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WFH Webinar: Stepping Up and Not Stepping Out A Nursing and Psychosocial Perspective to COVID-19 May 4, 2020

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MANAGING HEMOPHILIA AND COVID-19 IN DAILY LIFE

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Keeping in touch with your hemophilia team and treatment centre

All hemophilia treatment providers are available at all centres and continue to provide care. However, accessibility of hemophilia treatment centres during the COVID-19 pandemic will depend upon the national, regional and hospital advisories. The delivery of services and care may differ from usual. Nonetheless, people with hemophilia should rest assured that their hemophilia team is still at work, readily available, and overseeing their care.

The global crisis may lead to faster implementation of some modern techniques, such as clinical consultations by video. In many countries, video-calling using computers or mobile devices is accessible and these means of communication are available almost all over the world. People with hemophilia and family caregivers are advised to ask their hemophilia centre about options for telephone or video consultations.

COVID-19 ordinances and precautions, including approaches to COVID-19 screening and testing and preventive measures such as wearing of face masks in public, vary from country to country and place to place. It is advisable that individuals with hemophilia who test positive for COVID-19 inform their general doctor and/or hemophilia treatment centre.

Accessing the centre or hospital for treatment

For those who need to go to the treatment centre or hospital for bleed treatment, services might be provided elsewhere in the hospital or at a different hospital. Consult the specific regulations of your country, region and local hospital, and find out whether hemophilia treatment is still being provided at your centre, or elsewhere. Speak to your hemophilia team or general doctor about what to do in the event of an acute bleeding problem that requires going to the hospital.

Some hospitals may have special designated areas for suspected and non-suspected COVID-19 patients. Some entrances may be restricted and it may be necessary to enter the hospital by a different way than normally. It is also possible that extra precautions will be in place to minimize the number of visitors to the hospital. For instance, drop-in clinics may be suspended, appointments may be limited to certain hours, or entry may be restricted (e.g., only one parent allowed to accompany a child).

Some hospitals may have arranged for patients with hemophilia to have their bleeds be treated through home administration of factor concentrates. In some instances, young doctors have been trained in a very short time to visit patients at their homes to treat bleeding.

Surgery in COVID-19 time

Many countries in the past two months have postponed all planned surgeries until after the COVID-19 pandemic, but hospitals and hemophilia treatment centres continue to provide emergency surgical care if needed by any individuals presenting with acute medical emergencies. It is important to alert the emergency staff and physician that the patient has hemophilia or other clotting issues.

During the pandemic period, depending on local circumstances and government and hospital regulations, some aspects of surgical care may differ from usual. Length of hospital admissions may be shortened, patients may be restricted to having only one visitor or none, and follow-up may differ from normal processes.

How to manage stocks

The amount of factor that people are able to keep at home, at the hemophilia treatment centre, or in the region depends very much on where they are in the world. In countries and regions able to purchase clotting factor concentrates directly from the pharmaceutical companies, predominantly in Europe, the Americas, and Australia, there are no problems with factor supply and ample stocks to be able to treat all patients with bleeding disorders whether in clinic or for home therapy.

For those who receive treatment products via WFH humanitarian aid, the WFH is working very closely to ensure continued delivery of factor products into the countries. However, in some cases, there may temporarily be lower factor supplies and patients may be asked to be more cautious about the amount of factor being stored at home that isn't being used, to use lower doses, or to not use factor to treat smaller bleeds (in some cases, using alternatives such as DDAVP and/or tranexamic acid) to try to eke out the stock that is available.

In some countries, factor products can be delivered directly to patients at home via home care pharmacy companies but there are many countries where this is prohibited by law. The European Haemophilia Consortium (EHC) and the European Association for Haemophilia and Allied Disorders (EAHAD) have been able to get legislative changes to allow patients with hemophilia and other bleeding disorders to have factor delivered to them at home, which may consist of only one or two doses or sufficient supply to continue with their full prophylaxis.

