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Problems Faced by Parents of Thalassemia Children Aftermath of the Covid-19 in South Punjab

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ABSTRACT

The primary objective of this research study was to investigate the challenges encountered by parents of children with thalassemia in South Punjab in the aftermath of the COVID-19 pandemic. Beyond being a health crisis, the COVID-19 pandemic also had significant economic repercussions. Consequently, this study aimed to examine the factors contributing to unfavorable outcomes and the strategies employed to mitigate them. Qualitative data served as the foundation for this research, with the study's focus centered on parents of thalassemia patients residing in district Bhakkar. Respondents were chosen through convenient sampling techniques, resulting in a sample size of 17 participants, 15 of whom were parents of thalassemia patients from district Bhakkar. In-depth interviews were conducted, facilitated by an interview guide, which encompassed two focus group discussions and interviews with two thalassemia administrators. Following data collection, Nvivo 10 was employed for data analysis. The findings of this study shed light on the social, economic, and management challenges faced by parents of thalassemia patients due to the COVID-19 lockdown measures. Based on these findings, it is recommended that both government and civil society organizations take proactive measures, such as establishing blood banks, to ensure the timely transfusion of blood to individuals with thalassemia.

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Introduction

The terms "Thalassa" (meaning sea) and "haima" (meaning blood) have their origins in Greek etymology, and the nomenclature of various thalassemia syndromes is based on the specific globin chain that is affected or the abnormal hemoglobin involved. Thalassemia is a hereditary anemia resulting from abnormalities in hemoglobin (Hb) synthesis. Anemia in individuals with thalassemia is a consequence of both hemolysis and inefficient erythropoiesis. This condition, characterized by a reduction in the production of -globin chains, is associated with substantial morbidity and mortality across multiple organ systems. Despite the identification of over 300 -thalassemia alleles, a mere handful, approximately 40, account for more than 90% of all -thalassemia cases worldwide. Most instances of -thalassemia arise from point mutations, with deletions being a rare occurrence. Traditionally, patients with -thalassemia have been classified as having minor, major, or intermediate forms based on the imbalance in -globin or -globin chains, the severity of anemia, and their clinical presentation (Monaco et al., 2023).

Hemoglobinopathies, a group of disorders characterized by structural variations in hemoglobin, encompass conditions like sickle cell anemia, where the structure of the hemoglobin molecule is altered, and thalassemia, where the production of hemoglobin (either alpha or beta globin chains) is hindered. In both alpha and beta thalassemia, the severity of thalassemia symptoms escalates as more globin chains become affected. In severe cases, iron chelation therapy and transfusion dependence become necessary for survival (Amanda et al., 2023). Thalassemia presents a significant healthcare challenge globally, with diverse forms and varying levels of severity. Transfusion-dependent thalassemia (TDT) and non-transfusion-dependent thalassemia (NTDT) both demand careful management and pose distinct clinical complications. NTDT individuals, in particular, face the risk of bacterial infections, possibly aggravated by factors such as iron overload, stress on erythropoiesis, and adrenal insufficiency (Motta et al., 2020).

The emergence of the COVID-19 pandemic has further exacerbated the challenges faced by thalassemia patients. The pandemic has resulted in a substantial reduction in blood donations, which could potentially impact thalassemic individuals who rely on frequent blood transfusions for their survival. While packed cell therapy offers some relief, any decrease in hemoglobin concentration among thalassemic patients may have far-reaching consequences for their overall health (Hashemieh & Shirvani, 2021). The World Health Organization (WHO) has designated COVID-19 as a global pandemic, and its rapid human-to-human transmission, along with the high morbidity and mortality associated with the disease, has created unprecedented challenges for global healthcare systems. The closure of numerous blood donation facilities, coupled with a decline in donors due to social isolation and illness, has strained the supply of essential resources such as donor blood. Despite these challenges, public health efforts have been focused on managing and mitigating the impact of the pandemic. In certain regions, the demand for critical resources like donor blood has outpaced their availability (Baron, 2020).

