

Between Hope and Helplessness: The Hidden Struggles of Families Facing Thalassemia

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How to cite: Waheed G, Jameel T. Between Hope and Helplessness: The Hidden Struggles of Families Facing Thalassemia. *Avicenna J Health Sci.* 2025;02(04): 135-136

In Pakistan, a number of families are quietly fighting a tough battle. They care for children with transfusion-dependent β -thalassemia. A disease that requires regular blood transfusions to survive. While the medically related health issues are well known, the emotional and social burden often goes unacknowledged.¹ The families face fear, isolation, financial hardships and constant worry about their children's life, especially when it comes to marriage prospects and social acceptance.²

Why stigma happens

Thalassemia is a genetic condition, but the relatives and friends wrongly perceive that having a sick child means the family is cursed or flawed.³ This leads to gossip, blame, and fear especially about how it might affect the social acceptance of healthy siblings. To avoid this judgmental attitude by society, many parents keep the diagnosis secret. But this trend leads to isolation and stops families from getting support from friends or relatives.^{1,4}

How stigma hurts

Families dealing with thalassemia face three major burdens:

- **Mental stress:** Parents often suffer from anxiety, depression, and sleepless nights. Mothers, who usually take on the caregiving role, feel this stress even more.⁵
- **Social isolation:** Families withdraw from social life to avoid questions or because hospital visits take up so much time. Children miss school, and families lose their support systems.^{2,3}
- **Financial pressure:** The cost of transfusions, medicines, travel, and missed working hours adds to the misery. Many families go into debt, sell belongings, or cut back on essentials just to afford care. This financial strain adds to the hardships and secrecy.⁶

Because of these challenges, families live in a constant state of hope and helplessness. Hoping their child will survive and thrive but feeling powerless due to lack of money and support. Stigma makes things worse by delaying treatment and reducing follow-up care, which can lead to serious health problems over time.

What can be offered?

Simple and respectful solutions

There is a series of practical steps Pakistan can take to help these families. These solutions are affordable and culturally sensitive:

- **Add counselling to clinics:** Every thalassemia center should offer basic mental health support. A small team of counsellors or social workers can help parents cope and reduce secrecy. Peer-support groups run by trained volunteers can also make a big difference.⁷
 - **Offer financial help:** Small subsidies for medicines, travel expenses, or cash transfers tied to clinic visits can ease the financial burden. Free access to required blood. Pilot programs have already shown better attendance and fewer emergencies.^{8,9}
 - **Educate communities respectfully:** Simple messages like "Thalassemia is genetic, not contagious" can help. Working with religious leaders, teachers, and elders people the community trusts can reduce blame and open doors for support.¹⁰ One very important aspect is the generation of volunteer donation atmosphere. Donors should be honored & encouraged for their service to humanity.¹¹
 - **Keep screening private and respectful:** Premarital and antenatal screening can prevent new cases, but only if families feel safe. Confidential and culturally sensitive counselling is key.
- Support patient groups:** When families see others living openly with thalassemia, stigma fades. Patient associations can offer peer counselling, raise funds,

and connect families to legal and educational resources.³

Here are four simple steps to start:

1. Place one counsellor or social worker in each regional thalassaemia center.
2. Short leaflets explaining the condition and treatment in Urdu and local languages would be very helpful for the caring parents
3. Travel expenses and medicine subsidy can be started in one center and then be expanded according to the response.
4. Confidentiality should be strictly observed so families feel safe when seeking help. One may decrease the sufferings of parents by this way.

A Final Thought

Thalassaemia is a social challenge that affects dignity, family life, and future opportunities. In Pakistan, where family honor and social acceptance are deeply valued, stigma can cause long-lasting harm.¹² But with counselling, financial support, respectful education, and stronger patient networks, we can help families move from helplessness to hope.

If community leaders, doctors, and religious leaders work together, we can show families they are not alone and protect not just lives, but dignity and the future.

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