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DEVELOPMENT AND STANDARDIZATION OF A TOOL FOR THE ASSESSMENT OF QUALITY OF LIFE AMONG THALASSEMIA CHILDREN AND THEIR PARENTS

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Abstract

Thalassemia is a disease in which single gene get disordered, called an autosomal recessive pattern of disease. This disease has group of symptoms like inadequate production of normal haemoglobin due to decreased erythrocyte production and till the end of life need frequent blood transfusion. For timely assessment of these children is must .The researcher conducted a methodological study for developing a tool to assess the quality of life of thalassemia children and their parents.

A Sequential exploratory mixed Method design, the approach was Qualitative (Phenomenological), Quantitative (cross-Sectional) used .Tool developed by collecting the information through Delphi technique (face to face interview carried out by asking open ended questions to children suffer with thalassemia major and their family members (2 male child, 1 girl, 1 father, 1mother,1 adult and 1 sister and mother who lost brother or sister) and all verbal responses reco rded through voice recorder. Using software open code 4.02 word to word all verbatim typed, generated- items and subthemes), analysed items with extensive review literature, discussion with experts. Tool was validated in 3 rounds (8+30+ 15experts) and the Index of suitability: (IOS)= ∑ R/N = 90 to 100% agreement found for all items. After Pilot study 250 Thalassemia Major children and 250 parents of Thalassemia major children based on inclusion and exclusion criteria selected for the final study ,57 items on 5-point Likert scale (Strongly disagree, Disagree, neither agree nor disagree, Agree, strongly agree) used, RESULT: the frequency, Mean, SD followed by Inter item correlation was done, significant 49 items selected and 8 items (21,35,44,45,48,50,52,55) were deleted. The whole process was done by the help of SPSS.(a) For the QOL Assessment scale for Thalassemia major Children :Value of Cronbach's alpha (α) for whole scale with 49items were = .806 and Spearman-Brown Coefficient was = .748.Factor analys was carried out ,KMO =0.666(which is approximately 0.7 is acceptable so was considered adequate to apply further evaluation. **Communalities** found was .469 to .730, **Varimax rotation** further helped to assess how 49 achievement variables clustered under 14 factors have Eigen values >1.0 and all 49-variance distributed under F1 to F14. Further the confirmation of 14 factors carried out by scree plot.(b) the quality of life of parents of thalassemia major children assessment scale : 27 items on 5-point Likert scale applied 0n 250 parents of thalassemia children RESULT: the frequency, Mean, SD followed by Inter item correlation was done, significant 25 items selected and 2 items (5,21) were deleted. The Value of Cronbach's alpha (α) for whole scale with 25 items were = .751 and Spearman-Brown Coefficient was = .814.Factor analys was carried out ,KMO =0.682(which is nearly 0.7 is very good so was considered adequate to apply further evaluation. **Communalities** found was .291 to .759, **Varimax rotation** further helped to assess how 25 achievement variables clustered under 8 factors have Eigen values >1.0 and all 25-variance distributed under F1 to F 8. Further the confirmation of 8 factors carried out by scree plot. **Hence the hypothesis made by the researcher i.e. the developed and standardized tool will be effective** for the assessment of quality of life of thalassemia major children and **for the assessment of quality of life of parents of thalassemia major children at the level of p ≤ 0.05.**

INTRODUCTION:

Thalassemia is a disease in which single gene get disordered and passed through parents to child, called an autosomal recessive pattern of disease can be seen in both the sexes. This disease has group of symptoms like inadequate production of normal haemoglobin due to decreased erythrocyte production. The common type of thalassemia found are (a) Thalassemia minor: is very silent carrier and will not show any symptoms (b) Thalassemia trait: will have mild microcytic anaemia but will not have any physical ailment. (c) Thalassemia inter media:can have mild splenomegaly ,moderate to severe anaemia, not required regular transfusion but maintain Haemoglobin 7 grams/dl , receives blood transfusion < 8 per year by attaining the age of 4 years and (d) Thalassemia Major:β – globin chains are absent or reduced in β – thalassemia, is a very serious condition, starts transfusion at very early at 2 years and till the end of life need frequent blood transfusion, patients receives blood transfusion ≥ 8 per year, before attaining the age of 4 years.in India the general incidence of thalassemia trait is between 3% -17%, in Madhya Pradesh itself it is 20.7% among some communities can be seen.[1,2,3] It is estimated that every year more than 10,000 new thalassemia major children are born in India.[4]The treatment for thalassemia was found very expensive. For getting ideal treatment, it costs around Rs. 1, 25,000/annum. For 50,000 children the cost would be nearly Rs.620 crores and in US $3200 /child /year. This gives further burden to the developing country like India.[5]Measuring HRQOL will also be helpful to invigilate the progress of nation's health objectives and to analyse HRQOL surveillance data. Furthermore, it can identify subgroups with poor health and help to guide ways to improve their condition and avoid more serious consequences.[6]The data obtained can be helpful to identify needs for health policies and regulations, designation of resources based on unmet needs, guidance on development of strategic plans, and monitoring the effectiveness of broad community interventions. The importance of health-related quality of life and well-being is emphasized by healthy People 2020 underlying the goal of promoting quality of life even in Thalassemia major cases. Moreover, it was established as one of the healthy people 2020 for foundation health measures.[8]

