Journal of Rare Cardiovascular Diseases
ISSN: 2299-3711 (Print) | e-ISSN: 2300-5505 (Online)
www.jrcd.eu

RESEARCH ARTICLE

A Study to Assess the Effectiveness of Assertiveness Training on Assertive Behavior Among Nurses Working in Selected Community Health Setting

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Article History
Received: 10.07.2025
Revised: 18.08.2025
Accepted: 23.09.2025
Published: 26.09.2025

Abstract: A study was conducted to explore the lived experience of mothers caring for their children with thalassemia from selected hospitals. The study objective was to explore the lived experience of the mothers caring for their children with thalassemia. Qualitative approach was used. Saturation of the data was achieved with 12 samples. Non probability purposive sampling method was used. The tool consisted of demographic profile and guidelines. The data was collected through one to one in depth semi structured interview. The results of the study was obtained through a thematic analysis utilized based on the conventional content of analysis to analyze the collected data. Based on commonalities within the data, themes and categories were formulated. A total 6 themes, 13 sub themes and 22 codes were generated. Theme no 1: Physical experience with sub themes as body pain, inadequate sleep and tiredness. Theme no 2: Emotional experience with sub themes as anxiety, fear, anger and guilt. Theme no 3: Financial experience with sub theme as inadequate money. Theme no 4: Spiritual experience with sub themes as faith and loss of hope. Theme no 5: Social experience with sub theme as inadequate social interaction. Theme no 6: Family experience with sub themes as family support and quarrels in family. Mothers shared personal experiences with hospitalization, treatment concerns, caregiver effect, changing roles and coping methods. Research concluded that a child suffering with thalassemia has a major influence on mothers. Caregiving can limit one's independence and personal life.

Keywords: Thalassemia, Thalassemic child, Lived experience.

INTRODUCTION

An important global public health issue is thalassemia, a hereditary condition marked by decreased hemoglobin production. The prevalence of thalassemia is higher in Mediterranean, Middle Eastern, and South Asian nations, and it affects about 7% of the world's population, according to the World Health Organization[1] In India, thalassemia, a hereditary condition that affects hemoglobin synthesis, is a serious public health issue. India is responsible for a significant amount of the worldwide thalassemia burden, with an estimated 10,000–12,000 children born with thalassemia major each year [2] .Many thalassemia patients reside in Maharashtra, one of India's most populated states; numerous studies have shown that the area needs better thalassemia awareness, diagnosis, and treatment .[3] When it comes to managing their child's thalassemia and facing the challenges of chronic sickness, mothers are essential.[4] Understanding mothers' lived experiences and viewpoints is crucial in the Indian setting, where family dynamics and caregiving duties frequently fall disproportionately on them [5] Research on the lived experiences of mothers of children with thalassemia in India, especially in Maharashtra, is lacking, despite the significance of this issue. This qualitative study aims to address this gap by exploring the lived experiences of mothers of children with thalassemia in Maharashtra, India. By examining the subjective experiences and perspectives of these mothers, this study seeks to provide a deeper understanding of the complexities of thalassemia care and inform the development of targeted support interventions.

