

Thalassemia Disease Specific Quality Of Life (QOL) Health Model

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ABSTRACT:

Every individual is having their own perception for attaining their goals, standards, and expectations about their value system which affects the individual person's Physical health, Psychological health, Level of independence, Social and environmental relationships, etc. Beta (β) Thalassemia Major is a single gene autosomal recessive pattern of a disease that causes the inadequate production of normal haemoglobin due to absence or decreased synthesis of one of the normal β globulin chains of haemoglobin which further leads to severe haemolytic anaemia and chronic hypoxia and related complications. Timely assessment and intervention of certain factors can prevent these complications in some extent and for this needed some theoretical bases to understand the whole concept. Three concepts, (1) Quality of life developed by Dr Robert Schalock³, (2) Maslow's Hierarchy of needs⁴ and (3) Virginia Henderson ;Need theory with 14 basic needs adopted⁵ to develop a Thalassemia disease specific quality of life (QOL) health model. A sequential exploratory mixed method design, the approach was qualitative (Phenomenological) Quantitative (Cross-sectional) used. Delphi technique was used that includes disease related questions in open ended form asked to parents, children and all verbal responses were recorded by using software open code 4.02, later validation of generated items was done in 3 rounds with the help of 8+30+15 = 53 experts in total. With the completion of Pilot study, further modification, addition, or deletion in the tool was applied to 250 children and their respective parents. Data was treated with factor analysis, identified 14 factors or variables to assess the Quality of life of thalassemia children and 8 factors to assess the quality of life of children. The study concluded that: these generated 14 factors of QOL of thalassaemia children and 8 factors of parents of thalassemia children can be utilized in generating theory related to : thalassemia disease specific QOL health model in assessing the quality of life of these thalassemic children and their parents for timely assessment and intervention.

Key Words: QOL/QoL: Quality of life, Delphi technique, β : Beta thalassemia.

THALASSEMIA DISEASE SPECIFIC QUALITY OF LIFE (QOL) HEALTH MODEL

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I. 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^{1,2}. Every individual have their own perception for attaining their goals, standards, and expectations about their value system which affects the individual person's Physical health, Psychological health, Level of independence, Social and environmental relationship etc.

Conceptual framework describes about the scientific details on theoretical application of study regarding the selected problem of thalassemia disease specific children. Methodology undertaken in this present study provides the details on beliefs, assumptions, graphical representation of ideas, and further understanding of the studied phenomena. Overall, the framework will depict a basic, systematic structure and further explains relationship among factors which will be helpful in assessing the factors that affects the quality of life of these thalassemic children.

Thalassemia Major Disease is a single gene disorder, received from parents to child (called an autosomal recessive pattern of disease but do not affect the sex chromosomes), can be found in both the sexes. The inadequate production of normal haemoglobin due to decreased erythrocyte production is represented by the characteristics of absence or decreased synthesis of one of the normal globulin chains of haemoglobin. If α - globin chains are absent or reduced it is called α - thalassemia, if β - globin chains are absent or reduced is β - thalassemia⁶ which is a common type of thalassemia and has 4 categories: a) Thalassemia Major (Cooley anaemia) b) Thalassemia Intermedia c) Thalassemia trait and d) Thalassemia minor.⁷ In β -thalassemia: β -globulin chain production is either reduced or absent which further leads to a large number of unstable globulin chains which ultimately forms defective RBC that become rigid and gets easily haemolysed causing severe

haemolytic anaemia and chronic hypoxia with the symptoms of dizziness, fatigue, irritability, shortness of breath. Frequent increased RBC destruction and erythroid activity causes bone marrow expansion leading to skeletal changes/deformities (frontal and maxillary bossing) etc.^{8,9,10,11}

These thalassaemic children Haemoglobin level can maintain close to the normal by judicious application of transfusions, Chelation therapy (prevents reserve iron overload), and Bone marrow transplantation (if there is HLA compatible sibling/family member or unrelated alternative donors, cord blood transplantation and peripheral blood stem cell transplantation services can be offered when it will be indicated).

Internationally for the assessment of quality of life a validated frame work is available which was introduced by Dr. Robert Schalock in 3 broad areas: Independence, Social participation and well-being which were further divided into 8 domains with indicators i.e., 1. Emotional well-being (Contentment, self-concept, lack of stress), 2. Interpersonal Relations (Interactions, relationships, supports, recreation), 3. Material well-being (financial Status, employment housing), 4. Personal development (education, personal competence performance), 5. Physical wellbeing (health and care, activities of daily living leisure), 6. Self-determination (autonomy /personal control, personal goals and, choices, 7. Social inclusion (community integration and participation, roles, supports, 8. Legal Rights, human (respect, dignity, equality) in general (QOL or QoL) is that how the individual person is perceiving their daily life as well-being or lack thereof in relation with emotional, social and physical aspects and the health related quality of life is an assessment of an individual how the person affected at the time of disease, disability or disorder³.

IMPORTANCE AND NEED OF THE THEORY: Application of nursing theories is especially important, as without the function of the heart, survival of human is difficult in the same way for a correct provision of nursing practice the concept of theory is must. The main aim of the theory application in nursing is to provide quality of care which can give an impact of better Quality of life among patients. The focus of the nurses practices is also always based on the available evidence and each family members, health workers are committed to provide intentional, goal oriented care to the thalassemia child as well, which can be helpful to provide patient centered, family centered quality of care and trying to attain a high level of wellness.

