is supported by Beratis, Morge and Saho (2010) with similar study findings, where a positive correlation between stress domains and the caregivers age (r=0.32, p<0.05) and duration of contact (r=0.56, p<0.05) with the children admitted in the Thalassemia units were observed. Another study conducted by Samuel, Olsson, and Hwang (2010) showed a positive correlation between stress factors and availability of number of family members providing care to the children with

Thalassemia. Based on our study results, large scale study on caregivers of children with Thalassemia may be done along with a correlation study between stress domains and children's profile.

### CONCLUSION

The present study findings reveal stress dimensions of caregivers' experiences in providing long-term care and support to children with Thalassemia. The stress, experienced by caregivers, is due to lack of caregivers' knowledge regarding available support systems in the family and the society. It is the nurse's role to help caregivers cope with their family and hospital environment by providing adequate health teaching, and directing necessary resources for the caregivers.

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