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Thalassaemia prior and consequent to COVID-19 pandemic: The perspective of Thalassaemia International Federation (TIF)

Androulla Eleftheriou
Thalassaemia International Federation, Cyprus

Introduction

Patients with haemoglobin disorders mainly, β-thalassemia, Sickle Cell Disease (SCD) or combined forms, on account of their underlying disease pathology and the increasing complications which occur with age, are included amongst the high risk categories with regards to their vulnerability to potentially develop more severe complications consequent to infection with SARS-CoV-2. Patients who require treatment from birth in order to survive, over time, develop serious multiple medical complications, including cardiac, hepatic, endocrine disease (e.g. diabetes, stroke, renal failure and other serious pathology. Optimum clinical management as those recommended by medical experts in International Guidelines (TIF Guidelines for the Management of Transfusion Dependent Thalassaemia), including multidisciplinary approach and specialized and timely monitoring can prevent or minimize these co-morbidities. Sadly however, international experience through published literature but mainly through TIF's work over 35 years, indicates that less than 10% of patients globally actually benefit form from such care, while the vast majority who are born and live in countries of the developing economies, face many and multiple challenges and high rates of morbidities and early premature death are common.

Despite the fact that epidemiological evidence and clinical outcome concerning SARS-CoV-2 infection in these patients are currently limited across the world, it is expected that COVID-19 pandemic may not only have serious medical consequences. It is anticipated that the negative impact of COVID-19 on national economies, healthcare and social systems will affect severely the service delivery in most of the countries where the majority of patients live. COVID-19 pandemic has brought to the surface many and multiple concerns on behalf of patients and deeply challenged heath care professionals and health care systems.

Thalassaemia International Federation (TIF) in this present paper summarises the key challenges as expressed by the patients, their families in response to a questionnaire and a series of webinars. The objective being to provide information to governments to recognize that these patients belong to a vulnerable category and so require special attention in terms of social protection, adequacy of supplies and priority in vaccinations.

Recent Publications

Books, Scientific Publications & Online Publications

1. A Short Guide to the Management of Transfusion Dependent Thalassaemia Thalassaemia International Federation, 2017, ISBN: 978-9963-717-12-5
2. Beta Thalassaemia, Alpha Thalassaemia and Sickle Cell Disease Educational Community booklet Thalassaemia International Federation, 2014, ISBN: 978-9963-623-96-9
3. Community Booklets: Beta-thalassaemia, Alpha-thalassaemia & Sickle Cell Disease Thalassaemia International Federation, 2013, ISBN: 978-9963-623-96-9
4. Haemoglobinopathies on the Move: Is Europe ready? Thalassaemia International Federation, ENERCA, International Organization for Migration (IOM), 2013
5. Prevention of Thalassaemias and other Haemoglobin Disorders, Vol 1, 2nd Edition Thalassaemia International Federation , 2013, ISBN 9963-623-39-5

Peer Reviewed Publications

1. COVID-19 and thalassaemia: A position statement of the Thalassaemia International Federation, Farmakis, D., Giakoumis, A., Cannon, L., Angastiniotis, M., & Eleftheriou, A. European journal of haematology, 10.1111. 2020. PMID: 32573838
2. The changing epidemiology of the ageing thalassaemia populations: A position statement of the Thalassaemia International Federation, Farmakis, D., Giakoumis, A., Angastiniotis, M., & Eleftheriou, A. European journal of haematology, 105(1), 16–23. 2020. PMID: 32198891
3. EHA Research Roadmap on Hemoglobinopathies and Thalassemia: An Update Iolascon, A., De Franceschi, L., Muckenthaler, M., Taher, A., Rees, D., de Montalembert, M., Rivella, S., Eleftheriou, A., & Cappellini, M. D. HemaSphere, 3(3), e208. 2019. PMID: 31723835
4. Haemoglobinopathies in Europe: health & migration policy perspectives, Aguilar Martinez, P., Angastiniotis, M., Eleftheriou, A., Gulbis, B., Mañú Pereira, M., Petrova-Benedict, R., & Corrons, J. L. Orphanet journal of rare diseases, 9, 97. 2014. PMID: 24980780
5. The role of Thalassaemia International Federation (TIF) in the promotion of global, regional and national policy of control of Haemoglobin Disorders – A brief overview., Eleftheriou, A. Thalassaemia Reports. 2013.
6. The impact of migrations on the health services for rare diseases in Europe: the example of haemoglobin disorders. Angastiniotis, M., Corrons JL., Soteriades, E.S., & Eleftheriou,

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A. Scientific World Journal. 2013; 2013:727905. PMID: 23576907
7. Cross-talk between available guidelines for the management of patients with beta-thalassaemia major. Musallam, K.M., Angastiniotis, M., Eleftheriou, A., & Porter, J.B. Acta Haematologica. 2013; 130:64-73. PMID: 23485589