Concerning a thalassaemic child, a developed statistically proved factors needs to be assessed that would be helpful to have knowledge of positive or negative quality of life of these thalassemia patients. Based to these, time to time counselling must be planned for preventing further deterioration and help them to maintain the high level of wellness in all areas of health dimensions. There are certain driving forces which can push a thalassemia child to a positive dynamic state like becoming competent, proficient to determine the details about chelation therapy, dietary and treatment plans, consequences, health care resources etc. thereby helping them to develop and implement appropriate interventions and compromise with own treatment. Clinical judgement of nurses during hospital visits reflects the representation to take wise decisions with respect to patient care. Theoretical principles to develop and implement the plan of care are the major concepts of nursing care at hospital, community and at home. The thalassemia child must be respected among society, surrounded with helpful people, and trusted, cared by parents can help them seek a better quality of life. The realization of being competent than being powerless/weak child, must be mind-set for parent of a thalassemia children. Family members must understand the frequent necessity of expecting to continue the practice of important therapies, tests for the wellness of these children and having a good quality of life.

According to the theoretical concept in the specific situation to rule out the quality of life of a thalassemia child and their parents, the multi-dimensional orientation approach is important. As, these factors are interwoven with each other so it will be helpful to get even the minute information which is useful to give effective, efficient, and holistic care. All caretaker must be committed, goal oriented, proficient, and competent to depict a specific pattern of behaviour in performing when it requires to practice.

RESEARCH METHODOLOGY:

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

Research design: Sequential exploratory mixed Method design where used to explore the phenomenon. In initial phase, qualitative data were collected by using Delphi technique.

ETHICAL APPROVAL:

From the ethical committee and administrative authorities of all selected hospitals, Blood banks and the conference organizers of National Thalassemia welfare society, permission and approval were taken, informed consent also been obtained from children with thalassemia major and their parents: a) Before the preparation of the questionnaire (before the interview and recording) (b) Prior to filling of the questionnaire, confidentiality and anonymity had been maintained and they had the liberty to ask questions or refuse to participate in the study.

PROCEDURE ADOPTED FOR THEORY DEVELOPMENT: The initial development of items in this study uses Delphi technique. Responses were recorded using software open code 4.02 for the open-ended questions related to disease condition, problems, routines of daily life etc. Face to face interview was done with thalassemia major children, father, mother, brother, and sister of thalassemia child that were then typed word to word from which themes and related items were developed. Further review literature, discussion with guide and validation of generated items was done in 3 rounds with 8+30+15=53 experts. After pilot study, further modification, addition, or deletion was done and the developed tool was applied to 250 children and their parents. The received data was treated with factor analysis.^{12,13,14,15}

Factor analysis was used to identify underlying variables, or factors, that explains the pattern of correlations within a set of observed variables. These underlying factors were minimized after analysing those items with the correlation matrix and the multiple loadings under various factors. Finally, some items were deleted either due to smaller shared variance or multiple loadings on various factors.^{16,17} Eigen values supported the conclusion of variables to divide under 14 factors or domains. Rotated Factor Matrix table was used for maximising high item loadings and minimising low item loadings and given names that best represents the variables within factors. The software used for this purpose was 20 SPSS.^{18,19} Finally the developed items and factors were used to generate the **Thalassemia disease specific quality of life (QOL) health model.**

II. Theoretical Resources For The Theory Development:

THE CONCEPT USED: The present study is adopted concepts from frame work of Quality of life developed by Dr.Robert Schalock³, Maslow's Hierarchy of needs⁴ and Virginia Henderson need theory with 14 basic needs.⁵ It is known that thalassemia child is an individual who has own genetic features received from parents during intranatal period which can be improved if a child is offered a supportive environment. Further the overall physical, mental, social, and spiritual development of a child totally depends on parental supportive care, time to time stimulation, assessment, fulfilling play needs and timely socialisation with other children or siblings, family members. Maslow identified the hierarchy of needs in all human beings including children and each of it showed the extent with varying significances. At the bottom of the ranking the basic needs are given first priority as it is important for the survival of an individual. To lead an ideal life, these thalassaemic children have to fulfil all those needs in some extent and parents frequent support, guidance, encouragement is important so that even the children suffer with thalassemia disease but still will help the child to empower with those hierarchy of needs. These basic needs are: physiological needs, Safety needs, Psychological needs: belongingness and love needs (intimate relationship with friends and peers), Esteem needs (Prestige, feeling of accomplishment), Self-actualisation (achieving ones full potential including creative activities) makes the process of empowering their patients more understandable, simple and easy to adopt. In the first instances in concern with these thalassaemic children in some families it may be difficult to fulfilled these needs in some extent, including specific treatments required to maintain the health of these chelation. They must be treated as like normal children so that their self-esteem not been effected and psychologically they must feel secure, strong in carrying out normal life with full of robustness. The function of brain is very complicated and in a growing child, if the parents are responsible to offer a positive environment to manifest child to realize about his or her child's potentials for the desire of future ground work in the fulfilment of self-management, roles leading to the mastery in self actualisation and allow the child to exert their energy in the practice for leading an independent successful life.