PROBLEM STATEMENT:

A Methodological study for development and standardization of a tool for the assessment of quality of life among thalassemia children andtheir parents at selected states of India during the year 2016-2018.

1.4. OBJECTIVES OF THE STUDY

1. To develop and standardize the tool to assess the Quality of life of thalassemia children.
2. To test the psychometric properties (validity and reliability) of newly developedstandardized tool for the assessment of QOL of thalassemia children.
3. To identify the underlying variables or factors that explains the pattern of correlations within a set of observed risk factors of quality of life of thalassemia children.
4. To develop a standardised tool based on the cultural values to assess the quality of life of Parents of thalassemia children.
5. To test the psychometric properties (validity and reliability) of newly developed standardized tool for the assessment of QOL of parents of thalassemia children.
6. To identify the underlying variables or factors that explains the pattern of correlations within a set of observed risk factors of the Quality of life of parents of thalassemia children.

ASSUMPTIONS:

1. Thalassemia disease can alter the quality of life of children. The prepared standardized tool will be effective for the assessment of QOL among thalassemia children.

2. Thalassemia disease can alter the quality of life of parents of thalassemia children. The prepared standardized tool will be effective for the assessment of QOL of parents of thalassemia children.

HYPOTHESIS:

H_1: The developed and standardized tool will be effective for the assessment of Quality of life among thalassemia children at the level of $p \leq 0.05$.

H_2: The developed and standardized tool will be effective for the assessment of Quality of life among parents of thalassemia children at the level of $p \leq 0.05$.

OPERATIONAL DEFINITIONS

1. SELECTED STATES OF INDIA: In the present study the selected states of India included: 1) **Madhya Pradesh** (Indore): Chacha Nehru Bal Chikitsalay (for pilot study), Choithram Hospital Research centre and SAIMS Medical College Hospital, 2) **Rajasthan (Kota**): Kota Blood Bank, Kota J.K Lon Mother and Child Hospital. 3)Maharashtra (**Nagpur)**: Rughwani Child Care Hospital, Punyani Hospital childcare Centre and from **Nashik**: Jankalyan blood bank Thalassemia Centre, Smile Thalassemia Foundation, Nashik Blood Bank.4)DELHI: during National Thalassemia welfare society conference AIIMS, Delhi

2. THALASSEMIA CHILDREN: For the present study thalassemia childrenmeans all children between the age group of 8-18 years and are **affected** with thalassemia major which will be confirmed by thalassemia or identity data card or by treatment file.

3. DEVELOPMENT OF TOOL: For the present study development of a tool means: it is an act of gradual, vigorous collection of those facts which are likely to have an effect on quality of life of thalassemia children and putting of those facts in an order step by step scientifically.

4. STANDARDIZED TOOL : For the present study, the standardize tool means : all test items carefully developed with cooperative effort of panel of experts who reviewed ,scrutinized , refined scientifically and on the basis of analysed results of pre-test score results from a representative samples of thalassemia children (age group 8-18 years),evaluated with same grading measures which will be reflected in its norms are the information necessary for the interpretation of the test scores quite correctly with constant results .

5. QUALITY OF LIFE

1. **QUALITY OF LIFE OF A CHILD:** For the present study QOL of a thalassemia major child is a subjective concern that how individual child is adapted herself / himself (including with disease and treatment) to fulfil their needs in the environment relevant to the culture which help to attain positive or negative aspect of satisfaction, comfort and happiness.

