PAKISTAN ISLAMICUS
(An International Journal of Islamic and Social Sciences)
Volume:04, Issue:01, 2024, Pages:54-62
Journal Website: https://pakistanislamicus.com/index.php/home
Publisher Website: https://www.mircpk.net

MOTHERS' EXPERIENCES REGARDING THEIR CHILDREN WITH THALASSEMIA MAJOR IN MULTAN, PAKISTAN

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HEC "Y" Category
HJRS HEC Journal Recognition System

INTRODUCTION

ARTICLE INFO

Article History:

Received: January 03, 2024
Revised: February 12, 2024
Accepted: February 14, 2024
Available Online: February 16, 2024

Keywords:

Lived Experiences
Mothers
Thalassemia
Major Children
Psychological

Funding:

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

ABSTRACT

Thalassemia is a genetic blood disease which passes from parents to their kids. It is a main health disorder in Pakistan and South Asian nations. About 6-8 % of residents of Pakistan are thalassemia carrier's traits. The patients of this disease need medicines and ordered blood transfusions throughout their whole lives, but that process strongly impacts the patients and their families, mainly the mothers of the patients disturbed a lot. The main objectives of this research were to explore the issues of mothers having thalassemia major children and to dig out the effects of Thalassemia major on the mothers of the patients. This qualitative study explored the lived experiences of 20 mothers of children with thalassemia major by conducting semi-structured interviews. The present study was conducted at the Thalassemia Centre of the Children's Hospital & the Institute of Child Health Multan, Pakistan, and data were analysed by using content analysis. Ethical approval was obtained from the ethics committee of the Hospital for the data collection process. It was found that thalassemia major disturbs the well-being of the mother's life, and very few mothers had adequate knowledge about genetic disorders. The majority of the mothers were strained due to their children's sickness and regular transfusions of blood. They were afraid about their child's current status and their upcoming. They were anxious about the child's presence, learning and hitches. The majority of the mothers identified the effects of illness on their children's school presence. The study suggested that healthcare experts, including social workers, should teach and apprise the mothers obviously about the thalassemia disease, its management, and deterrence. Civic support agendas must be established officially to support thalassemia patients and their caregivers, especially their mothers.

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Thalassemia is a genetic blood disorder and a major public health problem in South Asia, especially in Pakistan. It is estimated that about 1.5 percent of the world's population is thalassemia minor (Karim,

Ismail, Hasan, Shekhar, 2016). It is estimated that about 80% of thalassemia patients are identified in developing countries (Suryani, 2020). About 6 to 8 % of the Pakistani population is suffering from the disease of thalassemia minor. Every year, more than 5,000 thalassemia major children are born, which depend on regular blood transfusions. Thalassemia patients require care throughout their whole lives. In addition, they required consistent blood transfusion and iron chelation healing. Most of the thalassemia major patients present with exhaustion and pallor depending on the degree of anaemia. (Cazzola et al., 1995, 1997; Cappellini et al., 2000). Thalassemia patients have enlarged spleens and livers, abdominal dropsy, infections, irregular heartbeat or heart failure, and short lifetime (Anie & Massaglia, 2001; Goldbeck, Baving, & Kohne, 2000; Louthrenoo et al., 2000). Despite the improvement in the control of thalassemia major patients, those living in emerging countries did not obtain the quality of treatment (Siddiqui, Ishtiaq, Sajid, & Sajid, 2014).

REVIEW OF LITERATURE

Furthermore, thalassemia disease shakes patients and their families mentally, for illustration with the feeling of grief, forfeiture and denunciation (Aydin, Yaprak, Akarsu, Okten, & Ulgen, 1997; Politis, 1998). Empirical findings and previous studies reported that thalassemia major as a chronic disease has a negative impact on the quality of life of mothers. (Caro et al., 2002; Goldbeck et al., 2000; Zahed et al., 2002). Karakul, Oymak, & Karapinar 2022; Hussain et al., 2021; Zulfiqar et al., 2021) reported that parents face more difficulty after identification of the chronic disease in their child. Abedi et al. (2020) highlighted that thalassemia adversely affected the psychological, physical, social and economic status of the parents whose children were facing thalassemia disease.

