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THE CONTRIBUTING FACTORS RESPONSIBLE TO IMPACT THE DISEASE BURDEN AND QUALITY OF LIFE AMONG THALASSEMIA CHILDREN AND THEIR PARENTS

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Abstract

"India has the largest number of children with Thalassemia Major in the world, about 1 to 1.5 lakh, and about 10,000-15,000 children having Thalassemia Major are born every year[2], affects **approximately 4.4 out of every 10,000 live births** throughout the world. A sequential exploratory mixed method design, the approach was qualitative (Phenomenological) Quantitative (Cross-sectional) used to identify the contributing factors responsible to impact the disease burden and quality of life among thalassemia children and their parents 250 Thalassemia major children and their 250 parents (father, mother / caretakers) by using a non-probability purposive) sampling technique selected, and result revealed that:

A) Among identified 14 factors **none of the factors the children neither scored excellent or Good and not even 50% of score.** The highest score of Excellent, gained in two Factors i.e., for **Factor: 12 (Social support and schooling**) 43.2%, And in **Factor 5: Financial impact and social crisis**: 38.4%. The highest score of Good: availed by these children were at the area of **Factor:14** (Support to health) 43.2%, **Factor 1**: (Physical wellness) 39.6%, and nearly 35% scoring received at Six areas i.e., for: **Factor 6**: (Peer support and schooling), **Factor 8**: (Coping up with challenges), **Factor 9**: (Emotional and cognitive level) and for **Factor 13**: (Academic issues and spirituality).

B) **8 Factors Identified to evaluate the impact of disease burden among Parents of thalassemia children on their quality of Life:** The assessment of overall scoring of **8 factors** reveals that the highest **score of** excellent was availed for **Factor F7**: 37.2% in Emotional control, 34% in **Factor F4:** Family support, **Factor F2**:26 % Financial status, **Factor F1**: 25.6% Physical health, **Factor F3** :25.2% Psychological domain, **Factor F8**: 21.6% Self- Satisfaction, **Factor F5**:22% Spirituality, **Factor F6**: 15.2%, but reveals Less than 40% in all factors. The highest score of Good was availed in **Factor F5**: Spirituality: 56.4%, in **F6 comfort level** 47.2% in comfort level and in other areas the score was less than 40%. Thus, it reveals that the QOL of these parents are affected, and the study concludes that the QOL of parents can have direct impact on, Thalassemic children's Quality of Life.

INTRODUCTION

The Constitution of the World Health Organization (WHO) explains: an individual is healthy, means he/she should be free from ailments related to physical, mental, social, and not merely the absence of disease. The continuous measurement of health status of individual is must for the early diagnosis of, disease related complications and the effects of health care must include, not only an evidence of frequency change and diseases severity but also an estimation of well-being and this can be assessed by measuring the quality of life.[1]

Thalassemia is a disease in which the single Gene get disordered and passed through parents to child, called an autosomal recessive pattern of disease, can be seen in both the sexes as autosomes are affected not the sex chromosomes. In Beta Thalassemia there is abnormal mutation observed can causes abnormal haemoglobin production and affected children will show the symptoms of: looking pale, poor appetite, fussy, can suffer with frequent infections, failure to gain weight (as expected with the age of the child), failure to thrive and without timely diagnosis and treatment child can have abnormal enlargement of the liver (hepatomegaly), enlargement of spleen (splenomegaly), enlarged heart, thin, brittle, and deformed bones etc., which can alter the quality of life of the children.

NEED OF THE STUDY

"India has the largest number of children with Thalassemia Major in the world, about 1 to 1.5 lakh, and about 10,000-15,000 children having Thalassemia Major are born every year[2].Thalassemia affects **approximately 4.4 out of every 10,000 live births** throughout the world. This condition causes both males and females to inherit the relevant gene mutations equally because it follows an autosomal pattern of inheritance with no preference for gender[3].Worldwide approximately with Thalassemia affected 4.4 out of every 10,000 live birth of children are born with the Thalassemia affected. In India itself every year more than 10,000 children are born with thalassemia but: Lack of poverty and treatment - 50% do not survive till the age of 20 years. More than four million Indians are carriers and more than 1,00,000 are patients. Reports shows that worldwide approximately 15 million people are suffering with thalassemia disorders and 240 million (1.5% of world population) are carriers of β thalassemia. In

India the number is 30 million with 505 in S.E. Asia. In India 1-17% is the carrier rate of thalassemia that means on an average 1 in every 25 Indians can be a carrier of thalassemia. The study related to the distribution of thalassemia revealed that the distribution is not uniform in India.[4]

Globally the data reveals that annually affected conceptions with thalassemia major are nearly 56,000 (β and α thalassemia are 42409 and 3,466), 30,000 who required regular transfusions and 5500 who die perinatally due to thalassemia major. Worldwide the estimated data of annual births with β thalassemia are 40,618, nearly 25,511 are transfusion dependent; annual number starting transfusions are 2989(11.7%); 22,522 dies annually because of not receiving of transfusion. Roughly 97630 known patients are currently living with regular transfusions; 37,866(39%) obtain iron-chelation medications and 3000 die annually in their teens or early 20s due to Iron overload.[5]

