

# Caregiver burden and related factors in parents of children with Thalassemia

Maryam Alizadeh<sup>1</sup>, Minoo Mitra Chehrzad<sup>2\*</sup>, Mahshid Mirzaee<sup>2</sup>, Ehsan Kazem Nejad Leyli<sup>3</sup>

<sup>1</sup>Pediatric Nurse (MSN), School of Nursing and Midwifery, Guilan University of Medical Sciences, Rasht, Iran, <sup>2</sup> Department of pediatric Nursing, Instructor, PhD Candidate, School of Nursing and Midwifery, Guilan University of Medical Sciences, Rasht, Iran, <sup>3</sup> Bio-Statistics, Associate Professor, Guilan University of Medical Sciences, Rasht, Iran.

**Correspondence:** Minoo Mitra Chehrzad, Department of pediatric Nursing, Instructor, PhD Candidate, School of Nursing and Midwifery, Guilan University of Medical Sciences, Rasht, Iran.

## ABSTRACT

**Background and objective:** Thalassemia affects not only the life of patients, but also leaves psychological, social, and economic burden on the parents, resulting in caregiver burden in parents. Thus, the objective of this study was to evaluate caregiver burden of parents of children with thalassemia major and factors related to it. **Materials and Methods:** In this descriptive-analytical study, 120 parents of children with thalassemia major were selected using proportional randomized sampling method. ZARIT caregiver burden questionnaire was used to collect data. Data were analyzed by using SPSS 21 software and descriptive and analytical tests. The mean and standard deviation of parental caregiver burden was  $16.43 \pm 7.76$  and 45.8% of parents tolerated high level of caregiver burden. There was also a significant correlation between caregiver burden and child education ( $P = 0.015$ ) and caring other child at home ( $P < 0.006$ ). **Conclusion:** given high level of parental care in children with thalassemia major, identifying factors involved in the incidence of caregiver burden and designing appropriate interventions to reduce the caregiver burden and improve the quality of life of caregivers and improve the quality of care provided to the patient seem to be necessary.

**Keywords:** burden, parents, children, Thalassemia.

## Introduction

Disease is one of the challenges faced by many people. It prevents people to perform their daily activities. Among diseases, chronic diseases have an increasing incidence in the world and require providing care and rehabilitation <sup>[1]</sup> due to the development of therapeutic methods and reduced mortality rate. Chronic disease is a health problem lasting three months or more. It affects the normal activities of the children and increases the need for providing cares at home or special medical care <sup>[2]</sup>. Thalassemia is a chronic disease and a common genetic disorder in the world. It includes a variety of hereditary

blood disorders caused due to defect in the rate of production of specific globin chains in hemoglobin <sup>[3, 4]</sup>. The two main types of thalassemia are  $\alpha$  - Thalassemia and  $\beta$  - Thalassemia.  $\beta$  - Thalassemia is the most common type of thalassemia and can be seen in four states: 1-thalassemia minor, which is asymptomatic carriers, 1-thalassemia trait, which causes mild microcytic anemia, 3-thalassemia intermedia, characterized by splenomegaly and moderate to severe anemia, and 4-thalassemia major, which causes severe anemia and is not possible without blood transfusion <sup>[4]</sup>. Three percent of the world's population is carriers of  $\beta$ -thalassemia <sup>[5]</sup>. It is estimated that about 15 billion people in the world to suffer from thalassemia disorders <sup>[6]</sup>. The prevalence of the disease in Iran is about 3-4% and there are more than 3 billion  $\beta$ -thalassemia carriers and about 25000 patients with thalassemia major <sup>[7, 8]</sup>. Due to the high prevalence of this disease, it causes many problems for the patient, the family and the health system <sup>[8]</sup>. Thalassemia is not just a health problem for patients and their families, but also imposes high costs for public health system. These costs include regular blood transfusions, excess body iron excretion, and frequent hospitalizations <sup>[9]</sup>. Children with

### Access this article online

**Website:** www.japer.in

**E-ISSN:** 2249-3379

**How to cite this article:** Maryam Alizadeh, Minoo Mitra Chehrzad, Mahshid Mirzaee, Ehsan Kazem Nejad Leyli. Caregiver burden and related factors in parents of children with Thalassemia. J Adv Pharm Edu Res 2019;9(S2):35-39.