With home delivery, patients who would ordinarily go to the hospital for their treatment or medications will no longer have to travel. This reduces their potential exposure to COVID-19 in hospital and in public spaces. It is hoped that after the pandemic is over, home therapy for people with bleeding disorders will be taken up and become the standard globally.

Pain management

It is recognized that many patients who are having bleeds are not treating with factor; some might think they can get away without factor treatment because they are currently less active, or some might not have access to factor at home or cannot get to the hospital for treatment. Even if a patient does not have access to clotting factor, treatment can be provided for pain from bleeding.

Bleeding pain can be treated and managed as ordinarily, using analgesia/painkillers and applying PRICE (protection, rest, ice, compression, and elevation) as appropriate.

With COVID-19, it is important to be aware and cautious about how some medications can affect people with bleeding disorders. There is some suspicion that some of the non-steroidal anti-inflammatory drugs (NSAIDs), particularly Nurofen®/Orbifen®, might have an impact on COVID-19 outcomes. Generally, as a rule, people with bleeding disorders are advised to avoid NSAIDs because they can interfere with blood clotting. Any patients who do take NSAIDs should discuss their use with their hemophilia team.

Managing normality in everyday life

It is important to obey the rules in your geographic area about going outside in public spaces and social distancing. As much as possible, people with bleeding disorders should continue to do the types of physical activities and exercises they would normally, and continue to follow precautions regarding activities not suitable to their condition.

There are many websites and social media platforms with both general and hemophilia-specific exercise advice. Many treatment centres will have information and resources developed by hemophilia physiotherapists. Consult your physiotherapist for hemophilia-specific advice on exercising and staying healthy.

There is a lot of concern among about how to manage your family if you yourself are sick. Think about who you could ask for help – a family member, friend or neighbour who can help with getting groceries or other tasks. Reach out for help from people in your community, including people that you wouldn't normally do. Those who are well should reach out and help others.

Being confined at home and restricted from going outdoors can be challenging, especially for those unaccustomed to being at home all the time with everyone they live with. Think about activities and new hobbies that can be done at home, such gardening, reading or painting, to help get through this time.

Take it one day at a time. Don't dwell on how long the pandemic will last – get through today and see how it is tomorrow. Do your best to remember and celebrate the good things – a birthday, a sunny day, a good rain for your flower or vegetable garden.

DEALING WITH ANXIETY AND FEAR IN COVID-19 PANDEMIC WORLD

Richa Mohan, MA M.Phil., Clinical Psychologist, India

The COVID-19 pandemic understandably may trigger a variety of mental health issues and potentially cause existing conditions to flare up. Common reactions, which vary from individual to individual, include panic, distrust, uncertainty, confusion, and anxiety.

Anxiety, fear and concern

Fear is the natural response when human beings encounter danger; it is a protective and adaptive response that involves fear, apprehension and appraisal of the danger, and a “fight or flight” response to reduce harm to oneself. Anxiety differs from fear in that it is not a reaction to danger or harm, but rather an emotional reaction about the consequences of an event, in this case COVID-19 pandemic, rather than the event itself.

For those experiencing anxiety for lengthy periods of time, it is important to pause and think about the triggers and nature of their anxieties and emotional reactions, e.g., loneliness due to isolation, discomfort about job loss or unproductivity, anxiety about access to treatment, or helplessness due to the uncertainties of COVID-19. Unhealthy emotions include depression, unhealthy anger, anxiety, and hopelessness. In contrast, healthy emotions include sadness, healthy anger, concern, realistic optimism.



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Concern can replace fear when there is no immediate threat and allow individuals to retain their hypervigilance for high-risk circumstances such as when they are out among other people at the hospital and other public spaces, or receiving home deliveries of factor products or other items.

It is important to manage worries and anxieties productively. Focus on immediate rather than abstract problems. Accept risk and uncertainty. Experiment with solutions and coping strategies. Focus on preventing or reducing harm. Seek out resources and support.