Development of balanced personality and overall development of a child is greatly affected by the warmth, care, encouragement, peer support, societal and financial condition of parents. Moreover, love, security, recognition, self-esteem, and self-actualization of a child also are important to practice in controlling the emotions. Virginia Henderson mentions 14 basic needs of a patient to be taken care off during hospital admissions for blood transfusions etc. The growth and development of child brings time to time changes, can alter due to painful events and other bitter experiences from the internal and external environment surrounded by the child. Despite of criticism a child needs supportive care which helps them to adjust with timely investigations, transfusions, daily medications, but restriction in activities and overprotection will not help them to handle the challenges on their own. This would lead to lack of self-confidence in thalassemia affected children when being tested on failures in life and thus the Quality of life will be in endanger.

The family and the environment with whom the child is exposed must provide the care by understanding of the child's goals, strengths, the basic needs, and health status. This will help the child to have an overall development and prepare a value system that will help the child to have continuous adjustment to internal and external environment. The role of continuous support of health care system is further helpful for the child and parents to maintain a holistic health and good quality of life. But in some instances, these children may suffer with the feeling of hopelessness, confusion about the goals of life and timely intervention as a part of helping the child to overcome these problems.

Virginia Henderson mentions the 14 basic human needs and nurses needs to support and guide parents through health education, to meet those needs for their thalassaemic children. The mind and body are indivisible. The physiological and emotional balance helps the child to achieve wholeness in themselves. Henderson believes that nurses perform independent role in providing knowledge and giving physical strength to receive therapies (like blood or other components transfusion to maintain the correct Hb level and chelation therapy to prevent Iron overload in the body) in a timely to maintain good quality of life.

MAJOR CONCEPTS OF DEFINITION:

Thalassemia child an Individual/person– In this study individual/person: is a child or adolescent, a victim of thalassemia disease and has own genetic loading. Many basic human needs (Physical mental, social, and spiritual) has to be satisfied from the environment surrounded by parents, other family members, peer groups, teachers and neighbours. The genetic nature and physical ailments of the body received from parents can bring abnormal changes in the body- physiology, even it can affect the appearance of a child. These all changes can turn into a negative self-image, and withdrawal symptoms. These children can have few invisible and visible sign and symptoms like fatigue, mood fluctuations, pain at anywhere in the body, etc. However, providing proper timely supportive care and treatment can be extremely important to prevent complications in some extent.

Every child will have some desired visions, goals and strengths in every steps and stages in life. If they want to be successful in life, they must gain social status, prosperity and ultimate result will be happy and successful. They will be confident, can lead themselves, never give up, organized, creative and have good problem-solving skills, able to do what they personally like to do. If the child has low confidence the attaining of top level of ranking according to Maslow’s theory will be affected. There will be full of positive mental abilities and attitude about themselves, self to find integration in the routine work. Parenting style for teaching the acceptance of failures and overcoming them, considering the disciplinary changes by modifying actions by the use of award and punishment, develops a great positive attitude in children. Frequent support, motivation, encouragement of activates helps in the timely development in a growing child and adolescent. Good parental support helps the child to acquire daily living skills, shaping the child’s personality and the installation of essential values inculcated in children is a foundation to learn, grow and behave in the world and can avoid behavioural problems, empower them to protect themselves against harmful effects of negative forces either from the internal or external environment. Also, coping with the stress related to frequent transfusions, medications investigations etc., when they live and act in the society to maintain a healthy qualitative life with thalassemia disease condition.

Still some children feel frustrated when being caught up with extreme mood swings, hopelessness, loss of interest, suicidal thoughts, etc., due to which they face obstacles to achieve their goals. This can make them vulnerable and upset, usually whose responds with dangerous act which is not fair. Early assessment and timely intervention as a part of helping the child to recognize what event triggered their behaviour and can also prevent problems among such children.

