



A PHENOMOLOGICAL STUDY TO DETERMINE LIVED EXPERIENCES OF PARENTS OF CHILDREN SUFFERING FROM THALASSAEMIA IN RAJINDRA HOSPITAL OF DISTRICT PATIALA, PUNJAB

¹Ms. Ravinder Kaur and ²Ms. Sanjna Kumari

^{1&2}Child Health Nursing, ¹Nursing Superintendent at Santosh Hospital and ²Senior Tutor at School of Nursing Science & Research, Sharda University
¹Chandigarh, India

Abstract

Thalassaemia is inherited autosomal recessive blood disorder characterized by abnormal formation of hemoglobin. In this needs a regular blood transfusion is needed every 3-4 weeks. So, in this study to know about the lived experience of children of parents suffer from thalassaemia to know about the impact on the family have been occurred.

Aim of study: The aim of the study is to determine lived experiences of parents of children suffering from thalassaemia.

Objective: To explore the lived experiences of parents of children suffering from thalassaemia.

Methodology: A Phenomenological study to determine lived experiences of parents of children suffering from thalassaemia in Rajindra hospital of district Patiala, Punjab. Criterion sampling technique was used. It included 9 parents data saturation was met. The data was collected by in-depth, semi structured interviews, which was tape-recorded. The interviews were transcribed and subjected to Colaizzi's data analysis framework and determined themes and meanings from the interview data.

Results: The findings of present study indicated that the lived experience of parents of children suffering from thalassaemia in various Physical problems, Emotional distress, Financial problem, Social distress, Knowledge deficit, Spiritual and Psychological support, Time management, Health Care Support.

Conclusion: It was concluded that, the lived experiences of parents of children suffering from thalassaemia in various Physical problems, Emotional distress, Financial problem, Social distress, Knowledge deficit, Spiritual & Psychological support, Time management, Health Care Support.

Recommendations: Similar study can be conducted by comparing impact of thalassaemia with other chronic illness.

Keywords: Thalassaemia, Lived experiences, Parents, Children.

Introduction

Having a child with chronic illness can cause considerable stress to parents, as the care which needs to be provided can be highly demanding. Consequently, it can have emotional repercussions, as well as affecting parent's daily life. Parents exhibited a variety of stress responses consistent with the nature of the illness and the care needed.

Thalassaemia (British English: thalassaemia), also called Mediterranean anemia, is a form of inherited autosomal recessive blood disorder characterized by abnormal formation of hemoglobin. The abnormal hemoglobin formed results in improper oxygen transport and destruction of red blood cells. Thalassaemia is caused by variant or missing genes that affect how the body makes hemoglobin, the protein in red blood cells that carries oxygen. People with thalassaemia make less hemoglobin and have fewer circulating red blood cells than normal, which results in mild or severe microcytic anemia. Thalassaemia can cause complications, including iron overload, bone deformities, and cardiovascular illness. However, this same inherited disease of red blood cells may confer a degree of protection against malaria (specifically, malaria caused by the protozoan parasite *Plasmodium falciparum*), which is or was prevalent in the regions where the trait is common. This selective survival advantage of carriers (known as heterozygous advantage) may be responsible for perpetuating the mutation in populations. In that respect, the various thalassaemia resembles another genetic disorder affecting hemoglobin, sickle-cell disease.

Globally, according to the WHO, statistics, around 19% of the total population is the carrier of thalassaemia gene in the Saudi Arabia Kingdom. Around 3.4% of the people are carrier of the thalassaemia and around 7000 to 10,000 children are born with thalassaemia per year in India. It can be of any type such as alpha thalassaemia, beta thalassaemia, delta thalassaemia and combination of other hemoglobinopathies.