Effective ways of dealing with the COVID-19 situation

Appraise the realistic risks and your personal coping resources, and identify strategies and activities that can give you a sense of accomplishment and control. Activities such as organizing your immediate surroundings (e.g., your work and living areas at home), cooking and gardening produce immediate and satisfying results.

Maintain a sense of belonging and community with friends and relatives by telephone, e-mail, video chats, and social media. Renew connections with those you have not been in touch with in some time.

Assess how you are feeling and coping, identify unhealthy and unproductive reactions, and figure out practical and productive ways to deal with the challenges. Develop a routine or plan of daily activities and follow it rigorously.

Obtain accurate and up-to-date COVID-19 information from reliable sources and limit the amount of time you spend reading, watching or listening to news related to the pandemic, which can cause information overload or trigger anxiety. Be aware of misinformation and conflicting information, especially on social media.

ISOLATION: BEING ALONE BUT NOT BY YOURSELF: NAVIGATING THROUGH FEELINGS OF ISOLATION AND SOCIAL DISTANCING

Edward Kuebler, MSW, LLC, WFH Psychosocial Committee Chair

Social distancing and isolation

Many countries around the world have put in place social distancing directives during the COVID-19 pandemic. Social distancing refers the practice of maintaining physical distance from other people and avoiding direct contact with people or objects in public places during the outbreak of a contagious disease in order to minimize exposure and transmission of infection.

Isolation refers to the state of being in a situation that is separate from other people or places. Social distancing can lead to feelings of isolation and psychological issues if people stop interacting with others – but this can be avoided by continuing to have social interactions with other people, including engaging in conversations and activities at a safe physical distance while following precautions such as wearing a mask.

Managing feelings of fear and hopelessness

For many people, including healthcare providers, the pandemic can provoke feelings of isolation, fear, anxiety, and hopelessness. It's important to understand some of triggers of these emotions, which can sometimes be connected to our childhood memories and past experiences, to be able to manage these feelings productively.

An effective coping strategy is to shift away from unhealthy emotions to focus on the actual challenges and the steps that you can take to adapt in order to stay safe and physically and emotionally healthy. It's important to remember that while the pandemic is causing major changes in our social interactions, we're not necessarily losing our support – but we're having to redefine how we connect with one another.

Navigating through fear and isolation

The COVID-19 pandemic requires us to change the way we live our lives. Some people with bleeding disorders and their families are experiencing major changes and some have expressed fear of not having access to clotting factor concentrates and other treatment. It is important to have a good understanding of the situation and find ways to navigate through it.

Most people in the bleeding disorders community have been through some very difficult circumstances and events in the past, from which we have gained resilience and remarkable skills. It is important to remember getting through the challenges individually and as a community, and apply the knowledge and skills learned to this pandemic – while recognizing that we are facing new challenges and uncertainties.

To navigate through the crisis, it's important to step back to get a broader perspective. Looking at the big picture, rather than focusing on the details, allows us to see things in a different way. By changing our outlook, we can often see other options, opportunities and possibilities.

Defining a new normal – for now and going forward

The pandemic requires us to change our behaviors and do things differently within the boundaries in place. It requires letting go of what we know, adapting to the new reality, and defining a new normal for how we interact with other people and how we live our daily lives.

For now, this includes staying informed on the situation and taking the necessary precautions – wearing a mask, frequent hand washing and social distancing – to protect ourselves and those around us. This will allow us to take back our power and define what we need and want our lives to look like going forward.

QUESTION & ANSWER PERIOD

GP: We are now going to move into a question and answer period. Before we do that, I do want to offer a special thanks to the Hemophilia Alliance. It's an organization here in the United States which works with most of our hemophilia treatment centres to provide clotting factor. Joe Pugliese of the Hemophilia Alliance has been funding travel grants, but since we are not travelling, he offered to fund webinars such as this and we appreciate that. We'll now go into questions and answers. We had a few that came in ahead of time.

I am very worried about the situation, what can I do to worry less?

