

Experiences of Mothers on Parenting Children with Leukemia

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ABSTRACT

Introduction: Childhood cancer is the leading cause of death among children. Leukemia is one of the most common childhood cancers.

Objective: The objective of this study was to explore the experiences of mothers on parenting children with leukemia.

Materials and Methods: A qualitative approach with phenomenological design was used. To collect depth information from the mothers of children with leukemia, purposive sampling technique was adopted. Data were collected from ten mothers. Semi-structured interview schedule was used to collect the data. Data were analyzed using Husserl's method.

Result: The themes derived are the pivotal moment in life, the experience of being with a seriously ill child, having to keep distance with the relatives, overcoming the financial and social commitments, responding to challenges, experience of faith as being key to survival, health concerns of the present and future, and optimism.

Conclusion: The study concluded that chronic illness such as leukemia in children results in negative impact on the child and on the mother.

Key words: Children, Experiences, Leukemia, Mothers, Phenomenology

INTRODUCTION

Chronic illness of childhood affects the parents' quality of life.^[1] Cancer accounts for the major cause of death in Indian children, next to infections and malnutrition.^[2] In India, 1.6–4.8% of all cancers are seen in children below 15 years of age, and incidence rate for India ranges from 38 to 124/million children per year.^[3] Leukemia continues to be the largest contributor to cancer-related mortality in children. In Karnataka, frequency of leukemia is quite high in Belgaum district when compared to other districts and totally absent in Bidar district.^[4] It is reported that parents of chronic ill children experience chronic grief^[5] and low quality of life.^[1] Available literature has also reported on experiences of mothers from developed

countries. Thus, the study was undertaken with objective to explore and describe the lived experiences of Indian mothers on parenting children with leukemia which will further help to provide holistic care to the child and family.

MATERIALS AND METHODS

The present study aimed at exploring the subjective reality of the mothers on parenting children with leukemia. Keeping in mind the conceptual basis of the phenomenon of the study, qualitative phenomenological design was adopted. Data was collected from a purposive sample of mothers of children between the age group

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of 1–16 years diagnosed with leukemia and undergoing chemotherapy in a Tertiary Care Hospital of Udipi District, Karnataka, either as inpatient or at the daycare center. Data was collected from the sample to the point of data saturation. The data saturation in this study reached when the data collection reached ten mothers.

Measurement

Semi-structured interview schedule was used for data collection, which consisted of two sections. Section A: Demographic proforma was used to collect data on the demographic background of the child and the mothers.

Section B consisted of 14 open-ended questions to explore the experiences of mothers. The lead question was “*What are your experiences having cared for a child who is undergoing treatment for leukemia in the hospital?*” Some of the probe questions were regarding how the mothers felt taking care of a child with leukemia, how would they and their family perceive the illness, perception of illness by others, effect of the illness on the family relationships, effect on the work, and role as a family member.

Ethical consideration

Formal administrative permission to conduct the study was obtained. Ethical approval was obtained from the Hospital Ethics Committee. An informed consent was taken from each participant before the interview. Assurance of confidentiality of their response was given, and anonymity was maintained throughout the study by giving them pseudo names.

Procedure of data collection

Data was collected from the mothers of children suffering from leukemia. The participants were interviewed using a semi-structured questionnaire, each interview lasting for an average of 45 min to 1 h per sample. The interviews were audio recorded using a voice recorder. The transcribed data were translated into English. The data was analyzed individually by coding, categorizing, and deriving themes from the significant statements of the participants’ transcribed verbatim. The derived themes and verbatim were validated by experts. After the data analysis, based on the common derived themes, a multicomponent holistic model was developed.

RESULTS

Demographic characteristics

Majority of mothers 4 (40%) were in the age group of 20–29 years, 4 (40%) of them had studied up to high school, 8 (80%)

mothers were homemakers, and 2 (20%) were skilled workers. With regard to disease variable, 8 (80%) of the children had been suffering from the illness for less than 1 year; 8 (80%) of the children had hospitalized for more than 5 times.

Analysis of the verbatim of the mothers

The narrations and derived themes are as follows.

The pivotal moment in life

Mothers responded in unique ways which varied from “shock and disbelief,” “deep sadness,” and “grief” to gradual adjustment to the diagnosis over time.

Mrs. R explained “*When I heard of the diagnosis of leukemia for the first time, I lost hope. I was shocked. No other family member of ours had such a problem. In our family, he is the first member.*”

Mrs. W expressed “*Feeling means...I just cannot explain it (crying tone). We did not even think of it in our dreams. We were that shocked (cries).*”

Mrs. X expressed “*We thought that the report may be wrong. We really felt sad and felt like crying. We lost confidence.*”

Mrs. T quoted “*It is a question mark to all of us. Probably, it would have been due to fall which she has had while she was 2 years old.*”

The experience of being with a seriously ill child

The mothers expressed a great deal of adjustments and changes in the lifestyle having to live with a child with leukemia. Mothers expressed concern over the fact that they would have to live with a child who was sick with uncertainty of the child’s prognosis.