Praveen K, Savita M (2010)[6] did an accelerated longitudinal design study and found 54% children suffer with significant psychopathology, in parents 10% with adjustment disorder, 33.3% depressive disorder, 10% anxiety disorder, 11% with somatoform disorder, parents of 95% newly diagnosed children expressed their feelings of shock, fear of death, hopelessness, anxious of separation and other problems with memory and concentration. Among children the quality of life improved with their progression of illness. **Shahraki-vahedA, Firouzkouhi M, and et.al (2017)**[7] done a descriptive phenomenological approach study done by selecting 15 patients by purposive sampling and by interview method data collected and the result was treated by Colizzi method to explore their personal experiences and found that these children affected with socio familial worries. **Hakeem G.L., Mousa S.O., Moustafa A.N., et.al (2018)**[8] done a case control survey in Minia University of Egypt by selecting 64 (8-18 year) children and applied peds QL™ 4.0 Generic score scale to find HRQOL the result revealed that physical, emotional, social, school performance, psychological and total score were decreased in control group. But the younger children's score was better than the elder thalassemia children the reason found was late start of blood transfusion led to. Hepatomegaly, poor physical QOL increase serum ferritin level was significantly, affected with poor social QOL. Parents and care givers of these children experiences repeated emotional problems due to repeated physical, emotional sufferings of their children and they perceive themselves responsible for their children's sufferings. They

always worried about their children's future. Financial burden is another important factor. Parents extra efforts for their childcare leads to exhausting and intolerable for them. These all factors directly affect the quality of life of thalassemia children. **Munirah I, Choong Y.C., Noor A.M.Y., Suzanaand et.al (2013)**[9] selected 75 thalassemia major children and 65 caregivers and done a cross-sectional study at Kuala Lumpur. The HRQOL of psychosocial aspect, School functioning and emotional functioning, frequent blood transfusion, iron chelation treatment were found statistically lower and affected the Quality of life of these thalassemia children. Parents increased mental and physical stress, low education level; psychosocial aspect also noted affected the poor Quality of life of these caretakers.

To improve the QOL the treating nurses better to adopt "SCOPE "strategies i.e., 'S for: Supportive: attained by financial, nutritional and psychological support. 'C' i.e., coping mechanisms can be developed by open discussions to provide necessary information. 'O' i.e., ongoing assessment and periodic monitoring of nursing need 'P' prevention of complications, timely administering of vaccines, drugs etc. 'E' i.e., Empowerment of thalassemia children and their parents. Recent advancement improved the life expectancy but quality of life of these children affected due to disease related complications. [10]

Based on the above-mentioned information the researcher was tried to identify the underlying factors responsible to impact the disease burden and quality of life among thalassemia children and their parents.

PROBLEM STATEMENT

An explorative study to identify the contributing factors responsible to impact the disease burden and quality of life among thalassemia children and their parents at selected states of India during the year 2016- 2018.

OBJECTIVES OF THE STUDY

1. To identify the underlying factors responsible to impact the disease burden and quality of life among thalassemia children.

2. To identify the underlying factors responsible to impact the disease burden and quality of life among parents of thalassemia children

3. To assess the impact of disease burden on quality of life among thalassemia children and their parents.

HYPOTHESIS:

1. The identified factors will have a significant impact of disease burden on Quality of life among thalassemia children at the level of $p \leq 0.05$.

2. The identified factors will have a significant impact of disease burden on Quality of life among parents of thalassemia children at the level of $p \leq 0.05$.

ASSUMPTIONS OF THE STUDY

1. There may be some factors responsible to impact disease burden and can alter the QOL of Thalassaemic children

2. There may be some factors responsible to impact disease burden and can alter the QOL of parents of Thalassaemic children

METHODS

The research approach used was Mixed research methodology i.e., Qualitative (Phenomenological) and Quantitative (cross-sectional) approach and the research design was Sequential exploratory mixed method design to explore the phenomenon were adopted. In the initial phase, qualitative data were collected by using Delphi technique which was later analysed with extensive review of literature and the domain experts of this field, helped the investigator to develop a tool which was further validated by group of experts. Quantitative data were collected to find the reliability and validity of the developing tool and by various statistical applications; descriptive, factor analysis and reliability of the tool were carried out to standardize the questionnaire. The instrument used for the study was divided into following parts: **Section A**: Socio-demographic variables of thalassemia major child (7 items), **Section B**: Clinical variables of thalassemia major children (17 items), **Section C:** Quality of life assessment scale for Thalassemia major children (14 factors with 47 Items), **Section D:** Mixed (Open and close end) Questions (4 open ended questions), **Section E:** Socio-demographic variables of the thalassemia major child's parent (Father /mother /Caretaker): 14 items, **Section F:** Socio-demographic variables of the thalassemia major child's parent (Father /mother /Caretaker): (8 factors with 25Items), **Section G:**

