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Health-related quality of life in children with Haemophilia in China: A 4-year follow-up prospective cohort study

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Health-related quality of life (HRQoL) has been brought up for decades. However, no data to date are available about long-term followed-up HRQoL of children with haemophilia. This nearly 4-year study aimed to assess the long-term HRQoL of haemophiliacs. A prospective cohort study among 42 haemophiliacs and their caregivers was conducted in August 2014, follow-up was completed in January 2018. Primary endpoint was the change in patients HRQoL evaluated by Canadian Haemophilia Outcomes–Kids Life Assessment Tool (CHO-KLAT) from baseline to year 4, secondary endpoint was the impact of bleeding rates, physical activity restriction, financial burden and treatment (prophylaxis vs on-demand treatment) on HRQoL, as well as the impact of treatment on event-free survival. 42 patients (mean age, 5.48[SD, 4.63] years) and 42 caregivers were included. 38 families completed 4-year follow up. Patients reported smaller increase in HRQoL from baseline to year 4. The mean scores of child self-report and parent proxy-report of CHO-KLAT at baseline were 60.69 (SD=20.28) and 61.01 (SD=12.14), respectively. Scores at follow-up were 64.69 (SD=13.71) and 65.33 (SD=15.78), respectively. Haemophiliacs without physical activity restriction, living in urban areas and had received prophylactic treatment and home injection, had higher HRQoL than the others. Bleeding rates were proportionally negatively correlated with HRQoL. Patients who had received prophylactic treatment had better event-free survival. In conclusion, HRQoL of children is influenced by bleeding rates, physical activity restriction, financial burden and treatment. Prophylactic treatment is a key factor contributing to event-free survivor prognosis and the optimal therapy for childhood haemophiliacs.

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