2.0 Literature Review

The current research focuses on thalassemia management, including public perceptions of thalassemia diagnosis, treatment, therapy, and preventative measures. The study that follows

examines the opinions and experiences of parents of thalassemia patients regarding thalassemia management. People should be made aware of the significance of lowering the chance of acquiring a chronic condition, even if the study's primary objective was to examine parental awareness of thalassemia prevention. According to Ahmed (2019), a person who feels they are a thalassemia carrier does not lead a regular life. Blood transfusions are a crucial component of healthcare (55.8% vs. 72.6% CR), and not understanding them could result in serious management errors. Significant reactions may happen when the blood transfusion operation is being performed. If you don't know this, it might be detrimental. The delay in diagnosis is brought on by a lack of awareness that thalassemia may be identified with a blood test. If parents are unaware that illness can be prevented, they will never agree to premarital counseling, prenatal testing, or other preventive measures.

Heidari and Ali (2020) conclude that patients with thalassemia must frequently inject blood and require chelating therapy. Like any other chronic illness, thalassemia affects all facets of a person's life, and despite therapy, the patient still deals with a variety of physical and psychological problems. Families have a wide range of psychological problems as a result of the chronic nature of thalassemia in children. Numerous pressures that can have a negative effect on their quality of life are experienced by families of thalassemia patients. Examples of these conflicts include disappointment, insecurity, worry, sadness, and issues with school, work, and treatment, as well as problems with welfare, culture, and families. As a result, the patient and family both need quality treatment.

Ahmed (2021). It was found that 2,000 children with thalassemia live in the Baluchistan province of Pakistan. These kids require regular blood transfusions, which puts them at a high risk for transfusion-transmitted illnesses (TTIs). We looked into how common TTIs were among these individuals who had had many transfusions in an area where WHO blood safety standards are not consistently followed. 400 children (mean age 7.7–4.70 years) getting thalassemia treatment at two Baluchistan thalassemia treatment facilities had TTIs found in their sera. Only two of the 72 people who tested positive for the anti-hepatitis C virus (HCV) and 11 (2.8%) of the 72 who tested positive for the hepatitis B surface antigen also tested positive for the other virus.

Cerami et al. (2021) carried out a cross-sectional study on the impact of the COVID-19 pandemic's unpredictable crisis span on the psychosocial dimensions of beta-thalassemia patients and found that patients had higher anxiety levels and a predominant transcendent coping profile to combat social isolation and habit change, which are particularly harmful in patients with insubstantial thalassemia. Socio-economic and management problems of parents with thalassemia children

The social issues that parents encounter as a result of their children's thalassemia are the subject of the current research. Social challenges in thalassemia that were related to evaluating quality of life, such as hypertension, pain management, and exhaustion, as well as depression, were some of the main study components. Examples of quality of life include sleep disruptions, emotional instability such as fury, sorrow, disappointment, and despair, a troublesome sexual life, and having to deal with excruciating pain. The pre-existing study would concentrate on

thalassemia and its effect on social problems in thalassemia patients and their families. As a result, experiencing social challenges as the parent of a thalassemia child was a significant goal of the study.

(Shafique et al., 2022). All costs spent during disease diagnosis, treatment, and therapy are included in the financial aspect of thalassemia cost management. The earlier research gave a more thorough explanation of how thalassemia affects finances and how much financial support affects life. Treatment for thalassemia involves ongoing medical care that a person from a middle-class family in our culture cannot afford, including therapy, blood transfusions, bone marrow transplants, doctor consultation fees, lab results, and other expenses.

Punaglom (February 2019) stated that because thalassemia requires ongoing care and therapy as well as numerous hospitalizations, the financial struggles seemed to be a regular source of anguish for parents of children who had the condition. Particularly among parents from lower socioeconomic levels, it was the most common problem. This demonstrates the value of financial aid in helping parents manage the stress of raising their children and improving the standard of care and quality of life for both the parents and their kids.

