

Lived Experiences of Mothers with Leukemic Children Residing in Kathmandu

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Abstract

Childhood leukemia is one of the expanding non-communicable diseases in Asian countries including Nepal with significant mortality and morbidity. The main objective of study was to explore lived experiences of mothers with leukemic children residing in Kathmandu. This was a hermeneutic phenomenological study conducted in 2017. Ten participants were selected purposively from hospital record of Kanti Children's Hospital, Nepal. In-depth interview guideline, case study method, digital recording and field notes were used for data collection. Data was analyzed using Interpretative Phenomenological Analysis and ATLAS.ti 7 software 7.5.7 version. Five major themes emerged: Socioeconomic Burden, Alteration in Life, Crisis Situation, Coping Strategies and Optimistic Attitude. Initially, mothers experienced distress, disbelief, denial and gradually accepted the condition. It has created distressing adverse impact on life. Hence, an educational package and counseling should be provided focusing on disease, child care and coping strategies to make aware to mothers and prepare them physically and emotionally.

Keywords: *Leukemia, lived experience, qualitative research.*

Introduction

Childhood cancers are unnoticed in developing countries, 80 % of the childhood cancer occur in the low-income and middle-income countries.¹ In India, leukemia is the most common childhood cancer with 25% to 40% of relative proportion which contributes to mortality in children.²

In the Western Development Region of Nepal, 33 cases recognized as childhood cancer among 1217 total cancer cases.³ In Nepal, among 755 children with cancer diagnosed at Kanti Children's Hospital, number

of Acute Lymphoblastic Leukemia Children was 300 from March 1998 to March 2012.⁴ Leukemia accounts for 36 cases among 77 new cases of cancer diagnosed in Kanti Children's Hospital between December 2015 to November 2016.⁵

Mother experience burden in emotional, mental and physical aspects which may affect quality of care provided to children and lead to imbalances in their own health.⁶

This study aims to explore lived experiences of mothers with leukemic children residing in Kathmandu.

Material and Method

Hermeneutic phenomenological, qualitative study was conducted in residence of participants who were selected from hospital record of Kanti Children's Hospital, Kathmandu. The total study period was eleven months (28/05/2017 to 13/04/2018). Ten mothers who had a Leukemia child having treatment in Kanti Children's Hospital were enrolled purposively in the

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study. After taking verbal and written consent, face to face interview was conducted in an actual, natural environment by using semi-structured In-depth interview guideline from 5th July to 28th July 2017. Among 10 participants, four were selected for case study that were distinct to each other and followed after 2 months. With permission, all interviews were digitally audio-taped and a field note was taken for unspecified behavior and critical information. Two to five interviews were taken from each study participant until data saturation.

The collected data were transcribed in Nepali language in reference to memos, field notes and tape recordings. Coding of transcripts was aided using ATLAS.ti 7 qualitative data analysis software of 7.5.7 version (1993-2017 Atlas.ti GmbH, Berlin). Data was analyzed thematically by using Interpretative phenomenological analysis.

Findings: Majority of the participants were from upper caste groups and advantaged janajatis. Nine out of the 10 participants belonged to nuclear family and Hindu religion. Half (5/10) of the participants had completed secondary level education, worked as homemakers and their spouse worked as abroad worker before child's diagnosis. Eight participants mentioned that their income was sufficient for less than 6 months.

Leukemia children were from age group 2-13 years and mean age was 5.8 years. Most of the children (6/10) were female. Half (5/10) of them were first born child and under Maintenance Phase of treatment. The duration of diagnosis at the first interview was 2-27 months and 6.7 months in average.

Five themes were recognized from various levels of analysis and **pseudonyms** were used:

1. Socioeconomic Burden
2. Alteration in Life
3. Crisis situation
4. Coping strategies
5. Optimistic Attitude

Theme 1: Socioeconomic Burden: All participants faced financial problem. Almost all (9/10) of them were residing in rented houses in Kathmandu for the sake of treatment of their leukemia child. They said that earning also stopped but anyhow treatment should be continued and had taken a lot of loans.

"If we had any asset, we would sell them but we have nothing to sell. If I could, I would sell my own body. But it is also not possible". [Rita]

"Earning has stopped as both of us (parents) are engaged in treatment of our son. Because of this we are unable to continue business". [Rama]

In response to treatment process, majority of participants perceived leukemia treatment as a long and expensive treatment process.