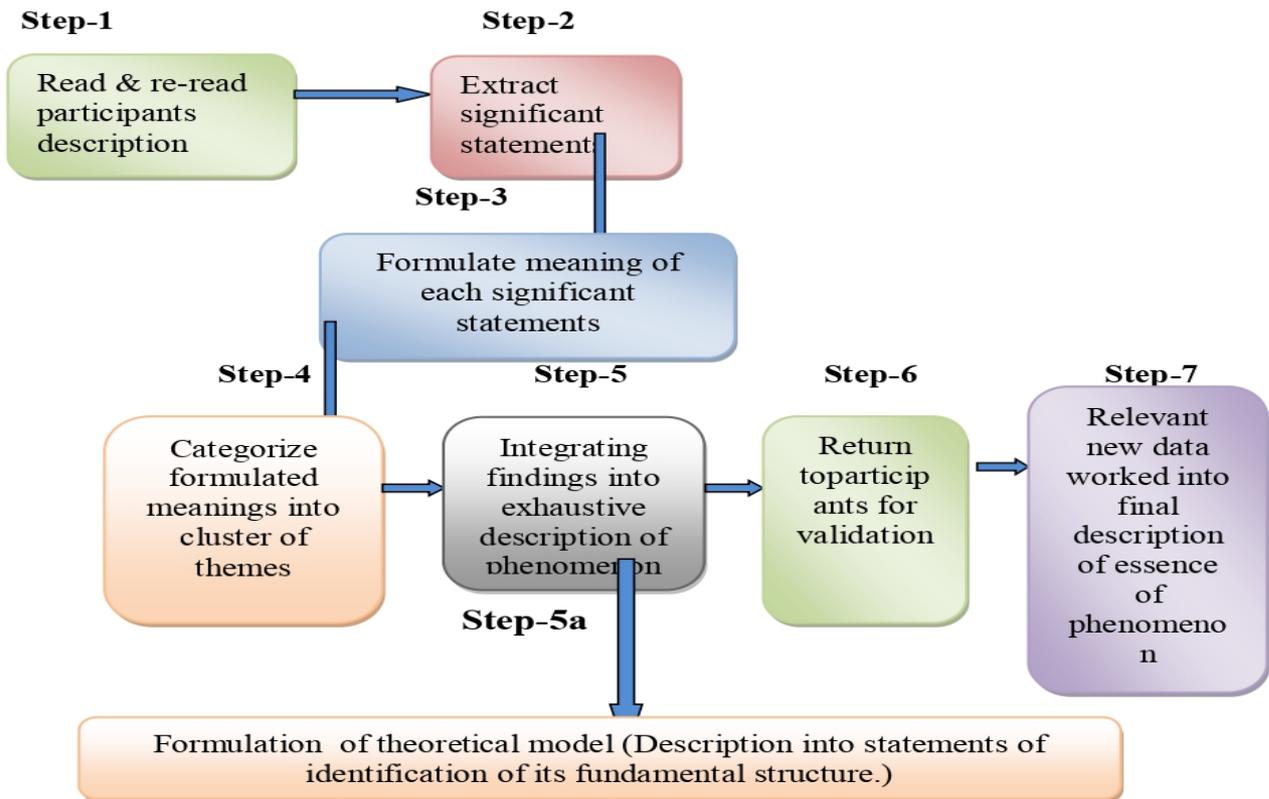
Methodology

Research Approach	
Qualitative	
↓	
Research Design	
Phenomenological Study	
↓	
Research Setting	
Thalassaemia ward at Rajindra hospital, district Patiala, Punjab	
↓	
Target Population	
Parents of thalassaemic children	
↓	
Sampling Technique	
Criterion sampling will be used which is a part of purposive sampling	
↓	
Sample	
5-10 parents of thalassaemic children	
↓	
Tool and Method of Data Collection	
Self report method is used	
Demographic variables	In-depth Semi structured, face to face Interview and were tape recorded
↓	↓
Plan for Data Analysis	
Colaizzi approach will be used for narrative data analysis	