A variety of psychological, emotional, and physical difficulties are linked to the condition in both afflicted persons and their families. Thalassemia, a genetic disorder affecting hemoglobin production, is a significant public health concern in India. With an estimated 10,000-12,000 children born with thalassemia major every year, India accounts for a substantial proportion of the global thalassemia burden [6]. Blood transfusion is a lifesaving treatment for thalassemia patients, enabling them to survive and lead relatively normal lives [7]. However, the frequency and volume of blood transfusions required can pose significant challenges for patients, families, and healthcare systems [8]. In Maharashtra, India, blood transfusion services play a critical role in managing thalassemia, with many patients relying on regular transfusions to maintain their hemoglobin levels and prevent complications . Despite the importance of blood transfusion in thalassemia care, there are concerns about the availability, accessibility, and safety of blood supplies, particularly in resource-constrained settings . Mothers of children with thalassemia often play a vital role in managing their child's condition, including coordinating blood transfusions and monitoring for potential complications [.9]However, the experiences and perspectives of these mothers are often underexplored, and there is a need for research that sheds light on their challenges, coping strategies, and support needs. Mothers, in particular, play a vital role in caring for children with thalassemia. They are often responsible for managing their child's condition, navigating complex medical regimens, and coping with the emotional and psychological stress associated with chronic illness . The caregiving role can be overwhelming, and mothers may experience feelings of anxiety, depression, and burnout Despite the crucial role of mothers in thalassemia care, their lived experiences and perspectives often remain underexplored. Existing research has primarily focused on the medical aspects of thalassemia, with limited attention to the psychosocial and emotional needs of mothers and families affected by the disorder . This gap in understanding can lead to inadequate support and resources for families, exacerbating the challenges associated with thalassemia care.[10] This qualitative study aims to address this gap by exploring the lived experiences of mothers of children with thalassemia.By examining the subjective experiences and perspectives of these mothers, this study seeks to provide a deeper understanding of the complexities of thalassemia care and inform the development of targeted support interventions.

METHODOLOGY

A qualitative research approach with phenomenological design was used to meet the study's desirable objective as the study exploring the experience of mothers of thalassemic child. The methodological framework was phenomenology.[14] Phenomenological study aims to explore the nature of life through mothers' daily experiences. This method helps to capture all aspects of mothers' engagement in caring for thalassemic children, emphasizing the significance of social interactions. Phenomenology explores real experiences to address particular questions through investigation. The study was conducted at thalassemia unit of selected hospital from Sangli-Miraj-Kupwad corporation area. Approximately, 35-40 children attending these centres for blood transfusion per month. The population of the present study comprised of Mothers of children with thalassemia who required blood transfusion. Mothers who are willing to give written consent for participation and Mothers who are caring the child 4 to 10 years were included in the study. Mothers of critically ill children were excluded from the study. Study consisted of 12 mothers of thallasemic children attending hospitals along with their children. Data saturation was reached with the stated sample size. A non-probability purposive sampling method was used to select the mothers.

Data collection Tool:

The study aims to explore the lived experiences to develop an in depth understanding of the mothers experience in order to have a wider outlook on raising children with thalassemia. The researcher created a tool which was used as guidelines to aid the interview process. The tool consisted of two sections. Section I :- Demographic data and Section II :- Semi - Structured interview guidelines. Demographic data which included Age (in years), Type of family, Number of children, Family income and Years of experience in parenting child with thalassemia. To bring out the points of mothers who are taking care of thalassemic children this segment had open ended questions. The questions were focused on experiences of mothers related to Physical experience, Emotional experience, Financial experience, Social experience, Spiritual experience and Family experience. Mother was sited in private room for individual interview, which were audio recorded and notes taken.

Data Analysis and Interpretation

Qualitative information aims to provide detailed insights into human subjects' experiences, quality of care, and caregiver satisfaction. Qualitative data analysis involves classifying, categorizing, and interpreting the data to offer a comprehensive understanding of the research issue. The investigator sought to find commonalities in the data received from samples audio recording. In section I, demographic data are provided in terms of frequency and proportion, rather than being collected numerically. Interviews were decoded, and the interviewer used appropriate language to convey crucial relevance. The interview aimed to gain a comprehensive understanding of the participants' experiences. Re-hearing was held to guarantee that the information was further broken down into smaller components to strengthen the results. Data was combined with represented components to establish a consistent characterization of the phenomena under study. The findings were developed using interview transcripts and references. The interpretation of important context and codes to build themes is supported in Section II. To establish definitions and make conclusions, associations between codes were identified. The material is decoded using tables and comprehensive themes descriptions.

