
An Analysis of Challenges Faced by Thalassemic Patient's Care Givers

Irsa Samar¹, Anam Iqbal², Gulnaz Anwar³, Sundas Niazi⁴, Saba Khan⁵, Asad Ali⁶

^{1,2,3,4,5,6}Students of BS Sociology, Department of Sociology, University of Thal Bhakkar, Pakistan

ABSTRACT: Thalassemic patient's caregivers face a great burden. It is key necessary to understand all these sufferings which are faced by caregivers for the sake of providing comfortable environment to the Thalassemic patients. The purpose of this study was to explore the problems faced by thalassemic patient's caregivers. Qualitative research method was used for obtaining information. Seven participants recruited including two fathers, four mothers and one grandmother. Data was analyzed by using thematic analysis. The findings of the recent study showed that caregivers have to face a lot of burden that have worse impact on their lives. This research may prove to be useful to gain the attention of the Government and society towards thalassemic patients.

Key Words: Caregivers, Stigmatization, Family support, Stress and anxiety, Fear of death and Social Isolation.

INTRODUCTION

Thalassaemia was originated from the Greek word "**thalassa**" meaning the sea and "**heamia**" meaning the blood because the disease was first discovered in populations living near the Mediterranean Sea. Thalassaemia is a genetic disorder in which body produce less hemoglobin which is an important part of RBCs. It is a chronic disease that adversely affects human body. It was first reported in 1925 by a Detroit Physician who examined Italian children with severe anemia, poor growth, and early childhood death. About 15 Billions of world's populations suffer from Thalassaemia. (Inamdar, Inamdar, &Gangrade, 2015) Regular Blood transfusion and iron chelation therapy which is very expensive is required for Thalassemic patients to survive. Mostly people are unaware of the thalassaemia disease they consider that it is due to iron deficiency but it is not like that they should try to understand that this disease is not due to iron deficiency so that iron supplements will not prove to be helpful to cure anemia rather it will lead to more iron buildup if the patient is already receiving blood transfusions. Due to iron efficiency the extra iron deposit in the organs of the body that lead to the abnormal functioning of body. (Manzoor&Zakar, 2019) Previous studies examined that as patient's age increase their need of blood also increase and they need more hospitalization, treatment and care. Due to more complications parents have to ban their work activities as a result of which they faces reduced quality of health and life and faces many challenges like economical, psychological and social. (Vizza&Julie, 2018) Though thalassaemia is preventable disorder but it is commonly widespread. In underdeveloped countries, 75% or above patients faced problem of blood of blood insufficiency. (Thalassaemia.org.cy). A study that was conducted in Iran showed that despite the high burden of care there was no social support provided to the thalassaemia patients caregivers due to this problem their burden increased twice. (Mashayekhi, Jozdani, Chamak, &Mehni, 2016) About 1.5 % of the world population or approximately 80 to 90 million suffers from beta thalassaemia. Pakistan is among the countries that are facing highest burden of thalassaemia in the world. According to a report, approximately one hundred thousand or one lac people are experiencing thalassaemia in Pakistan and every year thousand babies are born with this fatal disease. In the recent studies, patient's attitude and information about iron chelation therapy and drugs caused abidance treatment which helps in reducing complications. (Zeydi, Moonaghi, &Heydari, 2017). As Pakistan is developing country so keeping in view the economic condition of people in Pakistan they are suffering from the high economic crisis and psychological distress? Despite of all these difficulties thalassaemia plays a major role in uplifting their complications. Mostly people of rural area in Pakistan have conservative mindsets and they do not cooperate with the patients and their caregivers. People play a very significant role in pushing people towards depression, anxiety and social isolation. The earliest study of quality of life among Malaysian thalassaemia patients diagnosed children from 3 to 18 years old of blood transfusion dependent thalassaemia .They made use of PedsQLGeneric core scales to measure the effect of Thalassaemia on the patients standard of life .(Shafie, Chhabra, Wong, Mohammed, Ibrahim, &Alias, 2020)

SIGNIFICANCE OF THE STUDY

The significance of study is to elaborate the problems faced by thalassemic patient's caregivers. The persons who take care of patients or ill patients are called caregivers. In this study, we discuss the social and psychological problems i.e. stress, fear of death, anxiety, depression, stigmatization, social isolation, and economical problems faced by caregivers. This study aims to seek the attention of Government of Pakistan and elite class towards the hurdles faced by caregivers of thalassemic children so that they

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should formulate strategies and plans for their financial betterment as well as emotional support and counseling. This study portrayed the real image of societal attitude and behavior towards Thalassaemic patients and their caregivers. It also depicted the fear of death which emphasized the importance of life in humans.

