

Original Article

Effect of Implementation of COVID-19 Guidelines on the Lives of Haemophilia Patients Registered with the Haemophilia Treatment Centre, Rawalpindi

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¹ Conception of study

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Abstract

Introduction: The development of isolation strategies to prevent the spread of COVID-19 could affect the lives of Haemophilia patients beyond the risk of infection. In order to prevent this, the Haemophilia Treatment Centre, Rawalpindi, adopted additional combat strategies including the use of telephonic and video consultations, dispensing medicine at home and single-day treatments.

Objective: To assess the impact of the COVID-19 pandemic and associated lockdown and changes in Standard Operating Procedures (SOPs) on the working of Haemophilia Treatment Centre, Rawalpindi and on the lives of its registered patients.

Materials and Methods: An observational study was carried out at the Haemophilia Treatment Centre, Rawalpindi, between September 2019 and August 2020.

Results. Among patients on Low Dose Prophylaxis (LDP) regimen, no difference in musculoskeletal health, bleeding episodes, inhibitor status, psychosocial health and nutritional status was observed among the two time periods. None of the staff members or patients was affected by the COVID-19.

Conclusion: Our study shows that timely anticipation of the potential impact of a pandemic and prompt development of modified mechanisms can indeed make the working of a Health Care Centre successful and prevent side effects on the lives of its patients.

Keywords: COVID-19, Pandemic, Lockdown, Haemophilia Treatment Centre guidelines, Haemophilia, Haemophilia Treatment Centre.

Introduction

Haemophilia is one of the most common congenital bleeding disorders,¹ with the majority of patients having haemophilia A (80-85%).² Patients have a bleeding tendency, the severity of which correlates with clotting factor levels.² Regular infusion of factor concentrates to prevent bleeding in haemophilia is the treatment of choice.² However, the standard dose prophylaxis is very expensive, therefore, a low dose prophylaxis (LDP) project is currently underway at the Haemophilia Treatment Centre (HTC), Rawalpindi where 14 haemophilia A patients are currently on an LDP regime of 250 IU of factor concentrates once weekly.

The *Corona Virus Disease 2019 (COVID-19)* is a global crisis that has affected the lives of people around the world. To limit the spread of COVID-19, governments have been obliged to adopt isolation strategies ranging from social distancing to imposing lockdown measures in some areas. Healthcare centres are required to follow strict Standard Operating Procedures (SOPs) that include vigilant disinfection and social distancing.³

The HTC, Rawalpindi anticipated that such confinement may result in the lack of access to healthcare and medication and may also harm the psychosocial and physical health of its patients, including the 14 patients who were currently enrolled in the LDP trial. To prevent this, HTC encouraged haemophilia patients to use the services of telephone and video consultations. They were offered at-home dispensing of medicines. They were motivated to use alternative mechanisms to stay in touch with family and friends and modify physical activities that can be performed at home.

The purpose of this study was to assess whether HTC, Rawalpindi was successful in safely supporting all haemophilia patients during the pandemic, measured by assessing outcomes before and during the pandemic on the 14 patients enrolled in the LDP trial.

Materials and Methods

An observational study was carried out at the HTC, Rawalpindi from September 1, 2019, to August 31, 2020, to assess the effect of the implementation of COVID-19 guidelines. This timeline was divided into two periods:

- Pre-Pandemic (September 1, 2019 - February 29, 2020).
- Intra-Pandemic (March 1, 2020 - August 31, 2020)

The pre-pandemic period is defined as the 6 months before the arrival of COVID-19 in Pakistan. The intra-pandemic period is defined as the 6 months following the start of COVID-19 in Pakistan, including the introduction of strict SOPs to restrict the further spread of the disease.

As part of the LDP trial, patients were required to come to the HTC, Rawalpindi every week for Factor VIII infusions. The patient was assessed physically with a manual check-up of Joints, history of any bleed whether Spontaneous or Traumatic, limitations in activities and psychosocial integration

At the start of the pandemic in Pakistan, the HTC, Rawalpindi developed SOPs for staff based on recommendations by the World Federation of Haemophilia (WFH) and the World Health Organisation (WHO).^{3,4,5,6} These included regular handwashing, use of sanitisers, masks, gloves and overalls for all staff. Regular disinfection of frequently touched areas and social distancing was enforced. Only one attendant per patient was allowed and the children play area was closed. All HTC related events were delayed and all elective and non-urgent surgeries and procedures were postponed. The HTC remained open throughout the pandemic and patients were timely given life-saving treatments. Virtual and telephonic visits were conducted when possible.

To assess if patients were supported during the pandemic, we compared patient outcomes during the pre-pandemic period to the intra-pandemic period on the 14 patients on the LDP trial. Patient and treatment compliance & clinical outcomes were assessed. Patient compliance was assessed by the regularity of patients visits, both virtual & physical. Treatment compliance was assessed by their use of FVIII concentrates. The clinical outcomes of total bleeding events, hospital admissions, emergency HTC visits, inhibitor status, musculoskeletal health and psychosocial health were also compared between the two time periods. Musculoskeletal health was assessed using HJHS and psychosocial health was assessed by a proforma which measured the general sense of well-being, self-esteem & confidence of the family and the independence & interactions of the patient with other family members & a shift in treatment-related pain & fear of injections. All patients were advised to inform both the HTC and the hospital in the case were infected with the COVID-

19 so the treating physician would not misinterpret the coagulation status of the patient.

