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SOCIO-ECONOMIC VULNERABILITIES OF THE FAMILIES OF B-THALASSAEMIC CHILDREN IN RAWALPINDI AND ISLAMABAD, PAKISTAN

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ABSTRACT

This study explores the socio-economic challenges faced by families whose children have β-thalassemia and need frequent transfusions and medical attention, which puts a great deal of social, financial and emotional strain on the caregivers. Since the state does not pay for the disease's treatment as part of its social welfare program, the parents must bear the entire expense of the care. The present quantitative nature of study employed proportionate stratified random sampling of 410 respondents by using structured questionnaire. Data was gathered from two Thalassaemia Centers (one was public while the other was NGO funded) namely, The Thalassaemia Center of Shaheed Zulfiqar Ali Bhutto Medical University (SZABMU) Pakistan Institute of Medical Sciences (PIMS) Islamabad comprised 73.2% of respondents, while Jamila Sultana Foundation, Rawalpindi, Pakistan comprised 26.8% of the respondents. Study found that majority of the respondents precisely, 70% were young parents from rural settings with low socio-economic status, large families with little formal education. The socio-economic difficulties that such families face is immense since their children need frequent transfusions and medical attention. Given that the families must bear the entire cost of the disease's treatment study found that the patient's family's financial situation affects their ability to pay for specific expenses like food, transportation, consultations, and medication during the process despite having free treatments provided by Thalassaemic centers, the study revealed that the lives of families with β-thalassaemia patients were significantly impacted due to large family size with low incomes making things more difficult financially. Logistical burdens like traveling long distances for medical care,

parental employment, and disruptions to family dynamics all contribute to the economic burden to the families.

Keyword: Socio-economic problems, Families, β-Thalassaemic children, Economic cost

INTRODUCTION

Thalassaemia is a genetic inherited blood disorder which can be simply defined as the inability of the human body to produce sufficient amount of haemoglobin in red blood cell which creates severe anaemia (Chui et al., 2006; Thubthed et al., 2022). Thalassaemia major (TM) is a severe anemia requiring lifelong blood transfusions for patients to stay alive (Sahu et al., 2023). It has reduced life expectancy in children, the need for regular blood transfusions, daily medication, retardation in growth and sexual maturation. These are great challenges especially for Thalassaemia major patients and their families (Ahmad et al., 2004; Kattamis et al., 2022). About 50,000 to 100,000 children deceased due to TM in low and middle income countries annually, where as 7% of the world's population is a carrier of a hemoglobin disorder. The prevalence of thalassaemia in these countries is considered to be high and people are vulnerable toward the β-thalassaemia.

However,stan β-Thalassaemia is a major health problem which is the most prevalent genetically transmitted blood disorder (Khatak and Saleem, 1992; Das Das et al., 2023). Though there is no documentary figure available in Pakistan, however it is estimated that approximately 5000 – 9000 infants having β-thalassaemia are born every year. Studies on carrier rate of β-thalassaemia in general population has shown average rate is slightly over 5% (Ansari, 2012).

According to estimation the national β-thalassaemia carrier frequency rate is 4.6% in Pakistan (Samina et al., 2007; Modell, 2008). Research carried out it is expected that more than 4000 thalassaemic children are born in Pakistan annually (Saleem et al., 1996; Peng et al., 2023). However, it was pointed out those 6000 infants with TM and 8-10 million carriers bornevery year in Pakistan (Hafeez et al., 2007; Black et al., 2010). In another study that TM carriers were estimated to be 8 million in Pakistan (Qurat et al., 2011; Waheed et al., 2012).

Trends of consanguineous marriages, high fertility and birth rates, low educational level, early marriages, unawareness, poor health delivery system and insufficient national screening and prevention program have led Pakistan towards very high number of children with Thalassaemia major (Waheed et al., 2012; Choubisa et., 2022). However, the idea of

thalassaemia prevention is gaining motivation. It is very important to accept that prevention would be effective if it is carried out equally for the whole population (Baig et al., 2006; Ali & Saffiullah, 2015).