OBJECTIVES

- ✚ To determine the life problem of thalassaemia patient's caregivers.
- ✚ To determine the social problems faced by thalassaemia patient's caregivers.
- ✚ To identify the psychological problems of thalassaemia patient's caregivers.

METHODOLOGY

This qualitative study investigates the problems faced by thalassaemic patient's caregivers from Pakistan population. Purposive sampling is extensively used in Qualitative research for getting more extensive information. Participants were selected from Bhakkar, Pakistan. It was conducted from November 2021 to January 2022 at a thalassaemia center, DHQ hospital Bhakkar, Pakistan. Semi structured interviews were conducted for data collection. This study was conducted from seven participants. One grandmother, two fathers and 4 mothers participated in this study. In this article seven case studies were conducted and one is presented completely while remaining six case studies were elaborated through thematic analysis and coding. At first the objective of the study was to explain the problems which are faced by thalassaemic patient's caregivers. The guiding questions were designed to give a structure for discussion and for getting similar data from every participant. On the emerging issues by participants during exploring their experience additional questions were used. Until the data was saturated regular interviews were conducted. All interviews were conducted in Urdu by direct interaction at the most suitable date, time and place (in thalassaemia center in Bhakkar, Pakistan) from participants. All interviews were properly recorded and their duration was lasted from 40 to 60 minutes. Each interview was properly noted/written and read for several times to gain the overall understanding of the content.

FINDINGS OF THE STUDY

Case 1:

Socio demographic Profile of Respondent:

The respondent name was Muhammad touqeer. He was six years old. His father name was Muhammad Hafiz. They were two brothers. He was the elder one. His father was a heart patient. He belonged to a poor family. He lived in a rural area of District Bhakkar. His father was a laborer. His parents were first cousins.

Parents Experiences:

The respondent was diagnosed thalassaemic five to six months ago before that he was a normal healthy child. His parents faced many problems about the disease of the child and remained very depressed due to that fatal disease. They needed blood after every two months. There was no family support either it was financial or blood donation\emotional support. There were some friends who donated them blood or helped them to found blood. They faced blood shortage and stress during the special events like Eid, Moharram, etc. During the Corona Pandemic, they were depressed because nobody was willing for blood donation. There was no special policy or Government support for needy thalassaemic patients. Thalassaemia centre provided them blood just once in a month or two. As the family was poor they were not fully satisfied with the hospital services the reason was that there were certain medical tests and medicines that were not available in hospital and poor parents was not able to afford that expenditures. Even sometimes some tests remained pending because of expensive treatment. Parents were worried about the child's future. The fear of child's death always remained in their minds which made them stressed and depressed. They were also tensed about their child's education. Because of that disease the child left school. As the child was ill family and parents provided him extra care and love. They faced no stigmatization in their life. They were not facing the problem of child's mood swing. The child was also suffering from asthma. Asthma was their inherited disease. Despite of all that difficulties the parents had firm believe in **ALMIGHTYALLAH** that their son will get well soon **INSHA'ALLAH**.

Thematicanalysis:

1. Depression:

Depression is a medical illness/ issue that negatively affect a person's feeling, thinking, actions and behaviors. Depression makes people hopeless and sad and is deeply self damaging. Depressed people are very sensitive. Depression affects each human differently.

"When my child's condition suddenly worsens we fear death because the disease is so life threatening that I feel depressed."
(Participant no1,a 36 year old father)

Parents are very worried about their child's health. Akram told me that when his ill child's condition worsened, he would be in great pain and would have various whispers in his mind as to whether her child would stay with her any longer or not. Loving children is a natural process and there is no substitute for parental love it is the characteristics of human nature that he

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cannot see his loved ones in distress. Parents are the only ones who know what happens to their hurts when they see their child in trouble. And they are always worried about their child's prosperity.

"I have heard that this disease is fatal and doctors also said that a child cannot live beyond 18 years, that is why our night sleep is over"(Participant no,2 a 28 year old mother)

Thalassemia is a very dangerous and deadly disease and even doctors say that a person suffering from this disease can live up to 18 years at most. It was also clear from the parents' impressions and words that with each passing day their child is getting closer to death and When parents can't do anything to save their child, it only adds to their anxiety because it is the biggest pain in the world and there is no greater pain than not doing anything to save their child they are helpless. Poor parents were very worried about their child's safety. And the effect of all of this on their own health was quite visible.

2. Socioeconomic support:

Family support is a social bond in which two or more persons are related to each other by birth, adaption, or by marriage. Family support is necessary in a person's life either its emotional support or financial support. Financial support is essential for the individuals as well as for the smooth running of the family. Due to better financial condition, a person can cope with disease more effectively because he can afford best treatment and medical facilities.