Fig 2. Schematic Presentation of Research Methodology Plan for data analysis

The collected data was analyzed by the Colaizzi method and analytical procedure of data set, a brief description of data collected and transcripts formation was summarized below:

A semi-structured, face-to-face interview was conducted by using a pre-prepared interview guide. Participants were encouraged to talk freely and to tell stories using their own words. Each interview conducted lasted from 25minutes to 45minutes. Recorded interviews assisted me to maintain the quality of the conversation by not missing any data. I could return to interviewees’ actual words and statements, which kept the original form of the conversations. Voice recording helped me to maintain consistency without frequent interruptions or missing any verbal phrase, and to repeat them with no change. Recording interviews ensured that the collected information was accurate and completed, which helped me in the transcription and analysis stages to capture the complete conversation. Firstly, the data was recorded and then it was typed. After that reading and re-reading of participants descriptions were done. The significant statements were extracted followed by formulating the meaning for each other significant statement. Then categorizing of formulated meanings into cluster of themes was done. Then the extracted meaning and statements were validated by experts in the field of child health nursing. After careful analysis of the transcript of the in-depth interview, so many subthemes have been emerged. These subthemes were coded under the grouped analytical coding sheet by final description and categorizing the essence of phenomenon.



**RESULTS
SECTION-A
(Part-1)**

DESCRIPTION OF SAMPLE CHARACTERISTICS

This section deals with the description of sample characteristics and has been summarized in terms of frequency and percentage presented in Table 1.

**Table-1
Frequency and percentage distribution of sample characteristics
N-9**

S. No.	Demographic profile	Frequency	Percentage
1.	Relationship of respondent with child		
	Father	2	22.2
	Mother	7	77.8
	Other	0	0.0
2.	Educational level of respondent		
	Illiterate	3	33.3
	Primary	4	44.5
	Secondary	0	0.0
	Senior secondary	0	0.0
	Graduate & above	2	22.2
3.	Occupation of respondent		
	Government	0	0.0
	Semi-government	0	0.0
	Private	0	0.0
	Own business	2	22.2
	Unemployed	7	77.8
4.	Marital status of respondent		
	Married	7	77.8



	Widow	1	11.1
	Divorcee	1	11.1
5.	Family income (Rs.)		
	< 10000	0	0.0
	10000 – 20000	0	0.0
	20000 – 30000	0	0.0
	> 30000	9	100.0

Table 1 reveals about the demographic characteristics of the respondents, their frequency & percentage distribution. This table shows that the majority 7(77.8%) of the respondents were mother, 2(22.2%) were father. Regarding education level majority 4(44.5%) were having primary education, 3(33.35%) were illiterate, 2(22.2%) were graduate and above. Majority occupation of the respondents 7(77.8%) were unemployed and 2(22.2%) were own business. Most of the respondents were 7(77.85%) were married, 1(11.1%) was widow, 1(11.1%) was divorcee. According to family income 9(100%) were having >30,000 income per month.

(Part-B)**Profile of the patients enrolled in the study**

This section deals with the description of sample characteristics enrolled in the study and has been summarized in terms of frequency and percentage presented in Table 2.

Table-2
Frequency and percentage distribution of patients enrolled in the study
N-9

S. No.	Profile of patient	Frequency	Percentage
1.	Age of child (years)		
	5 – 10	3	33.3
	11 – 15	3	33.3
	> 15	3	33.4
2.	Gender		
	Male	7	77.8
	Female	2	22.2
3.	Birth order in family		
	The oldest one	4	44.5
	The youngest one	5	55.5
	Others	0	0.0
4.	Type of delivery		
	Normal	7	77.8
	Cesarean	2	22.2
5.	Age at time of diagnosis(years)		
	≤ 1	6	66.7
	> 1	3	33.3
6.	Duration of treatment taking(years)		
	≤ 10	4	44.5
	> 10	5	55.5
7.	Any other family member suffering		
	Yes	1	11.1
	No	8	88.9