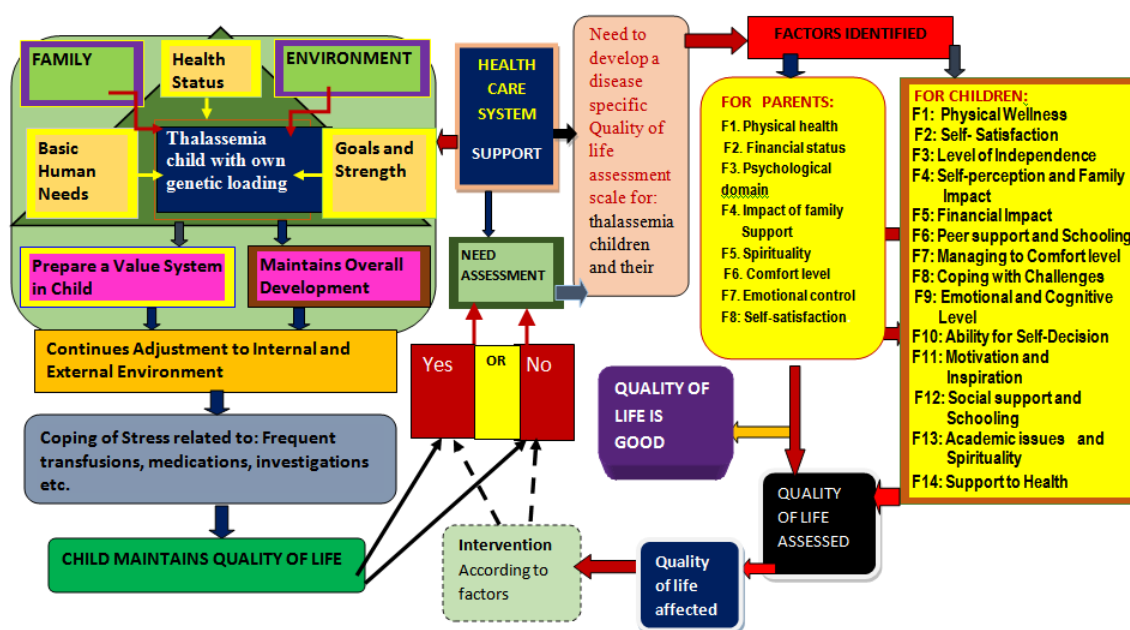


Figure No. 1.1: Thalassemia disease specific quality of life (QOL) health model

➤ **Environment:** A continuous adjustment to internal and external environment is possible with appropriate support system like father, mother, siblings, other members of the family, peers, and society are helpful to prepare a value and sound holistic health system which maintains overall child's growth and development. Above all, continuous support to attain education, job opportunities further improve confidence in them. Timely guidance and support of health care team and frequent evaluation helps the child or adolescent to cope with the stress due to frequent transfusions, investigations, and daily intake of medications by different routes (orally/subcutaneous/intravenous route) will be helpful to maintain the quality of life of these children. Frequent communication with family personals and child will be helpful in improving and sustaining high attitude of wellness.

➤ **Health:** In this study health of a child determines a child's comfortability, success in fulfilling hopes, expectations from the present movement of experience in relation with domains of emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights.

➤ **Nurse:** Nurse is an important person in the health care system whose continuous support to thalassemia effected children and their parents giving a lifelong resolution of various health problems and the child and their parents can maintain a good quality of life. They are responsible to provide holistic care which includes all basic and special needs mentioned by Maslow.

➤ **Attempt of output measurement:** It is an attempt of a healthcare worker to analyse the overall factors which affect the quality of life of these children by using the appropriate tool. This will help the health care worker to re-plan the care scenario and further help to maintain the health-related quality of life.

➤ **Thalassemia disease specific quality of life health model:** Inductive followed by deductive method used to generate the items for preparing QOL assessment tools: to assess the 1. QOL of thalassaemic children 2. QOL of parents of thalassaemic children. A newly developed standardized disease specific tool was developed and applied to 250 thalassemia children and the respective parents of thalassemia children and generated quantitative data was treated with factor analysis which helped the researcher to divide the items under various domains by finding Eigen values. This was followed by Orthogonal rotation (Varimax) of items and plotting graph (Scree plot) of the Eigen values against all the factors useful to determine specific factors and items that has to be retained. The former precisely generated specific domains and its related items grouping helped the investigator to develop the disease specific theory identified as the important factors which can affect the QOL of thalassemia children and their parents. The identified important factors which can affect. **The QOL of thalassemia children are:** Mentioned under **Section: A**, 2. **Factors affecting the QOL of Parents of thalassemia children** are mentioned under **Section: B**.

SECTION: A: Factors and Items responsible to assess the QOL of thalassemia children are

➤ **FACTOR 1: PHYSICAL WELLNESS:**

The items are: 1. I can manage my work if I have to live alone. 2. I can finish my work without anyone's help. 3. I have enough freedom to decide about my future. 4. I do my daily routine works, without anyone's help. 5. In spite of ill health, I get satisfaction from work necessary to fulfil my needs. 6. I can lead a normal life like other children

Children empower themselves to manage daily routines or work and have the feeling of ownership in their responsibilities to fulfil it without anyone's help. They feel the sense of freedom and confidence in their self-decision related to future endeavour, studies, job and other crucial life factors. These children are also seen to be more responsible to study and complete their school assignments. Being self-directed, a person shows acceptance towards their health and its limitations, which helps them to strive hard and go beyond their capabilities to attain wellness which ultimately helps to improve and maintain overall quality of life.

FACTOR 2: SELF-SATISFACTION:

The items are: 1. It gives me satisfaction, when I help my parents in their work at home. 2. I am happy with this life, even though i am suffering from thalassemia. 3. I practice my religious rituals/beliefs. 4. I am able to bear/tolerate the pain caused due to medical investigations and blood transfusions. 5. I can study continuously for more than one hour at home. 6. Due to less money in my family, my parents do not allow me to attend my friend's birthday party, etc. *

Even though the child is suffering with disease condition, still self-satisfaction brings them to have own purpose and goal in life. They will take initiative to help their parents or others in their jobs/works to prove that they are not lesser than anyone else. Maslow's view of self-actualisation from the part of child is important, which will help the child to understand the meaning of life. They are ready to survive and overcome problems when they challenged and if the health care workers, family members and the society will help them to maintain the balance in the environment and can have good quality of life. Frequent experience of pain due to medical investigations and blood transfusions may change moods, behaviour instead of a hardworking, productive, debilitate lives even may feel burdened to others. Children's acquisition of problem solving,

language, social development, and emotional control is facilitated by interactions with their parents. They can concentrate for their studies even more than an hour's. Parents instead of being overprotective, should take time to teach and encourage their children timely to learn a skill, so that as the child grows, they are independent in their work which is supported by a feeling of self-satisfaction. Sometimes economic burden of their parents can curtail the social activities of their children; still these children will be able to cope up the situation with great understanding.