"Treatment does not end after 1-2 months and it takes 3 years to complete the treatment course". [Sita] [Yamuna] [Gita]

One participant experienced distrust by friends and relatives as every time help is not possible and in case of leukemia, mothers were deemed as being unable to return back money so didn't get financial help every time. Three participants also expressed that financial support is not always possible from the hospital.

"There is no free service in hospital except in oncology ward. We don't always get chance and are not always lucky to admit in that ward". [Rama]

Participants expressed increased expenditure.

"I need money not only for expense of medicine but also for transportation, school fee, food for sick baby like meat and fruits". [Rama]

Participants could not attend any social functions as well as other's invitations as they can neither leave their child at home nor take them along. Almost all participants were isolated from relatives, friends, parents and neighbors. Four participants expressed that they could not contact their relatives as their homes were far. One participant used to avoid her parents to hide her problems and control herself. Two participants want to be on their own world.

"Feel sad when relatives come to visit. I am in my own world. Slowly, I will be maintaining to become fresh but when someone comes, I again remember the past days". [Rama]

Participants had restricted the relatives from smoking, wearing shoes in room, also limited visit of relatives who were not clean and the child was kept in distance with other sick children and who coughed a lot. They thought that others will infect their child.

Theme 2: Alteration in Life: Almost all of them experienced disturbance in work. Four of them had left their farming work and one can't continue business. Both of the parents can't do any work well as they are mostly devoted in caring for their leukemic child rather than in earning and other works. They are not able to complete any work as before.

"Daughters cook themselves and eat whatever they like. I am unable to care for them". "My elder son also has exam but I can't give him time during his study".
[Sita]

All interviewed participants expressed that they have no leisure time.

"Learned Boutique works and used to design clothes before child's illness. Now, I cannot do anything and just take care of my babies".
[Sita]

Participants experienced that care is unavoidable and must do work anyhow as majority of the participants were from nuclear family. Participants experienced increased work load.

"When I go to hospital my husband stay at home and vice versa, doing for the child without caring our own health".
[Ishwori]

"Work increased after child's illness. Require frequent hospitalization, investigations, blood transfusion and should maintain cleanliness in everything else".
[All participants]

Participants eating pattern and daily schedule were planned according to leukemia child's condition or days passed haphazardly without any plan.

"Our eating time is not fixed".
[Manita]

"Only eat those things which are healthy for my child. Previous eating pattern has changed".
[Prema]

Theme 3: Crisis Situation:

Nature of Leukemia: Three of the participants expressed that there is no disease more difficult in Nepal than leukemia which brings many sorrows in life. One of the participants was surprised to learn that it also occurred in children as only seen in elderly people. They experienced fear from time to time that it was incurable.

Most of the participants experienced that children with leukemia had multiple symptoms of leukemia which

were mild in appearance distressed participants when diagnosed as leukemia and symptoms were different in every child. Initial symptoms subsided itself or after giving minor cetamol/vitamins. Eight participants perceived diverse causes of initial symptoms occurred in children. Due to this, early diagnosis of disease was missed.

"Child had mild leg pain. He could go to school and come home regularly. I had once seen bluish patches at the side of his leg but thought that he had fallen somewhere and subsided itself without any treatment".
[Rama]

Period of agony, Disbelief and Denial: Participants experienced that their life became nerve-racking due to unpredicted happening while receiving breaking bad news. Initially, participants experienced distress. Most of the participants had visited various hospitals, blood tested repeatedly and sent bone marrow biopsy investigation to India for confirmation but report comes only after 14-20 days.

"Felt sad wondering about the report but even after receiving report I felt very sad".
[Rama]

"Felt that sky and earth joined each other". [Sita]

"I should have died first, instead, my child will die on my lap...how can I control myself".
[Rita]

"Felt what to do, what not to do and where to go to die".
[Lata]

"I felt uneasy and became blind surrounded by black cloud. I just remember carrying baby and not seeing anything in front of me".
[Prema]

Two participants experienced anxiety towards God and their fate.

"Used to say to God that you gave me child yourself then why you make my child suffer from such things. I wonder how much time I have left to stay with my child. I pray that God take her away soon if you have already planned to take her away from me. I cannot tolerate my child's pain anymore".
[Anita]

Uncertainty of Life: Participants felt self-doubting and experienced difficulty living with uncertainty. Participants experienced that anything can happen at any time when their child suffered from side effects.

Multiple Problems of Mother: After child was diagnosed with leukemia, participants experienced deterioration in their own physical health. Majority of them hide their own problems. They reported weight loss, severe headache, gastritis, increased uric acid, weakness, fatigue, leg pain swelling, whole body ache, anorexia, bitter taste, heart burning and low pressure.