RM: I have already shared a slide of productive and unproductive worry, and worry is one reaction to this situation. So, you can self-test yourself on a 1 to 10 scale of where your worry lies. If it is less than 5, then you are in the lesser worry situation; and if it is more than that, then look at the slides, which will be available to you and you can adjust your reaction and move yourself to productive worrying.

How can I overcome the mental stress from COVID-19 that results in skipping doses?

EK: The short and fast answer is: don't skip doses, no matter what. However, we did just go through some information about anxiety, stress and fear that can affect our normal routines. I would advise

anyone wanting to know how to manage this particular question to put your health first, to make sure you're doing everything you need to do to manage your bleeding disorder, and if you're having some issues around being depressed and not wanting to do things, that you reach out and talk to someone. But by all means, at the top of your chapter that you're going to write is, "I will take my doses and keep myself healthy."

What if you don't have the doses to take?

EK: So not having the doses definitely changes the situation. And as we know from before COVID-19, there are things we can do to protect our joints; there are things we can do to try to manage our bleeding disorder without having factor concentrate. And those are going to be really important at this time – that you do the things you know to do, to remember the things that you have learned so you can manage through this until we can get all of this in a better place. Definitely, if it starts changing how you feel, reach out and talk to somebody. But remember what you know about how to care of yourself in lieu of maybe not having enough factor.

How can I manage my fear and concern about my child/children?

RM: We have already talked about the strategies to manage the fear and concern. When it comes to the children, it is a little tricky situation. But you can, according to the age-appropriate child, still divide the tasks and work them into the household chores these days and they will willingly and happily do that. Again, the routine should not be disturbed; their study time, their playtime. Also of course we have talked social media; sometimes they can contact their friends through social media or through video-calling so that they feel that connectedness with their friends. So these could be some of the strategies that will bring down the fears and concerns of children.

Do you have advice to help parents manage the different, scary news about covid-19? How can I deal with unknowns?

GP: We've gotten a question on Kawasaki syndrome; a couple of more have come in as well. Flora, if you just could provide a broader perspective. Every week we are learning about a new organ system that is affected. So we have COVID toe, we have Kawasaki in small children. What should we be thinking about, with regard to the disease process as well as the virus that causes it?

FP: Regarding the disease, it's very important to understand how the disease is happening. As you know, the virus is attacking and making a big impact to the endothelia and that is happening mainly at the lung level but that's not the only endothelium, it could happen everywhere and that's what we are hearing everyday – the different clinical picture and that depends on which stage the patient arrives to our observation. So that's the reason why at the beginning of this epidemic, we were seeing the patients with problems such as respiratory failure or lung issues. But now we are starting to see other types of symptoms, like gastrointestinal problems, or dermatitis, or even you see in the children a new symptom like lupus or Kawasaki – because I think that's all the inflammation defense of our body against this virus attack to the endothelium. And that's the reason why we are facing off with a different picture.

So what we need to know, what I think for this audience is important to know, is that we are facing off with huge inflammation, at least in the first month. Because I think things are changing now, for two reasons. First, because the patients are arriving earlier. Secondly, I don't know if the virus is changing and is adapting to our life. But the severity of the disease seems to be less severe. But at the beginning they had huge inflammation due to the activation of the endothelium, which leads to the activation of the coagulation and sometimes also the autoimmune system could be activated, and that's I think what we are seeing everyday with the different picture.

Should I change my child's treatment (e.g., increase infusion frequency?)

GP: Along those lines, there's a related question: Is it possible to have more bleeds because of stress and anxiety?

