

A Study to Assess Perceived Stress Level among Care Givers of Child with Major Thalassemia in Selected Hospital Rajasthan

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Abstract

Introduction: 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. It is 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 care givers. *Method:* Descriptive cross sectional design with 70 care givers of children with Thalassemia Major admitted in Thallassemia unit of UMED hospital by using total enumerative sampling technique was selected and PSS instrument was used to collect data for 7 to 10 minutes through interview approach of self reporting. Association of demographic variables and level of stress was assessed by χ^2 and mean & SD. *Result:* In this present study the care givers experienced moderate level of stress last one month indicating that they have more burden in caring children with thalassemia Major. Study showed that there was no association exist between the demographic variables such as, number of children, and number of children with chronic illness occupation family income and diversion activity, other demographic variables such as age, respondents and, education had significant association. *Conclusion:* The care givers stress need to be addressed adequately with appropriate interventional package. Care givers need frequent guidance and counseling services and need to follow divisional activity to keep them healthy mentally. 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.

Keywords: Stress; Care Givers; Child 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 [1]. 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 β -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 [2]. Children with Thalassemia need monthly blood transfusion, regular iron chelation therapy and in some cases, bone marrow transplantation [3]. 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 [4]. 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. It is 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. Less work has been done regarding the stress level of care givers of chronically ill children [5]. Thus, it is important for the nursing staff to identify the perceived stress level of caregivers of children with Thalassemia. a study therefore was planned aiming to identify perceived stress level of care givers and its association with selected demographic variables.

Title

A study to assess perceived stress level among care givers of child with major Thalacemia in selected hospital Rajasthan.

Objective

1. To assess the perceived stress level among care givers of child with major Thalacemia in selected hospital Rajasthan.
2. To associate the perceived stress level with selected demographic variable of care givers of child with major Thalacemia in selected hospital Rajasthan.

Operational definitions

- *Assessment:* In this study it refers to the organized, systematic continuous of collecting Data from the care givers of children with Thalassemia Major.
- *Stress:* In this study, it refers to the psychological, physiological and sociological imbalance experienced by the care givers for last one month due to chronic suffering of children with Thalassemia Major, which is measured by perceived stress scale.
- *Care givers:* It refers to Father, Mother and grandparents, guardians or primary care giver of children with Thalacemia Major during their sick period.
- *Children:* It refers to the Children less than eighteen years who are in Thalassemia unit.
- *Thalassemia:* It refers to a group of inherited blood disorder characterized by reduced (or) absence of hemoglobin to oxygen carrying proteins inside the red blood cells.

Material and Methods

- *Research approach and design:* The research

approach used for this study is Qualitative approach. A descriptive cross sectional study design was adopted to assess level of stress among women with infertility

- *Research setting:* UMED hospital, Thalassemia unit.
- *Target population:* Care givers of children with Thalassemia
- *Accessible Sample:* Care givers of children with Thalassemia Major admitted in UMED hospital in Thalassemia unit from blood transfusion, Jodhpur.
- *Sample size:* a total of 70 Care givers who are willing to participate, who are coming to UMED hospital with their child for blood transfusion not less than 3 months, and who is able to understand Hindi, were included in the study and those who are physically and mentally ill and siblings of the Thalassemia child is excluded from the study.
- *Sample design:* Non probability total enumerative approach of purposive sampling technique was adopted. The entire population who is meeting inclusion criteria was included in the study.
- *Development and description of tool:* A standard tool Sheldon Cohen "Perceived Stress Scale" (PSS) for care givers tool was used. Tool contains 10 items, 4 positive stated questions and 6 negative stated questions. The Perceived Stress Scale (PSS) is a classic stress assessment instrument. The tool, while originally developed in 1983, remains a popular choice for helping us understand how different situations affect our feelings and our perceived stress. Individual scores on the PSS can range from 0 to 40 with higher scores indicating higher perceived stress. The questions in this scale ask about feelings and thoughts during the last month [6,7]. The tool was translated into Hindi version and back translated to check English to check the validity of Hindi version with help of expert opinion, and reliability was assess by test and retest method. The tool contains demographic variables also to assess the association. They includes, Respondent/care givers, Age of care givers, No of Children, Education, Occupation, No of other Children with chronic illness, Family income and Diversion activity followed
- *Reliability:* The reliability was established by assessing the stability of the tool by test-retest method using a correlation coefficient method. The tool was found to be reliable.

Table 2: Score and interpretation

Level of stress	Score
Mild stress	0-13
Moderate stress	14-26
Severe stress	27-40

Table 3: Method of score:

Rating	Negative item	positive item
Never	0	4
Almost never	1	3
Sometime	2	2
Fairly often	3	1
Very often	4	0

- *Validity:* The content validity of the tool was assessed by obtaining opinion from three experts in the field of Hindi literature and nursing. The tool was translated into Hindi version and back translated to check English to check the validity of Hindi version with help of expert opinion.
- *Ethical safeguard:* Informed Consent were obtained from the participants and explained about the purpose of the study. The ethical guidelines were followed throughout the study.
- *Pilot study:* The pilot-study was conducted from for 10% of total sample. During the study, practicability of the tool and feasibility of the study was assessed. Subjects were given a questionnaire to assess the level of stress among infertile women with reproductive age group.
- *Actual data collection:* The purpose of the study was well explained before data collection. Data were collected by giving standard questions to the care givers after obtaining informed consent. It took 7 to 12 minutes to administer standard PSS for care givers. Survey approach under self reporting method was used to collect data. Data was collected for the duration of one two months time period.
- *Analysis:* Descriptive statistics such as table, mean and standard deviation and inferential statistics such as chi square(χ^2) was used to analyze the data and infer the result.