➤ **FACTOR 3: LEVEL OF INDEPENDENCE:**

The Items are:1. As my teachers scolds me, I do not like to go to school *. 2. I am unable to solve my problems alone * 3. I need someone to help me walk inside the house*

➤ For the appropriate growth of level of independence, offer proper opportunity to grow, to learn and give timely guidance and freedom to do things independently. Children's ideas, wishes should be respected, considered, and allow them to perform if it is useful for their transformation. Together parents and teacher's constant guidance, motivation will help them to enhance their skills and boost up their confidence. Arranging interactive sessions between students will encourage them to think positively about the world they live in. Acceptance of a child's interest is important for improving the quality of life of a child, what to eat, what information to be shared with friends and how to maintain daily routines will help the child to be independent in his personal needs. In a family, if a child is sick, it affects the emotional state of parents, leading to mood swings, increased anxiety, separation from other family members and uncooperative society. Certain factors are also responsible to affect the quality of life of parents, which directly affects the quality of life of children.

➤ **FACTOR 4: SELF-PERCEPTION AND FAMILY IMPACT:**

The Items are:1. I feel sad, when my relatives do not talk to my parents because of my sickness. *2. My brother/sister does not like my parents spending more time and money on me. *3. My parent's curse their fate for giving birth to me as a sick child that makes me feels guilty. * 4.I feel sad/ lose hope when doctors tell my parents about no recovery in my illness. * 5. My weight and height are similar/equal to that of my friends

➤ Good family communication among relatives will help the parents to face every challenge as an opportunity to grow and to find their coping strategies. If the sick child has another brother or sister, then parents must see that other children are not pushed aside by the demands of their sick child. Acceptance from family members, encouragement rather than criticism, preventing the use of cursing words from own parents upon birth of a thalassemia child, proper acceptance of scientific advancement for care and medical help will help the thalassemia major children to maintain good physical health. Giving children a feeling of their good or attractive appearance further help them to progress to a greater extent in all aspects of daily life and have a positive attitude towards themselves.

➤ **Factor 5. Financial Impact and Social Crises:**

The Items are:1. My treatment is an extra additional financial burden on my parents* 2. My parent's income is sufficient to provide treatment and food for me and my family. 3. People avoid me and make fun of me in public places *

➤ This is a big challenge that strikes every parent especially when their child suffers from a chronic disease condition. Parents are expected to have enough finances for the regular expenses of these thalassemia major children and other expenses at the hospital for investigations, blood transfusions, and medications, etc. These extra-financial expectations eventually impact the care of a child's basic needs. Families tend to avoid social gatherings and stay away from the community, instead, they must consider them to approach a welfare service from the area where the child resides. If parents find a way to solve the financial crises' problem, they will be comfortable in providing treatment and food for the whole family. Society should be educated to respect, support, avoid mockery, which would help the family to maintain the QOL of a thalassemia major child. Lacking support in these areas can cause a family to face a problem and in adjusting with other people in society.

➤ **FACTOR 6. PEER SUPPORT AND SCHOOLING:**

The Items are:1.My classmates understand my sickness and help me in studies whenever required.2. My classmates help me in finishing my homework, when ever needed 3.Iam comfortable in sharing my problems with my friends.

➤ Counselling other students by the teacher is very important to know about the nature of sickness that these students can support these thalassaemic children in learning, finishing homework as well as becoming comfortable in sharing their problems. Empathetic listening, encouragement, assistance in solving problems, support to cope day to day stress factors regarding schooling will help them to cope with their studies and

performing assignments. All would aid them to fulfil their educational requirement without fail and can live a balanced quality of life.

➤ **FACTOR 7.MANAGING TO COMFORT LEVEL**

The Items are:1. After just few minutes I feel tired and need to stop playing outdoor games* 2. I find it difficult to complete my school assignments due to my frequent / continuous absence* 3. If I get a chance, I eat supari or gutka*4. I maintain healthy personal hygiene without anyone's help.

➤ Experiencing moments free of pain and sufferings can provide a positive impact towards a well-adjusted routine, eventually minimizing stress and producing sense of familiarity, security, and certainty. However, if a person is out of their comfort zone, there will be more probability of stress and anxiety which would eventually affect their behaviour and all other activities. In school a child may struggle while completing their school assignment, less interest towards games and activities but able to adjust with the problems by adopting methods like rest in between these kinds of strenuous act. To ease the frustration, they tend to get addicted to Gutka or supari and these practices eventually affect their QOL.

➤ **FACTOR 8. COPING UP WITH CHALLENGES:**

The Items are:1.My tiredness indicates the need of blood transfusion* 2. I do not like to pray as God has done injustice to me in the form of my disease* 3. Body pain creates problem in sleeping *

➤ There are challenges in life but trying to find out ways to achieve the goals. Finding acceptance is the key to happiness, and ease for living without suffering. Timely transfusions can minimise tiredness, body ailments and can have good sleep among these children. True acceptance minimises the feeling of dissatisfaction upon not meeting their needs and a child would strive their best in midst of negative compliment to achieve the results which although may not be perfect but would comfort them and would reinstate "I am better" feeling in them. They will not complain of not like to pray as God has done injustice to me in the form of disease. This energises a person and gives them internal force and develops hope.