Table 2 reveals about the demographic characteristics of the child, their frequency & percentage distribution. This table shows that age of the child 3(33.3%) were 5-10 years, 3(33.3%) were 11-15 years, 3(33.3%) were more than 15 years. Regarding the gender majority of the child 7(77.8%) were male and 2(22.2%) were female. The birth order majority of the samples 5(55.5%) were the youngest one and 4(44.5%) were the oldest one. Majority of the child were born by normal delivery 7(77.8%) and 2(22.2%) were born by caesarean section. Mostly <1 year old at the time of diagnosis 6(66.7%) and 3(33.3%) were >1 year at the time of diagnosis. Regarding the treatment majority 5(55.5%) were taking treatment > 10 years, 4(44.5%) were taking treatment <10 year. Most the



family history of thalassaemia majority 8(88.9%) were not suffering from thalassaemia and 1(11.1%) were suffering from thalassaemia.

SECTION-B

SELECTED SIGNIFICANT STATEMENTS, FORMULATED MEANINGS AND THEMES

This section deals with description of significant statements, formulated meanings and themes.

Table-3

Theme 1: Physical problems

Significant statement	Meaning	Theme	Transcript no
He looks different. I went for taking an appointment for his medicine today. They asked the age of my child that I might have written wrong. I asked why? In the age of 16, a child is in his full youth.	Delayed growth.	Physical problems	04
No, not too much. We sent him school late because he started walking late as he was weak. His legs were weak.	Delayed growth.		02
He used to sleep a lot. He used to eat very less. His diet was also less. He was also suffering from diarrhea. As we took a little while to work, his stool (poop) turned to green by lying for some time.	Health problems is increased due to disease condition.		01

Theme 2: Emotional distress

Significant Statement	Meaning	Theme	Transcript no
We have been crying for the last 16 years. We have no hope. We spent our whole money in it. If any sudden accident happens then we do not spend our whole money in that. We fulfill his all wishes but we have no hope.	Feeling burn out	Emotional distress	04
There is no chance of survival everything is in God's hand and we have only option to serve the sick child.	Feeling negative emotions		04
We don't know that what would happen with the girl. Relatives also say that who will marry her as she has no guarantee. Doctors say that she can survive with blood infusion only. It is very difficult for a girl that's why all are worried what she will do if she will be fine even we can't do her marriage by telling any lie.	Feeling anxious		08
We do not feel good. Our mind is upset. When we come here we feel very bad. Sometimes, we have to come twice a month. I get tension before four days that we have to go to hospital.	Feeling frustrated and fed up		08



Theme 3: Financial problem

Significant statement	Meaning	Theme	Transcript no
Expenses are a lot and problem is also there. But we have to spend money on it. We can reduce the home expenses. We can't reduce his expenses. We have to give money to doctor as he says. We can't say no to Doctor.	Parents suppressed their feelings.	Financial problem	01
Yes, we have difficulty with expenses. We have no enough money. I borrowed Rs 500 from the person yesterday where I do work. My father-in-law used to give money but now he is sick also due to heart attack. We have difficulty with expenses as earner is only one and we are more.	Seeking financial help from others.		03
It is difficult. All the things are expensive. There are a lot of expenses like bus fares and expenditure of food items and medicine. Inflation is too much nowadays. When we come here, every month we have to spend 1500 rupees and sometimes it increases.	Increase financial burden.		08
Yes, there are lots of expenses like household expenses, her study, books and tuition and diets expenses also. We can reduce our own expenses. So there will be no problem in expenditure like we have to give her blood time to time.	They control our own expenses.		06