2. **QUALITY OF LIFE OF FATHER / MOTHER/ CARE TAKER :**For the present study quality of life of thalassemia major children's father /mother/ caretakers (near relatives) are those committed, responsible people, who really provide care for these children for the fulfillment of overall requirement of their children , in spite of their physical,emotional ,family and social functioning burden, lack of family support,finances,social life relationship and busy schedule of daily living.

6. ASSESSMENT: In the present study assessment refers to find the effectiveness of standardized tool to the quality of life of children who is suffering with thalassemia major.

RESEARCH METHODOLOGY:

Research approach :(mixed method): Qualitative (Phenomenological), Quantitative (cross-Sectional) approach was adopted.

Research design: Sequential exploratory mixed Method designwhere used to explore the phenomenon.In initial phase, qualitative data were collected by using Delphi technique[9, 10, 11, 12] 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 statistics ,Inter item correlation, Cronbach's alpha, Spearman-Brown Coefficient, Factor analysis (KMO, Bartlett test, Finding of factors for the assessment of : Quality of life for thalassemia children and their parents)[12,13,14,15,16]

Ethical approval: Through ethical committee and from administrative authoritiesof all selected hospitals, Blood banks and the conference organisers of National Thalassemia welfare society, permission and approval was taken.The participation of subjects was established by obtaining written consent from children with thalassemia major and from their parents:a)Before the preparation of the questionnaire (before interview and recording) (b) Prior to filling of the questionnaire (during which they had the liberty to ask questions or refuse to participate in the study).

THE POPULATION

Target Population: The children suffering with thalassemia major and their parents (father /mother/caretaker) who accompany the child.

Accessible Population: All children suffering with Thalassemia Major and their parents: admitted inselectedhospitals for blood transfusion or from blood banks who visited for blood transfusion or from educational gathering (conference) arranged only for thalassemia patients.

THE SAMPLE SIZE AND SAMPLING TECHNIQUE: 250 thalassemia children and their 250 parents': selected by: Non-Probability Sampling (Purposive Sampling) technique.

The Cochran formula is: $N_0 = \frac{z^2}{e^2} pq$ applied, p=17% (prevalence In India)[17]The sample size found to be 216.8and 246 (If p= 20%) Henceforth, a sample of size of 250 children suffer with thalassemia and 250 parents of thalassemia children or more found to be feasible for this study.

SAMPLE SELECTION CRITERIA

A) Delimitation: The study was delimited to: 1. Child with thalassemia major 2.Father / mother / Caretaker who is directly involved in caring and (3). Available at the time of data collection.

B) Inclusion criteria of samples as follows:

a) **The thalassemia major children and adolescents who were:** Confirmed diagnosis (Samples whose medical records / ID are available), Age group of 8 – 18 years old, both genders (Boy /Girl), able to complete the questionnaire or able to answer correctly, stable medical conditions, with no cognitive impairments, who could speak / write Hindi / English / Marathi.

b) **The parents of thalassemia major children and adolescents who were:** Willing to participate for the study, can communicate well/can fill up the Questionnaire well in Hindi /English/Marathi, with no cognitive impairment.

C) Exclusion Criteria of samples as follows: The thalassemia children and adolescents who were: very sick and not able to participate in the study, thalassemia with Sickle cell

disease, who has Positive results of HIV, suffering from any other chronic diseases, suffering with psychiatric problems.

METHODOLOGY:

Development of Tool: By adopting Delphi technique(9,10,11,12,13,14), during 1st round:face to face interview carried out by asking open ended questions to children suffer with thalassemia major and their family members (2 male child, 1 girl, 1 father,1mother,1 adult and 1 sister and mother who lost brother or sister) and all verbal responses recorded through voice recorder. Using software open code 4.02 word to word all verbatim typed, generated- items and subthemes. Extensive review and discussion with guide helped to remove unclear and repeated items[16]. The prepared tool validated in 3 rounds (8+30+15 experts) those who are working in the field(**Nursing experts:16, Medical Experts (Paediatric consultants): 07, Medical college paediatric professors :04, Psychologists: 04 ,Psychiatrist : 01, Social workers : 02, Statistician: 01, Scientist (Expert in genetics) :03,Adult Thalassemia Patient :1,Nursing staffs in groups :08,Nursing Tutor(posted at Thalassemia ward:01).**

