

Emotions and Opinions of Adult Patients with Haemophilia During the COVID-19 (Coronavirus Disease 2019) Pandemic Caused by SARS-CoV-2: A Monocentric Survey

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Background

The ongoing pandemic calls on doctors to cope with new specific patient needs, associated with the isolation and need to avoid face to face contacts if not strictly necessary. Following some calls by haemophilia patients followed by our Reference Regional Centre for questions related to regular replacement therapy with factor VIII and IX concentrate supply and availability, and also for reassurance related to safety of plasma-derived concentrates from Coronavirus potential infections, we have sent by email or mobile apps a short survey to our patients with severe haemophilia and asked them to reply within 24 hours. The survey was elaborated by our psychologist with the following questions: How much are you concerned about the regular replacement treatment supply and safe drug production process during the COVID-19 pandemic? The only available option to avoid further widespread infection is isolation, do you feel the weight of this? Do you agree that anxiety and worry do not help in the management of this emergency? How important for you are the support and availability of the haemophilia centre personnel? For each of the above reported questions, according to a Likert scale, patients may select one of the following four options: not at all, a little, well enough, very much. Further, the following open question was reported: How are you personally coping with the COVID-19 pandemic? The survey was sent to 30 patients, 23 of them replied within 24 hours. We report here the survey results.

Methods

The COVID-19 (Coronavirus Disease 2019) pandemic may determine psychological consequences that have been partly already evaluated in the general population,¹ in patients with cancer² and among healthcare practitioners.³ Patients affected by severe inherited bleeding disorders requiring chronic treatment, either on demand or prophylactically, may experience further unique fears during the pandemic. In the current short survey, we aimed to evaluate the impact of the pandemic and isolation measures on Italian patients with haemophilia under regular prophylaxis followed by our Reference Regional Centre. Following several phone contacts with the centre by patients with haemophilia for concerns related to the availability of

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coagulation factor concentrates and their regular supply, our psychologist developed a short survey and sent it by email or mobile apps to patients with haemophilia under regular prophylaxis with coagulation factor VIII and IX. The following questions were reported: How much are you concerned about the regular replacement treatment supply and drug production process during the COVID-19 pandemic? The only available option to avoid further widespread infection is isolation, do you feel the weight of this? Do you agree that anxiety and worry do not help in the management of this emergency? How important for you are the support and availability of the haemophilia centre personnel? For each of the above reported questions, patients may select one of the following four options on a Likert scale: not at all, a little, well enough, very much. Further, the following open question was also reported: How are you personally coping with the COVID-19 pandemic? The survey was launched on 25 March 2020 and remained open for 24 hours. The survey was sent to 30 patients with haemophilia A and B, inhabitant in the city of our Centre (Palermo, Italy); overall, 23 patients replied. Each participant, before taking part in the survey, formally agreed online to participate and to share results in respect of current regulations on privacy. The survey was notified to the Internal Review Board of the University Hospital “AOUP, P. Giaccone”, Palermo (approval code 138/2020). The current study complies with the Declaration of Helsinki.

Results

Table 1 summarizes the demographic characteristics and social status of respondents. Patients were concerned about regular drug supply and production, and they were anxious and frightened. Most patients judged the support and availability of the haemophilia centre personnel as

Table 1 Demographic Characteristics and Social Status of Patients with Haemophilia Responding to the Survey

Characteristics	n
Number of patients	23
Mean age, years (range)	29 (18–63)
Haemophilia A	21
Haemophilia B	2
Under regular prophylaxis	23/23
Employed	12/23 (52%)
Student	5/23 (22%)
Unemployed	3/23 (13%)
Waiting for first employment	3/23 (13%)
Married	10/23 (43%)
With children	7/23 (30%)
Single	13/23 (56%)

sufficiently important (Table 2). Answers to the open question reported a high to very high level of fear for the current situation. The very high response rate to the survey (76.6%) reported within 24 hours shows that most haemophilia patients stayed connected and needed to share feelings and actively communicate with the treatment centre during the pandemic and isolation. Living close to the hospital does not seem to mitigate the fears related to the COVID-19 pandemic. Isolation shows an equal distribution among all the qualitative options proposed. Patients with severe haemophilia may thus commonly experience this feeling in their emotional life, regardless of the pandemic. This may mirror the individual impact that suffering from an inherited bleeding disorder has in contemporary society, even if current treatment strategies and haemophilia comprehensive care aim to guarantee a “normal” life. Current results have helped us, first, to better deliver information related to regular drug availability and supply; after this survey we have contacted by phone all of the patients followed at our

Table 2 Questions and Responses to the Survey

Questions	Very Much	Well Enough	A Little	Not at All
How much are you concerned about the regular replacement treatment supply and drug production process during the COVID-19 pandemic?	14/23 (60.9%)	9/23 (39.1%)		
The only available option to avoid further widespread infection is isolation, do you feel the weight of this?	5/23 (21.7%)	7/23 (30.4%)	9/23 (39.1%)	2/23 (8.6%)
Do you agree that anxiety and worry do not help in the management of this emergency?	15/23 (65.2%)	7/23 (30.4%)	1/23 (4.3%)	
How important for you are the support and availability of the haemophilia centre personnel?	13/23 (56.5%)	8/23 (34.8%)	2/23 (8.6%)	

Notes: Blank cells indicate no value.

Reference Regional Centre to better explain that quarantine will not interfere with regular treatment availability, supply and safety of the commercially available factor concentrates (either recombinant or plasma derived). International⁴ and national⁵ haemophilia foundations had already published online recommendations for people with haemophilia during the COVID-19 pandemic at the time this survey was sent; however, our results have highlighted the need for patients to receive personal reassurance about the local condition and directly by their treating physicians, measures recently reported as effective tools to afford the pandemic.⁶

Conclusion

Inherited rare bleeding disorders require specific management. Italian physicians are currently living for the first time with the strong measure of quarantine, this may impact their work and behaviour; fears and opinions expressed in the current short survey will help to continue to take care of haemophilia patients with their new needs during isolation. Haemophilia treaters are now called to adapt and help patients by digital tools and social networks during the COVID-19 pandemic, and the healthcare professionals will also need to be supported and adequately trained to afford the potential long-term changes after the quarantine period.

Ethics

The survey was notified to the Internal Review Board of the University Hospital “AOUP, P. Giaccone”, Palermo (approval code 138/2020). The current study complies with the Declaration of Helsinki.

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Author Contributions

All authors made substantial contributions to conception and design, acquisition of data, or analysis and interpretation of

data; took part in drafting the letter or revising it critically for important intellectual content; gave final approval of the version to be published; and agree to be accountable for all aspects of the work.

Disclosure

MN acted as consultant for Bayer, BIOFVIIIx, Novonordisk, and Amgen and received speaker fees from: Kedrion, Octapharma, Baxalta, CSL Behring, Novonordisk, and Bayer. SS acted as consultant for Bayer, BIOFVIIIx, and Novonordisk and received speaker fees from: Kedrion, Octapharma, Amgen, Baxalta, CSL Behring, Novonordisk, Bayer, and Novartis. All other authors have no relevant conflicts of interest to declare.

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