Structured open-ended questions: (4 items). The sample size was calculated using the formula i:e Cochran's Sample Size Formula.[12,13]: $N_0 = Z2e2pq$ where: e is the desired level of precision (i.e., margin error), p is the (estimated proportion of the population which has the attribute in question, q is 1-p. Researcher assumed that p=0.17 (prevalence In India)[11], Confidence level = 95% of confidence level gives Z values of 1.96 per the normal tables $(1.96)^2/(0.05)^2$ =3.8416/0.0025 = 1536.64 x .17/100x0.83= 216.8. The sample size found to be 216.8 (If p= 0.17%) and 246 (If p= 0.20%). Henceforth, a sample size of 250 thalassemia children and their 250 parents (Father/Mother/caretaker) were selected by Non–Probability (Purposive) sampling technique. After pilot study Main study was done and sample was collected from INDORE: Choithram Hospital Research centre, SAIMS Medical College Hospital, RAJASTHAN: Kota Blood Bank, Kota J.K. Lon Mother and Child Hospital, NAGPUR: Rughwani Child Care Hospital, Punyani Hospital Child Care Centre, NASHIK: Jankalyan Blood Bank Thalassemia Centre, Smile Thalassemia Foundation, Nashik Blood Bank, DELHI: National Thalassemia Welfare Society Conference, AIIMS, Delhi who fulfilled the inclusion criteria.

Data collection Procedure

After Ethical approval obtained from all selected institutions, participants from the target population, 250 thalassaemic children suffering with Beta thalassemia major and their 250 parents were elected according to the set inclusion and exclusion criteria by using a non- probability purposive) sampling technique. During the initial period of data collection, the purpose of the study, the data collection procedure was explained, and written consent was obtained in their comfortable language Hindi/English/Marathi), questionnaire was administered, confidentiality with the information was achieved by maintaining the anonymity of the participants. The duration of study was 07 September 2016 to 30th April 2018 and used 30-40 minutes to fill the questionnaire. The investigator assured about the confidentiality of the data.

FINDINGS AND DISCUSSIONS

SECTION A: Socio-demographic Variables of child

The present study included 250 Thalassemia major children and their 250 parents (father, mother/caretakers). The result of the study suggested: Majority of Thalassemia children were in the age group of 14 years: 31 (12.4%), 30 (12.0%) were in the age

group of 18 years and very less age group found were 11 years i.e., 10 (4%). Male thalassemia major children were outnumbered 152 (60.8%) and the females were 98 (39.2%). Maximum of them 101 (40.4%) acquired secondary level of education (6-10th) class followed by 86 (34.4%) revealed the level of education was Primary education (1-5th class), higher secondary level of education (11–12th class) was acquired by 36 (14.4%) children, while only one child i.e., 0.4% has never been to school. On viewing birth order 120 (48.0%) thalassemia major children noted as 1st born at birth order while 97 (38.8) were obtained 2nd but third opined by 25 (10%) while only few 8 (3.2%) thalassemia major child revealed that their order of birth was fourth. Data also highlights that the maximum frequency of 127 (50.8%) children revealed of having two living siblings and 1 (single child) and 3 living siblings reported by 55 (22.0%) and 57 (22.8%) respectively. Four living siblings reported by 10 (4.0%) children, but one child (0.4%) revealed of five living siblings in the family. The Distributions of Number of living siblings (including you) of thalassemia major children data highlights that the maximum frequency of 127 (50.8%) children revealed of having two living siblings and 1 (single child) and 3 living siblings reported by 55 (22.0%) and 57 (22.8%) respectively. It also revealed that: out of 250 samples 18 (7.2%) siblings of thalassemia children affected with thalassemia major and out of them 9 were died, 144 (45.6%) were thalassemia carriers, but 28 (11.2%) thalassemia children not done the investigation and remaining 44 siblings found normal & 46 (18.4%) were found single child.

SECTION B: Clinical Variables of child

The result highlights: 49 (19.6%) thalassemia children were diagnosed as Beta thalassaemia Major at 3 months, 46 (18.4%) at 6 months, 40 (16.0%) at five months, 39 (15.6%) at the age 4 months, and remaining were diagnosed within 24 months. Before final diagnosis: 193 (77.2%) of them had frequent history of temperature, 106 (42.4%) pale appearances, 80 (32.0%) no height and weight gain, 52 (20.8%) very weak/dull/less active, (34, 13.6%) less appetite and haemoglobin near about 4 mg%, irritation (28, 11.2%), loose motion and vomiting (26, 10.4%), and cough and cold (27, 10.8%) respectively. **On the day of data collection (Data from records),** before the administration of blood, Hb% was lies in the range between 7-9 gm/dl among 135 (54%), 9-11 gm/dl, among 88 (35.2%) thalassemia children, 5-7 gm/dl found in 23