(**First Round**: 8 validators were requested to give their opinion under: 1. Agree, 2. Disagree, 3. Remark, **Second Round**: 30 Validators (8Old + 22 New)were requested to give their opinion under: 1: Agree 2: Moderately agree 3: modified 4: can be deleted, **Third (Final round)** 15 validators requested to give the scoring on 5 point likert scale **Score1**: Irrelevant one should be deleted, **Score 2**: Seemingly relevant but large scale revision is required**, Score 3**: Relevant but in need of small adjustment, **Score 4**: Relevant, but needs re-wording, **Score 5**: Relevant, clear and Precise prepared; Based on their response validity of the scoring was done by applying the formula:**Index of suitability: (IOS)**= $\sum$ R/N = 90 to 100% agreement found on all items with few additions. The final items are generated under the headings of (Before sending for 1st validity):

1. Socio demographic variables of child,
2. Clinical variables of child
3. Open ended questions (for a child).
4. Socio-demographic Variables of parents

5. Open ended questions (for parents)

6. Quality Assessment Scale(a)The assessment of quality of life among thalassemia majorchildren . (b)To assess the QOL of parents of thalassemia major children)

(a)**Quality of life assessment scale for Thalassemia major children =**After face to face interview with thalassaemic children: 127itemsgenerated.Extensive review of literature, information gathered, discussion with experts and guide, all together reviewed the prepared items and removed unclear, repeated items ,the remaining items send for 1st validation i:e 52 items ,,2nd Validation:60 items ,3rdvalidation :59 items ,For pilot study :63 items, for final study :57 items and **finally for original tool the number of items are** :49 items .

(b) **Quality of life Assessment Scale for parents of thalassemia majorchildren:**After face to face interview with parents of thalassaemia major children and Adult patient: 42items generated .Extensive review of literature, information gathered, discussion with experts and guide, all together reviewed the prepared items and removed unclear, repeated items ,the remaining items send for 1st validation i:e 40 items ,2nd Validation:59 items ,3rd validation :27 items ,For pilot study :30 items, for final study :27 items and **finally for original tool the number of items are** :25 items.

PROCEDURE FOR DATA COLLECTION (PILOT STUDY)

20 children suffering from thalassemia major and their parentsvisited at Chacha Nehru Bal Chikitsalay (Children's Hospital)Indore, between 12/4/2016–6/5/2016were deemed fit were chosen by using a non-probability sampling technique (purposive sampling) for the pilot study. Cronbach's alpha (α) of QOL assessment scale for thalassemia children factors :1 to 5 and 9 was fine but for factors such as self-control (-1.840), financial (0.004), comfort level (-0.145) was very less even negative and couldn't be established as a factor.The sample size (N=20) was very less weren't adequate to apply Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy and Bartlett's test of sphericity and hence couldn't be carried out.The study was concluded that: Null Hypothesis is rejected, and alternative hypothesis therefore is accepted which indicated that the developed tool may be found effective in the assessment of QOL among thalassemia major children.

Cronbach's alpha (α) of QOL assessment scale for **parents** of thalassemia major children factors:3 was fine but for factors such as psychological (-0.452) and financial (-0.930) was very less even negative and couldn't be established as a factor. Therefore, marked as not suitable for present pilot study and for main study must reassess inter-correlation between them with increased number of items.

Finally, study indicated that lack of conformity of factors due to small sample (N=20) size and thus to reconfirm the factors to assess the quality of life of Thalassemia major children and among parents of thalassemia major children which needs further application of tools with large number of samples.

PROCEDURE FOR DATA COLLECTION (FINAL STUDY)

The children suffering from thalassemia major and their parents visited at various hospitals INDORE: Choithram Hospital Research centre, SAIMS Medical College Hospital, KOTA (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, Thalassemia children and their parents attending National Thalassemia welfare society Conference at AIIMS, Delhi, further met the inclusion and exclusion criteria were selected for main study during specified schedule. 260 children suffered from thalassemia major and their 260 parents were screened and chosen by using a nonprobability sampling technique (purposive sampling). They had explained about the complete study in his/her own language (Hindi/English /Marathi) and his/her willingness to participate in the study had recorded in a consent form duly signed by him/her.The investigator herself and with the help of few health care workers questionnaire administered in the language, they were comfortable with (Hindi/English /Marathi). However, the questionnaire initially comprised of 57 questions to assess the quality of life (QOL) of thalassemia major children while 27 questions used to assess the QOL of parents of thalassemia children. The questionnaire also included various open-ended questions to assess the QOL of thalassemia major children and their parents. The study was carried out in the same way as that of pilot study. The duration of study was 07 September 2016 to April 2018. The duration for filling the questionnaire was 30-40 minutes. The investigator assured about the confidentiality of the data.The investigator

did not face any problem during data collection rather they were enjoyed filling the form. The investigator terminated the data collection procedure by thanking the participants for their cooperation. Only fully completed tools were considered and that was only250.