**Source of Support:** Nil, Conflict of Interest: None declared.

This is an open access journal, and articles are distributed under the terms of the Creative Commons Attribution-Non Commercial-ShareAlike 4.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as appropriate credit is given and the new creations are licensed under the identical terms.

thalassemia major require long-term treatment and regular blood transfusions, imposing social problems and financial costs for patients, families and the health care system. Thalassemia has a significant impact on the lives of children. These patients suffer from anemia, and thus, physical activity becomes boring and intolerable for them. In addition, overstimulation of bone marrow causes facial changes, delayed growth, osteoporosis, ascites, enlarged liver, and finally arrhythmias and death caused by heart failure <sup>[10]</sup>.

Although regular blood transfusions increase the patients' life span <sup>[8]</sup> and optimal therapeutic measures have reduced the difficulties of thalassemia, psychological and social problems of the family have special importance <sup>[11]</sup>. The results of the research conducted by Kim showed that having an ill child causes severe mental and psychological complications for all members of the family, especially mothers <sup>[12]</sup>. Manor-Binyamini showed that the mental and psychological status of mothers of families with children suffering from chronic disease is significantly worse than that of other mothers <sup>[13]</sup>. The results of the research conducted by Papastavrou et al showed that caregivers of cancer patients experience high levels of care strain and depression <sup>[14]</sup>. In addition, the results of the study conducted by Mazzone et al. on the problems of families of patients with thalassemia showed that families face with many psychological and emotional problems <sup>[8]</sup>. As the family is the most important element of the community, it is responsible for providing proper and appropriate health care to the patient, so that informal care or family care has entered health literature since 1980 and it is nowadays considered as the key of the long-term care system. The process of transfer of care from the hospital to the home imposes caregiver burden to family <sup>[15]</sup>. Caregiver burden is defined as a certain degree of stress and difficulty expressed by the caregiver or family of the patient, which includes a range of psychological, emotional, social, psychological, and economic problems <sup>[16]</sup>. Caregiver burden is a complex and general concept and is defined as a negative reaction, which caregiver experiences as a result of proving the care <sup>[17]</sup>. Caregiver burden is defined as physical, mental, and social responses of caregiver resulting from imbalances between care needs or other care tasks. This imbalance relates to social, personal, physical, emotional and financial resources of caregiver <sup>[18]</sup>. Caregiver burden have two objective and subjective dimensions: objective caregiver burden can be considered as duration and the level of effort required to meet the needs of others, which includes the problems related to financial, family, and social costs, and the subjective health burden refers to level of experience of caregiver's access in facing with objective caregiver burden, which includes emotional and behavioral problems caused by disease <sup>[15]</sup>. Chronic caregiver burden deeply affects the quality of life of caring parents and reduces their mental satisfaction with common life. In addition, the effect of the caregiver burden on the family's function needs to be examined <sup>[14]</sup>.

Caregiver burden is the most important determinant of quality of life of caregivers. In addition, there is a direct and significant relationship between quality of life of children and mothers

because one of the factors affecting the quality of life of children is parental health and it can be influenced by caregiver burden <sup>[18]</sup>. The caregiver burden strongly affects the quality of life of parents providing the care and reduces their mental satisfaction with shared life <sup>[16]</sup>. Studies have shown that several factors affect the caregiver's caregiver burden. The results of research conducted by Wang et al to evaluate the predictive factors of caregiver burden in parents of children with leukemia showed that factors such as duration of care, anxiety, general health, family income, social support and number of caregivers are predictors of caregiver burden in parents of these children <sup>[19]</sup>. Other studies have identified the level of social support, the type of disease, the increase in the duration of the disease and the increase in clinical symptoms of the disease in the patient as factors affecting the caregiver's caregiver burden <sup>[20-22]</sup>. Given the high prevalence of thalassemia and the many problems imposed on patient, family, and health system, and as caregiver burden is high in the parents of ill children and given its adverse impacts on the caregiver burden, early diagnosis of it and associated factors can play major role in enhancing the health level of parents and improving the quality of life of these patients and correct planning in this regard requires having adequate knowledge. Therefore, investigating the parental caregiver burden of these children seems to be an essential to provide solutions, design and implement a program which can reduce parental caregiver burden and reduce the negative effects of this process on the lives of parents and lead to an improvement in the quality of life of parents of these children.