Section I: findings related to demographic variables of Mothers who are taking care of thalassemic child

Table no. 1: Frequency and percentage distribution of demographic variables

(n=12)

Sr. No.	Demographic variables	Category	Frequency	Percentage (%)
1	Age (in years)	25-30	5	41.66
		30-35	7	58.34

2	Type of family	Nuclear	8	66.66
		Joint	4	33.34
3	Years of experience in parenting child with thalassemia.	4-6	5	41.66
		7-10	7	58.34
4	Number of children	1	2	16.66
		2	8	66.66
		3	2	16.66
5	Monthly family income (In Rs.)	5000-10000	8	66.66
		10000-15000	3	25
		15000-20000	1	8.34

The data provided in table 1 reveals that, out of 12 participants, 5 (41.66%) were in 25-30 age group and 7 (58.34) were in age group 30-35 respectively. 66.66% mothers were from nuclear family and only 33.34% mothers were from joint family. 41.66% mothers had 4-6 years of experience in parenting child with thalassemia and 58.34% mothers had 7-10 years of experience in parenting child with thalassemia.

Section II: Analysis of data among the samples that are taking care of the child with thalassemia.

This section analyzes data collected from 14 individuals through face-to-face interviews. The collected information was translated into the participants' dialect, and the transcript was returned for ensure reliability and validity to participant.

The terms participants used to describe their experiences throughout parenting were evaluated. Each word verbalized by the participants was characterized by the researcher in order to formulate themes that could further clarify the experiences under different diagrammatically represented titles.

The theme developed from the transcribed information revealed that the participants' encounters included how they interpreted the circumstance in which they were. Many individuals reported feeling pressured by the child's illness process, which affected their daily activities. Several circumstances influenced their dedication to caring for a child diagnosed with thalassemia. They reported diverse caring reactions and acknowledge that it is also a type of stress. Participants said that positive reinforcement and coping techniques helped them cope with challenging situations. In order to obtain a better understanding in the form of sub-themes as represented here, each theme was analyzed into smaller topics.

Table no 3: Description of the sub theme generated from the theme. **(n=12)**

Sr. No	**Theme**	**Sub Themes**
1.	Physical Experience	Body Pain
		Inadequate sleep
		Tiredness
2.	Emotional Experience	Anxiety
		Fear
		Anger
		Guilt
3.	Financial Experience	Inadequate money
4.	Spiritual Experience	Faith
		Loss of hope
5.	Social Experience	Inadequate social interaction
6.	Family Experience	Family support
		Quarrels in family

Table No.3 defines a total of 6 themes, of which 14 sub-themes have subsequently been clarified in additional tables. Each theme is grouped into sub themes so that it can be better understood.

Physical Experience

While conducting the interview, it was seen that most of the mothers says that while taking care of the thalassemic child, they were suffered negative impact on their physical health. Some mothers have body pain some have tiredness and inadequate sleep.

Body pain

In connection to why they suffered body pain while parenting the child they expressed that they have to take special and more care of the thalassemic child rather than a normal healthy child.

Inadequate sleep

Many mothers struggling to get enough sleep because of the disturbed sleep pattern. Due children's tension and anxiety they don't sleep properly and suffering trouble in sleeping.

Tiredness

Many participant shared one common complaint about physical health is tiredness. Frequent hospital visits for transfusion and travelling induce more fatigue and tiredness to the mothers.

Table no. 3.1: Description of theme related to physical Experience (n=12)

Sub themes	Codes	Verbatim
Body Pain	• Headache • Back ache • Knee pain	• Badan derd hota hai bahot • Sarr dukhta hai • Gudghe duktat, kambar dukhte, dok dukhtai
Inadequate sleep	• Sleep deprivation	• Pahele to nind hi udd gayi thi • Ek ek veli zop lagate, ekda nahi.
Tiredness	• Fatigue • Weakness	• Hospital ati hoon to thakan mahesoos hoti bahot. • Thakwa khup janvato.

Emotional Experience

Child diagnosed with thalassemia has a great impact on mother's mental health. While taking care of child, mothers gone through various faces of their emotional status. Many mothers suffer with emotional problem like anxiety, fear, anger and guilt.

Anxiety

Thalassemia is the lifelong disease which creates more anxiety in mothers while parenting of the children regarding their treatment, health issues and future life of the children.

Fear

During interview mothers expressed their real emotions regarding their children's health condition. They have fear and worry about children's health and how child tackle their life problems without or in the absence of them.