RESULTS OF THE MAIN STUDY:

Characteristics of selected Thalassemia major children: The selected thalassemia major children's mean age was 13.18±3.258 years had ranged from 8 to 18 years,consisting of 152(60.8%)males,maximum proportion 101(40.4%) of the children was acquired secondary level education (6-10th class),all thalassemia children diagnosed before 2years ,the major health problems among 250 children with thalassemiamajor before diagnosis found are frequent history of temperature193(77.2%), pale appearances106 (42.4%), no height and weight gain 80 (32.0%), very weak/dull/less active52(20.8%),less appetite (34,13.6%) , less haemoglobin, irritation , loose motion andvomiting and cough and cold respectively. The Hb%before administration of blood noted in the range between 7-9gm/dl among 135(54.0%) and 7-9gm/dl among 88(35.2%) thalassemia children. The distribution of number of transfusion per month among thalassemia major children reveals:among 177(70.8%) thalassemia children was done more frequently twice in a month and once in a month 72(28.8%) and the type of blood among 120 (48.0%) arefresh packed red blood cells, followed by leukocyte filtered blood 113(45.2%) cells and only 7(2.8%) children are receiving whole blood. All 100%of them are receiving Iron Chelation drug either by oral or injectable form.

Characteristics of selected parents of Thalassemia children: Most of the parents of the thalassemia children from whom the data was collected 195 (78%) of them were fathers, 74(29.6%)were betweenthe age group 40-45 years.Most of them were 171(68.4%) were Hindu's , 157(62.8%)belongs to general category,134 (53.6%) were vegetarians, most of them97(38.8%) are graduates and54(21.6%) are intermediate or post high school diploma education,106 (42.4%) had private jobs or independent business, 98(39.2%) parents belong to social class 11 (based on BG. Prasadscale) and whose income lies between Rs. 3123Rs. 6255 per capital income.Nearly 3/4th212(84.8%) were having pukka houses,210 (84%) had nuclear family and 204

(81.6%) is from urban population.Concerning identification of carrier status 100% both parents had not done any investigation before and after marriage. After the birth of sick child 214 (85.6%) of both parents found out the carrier status and noticed that 213 (85.2%) fathers were minor and one is major, 214 (85.6%) mothers were found thalassemia carriers.Regarding carrier status of other children, it was noticed that among 1st child (119(47.6%) they are singlesufferer with thalassemia major and 59(23.6%) were minor (carriers), among 2nd child 105(42%) were sufferers with thalassemia major and 42 (16.8%) were thalassemia carriers (minor), among 3rd child 27 (10.8%) were thalassemia major and normal and 22 (8.8%) were suffer with thalassemia minor.207(82.8%) were the member of thalassemia society and most of them mentionedthat 75 (30%) were benefitted by attending national thalassemia conference andgettingmagazineregularly, 74(29.6%) get treatment (blood, medicine, Investigations, medicalCheck-up) in discount.

RELIABILITY OF THE SCALE

1st TOOLRELIABILITY: "FOR THE ASSESSMENT OF QUALITY OF THALASSEMIA MAJOR CHILDREN": Newly developed tool applied to 250 children suffer with thalassemia Major with 57 items .The scoring of 57 items available on 5-point Likert scale (Strongly disagree, Disagree, neither agree nor disagree, Agree, strongly agree) used to find the frequency, Mean, SD followed by Inter item correlation was done, significant 49 items selected and 8 items (21,35,44,45,48,50,52,55) were deleted. The whole process was done by the help of SPSS.

- For selected items the psychometric properties (validity and reliability) done by adopting 2 methods :1. The Cronbach's alpha. 2. Spearman-Brown Coefficient(Split half Method).

Reliability of a Constructed tool: for the selected 49items:

a) The value of Cronbach's alpha (α) for whole scale with 49items were = .806

b) The value ofSpearman-Brown Coefficient for whole scale with 49 items were = .748

The result depicts: the stronger correlation between all selected items on the newly developed questionnaire and the newly constructed measuring scale to assess the quality of life among thalassemia major children found to be highly reliable.