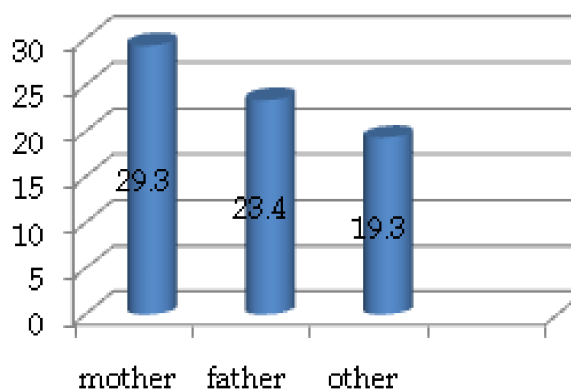
Result

From the table-1 it is understood that mostly mother is accompanying the children during their hospital visit, and respondent below 35 years are seems to be more than above 35 years. Most of the respondent has 2 children. As per

educational qualification most of them had finished matriculation, regarding employment status all most half of the respondent are employed, two respondent have more than 1 children with chronic illness. Only 35.5% of respondent was following one or other divisional activity,

Table 4: Frequency and percentage distribution of demographic variables

Demographic variables	Frequency	Percentage (%)
1. Respondent		
a. Mother	30	42.9
b. Father	23	32.9
c. Other	17	24.2
2. Age		
a. 21-35 years	41	58.6
b. > 35 yrs	29	41.4
3. No of Children		
a. 1	14	20
b. 2	45	64.3
c. >2	11	15.7
4. Education		
a. Uneducated	9	12.9
b. Matric	37	52.9
c. Gradate	24	34.2
5. Occupation		
a. Umemployed	32	54.3
b. Employed	38	45.7
6. No of other Children with chronic illness		
a. 1	68	97.1
b. >1	2	2.9
7. Family income		
a. >10000 Rs	12	17.1
b. 10000-30000 Rs	30	42.9
c. >30000 Rs	28	40
8. Diversion activity followed		
Yes	25	35.7
No	45	64.3

**Fig. 1:** Mean score of the respondents:

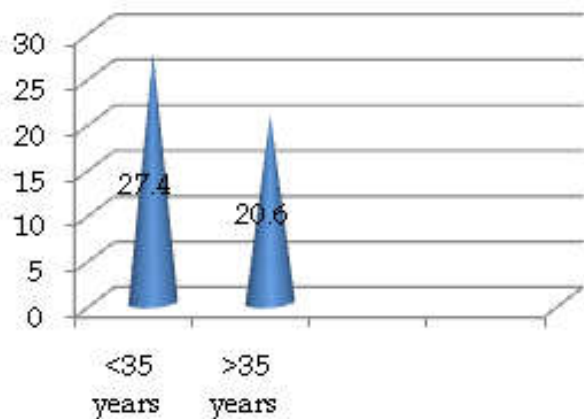


Fig. 2: Mean and age of sample

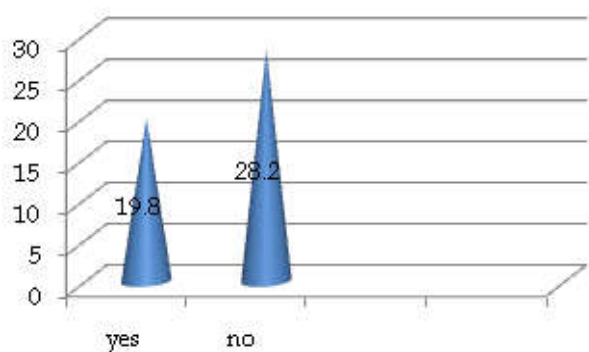


Fig. 3: Mean and divisional activity followed

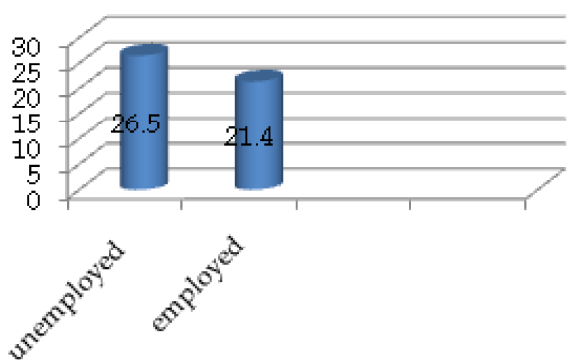


Fig. 4: Mean and occupation of the respondent

Among respondent the mother stress was higher (mean 29.3) comparing to father stress level (mean 23.5) and other respondent, care givers >35 years had higher stress level (mean 31.3) than <35 years, there is no much variations observed in the mean score of care givers with number of children, and number of children with chronic

illness, occupation and family income. Graduated person exhibited mild stress level where as other two categories had moderate to severe stress level. Occupation of the care giver influenced the level of stress and mean score of an unemployed care giver was 26.5. The care givers who had one or other form of diversion activities had less stress level (mean 19.8) comparing with others those who do not.