➤ **FACTOR 9. EMOTIONAL AND COGNITIVE LEVEL:**

The Items are: 1. I find it difficult to restrict myself from food containing green leafy vegetables, jaggery, etc. * 2. I find difficulty to learn and memorize/remember my lessons. * 3. I can complete my homework without anyone's help.

➤ When parents realize that their child is suffering with thalassemia, they are struck with a feeling of guilt and sadness in their mind which causes feeling of overprotection. Higher stress due to better care and support for treatment or fulfilling the needs of their child can reflect on attitude of child's care like restricting certain foods (green leafy vegetables, jiggery, etc). Failure in providing familial and societal support, can affect the child's behaviour, eating habits, memory and interest towards responsibilities related to completion of home work without assistance, even find difficulty to learn and memorize any lessons given to them which leads to poor QOL due to the poor achievements in life.

➤ **FACTOR 10. ABILITY FOR SELF-DECISION:**

The Items are: 1.I am unable to decide what job I should do in future.*2. According to my will, my parents take me for any treatment. 3.Even if I am ill, I help my parents to earn money by helping them in their work.

➤ Primitive stages of ability of self-decision requires reaching out to people for help and learning which empowers patient to increase their own confidence. This aids in improving self-perception, builds skill knowledge, support problem solving and decision-making abilities and helps thalassemia children go beyond the secure personality. This further fosters a sense of responsibility for their own health. Developing confidence in their self-choices, feeling more comfortable with decision making like when to visit hospital for blood transfusion, carrying out daily routines along with helping their parents in their daily routines when at home or outside. Earning money from their work will make the child feel wanted and useful among people.

➤ **Factor 11. MOTIVATION AND INSPIRATION:**

The Items are: 1. I eat dairy products (milk), cereals (Dal), etc, in my daily diet. 2. My teachers encourage me to participate in extracurricular activities 3. I like going to school because of my friends.

➤ When school environment is supportive, it helps the child to give a better performance and gives success in their learning. Student's relationships with friends, encouragement from teachers gives them a feeling of motivation. A child if supported well will show better acceptance towards taking participation in different stage activities at school and in community. The feeling of security helps child to feel more motivated to follow instructions of the health personal related to their treatment routines, regulation of diet like: addition milk, cereals and dairy products etc.

➤ **FACTOR 12. SOCIAL SUPPORT AND SCHOOLING:**

The Items are: 1. People, other than my relatives, provide/donate/give blood whenever required. 2. Whenever needed, consideration for leave is given to me for blood transfusion. 3. My parents cannot pay my school fees on time that is why I have stopped going to school. *4. I complete my schoolwork on time.

➤ Assistance from the society is especially important to improve health conditions and treatment outcomes. It can be given in the form of financial assistance, care, value to think well and having a feeling of acceptance and being cared. There are varieties of reasons due to which parents are not able to pay school fees timely. Instead of parents withdrawing their child from the school, it is better to make alternative arrangement within the society to ensure the ongoing enrolment of the child. Society support in terms of assess of health care, treatment compliance in the form of easy availability of blood for transfusion, investigations, and chelative drugs etc would be helpful to give the suffering family a sense of acceptance from the society. From the school: regular consideration of leave for treatment from school authorities and support from peer group for learning lessons and timely paying of school fees would help a thalassemia child to continue their education. Moral support can prevent anxiety and poor performance of a child at school and in the society.

➤ **FACTOR: 13. ACADEMIC ISSUES AND SPIRITUALITY:**

The Items are: 1. I am punished by the teachers for not completing my assignments * 2. I attend religious sermons / preaching /services.

➤ Interaction of a child with other children is very important for the child's cognitive, emotional and social development .If the child is not accepted in group, they develop low self-esteem and are more prone to be rejected in their future which would lead to a negative social interaction pattern. The parents at home and the teachers at school should help the child to have successful regular interaction with other children even if they are sick, so that we can avoid the feeling of rejection. Frequent admissions in hospital by the sick child leads to frequent days of absenteeism from school. This leads to incomplete school assignments that may lead to some sort of disciplinary action from teachers. But it will be better if we provide them a positive experience and encouragement to learn which would help child develop the qualities of self-discipline and being responsible. Children should be encouraged to take help from their parents to work out the solution. Balancing and supporting them by spiritual strength would help to fight against anxiety in some extent. A sense of feeling and hope to always believe that God would heal them. Encouraging to develop a healthy lifestyle by leading a normal life like other children can maintain a good quality of life.

➤ **FACTOR:14. SUPPORT TO HEALTH:**

The Items are:1. I receive free blood from people which further reduces financial burden of my family.

➤ Regular transfusions and intake of iron chelators among thalassemia children can prevent complications and even help to promote recovery and maintain wellness. High expenses and unavailability of these blood products and medicines often are an obstacle for the regular follow up of treatment. A help from the Government, social agencies, health care providers, health insurance companies would play a vital role, and would give answer to the regular concerns with medications and timely blood transfusions available at free of cost or at a lower cost can reduce financial burden and can maintain the QOL .