2nd TOOL RELIABILITY: "FOR THE ASSESSMENT OF QUALITY OF LIFE OF PARENTS OF THALASSEMIA MAJOR CHILDREN":

Newly developed tool with 27 items were applied to 250 parents of thalassemia major children.Scoring of 27 items available on 5-point Likert scale used to find the frequency, Mean, SD followed by Inter item correlation was done, significant 25 items selected and 2 items (5,21) were deleted. The whole process was done by the help of SPSS.

Reliability of a Constructed tool: for the selected 25 items

a) The value of Cronbach's alpha (α) for whole scale with 25 items were =.751
b) and the value ofSpearman-Brown Coefficient is =. 814

The result depicts: The stronger correlation between all selected items on the newly developed questionnaire and the newly constructed measuring scale to assess the quality of life among parents of thalassemia major children found to be highly reliable.

FOR GENERATION OF FACTORS:

FACTOR ANALYSIS methods adopted……[24, 25, 26,27,28,29]

1st Scale: "FOR THE ASSESSMENT OF QUALITY OF LIFE OF THALASSEMIA MAJORCHILDREN":

1. Assessment of Kaiser Meyer Olkin Measure of sampling adequacy: was found 0.666 which is approximately 0.7 is acceptable so was considered: Good and sample size (N=250) found to be adequate to apply furtherevaluation.The Bartlett's test of sphericity was approx. chi square value is 3.647E3 significant at<.000 at 1176 degree of freedom proves there is strong correlationamongvariables. The present study rejected this null hypothesis sincethe Bartlett'stest of Sphericity is significant (p=0.000) which proves that factor analysis canapply further.

2. Finding of communalities: The estimates of the variance in each variable found different that ranges from .469 to .730, means that the variables are highly correlated to provide a reasonable basis for factor analysis for the present study.

3. Factor analysis with Varimax rotation was conducted to assess how 49 achievement variables clustered 14 factors have Eigen values >1.0 and all 49-variance distributed under F1 to F14. Further the confirmation of 14 factors carried out by scree plot.

4. The Scree Plot: The Scree Plot further helped to decide the initial Eigen values. It can be noted that both the scree plot and the Eigenvalues support the conclusion that these 49 variables can be reduced to 14 components.

5. Rotated Component Matrix: Varimax for factor rotation and loadings further helped 49 items to be divided into 14 variables according to most important items. **The loadings of extracted underlying factors from F1 to F14 is:** In the present study the **Factor-1** consist of 6 items (3,4,5,1,2,9) listed first factor loading: .775,.744,.620,.549,.495,.475; **Factor-2** consists of 6 items (31,30,28,23,8,32) with factor loading .686,.686,.546,.544,.419,.410; **Factor-3** consisted of 3 items (13,38,37) with factor loading .685,.629,.482; **Factor-4** consists of 5 items (26,19,25,20,29) with the loading .695,.637,.525,.501,.394; **Factor-5** consists of 3 items (18,53,17) with the loading. .706,.591,.528; **Factor-6** with 3 items (41,36,22) with loading :.811,.774,.383; **Factor-7** with 4 items (10,7,47,6) with factor loading: .660, .525,7.725E-6,-.319; **Factor-8** with 3 items (57,34,56) with factor loading: .748,.553,.503; **Factor-9** with 3 items (33,42,43) with factor loading: .692,.506,.453; **Factor-10** includes 3 items (24,40,49) with factor loading : .655,-.607,.402; **Factor-11** includes 3 items (46,11,12) with factor loading : .682,.612,.546; **Factor-12** consisted of 4 items (16,14,51,39) with factor loading : .643,.582,. 450,-.366; **Factor-13** consists of 2 items (15,27) with factor loading : .770, .438 **Factor-14** consisted with 1 item with factor loading of .788 (Item 54) Over all the loadings of extracted underlying factors are from F1 to F14 had ranges from: -.366 to .814 and naming of factors done i.e. Physical wellness ,Self-satisfaction, Level of independency, self-perception and family impact, financial impact and social crisis, peer support and schooling, managing to comfort level, coping up with challenges, emotional and cognitive level, ability for self-decision , motivation and inspiration, social support and schooling, academic issues and spirituality, support to health.