Anger

Due to stressful life and children's health issues many mothers were suffer an anger issues. Mothers get emotional and getting angry on ourselves or others due to imbalanced emotional status.

Guilt

Many mothers blaming ourselves for children's disease and having guilt about it.

Table no 3.2: Description of theme Emotional Experience (n=12)

Sub themes	Codes	Verbatim
Anxiety	• Tension arises	• Tensionach yaych. • Fakt ajarach tension ahe.
Fear	• Fear of future	• Bhavishyach kai hoil. • Amchya nantar kai honar.
Anger	• Irritation • Frustration	• Chid-chid hote. • Chidti hu. • Rag-Rag hotai
	• Intolerance to comments	• Koni bolalela sahan hot nahi.
Guilt	• Self-blaming	• Apne wajah se. • Amhi doghe minor ahot mhanun.
	• Own Sins	• Magchya janmache karma fedayla

		lagtat. • Gelya janmach asel kahi tari.

3.Financial Experience

To provide continuous treatment, good nutrition and extra care of thalassemic child imposes financial burden on parents. Parents trying to arrange sufficient money for treatment of their children. It create financial burden on them.

Inadequate Money

Many thalassemic child belongs to poor and under privilege family who don't have enough money for proper treatment and nurturing. Mothers have to arrange the money each time for blood transfusion of their children.
Participant (1) stated, *" Bachche ko hospital lane ke liye paise arrange karne padte hai."*
Participant (7) verbalised, *" Paise nahi rahe to blood transfusion ko late hota hai."*

Participant (9) stated, *" Hospital la Jayla – yayala paise nastat kadhi-kadhi.*"

Participant (11) expressed, *" Ghar kharcha ani balachi treatment kashi karto amcha amhla mahit."*

4.Spiritual Experience

When mothers understand their child diagnosed with thalassemia which required lifelong treatment and care, they loss their faith and trust towards God. Many mothers discontinued their spiritual practices because of loss of faith towards God. At the same time many mothers doing more worship of God hoping their child's good health.

Faith

Mothers have their particular faith and trust towards their respected God about their children's disease condition. According to their faith and trust they were doing their spiritual practices to cure the children's disease condition.
Participant (1), (2) and (7) expressed, *" Namaz padti hoon 5 time ki aur Allah se dua mangti raheti hoon."*
Participant (4) stated, *" Bala sathi prattek ravivari aarti la jatoy balu mamachya."*
Participant (12) verbalised, *" Santoshi mate chi Nirankar upwas karte mi mazya muli sathi."*

Loss of Hope

Due to lifelong disease condition of children and frequent health issues arises for the children many mothers losses their hopes towards their respected God and complaining to the God.

5.Social Experience

During interview mothers expressed, Involving more time in caring and treatment of thalassemic child, mothers can't socialize and spend time with their friends and loved ones. This leads them to decreased social interaction and can't get enough time from their child to interact with society.

Inadequate time for social interaction

Due to required frequent blood transfusion to the children, many mothers expressed that they didn't get time to do their own wishes and socialize with people. They have to take care of their children any how without any interruption otherwise their children get illness easily.
Participant (2) stated, *" Bachche me se time hi nahi milta dusra kuch karne ko."*
Participant (3) expressed, *" Time kuthe ahe tevdha baher Jayla…….divas bhar balatach jatai."*
Participant (8) stated, *" kam ani ha mulga ya madhun vel nahi milat kahi karyla."*

Self-Isolation

Involving maximum time in children mothers suffer decreased social interaction. Even they don't get time to spend quality time with their own parents.
Participant (1) stated, *" Bachche ki wajah se mai duniya se alag rahene lagi hoon."*
Participant (5) expressed, *" Baher nahi jata yet balala sodun………khup kami jana hot baher."*

6.Family Experience

Presence of thalassemic child in family affects family relationships also. Because of ignorance in care and treatment of child or feeling like this, quarrels in family happen. Most of the time husband-wife fights because of child and blaming each other.