(9.2%) and > 11 gm/dl found in only 3 (1.2%) of thalassemia major children with the blood groups of O^{+ve} found most common among 78 (31.2%) and B^{+ve} in 77 (30.8%) thalassemia children and that followed by (61, 24.4%) had A^{+ve}, The blood group of (22, 8.8%) thalassemia children were AB^{+ve}. The blood groups $^{AB-ve}$, B^{-ve}, O^{-ve} and A^{-ve} found to be rare diagnosed in less than 3% in thalassemia children respectively. The **Most** (177, 70.8%) of the thalassemia children done transfusion twice in a month, 72 (28.8%) once in a month and only 1 thalassemia child (0.4%) done thrice in a month and weekly. **The type of blood received by these** children are fresh packed red blood cells 120 (48.0%) are the most common type of blood received and was followed by leukocyte filtered blood 113 (45.2%) cells as it was available easily at any time for transfusion and in free of cost, so, used. Whole blood, net tested blood, fresh packed red blood cells with leukocyte filtered blood was uncommonly observed way of receiving blood. Out of 250 thalassemia children after transfusion, Fever was the most common complication detected among (19, 7.6%) children with thalassemia and followed by (7, 2.8%) that experienced fever with rigor, but (204, 81.6%) does not had any complication due to transfusion. The ferritin Level almost in 228(91.2%) thalassemia major children maintained in between 1000 -5000 ng/ml followed by 9 (3.6%) had 5000-10000 ng/ml and 8 (3.2%) had ferritin level <1000 respectively and only in 4 (1.6%) had ferritin level was between 10000 – 15000 ng/ml and only in 1 (.4%) children's ferritin level was between 15,000- 20,000 ng/ml despite regular oral chelation therapy by all 250 (100.0%) children with thalassemia. The therapy started in majority 67 (26.8%) from the age of 4 years, 56 (22.4%) at 3 years, 37(14.8%) at 5 years, 36 (14.4%) at 6 years, 25 (10.0%) at 2 years and the minimum age was noted was 10 years in 1 (.4%) sample. The most common Iron chelating drug Tablet Desirox received by 100 (40%) of the children, the second most received Iron chelating drug found to be Deferasirox /Asunra 94 (37.6%). Tablet Kelfer / Defriprone received by 84 (33.6%) children while the Injection Desferal (Deferoxame) received only (20, 8%) children with thalassemia major. Even though all of them received oral chelating drug still few (10,4%) received subcutaneous and Intravenous to reduce the high value of ferritin level in blood. The money spent every month for Iron chelating drug found that most of 148 (59.2%) are getting free of cost from government hospitals or from thalassemia society organizations, 68 (27.2%) are spending Rs. 1000–5000, 18 (7.2%) are spending Rs.

5,000-10,000, 5 (2.0) are spending Rs. 10,000-15,000 and even 5 (2.0%) were spending Rs. >15,000 only for chelation therapy and drugs. The common medicine folic acid, multivitamin and calcium found to be taking nearly about 99% thalassemia children. It was also noted that (7, 2.8%) of the children with thalassemia were taken wheat grass tablet. (2, 0.8%) thalassaemic children after the physician's prescription: Insulin, Zinc and Vitamin D3 regularly and tab Testosterone 100 mg for 3 months or for 15 months, were taken. Few of them (1, 0.4%) thalassemia children were treated for Hormonal or cardiac conditions by administering medications like Thyroxin, Beta Blocker, and Priminorm etc. To identify the early complications, time to time assessment of specific functions and values of organ system like the status of ferritin level in blood done among 148 (59.2%) thalassemia children carried out at three times in a year, 78 (31.2%) children done at twice and 24 (9.6%) done at once. Vitamin D and calcium level in blood: 203 (81.2%) samples carried out at once in a year and 4 (1.6%) twice, 3 (1.2%) thrice in a year and in 40 (16.0%) children were not done. To assess the cardiac condition, magnetic resonance images (MRI) once in a year 160 (64.0%) thalassemia children, twice 3 (1.2%) and 1 (.4%) thrice in a year and remaining thalassaemic children were not done. The human leukocyte antigen (HLA) typing was done among 83 (33.2%) thalassemia major children to identify antigens on blood cells to determine the compatibility between an organ recipient and a donor organ. Only 83 Thalassaemic children HLA typing done and result reveals that only 1 child found 100% matching with his younger brother, 125 (50.0%) children's HLA typing not done and 42 (16.8%) not aware of this procedure.

