

The Impact of the COVID-19 Pandemic on Patients with Thalassaemia & Sickle Cell Disease

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Questions and Answers:

1. What should a patient do in case of fever?

Response:

First of all, the cause of the fever may be any infection and not necessarily the COVID-19 virus. The possibility of fever, however, is greatly increased during the epidemic and advice should be sought as soon as possible. This does not mean rushing to the emergency department or the haemoglobinopathy clinic; such an act will increase exposure to the coronavirus, both for the patient and for the people in the healthcare facility. The first step should be an early phone call to doctor/s treating the patient, to the emergency phone numbers or the patient's family doctor, as advised by healthcare authorities dealing with the epidemic.

The response to such a call will be initially a series of questions to see what symptoms the patient has and then what contacts they have had which are likely to be the source of infection. Following these questions, advice will be given as to what to do next. Advice could vary from stay at home and take paracetamol to an emergency admission – each case will be different, based on a positive test result for the COVID-19 virus or other cause of the symptoms. The severity of the clinical picture will also be considered.

2. During the flu season, many clinics often suggest that patients should interrupt their chelation therapy (with any chelator) in the event of fever. Should this apply to the current pandemic?

Response:

The question concerning interruption of iron chelation is an important one. The original guideline was to stop chelation with Deferoxamine in the event of fever – this is related to the possibility of a Yersinia infection which DFO would make worse. However, stopping the oral chelators is not in the guidelines and patients should be counselled to

continue their treatment. Perhaps the only precaution is to more closely monitor the white blood count, especially for those taking Deferiprone, since agranulocytosis may occur (not due to the virus, but to the medication), which may predispose to a bacterial sepsis.

All this should be discussed with the treating haematologist and patients should not take the initiative to stop any treatment. Each individual case may have factors which will determine a medical decision for the benefit of that individual. Generalizations do not always help.

3. What should a sickle cell patient do in case of pain?

Response:

Pain may signal the onset of a sickle cell crisis. This does not mean rushing to the emergency department or the haemoglobinopathy clinic; such an act will increase exposure both of the patient and to the people in the healthcare facility. The first step should be an early phone call to doctor/s treating the patient or to the emergency phone numbers, provided by healthcare authorities dealing with the epidemic.

According to the patient responses, he/she may be advised to stay home and deal with the pain, through pain killers and adequate hydration. In case the symptoms get worse and the patient needs intravenous treatment, then the doctor should be able to direct the patient to the appropriate service.

4. There are also some questions as to who is more susceptible to infection by Coronavirus - there was one report that people with blood type A may be more susceptible, while those with blood type O may be less susceptible to infection. Is this true?

Response:

Blood group susceptibility has been reported from China, but this should be confirmed by new experience (now that the virus is spreading). The degree of susceptibility according to blood type should be calculated in a large number of infected individuals across many countries in collaborative study. Even if proven correct, this probably will not make much difference to the necessary control measures or the management of cases.

5. Do people with thalassemia trait (carriers of thalassaemia) have any increased susceptibility to acquiring Coronavirus?

Response:

There is absolutely no evidence that thalassaemia trait makes carriers more susceptible to the virus. Nor is there any logical reason why they should. Patients with beta thalassaemia trait (or minor) have no increased risk of infection from the coronavirus, compared to other healthy individuals. Therefore we advise you to follow your country's instructions to the general population.

6. *Patients are very worried about a shortage of blood as blood drives are being cancelled and donors become reluctant to come forward. Should they try to secure a pool of directed donors to help get them through a potential shortage?*

Response:

Shortage of blood is a major concern for many countries during this pandemic. Blood services are alert to this fact and TIF urges them to be proactive, so that adequate blood supplies are ensured. In the US, [AABB has already published guidelines on this issue](#), which is a great help to other countries also.

Developing a pool of donors for each patient is a good suggestion. This pool should be tested regularly for the virus and questioned about possible exposure, and of course be fully compatible with the recipient. Family members and the local community should be contacted to assist in locating volunteers to join the 'pool'.

7. *Should children with thalassaemia be kept home from school in the event that their school remains open during the pandemic?*

Response:

Children with thalassaemia with no vital organ complications may not be as vulnerable as adult cases with iron overload and affected vital organs. However, avoiding crowds is a good precaution for all patients.

Staying away from school as a protection measure depends on how fast the virus is spreading in the area where the patient lives. From most countries' experience, spread is rapid and TIF advice is to stay home after consulting with the local health authorities. Thalassaemia and sickle cell disease must be regarded as high risk groups.

8. *Should adult patients try to work from home when their employers are reluctant to allow this?*

Response:

Working patients must consider whether their work environment is exposing them to crowds and whether they are likely to come into contact with possibly infected individuals. In such a case, they must stay at home. In some countries arrangements have been made to ensure that no loss of earnings will occur for vulnerable patients forced to stay indoors and that these patients will be supported financially until the danger is over.

Patient support organisations must ascertain that this social support is provided and TIF is encouraging its member organisations to address this issue to their local authorities. Hopefully universal health coverage will help in that there will be no interruptions in treatment.

9. Are splenectomised patients in more danger from the COVID-19 virus?

Response:

Splenectomy renders all patients vulnerable to mainly bacterial infections, especially to the pneumococcus. Thalassaemia patients, particularly of the older age groups were frequently splenectomised and sickle cell patients have often a condition equivalent to splenectomy (functional hyposplenism or asplenia). This renders all patients vulnerable to bacterial infections and trigger serious and life threatening sepsis.

There is no direct danger from the COVID-19 virus in these cases, but if infected patients' progress to a more severe disease (mainly pneumonia), they may also develop secondary bacterial infections. All patients should ensure that they have received the relevant vaccines for their protection (Pneumococcal, haemophilus influenza type B and Neisseria meningitides).

10. Should I wear a mask when I go out?

Response:

Masks should only be worn by individuals with upper and lower respiratory symptoms (such as cough or fever) and those caring for infected patients, either at home or in a healthcare facility. Health workers in contact with the public, e.g. those coming to an emergency room or outpatient clinic, should also wear a mask. If you have no symptoms, there is no need to wear a mask unless in a crowded environment.

11. I saw that WHO recommended that people with COVID-19 symptoms avoid taking ibuprofen: https://www.sciencealert.com/who-recommends-to-avoid-taking-ibuprofen-for-covid-19-symptoms?fbclid=IwAR2QQqYe_TQHGCRKbj8BMf7yE5qqTenhURygXAC-z9JA30ErFUmlqdfTLbo

Response:

Most infectious disease experts say there's no good scientific evidence at this point to support the claim that non-steroidal anti-inflammatory (NSAIDs) products, including ibuprofen, used for the alleviation of COVID-19 symptoms, may have adverse effects on the course of the disease. However, the medical community should stay alert to the possibility and issue a report as more cases are treated and affected patient histories are taken.

Steroids, on the other hand, like prednisone and hydrocortisone taken orally (not so inhaled steroids), may reduce the immune response and should be used with caution. Patients on these medications, especially those on high doses due to pre-existing conditions, should be put in a high risk category, despite inadequate clinical experience at present. Patients, however, should not discontinue any medication without the treating doctor's advice.