Zafari *et al.* (2020) concluded that 499 patients with sickle cell disease and B-thal hemoglobinopathies participated. Only 13 cases have COVID-19 verification. Patients of all ages were shown to be contagious for COVID-19. Clinical signs of this illness include mild to severe pneumonia and respiratory failure. A higher percentage of people over 65 were hospitalized. Patients with chronic conditions such as transfusion-related problems, heart failure, pulmonary hypertension, and diabetes who have thalassemia are susceptible to COVID-19.

Jyoti and Babita (2022) revealed that the majority of parents said that because of lockdown, they had to manage their finances and even take care of their homes' basic requirements. These results corroborated Aditi Kumar's (2021)11 report that iron chelation therapy patients would find it challenging to obtain the medications during a lockdown. Since they could not otherwise afford them, many low-income patients relied on the civil hospital to provide them with their medications. When that supply ran out, many of them were compelled to stop taking the medications.

Yousuf R et al. (2022) declare that even though they were said to have received support, a related study conducted in Athens revealed moms of thalassemia patients were worried about psychological suffering and death fright and had problems managing their emotions. Thalassemia management requires social support for the patient and parents. Respect for the individual and encouraging words from family, friends, and the community form the cornerstone of this assistance. Patients and their families experience severe psychosocial pressures when there is a lack of social support. To combat the sickness and lift the burden, assistance from family, friends, the community, and medical experts is crucial.

Manzoor *et al.* (2019) explained that parents' knowledge of the availability of prenatal and premarital screening services was cross-tabulated with sociodemographic parameters. It was shown that there was no significant relationship between the participant's age group and their knowledge about screening services. There was a considerable disparity in awareness between the two genders when it came to premarital screening. In terms of detecting the thalassemia trait in the

premarital phase, females had less knowledge than males. The understanding of how to provide screening services was significantly related to educational status. People in the group who were less informed about prenatal screening and premarital screening were unaware of screening.

Al-Riyami and Daar (2020) In the early treatment of BTM patients in the middle of the 20th century (due to severe anemia), growth retardation and/or increased symptoms of inefficient erythropoiesis (e.g., skeletal abnormalities, massive splenomegaly) and heart failure have been recorded. It will be important to find out if people with SCD experience an increase in the rate of recurrent strokes. Additionally, it will be necessary to look into how the current situation is affecting this group of patients' quality of life due to difficulties getting to hospitals during a lockdown, difficulties getting enough blood to achieve target Hb or target HbS, and concerns about catching SARS-CoV-2 during hospital stays.

Esmaeilzadeh (2021) illuminated that in this study, based on Altman's nomogram for determining sample size in the graphical technique and the number of independent variables, the number of samples required to estimate expenses was calculated to be at least 170 people. As a result, 200 individuals were chosen at random, and 198 patients with sufficient awareness and consent were included in the study. To estimate expenses, the bottom-up method and the prevalence-based approach were utilized. Iron chelation therapy, blood transfusions, doctor visits, drugs, laboratory testing, and hospitalization expenditures are all examples of direct treatment costs. Interviews with patients, their family members, and physician tariffs, as well as a review of the patients' medical records and health insurance information, were used to calculate these expenses.

3.0 Methodology

An exploratory research design was employed to investigate the experiences of parents of thalassemia patients in the context of the COVID-19 pandemic. Thematic analysis was conducted to gain a deeper understanding of these experiences. The study was conducted in various districts within South Punjab. A purposeful sampling strategy was utilized, which involved selecting two administrators from thalassemia center management and 17 parents of children with thalassemia from thalassemia care centers, resulting in a total sample size of 19 respondents.

Fifteen parents of children with thalassemia who were actively involved in their child's therapy were interviewed using a structured interview guide. Additionally, two executives from thalassemia management were interviewed. Open-ended questions were posed to collect information. Verbatim transcriptions of the interview data were created and rigorously reviewed during the analysis process. The qualitative data analysis was conducted using the NVivo 10 software package developed by QSR International. The software facilitated the organization of data into nodes and topics, enabling the development of a comprehensive coding framework.