Emotional Disturbance: Six participants experienced tension and three of them started to forget things. One of them had sleep problem and experienced fear. Participants experienced being preoccupied in thoughts even during leisure period.

“Now-a-days, I used to forget things and when I go for one work, I end up doing something else”. [Anita]

Participants experienced restlessness when they left their children at hospital with other family members. They experienced speechless or difficulty in answering queries of child and other people.

Theme 4: Coping Strategies: All participants used to ventilate their emotions by crying. They relieved stress and pain when they went to hospital and shared feelings with friends who had same problem. Also, participant and child used to support each other; participant, by taking good care of child emotionally, physically, mentally and child, by providing reassurance to participant when she felt tensed. Almost all participants strengthened their inner power to control self and accepted the unavoidable condition as well.

“Now I feel that there is no solution by crying”.
[Anita]

“I make my heart little bit strong. I feel that if I take good care of him, he will become healthy and recover soon”. [Yamuna]

Participants hide their pain and spend time in rearing and caring child. When they involve with children, they forget their difficulties.

Nine participants expressed that they had no time to do any alternative therapy such as yoga, recreational activities and meditation. However, one of the participants who is from Newar community used to meditate occasionally. One of the participants used smoking as coping strategy to relieve stress.

Theme: 5 Optimistic Attitude: All participants

had strong faith in God. They believe that child will get well as God may favor them positively.

“I keep praying to God to save my daughter. For her health, performed Pooja and also went to Phukne Manchhe. What is written in our fortune...Just hope to God”. [Manita]

Nine participants expected for recovery from the disease.

“I have seen others being recovered so if there is no any obstacles, he eats well and if we also care properly in all things it will be recovered”. [Rama]

Participants experienced untiring attempt for the sake of child's treatment as they had hope of recovery. They experienced sense of responsibility and determination as they said that they will do whatever they can for their child. All of them regularly maintained leukemic child's health.

“I will save her by doing anything and facing any difficulties. Our asset is our daughter. If she is with us, we have everything and if she is not with us, nothing in our life”. [Anita]

Participants experienced sense of positivity due to harmonious relationship with Family. They trust doctors and nurses for recovery of their children. One participant being optimistic expressed that she will make her son doctor and another participant had planned to educate her child well in future.

Participants had positive attitude towards recovery as they got some help from others and hospital has managed free bed charge, free investigation and distributing available medicines in oncology ward.

Triangulation between In-Depth Interview and Case Study Findings: The case study findings were congruent with the verse of the participants. Somatic problems of participants continued as they undermine own health in front of their child's condition. Some contradictory findings as the duration of diagnosis and type of leukemia vary. Contradictory findings after 2.5 years of treatment as child's health was improving and hospital visit for child's treatment had decreased. Participants worried about relapse of disease. All participants had fear regarding side effects of the treatment and upcoming emergency situations. This fear was present constantly.

Discussion

Participants experienced many financial challenges during treatment which is a long process. Similarly, another study mentioned that mothers face financial burden regarding treatment.⁷

Participants were isolated from relatives, friends, parents and neighbors. This finding is supported by another study which showed that the treatment process had restricted social interaction as they spent a lot of time in taking care of the sick child.⁸

Majority of parents had left their work and were not able to complete any work as before. This is in consistent with the Canadian study which revealed that 64% of mothers left their job after their child's diagnosis.⁹

Participants experienced that their life became scary because of unexpected happening. These findings were supported by other study which mentioned that mothers experienced sadness and grief.⁷

Participants felt insecure as leukemia child had various side effects and experienced that anything can happen at any time. Another study reported that basic feelings of security departed and family members underwent more vulnerable when confronted with facts about disease.¹⁰

It was found that uneducated participant felt difficulty in coping as child's treatment option was bone marrow replacement and more worried in comparison to other educated participant. This finding is supported by other study which mentioned that those having lowest level of education had more psychological distress than those with university education.¹¹

Conclusion

Child's Leukemia affected mothers socially, physically and psychologically. Almost all participants faced financial challenges, alteration in their daily routines and crisis situation. Most of the participants coped effectively but one participant coped ineffectively. Participants need help to cope in such situation. Support group and self help group need to be formed in order to safeguard mothers having leukemia children.

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Ethical Clearance: The ethical permission was

obtained from Tribhuvan University, Institute of Medicine and Kanti Children's Hospital, Maharajgunj, Nepal before conducting the research.

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