Treatment of β-thalassaemia patients like safe blood transfusion and iron chelation therapy are beyond what people of third world countries can afford (Vanichsetakul, 2011; Ishaq et al., 2012; Shahzad et al., 2017). However, PMS, genetic counseling of carrier and prenatal diagnosis are prevention of β-thalassaemia which are the best choice of individuals to control the affected births in developing countries (Asadi & Doroudchi, 2004; Ishfaq et al., 2013).

The bone marrow transplant is the only treatment for β-thalassaemia, however this facility is available at very few health centers in Pakistan. The bone marrow transplant is very expensive and costs USD 25-40 thousands that is beyond the resources of large proportion of Pakistan (Ishfaq et al., 2016; Lingen, 2016; Sattari et al., 2019; Chaichompoo et al., 2022). Keeping in view and in continuation to an already published study on Knowledge, Attitude, and practices (KAP) of parents of thalassemic children toward β-thalassaemia (Clarke et al., 2010; Riewpaiboon et al., 2010; Shahraki et al., 2017; Bangash et al., 2022). The current study was aimed to assess socio-economic problems faced by parents of thalassemic children in Thalassaemia Centers of Rawalpindi and Islamabad.

Materials and Methods

This cross-sectional descriptive study was conducted with proportionate stratified random sampling technique. Study population comprises the families of the registered patients of β-thalassaemia at Thalassaemia Centre of SZABMU-PIMS, Islamabad and Jamila Sultana Foundation, Rawalpindi, Pakistan. A sample of 410 was collected from the parents of the β-thalassaemia children by using structured questionnaire. The patients' parents were informed about the study's overall objectives and voluntary nature of their participation in it. Verbal informed consent for participation in the study was also priorly sought. Those who were not willing to participate or have other blood disorders were excluded from this study. The data was analyzed statistically through Statistical Package for Social Sciences (SPSS).

Results

Interviews with 410 families of patients with thalassemia were conducted; of these, 73.2% were from SZABMU-PIMS while 26.7% were from Jamila Sultana Foundation.

43.7% of the respondents were fathers while 56.3% of the respondents were mothers who were providing care to their thalassaemic children. 69% of the parents were from rural settings while 31% were from urban settings. With respect to parents' educational attainment, of the 179 fathers, 18.3% were illiterate, 10.5% were primary, 19.5% were middle, 24.9% fall in Secondary School Certificate (SSC) level category, 12.4% were in the Higher Secondary School Certificate (HSSC) category, 9.5% were graduates, and only 4.9% of the fathers held a postgraduate degree or higher. The study generally found that parents' understanding and knowledge of thalassemia was inadequate but it was worst among illiterate parents (Shahzad et al., 2017).

The mothers' educational attainment levels reveals that 32.9% of the 231 mothers were illiterate. 12.7% of the mothers had a middle literacy level while 13.7% had a primary literacy level of education. 40.8% of them fall in SCC to postgraduate level group, with 20.5% mothers with secondary school certificate, 10% with higher secondary school certificate, 7.6% bachelor's degree, and 2.7% postgraduate degree and above.

The study found that majority of the families particularly mothers with less education had a tendency to use ethnomedical treatments and following their spiritual rituals of visiting saints and shrines either complicated and prolonged the course of treatment for their children.

Since the majority of the parents were from rural settings with low incomes and low levels of education. 2.0% families had no regular source of income while 22.7% of the 410 sampled families did not earn more than 10,000 rupees annually. 26.8% of respondents had an income of Rs.10001–15000, followed by 17.6% with an income of Rs.15001–20000, 6.8% with an income of Rs. 20001–25000, 6.3% with an income of Rs. 250001–30000, and 5.4% with an income of Rs. 30000–35000. 11.5% had Rs.350001-40000, 0.7% had Rs. 40001-45000 rupees and only 0.2% respondent's monthly income was greater than Rs. 45000 rupees such low socio-economic status & low parental income makes treating of disease a financially challenging task.