Studies reported that mothers played a very significant role in caring for their thalassemia major children and spent much time with them (Krepia et al., 2006; Mashayekhi et al., 2016). The majority of the respondents were usually busy with the caring process of their kids during the long periods of thalassemia major treatment, which caused a social, psychological, physical and financial burden on them (Heidari & Ahmadi, 2020). The numerous types of tensions faced by mothers due to their Thalassemic child affect their lives negatively. Furthermore, it was highlighted by (Punaglom, Kongvattananon & Somprasert, 2019) that thalassemia is a major disease that affects the well-being of patients and their mothers. This study is conducted to explore the issues of mothers having thalassemia major children and to dig out the effects of Thalassemia major on the mothers of the patients. The reason behind this qualitative study was to provide a deeper understanding of the experiences of mothers having thalassemia major children.

RESEARCH METHODOLOGY

The current study was done at the Thalassemia Centre of the Children's Hospital & the Institute of Child Health Multan. A Qualitative exploratory research design was explited to explore the lived experiences of mothers of thalassemia major children. The present study found the impact of thalassemia major on caregiver mothers, how they perceived, and how they felt and thought about their lives. The present study was qualitative because qualitative research is useful when the researcher needs to collect in-depth information about the problem, setting, and situation. A total number of 20 mothers with thalassemia

major children who were blood-dependent participated in the present study. All the mothers were aged between 25 to 50 years. The respondents were mostly domestic wives, and the ages of their kids ranged between 02 to ten years when diagnosed with thalassemia major. The mothers who had cared for thalassemia major children in the last year were included in this study. The data was gathered through in-depth interviews with mothers of thalassemia major children. Before data collection, informed consent was taken from all the participating mothers. All the respondents were primary caregivers of their thalassemia major child. In-depth interviews took place in a relaxed setting selected by the respondents. Before data collection, ethical consent was obtained from the Ethical Committee of the Hospital. The interview guide was prepared and approved by two clinical haematologists with more than 10 years of experience in treating thalassemia major disease. The questions regarded the experiences of mothers having a thalassemia major child, their feelings about thalassemia major children, relevant information they received about thalassemia child, how the information was helpful, their experiences since the diagnosis of the child, problems in caring for thalassemia children. Prior permission was given from all the mothers to record, transcribe, and translate the interviews. Codes were given to the respondents to ensure confidentiality and anonymity. To get the complete standpoint of the respondents, each record was read appropriately and shortened by the investigator.

RESULTS

All the respondents reported that their lives were significantly affected due to thalassemia major disease of their children. A total number of 6 themes were identified, i.e. (i) Knowledge about Thalassemia, (ii) Psychosocial Glitches, (iii) Social Support, (iv) Financial Constraints, (v) Health Care Services, (vi) Future Concerns.

Knowledge About Thalassemia

The majority of the respondents reported that they had been unaware of the symptoms of thalassemia. After the diagnosis, they received information from staff nurses, which seems insufficient knowledge about thalassemia disease.

The majority of mothers expressed that they had very low-level knowledge of thalassemia disease, treatment, prevention, and control. Mothers were not familiar with premarital screening and prenatal diagnosis. When mothers were examined and given confirmation of their thalassemia carrier status, it was excessively late for prenatal identification. The majority of the mothers were referred for genetic counseling after the birth of a thalassemia major child, which is very alarming. One of the mothers said that her child's colour was pale, and she took him to a surgeon, who gave him some medications, but he could not recover. She visited another doctor, and he advised some medical tests. After investigation, he diagnosed her child as suffering from thalassemia major, and he would require regular blood. Some mothers shared that they were confused about their understanding of genetic counselling. Most of the mothers reported that they had insufficient knowledge regarding genetic counselling, premarital screening, and prenatal diagnosis.

