Thalassemia & Covid-19 In Khyber Pakhtunkhwa (KP) Pakistan

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Thalassemia is a preventable hereditary disorder, each of the parent must be autosomal recessive to have a child with serious symptoms of the major disease. Thalassemia occurs due to abnormal or deficient Hemoglobin (an iron containing proteins) in Red Blood cells. Depending upon the type of proteins involved, there are two types of Thalassemia, α Thalassemia and β Thalassemia ^{1,2}.

Though Thalassemia is present in all part of the world, it is more common in Mediterranean and Asian countries including Pakistan³. α -Thalassemia (1-30%) is more frequent in Southeast Asia than in other areas of the world ^{4,5}. Due to lack of registry the exact figures are not known, however, according to one estimate 5000 9000 children are born per year with thalassemia in Pakistan ⁶. Quality of life of the children with major symptoms is highly compromised while families have to bear mental and financial strains till the child is alive. Usually, such children don't survive first decade of life, however, there are exceptional cases where they survive third decade of life, depending upon the quality of care ⁷. In order to live these patients, need constant blood transfusions after every 2-5 weeks with medicines called chelating agents to reduce Iron over load due to transfusions ⁸. Cause of death is usually cardiac disease due to iron over load⁹. The only curative treatment is stem cell and bone marrow transplant¹⁰.

In Khyber Pakhtunkhwa, two major Medical Teaching Hospitals, Lady Reading Hospital and Hayatabad Medical Complex are providing counselling and medical services to such families and patients. There is a need to strengthen testing especially Prenatal testing facilities at these centers. Regional blood centers (Public sector) have been active to provide free blood donations to these hospitals. There are certain private

Thalassemia centers like Fatmid, Hamza Foundation and Frontier Foundation¹¹ who are catering these patients as well. They provide screening & testing services, blood transfusions and Iron chelating agents at their centers, but the quality of care they provide needs constant monitoring and supervision by Blood transfusion Authority and Health Care Commission. For Bone marrow or stem cell transplant, the family has to travel to either the federal capital or Lahore or Karachi. Social health protection to must cover Thalassemia patient's treatment. Along with patient's registry there is a need to register donors who are willing to donate their bone marrow and stem cells, equally important is promoting placental blood banks in Khyber Pakhtunkhwa.

Furthermore, at policy level, in last decade, Provincial, National Assembly and Senate passed 2009 Preventive Health Act¹², 2017, Thalassemia Patient Bill¹³ and 2019 Senate Thalassemia Disease bill¹⁴ respectively. These laws emphasize on the preventive measures and focus on premarital counselling, screening and testing of the patients and the blood relatives generally and the couples specifically before entering into wedlock. However, these laws need to be implemented in true spirit.

Pakistan needs at least 3,000,000 blood bags/year to fulfill the need of the 100, 000 Thalassemia major patients¹⁵. COVID-19 pandemic has affected every aspect of life including the transfusion-dependent thalassemia major patients¹⁶. The pandemic has taken a toll on all blood banks in the province who are reporting dwindling supplies¹⁷ of this scarce resource. This is largely attributed to off and on Lock downs, lack of awareness in the general public, resulting in fear of acquiring the infection by visiting the blood bank or during the process of donation¹⁸.

The university and college students are the most dependable and frequently tapped donors in any disaster situation followed by formal appeals at

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the religious gatherings in mosques. However, closure of educational institutions¹⁹ and banning of religious congregations lead to shortage of blood. To tackle this unprecedented scenario in the provincial capital, the Peshawar Regional Blood Center formulated a response plan and adopted a targeted approach based on experience in other countries. The blood center issued a call to healthy repeat donors through the Directorate of Student Affairs in respective academic institutions. The donors were urged to visit the blood center in vacations and donate blood amid the pandemic. The blood center also proactively coordinated with the print, electronic, and social media so that the general public is sensitized of the donation process safety and blood needs. All these rigorous efforts have so far proven to be effective in communicating the message and restoring the public confidence as the number of donations have greatly improved and hence supply of safe blood and blood components to the thalassemia patients²⁰.

In order to reduce morbidity and mortality associated with Thalassemia, KP needs to strengthen provincial Thalassemia control program including surveillance, screening, management and continuous advocacy with social mobilization.