The development of secondary sex characteristics:

From 152 boys 123 (49.2%) and from 98 girls 74 (29.6%) not attained secondary sex characteristics till the age of 17 years. But from remaining age group children attained secondary sex characteristics: 21 (8.4%) boys and 16 (6.4%) girls at the age of 15-17 years, 6 (2.4%) boys and 8 (3.2%) girls at the age of 13-14 years, only 2 boys were attained secondary sex characteristics at the age of 10 -12 years. On growth chart, height (in cm) according to Indian Academy of Paediatrics (IAP) the growth parameter of height (in cm) most of thalassemia children (94, 37.6%) lies between the range of 3 and <10, 2nd common range 10 and <25 in this range 62(24.8%) the 3rd most common height percentile of < 3 measured in 22.4% and followed by (25,10%) who had height

between 25 and < 50 percentiles, (12,4.8%) had height between 50 and <75 percentiles while only one thalassemia child had between 75 and <90 percentiles .Further IAP result indicates percentile of growth parameter weight (in kg), most of (84, 33.6%) lies between the range 3 and <10. 2nd common range 10 and <25 i.e. (69, 27.8%) 3rd common weight percentile of < 3 is (52, 20.8%), followed by (34, 13.6%) who had weight between 25 and < 50 percentiles, (9, 3.6%) had weight between 50 and <75 percentiles while only two thalassemia children had between 75 and <90 percentiles. The Ferritin level revels: > 90% (238, 94.9%) suffered with increased level of serum ferritin level of ≥1000 ng/ml. Complications found were: splenomegaly revealed by (80, 32%), 6 (2.4%) suffered from diabetes, other complications reported as 17 (6.8%) chronic liver conditions and surgical conditions like Splenectomy was done in (2, 0.8%) children while one (0.4%) observed with cardiac and Hepatitis B respectively. Hepatitis B Vaccination was received by 228 (90.6%) thalassemia children while rests (22, 8.8%) didn't receive vaccination. Another remedy tried to treat thalassemia done by 6 (2.4%) in the form of Ayurveda, wheat grass tablet etc. but was not found affective to treat thalassemia.

Development of QOL Scale Scoring for Thalassemia children:

The Quantitative data of quality of life of thalassemia children and their parents used to develop a new tool. The method adopted was by modifying a measurement technique based on: Quartile percentile.

1. The newly constructed tool (questionnaire) is designed to assess the quality of life of thalassemia children consisted of 57 questions before deduction and after deduction it was 49 (comprised of 28 positive and 21 negative questions).

2. To assess the quality of life of parents of thalassemia children consisted of 27 questions before deduction and 25 questions (comprised of 13 positive and 12 negative).

3. Likert Scale Format is used for the Assessment and Scoring of Quality of Life.

4. The option for each question were: (a) strongly disagree (b) disagree (c) neither agree nor disagree (d) agree and (e) strongly agree.

Descriptive Statistical evaluation of data for the quality of life of Thalassemia children and their parents (After deducting of items): Tool finalised and applied:

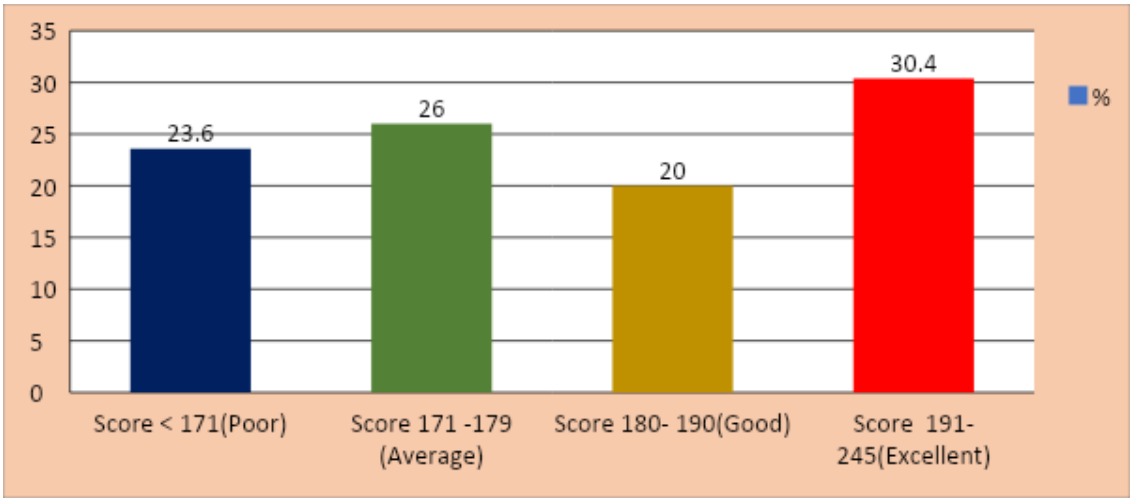
Statistics	Mean score of children	Mean score of parents
N	250	250
Mean	181.4	86.46
Median	136	87
Std. Deviation	15.48	10.64
Range	89	67
Minimum	136	47
Maximum	225	114

a) The mean scores found for the quality of life of thalassemia children was 181.4 ± 15.48 (Mean ± Standard deviation), points with a minimum range of 136 and maximum range of 225 points.

b) The mean scores found to determine the QOL of parents 86 ± 10.64 points with a minimum range 47 and maximum range 114 points.