The distribution of disease among consanguineous marriages revealed that 65.4% of the marriages were endogamous while 17.1 % were exogamous. while 8.5% were exogamous. Since there is a possibility that one of the parents might be thalassemic major or minor, blood screening of the couple was not considered a socially or culturally acceptable practice before marriage, there was no idea of testing for the condition to rule out its possibility. Due to ignorance and social rejection, comparable patterns were also observed in exogamous marriages.

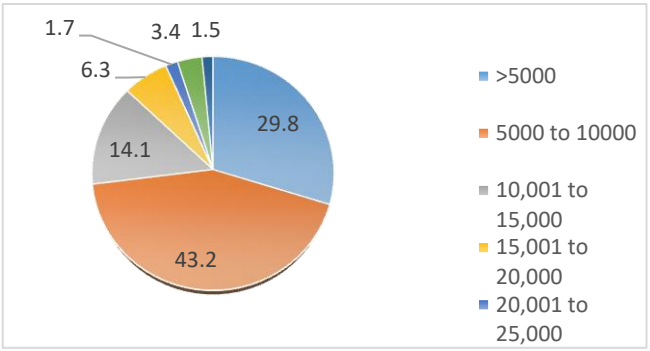

Figure 1: Monthly cost of treatment of thalassaemic children borne by the families [1]

Table I: Socio-economic Problems due to Thalassaemia

Variables	Excessively	Moderately	Slightly	Not at All
Effect of economic Status due to β-thalassaemia	104 (25.4%)	163 (39.8%)	87 (21.2%)	56 (13.7%)
Borrowed Money due to thalassaemia	48 (11.7%)	107 (26.1%)	113 (27.6%)	142 (34.6%)
Unable to attend social gathering due to β-thalassaemia	46 (11.2%)	181 (44.1%)	137 (33.4%)	46 (11.2%)
Family life was affected	42 (10.2%)	124 (30.2%)	177 (43.2%)	67 (16.3%)
Unable to concentrate on daily routine work	44 (10.7%)	195 (47.6%)	141 (34.4%)	30 (7.3%)
Disturbed sleeping pattern	23 (5.6%)	71 (17.3%)	194 (47.3%)	122 (29.8%)
Take stress reliving medicine	3 (0.7%)	5 (1.2%)	73 (17.8%)	329 (80.2%)

[1] The financial estimates are as of the study period during year 2015, the inflation rate was 2.53 % in 2015 whereas in the year 2023. it moved to 30.77% (Data, 2024).

Scale: 4 = Excessively, 3 = Moderately, 2=Slightly and 1 = Not at All (Source: Primary Data)

Figure 1 depicts parent's monthly expenditure for the treatment of their thalassaemia children. Results revealed that 29.8% of the families spend less than Rs. 5000 for treatment, 43.2% paid Rs. 5000-10000 rupees, 14.1% spend Rs. 10001-15000, 6.3% approximately paid Rs. 15001-20000, 1.7% spent Rs. 20001-250000, 3.4% paid Rs. 25001-30000 while 1.5% respondents' approximate cost of the treatment of thalassaemia was greater than Rs. 30000 rupees in a month.

Table 1 presents that family's socio-economic status affected by having thalassaemic patient in the family wherein 86.4% families were badly affected economically whereas 13.7% were not affected at all as they could afford the medicines for their affected children. Among 86.4 % families, 21.2% were slightly affected, 39.8% moderately and 25.4% were excessively affected. Majority of parents 65.4% had to borrow money from relatives or friends to fulfil the needs of their affected children however, 34.6% never borrowed for this purpose. Among 65.4% responses, 27.6% slightly, 26.1% moderately and 11.7% excessively borrowed money from others to meet economic expenses.