"Our relatives have a good relationship with us but when it comes to helping financially people fall behind" _ (Participant a 65 years old grandmother)

To live a good and happy life one needs social and economic support from his close relatives. Men alone cannot do anything and it depends on others especially when he is in trouble. Thalassaemia is a disease that costs a lot and a person also has to face inconvenience in life. People who have a patient with the disease in their home are not economically helped out by their close relatives like siblings etc. No one cares because according to them this problem is a not of single time and it will last long so they have their own expenditures and in this time of acute inflation they are not able to help them. Furthermore, their impressions and words reflected that their relatives were reluctant to help them financially so that they would not repeatedly demand this help from them and start relying on them.

"How can we expect from others when our close relatives leave us in difficult situations, this pain is worse than death" _ (Participant no, 4 a 30 years old mother)

Hard times are a decisive moments that exposes the traitors hidden in you and your loved ones in an instant. This time decides who is actual your friend or who is just by name but if the friend are left behind then your own close and blood relatives support and encourage you. But if at that time even your own close and blood relatives leave you helpless, and then you have no one to support you. So with whom should a person share his grief in this difficult time and with whom should he seek help? While talking, when a mother suddenly started crying, her tears were reflection that how much grief is hidden inside her because the wounds inflicted by one's loved ones are not healed. They become fistulas and cause pain for the rest of lives.

3. Stigmatization:

When society negatively labels a person, it adversely affects a person social and mental health.

"Now people are getting to know about thalassaemia, but in the past people wouldn't even let their children play with our children lest their children get sick, which made our child feel inferior" _ (Participant no,5 35 years old father)

Earlier people did not have complete knowledge about Thalassaemia , so they considered that a contagious disease and tried to keep their children away from thalassaemic children as much as possible, which had a very bad effect on children's psychological health. At the same time, people began to recognize that thalassaemia is not a contagious disease. It is a good thing that the problems of children and their families have been solved and now they look satisfied because negative attitude causes mental and physical illness in people.

"_Even with this disease more people's words hurt. People blame us that our child is sick because of some of our sins" _ (Participant no,6 a 41 year old mother)

It was clear from the parent's impressions that because of what people were saying, they sometimes felt responsible for the child's illness. Because no matter how hard a person tries, People's words affect him and sometimes they leave a deep impact on the human mind.

According to Islam:

The child cannot be punished for the sins of the parents.

4. Spiritual belief:

As we know, religion provides guidance in every aspect of life. It provides hope and light to disappointed people. It also works like opium for depressed persons.

"Children are very dear to their parents. Even if the child is in pain, they do not get relief. In this disease we are always afraid of the Death of our child but we are Muslims so we are sure in ALLAH that our child will be healed, He can do miracle if He wants." (Participant no 7, a 45 years old mother)

The lives of children with thalassaemia depend on the blood they receive. This is why parents give priority to their sick child over all their children because they are afraid of losing their child. That is why children with thalassaemia are closer

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to their parents. Patients with thalassaemia need blood all the time. Whenever parents turn to their relatives for help for their child, they refuse further which is very painful. When their own people don't support them in difficult time, they have to fight this war alone which is very difficult. The only thing that give them strength is that difficult times is firm belief in ALLAH that He will never leave them alone in difficult times . Their strong belief system helps them cope with every situation bravely and hopefully.

DISCUSSION

This current study showed that Families of the thalassaemic patient had a high level of stress and majority of the families' faced\tolerated high level of caregiver burden. This study showed that the most crucial issue was stigmatization. Mostly people in the society blamed the patient's parents for their child sickness. People believed that thalassaemia was caused by some supernatural force\power or was the result of a punishment given to them by ALLAH. This led to the child and families being criticized by society resulting in social isolation, stress and anxiety.