Psychological Glitches

The results showed that the majority of the mothers face mental issues due to the enduring disease faced by their kids. One of the mothers was asked to share her feelings about her thalassemia major child as a caregiver. She said that due to her child, she faced many psychosocial problems because the thalassemia child needed regular blood transfusions and medicines, which are very costly. She reported that her child's chronic sickness was related to high psychosocial problems. She expressed her experiences that due to her child's appearance, educational difficulties, school absenteeism, expensive treatment, and repeated blood transfusions, she faced psychosocial problems. Her child could not play outside with other children, and if she let him go and play, then he got a fever and turned pale. The mothers realised that their children's illness affects school attendance". Another mother shared that her child remained absent due to his poor health, and teachers said if he remained absent, he would not be able to take exams with his class. Sometimes, he attended 3 to 4 days a week. Some mothers were worried about the possibility of removing splenectomy in the coming. They desired to know whether their kids would be well and grow like the other kids after the operation or not. One of the mothers said:

> "She was depressed after the identification of the disease in her child. In the beginning, the period of blood transformation was three to four months. It was severe when doctors suggested blood transformation every month. She further said it was a challenge for her and her family to provide the required blood for their child. She said that she became a psychic patient after her child's disease."

Social Support

The majority of the respondents were depressed due to their children's disease. The researcher asked them about the social support received by them regarding the blood transformation of their child. It was found that the majority of the respondents did not receive help from any donor organisations, but those who received help were thankful for the process of blood transformation. One of the respondents shared her experience regarding the valuable role played by different organisations in the process of blood transformation of her child. She said that:

> "There were different organisations that helped them frequently for blood donors, such as the Fatimid Foundation and Thalassemia Centre, the Children's' Hospital, and the Institute of Child Health Multan. Still, sometimes, they faced the issue due to the non-availability of blood. She appreciated the role of these organisations for the welfare of thalassemic patients."

The majority of the respondents faced different types of social issues, such as neglect and social distance by their close friends or relatives after identification of thalassemia in their children. One of the mothers said that:

> "After the identification of the chronic disease in their child, people started to ignore them, and they felt themselves as alone and isolated."

Financial Constraints

During the study, it was found that the majority of the mothers expressed that they were anxious about their kids' monthly blood transfusions, medicines, and social changes. Furthermore, the majority of the mothers shared that thalassemia major treatment was very costly, and their child needed regular medicines daily. The other difficulty they shared was conveyance and living charges during their kids' admission to the hospital. One of the mothers expressed that:

> "She was the focal earner of the household, but when her child was ill, she did not work more, but treatment and transportation expenses were too high. Her focus was for her child to become stable, and she should go back to work. Sometimes, her child needed a check-up twice a month, and sometimes, she did not have money. If we did not arrange money, her child would become more serious, and it was not good for her."

Another mother said her feelings about transportation:

> "Every month, they have to travel to the thalassemia centre for chelation therapy and blood transfusion. It is very difficult to bring my child and blood donor and pay all the expenses."

Health Care Services

Most of the respondents were gratified with the health care facilities provided by the hospitals mentioned above, but on the other hand, some mothers told their worst proficiencies. One of the mothers shared that due to overburden, they could not receive blood and medicines. Some mothers reported that they came to the hospital at their own expense, and when doctors asked them to purchase medicines and arrange blood and blood bags and syringes, it created too much stress on them.

Most of the participants used two types of public health facility institutions: the provincial and the community hospitals. The respondents articulated their approaches to healthcare services at the community hospital level, particularly regarding blood transfusion therapy. They stated that approaching the hospital was time-consuming and tedious. They claimed the insufficient quality of services in public hospitals. They were worried about the cash that they needed to take their patients for treatment. Even though cures were free of cost, they still could not afford the transportation charges. One of the mothers also spoke about the cost of transportation:

> "The toughest part was the cost of transport in the treatment process of their child. She further said that she has to miss work on the appointment day of her child at the hospital. She had to see the doctor at the provincial clinic every month."