The newly constructed measuring scale to assess the quality of life among children with thalassemia major found to be reliable since the value of **Cronbach's alpha (α)** for

whole scale 49 item was .806 and **Spearman-Brown Coefficient was .748 and** the factor scoring of individual item on developed scale was -.319 TO .814 with 14 factors . **Hence the hypothesis made by the researcher i.e. The developed and standardized tool will be effective for the assessment of quality of life of parents of thalassemia major children at the level of p ≤ 0.05.**

THE DEVELOPED NEW: STANDARDIZETOOL "TO ASSESS THE QUALITY OF LIFE OF THALASSEMIA MAJOR CHILDREN".

Note: Prepared Tools and the scoring system for this research work has been published in Volume 9 Issue 1, Jan-March 2020, PN 37-55.

FOR GENERATION OF FACTORS: FACTOR ANALYSIS[24,25,26,27,28,29] methods adopted for ……

2nd Scale: "FOR THE QUALITY OF LIFE OF PARENTS OF THALASSEMIA MAJOR CHILDREN ASSESSMENT SCALE ":

1. Assessment of Kaiser Meyer Olkin Measure of sampling adequacy: KMO = 0.682 This was nearly .7 so it is very good.The Bartlett's test of sphericity was approx. chi square value is 1.434E3 significant at <.000 at 300 degree of freedom proves, there is strong Correlation among variables. The present study rejected this null hypothesis since the Bartlett's test of Sphericity is significant (p=0.000).

2. Finding of communalities: Extraction of communalities are the estimates of the variance in each variable found different that ranges from .291 to .759 and the responses < .3 are discarded.

3.Finding of Eigen values: Factor analysis with Varimax rotation was conducted to assess how 25 achievement variables clustered under 8 factors have Eigen values >1.0 and all 25-variance distributed under F1 to F8. Further the confirmation of 8 factors carried out by scree plot.

4. The Scree Plot further helped to decide the initial Eigen values. It can be noted that both the scree plot and the eigenvalues support the conclusion that these 25 variables can be reduced to 8 components.

5. Rotated component matrix: further helped 25 Items to be divided into 8 factors according to most important items mentioned down as **Factor-1 consist of** 4items(9,16,11,1) with a factor loading of .749,.724,.633,.495;**Factor-2 consist of** 4items(23,22,19,15) with a factor loading of .790,.730,.439,.410; **Factor-3 consist of** 5 items(2,18,20,17,3) with a factor loading of .748,.629,.509,.318,.612; **Factor-4 consist of** 3 items (25,10,14)with a factor loading of .653,.640,.536; **Factor-5 consist of** 2 items (26,27) with a factor loading of .865,.828;**Factor-6 consist of** 3 items(8,6,24) with a factor loading of .782,.715,.365; **Factor-7 consist of** 2 items(13,7) with a factor loading of .725,.632;**Factor-8 consist of** 2 items (12,4) with a factor loading of -.705,.510.Over all the loadings of extracted underlying factors are from F1 to F 8 had ranges from: .318 to .865 and naming of factors done are :Physical health , Financial status, Psychological domain ,Family support, Spirituality, Comfort level, Emotional control and Self-satisfaction. The newly constructed measuring scale to assess the quality of life among parents of thalassemia major children found reliable since the value of **Cronbach's alpha (α)** for whole scale with 25 item was: .751 and **Spearman-Brown Coefficient was .814 .Hence the hypothesis made by the researcher i.e. the developed and standardized tool will be effective for the assessment of quality of life of parents of thalassemia children at the level of p ≤ 0.05.**

After the application of developed tool the obtained Quantitative data was treated with SPSS and converted into Quartile percentile. **The view of Zungs scale[21], The Global QO Life scale[22]and Anderson LK.Burckhardt and Anderson conducted a study in (2003)[23]** were adopted.

Scoring of Thalassemia children scale		**Scoring of Parents of Thalassemia children scale**	
SCORES	GRADE	SCORES	GRADE
Score < 171	Poor	Score < 80	Poor
Score 171 -179	Average	Score 80-86	Average
Score 180- 190	Good	Score 87-89	Good
Score 191-245	Excellent	Score 90 -125	Excellent

THE DEVELOPED NEW: STANDARDIZE TOOL "TO ASSESS THE QUALITY OF LIFE OF PARENTS OF THALASSEMIA MAJOR CHILDREN".

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