A RESEARCH CRITIQUE ON LIVED - IN EXPERIENCES AMONG MOTHERS OF UNDER FIVE CHILDREN WITH CONGENITAL CARDIAC ANOMALIES

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Abstract - The presence of congenital cardiac anomalies often results in an enormous emotional and financial strain on young family members. Hence the investigator conducted a research critique on the lived-in experiences of mothers with fewer than five children who were diagnosed to have congenital cardiac anomalies. The study explored and extrapolated the lived in experiences in various dimensions among 15 mothers of fewer than five children. Interview was conducted using audio tape using open ended questions. the following were explored. In Physical Dimension-Mothers Reported Significantly More Somatic Symptoms Like Sleeplessness, Decreased Food Intake ,Headache And Fatigue, Psychological Dimension-The Results Showed That Mothers Experienced Fear Sadness, Frustrations, and Hopelessness, Denial Of Child's Illness, Anger And Suicidal Thoughts, Economical Dimension-Mothers Expressed Financial Burden And Lack Of Financial Support To Meet The Ends., Social Dimensions-Mother Experienced Lack Of Support From Family And Friends. They Feel That Their Children Are Socially Less Competent. And in Spiritual Dimension-It Was A Mixed Expression Of Belief And Unbelief Towards God. They Expressed Anger, Bargaining, Questioning, and Hope In God.

Keywords - Somatic Symptoms, Sleeplessness, Decreased Food Intake, Headache and Fatigue,

I. INTRODUCTION

“Children and mothers never truly part-Bound in the beating of each other’s Heart.”

-Carlotte Gray

Congenital cardiac anomalies are most frequent malformation at birth. Despite recent developments in interventional and surgical techniques, congenital cardiac anomalies in children continue to be an important cause of morbidity and mortality. Mother is the person who loves her child most divinely not when she surrounds him with comfort and anticipates his wants, but when she resolutely holds him to the highest standards and is content with nothing less than is best. After learning the diagnosis, mothers are initially shocked and then tend to experience intense stress and anxiety.

1.1 Statement of the Problem

A research critique on lived - in experiences among mothers of under five children with congenital cardiac anomalies admitted in B3 pediatric ward at Sri Ramachandra Hospital, Porur, Chennai - 600 116.

1.1.1 Objectives

- Explore the lived-in experiences among mothers of under five children with congenital cardiac anomalies.
- Extrapolate the various experiences of the mothers of under five children with congenital cardiac anomalies.

1.1.2 Purpose

Develop a coping strategies module for the mother’s of under five children with congenital cardiac anomalies.

1.2 Operational Definitions

1.2.1 Critique

Analysis and synthesis of concepts from the experiences revealed by the mothers of under five children with congenital cardiac anomalies.

1.2.2 Lived - in experience

Thoughts, feelings and experiences about day-to-day events perceived by the mothers of the children with congenital cardiac anomalies.

Mother A biological and social female parent of a child with congenital cardiac anomalies.

Under five children with congenital cardiac anomalies

A female or male child under five years of age is born with a structural abnormality of the heart or intra thoracic great vessels that is actually or potentially of functional significance.

1.3 Assumptions

- The perception of phenomenon varies with each individual.

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• Sharing of experiences with others promotes sense of wellbeing.

II. METHODOLOGY

2.1 Research Design
Qualitative research design and phenomenological approach was selected for the study.

2.2 Setting of the Study
The paediatric B3 ward of Sri Ramachandra Medical Centre

2.3 Population
The study population includes the mothers of under five children diagnosed with congenital cardiac anomalies.

2.4 Sample
The study sample consists of mothers of under five children with congenital cardiac anomalies admitted in pediatric B3 ward during the study period.

2.4.1 Sample Size
The size of the samples selected for the study was 15.

2.4.2 Sample Technique
Convenience sampling technique of non-probability type was used to select the samples.

2.4.3 Sampling Criteria
Inclusion criteria
a. Mothers of under five children with congenital cardiac anomalies within the age group of 21 to 40 years.
b. Mothers who were able to communicate well either in English or in Tamil.
c. Mothers who had under five children with congenital cardiac anomalies.

Exclusion Criteria
a. Mothers who were not willing to participate.
b. Mothers with hearing and visual impairment
c. Mothers of children suffering from disorders other than congenital cardiac anomalies.

III. DESCRIPTION OF THE TOOL

The tool used for the data collection was interview schedule with open ended questions.

The tool consist of two sections.

Section A  Demographic Data An interview schedule was used to find out the demographic variables such as age, education, occupation, income, religion, residential place, type of family, number of hospitalization and type of congenital heart disease.

Section B Interview schedule with open ended questions to explore mothers experiences.