## Methodology

This study is analytical and cross sectional type of study. The research population included 149 parents (father or mother) of a child with thalassemia major aged below 21 years, who admitted to all treatment centers providing thalassemia services to the general population of Gilan province in 2017. Proportional randomized sampling method was used and sample size was determined to be 149 people based on the results of the same study <sup>[16]</sup> with 95% confidence and 90% test power. From each center, 80% of the parents of thalassemia major children were included in the study. The inclusion criteria of study included the lack of mental disease in primary caregiver, reading and writing literacy, both parents are living, the child's life with both parents, the follow up of parents in the treatment of the child, having a child with thalassemia major below the age of 21 years and willingness to participate in the study. For this purpose, the license of the Ethics Committee with the code of IR.GUMS.REC.1396.258 was obtained. Then, the introduction letter for research project was obtained from Research Deputy of Gilan University of Medical Sciences. After necessary coordination during the three months from January to March 2017, the researcher attended at all departments of all hospitals of the province. Receiving the written consent form of the parents, questionnaires were provided for the parents. The

questionnaires were completed verbally and face to face interviews with parents. The data collection tools included two questionnaires.

- 1) Demographic information questionnaire: it included parent and child characteristics.
- 2) Zarit Caregiver Burden Interview (ZBI-12) questionnaire: it included 12 questions in two domains of personal strain and role strain: each question is scored in 5-point Likert scale from never = 0 to always = 4, with scores range between zero and 48. The score of 17 or more indicates a high caregiver's caregiver burden. This questionnaire was validated in 2015 by Rajabi et al in Mashhad University of Medical Sciences-Iran [23].

After collecting data, there were entered into SPSS 21 software. To describe the quantitative variables, the statistical variables of mean, standard deviation, median, minimum, and maximum with confidence interval of 95% were used, to compare the child and family quantitative variables, independent t-test was used, and to compare the child and family qualitative variables, Chi-square test was used.

## Results

The results showed that the majority of parents were female (76.7%). The age of majority of parents was 41-50 years (55.8%) with mean age of  $43.5 \pm 6.77$  years). Majority of them did not care another patient at home (85.8%) and were not supported by governmental institutions (88.3%). Majority of children were female (55.8%) with age of 12–21 years (75.8%) and mean age of  $15.34 \pm 4.77$ . In addition, majority of them had high school level of education and higher (32.5%). The highest frequency of visits for blood transfusion was once per month (58.5%). Mean and SD of prenatal caregiver burden of children with thalassemia major was  $16.43 \pm 7.76$  within the range of 0-48. This range was  $11.25 \pm 5.5$  in the role strain domain and  $5.18 \pm 3.16$  in the personal strain domain (Table 1). The majority of families of children with thalassemia major had high caregiver burden (54.2%) in the personal strain domain, and in total, 45.8% tolerated high caregiver burden (Table 2). Based on Chi-square test, a significant positive correlation was found between caregiver burden education level of children ( $p=0.015$ ) and caring other patient at home ( $p=0.006$ ) (table 3).

**Table 1: statistical indices of caregiver burden score in general and separately for domains**

| Statistical indices    | mean  | SD   | median | min  | max | Lower bound of confidence interval 95% | Upper bound of confidence interval 95% |
|------------------------|-------|------|--------|------|-----|--|--|
| Caregiver burden score |       |      |        |      |     |  |  |
| Role strain            | 11/25 | 5/85 | 11     | 0/00 | 27  | 10/19                                  | 12/31                                  |
| Personal strain        | 5/18  | 3/16 | 5      | 0/00 | 12  | 4/6                                    | 5/75                                   |
| Total score            | 16/43 | 7/76 | 16     | 0/00 | 35  | 15/02                                  | 17/83                                  |