In the analysis, the terms’ "themes" and "nodes" (used interchangeably) were accurately identified and coded within the Nodes tab of NVivo, with specific attention to the demographic profiles of the respondents. Several analytical techniques were applied:

- Negative case analysis was conducted to delve deeply into any instances

where respondents reported contrary experiences or perspectives.

- Cluster analysis involved categorizing similar words and concepts, with these categories subsequently serving as a basis for comparative analysis.
- Contextualizing strategies were employed to interpret narrative data within the broader context of the entire text, focusing on the interconnectedness of statements.
- Similarity vs. contrast analysis was carried out using various graphical representations and charts to highlight patterns and differences in the data.

4.0 Results

The respondents' various traits included a number of them. To protect their identities, the respondents have been given pseudonyms: R01, R02, R03, R04, and R05; and for the three participants in the focus groups, P01, P02, P03, P04, P05, and P06. Additionally, two key informant interviews with thalassemia center management were conducted. The jobs of each of the respondents varied. There were several respondents from the private sector. Eight males (the father of the kid with thalassemia) and nine females (the mothers) out of the 17 parents were interviewed, and two respondents worked in thalassemia management. Most parents work daily wedges; however, others work in the public sector. Their monthly salary ranged from 8,000 to 20,000.

Thematic Analysis

Three overarching themes have been identified in this study:

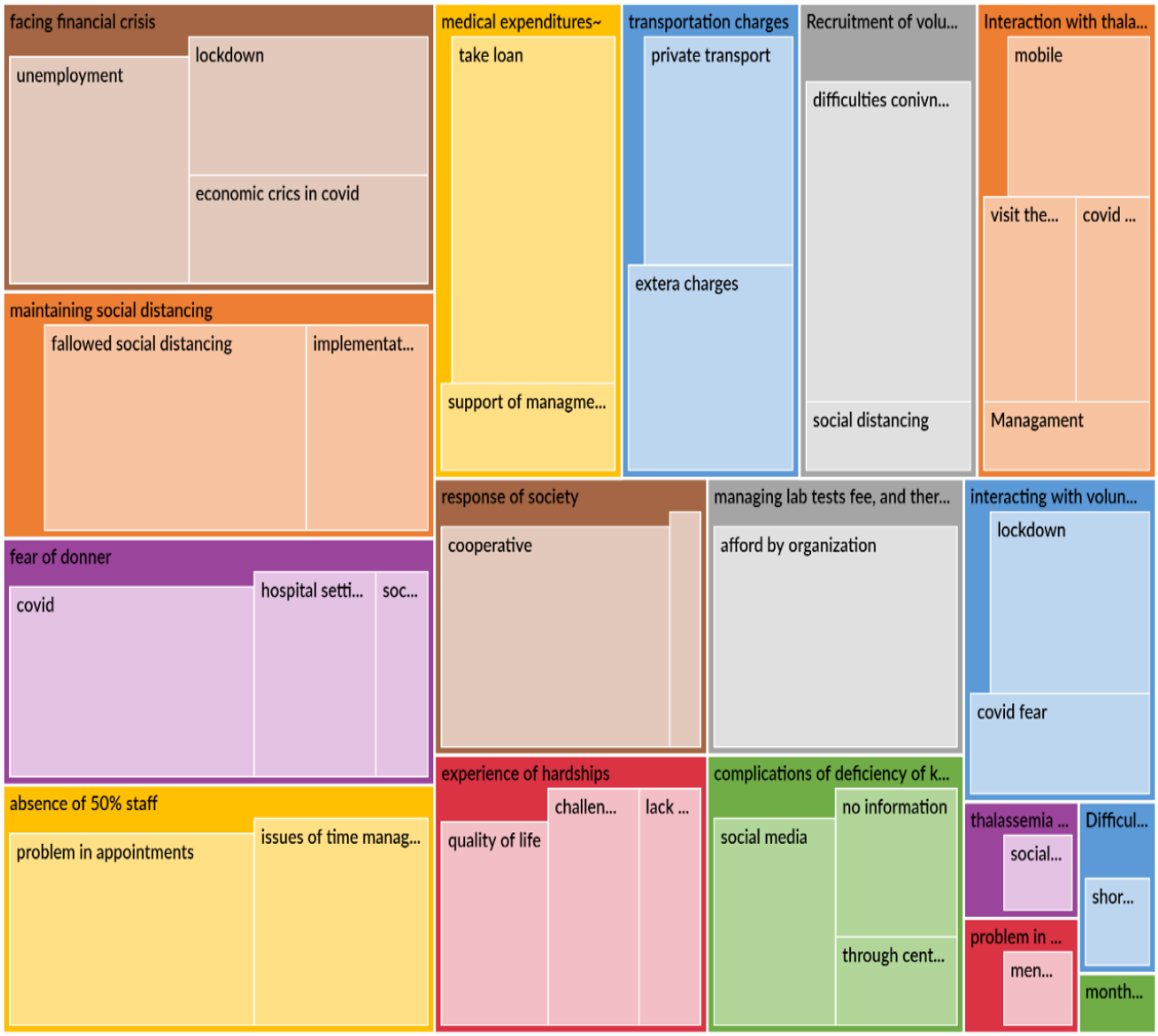
1. **Social Problems Faced by Parents of Thalassemia Afflicted Children:** This theme centers on the challenges and difficulties encountered by parents in the care and support of their children with thalassemia.
2. **Economic Challenges Encountered by Parents of Thalassemia Children During the COVID-19 Pandemic:** The second theme explores the financial hardships experienced by parents of thalassemia children amid the COVID-19 crisis, which has added an extra layer of economic strain.
3. **Issues Pertaining to the Administration of Thalassemia Centers:** This theme encompasses a variety of subtopics, including communication and interaction within the family and social support networks, the availability of transportation for accessing healthcare services, financial crises related to treatment expenditures, management challenges during the COVID-19 pandemic, and the awareness levels regarding thalassemia among affected families.