The current study showed that parents of children suffering from thalassaemia also suffered from stigmatization. Society considered the parents responsible for the miserable condition of their child. People emphasized that parents bad actions were the main reason behind this fatal disease. This stigma pushed people towards ignorance, disappointment, isolation and psychological distress .Due to less social support and stigmatization people became social isolated and quit all the social activities of life because according to them they are not understood by the society. That lack of social and psychological support let them to avoid sharing their problems even with their friends and close family members.(**Pouraboli, Abbaszadeh, Kazemi, & Abedi, 2017**)In this fatal disease social ties and social support can play a very significant role in tackling Thalassaemia because of lack of education and awareness especially in rural communities of Pakistan caregivers of Thalassaemic patients are still facing the issue like stigmatization and social isolation.(**Rashid, Abbasi, &Manzoor, 2020**). The findings of this current study stated that the caregivers of the Thalassaemic patients were suffering through the economic crisis due to lack of money they did not afford some tests of their ill child. Furthermore low economic status aggravated their health problems due to poor nutrition. A study conducted by previous researchers also supported the current findings by stated that financial problems seemed to be a universal cause of suffering and over burden of caregivers with children with that fatal disease thalassaemia, since the disease required prolonged care, treatment and frequent hospitalization. It was the major issue seen especially among parents belonging to lower socio economic group.**Bangkokmediajournal.com** Caregivers admitted that very expensive treatment and unaffordable hospitalization compelled them to quit their treatment which imposed very severe and negative ramifications on their health.(**Soleimani, Badiee, &Arian, 2021**)Among caregivers especially mothers faced many psychological, mental and health issues such as anxiety, depression, sleep sickness, body pain, sugar and cardiac problems. They also faced some Social and economical issues. According to mothers these all disease were due to tension about their child health we were constantly thinking about our child safety and also we did not have enough any time to take care of themselves. Due to heavily expenditures on child health we can't afford the good nutrition and health care. Awareness, knowledge and counseling are some measures that can lessen the problems of mothers. Previous literature also supported the current study by elaborating that Caregivers suffered a lot due to Thalassaemia a study which was conducted by the Shahraki,. et Al 2017 showed psychological distress among mothers if Thalassaemic patients. The main symptom noticed was stressful life of mothers and their insomnia because Thalassaemia had changed their quality of life.(**Vahed, Firouzkouhi, Mohammed, &Ghalgaie, 2017**)In recent study it was found that thalassaemic patient's caregivers faced the problem of blood donors during special events especially during the COVID pandemic. Previous Literature also supported the current study by emphasizing thatduring pandemic situation majority of Thalassaemic patient caregivers faced the problems of blood transfusion because the blood bank suffered from acute shortage of blood donors. This recent study examined that there was no social support provided to the worried and depressed caregivers of the Thalassaemic patients. Apart from financial crisis caregivers also suffered a lot from psychological stress because they had no support from their friends and family financially that add more to their tensions. A study that was conducted in Iran showed that despite the high burden of care there was no social support provided to the thalassaemia patient's caregivers due to this problem their burden increased twice. (**Mashayekhi, Jozdani, Chamak, &Mehni, 2016**)The current study showed that people were a firm Believer of ALLAH. They had a strong faith in ALLAH. They felt comfort by sharing their worries to ALLAH by praying and by reciting Holy Quran. They believed that thalassaemia was just their test of patience from ALLAH. The previous study, Thalassaemia patient's caregivers believed that disease as a blessing of God for them. They seek comfort by recitation of the Holy Quran, meditation and prayers because they believed that these practices brought them about increased self care and stress reduction. (**Waheed F.,2015**)&(Zahra, Hasan, &Adis, 2020)

CONCLUSION

Finding of the recent study was that Thalassaemia not only majorly influences the patient but also the caregivers in many aspects such as economical crisis, psychological distress and social life. This study focused/emphasized on the counseling of psychological relief of caregivers. This study also demonstrated the association between the lack of blood donors and caregivers stress. This study depicted that how much role a society played in lessening or increasing the caregivers stress level. This finding portrayed that how

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thalassemia adds up to the caregiver's economical burden. This research also showed the psychosomatic illness among mothers of the Thalassemia patients because of the fear of death of their children. This study explored the power of strong belief system.

LIMITATIONS

This study was conducted in the DHQ (District Head quarter Bhakkar) Thalassemia center Bhakkar the respondents were from rural areas and mostly were uneducated they can't properly express their views. If the study was conducted in the urban areas then results can be changed. Also Researchers have limited budget if the data was taken from Sundas foundation Lahore then different results can be obtained. Possible limitations of the study include less generalizability due to small sample size furthermore the research was qualitative which also included the human error like biasness. Many researchers analyzed the data individually which can leads towards biasness.

RECOMMENDATIONS

- ✓ It is recommended that Government should formulate a policy in which financial support shall be provided to the families.
- ✓ Media should play a significant role to sensitize the community to help the families of the Thalassemic children by donating blood because this disease required regular blood transfusion.
- ✓ Furthermore, counseling centers should be established for the Thalassemic patient's caregivers to lessen their psychological distress.
- ✓ Another challenge faced by daily wages workers was that the tenant fired them from work due to abundant absence at workplace. In this regard, it is suggested that Govt. should formulate such policies and strategies which facilitates the Thalassemic patient caregivers by providing them financial aid and blood donors.
- ✓ Government should also establish blood banks in the District Bhakkar for the provision of immediate help to the Thalassemia patients and also for the emergency situations.
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