Family support

Providing treatment to the thalassemic child and good nurturing mothers required positive support from their family. Many mothers experienced good family support which enhances confidence of mothers.
Participant (3) stated, *" Sasu-Sasare sagle balala baghtat…te sagla kartat balach."*
Participant (7) expressed, *"Meri ammi, meri bahen support karti hai bachche ke bare me."*
Participant (11) verbalised, *" Gharche khup supportive ahet…….te ahet mhanun sagla chalalai."*

Quarrels in Family

Due to negligence to the thalassemic child, internal conflicts and blaming each other, quarrels were happen in the family.
Participant (3) stated, *" Bala mule sarkha amchyat chid-chid pana danga hotoy."*
Participant (8) expressed, " Mula kade laksh kami zala na maz tr mag maze mister ordayla chalu kartat mala.
Many participants stated that quarrels were happen because of inadequate money and stress.

CONCLUSION

This research examined experiences of mothers who are taking care of children with thalassemia. Participants shared personal experiences with hospitalization, treatment concerns, caregiver effect, changing roles and coping methods. Research indicates that a child suffering from thalassemia has a major influence on mothers. Caregiving can limit one's independence and personal life, as noted in literature. Participants in this study identified several pressures and inadequacies, including limited social life. Limitations in opportunities might stem from emotional issues including despair, remorse, and dishonour, as well as several caregiving responsibilities. In addition, authorities should give educational and infrastructure support to decrease the financial struggle and emotional imbalance of mothers. More research is needed to provide personalized support models for families caring for child with thalassemia. The present study's findings bring up the need for strategies to alleviate the load on mothers who care thalassemic child.

Acknowledgement
The researcher acknowledges the institutional authorities of BVCON, Sangli and the study participants for the co-operation and all the stakeholders involve in completion of the research study.

Conflict of Interest
No conflict of interest involved.

REFERENCES:

1. Yadav S S, Panchal P, Menon K C: Prevalence and management of β-thalassemia in India. Hemoglobin. 2022, 46:27-32. 10.1080/03630269.2021.2001346
2. (9789290228516). https://www.who.int/publications/i/item/9789290228516.
3. Khodaei G H, Farbod N, Zarif B, Nateghi S, Saeidi M: (2013: Frequency of Thalassemia in Iran and Khorasan Razavi. International Journal of Pediatrics.2013. 1:45-50. 10.22038/ijp.2013.2044
4. Kattamis A, Forni G L, Aydinok Y, Viprakasit V: Changing patterns in the epidemiology of β-thalassemia. European Journal of Haematology. 2020, 105:692-703. 10.1111/ejh.13512
5. Singh P, Shaikh S, Parmar S, Gupta R: Current status of β-thalassemic burden in India: prevalence, mutation spectrum, prevention and therapeutic efforts, and awareness programs. Hemoglobin. 2023, 47:1-10. 10.1080/03630269.2023.2269837
6. Majedeh N, Fatemeh C, Farshid S et.al: A Qualitative Study Exploring the Experiences of Mothers Caring for Their Children with Thalassemia in Iran. Ethiop J Health Sci. 2021, 31:1287-1294. 10.4314/ejhs.v31i6.25
7. Amit Saxena, Mumtaz Sharif, Sadaf Siddiqui et.al: Knowledge, practice and experiences of parents with a thalassemic child. International Journal of Contemporary Pediatrics. 2017, 4:1630-1633. 10.18203/2349-3291.ijcp20173607
8. Islam F, Seemanta S, Rezina S et. al.: Depression anxiety and stress among mothers of children with thalassemia in Bangladesh: a cross-sectional study. BMC Women's Health.2025. 221. 10.1186/s12905-025-03762-8
9. Nedruetai Punaglom, Puangpaka Kongvattananon, Chomchuen Somprasert: Experience of Parents Caring for Their Children with Thalassemia: Challenges and Issues for Integrative Review. The. Bangkok Medical Journal. 2019, 15:100-106. 10.31524/bkkmedj.2019.02.018
10. Prasomsuk S, Jetsrisuparp A, Ratanasiri T, Ratanasiri A et.al: Lived experiences of mothers caring for children with thalassemia major in Thailand. 200712, 1-13. 10.1111/j.1744-6155.2007.00085.