Theme 4: Social distress

Significant Statement	Meaning	Theme	Transcript no
Our neighbors also know about it and they say for how long he has to give blood. He can't be fine. It is our bad luck what we can do.	Negative views from others.	Social distress	03
Relatives don't do anything it's our hard time. Nobody help us. My nephew has come from Dubai. He is well settled there but he does not help us.	Lack of support from relatives and friends		09
I can't come alone because when they insert needle in him, he cries a lot. I can't handle him alone. It is very difficult. We have to come by leaving our work. Relatives do not come with us.	No helping hands from others		06
When we go to outside then other people say that is your child sick? Then we say that she is suffering from fever. If we say that she has thalassemia then everyone says that what is this? They used to say different things which hurt us.	Worry about reaction of others		08



Theme 5: Knowledge deficit

Significant statement	Meaning	Theme	Transcript no
No, we didn't know anything. If we knew that we would get a test at PGI, this test has to be done within two and a half months.	No information about disease.	Knowledge deficit	01
No, we did not know about this disease before if we knew we could take the tests. We have done that now.	They don't have idea about this disease.		08
No, we had no information. We never heard about thalassemia. Not even in our relatives like our relatives' children falls ill and they also do the treatments. Nobody has this disease I did not hear before marriage.	No acquaintance about this disease.		06
No, we had no information but we heard from our mother and grandmother. She used to tell us that there is a disease which we call thalassemia now. Then we didn't know about its name.	Lack of Knowledge.		04

Theme 6: Spiritual and Psychological support

Significant Statements	Meanings	Theme	Transcript no
We are alive because of the God. We all will die one day but we have a hope in our hearts. He can live with us for the whole life but we don't know when this bad thing would happen with us. We convince ourselves and believe in the God. What the God has written that will happen.	Have faith in God.	Spiritual and Psychological support	04
We are illiterate. Doctor said he would be fine. They gave us courage. Then we came to know about the disease slowly.	Support from doctor.		05
All are shocked to hear about this disease that our daughter needs blood infusion for whole life. Some says that doctors are making fool of you. You can go somewhere else because no one has heard about it.	Cultural barriers and stigma.		08

Theme 7: Time Management

Significant statement	Meaning	Theme	Transcript no
Sometimes she does not sleep at night and I have to stay awake with her then I feel lazy on the next day and I can't do my work properly. She used to stay with me and if I do any work I feel afraid that she will not be sick. If she is sick then we have to go to hospital immediately by leaving all the works.	Effect the daily activities	Time management	08
Firstly I used to do a job. But there was a difficulty they said that you take too much	Measures taken		



leaves due to this I left the job and then I started my own business.	to manage time		09
He does not let me do work. He does not stay with anyone else. He stays with me or his father when his father comes home from work. Then he takes care of him then I do household work.	Involvement in unpaid work		07
It affects a lot. We have to come here by leaving all the works. No work is done on time due to her disease.	Effects daily routine		06

Theme 8: Health care support

Significant Statement	Meaning	Theme	Transcript no
Tests should be done before marriage. We are sad but the coming generation should not face it. We are suffering and others should not. All the children should be fine. Counseling should be done before marriage.	Need for pre-marital counseling	Health Care Support	02
Yes, counseling should be done before the marriage. So that no one have this problem.	Need for pre-marital counseling		03
Yes, it should be. First, the counseling should be done after that we should think about marriage.	Guide before marriage		04
I ask everyone but nobody know about it before. Some people have their first baby but they do not know about it. So the doctors and govt should do some efforts to make the people aware about this disease.	Need for organize seminars and campaigns		06

SECTION-C

FREQUENCY DISTRIBUTION OF FORMULATED EXPERIENCE REPORTED BY RESPONDENTS

This section deals with frequency distribution of formulated experience reported by respondents

Table-4

S. No.	Formulated responses	Frequency (%)
1.	Experiences related to physical aspect(n-43)	
	Fever	6(14.0)
	Vomiting	3(7.0)
	Heaviness of abdomen	3(7.0)
	Excessive sleep	1(2.3)
	Inadequate diet	3(7.0)
	Loose motions	3(7.0)
	Continuous crying	1(2.3)
	Weakness	3(7.0)
	Pale face	1(2.3)
	Child get tired while playing/Lazy	5(11.6)
	HIB positive due to disease	1(2.3)
	Under growth and delayed development	4(9.3)