Section: B. Factors and related Items affecting the QOL of Parents of thalassemia children:

PARENTS DOMAIN

Fulfilment of basic needs of a child is an important function for parents. When both the parents and the child are introduced for the first time to the disease condition, it can cause mental shock, stress, anger, sorrow, thinking themselves to be responsible for giving birth to a child with thalassemia. Parents feel that their child's success and failure solely depend on them. Some parents may also feel self-desperate to manage the situation. Sometimes they only focus on the short-term needs without planning on long-term objectives, so many parents eventually surmount themselves with difficulties. They even question themselves about their ability to support their child during frequent painful treatments and the outcome of treatments, fear for an emergency and avoidance to convey the disease condition to their friends and family. The role of health team members is greatly beneficial when they are made aware of the ongoing parental stress due to their child sickness. Parents, teachers, and health care team must help the child and family to adopt constructive ways and methods to tackle the issues and challenges.

➤ **FACTOR 1. PHYSICAL HEALTH:**

The Items are:1. I get relieved when i see my child's tolerance to pain caused by medical Investigations and blood transfusions. 2. I take sound sleep at night. 3. I am happy that my child manages education related work himself/ herself .4. I do my job with responsibility, despite the sickness of my child.

➤ There are notable consequences found in parents of children suffer with thalassemia. Like low mood, anxiety, and sleeplessness especially when the child will be admitted in the hospital for treatment. But it is

especially important to know by the parents that they are the first and biggest influencers behind a child's success towards coping of painful events of treatment etc. Parent's feelings of comfort of their children bring realisation in the mind of a child to have emotional preparedness to improve tolerance of pain during medical investigations and blood transfusions, managing of education related work by himself or by herself etc. This will reflect parent's satisfaction, further helpful in better performance in job with responsibility and will have sound sleep at night to maintain a sound health of self and in their children to maintain a good quality of life.

➤ **FACTOR 2. FINANCIAL STATUS:**

The Items are: 1. My child's costly treatment, transportation to and fro to hospital, equipment, medication, etc., affected my family's financial condition* 2. It is difficult to arrange the money needed for the iron overloaded preventive medication* 3. I am concerned, that my child might get infected from the blood he/she receives* 4. My relatives give me financial support as they understand my condition.

➤ Acquire support from friends and relatives is something difficult to do by parents but it has been observed that this has been beneficial in arranging the treatment modalities, sharing experiences and finding of solutions. It is advisable for the family to seek professional help when it is beyond their limit to sustain especially when they have to do frequent travel (to and fro to hospital) for blood transfusion, medication (for the iron overload preventive medications), needs which can lead to financial burden and put strain and anxiety in families. Funds and sometimes extra financial aids from governmental agencies, financial support from relatives can be helpful in relieving these kinds of stress. Still the concern of child getting infected through transfusion remains. Careful planning about how to manage their money now and in the future can further help to reduce the economic crisis.

➤ **FACTOR 3. PSYCHOLOGICAL DOMAIN:**

The Items are: 1. The dietary restrictions to my child always bother me* 2. I feel disturbed, that I am not capable to do proper treatment of my child* 3. My child's sickness limits his/her career opportunities, which adversely affects/disturbs me* 4. I frequently have headache & body ache without any reason* 5. My child's sleeping difficulty bothers me*

➤ Each family member has to play a different role in their family, illness brings disruption in all family routines. When parents realize that their child is suffering with thalassemia, a sudden feeling of guilt and sadness comes in their mind followed by increased stress level mainly on dietary restrictions, disease specific medications and treatment, limitations in carrier opportunities of a child etc. Higher stress levels due to being frequently questioned come in their mind eventually can affect and deteriorate the quality of life of parents which will be depicted as frequent headache and body ache without any reason.

➤ **FACTOR 4. FAMILY SUPPORT:**

The Items are: 1. I do not like to pray as God has done this to my child. *2. I find myself helpless about my child's condition and ill appearance* 3. Other members of my family help me in taking care of my child.

➤ Parents are the key members who play an important role to transfer traditions, values, and set their standards of interaction for children within and outside the group. Uncontrollable anger, depression of parents causes an unbelief towards praying to God with the feeling of keeping God responsible for their thalassemia child. They find themselves helpless about their child's condition and ill appearance. If the bond among the family members are strong then members of the family help the parents in taking care of their child and the child takes initiative to learn their roles in the family and tries to do their best to fulfil it.

FACTOR 5. SPIRITUALITY:

Items are: 1. I perform religious rituals for my child's recovery. 2. I believe that God will heal my child.

➤ Spirituality increases the sense of purpose and meaning of life which helps in changing the lifestyle of a sick child and their parents with willingness. Performance of prayers and religious rituals for the recovery of their child can release the positive energy, encouraging them to believe on God's healing. This will help them to cope up with the disease management by their sole healing.

➤ **FACTOR 6. COMFORT LEVEL:**

Items are: 1. I am not in stress as I am able to give my child a proper treatment. 2. I am happy, that my child can play like other children. 3. I control my anger after seeing child's will power to bear the pain

➤ The decision to seek medical advice is complex. The family and their child have intense wish to learn technique which can ease their problematic situations. When the mental health of children is dominated by the fear from parents, their faith on parents eventually declines. The need of mutual understanding among parents is a must. The parents should train and motivate their children to struggle, discover and succeed. As a parent they are the best person who knows their children better and could better guide them how to cope with the painful

procedures. The parents should take effort to answer questions from the child. It would lead to improvement in the child's inner strength and self-control. Parents must be assured that their child is getting right treatment. Parents should be hopeful, controls own anger when they see their child's will power to bear pain in day to day tasks which would make them comfortable and confident in their life.

