

## A study of quality of life among parents having children with Thalassemia

Gavneet Kaur Pruthi<sup>1\*</sup>

### ABSTRACT

**Background:** The present study investigated, 'Quality of life among parents having children with Thalassemia. Thalassemia refers to a group of genetic disorders, characterized by insufficient production of hemoglobin. Children with thalassemia for survival have to regularly attend hospital for blood transfusion, which creates a lot of burden for the families, and hamper their quality of life. **Methods:** 40 participants (caregivers), 20 having children with thalassemia, and 20 as control group, from hospitals in Delhi were enrolled and they were given WHOQOL-BREF (Murphy et al., 2000), in a semi structured interview form. **Results:** indicated poor quality of life and health in, parents of children with thalassemia group, as compared to the control group. Further, due to the complex treatment and regular visits to hospitals, the psychological aspects in the caregivers of thalassemia group, was most affected. **Conclusion:** Poor quality of life in caregivers of children with thalassemia, indicates the importance of a lifelong psychosocial support for prevention of mental health issues, including promotion of a clear understanding of the disease.

**Keywords:** *Thalassemia, Caregivers, Quality of life*

Thalassemia refers to group of disorders, characterized by insufficient production of hemoglobin. The disease originates from genetic mutations in the gene responsible for globin chain biosynthesis which is a constituent of normal adult hemoglobin. It leads to ineffective erythropoiesis and finally results in anemia. According to (Choudhary, 2000), 3.9 percent of the existing population in India, carries the thalassemic genes. Thalassemia major as chronic illness has a negative impact on quality of life of mothers was reported by (Caro et al., 2002). Although optimal medical management has reduced the difficulties faced by thalassemics and their families, but psychosocial impact, and disturbed quality of life on the development of the victim and family is a continuous process, throughout life. Children with thalassemia for survival have to regularly attend the hospital for blood transfusion, which creates a lot of burden for the families (Nahalla & Futzgerald, 2003). Also many causes including the chronicity of disease burden, of treatment modalities, morbidities and the expectation of early death, resulting from disease complications, of thalassemia, may lead to psychosocial burden in parents, which was reported by (Yesim et al., 2005).

<sup>1</sup>Clinical Psychologist, IHBAS, New Delhi, India

\*Responding Author

Received: April 1, 2020; Revision Received: May 12, 2020; Accepted: June 25, 2020

### ***Quality of Life***

Quality of Life (QOL) as a concept has been increasingly accepted as an important outcome measure in patient's and caregiver's of chronic illnesses. Quality of Life (QOL) has been defined by the (World Health Organization, 1994) as individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad concept incorporating the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of the environment.

QOL is especially relevant to conditions that are chronic and impairing, such as thalassemia major.

Care giving and its related burden is considered to be an important aspect in determining the quality of life of caregivers. In the present study, quality of life of parents having children with thalassemia major, are studied. Thalassemia major makes a person incapable of living an independent life. In India, family bears the main burden of caring for such a person unlike in the developed world. Family members, particularly parents are most affected by the condition. There is need to find out how thalassemia major affects the family, in order to help those who are having negative impact. Taking into consideration the same, the present study was planned, with the following aim: - to study the quality of life among parents having children with thalassemia major.

### **MATERIAL AND METHODS**

A case control study, to determine the quality of life among parents of children with thalassemia and control group was undertaken in hospitals having thalassemia ward in Delhi. After obtaining permission from the head of the hospital, a written informed consent was obtained from parents of children with thalassemia before inclusion in the study. Those parents were not included in the study who did not give consent and who had any other child with any other physical or mental disease, disability or disease. 20 participants (caregivers) aged 18 years and above, with children aged from birth to 12 years and having confirmed diagnosis of thalassemia major (20), and those having children without thalassemia or any other physical or mental disease or disability from birth to 12 years i.e., control group (20), were enrolled for the study. The subjects in the control group were matched in all parameters to the other two group subjects, except them having no physical or mental disease, disability or illness. The samples were selected by purposive method.