**Table 2: Distribution of the status of families of children with thalassemia major in terms of caregiver burden in general and separately in different domains**

| frequency                | Caregiver burden status | n   | %    | Lower bound of confidence interval 95% | Upper bound of confidence interval 95% |
|--------------------------|-------------------------|-----|------|--|--|
| Role strain              | Low caregiver burden    | 77  | 64/2 | 55/3                                   | 72/3                                   |
|                          | High caregiver burden   | 43  | 35/8 | 27/7                                   | 44/7                                   |
|                          | Total                   | 120 | 100  | -                                      | -                                      |
| Personal strain          | Low caregiver burden    | 55  | 45/8 | 37/1                                   | 54/8                                   |
|                          | High caregiver burden   | 65  | 54/2 | 45/2                                   | 62/9                                   |
|                          | Total                   | 120 | 100  | -                                      | -                                      |
| General caregiver burden | Low caregiver burden    | 65  | 54/2 | 45/2                                   | 62/9                                   |
|                          | High caregiver burden   | 55  | 45/8 | 37/1                                   | 54/8                                   |
|                          | Total                   | 120 | 100  | -                                      | -                                      |

**Table 3: Comparison of caregiver burden status of parents of children with thalassemia major in terms of individual- social variables of children and parents**

| individual- social variables |                    | Caregiver burden |       |      |       |       |     | p*    |
|------------------------------|--------------------|------------------|-------|------|-------|-------|-----|-------|
|                              |                    | low              |       | high |       | total |     |       |
|                              |                    | n                | %     | n    | %     | n     | %   |       |
| Child education              | illiterate         | 4                | 66/7  | 2    | 33/3  | 6     | 100 | 0/05  |
|                              | Elementary         | 9                | 42/9  | 12   | 57/1  | 21    | 100 |       |
|                              | Secondary school   | 6                | 27/3  | 16   | 72/2  | 22    | 100 |       |
|                              | High school        | 23               | 71/9  | 9    | 28/1  | 32    | 100 |       |
|                              | diploma and higher | 23               | 59    | 16   | 41    | 39    | 100 |       |
|                              | total              | 65               | 53/56 | 55   | 46/44 | 120   | 100 |       |
| Caring other                 | no                 | 61               | 59/2  | 42   | 40/8  | 103   | 100 | 0/006 |

|                 |       |    |       |    |       |     |     |
|-----------------|-------|----|-------|----|-------|-----|-----|
| patient at home | yes   | 4  | 23/5  | 13 | 76/5  | 17  | 100 |
|                 | total | 65 | 41/35 | 55 | 58/65 | 120 | 100 |

\*Chi-Square Test

## Discussion and Conclusion

The results of this study showed that the majority of families of children with thalassemia major had a high level of personal stress, and in general, 45.8% of the families tolerated high level of caregiver burden. In this regard, the results of the study conducted by Talebi et al under title of care strain imposed on caregivers of patients with kidney failure showed that 74.7% of the samples were under severe care strain in personal, social, emotional and economic domains <sup>[1]</sup>. The results of the research conducted by Abbasi et al under the title of relationship between care strain and coping strategies of family caregivers of cancer patients also showed that 45% of participants tolerated care strain higher than the average level <sup>[24]</sup>. The results of the mentioned studies were consistent with the results of this study. The results of the research conducted by Saritas et al on the caregiver burden and social support of caregivers of oncology patients showed that the mean caregiver burden was  $25 \pm 13.59$  and the family had a high level of care <sup>[25]</sup>, which is consistent with the findings of the present study. The results of the research conducted by Bamary et al under the title of "investigating the caregiver burden of primary caregiver of patients with type 2 diabetes", indicated the moderate level of caregiver burden <sup>[11]</sup>, which is not consistent with the results of this study. Due to the difference in the type of disease and the age of the patients, the result can be justified in this way that with increasing the age, physical and psychological problems may also increase, imposing higher level of caregiver burden on these people. Moreover, in this regard, it can be stated that as chronic diseases are associated with symptoms and disabilities, which require long-term treatment and patients would tolerate the disease by the end of their life and face its severe conditions and complications and due to problems caused by chronic patients in a caregiver, and as caregivers of thalassemia patients are required to meet their needs and their patients simultaneously, an additional burden is imposed on caregiver, leading to disorder in playing their roles. In this study, there was a significant correlation between the caregiver burden in terms of child education and caring other patient at home, so that children with primary or secondary education imposed a greater caregiver burden on the family. In addition, families who cared other patient at home tolerated high level of caregiver burden. The results of the research conducted by Bamary et al showed no significant difference between caregiver burden and caregivers' gender, chronic diseases of caregivers and patients' gender <sup>[11]</sup>, which is in line with present study. In this regard, the results of the research conducted by Ahmadi et al on caregiver burden of parents of children with cancer and its related factors showed a significant reverse correlation between caregiver burden and parental age and family income and a significant positive correlation between caregiver burden and

number of hospitalizations <sup>[26]</sup>. It is not consistent with present study. This difference might be due to frequent hospitalization in children with cancer due to disease complications and chemotherapy.