Data were obtained retrospectively from written medical records for the pre-pandemic period and prospectively during the intra-pandemic period.

Results

All SOPs for preventing the spread of COVID -19, were strictly followed by the staff, patients and their attendants. Throughout the pandemic, patients were provided timely life-saving treatments. All staff members continued working throughout the intra-pandemic period. During this period, only two staff members developed fever, sore throat and body aches. They were advised to stay home and get COVID-19 testing done, both of which were negative.

A total of 1483 and 1562 in-person visits occurred during the pre and intra-pandemic periods, respectively (Table 1). There was a small increase in virtual visits and a marked increase in telephonic communication.

Table 1: Comparison of HTC and Patient Visits between Pre- and Intra-Pandemic Periods

<i>Parameter</i>	<i>Pre-Pandemic Period</i>	<i>Intra-Pandemic Period</i>
Patient Visits, N	1483	1562
Virtual Visits, N	9	15
Telecommunication, N	60	116
Treatment Compliance, N (%)	14 (100%)	14 (100%)
Factor VIII Administered, IU	1375950	1200530

Among the 14 patients on LDP, treatment compliance was 100% (Table 2). None of the patients developed an inhibitor, only one was referred to the orthopaedic department for assessment of painless swelling of his knee causing him to have an emergency department visit. They visited regularly for joint assessment. And their nutritional and psychosocial status remained optimum.

Table 2: Comparison of Outcomes in LDP patients between Pre- and Intra-Pandemic periods

<i>Parameter</i>	<i>Pre-Pandemic Period</i>	<i>Intra-Pandemic Period</i>
Bleeding Episodes, N	420	425
Hospital admission, N	Nil	01

Emergency HTC Visits, N	0	0
Joint Assessment	14 (100%)	14 (100%)
Compliance		
Inhibitors, N	0	0
Nutritional Status	Optimum in 14	Optimum in 14
Psychosocial Status	Optimum in 14	Optimum in 14

Discussion

Since the declaration of COVID -19 pandemic and imposition of SOPs, the WFH recommends minimising hospital visits and postponing non-urgent and elective surgeries for haemophilia patients.⁴ The same guidelines were adopted by the HTC, Rawalpindi.

The above radical changes could lead to patients losing contact with the HTC and thereby losing access to healthcare and medication. It was pertinent to keep in touch with patients that were part of the LDP project to assess their bleeding phenotype and ensure they had access to their weekly dosage and continued being part of this clinical trial. Considering the above factors, HTC encouraged its patients to keep in touch via telephone and video conferences. Through virtual visits, patients were able to get an appreciation for adhering to medication and exercise and discuss symptoms such as bleeding and pain. A drastic rise in telephone communication occurred during the Intra-pandemic period and overall no change in visits was observed among the two time periods. Telemedicine has proven to be a great solution to address such a global crisis.^{7,8,9,10} Patients can discuss bleeding number and location, amount of factor concentrates administered, the type of physical activity they are engaged in, and were motivated to continue adhering to treatment.⁷

The HTC offered its patients at-home dispensing of medication so they didn't have to visit the Centre frequently, thereby minimising the risk of being infected with the COVID-19.¹¹ The difference in overall consumption of factor concentrates among the two time periods was mild. None of the patients lost access to medication. The LDP patients continued taking their weekly dosage without any delay and none developed inhibitors. No significant difference in bleeding episodes was observed between the two time periods. The haemophilia patients are physically less active than the normal population because of fear of bleeding and already established arthropathy. The COVID-19 pandemic and associated social distancing could further increase such confinement and cause

worsening of quality of life.¹² Home exercise programs have been shown to be equally effective.¹² The HTC encouraged its patients to remain active even if they could not go out for walking, cycling or jogging. Through telemedicine, patients were assessed regularly and recommended modified exercise programs, frequency of practice and intensity accordingly. All haemophilia patients that were part of the LDP project, remained physically active.

The COVID-19 pandemic has caused an increase in anxiety and depression among the general population due to social isolation, fears of infection, loss of work and changes in routine¹³. Fear of lack of access to health care, medication and home help, and continuing clinical trials are additional stressors faced by the haemophilia patients.¹⁴ The HTC, Rawalpindi motivated its patients to stay in touch with family and friends, continue performing daylight activities, use bed only for sleep and maintain a regular sleep-wake schedule. Full emotional support was provided to the LDP patients throughout the pandemic. Therefore, their psychosocial health remained optimum.

Musculoskeletal disorders can cause chronic pain among haemophilia patients leading to significant suffering and worsening of quality of life.¹⁵ Through telemedicine, patients were able to contact the HTC well in time for pain management. Among the LDP patients, joint health remained optimum.

Increased body weight, reduced sun exposure and mood disorders, all are side effects of confinement at home.¹⁴ The HTC recommended its patients to remain active and eat a balanced diet. They were encouraged to continue taking their weekly vitamin D supplementation to benefit bone mineral density and for protection against respiratory infections.^{14,16,17} The nutritional status of LDP patients remained optimum throughout the pandemic.

Although social distancing and confinement is a smart strategy to restrict the spread of the COVID-19 pandemic, it could affect the lives of the population (especially those already suffering from additional stressors), much more than the COVID-19 infection itself. However, timely anticipation and modified strategies to overcome such stressors can make the working of a healthcare centre successful.

Conclusion

Our study shows that timely anticipation of the potential impact of a pandemic and prompt development of modified mechanisms can indeed

make the working of a Health Care Centre successful and prevent side effects on the lives of its patients.

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