After obtaining consent form from parents, basic data identification schedule, was used to elicit information regarding demographic details of children and caregivers, and thereby WHOQOL-BREF developed by (Murphy et al., (2000), was administered on the parents. WHOQOL-BREF, of 26 items, was used to measure quality of life. Its 26 items are rated on a 5 point scale, which gives a profile with four domain scores (physical health, psychological health, social relationship and environment) and two individually scored items about an individual overall perception of quality of life and health (Q1 and Q2). The four domains are scaled in positive direction, with a score range of 0-100 and higher score denoting higher quality of life. WHOQOL-BREF – World Health Organization Quality of Life BREF – Assessment Instrument: short version - contains 26 questions divided into four domains:

- A. *Physical health*: general health assessment, pain and discomfort, dependence on medication and medical aids, energy and fatigue, sleep and rest, ability to work and perform daily living activities, mobility.

## A Study of Quality of life among Parents having Children with Thalassemia

- B. *Mental health/Psychological*: body image, positive and negative feelings, self-esteem, personal beliefs, spirituality, religion, thinking, learning, memory and concentration.  
*Social relationships*: personal relationships, received social support, sexual activity.
- C. *Environment*: freedom, safety, environment, physical environment, transport, finances, information, accessibility of health and social care, leisure time.

Each question is assigned an appropriate number of points from 1 to 5, and the patient must choose from the following possible answers: 1 point – very dissatisfied, 2 points dissatisfied, 3 points – neither satisfied nor dissatisfied, 4 points – satisfied, 5 points – very satisfied. The scale includes items (questions) that are analyzed separately: Question 1: pertaining to the individual overall perception of quality of life; Question 2: pertaining to the individual overall perception of own health.

### Statistical Analysis

For the statistical analysis, Mean Standard deviation, Chi-square and ANOVA was calculated.

## RESULTS AND ANALYSIS

The sample for the present study consisted of 20 participants (caregivers), aged 18 years and above, with children having confirmed diagnosis of thalassemia major, from birth to 12 years. 20 participants were taken as control group, having children without any physical or psychological illness, disease or disability. The mean age of participants/caregivers in thalassemia group was 31.6, with age range of 24-45 years, and the mean age for control group participants was 32.6, with age range of 25-40 years. The female: male ratio in the two groups was as follows- 19:1, 20:0, and showing that most of the participants in the study were females and mostly mothers of children. The educational qualification of most of the participants was graduate. The monthly income, of majority of participants falls in the category of 8000 - 15000 [Table I].

	Thalassemia group	Control group
<b>N</b>	20	20
<b>Range</b>	24 – 45	25 – 40
<b>Age <math>\bar{x}</math></b>	31.6	32.6
<b><math>\sigma</math></b>	10.60	1.64
<b>Sex F</b>	19	20
<b>M</b>	1	0
<b>Education</b>		
<b>6 – 9</b>	0	1
<b>10 – 12</b>	6	8
<b>Graduate</b>	14	11
<b>Income (Monthly)</b>		
<b>Up to 7000</b>	0	7
<b>8000 – 15000</b>	18	9
<b>15000 and above</b>	2	4
<b>Occupation:</b> Most of the participants were housewives (n = 30), teachers (n = 7), service in private sector (n =3).		
<b>Relationship with the child:</b> Most of the participants were mothers of the child (n = 29, rest father n= 11).		

**Table I: Description of the Identified Sample**

## A Study of Quality of life among Parents having Children with Thalassemia

**Table 1:  $\chi^2$  for Item No. 1, WHOQOL-BREF (overall perception of quality of life,) frequencies in three groups**

	Very Poor	Poor	Neither Poor Neither Good	Good	Very good
<b>Thalassemia group</b>	12	7	1	0	0
<b>Control group</b>	0	0	0	16	4

$\chi^2$  64.94, df 8, found to be significant at .01 level.