It is important to note that these themes underwent a rigorous review process involving two independent researchers to reduce potential bias. While there may be variations in the terminology used to describe these themes, the underlying content and context remain consistent. Each theme

is accompanied by a detailed description of its sources and references. For instance, although the terms "problems supplying the blood chain" and "problems collecting blood" may be used interchangeably, they have been treated as distinct concepts in this analysis.

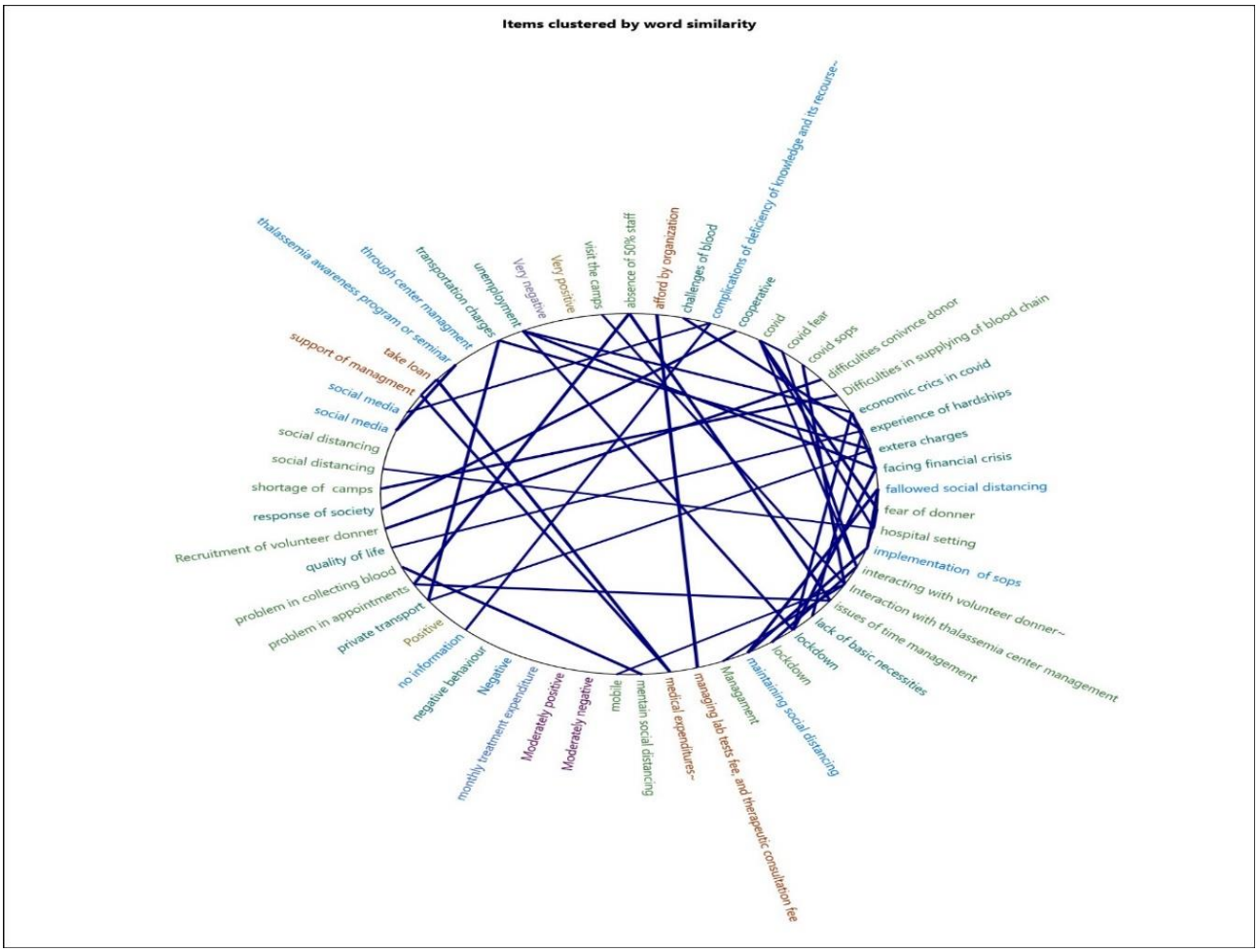
Similarity vs. Contrast Analysis

To compare and contrast various themes and codes, a tree map, a graphical depiction of themes and coding against each theme, was developed. A series of rectangles with different widths serve as a tree map's representation of hierarchical data. The number of code references for each theme on the page is indicated by the size of the rectangles. The number of nodes coding the source is indicated by the color of the rectangles.



The extensive range of outcomes indicates that a predominant portion of the references within the dataset is grappling with financial hardships while caring for children with thalassemia during the COVID-19 pandemic. Economic downturn, unemployment, and the lockdown measures imposed due to COVID-19 emerge as substantial themes in the dataset. Another noteworthy concern highlighted by numerous comments pertains to the insufficient staffing levels at thalassemia centers during the COVID-19 crisis. A majority of the instances cited relate to issues involving scheduling and time management. The issue of social isolation is also underscored in authoritative sources, with particular emphasis on the implementation of Standard Operating Procedures (SOPs) and the subsequent social distancing measures. Medical expenses continue to be a recurring theme, with 20 references once again emphasizing the burden of medical bills. The most frequently mentioned example pertains to the provision of management assistance, which aids individuals in obtaining their required medications. "Take loan," denoting the practice of borrowing medications from sources other than the thalassemia center's dispensary, represents the second prevalent topic.

Circle Graph of Theme Clustered by words Similarity



Display themes in an organized manner with connections based on word similarity. According to these findings, problems that are similar have been put together in the Covid 19 report, Problems Faced by Parents of Thalassemia Children. To ascertain how similar or distinct a theme's coding is, cluster analysis was performed. A point on the circle serves as the representation for each item in a circle graph. Linking lines of varying colors and thicknesses communicate thematic similarities. Red lines denote dissimilarity, whereas blue lines indicate similarity. The similarities or differences between the two become more obvious as the thickness increases.