5. **Finding of: Total Item score of newly developed tool:** Tool for thalassemia children total selected items were: 49, and (i) the **Maximum Score** on 5 Point Likert scale = 49*5= 245 and (ii) The **Minimum Score** is = 49*1=49

6. **SPSS software applied. The data for Quartile scale on 25%: score is 171, on 50%: Scoring is 180 and on 75%: Scoring is 191. So, the Quality-of-life Scale scoring categorized under:** Score: <171: Poor QOL, Score: 171-179: Average QOL, Score: 180-190: Good QOL Score: 191-245: Excellent QOL. After converting the collected data from percentile to percentage the quality of life of life of children was assessed and found that only 76 (30.4%) thalassemia children are found to be in excellent category 50 (20%) in good category, 65 (26%) average and 59 (23.6 %) are in poor category.



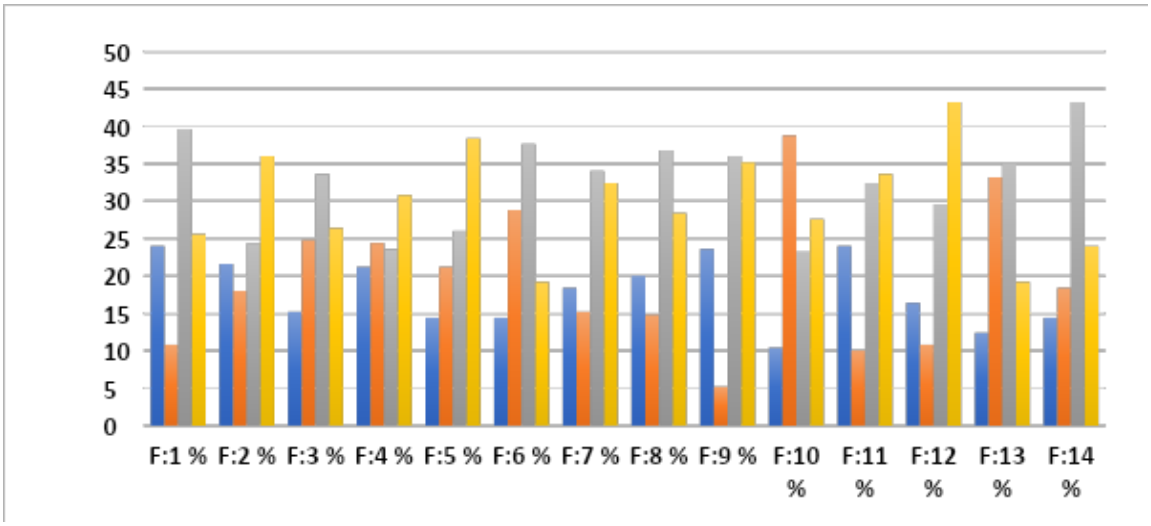
Quality of life of thalassemia children in %

To find out the actual area of affected factors on their quality of life, the collected data of **250 thalassemia children were analysed the result reveals that:**(**Factor-1)** For the physical wellness only 99 (39.6%) were in good, 64 (25.6%) were in excellent and remaining 60 (24%) in poor and 27 (10.8%) were in average category which means not even < 50% these children can manage, finish their work, can decide about their future, and get satisfaction from their work necessary to fulfil their own needs. **Factor-2: Self-satisfaction**: 90 (36%) were in excellent, 61 (24.4%) were in good and remaining 54 (21.6%) in poor and 45 (18%) were in average category, gives the information that <40% children have excellent or good satisfaction, even they help their parents in their work at home, able to practice religious rituals, able to tolerate pain caused due to medical investigations and blood transfusions and even can study continuously for more than one hour at home. **Factor-3: Level of independency**: 84 (33.6%) were in good, 66 (26.4%) were in excellent and remaining 62 (24.8%) in average and 38 (15.2%) were in poor category, reveals that the area of independency also found <40% in thalassemic children as they found good or excellent reveals unable to solve their problems alone, need someone to help them to walk inside the house and even when their teachers scold them, they avoid going to school. **Factor- 4: Self-perception and family impact** 77 (30.8%) were in excellent, 61 (24.4%) were in average category and remaining 59 (23.6%) % good and 53 (21.2%) were in poor category reveals 30% or less as the children feel sad when their relatives do not talk to their parents because of their sickness and at their home even own brother/sister does not like parents spending more time and money on these thalassemic children so their parents curse