**Table 2:  $\chi^2$  of WHOQOL-BREF; Item No. 2 (Overall Perception of health)**

	VD	D	N.S. N.D.	S	V.S.
<b>Thalassemia group</b>	2	11	6	1	0
<b>Control group</b>	0	0	2	15	3

$\chi^2$  47.78, df = 8, significant at .01 level

**Table 3: Mean & Standard Deviation of two groups on Item No. 1(WHOQOL – BREF)**

	$\bar{x}$	$\sigma$
<b>Thalassemia group</b>	2.15	0.59
<b>Control group</b>	4.15	0.37

As can be seen from the table, the mean for the thalassemia group was lower than control group, on item No. 1, which assess the overall perception of quality of life.

**Table 4: Mean & Standard Deviation of two groups on Item No.2 (WHOQOL – BREF)**

	$\bar{x}$	$\sigma$
<b>Thalassemia group</b>	2.30	0.73
<b>Control group</b>	4.15	0.49

As can be seen from the table, the mean for the thalassemia group was lower than control group on item No. 2, which assesses the overall perception of health.

**Table 5: Mean & Standard Deviation on 4 domains of WHOQOL-BREF in each of the two groups.**

	Physical	Psychological	Social	Environmental
<b>Thalassemia group</b>	$x = 40.85$ $\sigma = 9.96$	$x = 36.6$ $\sigma = 7.35$	$x = 50.75$ $\sigma = 15.49$	$x = 44.45$ $\sigma = 9.09$
<b>Control group</b>	$x = 73.6$ $\sigma = 11.72$	$x = 75.3$ $\sigma = 10.18$	$x = 81$ $\sigma = 8.98$	$x = 72.25$ $\sigma = 13.16$

## A Study of Quality of life among Parents having Children with Thalassemia

The mean for thalassemia group was lowest in the, psychological domain, followed by physical, environmental and social domain and as compared in the control group, there was not much difference found in the mean of the four domains.

**Table 6: Showing the *F* (AVONA) values for the 4 domains of WHOQOL-BREF, for the two groups**

	Physical	Psychological	Social	Environmental
<b>F Values</b>	66.82	68.13	52.79	268.21

*F values in all the four domains were significant at .01 level.*

### DISCUSSION

Care-giving is a normal part of being the parent of a young child, but this role takes on an entirely different significance when a child experiences functional limitations and possible long-term dependence. The impact of children with thalassemia on parents and other family members has long been of interest to professionals. Consequently understanding relationships within the family has grown considerably over time. In the present study an attempt has been made to assess the quality of life in parents of children with thalassemia as compared to the controlled matched group, so that they could be helped to manage these problems in the best possible way.

#### Quality Of Life

Talking about the Quality of Life, the results of the study revealed that, overall perception of quality of life and perception of health (WHOQOL-BREF), was very poor and dissatisfied, in the thalassemia group participants, as compared to the control group participants, among whom quality of life was found to be good. The mean for the Item No 1 & 2 (WHOQOL-BREF), for the thalassemia group was found to be 2.15 & 2.30 respectively, which was found to be lower than matched controlled group mean i.e., 4.15 & 4.15 respectively ( Table 3 & 4), thus indicating very poor quality of life and perception of health in this group. Further, more frequencies were in the sphere of very poor and poor category of (Item No 1 WHOQOL-BREF) (Table No 1), in the thalassemia group, as compared to the controlled group, in which frequencies were found more in the good and very good category.

In the same line, in the thalassemia group participants, more frequencies were found in the very dissatisfied and dissatisfied category of perception of health (Item No2 WHOQOL-BREF) (Table No 2), as compared to the controlled group, where more frequencies were found in the category of satisfied and very satisfied category. These results are also in line with Chi – Square, for Item no 1 & 2 i.e., 64.94 & 47.78 (Table 1& 2), which was found to be significant, thus showing difference in overall perception of quality of life and health in the two groups. During the semi structured interview also, it was found that mothers of children with thalassemia, reported greater no of physical problems and feelings of meaninglessness of life and dissatisfaction with their own self, as compared to the controlled group participants.