S. No.	Formulated responses	Frequency (%)
	Fell ill frequently	3(7.0)
	Avoid injuries/Need precautions	3(7.0)
	Can't do heavy work/ Don't do activities like other children	2(4.7)
	Feel tired. Breathlessness, Cannot run	1(2.3)
2.	Experiences related to emotional distress(n-16)	
	Stubborn/child not taking medicine	3(18.8)
	Need emotional support	5(31.3)
	Need help in daily activities	2(12.5)
	Should play inside house	4(25.0)
	Worried/hopeless about future and marriage	2(12.5)
3.	Experiences related to financial aspect(n-10)	
	Disease effects financially badly	4(40.0)
	Need financial support	4(40.0)
	Relative are not supportive	2(20.0)
4.	Experiences related to social-distress(n-7)	
	Friends/teachers are supportive	6(85.7)
	Effects family ties	1(14.3)
5.	Knowledge deficient(n-17)	
	No previous knowledge	8(47.1)
	Don't know about marriage in blood relation	9(52.9)
6.	Experiences related to psychological and spiritual aspect(n-26)	
	Felt miserable	4(15.4)
	Sorrowful	4(15.4)
	Hopeless about survival	2(7.7)
	Feeling sad/bad	4(15.4)
	Depressed	2(7.7)
	Hopeful, doctor is supportive	1(3.8)
	Tensed and worried	3(11.5)
	Have faith in baba	2(7.7)
	Orthodox family	1(3.8)
	Our fate, We are now habitual	3(11.5)
7.	Time management(n-16)	
	Have to hold household activities	5(31.3)
	Take precautions, can't leave alone	1(6.3)
	Effects household activities	1(6.3)
	Have to observe always	1(6.3)
	Need extra care	8(50.0)
8.	Health care support(n-18)	
	Pre-marital counseling	9(50.0)
	Medical tests before marriage	6(33.3)
	Awareness campaigns by govt.	1(5.6)
	Seminar	1(5.6)
	Knowledge to pregnant mothers	1(5.6)

Themes

The sample consists of 9 participants who were interviewed. The 9 interviews yielded. The significant statements and their formulated meanings evolved into eight prominent themes (see Table 2). The themes derived from this qualitative study to determine the lived experiences of parents of thalassaemic children.

- 1) Physical problems
- 2) Emotional distress
- 3) Financial problem
- 4) Social distress



- 5) Knowledge deficit
- 6) Spiritual and Psychological support
- 7) Time management.
- 8) Health Care Support

Theme 1: Physical problems

Each caregiver interviewed spoke about their experiences related to physical problems of their children. One participant spoke about their health issues “The parents said that this child was always sick. We always worried anytime anything will happened these child easily get exhausted. The children overall health is disturbed day by day they were fragile and everyone said according to age they look small height and weight is not increased.”

The participant describe the health problems of their children which they suffered from growth retardation, low body strength and inability to perform their daily activities.

Theme 2: Emotional distress

The illness and experiencing negative reactions from others had different psychological consequences. Most of the participants suffered from anxiety, worry, grief, loneliness and depression. A participant said “We don’t know that what would happen with the girl. Relatives also say that who will marry her as she has no guarantee. Doctors say that she can survive with blood infusion only. It is very difficult for a girl that’s why all are worried what she will do if she will be fine even, we can’t do her marriage by telling any lie”

Theme 3: Financial Problem

The participants experiencing financial loss they seek help from others and some are reduced their own expenses to provide proper treatment to their child. The participant said that “Yes, we have difficulty with expenses. We have no enough money. I borrowed rupees 500 from the person yesterday where I do work. My father-in-law used to give money but now he is sick also due to heart attack. We have difficulty with expenses as earner is only one and we are more.”