The results of the research conducted by Abbasi et al under the title of care strain and its related factors in patients undergoing hemodialysis showed that there was a significant correlation between total care strain and duration of diseases and age of the caregiver, and caregivers with bad economic status significantly tolerated more care strain <sup>[27]</sup>. This finding is not consistent with that of present study. The reason for this difference seems to be high frequency of hemodialysis during the week as well as the increased age of caregivers and the limitations and issues related to aging process. In this regard, it can be stated that thalassemia, as other chronic diseases, is associated with many challenges, such as the strains of disease control, compliance with the therapeutic program, complicated and costly cares, doing tests and referring to physician, concerns about the future of the disease and disruption in social and family relationships. In this regard, the role of other variables such as age, gender, and economic status, level of education and family factors should not be ignored and they should be taken into consideration when providing nursing cares to improve the caregiver burden.

In general, the results of the present study suggest that families with major thalassemia patients tolerate a high level of caregiver burden. As family members are one of the key components of the care system of patients with chronic diseases, such as thalassemia, and as the main goal in nursing of children is improving the care provided for children and their families, it is suggested that the parents of children with thalassemia major to be evaluated by members of the care team and based on its results, appropriate strategy and interventions are provided to meet the needs and improve the function of the parents in providing the care for children.

## Acknowledgment

This paper was adopted from a master thesis on children's nursing. The research project was approved with code of 96070110 in Health Research Center of Gilan University of Medical Sciences. We thereby appreciate the Research Center for Social Factors Affecting the Health and the honorable Research Deputy, all professors, and staff of thalassemia units as well as parents of thalassemia children for their cooperation in this research.