➤ **FACTOR 7. EMOTIONAL CONTROL:**

Items are: 1. I feel uncomfortable in disclosing my child's thalassemia status to my friends, family and others related to him/her * 2. I feel guilty that I am responsible for my child's Thalassemia disease *

➤ When the child is sick, the parents are worried about the future of the child and the upcoming different painful treatment. Socially they may get isolated due to busy schedule with the child, which can disturb their family roles and relationship, and even other children of the family being disturbed due to non-attention of their parents. In spite of blaming themselves for the birth of a sick child, thinking positive and trying to find the abilities and interest of the child by the parents would help them to develop a deeper and meaningful relationship with the child and which eventually would give them more emotional stability.

➤ **FACTOR 8. SELF-SATISFACTION:**

Items are: 1. My other children understand the sickness of my thalassemia child and help us to take care of him/her. 2. It gives me satisfaction because I can support my child to cope up with his /her class work

➤ Parents feel satisfied when they find their sick child managing things by their own strength, able to accomplish assigned task, values their own existence in nature, and develops a meaning for their life. Parents should enjoy helping other children of the family to understand the sickness of the thalassemia child and help them to take care of the sick child. This helps the child to have a feeling of ease, satisfaction which eventually strengthens and encourages parents to support their children in their school home works etc.

Application of Thalassemia disease specific quality of life (QOL) health model:

Application of nursing theories is especially important, as without the function of the heart, survival of human is difficult in the same way for a correct provision of nursing practice the concept of theory is must. The main aim of the theory application in nursing is to provide quality of care which can give an impact of better Quality of life among patients.

PRACTICE: The need of the thalassemia child in some extent will be reflected on his / her cultural background, values,religious beliefs inculcated by their primary care givers. The QOL of parents are the foundation to maintain QOL in thalassemia children. The disease specified theory will be helpful for a professional nurse or health worker to do early identification of factors influencing the QOL among thalassemia children and their parents separately and they can give focused plan of care on affected domains to improve the QOL in both. Based on the developed domains, needs can set on priorities, goals,specific interventions, and frequent evaluation helpsto bring improvement in specific area. Concerning a thalassaemic child, a developed statistically proved factors needs to be assessed that would be helpful to have knowledge of positive or negative quality of life of these thalassemia children and their parents. Based to these, time to time counselling must be planned for preventing further deterioration and help them to maintain the high level of wellness in all areas of health dimensions. There is certain driving force which can push a thalassemia child to a positive dynamic state like becoming competent, proficient to determine the details about chelation therapy, dietary and treatment plans, consequences, health care resources etc. Thereby, helping them to develop and implement appropriate interventions and compromise with own treatment. Clinical judgement of nurses during hospital visits reflects the representation to take wise decisions with respect to patient care. Theoretical principles to develop and implement the plan of care are the major concepts of nursing care at hospital, community and at home. The thalassemia child must be respected among society, surrounded with helpful people, and trusted, cared by parents can help them seek a better quality of life. The realization of being competent than being powerless/weak child, must be mind-set for parent of a thalassemia children. Family members must understand the frequent necessity of expecting to continue the practice of important therapies, tests for the wellness of these children and having a good quality of life.

Education:According to the theoretical concept in the specific situation, to rule out the quality of life of a child the multi-dimensional orientation approach and is important. As, these factors are interwoven with each other so it will be helpful to get even the minute information which is useful to give effective, efficient, and holistic care. All caretaker must be committed, goal oriented, proficient, and competent to depict a specific pattern of behaviour in performing when it requires to practice. The health workers, graduate and undergraduate students can be benefited by this theory to identify the actual domains affected due to thalassemia disease condition in children suffer with thalassemia and their parents, and further correlation with the results can reveal how the quality of life of parents can directly affect the quality of life of a thalassemia child or vice versa.

Research: The focus of the nurses' practices is always based on the available evidence and each family members, health workers are committed to provide intentional, and goal oriented care to the thalassemia child, which can be helpful to provide patient centred, family centred quality of care and trying to attain a high level of wellness. The students can conduct study by applying this developed model to test its effectivity. The rapid advancement in the field for health promotion, health maintenance is the public demand for quality of life. To meet new challenges frequent assessment of thalassemia child and parents are important so that application of intervention by the health worker will become a part of nursing practice.

Applications of steps of nursing processes will be particularly useful to do nursing assessment and for providing individual, family centred care. For preventive, promotive, and curative care to these children.

III. Conclusion

Thalassemia disease specific quality of life (QOL) health model is mainly to identify the problems in time faced by these thalassemic children and their parents for timely intervention. Sometimes familial, social environmental factors may be responsible to bring vulnerability in children's life. However, the developed disease specific model will contribute to identify the areas of clinical practice theory and research adding to today's base of improving nursing knowledge. The health worker always strives to hard to maintain the Quality of life of these children and their parents. Based on the correct intervention the nurses help the thalassemia children and their parents to maintain equilibrium in surrounded environment.

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