Counselling of the patients and families is required along with information about available resources, outreach service & social workers, patient-to-patient/ parent-to-parent connections or support groups²¹. Carrier screening, counselling and prenatal diagnosis are three main effective approaches to prevent and eliminate thalassaemia from Khyber Pakhtunkhwa.²²

REFERENCES

- Weatherall DJ, Clegg JB. The thalassaemia syndromes. John Wiley & Sons; 2008 Apr 30.
- Spritz RA, Forget BG. The thalassemias: molecular mechanisms of human genetic disease. *American journal of human genetics*. 1983 May;35(3):333-9.
- Colah R, Gorakshakar A, Nadkarni A. Global burden, distribution and prevention of β -thalassemias and hemoglobin E disorders. *Expert Review of Hematology*. 2010 Feb 1;3(1):103-17. (<http://www.ironhealthalliance.com/disease-states/thalassemia/epidemiology-and-pathophysiology.jsp>)
- Xu XM, Zhou YQ, Luo GX, Liao C, Zhou M, Chen PY, Lu JP, Jia SQ, Xiao GF, Shen X, Li J. The prevalence and spectrum of α and β thalassaemia in Guangdong Province: implications for the future health burden and population screening. *Journal of clinical pathology*. 2004 May 1;57(5):517-22. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3243455/#:~:text=An%20estimated%205000%2D9000%20children,the%20total%20population%20%5B3%5D>.
- Tanveer T., Masud H., Butt Z.A. Are people getting quality thalassemia care in twin cities of Pakistan? A comparison with international standards. *Int J Qual Health Care*. 2018;30:200207. doi: 10.1093/intqhc/mzx198. [PubMed] [CrossRef] [Google Scholar] [Ref list]
- Modell B. Total management of thalassaemia major. *Archives of Disease in Childhood*. 1977 Jun;52(6):489-94.
- Galanello R, Origa R. Beta-thalassemia. *Orphanet journal of rare diseases*. 2010 Dec;5(1):1-5.
- Zaidi U, Shamsi TS, Farzana T, Ansari SH, Borhani M, Munzir S, Samad S, Parveen K, Anjum N, Mirza IG, Safdar D. Capacity building of stem cell transplantation facilities in Pakistan: joint efforts of NIBD, government, and private-sector institutions. *Blood advances*. 2019 Dec 6;3(Supplement 1):41-4. <http://www.curethalassemia.org/thalpedia/thalassemia-treatment-centers-in-pakistan/>
- http://kpcode.kp.gov.pk/uploads/the_Khyber_Pakhtunkhwa_Preventive_Health_Act_2009.pdf
- <https://tribune.com.pk/story/1320014/legislation-national-assembly-passes-thalassemia-screening-bill#:~:text=Legislation%3A%20National%20Assembly%20passes%20thalassemia%20screening%20bill,-Lawmakers%20protest%20removal&text=ISLAMA%20BAD%3A%20The%20National%20Assembly%20on,tested%20before%20entering%20into%20wedlock.>
- http://www.senate.gov.pk/uploads/documents/1548128574_227.pdf
- Ali SA, Azim D, Hassan HM, Iqbal A, Ahmed N, Kumar S, Nasim S. The impact of COVID-19 on transfusion-dependent thalassemia patients of Karachi, Pakistan: A single-center experience. *Transfusion Clinique et Biologique*. 2021 Feb 1;28(1):60-5.
- Ali SA, Azim D, Hassan HM, Iqbal A, Ahmed N, Kumar S, et al. The impact of COVID-19 on transfusion-dependent thalassemia patients of Karachi, Pakistan: A single-center experience. *Transfusion Clinique et Biologique*. 2021 Feb 1;28(1):60-7.
- Waheed U, Wazeer A, Saba N, Qasim Z. COVID-19 pandemic: Implications on blood transfusion needs of thalassemia major patients. *Global Journal of Transfusion Medicine*. 2020 Jul 1;5(2):235-9. <https://www.arabnews.pk/node/1689746/pakistan>, <https://arab.news/6yr6>
- COVID-19: Pakistan Extends Lockdown until 30 April 2020. Available online: <https://www.aa.com.tr/en/asia-pacific/covid-19-pakistan-extends-lockdown-until-april-30/1804544> (accessed on 17 April 2020).
- <https://www.sbtp.gov.pk/regional-centres/regional-blood-centre-peshawar/>
- <https://thalassemia.com>
- World Health Organization. Prevention and control of birth defects in South-East Asia region: Strategic framework (2013-2017). WHO Regional Office for South-East Asia; 2013.