Theme 4: Social distress

In some families having a chronic illness could cause feelings of shame and stigmatisation which led some parents to hide the fact that their children had been diagnosed with BTM and that they regularly received blood transfusion and iron chelating therapy. The participant spoke that

“I did not tell all my family members that my daughter was diagnosed with thalassaemia. Only me, my husband and my family in law knew about her disease and blood transfusions. I didn't want to discuss this with anybody right now. No, no, no, even my close friends. You know how people stigmatized us... You know what I mean?”

Theme 5: Knowledge deficit

‘Unknown family history’ means that either mothers or fathers did not have diagnosed patients with the defective gene in their family, that they were not aware of carriers in either family, or both. In such cases, family members could be dormant carriers of the defective gene, only learning about their own genetic status when they had a first child with BTM, as was revealed during the interviews from the following participants:

“I never in my entire life heard about it [thalassaemia] until I had initial of her son”

“I did not know that I was a carrier... no, it never crossed my mind even to check or do any blood tests.”

“I did not know that I and my husband were carriers of the disease...”

“I swear to God. I don't know what thalassaemia is. They diagnosed her at the beginning with ‘iron deficiency anaemia’ after she started taking blood. The PGIMER doctors told me that she had thalassaemia, and that it is a genetic disorder and that my daughter didn't have just anaemia.”

Theme 6: Spiritual and Psychological support

Parents often reacted positively to bearing and enduring the pain which is a part of their experience of caring for their children. They have the attitude of not complaining to others about their situation, which are culturally and religiously considered unacceptable behaviours. Furthermore, parents tended to be long-suffering and made sense of the situation by changing their behaviour. They preferred to keep calm and silent, bearing in mind that illness is something from God and as such, everyone is obliged to accept it: The participants said that “We are alive because of the God. We all will die one day but we have a hope in our hearts. He can live with us for the whole life but we don’t know when this bad thing would happen with us. We convince ourselves and believe in the God. What the God has written that will happen.”



Theme 7: Time management

The participants observed the strongest impact of this disease on their time management foremost of the participant the routine was fixed and they were following it from the year and when suddenly their children got this disease they make attempts to structure their time more worthy. The participants said that “He does not let me do work. He does not stay with anyone else. He stays with me or his father when his father comes home from work. Then he takes care of him then I do household work.”

Theme 8: Health care support

Lack of regular programme for thalassaemia lack of up-to-date education, advertisement in the media and being ignored were the causes of great suffering for the patients. A patient whose children has thalassaemia said that “I ask everyone but nobody know about it before. Some people have their first baby but they do not know about it. So, the doctors and govt. should do some efforts to make the people aware about this disease.”

Furthermore, neither fathers nor mothers knew about their family health history of having genetic disorders “I didn’t know that, my husband and I were carriers... We didn’t know even that it’s inherited. We were not related to each other before we were married... None of his family members had any disease like that, or even me. That was really shocking... I had never heard about thalassaemia before.”

“Oh my God... We were all surprised and shocked... We went through different tests many times. It took them three months to confirm to us the diagnosis because at first they said it was only blood anaemia.”

Another father said:

“When we had a child diagnosed with the disease [thalassaemia] we started to know about it... Actually, I knew nothing about thalassaemia before that time, and before knowing that my wife and I were carriers.”

Discussion

This chapter deals with the major findings of the study in relevance to the objectives framed and discussed in relation to similar studies conducted by other researchers. It was a phenomenological study to determine lived experiences of parents of children suffering from thalassaemia in Rajindra hospital of district Patiala, Punjab. The main aim of the study was to determine lived experiences of parents of children suffering from thalassaemia. This study accentuates our knowledge about what are the lived experiences of parents of children suffering from thalassaemia.