Social problems of the parents with thalassemia children

Parents expressed tremendous concern regarding their inability to communicate with the thalassemia management because to the COVID shutdown when it comes to the challenges, they have communicating with them. Parents' increased worry about their issue includes elements like interactions with volunteer donors for blood arrangements, worry about the course of treatment, and problems.

> "*We were only able to communicate via mobile phones because covid sops prevented us from visiting the thalassemia center. We found it challenging to get in touch with management whenever there was news of a blood shortage because to the current state of covid. Finding the donor was extremely challenging because seminars were not being held and colleges were closed due to COVID. The main reason why people were hesitant to donate blood was their concern of COVID. They believed that going to locations like hospitals would make them vulnerable to Covid"*

> "*Due to a blood shortage at the thalassemia center, they requested that we arrange the blood. Sometimes my friends refused to donate blood to my child because after every 15 days, it is impossible for one person to donate, so I beg of other people to donate blood and save my child's life. Finding donors for my child during covid was particularly challenging because most people refused to do so, claiming that if they did, their immune systems could be compromised, making them susceptible to covid."*

Economic problems of the parents of thalassemia children during covid 19

Parents were in financial difficulty. Costs associated with transportation and medical care during a Covid lockdown. All commercial activity was shut down due to the COVID lockdown, and the majority of the female respondents worked in private institutions. Male respondents who worked as a maid at a school or someone else's household were employed on a daily wage. Regarding the financial crisis, they all have the same response: Whether they work in a factory or have a private employment, they are not paid. They claimed that during the COVID lockdown, they experience really difficult conditions. They claimed that occasionally, they even lack the funds to buy food for their children.

> *''One parent of a child with thalassemia revealed his financial situation, he said. Since I live alone and there are no parks or other places to go during a covid lockdown, I am forced to stay at home all day. As a result, my financial situation deteriorates, and occasionally I borrow money from friends and neighbors to meet my child's needs''.*

Participants reported using private transportation while the center was under lockdown as all public and local transportation was prohibited. Therefore, transporters demand additional fees. The majority of them claimed to use their own motorbike or a friend's vehicle to avoid the extra fees, but occasionally they are left with no choice but to pay them; in these cases, they borrow money from friends or family members due to their difficult financial situation. Parents reported that managing medical expenses was more difficult due to the financial crisis because their situation was already precarious and they primarily borrowed money from friends to pay for their children's medical expenses.

> *''Because of the economic turmoil we were experiencing at the time I sold my gold ring to pay for my child's medications, it was challenging to handle the medical expenses for my child''.*

Management issues during covid 19

Management concerns included the failure to find volunteer donors for 50% of the personnel and social estrangement.

> *''Only 50% of the employees were permitted to work during the lockdown, just as only 50% of the staff was permitted in the thalassemia center. According to the respondent, a lack of employees causes several issues for them, such as making them wait for several hours before speaking with them. They wait for their child's blood transfusion for several days. However, the staff workers were preoccupied at the moment with patients who were receiving blood transfusions. Additionally, parents were performing additional responsibilities due to a staffing shortage, making it difficult to contact them to obtain information about the state of their child''*

Additionally, scheduling appointments with doctors and other staff members was difficult due to the strict adoption of sops. One parent mentioned during a conversation about volunteer giving that

> *''Many were not willing to give blood at any cost. Some people even altered their behavior when they saw me because they knew I would want their blood, which is really unpleasant to convey''.*

A significant issue for both parents and the administrators of the thalassemia center was social estrangement. As the government established various covid sops. Participants claimed that thalassemia management properly adhered to guidelines. Without a mask and after washing their hands, they were not permitted to enter the center. Sanitizer was accessible at the facility, and the administration took the necessary precautions for social distancing sops and ordered people to engage with one other and staff members at a distance of six feet.

Discussion

When a person has a chronic illness like thalassemia, it has major social and economic repercussions for them and their family. Thalassemia patients need to be followed up on frequently for the remainder of their lives. It is a chronic illness that has a terrible impact on the lives of patients and their families. The results of this study indicate that parents of children with thalassemia experience social challenges during COVID, such as in relations with donors and management, because children with thalassemia need two blood transfusions each month. Another study done in Karachi found that 221 patients needed blood transfusions twice a month, and the percentage was the same (65%). It's challenging for parents to arrange for their child to receive blood transfusions.