A thalassemic child affected the social gatherings of about 88.7% of parents, whereas 11.2% were never impacted. Of the parents impacted, 33.4% were slightly worried, 44.1% moderately worried, and 11.2% excessively bothered. 16.3% of families said that having a thalassaemic child had no effect on their family life. By comparison, 30.32% of families had moderate disturbances, 10.2% suffered significant disruptions, and 43.2% reported minor disturbances. 34.4% of families reported somewhat disruption in their daily routine, 47.6% reported a severe disruption, and 10.7% reported no disruption at all. Routine work was unaffected in just 7.3% of cases.

According to parents' responses, 29.8% of them reported no change in their sleep pattern, 47.3% reported a slight change, 17.3% reported moderate change, and only 5.6% reported excessive change in their sleeping schedule. When asked if their thalassaemia children were medicated for stress or depression, parents' responses revealed that 80.2% of them did not use any form of medication, although 17.8% frequently took antidepressants, 1.2% took medications moderately, and 0.7% took medications excessively. 16.3% of families with thalassaemic children reported that their family life remained unaffected compared to 43.2% reported little disturbance, 30.32% reported moderate disturbance and

10.2% who reported significant disturbance respectively. The disruption of daily routine work by families shows that just 7.3% of routine work of parents was unaffected, whereas 34.4% were somewhat affected, 47.6% was highly affected, and 10.7% was extremely affected.

Discussions

Thalassaemia is a genetic disorder of autosomal inheritance and both parents of the thalasaemic child must be silent carriers and asymptomatic (Mallik et al., 2010; Mufti et al., 2015; Mashayekhi et al., 2016). Thalassaemia severely impairs a child's regular health and activities and places a heavy burden on the parents. According to the current study, there were 12.6% more female respondents than male respondents among the impacted families. A study from the Thalassaemia Centre, Sir Ganga Ram Hospital, Lahore, revealed a similar majority of females (Aziz et al., 2012). The level of education of parents often plays a role in raising awareness, which is the foundation of prevention.

The majority of parents in the current study had low educational levels and little understanding of health education, with illiterate mothers making up a larger percentage of the population than fathers. On the other hand, compared to others, parents with greater education were more proactive in screening. Similar findings were obtained from a study carried out in Multan, where the majority of parents of children with thalassaemia were illiterate (Petrakos et al., 2016).

Regarding endogamy, the current study underlines the significant influence of Pakistan's *Baradri* system and predominant family structure, as over 80% of the respondents had endogamous marriages, which is a source of thalassaemia. In Pakistan, consanguineous marriages are both common and lawful, making them a significant risk factor and contributing to the rise in thalassaemia. Research indicates that the prevalence of autosomal recessive illnesses such as thalassaemia is elevated in consanguineous marriages (Yengil et al., 2014; Altinoz et al., 2012). Only 18.5% of the respondents experienced exogamy. These outcomes were likewise strong in an Iranian study (Wahidin & lai 2021; Sahu et al., 2023) that discovered a strong correlation between TM and cousin marriages. There seems to be a high rate of cousin marriage in certain other studies wherein high rate of cousin marriage among the parents was found as one of the reasons in most of the TM patients (Weslati et al., 2019; Masud et al., 2020; Mandal et al., 2020).