## References

1. Talebi M, Mokhtari Lakeh N, Rezasoltani P. Caregiver Burden in Caregivers of RenalF Patients under

- Hemodialysis. *Journal of Holistic Nursing and Midwifery*. 2016;26(2):59-68.
2. Jafari S, Mohtashami J, Alaei Karahroudi F, Mansouri S, Rassouli M. Perceived Social Support and Its Correlated Factors in Adolescents with Chronic Disease. *Journal of hayat*. 2016;22(1):65-78.
3. Keshvari M, Ebrahimi A, Abedi H. Relation between Children's Well-Being and Family Function in Children with Thalassemia Major in Isfahan in 2013. *Global Journal of Health Science*. 2016;8(12):170.
4. Hockenbery, J M. Wong's Nursing Care of Infants and Children Arezoomanians S. Tehran. 2011; 9:892.
5. Inamdar S, Inamdar M, Gangrade A. Stress level among caregivers of thalassemia patients. *Ntl J of Community Med*. 2015;6(4):579-82.
6. Varghese A, Ukande U. Impact of selected socio-demographic variables with selected clinical variables and growth parameters among transfusion dependent thalassemia children. *IJAR*. 2017;3(3):38-44.
7. Mirzaei K. The Relationship between Social Support and Depression in Patients with Thalassemia Major in Bushehr, Iran. *Nursing of the Vulnerables*. 2015;2(4):1-14.
8. Pouraboli B, Abedi H A, Abbaszadeh A, Kazemi M. Silent Screams. Experiences of Caregiver Suffering by Parents of Children with Thalassemia: A Qualitative Study. *J Qual Res Health Sci* 2015;3(3):281-91. 8
9. John K. Depression and Thalassemia in children, adolescents and adults. *Health science journal*. 2013;7(3).
10. Pouraboli B, Abedi H A, Abbaszadeh A, Kazemi M. The Burden of Care: Experiences of Parents of Children with Thalassemia. *Journal of Nursing and Care*. 2017.
11. Radha Aziz A, Hashim Mohammed S, Fakhir Aburaghif L. Burden of Caregivers Care for Children with Thalassemia at Babylon Child and Maternity Teaching Hospital / Babylon Governorate / Iraq *Journal of Nursing and Health Science*. 2015;4(6):82-7.
12. Mashayekhi F, Rafati S, Rafati F, Pilehvarzadeh M, Mohammadi-Sardo M. A study of caregiver burden in mothers with thalassemia children in Jiroft, 2013. *Modern Care Journal*. 2014;11(3):229-35.
13. Manor-Binyamini I. Mothers of children with developmental disorders in the Bedouin community in Israel: Family functioning, caregiver burden, and coping abilities. *Journal of autism and developmental disorders*. 2011;41(5):610-7.
14. Papastavrou E, Charalambous A, Tsangari H, Karayiannis G. The burdensome and depressive experience of caring: what cancer, schizophrenia, and Alzheimer's disease caregivers have in common. *Cancer Nursing*. 2012;35(3):187-94.
15. Bamari F, Madarshahian F, Barzgar B. Reviews burden of caring caregivers of patients with type II diabetes referred to diabetes clinic in the city of Zabol. *Journal of Diabetes Nursing*. 2016;4(2):59-67.
16. Arshi M, Gholami Jam F, Nazif A, Imani F. The Relationship Between Caregiving Burden and Family Function of Children with Cancer. *Quarterly Journal of Social Work*. 2016;4(4):35-41.
17. Bagherbeik Tabrizi L, Navab E, Farokhnezhad Afshar P, Asadi Noghabi AA, Haghani H. Effect of Cognitive-Behavioral Intervention on Burden of Family Caregivers of Patients with Alzheimer's Disease. *Journal of hayat*. 2015;21(1):94-102.
18. Valizadeh L, Joonbakhsh F, Pashae S. Determinants of care giving burden in parents of child with cancer at Tabriz children medical and training center. *Journal of Clinical Nursing and Midwifery*. 2014;3(2):13-20.
19. Wang J, Shen N, Zhang X, Shen M, Xie A, Howell D, et al. Care burden and its predictive factors in parents of newly diagnosed children with acute lymphoblastic leukemia in academic hospitals in China. *Supportive Care in Cancer*. 2017;25(12):3703-13.
20. Kahriman F, Zaybak A. Caregiver burden and perceived social support among caregivers of patients with cancer. *Asian Pac J Cancer Prev*. 2015;16(8):3313-7.
21. Wang LJ, Zhong WX, Ji XD, Chen J. Depression, caregiver burden and social support among caregivers of retinoblastoma patients in China. *International journal of nursing practice*. 2016;22(5):478-85.
22. Choi YS, Hwang SW, Hwang IC, Lee YJ, Kim YS, Kim HM, et al. Factors associated with quality of life among family caregivers of terminally ill cancer patients. *Psycho-Oncology*. 2016;25(2):217-24.
23. Rajabi-Mashhadi MT, Mashhadinejad H, Ebrahimzadeh MH, Golhasani-Keshtan F, Ebrahimi H, Zarei Z. The Zarit Caregiver Burden Interview Short Form (ZBI-12) in spouses of veterans with chronic spinal cord injury, validity and reliability of the Persian version. *Archives of Bone and Joint Surgery*. 2015;3(1):56.
24. Abbasi A, Shamsizadeh M, Asayesh H, Rahmani H, Hosseini S, Talebi M. The relationship between caregiver burden with coping strategies in Family caregivers of cancer patients. *Iranian Nursing Scientific Association*. 2013;1(3):62-71.
25. Saritas SC, Kavak F, Aksoy A, Saritas S. Examination of the Care Burden of Caregivers of Oncology Patients and the Perceived Social Support from Family. *International Journal*. 2017;10(1):447.
26. Ahmadi M, Rassouli M, Karami M, Abasszadeh A, Poormansouri S. Care burden and its Related Factors in Parents of Children with Cancer. *Iran Journal of Nursing*. 2018;31(111):40-51.
27. Abbasi A, Asayesh H, Rahmani H, Shariati A, Hosseini S, Rouhi G. The burden on caregivers from hemodialysis patients and related factors. *Journal of Research Development in Nursing & Midwifery*. 2011;8(1):26-33.