

LETTER TO THE EDITOR

Care for children with haemophilia during COVID-19: Data of the PedNet study group

The care of hospitals was compromised due to the COVID-19 pandemic in 2020. The hospitals needed to make adjustments for the incoming COVID-19 patients, which had an impact especially on the care for outpatient clinics. In haemophilia, concerns about the impact on treatment for patients were raised.¹ Especially in young children not yet on home treatment, acute care for the treatment of bleeds for patients might have been jeopardized. This was reason for the PedNet study group for a survey on this topic in the participating centres.

The PedNet study group is an established network of 31 haemophilia treatment centres (HTCs) from 18 countries specialized in the treatment of children with haemophilia (www.pednet.eu).² A survey was designed and agreed upon by three members of the group including the topics that seemed most relevant and send to the principal investigator of each centre. It collects data from 11 March 2020, in which the WHO declared the COVID-19 outbreak as a pandemic until July 20th and investigated the following aspects of care; the access to the HTC, use of telemedicine programme, supportive care, the way patients were informed about changes, treatment, clinical trials and external monitoring schedule. The full survey was only sent once to the centres and a single specific question about if there were any delays in acute care, and the start of prophylaxis in young children was added in December 2020. All centres who initially responded also respond to the second query.

A total of 20 (64%) centres out of 31 participated in the survey. Of these centres, 18 were from Europe, one from Canada and one from Israel. None of the HTCs had cancelled all outpatient clinics, a telemedicine programme was used in 65% of HTCs, and supportive care was not in its usual form in most HTCs (Table 1). The HTCs used different methods of informing the patients about the changes in care; the most popular way was to phone the patients individually (65%). The continuation of prophylaxis was realized in all children with severe haemophilia although it has not been evaluated whether the prescribed doses coincide with those administered and therefore whether the patient's adherence has not been modified by the situation. Clinical trials were affected in 35% of HTCs, and in only 15% of the HTCs did recruitment continue. External monitoring continued in 10%. HTCs reported no delays in acute care and the start of prophylaxis in young children.

There has not yet been any research published on the impact of the pandemic on children with haemophilia. This survey shows that no outpatient clinics were cancelled; however, some

HTCs implemented telemedicine instead of face to face meetings. Prophylaxis treatment continued in all patients; however, clinical trials were paused in some HTCs. We will repeat a survey at the end of the pandemic and analyse our data on bleeding and treatment to offer a more complete picture of the effect of the whole pandemic.

A survey among German patients and caregivers of children with inherited bleeding disorders was performed about the impact of COVID-19.³ Caregivers reported to feel well taken care of by doctors despite having more thoughts, worse feelings and worries caused by the pandemic than the adult patients. Almost all patients and caregivers found their HTC to retain their accessibility even though doctor's appointments were postponed or cancelled. This is in concordance with the findings of current survey.

The accessibility of HTCs could be affected by the pandemic.¹ For instance, during the lockdown in Wuhan, China, meetings in person were not feasible.⁴ In a quarter of the HTCs of PedNet, outpatient clinics resumed as usual.

The use of distant communication and telemedicine is a measure to continue treatment in HTCs instead of face to face meetings.⁴⁻⁸ Telemedicine has been used to help persons with haemophilia prior to the pandemic.⁹ The patient's response to telemedicine has overall been very positive.⁸ Telemedicine programmes were used in the majority of the HTCs of PedNet. Most HTCs phoned the patients individually to inform them about new developments in care.

Regular prophylactic treatment could continue in haemophilia patients in the epicentre of the pandemic Wuhan, China.⁴ In the HTCs connected to PedNet, this was also the case.

The availability of supportive care, such as physiotherapy, home care by nurses and summer camps, could also be compromised by COVID-19. In an HTC in Ireland, the number of physiotherapy consultations was lower than the year before and after the introduction of telemedicine; the number was higher than the year before.⁸ In almost all of the PedNet HTCs, physiotherapy was not available as usual. We saw that especially physiotherapy care was decreased to only 15%. Home care by nurses and social workers was available as usual in as many HTCs as it was not. Summer camps were only held in one HTC.

It should be mentioned that covering the usual needs but doing so in most cases by using telemedicine.

Telemedicine and the use of the app by the patients during the pandemic is essential to inform the patients about the changes made in the HTCs and to identify those who need to go to the centre. This


TABLE 1 Results of the survey in percentages

		%
Limited access to HTC	All outpatient clinics resumed as usual	25
	All outpatient clinics were cancelled	0
	For outpatients, emergency visits were allowed	55
	Other	20
Use of telemedicine programme	Yes	65
	No	35
Supportive care available as usual	Homecare by nurses	40
	Physiotherapy	15
	Social workers	45
	Summer camp	5
Informed about changes	By sending letters	15
	Via website	15
	Via phone individually	65
	Via webinar	10
	Other	30
Treatment	Continuation prophylaxis in severe patients	100
Clinical trials	Affected	35
	Continuation of recruitment	15
Change in external monitoring schedule	Cancelled by HTC	40
	Cancelled by CRO company	15
	Cancelled by HTC and CRO company	25
	Continued as usual	10
	Not applicable	10

Note: All the centres answered all the questions, but they did not add up to 20 (100%) since any of them were a multiple choice question.

way, all of them will be properly treated at an early stage, minimizing the risk of being infected in the centre. It is essential for the duration of the pandemic to treat patients early and adequately, minimizing the risk of infection by going to the centre.

All HTCs have taken great care in the paediatric population without neglecting the immediate treatment of bleeding or the initiation of prophylaxis, two key elements to avoid major long-term sequelae. Undoubtedly, the use of telemedicine, app, webinar, etc., have helped to maintain close contact with patients.

1 | CONCLUSION

Care for children with haemophilia was different during the COVID-19 pandemic. Treatment remained accessible but in adapted form. Although all the centres have tried to preserve the care of paediatric patients, there are areas that have been strongly impacted. Only 15% of the HTCs retained the attention of the physiotherapists; this attention is essential in alerting us to unrecognized or

poorly resolved joint bleeds, and in advising active patients in how to prevent bleeds. They can only do this assessment effectively with in-person physical examination. Similarly, only 45% of HTCs did allow social workers to work and most of them also used telemedicine, which may have had an impact on quality of care.

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MTAR and KK designed the research, analysed the data and wrote the paper. PedNet group analysed, revised critically and gave final approval of the manuscript.

KEYWORDS

children care, COVID-19, haemophilia, telemedicine

DISCLOSURE

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CSL Behring, Novonordisk, Roche, Sobi and Shire/Takeda and honoraria for advisory board from CSL Behring and Shire/Takeda.

DATA AVAILABILITY STATEMENT

Data available on request from the authors.

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