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A Survey of Survival Status of 601 Hemophilia Patients in Guangdong Region during COVID-19 Pandemic: Investigation and Implications

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Blood (2020) 136 (Supplement 1) : 21.
http://doi.org/10.1182/blood-2020-139241

Objective: Investigation the survival status of patients with hemophilia in Guangdong during the COVID-19 pandemic, and exploring the effectiveness of coping strategies to provide some experience and inspiration for the management of rare chronic diseases such as hemophilia during public health emergencies.

Methods: Retrospective analysis of the disease characteristics, lifestyle, treatment, psychological, EQ-5D life quality assessment, as well as participation and effectiveness of local response measure participation and effectiveness of 601 cases of hemophiliac patients in Guangdong area before and after the COVID-19 pandemic (October 23, 2019 to April 22, 2020).

Results: The 601 patients were all males, Including 22.46% patients under 6 years old, 22.96% among 7-12 years old, 13.98% among 13-20 years old, 40.44% among 21-60 years old and 0.17% over 60 years old. Hemophilia A accounted for 86.52% (520 cases) and hemophilia B 13.48% (81 cases). There were 352 cases (58.57%) of severe hemophilia (F#<1%), 219 cases (36.44%) of medium (F# 1~5%), 17 cases (2.83%) of 13 cases (F# 5~40%), and 13 cases (F# 2.16%) is not clear. There were 50 patients had inhibitors. Before the COVID-19 epidemic, 54.58% of the patients had been working or studying at home for a long time. During the epidemic, the patient’s outing activities decreased. During the 3 months of the epidemic, the frequency of hospital visit was 3.40±4.09 times per month, which was significantly lower than 4.14±4.05 times per month in the 3 months before the epidemic (P=0.000) #6.00±8.34 clinical
bleeding events developed during 3 months of the epidemic, which is significantly increased from 5.47±8.09 times 3 months before the epidemic (P=0.000). The patient's self-assessment score about healthy decreased significantly (70.67±23.76 points vs 75.01±22.28 points, P=0.000). 74.71% of patients were able to maintain the original treatment, the changes in treatment were generally different (P=0.030), and 152 patients switched treatments. Only 34 (5.66%) patients often develop symptoms of anxiety. In the EQ-5D assessment, the proportions with no difficulty in mobility, self-care, and daily life were 55.57%, 73.88%, and 56.57%; the proportions without pain/discomfort and anxiety/depression were 35.27% and 44.26%, the proportion of patients with difficulty and severe pain and anxiety is not high. Regarding the participation of our response measures, 34.28~48.25% patients chose to use the "network platform" for diagnosis and treatment, and the number of patients increased significantly during the epidemic (P=0.000); the number of patients benefited from the medical insurance policy also increased (9.65% vs 13.48%, P=0.023). During the epidemic, the patient's awareness of hemophilia knowledge (7.59±2.16 points) was significantly improved (P=0.000) compared to that of 3 months ago (7.17±2.34 points).

**Conclusion:** The COVID-19 epidemic had a certain impact on the condition of hemophilia patients in Guangdong. Various measures by the Guangdong Hemophilia Center and the government, especially "the online diagnosis and treatment model", and the "long prescription" medical insurance reimbursement policy has a positive effect on hemophilia patients in the region, make the disease generally controllable, and may bring long-term profound benefits for management of such rare disease in future.

**Disclosures**
No relevant conflicts of interest to declare.

**Author notes**
* Asterisk with author names denotes non-ASH members.

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