Aimed to low socio-economic status of the parents, they have to seek medical treatment of their children from public facility where they can get a diagnosis, prescription drugs, blood transfusions, and some medications for free or at minimal charges. On the other hand, the children's supper was provided free of cost along with these amenities in the private center managed by an NGO. Even though both these provided the thalassemic children with medication and blood transfusions, their families were still responsible for covering additional costs associated with managing the disease and other associated expenses in the form of food, shelter, transportation and related socio-economic challenges faced by the families. Due to financial constraints, Parents were compelled to bring their children to these centers for medication and transfusions, yet the disease affected the family badly for whole life both socially and economically. The study's finding resonates with Saleem et al. (1995) who found that there are an estimated 5–6 million carriers in Pakistan. In addition to additional blood requirements, the average annual cost of therapy for a single affected child is Rs. 10,000, which is expensive given families' poor resources and low economic standing. Similarly, a study (Biswas et al., 2018) demonstrated that this disease affected parental financial state very badly in which majority of the affected children's families were poor and unable to afford the costly treatment. Studiesin Iran (Hockham, 2017; Mohapatro et al., 2017) and Pakistan (Goodman & Malik, 2016) confirmed that thalassaemia causes financial impact on patient's family. Similar results were reported in a other studies that thalassemic patients are a source of socio-economic burden on families and as well as societies (Khairkar et al., 2010). Due to constantly blood transfusion children suffer from many other complications like large spleen, infections, bone problems, overloaded iron, risk of Hepatitis B and C for which parents required more money for treatment. Furthermore, majority of the parents visiting these centers were from outside Rawalpindi and Islamabad mainly from periphery areas of AJK, Jhelum, Attock, Chakwal, Gujrat, and Khyber Pakhtunkhwa. Parents from these areas must visit these centres at least twice or thrice in a month, besides expenses on treatment they were also bear transportation, food, and accommodation expenses.

These are the factors also affect the economic status of the families. Results regarding financial burden to the families supported by a study in India (Mashayekhi et al., 2016) found financial burden on the families to treat the thalassaemia in India. Where about 70% of the study population had to spend up 20% of their total family income for treatment of

thalassaemic children, however 20% population spent 21- 40% and 10% spent above 40% of their annual income respectively.

The primary sources of dependency and expenses for low-income families include borrowing money from others for medical care, travel, and food for sick children. Similar findings were reported in other studies (Yengil et al., 2014, Reed-Embleton et al., 2020, Qamar et al., 2022) where blood was available free of cost while majority of the expenses were incurred by the patients' families for travel, lodging, and food. A study conducted in Iran (Nazlıcan et al., 2013) found that most of the affected children's families were impoverished and unable to pay for the expensive treatment, indicating a serious financial impact of this condition on families. A study carried out in Multan produced results that were comparable (Thein & Rees, 2015).

The study also found that many parent's social gatherings were impacted. Similar findings were observed in studies conducted in Lahore and Multan (Yengil et al., 2014) where many parents experienced limitations in their social activities due to their child's illness. Because the parents of these children were unable to fully attend to the educational, financial, and social requirements of their other children, majority of the parents' family life was also disrupted. Similar results were observed in a study where families may endure social isolation in addition to having to deal with unique and severe obstacles in caring for their children who have thalassemia (Rehman et al., 2023).

Regarding parents' daily work routines caused by thalassaemia children, the current study found that many parents experienced stress because their children's thalassemia disturbed their daily indoor and outdoor activities. Research also shown that parents avoided getting together socially and even had tense relationships with one another (Asadi et al., 2004; Ishaq et al., 2012). Parents of patients who experienced disturbed sleep patterns because of caring for them said that the illness had an impact on the patients' social lives as well as their psychological and mental well-being. Overall, the current study shows that a small percentage of parents need to use medication to relieve stress and despair brought on by their sick children.

Conclusions

There is a strong correlation between thalassaemia and the financial strain of covering treatment costs by the families of the children. According to the study's findings, many parents had to deal with a variety of social and financial issues because of having

thalassaemic children. 86.4% of the households were negatively impacted by the socioeconomic situation, majority of parents (65.4%) were also forced to borrow money from friends or family. 97% families with thalassaemic children had faced disruptions in their daily routine while 87% percent of the parents faced negative effects on their social lives. Even though Thalassaemia Centers provided blood transfusions and medications to affected families, families were still responsible for covering additional costs associated with managing the disease, such as providing food and transportation, food and shelter. The study suggests that to lessen the impact of thalassaemia in Pakistan, health insurance should be included in current health policies likewise education and awareness campaigns for carriers and the public are also crucial for eradicating the disease.

Limitation of the Study

The limitation of current survey was that participants were only from Thalassaemia centres however view of the general population could be not accessed in the study.

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