Similar findings were found in a study done by (Sandra, 2015), at St. John's Medical College Hospital (SJMCH), Bangalore on the level of stress and coping among parents of children having thalassemia. A total of 100 study subjects were selected using purposive sampling

## **A Study of Quality of life among Parents having Children with Thalassemia**

technique. Parents having children with Thalassemia had severe financial stress (74%). The problem oriented coping mechanisms were used effectively by 57% of the parents.. 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.

In another 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, by (Sengupta, 2008), 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%).

### ***Four Domains Of WHOQOL-BREF***

Results of the study also signify that there was a significant difference in four domains of WHOQOL-BREF, in the two groups. The ANOVA values (Table 6), in the two groups for the four domains, came out to be significant, thus showing difference in four domains of quality of life in two groups. In thalassemia group, the quality of life was poorest in the domain of psychological domain (Mean=36.3), followed by physical domain (mean=40.85), environmental domain (mean=44.45), and social domain (mean= 50.75) (Table 6). In our research, comparing the psychological domain of parents of children having thalassemia and parents of healthy children, the biggest differences were in the assessment of enjoyment of life, the meaning of life, acceptance of physical appearance and experience of negative feelings. The parents of healthy children chose the more positive answers for all the questions.

These findings are supported by the qualitative study done by (Prsasomsuk et al., 2007), who 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 noneffectiveness of health care services. These findings suggested that a holistic, culturally sensitive nursing approach should be considered when caring for children with Thalassemia.

Similar results were also found in a study done by (Prasomsuk, 2007), 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.

## CONCLUSION

To conclude, the results of the present study points, that since there is poor quality of life and health, among parents of children with thalassemia as compared to the controlled matched group, therefore it is imperative to provide psychosocial support, including promotion of a clear understanding of the disease to these participants. However, our results should be interpreted in the light of small sample size and more studies with large sample sizes are required.

## REFERENCES

- Caro, J. J., Ward, A., Green, T.C., Huybrucks, K., Asoma, A., Wait, S. (2002). Impact of thalassemia major on patients and their families. *Acta Hematologica*, 107, 150-157.
- Choudhary, V. P. (2000). *Thalassemia: Care and Control in the new millennium*. Mumbai, India: Novert India.
- Nahalla, C. K., Fitzgerald, M., (2003). The impact of regular hospitalization of children living with thalassemia on their parents in Sri Lanka: a phenomenological study. *Int J Nurs Pract*, 9 (3): 131-9.
- Prasomsuk, S. (2007). Lived experiences of mothers caring for children with Thalassemia major in Thailand. *Journal for specialists in Pediatric Nursing*, Jan; 12 (1): 13-23.
- Prasomsul, S., Jetrisuparp, A., Ratanasiri, T., Ratnasiri, A. (2007). Lived experiences of mothers caring for children with Thalassemia Major in Thailand. *Journal for specialisat in Pediatric Nursing*, 12 (1),
- Sandra, J. S. (2015). Stress and Coping among Parents of Children Having Thalassemia. *International Journal of Science and Research*, Volume 4 (7), 849-853.
- Sengupta, M. (2008). Thalassemia among the tribal communities of India. *Journal of Biological Anthropology*, 1 (2):1939-50.
- WHOQOL Group. (1994). Development of the WHOQOL: Rationale and current status. *Int J Mental Health*, 23: 24-56.
- Yesim, A., Serpil, E., Nagihan, B., Deniz, Y., Ufuk, S. (2005). Psychosocial implications of thalassemia major. *Pediatrics International*, Vol 47, pp. 84-89.

## Acknowledgements

The author appreciates all those who participated in the study and helped to facilitate the research process.

## Conflict of Interest

The author declared no conflict of interest.

**How to cite this article:** G K Pruthi (2020). A study of quality of life among parents having children with Thalassemia. *International Journal of Indian Psychology*, 8(2), 21-27. DIP:18.01.003/20200802, DOI:10.25215/0802.003