KK: I don't think you should change your child's infusion frequency unless there is a reason to do that, that is bleeding disorder related. Two reasons for that. One is if you only have a limited amount of stock, of factor, and you use it up and can't get anymore, then actually you won't have any factor to treat your child or yourself if you bleed. And unless you're moving from on-demand treatment to prophylaxis in a way that was already planned, there is no real reason to change. What I would say though is that if you're on prophylaxis and you're supposed to give it to your child three times a week and you've only been doing it twice a week, then actually there's an argument that you should try to stick to the treatment as prescribed because if we can stop your child from bleeding or you from bleeding so that you don't have to go to hospital, then that's obviously the best situation for everybody. With regard to stress causing more bleeds, I have heard arguments in both directions. So some people say they bleed more when they're stressed. I think if you're thinking about why that might be – if you're rushing around and you're maybe a little less cautious than you normally would be, you might be more likely to fall and injure yourself. So perhaps you might bleed a little bit more. I don't think there's any real reason that we could explain other than that as to why that might be.

I am getting restless at home, what can I do?

KK: I think as Richa said earlier – it's trying to maintain the normality of your life. So, getting up in the morning and getting dressed and going out for a walk if that's what you normally do. Going out to work if you're allowed and if you can. To think about if you have children, trying to do some schoolwork with them but also not making it too stressful at home. It's not all about education in terms of book learning, you could be teaching your children new skills, maybe painting or making cake or something. So try to do some things, and plan to do them and do them if you can. If you're allowed out to take exercise, even if that's just walking the dog or walking around the park, then try to do that as well. Because actually being outdoors does make you feel better.

Are there psychosocial risks associated to the end of self-isolation/confinement?

EK: I was trying to understand what this question was asking about psychosocial risks to being able to now go out and be around people and be out and about. I'm not sure what the risks would be other than getting too happy and too excited and running around but I think it's just important that it will be again a change but it will take us back to hopefully our normal, or a part of our normal. And remember that's very important for how we will feel psychosocially, psychologically, is that it's then reminding us that we still have some things we have to pay attention to, but definitely taking us back to a normal. So I'm not sure of any psychosocial risks. I don't know if Richa has any ideas on that but it seems like it's a pretty good thing if we can get to the end of self-isolation and confinement.

RM: Just to add a bit. It could be... what we can understand here from the psychosocial risk of the pandemic, is what could be the mental health? And people can still be anxious and still be fearful. So as we have already talked about, look at the strategies, look at the things which you were doing before. It has to be contained and it has to be done regularly even in the post-lockdown or COVID-19 situation.

EK: I was also thinking, even before the webinar was set up, that there will be some issues around post-traumatic stress, especially for those people that have been on the front lines, those people that this has triggered some things for. And it may be important to pay attention to, as Richa was saying, some of these things post-pandemic that we see showing up and that we need to be aware of. So other than just the joy of, now I can go out of my house for a lot of people, this can create some stress or post-traumatic stress disorder can come out of it. So it definitely is something to pay attention to, and maybe what this person asking the question was referring to.

How will this affect the countries on factor donations?

GP: The WFH Humanitarian Aid Program is continuing and under the leadership of Assad Haffar they have had to get very creative with some of these shipments. Many small airports have been intermittently closed, not only to passengers but to cargo. And so we've have some spot shortages in various countries that were due for a shipment but because of COVID-19 have not been able to receive it. I think that the team in the WFH headquarters in Montreal has been able to deal with most of that, but it has resulted in some compromise in the treatment plans for patients, which is difficult. So people that were on some prophylaxis we've asked each of the treatment centres to restrict it as needed based upon their supplies until we can get more to them. We have some related questions.

The community in the past has gone through HIV – are we more prepared? And along with that, have you noticed that the past traumas for people with bleeding disorders are coming up again in the midst of this trauma?

KK: I think that as a community, certainly people with hemophilia and other bleeding disorders, have gone through already horrible stories that they have coped with and that shows a huge degree of resilience within the community, and I think that is something that you can share and continue with as individuals to be resilient and to cope. And I think you've got through other things, we'll get through this. I don't know; I haven't come across anybody who is suffering more about HIV now than they were before.

MB: Yes, I've seen a lot of them but as you've already said, there is a lot of resilience and I think we can get through this as well.

