LETTER TO THE EDITOR

Transfusion-dependent beta thalassemia in Afghanistan: current evidence amid COVID-19 and future recommendations

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Introduction

Transfusion-dependent beta thalassemia (TDT) is a severe form of beta thalassemia in which there is a minimal to no beta globin chain production in the body [1]. This situation eventually leads to major profound and lifelong transfusion-dependent anemia with a high mortality rate of about 85 percent if left untreated [2,3]. TDT patients in older age groups often suffer from functional hyposplenism or asplenia. This increases the risk of bacterial infections leading to serious illness or life-threatening sepsis [2]. Without blood transfusions, thalassemia patients usually die before reaching adolescence. Blood transfusions can help patients have a healthy life and reach adulthood with a near-normal life expectancy. Proper management of thalassemia substantially impacts on the patient’s quality of life [1].

Afghanistan, a developing country with a fragile healthcare system and over-burdened by many diseases, has seen little investments to address the needs of TDT patients. The country needs substantial improvement in various aspects including prevention, diagnosis and treatment of TDT. The impact of COVID-19 on TDT health services can hardly be overestimated in Afghanistan. In this paper, we aim to highlight major challenges that TDT patients face in Afghanistan as well as their current situation amid COVID-19. We also provide some key recommendations to address their needs.

Challenges

The biggest challenge in this area is the lack of information and data crucial to policy, services and interventions. This is due to very few researches conducted on thalassemia. There are no reliable statistics available on this disease except for one study stating that 1–1.5 million B-thalassemia-carrier people has been estimated in Afghanistan [4]. Healthcare workers state that the number of thalassemia patients is over three thousand. High costs associated with the treatment of thalassemia is a formidable issue which remains unresolved. Diagnostic tests such as prenatal tests and testing the blood of pregnant women are inaccessible and unaffordable. The treatment of thalassemia needs pack cell and bone marrow graft which is highly expensive and unaffordable in the country. This makes it hard for the patients of low economic status to afford the treatment thus they often neglect seeking treatment [5,6].

Illiteracy is another major problem that has hindered the treatment of thalassemia patients in the country. Patients with minimum knowledge often neglect the treatment of thalassemia as they are unaware of its complications [7]. They also delay the on-time referral to the healthcare centers and by the time they are referred to seek treatment, the complications have already set in. Gender plays an important role in the access to healthcare services in Afghanistan particularly in its rural areas [8]. Due to traditional views and beliefs, a female patient cannot seek treatment unless she is accompanied by her mahram (a husband or a male relative of patient). However, since their mahrams are usually busy with their daily routine, the patients miss treatment appointments. In the same vein, lack of diagnostic facilities (equipped laboratories, testing capacities) with the ongoing strife of war and conflicts present barriers for the healthcare system to properly address the needs of TDT patients.

Transfusion-transmitted infections, including viral, bacterial, and parasitic infections, are major risks associated with regular blood transfusion. Thus, the World Health Organization (WHO) recommends screening for HIV, HBV, HCV, and Syphilis of all donated blood [9].

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However, most of thalassemia patients have limited access to regular and safe blood transfusions in Afghanistan. When blood is ready, there is no widely available screening test for the blood to ensure there is no sign of HBV, HSV, and HIV infection. The dilemma of screening test shortages puts the patients at risk of contracting these infectious diseases.

The COVID-19 pandemic has disrupted essential healthcare services in Afghanistan [10,11], and thalassemia is not spared. Although the exact number of TDT patients infected by COVID-19 is not clear, their lives were directly or indirectly affected by the pandemic. Due to transport restrictions, the patients faced lack of vital drugs such as Desferrioxamine (Desferal), a drug which is used to remove excess iron from the bodies of TDT patients to relegate iron level of their bodies. Excessive amount of iron is toxic that can lead to serious complications such as liver damage, diabetes, and endocrine diseases. The pandemic has also resulted in significant decrease in blood donation due to the lockdown, cessation of blood donation camps and disruption of transport services. This is worrisome as TDT patients’ lives depend on regular blood transfusion. Afghanistan is more vulnerable than many other countries in this regard due to lack of standard and sufficient blood banks. Moreover, a number of health professionals working in this area were infected by COVID-19 resulting in disruption of health services. Poor economic status of TDT patients who have challenging economic background, was aggravated by loss of jobs during the pandemic, making them unable to seek treatment [12].

**Recommendations and conclusion**

TDT patients face many challenges in Afghanistan. Lack of reliable data, low level of awareness, and high cost associated with its treatment have hampered its healthcare services. Their already dire situation was aggravated by the emergence of COVID-19. The implementation of several complementary approaches are needed to mitigate the unfavorable health condition of TDT patients in Afghanistan. More research projects in this area are needed to provide evidence-based findings for policy makers to address the needs of TDT patients. Primary prevention, such as educating and raising awareness of the community regarding the importance of premartial and prenatal diagnostic tests for couples and avoidance of marrying close family blood lines are of paramount importance. This can be achieved through leveraging regional and local media, and influential religious leaders.

Moreover, a multi-sectorial coordination between governmental and non-governmental organizations regarding prevention, diagnosis, and treatment needs to be strengthened and institutionalized. It is essential to increase the number of skilled health professionals in this area to offer prevention, diagnosis, and treatment services to thalassemia patients. The capacity and the number of high quality and well-equipped blood transfusion services and banks need to be improved. The capacity for diagnostic tests, and the registration system must be built to ensure reliable data on the exact number of TDT patients which will allow proper decisions on the next steps to be taken.

As secondary prevention, early diagnosis, admission and supportive therapy are essential for the management of the patients. The government, with the cooperation of international donors, needs to provide drugs and blood for them. During the current pandemic, a special focus should be directed towards TDT patients due to their high susceptibility to the virus and the subsequent complications such as secondary bacterial infections. They also need to be prioritized in receiving COVID-19 vaccines.

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