their fate for giving birth to me as a sick child that makes them feels guilty, also feel sad / lose hope when doctors tell my parents about no recovery in my illness. **Factor-5: Financial impact and social crisis:** 96 (38.4%) were in excellent, 65 (26%) was in good category and remaining 53 (21.2%) in average and 36(14.4%) were in poor category found < 40% and children feels that as treatment is an extra additional financial burden on my parents still my parent's income is sufficient to provide treatment and food for me and my family. **Factor-6**: **Peer support and schooling:** 94 (37.6%) were in good, 72 (28.8%) in average remaining 48 (19.2%) excellent and 36 (14.4%) were in poor category which reveals by the children that in this area < 40% of their classmates understand their sickness, help them in their studies whenever required, help them in finishing homework and also found comfortable in sharing their problems. **Factor-7**: **Managing to comfort level** 85 (34%) were in good, 81 (32.4%) were in excellent category, remaining 46 (18.4%) in poor and 38(15.2%) were in average category, reveals <35% thalassemic children were managing their comfort level by just few minutes when they feel tired and need to stop playing outdoor games, found it difficult to complete them school assignments due to their frequent or continuous absence and maintain healthy personal hygiene without anyone's help. **Factor-8: Coping up with challenges** 92 (36.8 %) were in good, 71 (28.4%) were in excellent category and remaining 50 (20%) in poor and 37 (14.8%) were in average category. This results also reveals only <40% Thalassemic children, when feels tiredness, can indicates the need of blood transfusion, had body pain creates problem in sleeping which made them not liking to pray as God has done injustice to them in the form of disease person. **Factor-9: Emotional and cognitive level** 90 (36%) were in good,88 (35.2%) was in excellent category and remaining 59 (23.6%) in poor and 13 (5.2%) were in excellent category. This data explains that only <40% of the children find difficulty to learn and memorize/remember lessons and can complete homework without anyone's help. **Factor-10**: **Ability for self-decision** 97 (38.8%) were in average, 69 (27.6%) was in excellent 58 (23.2%) in good and 26 (10.4%) were in poor category. This result reveals < 40% thalassemia children will, be able to decide when their parents take them for any treatment, children help parents to earn money by helping them in their work, but they themselves unable to decide what job they should do in future even if they are ill. **Factor-11: Motivation and inspiration** 84 (33.6%)

were in excellent, 81 (32.4%) were in good category, remaining 60 (24%) in poor category and 25 (10%) were in average category, reveals < 35% can decide what they can eat, like dairy Products (milk), cereals (Dal), etc, in my daily diet. Children are motivated to go to school as their teachers are encourages them to participate in extracurricular activities and because of their friends **Factor-12**: **Social support and schooling** 108 (43.2%) were in excellent,74 (29.6%) were in good,41 (16.4%) poor and 27 (10.8 %) were in average category, < 45% children explain. People, other than my relatives, provide/donate/give blood whenever required. Consideration for leave from the school was given them for blood transfusion but their parents cannot pay their school fees on time that is why they have stopped going to school. **Factor-13**: **Academic issues and spirituality** 88 (35.2%) were in good, 83 (33.2%) were in average, 48 (19.2%) in excellent and 31 (12.4%) were in poor category. < 40% children revealed they had been punished by the teachers for not completing their assignments, but they attend religious sermons /preaching /Services regularly. **Factor- 14: Support to health** 108 (43.2%) were in good, 60 (24%) were in average, 46 (18.4%) in excellent and 36 (14.4%) were in poor category. <45 % children were told that as they receive free blood from people which further reduces financial burden of their family. **From the above-mentioned data, the study revealed that in none of the factors the children neither scored excellent or Good and not even 50% of score.** The highest score of Excellent, gained in two Factors i.e., for **Factor: 12 (Social support and schooling**) 43.2%, And in Factor 5: Financial impact and social crisis: 38.4%. The highest score of **Good**: availed by these children were at the area of **Factor: 14** (Support to health) 43.2%, **Factor 1**:(Physical wellness) 39.6%, and nearly 35% scoring received at Six areas i.e., for: **Factor: 6**: (Peer support and schooling), **Factor 8**: (Coping up with challenges), **Factor 9**: emotional and cognitive level) and for **Factor 13**: (Academic issues and spirituality). The highest score of average attained 38.8% in those areas like **Factor: 10** (Ability for self-decision), 33.2% in **Factor: 13** (Academic issues and spirituality). The Highest score of **poor** nearly 24% Thalassemia children were attained at the area of **Factor: 1** (Physical wellness), **Factor: 9** (Ability for self-decision) and for **Factor: 11** (Motivation and inspiration).The study concluded that all the domains which notify the QOL of these children were affected due to Beta Thalassemia as the overall scoring of assessed domains reveals that only 35% children are found in excellent

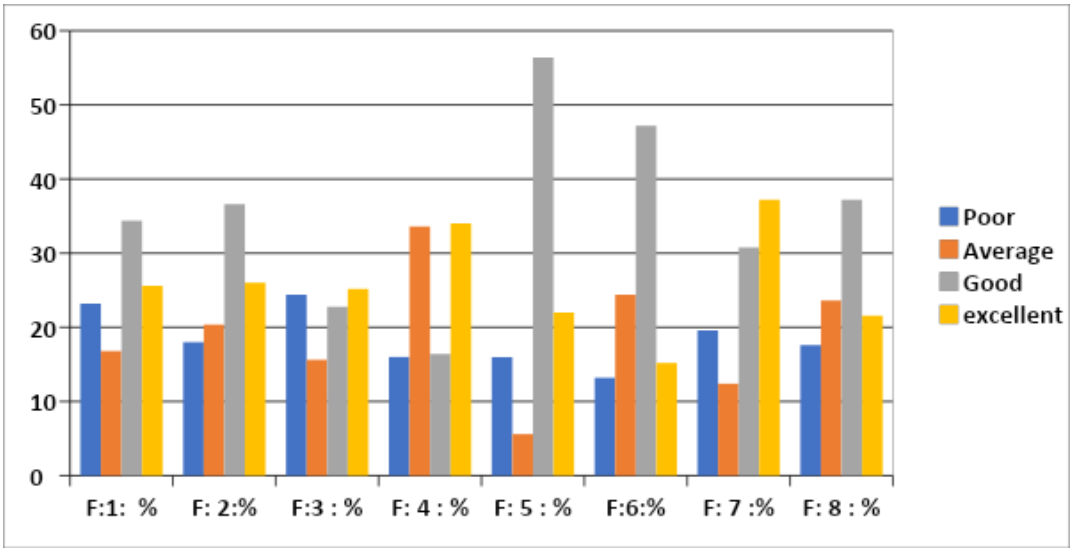
category and only 25% are found good in all areas of QOL domains. But remaining children's QOL are affected in one or other areas of domains.



