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LETTER TO THE EDITOR

Inherited bleeding disorders in Afghanistan: The current situation amid COVID-19

1 | INTRODUCTION

Inherited bleeding disorders consist of a heterogeneous sort of diseases that reflect abnormalities of blood vessels, coagulation proteins and platelets.[1] Von Willebrand disease (VWD) is the most common type of these bleeding disorders, followed by haemophilia A and haemophilia B, which are both x-linked recessive disorders, mainly affecting men.[2] Haemophilia occurs in all ethnic groups throughout the world. Based on the World Federation of Hemophilia findings, 43% of the world's haemophilia patients live in India, Bangladesh, Indonesia and China, of which only 12% have been diagnosed.[3]

Afghanistan, a country ravaged by decades of war and conflict, with a fragile healthcare system, does not have reliable data on the exact number of haemophilia patients. The data of the central blood bank of Kabul and of the Afghanistan Hemophilia Association show that there were 87 haemophilia patients in 2012 which increased to 288 in 2016.[4,5] Based on the latest data by the United Nations, the country's population is 39,594,675, and the number of haemophilia patients is estimated to be 7919.[6] Studies show that consanguineous marriage is a major contributing factor in inherited bleeding disorders. Since the rate of consanguineous marriage is very high in Afghanistan, it is assumed that the number of patients afflicted with this disease is also high in the country.[7] The implementation of health developmental programmes, such as Basic Package of Health Services (BPHS) and Essential Package of Hospital Services (EPHS) in 2003 and 2005, has led to 66% improvement in accessibility to health services in seven of the most urgent health priorities. However, these packages did not include rare diseases such as haemophilia.[8] This paper aims to elucidate the challenges haemophilia patients face in Afghanistan.

2 | CHALLENGES

The general lack of skilled health professionals in Afghanistan's healthcare system (only 9.4 skilled healthcare workers and 1.9 physicians per 10,000 population) and a severe shortage of genetic counsellors, with specific expertise on the topic, are major concerns for all kinds of diseases, including haemophilia. There is scarcity of doctors nationally, and healthcare workers are disproportionately distributed across the country with only 7.2 physicians per 10,000 in urban areas and 0.6 per 10,000 in rural areas.[9] This condition leads to the delay and mismanagement of late complications of haemophilia which include disabilities after arthropathy, infection from plasma-derived products and development of inhibitors.

Moreover, insufficient factors including factors VII, VIII and Von Willebrand factor (VWF) in health facilities and disproportionately distributed blood bank and blood transfusion organizations have led to a higher rate of direct transfusion (without donor screening) and the booming of the black market. This has brought an immense concern about infection from plasma-derived infection and co-infection with human immunodeficiency virus (HIV), hepatitis B virus (HBV) and hepatitis C virus (HCV). Co-infection with HCV and HIV accelerates the development of liver disease that may not respond well to treatment.[10] Even in the absence of factors, the patients are forced to use fresh frozen plasma (FFP) or whole blood instead of needed factors. Such attempts cause circulatory overload, allergic reactions from hives to anaphylaxis and septic reactions.

The development of inhibitors is a serious complication in patients with severe haemophilia, which consists of the production of alloantibodies that blocks the activity of the exogenous factor and neutralizes treatment. Inhibitor incidence seems to happen at high rates in Afghanistan due to insufficiency of factors. Hemophilia Treatment Center (HTC) in Kabul, the only treatment centre for haemophilia, which addresses the needs of most haemophilia patients of the country, face lack of factor XIII or Von Willebrand. This leaves physicians with no choice but to refer the patients to other countries or engage in treating haemophiliacs with different classes/families of factors (recombinant and/or plasma derived).[11]

Furthermore, there is no national programme implemented for preconception counselling and tests, prenatal evaluation of carriers and affected pregnant women with haemophilia in Afghanistan. The factor activity level should be tested at least once during pregnancy (eg, avoidance of invasive fatal procedures and forceps, vacuum-assisted delivery or invasive diagnostic testing such as amniocentesis or chorionic villus sampling).

With the emergence of COVID-19, the unprepared healthcare system was unable to cope with the overwhelming burden. Timely decision was taken to prioritize COVID-19 over other diseases. As a parallel consequence, haemophilia patients were largely neglected amid the pandemic. Its single national treatment centre was closed to patients, thus leading to an escalation of health problems for haemophilia patients.

What is known so far is that there is no strong evidence that suggests haemophilia is a risk factor for COVID-19. Both

non-haemophilic and haemophilic patients have shown similar symptoms of COVID-19.[12] As of this writing, the country has lifted much of the restrictions, and healthcare facilities are open to provide healthcare services for patients. Hence, we assume the situation of haemophilic patients has improved than the first wave of COVID-19.

3 | CONCLUSION

Despite tangible improvements and advancements in Afghanistan's healthcare system, haemophilia has seen little investment. The patients are exposed to low quality of life and low life expectancy due to insufficient diagnostic facilities, inadequate access to treatment and counselling services, lack of clotting factors and a prevailing financial issues. In light of the COVID-19 pandemic, Afghanistan's weak healthcare system focused solely on COVID-19, aggravating the health status of haemophilic patients. This paper argues the need for more attention to haemophilic patients. As responses to manage COVID-19 are being enhanced, other severe diseases such as haemophilia should not be neglected. Moreover, further research in this area is needed to find the exact and latest number of haemophiliac patients, to fill data gaps and better address the needs of the patients.

KEYWORDS

Afghanistan, challenges, COVID-19, Haemophilia, inherited bleeding disorders

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CONFLICT OF INTEREST

The authors declare that no conflict of interests exists.

AUTHOR CONTRIBUTIONS

Sayed Hamid Mousavi and Shohra Qaderi conceptualized the idea. Sayed Hamid Mousavi, Shohra Qaderi, Shekiba Madadi, Shamim Arif, Mohammad Yasir Essar and Attaullah Ahmadi wrote the draft of the manuscript, collected data and literature. Don Eliseo Lucero-Prisno III assisted in article interpretation and language edit. All the authors read and approved the final draft.

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