Sample characteristics of respondents

The investigator found that majority 77.8% of the respondents were mother, 22.2% were father. Most of the respondents 44.5% education level were primary education, 33.35% were illiterate, 22.2% were graduate and above. Regarding occupation of respondent majority 77.8% were unemployed and 22.2% were own business. Most of the respondent 77.85% were married, 11.1% was widow, 11.1% was divorcee. All the respondents 100% family income were >30,000 income per month.

Sample characteristics of child

The investigator found that majority age of the child i.e. 33.3% were in between 5-10 years age group and 33.3% were 11-15 years age group 33.3% were >15 years. Most of the children 77.8% were male and 22.2% were female. According to birth order majority 55.5% of the child were the youngest one, 44.5% were the oldest one. Most of the child 77.8% were born by normal delivery and 22.2% were born by caesarean section. Maximum 6(66.7%) child were <1year old at the time of diagnosis and 3(33.3%) were >1year at the time of diagnosis. Regarding the treatment majority 5(55.5%) were taking treatment > 10 years, 4(44.5%) were taking treatment <10 year. The majority of sample 88.9% were not having any family history of thalassaemia and 1(11.1%) was having family history of thalassaemia.

The findings of respondent’s characteristics were supported by the study conducted by **Khetam Mohammed Al-Awamreh(2014)** then he reported 50% men and 50% women for their data collection. They reported that 50% of the participants (i.e., the mothers) were not employed, 10% of fathers were retired and 40% were still in secure full or part time jobs. The findings of their study showed that there are 73% participants had completed high school, 20% had diplomas and 7% had university degrees.

The findings of their study shows that 70% were female and 30% were male children who were diagnosed before the age of one year. They reported that 66% children were in the school age group, 11.3% were in the toddler and preschool age groups and 11.3% patients were young adults.



Objective: To explore the lived experiences of parents of children suffering from thalassaemia.

The findings of present study indicated that the lived experience of parents of children suffering from thalassaemia in various Physical problems, Emotional distress, Financial problem, Social distress, Knowledge deficit, Spiritual and Psychological support, Time management, Health Care Support.

A study conducted by Pouraboli Batool, Abedi Ali Heidar, Kazemi Majid (2014) "A qualitative study on the experiences of self-care suffering of patients with thalassaemia." Data analysis resulted in the emergence of the four central categories of Physical exhaustion, Mental and spiritual restlessness, Society's behavior and beliefs and surviving a hard life, which were the suffering theme of the patients. Result showed that thalassaemia in the physical, psychological, social and spiritual aspects is very stressful for patients.

References

1. Mayo Clinic. Thalassaemia [Internet]. 2014 October 17 [Cited 2015 NOV]; Available from: [http://www.mayoclinic.org/diseasesconditions/thalassaemia/basics/definition /con-20030316](http://www.mayoclinic.org/diseasesconditions/thalassaemia/basics/definition/con-20030316)
2. Weatherall, David J, Lichtman MA, Kipps TJ, Seligsohn U, Kaushansky K, Prchal, et al, editors. The Thalassaemias: Disorders of Globin Synthesis. 8th ed. Ch. 47
3. Mayo Clinic. Thalassemia Complications. [Internet] 2011 Feb 4. Retrieved 2011 September 20 [Cited 2015 NOV 22]; Available from: <http://www.mayoclinic.org/diseasesconditions/thalassaemia/basics/complications/con-20030316>
4. Prasomsuk S <http://www.annalsnyas.org/cgi>. Accessed August 5, 2008. [11].
5. Khetam Mohammed Al -Awamreh. Experiences and coping strategies of Jordanian parents of children with Beta thalassaemic major; Available from <http://hydra.hull.ac.uk/assets/content>
6. Pouraboli Batool, Abedi Ali Heidar, Kazemi Majid. Iran J Nurs Midwifery Res. 2014 Feb; 19(7 Suppl 1): S77-S82; Available from www.ncbi.nlm.gov