



A QUALITATIVE STUDY ON THE LIVED IN EXPERIENCE OF MOTHER CARING FOR THEIR CHILDREN WITH THALASSEMIA IN IGICH HOSPITAL, BANGALORE, KARNATAKA, INDIA

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Abstract: This study was aimed to explore the lived experiences of mothers who have children with thalassemia. A qualitative approach was used to obtain rich data. Twenty mothers were participated in IGICH hospital thalassemia day care center unstructured indepth interviews were used. Data were analyzed by thematic analysis method was based on guidelines as set forth by Colaizzi (1978) and Osborne (1990).

The mothers lived in experiences with their thalassemia children needs are framed by dimensions that exist in an inside world at home: in the world outside the home and in a going between world. The complexity of caring involves four dimensions for mothers. These are care giving that compromises normal mothering, technical care-giving, constant instability; constant observation; a no-choice situation; knowingness; unknowingness; and constant communication.

In IGICH hospital, where the number of thalassemia children is growing, the concern for mothers' quality of life is one of the substantial issues for successful thalassemia child care. Mothers, who are the main caregivers, struggle with a number of psychosocial issues, financial burdens and deficiency in knowledge. It is acknowledged that the role of health care providers is vital in order to strengthen the role of caregivers. Health education provided by nursing and medical staff is the way to relieve the vast majority of these stressors and enhance mothers' capacity to deal effectively with their children with minimal interruption of their day-to-day life activities.

Key words: Thalassemia, bone marrow transplant, caregiving.

I. INTRODUCTION

Thalassemia is an inherited blood disorder characterized by defective production of hemoglobin and excessive destruction of red blood cells, which leads to anemia. It is a chronic disease that presents a range of serious clinical and psychological challenges.

The term "Thalassemia" was first used by Whipple and Bradford in 1932 based on a Greek word which meant "The Sea". This was probably their attempt to specify that the disorder occurred around the Mediterranean Sea. Thalassemia is one of the commonest genetic diseases known to mankind.

It refers to a group of hereditary blood disorders that affect a person's ability to produce hemoglobin. Decreased levels of hemoglobin results in anemia. Hemoglobin is made up of heme and globin proteins.

There are several types of globin proteins of hemoglobin molecule in our body. If genes for beta globin proteins are defective it is called as beta Thalassemia. If genes for alpha globin proteins are defective it is called as Alpha-Thalassemia.

Thalassemia can lead to physical deformity, growth retardation, delayed puberty and severe complications like heart failure cardiac arrhythmia, liver and endocrine disorders and other infections. These problems affect a Thalassemia child's physical and psychological functioning leading to emotional burden.

Thalassemia can be fatal if proper treatment is not provided to the child. The development of new treatments and clinical management like regular blood transfusion during the past decades has markedly improved the prognosis and 2 survival rate of children with Thalassemia.

Thalassemia is a chronic disease where a cure is not attainable and treatment may be prolonged. Therefore, the parents should be reinforced continuously to care for their children with Thalassemia.

II. METHODOLOGY

The study was conducted in day care center of Indira Gandhi Institute of Child Health Bangalore which is situated 5 km from the Dayananda sagar college of nursing. At present I.G.I.C.H hospital had 20 Thalassemia beds in daycare center and children's coming for blood transfusion all week days except Sunday.

The average Thalassemia children receiving health care services at day care center is about 20 to 25 per day. Universe of the study All the caregivers of Thalassemia children and participated in the care of their clients in the day care center of I.G.I.C.H hospital Bangalore constituted the universe of the study. 24 Samples According to pilot and Hungler, (1990) the sample is of a population selected to participate in research study, sampling refers to the process of selecting a portion of population for the purpose of the study based on the availability of caregivers of children with Thalassemia. 20 caregivers of Thalassemia children's, were selected for the study using non probability purposive sampling technique. Sampling technique Selection of participants who had facing different sorts of difficulties while caring their children with Thalassemia for qualitative study.

Children's suffering from Thalassemia are treated in 7 days of week. The 20 subjects were fulfilling the inclusion criteria who were selected on every working day of day care center.

The study purpose using non probability purposive sampling technique, it took total period of 20 days to complete the intake of 20 subjects. An unstructured open ended questions was developed through the review of literature, clinical experience and according to care givers experiences.

III. ANALYSIS AND DATA INTERPRETATION

The purpose of this study was to apply phenomenological research strategies to the lived in experiences of mothers of thalassemia children and analyze it. The intention was in develop a rich and thick portrait of the care givers experience to gain greater insight into perception of caregivers of children with thalassemia.

This chapter presents the socio-demographic profile of all on lived-in experiences of caregivers of thalassemia children. The findings of the study are described under the following heading.

- 1.socio-demographic profile of study participation.
- 2.organizing and analyzing data.
3. Discussion of the themes.

IV.RESULTS

In this study the participants expressed different sorts of problems that are divided into four dimensions as physical, psychological, social and economic dimensions.

After taking 20 mothers experiences of different dimensions articulated an extract of significant statements shows as below:

Physical dimension: Most of the mothers expressed every time while coming blood transmission they are facing tiredness and health issues even child also having IV cannula pain. After travelling from the hospital if they tired also they need to do house hold works and they have to go for work also.

Psychological dimension: After diagnosing the thalassemia most of the mother's immediate response they were shocked they felt like ending this life and very much scared about the diseases. Late response of the mothers when they saw the other child suffering from thalassemia felt little bit relief. Present response of most of the mother felt slight relief but it is always very disheartening and some mothers cried and unconvincingly.

Social dimension shows that most of the mothers having inferiority complex about their children disease and they are not ready to discovering to relatives about this some of the mothers faced mocking from the relatives about their child condition. One mother told that after diagnosing child disease her husband left her because of child condition they are telling we feel hopeless.

Economical dimension: Mothers facing so much of economic problems because they need money for coming hospital every time from far places and every time they need bus fare, food and medicine as well. And most of the mother's economic status very unstable still they need sufficient funds to get the child operation.

V.SUMMURY AND CONCLUSION

The above qualitative analysis reveals that there are various contributing factors for facing different sorts of problems which was organized under various dimensions/themes. It is understood from the responses that factors related to physical, psychological, social and economic dimensions had a significant contribution towards the level of lived experiences of mothers.

In IGICH hospital, where the number of thalassemia children is growing, the concern for mothers' quality of life is one of the substantial issues for successful thalassemia child care. Mothers, who are the main caregivers, struggle with a number of psychosocial issues, financial burdens and deficiency in knowledge.

It is acknowledged that the role of health care providers is vital in order to strengthen the role of caregivers. Health education provided by nursing and medical staff is the way to relieve the vast majority of these stressors and enhance mothers' capacity to deal effectively with their children with minimal interruption of their day-to-day life activities.

Most of the mother during the qualitative interview expressed that the nursing interventions given by the investigator had helped them to introspect and explore the various barriers for control and management of thalassemia.

Key points for policy, practice and/or research

- Mothers providing care for thalassemia children suffer from psychosocial stressors that might exceed their capacity and tolerance.
- Knowledge deficit and financial burdens add further distress for these mothers.
- The ability of health care providers to discover these challenges is a mainstay of treatment.
- Support and health education are key to mitigating these stressors and improving the quality of life of mothers.

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