Mrs. P expressed her feelings as “*Ever since he was ill, I have not attended anybody’s invitation for family function and other social gatherings. I am bound by the fear that something might happen at home during my absence. That is why I am not going.*”

Mrs. R expressed now “*we don’t let the relatives come to our house. We isolate ourselves from our family members.*”

Mrs. P found that it was very difficult paying attention to other children at home. She expressed “*At home, there are school-going children. They are also to be looked after. My husband is only earning member, and he has to go for work. I alone find it difficult to attend other children, visit to hospital and we also face financial problems.*”

The child’s suffering has brought a lot of impact on the parents. They undergo a lot of changes having to live with the sick child.

Mrs. R expressed her feelings as *“he cannot eat anything from outside; we need to get food from home only. It is very difficult to bring the food as our house is too far. Afternoon and night, we need to get different food.”* She further explained *“If he falls sick, we keep distance from both the children. And, as our younger son is also feeling sad, he is not ready to go far from the elder son. He is not ready to adjust with any of our family members. When I leave him at home, I feel tensed.”*

Many of the children were unable to accept the changes in their life due to the physical conditions. Mrs. S explained *“how her daughter reacted towards her own mother in response to frequent hospitalization and the course of treatment.”*

She quoted *“Then, she would be stubborn, she would scold. She speaks alone. She recalls all the past memories such as beatings and scolding that she received from me. Since the commencement of the treatment she scratches and screams like mad. She scolds me which is very painful. She does everything to pain me.”*

Mrs. U expressed *“She has to be pampered giving toys, and it is extra expenditure to us. If we don't provide her with new toys everyday, she gets irritated. She becomes wild and beats us and breaks domestic articles.”* Almost all the mothers faced a great deal of emotional stress as their child was undergoing great difficulties.

Mrs. U wept and quoted *“Our personal life is empty and hollow. We are tired of life itself. I could not go to shop. It is not possible to go along with her. Not even possible to leave her behind at home.”*

Mrs. P was also undergoing similar feelings. She quoted *“(in shocking voice) Tension means mothers feeling towards her children ... type of sadness.”*

Mrs. S was unable to see her child suffer. She quoted *“I too cannot bear her taking this pain. I find it very difficult to be here. But, I cannot leave her alone.”*

Mrs. Z expressed her feelings saying, *“Sometimes I feel like ending of my life. But, if I end only, I will go others will remain. If my daughter and I go, then my son will remain. All others will suffer because of me.”*

Having to keep distance with the relatives and the society

The mothers had to restrict the relatives from coming home to prevent the child from getting the infections. Many of the parents also ended up breaking the relationship with the relatives.

Mrs. U explained that she had to live separate from the relatives for the sake of the treatment. She quoted *“Nobody*

has asked us. Our troubles are confined to us only. Our staying separate makes them think that we are happy to live separately (expression was painful). They don't understand our pain” She quoted further *“There is not even phone call. Probably, they might think that they may get infected like us if they speak to us. They don't even visit at the hospital.”*

Mrs. Z expressed that *“Earlier, we used to bear all expenses of our family's religious beliefs. But now, since we are not bearing the expenses, they don't talk to us.”* Few mothers expressed a fear that if the news regarding the child's diagnosis was known to the neighboring people, they would seclude him from their children.

Mrs. Q quoted *“If we tell the diagnosis to any one person, it will spread out to entire village. If our village people come to know about cancer, they start spreading the information to everyone and our life will become difficult by their words, which is why the matter has not been disclosed to anyone in our village.”*

Mrs. Z expressed *“People keep talking about my child. When my child goes to others house to play, neighbor children never used to play nor used to talk to her. I had to cry a lot during this time.”*

Overcoming the financial burden

The financial status of the parents is not in consistency with the required amount to be spent for the parents. They also faced lots of financial challenges which would hinder providing care to the child.

Mrs. T whose husband is an auto rickshaw driver expressed her difficulty and quoted *“My head is paining, we have money problem.”* She continued *“We have kept all the jewelry in the bank. We have also taken a lot of loans. I used to roll beedies at home. But now, doctor has advised not to roll beedies as it causes infection. Hence, I have stopped it.”*

Mrs. P whose husband is a bus driver and has taken loan to construct the house quoted *“Something has to be done. We own a small house in 3 cents land. Now, we have to dispose the house to repay the loan money and for treatment (sigh).”*

Responding to challenges

Mothers demonstrated their willingness and ability to cope with the challenges in managing their child's illness and therefore emerged as an important theme.

Mrs. W was ready to sacrifice anything for the sake of her child. She quoted *“If my daughter will be alright, I am ready to bear any kind of difficulty that I am going to face. My only feeling is that my daughter is suffering.”*

Mrs. Y expressed that though they faced the challenge of finance in the treatment, they were ready to earn and live the rest of the life if only their child would be alright. She quoted *“We will try to earn and live. Our only wish is our child should be alright.”*

Mrs. T had a strong feeling and expressed *“It’s our duty to take care of kids and if we are not, there who will take care of them. We are ready to face any problems which come our way.”*

Experience of faith as being key to survival

The families who had very strong faith in God found this to be a very supportive experience. Families felt that their beliefs assisted them in finding meaning in their life, and it also provided a sense of assurance that their child would get well.