Most of their parents' monthly income was insufficient to cover the cost of blood transfusions and medication. Another study that they conducted yielded results that were comparable. Out of all the responses, just 29 (5.8%) are aware that thalassemia is an inherited condition, while the remaining 471 (94.2%) are not. (Sattari *et al.,* 2012).

Voluntary blood donors were unable to travel freely due to the COVID lockdown. Even though managing common blood types was challenging, getting blood became harder over time. Before the epidemic, Pakistan's blood supply was dependent on student-run non-governmental organizations (NGOs), but now these organizations are the main force behind blood donation and collecting efforts, frequently setting up camps in universities, schools, and businesses. As COVID-19 spread, blood supplies became low, putting thousands of children with thalassemia at risk. A related study identifies crucial elements of donor management and takes into account how the COVID-19 pandemic would affect the blood supply. We also go through how the COVID-19 crisis's prevention and control measures may have impacted the prevalence of anemia, and we emphasize problems with anemia detection and management in patients needing either elective or urgent surgery. (Shander *et al.,* 2020).

Blood donors during the COVID era shied away from giving blood out of fear of contracting the disease, which they believed would make them more susceptible to COVID attacks. They also refused to visit hospitals due to the COVID-friendly environment of those facilities, as the number of confirmed cases grew daily. They struggled to make ends meet because it was necessary for them to visit a thalassemia center for their child's blood transfusion during the COVID lockdown. As a result, they used private transport and paid additional fees. Similar research took into account the 200,000 patients whose lives depended on routine blood transfusions. Many nations have implemented an extraordinary lockdown to reduce the spread of the COVID-19 pandemic. Thalassemia sufferers are in a life-threatening scenario as a result of a severe lack of blood due to restrictions on national human mobility and concern over the COVID-19 infection. (Hossain *et al.,* 2020).

The biggest issue was the lack of employees, as the government only permitted 50% of the staff to carry out their duties, which made it difficult for the administration of thalassemia management to recruit voluntary donors for the supply of courageous change. According to a different study, it would be challenging for patients and their parents to access their regular clinics for blood transfusions while our nation was under lockdown. Additionally, the lockdown has significantly decreased the number of voluntary blood donations, leading to a scarcity at blood banks. Yadav and Pal 2020.

Conclusion

A study revealed that parents of children with thalassemia faced heightened social and financial challenges. The scarcity of blood at the thalassemia center during the COVID lockdown made it challenging to persuade potential donors to contribute blood for their children, as parents feared losing their children at a young age. Insufficient understanding of the disease's etiology, prevention, control, and treatment heightened the risk of parental distress during the child custody lockdown. This distress was compounded by severe financial difficulties, which made it challenging to meet even their child's basic needs. The study's findings underscore the adverse impact of thalassemia on economically disadvantaged segments of society, both in terms of the financial burden of treatment and the lack of awareness regarding disease prevention and pandemic management. Overall, the study determined that parents of thalassemia patients encountered a multitude of challenges related to their child's blood transfusion, primarily due to blood shortages at the center and difficulties in finding suitable donors for blood transfusions. These challenges were exacerbated by a lack of awareness about the critical need for blood in thalassemia care and the limited resources available to address these needs. Parents with lower levels of education faced even greater difficulties, as they had limited access to information through social media. To address this, thalassemia management-initiated awareness campaigns to inform parents about blood donation availability during COVID-19 lockdowns. The study underscores the urgency of public education on the significance of blood donation for children with thalassemia and the importance of collaboration with parents, especially in the context of the COVID-19 pandemic.

Aqsa Atta: Problem Identification and Model Devolpement
Tahira Rubab: Data Collection, Results and Analysis
Amina Javed: Literature search, Methodology and final drafting

Conflict of Interests/Disclosures

The authors declared no potential conflicts of interest in this article's research,authorship, and/or publication.

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