Form the table 5 it was inferred that the 40 samples were suffering with moderate level of stress care givers are suffering with moderate level of stress as the mean score was 24 with the SD of 3.17.

There was a association exist between the demographic variables such as, occupation family income and diversion activity, other demographic variables such as age, respondents, education, number of children, and number of children with chronic illness had no significant relationship.

Discussion

A study conducted on lived experiences of mother carrying for children with thalassemia major in Thailand. This quantitative study explored the lived experiences of 15 mothers of children with thalassemia major by conducting semi-structured interviews; the data were analyzed utilizing content analysis. Six themes were identified: lack of knowledge about thalassemia, psychosocial problems, concerns for the future, social support systems, financial difficulty and the effectiveness of health services. These findings suggested that a holistic, culturally sensitive nursing approach should be considered when carrying for children with thalassemia [8].

A study conducted about a qualitative study on the experiences of mothers caring for their children with thalassemia in Athens, Greece. Using a semi structured questionnaire, the researchers interviewed convenient sample of 19 mothers who have children with thalassemia. A considerable failure to provide information regarding carrier testing prior to married or genetic screening for thalassemia during early pregnancy at the time of the participant's pregnancies was noted. Emotional distress, fear of death, and difficulty in dealing with feelings were some of the mothers concerns [9].

Table 5: Frequency, Percentage, Mean, Median and Standard Deviation of perceived stress level:

Score	Interpretation	Frequency	Percentage	Mean	Median	Standard deviation
0-13	Mild stress	21	30	24	24.4	3.17
14-26	Moderate stress	40	57.1			
27-40	Severe stress	9	12.9			

A study Conducted on analysis of parenting problems for caregivers of children with thalassemia. A situational analysis of problematic situations was conducted for 37 caregivers of children with thalassemia who ranged in age from 5-13 years. Participants responded to a semi-structured interview related to caring for a child with thalassemia. The interview included the domains of medication adherence, nutrition, minimizing and coping with pain episodes, social problems, academic difficulties and children's expression of negative feelings related to having thalassemia. Caregivers described 356 problems. Almost all caregivers reported experiencing problems with their children's nutrition, minimizing pain episodes and their children expressing feelings about having thalassemia. Moderately challenging and emotionally upsetting problems were reported for coping with symptoms. Nutrition issues were more frequently reported for younger children. Findings have salient clinical implications for the care of children with thalacemia [10].

From the present study it was inferred that the care givers are suffering with moderate level of stress and the mean score was 24 and the range is towards upper limit, it indicates that over the period of time they may develop severe level of stress. Among respondent the mother stress was higher (mean 29.3) comparing to father stress level (mean 23.5) and other respondent, care givers >35 years had higher stress level (mean 31.3) than <35 years, there is no much variations observed in the mean score of care givers with number of children, and number of children with chronic illness, occupation and family income. Graduated person exhibited mild stress level where as other two categories had moderate to severe stress level. Occupation of the care giver influenced the level of stress and mean score of an unemployed care giver was 26.5. The care givers who had one or other form of diversion activities had less stress level (mean 19.8) comparing with others those who do not.

There was no association exist between the demographic variables such as, number of children, and number of children with chronic illness occupation family income and diversion activity, other demographic variables such as age, respondents and, education had significant association.

Conclusion

In this present study the care givers experienced moderate level of stress indicating that they have

more burden in caring children with thalassemia Major. Study showed that there was no association exist between the demographic variables such as, number of children, and number of children with chronic illness occupation family income and diversion activity, other demographic variables such as age, respondents and, education had significant association. The inherited disorders of hemoglobin are responsible for an extremely complex series. Sickle cell anemia and Thalasemia can cause chronic ill-health and can be life-threatening. Thalassemic children are not like children with blood malignancies, who are treated with chemotherapy protocols and marrow transplantation, where as thalassemic children need monthly blood transfusion and regular iron chelation. Thus, parents of these children are exposed to practice emotional suffering very frequently and constantly for their off springs' devastating health problem. They are usually responsible, guilty and hopeless, as well as worried about the health and future of their child. The care givers stress need to be addressed adequately with appropriate interventional package. Care givers need frequent guidance and counseling services and need to follow divisional activity to keep them healthy mentally. 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.

Recommendations

The present study assesses only the perceived level of stress of care giver but not the coping ability, the coping ability in relation to perceived level of stress can be assessed by using coping check list, correlation can be done between these variables, and also the study sample is only care givers of child with major thalacemia who is in need of blood tansfusion and visiting to UMED hospital thalacemia unit every 10 days once, but similar study can be conducted for care givers of children with thalacemia major and minor and comparison can be mad.

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