Another respondent said that the medical services at the provincial hospital were not up to the mark. She further said:

> "They say that now we have the 30-baht health card that we could use in the hospital to get yourself treated. If we have this card, we will not have to pay for treatments. Sometimes, we bring him here to the clinic first. If we go to the

> hospital, it's a waste of time. It takes time for the doctors and nurses to prepare medicines for everyone at the hospital. Doctors know that this is thalassemia, but all they do is give us medicines and blood tests. There are too many procedures here at the hospital. After surgery, they will give us medicines and blood tests. We think it is better to go to the local clinic than to the big hospital. It is a waste of time to go there."

Future Concerns

The researcher asked about the prospect of their children. The majority of the respondents were disappointed regarding their children's future but also hopeful for their recovery. They were waiting for the new treatment for the speedy recovery of their children so that their children would have healthy life in the future. One of the mothers said:

> "I want to see my child healthy, happy, get an education, do a job, have a marriage, and spend a very successful life in society, but with all these ambitions, I am frightened as well due to the chronic disease faced by my child."

Another mother said:

> "I am afraid of my child because the life expectancy of the children suffering from thalassemia is not satisfactory. I and my family members are always worried about the future uncertainty of our child."

DISCUSSION

There is a strong relationship between a healthy life and the well-being of the individual. The health of the person has a vital role in the functionality of the individual life. The individual who was suffering from thalassemia not only faced problems in completing his daily life activities but actually burdened' his family as well. The current study was qualitative in nature. The researcher selected 20 mothers of children with thalassemia major. The main objectives of the research were to find out the lived experiences of mothers having thalassemia major children. The results showed that the majority of the participants belonged to poor socio-economic backgrounds. The majority of the respondents had inadequate knowledge about thalassemia major, its treatment, premarital screening, prenatal diagnosis, prevention and control.

The majority of the respondents faced a lot of psychological problems due to their child's disease. Previous researchers also highlighted psychological problems such as the tension about the physical appearance of the child, illness, and the treatment of the child confronted by the families who have thalassemia child. The future of the child also tickles the respondents frequently. They families suffered a lot due the social stigmatisation related with the child health (Tedsiri, 1994).

The process of blood arrangement and transformation had badly affected the psychological mother's well-being. It was found that children's personal disturbance, pain, and future uncertainty strongly hit the psychological well-being of the mothers. It was found that the majority of the respondents did not receive help from any donor societies, but those who received help were thankful for the process of blood

transformation. On the other side, it was also found that the patients of thalassemia and their families also faced social issues such as ignoring social space by their friends or lineages after the diagnosis of thalassemia in their children. The study found that the majority of the respondents faced financial constraints in the monthly blood transfusions and medicines.

It was found that the majority of the mothers were gratified with the healthcare services provided by the thalassemia Centers. Still, some respondents shared their poorer experiences regarding a doctor's conduct, unsuitability of healthcare services, and lack of medicines. The respondents highlighted their worries about purchasing costly medicines. They demanded a free of cost treatment of the thalassemia from the government. It was found that the majority of the respondents were disappointed about their children's future but also hopeful for their recovery. They were waiting for the new treatment for the speedy recovery of their children so that their children might have a healthy life in future (Prasomsuk et al., 2006).

Thalassemia was a problem to the mothers because it destructively impacted their children's excellence in life; for example, they had common absences from their schools, uneasiness while receiving blood transfusions, corporeal limitations, and other problems resulting from the disease itself. The respondents also felt the sway on their financial status, livelihood, time for childrearing, and general meaning. The necessity for psychosocial provision for these mothers was domineering, and it is necessary to deliver more inclusive management of the kid with thalassemia that contains psychosocial and economic provision from self-help groups in the public.

These findings can help all healthcare providers better understand the process of how they should conduct thalassemic management and better understand the reasons that should guide this management. The method of providing mothers with information about thalassemia should be adjusted to be relevant to the social context in each region, especially regarding education programs and decision-making for their children's educational programs. Empowering these mothers may directly enhance their sense of mastery and control over the condition.

RECOMMENDATIONS

Based on the findings, it is recommended that the government may have to facilitate the thalassemic children and their families as well. The concerned departments may have to provide socio-psychological, financial, and even blood transfusions to the thalassemic children and facilitate their families as well.

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