Cylindrical diagram showing the individual factors affected on QOL of thalassemia children.

Ansari S., Baghersalimi A., Azarkeivan, M. Nojomi, Hassanzadeh A.R. (2014)[14] done an analytic case control study and selected 251 thalassemia patients and 51 participant as control and by using WHOQOL BREEF scale assessed the Quality of life on a 5 point Likert scale. The result showed the low QOL score on overall health, physical, psychological, social, and environmental relationship were found low in thalassemia patient than control group **in the present study also, assessment of factors found affected among Parents of thalassemia children on their quality of Life:** The different factors studied to assess the quality of life of parents of Thalassaemic children. The data revealed that among 250 parents, In **Factor: 1** (**The physical health**) 86 (34.4%) were in good, 64 (25.6%) were in excellent, 58 (23.2%) in poor and 42 (16.8%) were in average category which reveals that parents feel their thalassemic children take sound sleep, have tolerance to pain caused by medical investigations and blood transfusions. **For Factor: 2** (**Financial status**) 89 (36.6%) were in good, 65 (26%) were in excellent, remaining 51 (20.4%) in average and 45 (18%) were in poor category as the family's' financial condition affected due to costly treatment, transportation to and fro to hospital, equipment, medication even finding difficulty to arrange iron overloaded preventive medication were affected. **Factor: 3 (Psychological domain**) 63 (25.2%) were in excellent, 61 (24.4%) were in poor and remaining 57 (22.8%) in good and 39

(15.6%) were in average category which reveals parents feel disturbed as they are not capable to do proper treatment for their children, limits child's career opportunities and even sleeping difficulty bothers them. **For Factor:4 (Impact of family support)** in 85 (34%) was in excellent, 84 (33.6%) were in average category and remaining 41 (16.4%) in good and 40 (16%) were in poor category as the parents feel helpless about child's condition and ill appearance but other members of the family help the parents in taking care of their child. **For Factor: 5 (Spirituality**) 141 (56.4%) were in good, 55 (22%) were in excellent category and remaining 40 (16%) in poor and 14 (5.6 %) were in average category as parents believe that God will heal their child so still perform religious rituals for their child's recovery. **For Factor:6 (Comfort level)** 118 (47.2%) were in good, 61 (24.4 %) in average, remaining 38 (15.2%) excellent and 33 (13.2%) were in poor category, as parents feels that their child can play like other children and even have power to bear the pain due to thalassemia. **For Factor:7 (Emotional control**) 93 (37.2%) were in excellent, 77 (30.8%) were in good category, remaining 49 (19.6%) in poor and 31 (12.4%) were in average category. **For Factor: 8 (Self-satisfaction**) 59 (23.6%) were in average, 53 (37.2%) were in good category and remaining 53 (37.2%) in excellent and 44 (17.6%) were in poor category which reveals parents realise that other children of their family understand the sickness of thalassemia child and help the parents to take care of them and gives satisfaction because parents can support their child to cope up with his /her class work.



Individual factors affected on QOL of parent of thalassemia children in %

Cylindrical diagram showing the Individual factors affected due to disease condition among parents of thalassemia major children F1: Physical health, F2: Financial status, F3: Psychological Domain, F4: Family support, F5: Spirituality, F6: Comfort level, F7: Emotional control, F8: Self Satisfaction

CONCLUSION

The assessment of overall scoring of **8 factors** finally reveals that the highest **score of** excellent was availed for **Factor F7:** 37.2% in Emotional control, 34% in **Factor F4:** Family support, **Factor F2**:26 % Financial status, **Factor F1**: 25.6% Physical health, **Factor F3**: 25.2% Psychological domain, **Factor F8**: 21.6% Self- Satisfaction, **Factor F5**: 22% Spirituality, **Factor F6**: 15.2% but reveals less than 40% in all factors. The highest score **of Good** was availed in **Factor F5**: Spirituality: 56.4%, in **F6 comfort level** 47.2% in comfort level and in other areas the score was less than 40%.

Thus, the researcher concludes that the QOL of these parents are very badly affected and surely the QOL of parents can directly affect their Thalassemic children's Quality of Life.

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