Mrs. T expressed strong faith in God and expressed *“I keep praying to God to save her after undergoing so many difficulties.”*

Mrs. U also expressed her faith in God as *“We have belief in God. For her health, we have performed Pooja. God will cure her. With this ultimate truth, we have started treatment for her.”*

Mrs. W quoted her belief as *“I have lot of belief in God. I pray to God daily. Not only now, but I believe in God before this also. At once I felt that is God angry with me for some reason, but now, I felt that we should bear all the suffering. Many times, I go to the prayer room, sit quietly praying to God.”*

Health concerns of present and future

Many parents expressed some concern about the future.

Mrs. P quoted *“Death is inevitable to everyone. But, this should not occur to younger ones in front of their parents.”*

Mrs. R said *“Whatever others may say and give confidence to us when he falls sick, and his condition worsens, we get very scared.”*

Mrs. T felt that the future of her child was uncertain and quoted *“That is a big tension and a question mark to all of us. I do not know what to say. Sometimes, I get very scared. But other times, I feel bold and speak to doctor.”*

Optimism

Some mothers experienced a sense of optimism and hope with regard to the cure of the child’s condition.

Mrs. S expressed *“I have no doubt. I am fully confident. I trust the doctor. I will keep the confidence.”*

Mrs. Z expressed *“I have full hopes that my child will be alright.”*

Mrs. W expressed great confidence in the health system and had confidence in that her daughter would recover. *“I have great confidence in the doctor. Hence, I have no fear feeling. I am confident that my daughter will recover. I will get her back.”*

Mrs. X also endorsed similar feelings *“While I see other children who have recovered completely from the disease, I still have hopes.”*

Based on the findings of the study, the researcher developed a structured phenomenon as the holistic model on the lived experiences of mothers on parenting children with leukemia which explained the various aspects of parenting and how each aspect had been affected by the illness of the child with leukemia [Figure 1].

DISCUSSION

The findings of the present study were consistent with the findings of other researches done in different parts of the world. In the present study, mothers were shocked when they heard of the diagnosis of the child and went through a process of grief, and gradual acceptance had taken place. Many of the mothers had felt emotionally unstable and cried while they heard of the diagnosis. This finding is supported by a meta-analysis which revealed that all the mothers go through a process of grief, particularly related to the diagnosis.^[6] In the present study, a few mothers were doubtful on the reliability of the report which is consistent with the findings of the study in which, 89.7% of the parents entertained doubt about whether a correct diagnosis had been established.^[7] The present study finding also revealed that the condition of the child resulted in emotional impact on the mothers which is congruent with

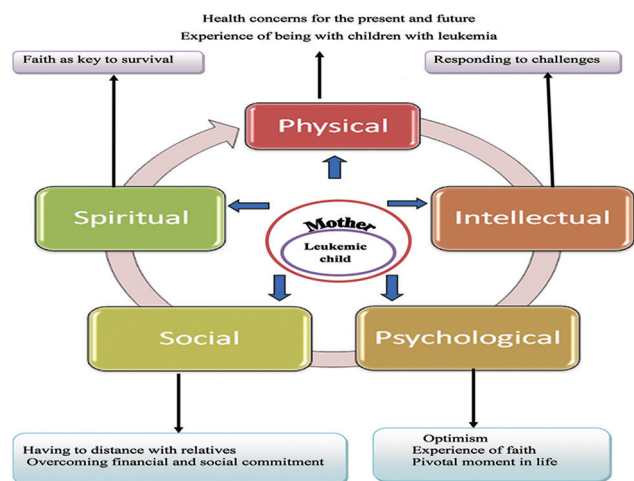


Figure 1: Holistic model on the lived experiences of mothers on parenting children with leukemia

the findings of the study conducted in Sweden.^[8] The study also reports that mothers found support from others,^[9] which is contradictory to the findings of the present study which found that mothers had to distance from the relatives because of the restriction of the visitors that created fear of seclusion from the society and isolation. The present study utilized phenomenological approach to explore the understanding of the subjective experiences of the mothers of leukemic child. Understanding these experiences helps the nurses in providing holistic care to a child with leukemia, apart from providing physical comfort to the child, she also needs to shift her attention toward the other dimensions of the child's personality and address the needs of mothers. The study findings cannot be generalized to the entire population as it was conducted in a single setting.

CONCLUSION

The study concludes that chronic illness such as leukemia in children results in negative impact on the child and on the mother who is the primary caregiver. Child becomes the focus of care in the family that may affect the well being of other siblings in the family. The greatest burden that mothers face with children suffering from childhood leukemia is financial burden related to the treatment and the follow-up.

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Conflicts of interest

There are no conflicts of interest.

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