3.1 Physical Dimension
All 15 mothers (100%) expressed that they had lack of sleep at night and irregular diet pattern. Six mothers (40%) expressed that the problem of fatigue [2]. Other problems expressed by the mothers were loss of weight, chest congestion, headache, disturbance in husband and wife relationship.

“No proper sleep due to frustration and lack of financial support”.
“Thinking about my child’s future and not able to sleep at night”.
“I am unable to eat as I am burdened about my child situation”.
“Due to sleepless nights and irregular food pattern I get severe head ache”
“Sleepless night, irregular food pattern and prolonged hospitalization make me to feel fatigue and tired”.

The above findings were consistent with the study of Monsen (2000) who investigated the lived-in experiences of 13 mothers of under five [3] children with congenital cardiac anomalies. The researchers used phenomenological methodology. Data revealed the mothers experienced more of physical illness and psychological problems.

3.2 Psychological Dimension
All 15 mothers (100%) expressed fear and sadness about child’s future, Hospital expenses, illness and hospitalization. 11 (73.3%) mothers expressed frustration due to helplessness, four (26.6%) mothers experienced hopelessness and other problems like denial of illness, anger and suicidal thoughts.

“Now no tears in my eyes as everything has been poured out”
“What about my child’s future, will the child be normal or will it face any serious problems?”
“Why God as given me this child and why this trouble to me?”
“I could not believe that my child is having this illness and I could not accept that my child is undergoing surgery”.
“Till today I am unable to think about my child’s illness”.
“I feel like dying”;
“I hate this life”.
“My husband is not showing any interest towards my child’s treatment”.

Eakes (2001) conducted a study by using qualitative techniques of grounded theory in identifying lived-in
experiences among 10 mothers of underfive children with congenital cardiac anomalies. The findings were eight mothers developed sorrow stress, and higher grief-related feelings were more often identified.

3.3 Economical Dimension
All the 15 mothers (100%) expressed financial difficulties and some mothers expressed that they had received financial support from the government.
“What I am going to do for treatment?”
“House and jewels are kept on loan and that money is used for expenses”.
“I am happy that I got money for the hospital expenses through C.M. Fund”.
“I took money from a finance company for the hospital expenses.”
“I sold my house and land for the hospital expenses”.

The above findings coincide with the study of Wigert (2006). Identified the lived in experiences of 10 mothers of children with congenital cardiac anomalies. The investigator has done an indepth interview and data were transcribed into verbatim. The data revealed that they had physical, psychological problems and had a higher state of economical problems like lack of financial support.

3.4 Social Dimension
In this study nine mothers (60%) stated that they had inadequate family support and six mothers (40%) expressed that they had adequate family support. Seven mothers (46.7%) said that they received help from relatives, three (20%) received help from their friends.
“No one to help me”.
“My mother is the only person who helps me throughout the hospitalization”.
“My friends help me a lot and they supported me”.
“My neighbors supported me when I was helpless”.

The above findings supported with the study of Simpson (2002) who explored the lived-in experiences of mothers of children with congenital cardiac anomalies mothers experienced lack of social support and their children were socially less competent.

3.4 Spiritual Dimension
In this study nine (60%) mothers expressed that they believed in God, six (40.0%) mothers had no belief in God, eight (53.3%) mothers prayed to God to minimize the child’s sufferings, seven (46.7%) mothers prayed to God to speedy recovery of their child, eight (53.3%) mothers expressed that they were angry towards God and seven (46.7%) mothers expressed that they were angry towards their husband.
“After this treatment we are planning to go Holy places and render special offerings”.
“I will not blame God because He helped me to identify this illness in the early stage itself.”
“I hope, by God’s grace my child will be alright, God will reduce my child’s sufferings”.
“I believe and worship all Gods with belief in any one God will save my child”
“Why God gave me this child instead he would not have given this child to me”.

The similar findings were explored by Kars (2000). He conducted an phenomenological study among 12 mothers. A grounded theory was undertaken in a Dutch University Hospital, an indepth interview was done. The data were transcribed into verbatim. The mothers experienced that they believe & worshipped God to seek help from Him.

3.4 Limitation
Continuity of audio tape recording was interrupted in some samples due to the children’s cry.

IV. IMPLICATIONS AND RECOMMENDATIONS

Nursing Practice- Good Nurse - Patient Relationship
Nursing Administration- Setting Up of Guidance And Counselling Clinic For Parents Of Children With Congenital Cardiac Anomalies.
Nursing Education- Organise Workshops, Seminar And Educative Activities To Promote Social Skills In Holistic Care.
Nursing Research- Provides Information Of In-depth Experiences Of Mothers Facilitating Evidence Based Care. Further Study Can Be Conducted Among Fathers Of Adolescents With Other Major Disorders.

References