FP: I think actually this is not really comparable to HIV and we have to differentiate these situations. In that I think the situation that we were living was really something related to this society. And it was completely different. Fortunately for COVID-19, there is no association between coagulopathies and COVID-19 infection – and that should be made very clear for the patients. All the discussion is around, if a patient with coagulopathy gets infected, how we have to face off with that. But over there, there was a high association between the HIV and the situation of the patients with coagulopathies. But here the situation is completely different; I would differentiate that.

GP: There is another question regarding antibodies against COVID-19. I just saw the summary of the last couple of days' news this morning. And we still don't know for sure if developing antibodies is protective from reacquiring COVID-19, or protective from you transmitting to another person. There is a little controversial information, yes or no, so I think within the next couple of weeks we'll have a better understanding of what antibodies can and cannot do. But for now it's not clear so hang on and stay in touch with the news.

Another question on non-steroidal anti-inflammatories for joint pain.

FP: I saw the presentation. I think there is no scientifically valid association to confirm that we do not have to use a specific drug. A part of what we know, we cannot use aspirin, we cannot use those drugs that could alter the coagulation in the first step and interfere with the work of the platelets. So that kind of product we were not using anyhow. But a part of that, I think no really scientific recommendation could be done for any specific drug. So the most important information that I want to say is, start the treatment as soon as possible because once the endothelium gets attacked, the inflammation is starting. The process is like a cascade, you cannot block it anymore. The most important thing is to start the treatment as soon as possible.

GP: I think I've covered most of the questions. If anyone sees a question I've missed, feel free to jump in. There is one other. Some people have lost their jobs and are really in some more severe financial



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difficulty than they may have otherwise been. Do any of our panelists want to comment on that situation? It affects everyone but in our particular community, the impact of that?

EK: I would comment that it is really challenging because I'm watching the news every morning and they list in the United States how many people are out of work, how many people are filing for unemployment. And then you take that to other countries, and then countries that have less than we do, it has to be very, very devastating and it has to be frightening for a lot of families. And what I look for in those reports from trusted news sites is that there are places that are helping, there are places that are helping with food if you need it. I see a lot people, organizations and private companies stepping up, at least here in the United States, to help with food. I see there is news about a lot of the institutions, banks and places are giving a grace period for home loans and things like that. So I don't know that there is a good answer to that, other than some of the skills that we talked about in this session and some of the things that you can do at least within your own homes and where you are, is to try to not sink into it with the realities going on around you; that I just don't have enough, how do I feed my family, how do I take care my rent. There is no easy answer for that, other than to get rid of this virus, to do everything we can to minimize what's going on down a place where we can get to work, we can get back to the things that are important. So I wish I had something more other than look locally where you live and see where there are places that are offering support. And as someone said in the talk, ask for help. As I said, I listen every day and I hear about new resources every day, so that would be my only thoughts and suggestion on that.

FP: If I can add something. I think it is probably a political issue but I think we do need to have a kind of harmonization about how do face off with this phase 2 step, because there is such a heterogeneity even in Europe. So today for the first time fortunately after two months we are opening partially in Italy. But you know the children will stay home but some of the mothers should start to work, but how can they? So there is really not good organization and I think that's really a difficult big issue but it's not an easy job for the government. I think they have to put together and they have to come up with a harmonized way and thinking of people and the future of this society.

MB: Here in the Netherlands as well, schools will be opening again and parents are very afraid of sending their children into the schools again and I hear a lot of anxious parents saying should I keep my child at home, should I send them to school. And I agree there has to be equal advice of what is good or what is dangerous.

GP: You both have raised an important full category of issues in the phase 2 for reopening each of our countries and the stresses that we'll undergo there. So I think that could wind up being the topic of another webinar in the near future, something for us to consider, because there are a lot of variables. We share common ones, but we're all on different timelines. With that. I think we've covered it all and I'm going to sign off. I want to thank our panelists, for a well-organized and coordinated series of presentations; and thank our audience for all of the comments. Many comments have been raised in both the chat box as well as questions and answers. So if you've been tracking those, a lot of good ideas have also come up from that. Thank you all.

With special thanks to Hemophilia Alliance.