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A survey among patients with hemophilia and inhibitors seeking treatment in non-hemophilia treatment centers

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Abstract

Objective: Acute bleeds in patients with rare bleeding disorders (RBDs), including congenital hemophilia with inhibitors (CHwI), acquired hemophilia, congenital factor VII deficiency, and Glanzmann's thrombasthenia (GT) must be treated as quickly as possible. This study evaluated the obstacles and experiences of patients with CHwI, or their caregivers, for the early treatment of acute bleeds in non-hemophilia treatment centers (HTCs).Methods: Patients in the United States (aged 18–65 years [or caregivers of patients <18 years]) with CHwI, who currently have or have had inhibitors in the last 3–4 years, and who sought treatment in a non-HTC, underwent an interactive online qualitative discussion over 7 days.Summary: The survey was completed by 23 respondents (seven patients and 16 caregivers; all patients with CHwI). Respondents were aware of the need to treat bleeds quickly, which had been taught to them by physicians and learned from experience. Delays in respondents initiating their treatment were typically due to: technical issues (e.g., 7/23 respondents had difficulty gaining access to a vein or port); delay in diagnosis (e.g., 5/23 respondents' child does not inform caregiver of the bleed); convenience (e.g., 3/23 respondents were unwilling/unable to take treatment out of the home); or financial issues (e.g., one respondent had inadequate insurance). Respondents tended to visit a non-HTC as a last resort, often due to the long distance to an HTC when emergency treatment was needed, unsuccessful pain management, or unsuccessful factor administration at home. Most patients/caregivers (20/23) reported treatment delays in emergency departments (EDs). Delays in EDs were often due to healthcare professional's (HCP) lack of knowledge (16/23 respondents; 4 hours average wait until treatment) and four reported delays due to lack of available treatment (14 hours average wait for treatment). All patients/caregivers reported that they had dealt with uneducated/unaware HCPs, having to spend significant time educating the ED staff. Three respondents reported not waiting for treatment—partly because they chose hospitals very carefully, and because they had educated their closest hospital prior to needing an emergency service. Patients/caregivers with negative experiences reported that HCPs were unwilling to listen to them, did not seek consultation quickly, dismissed their instructions, and directed care that forced an outcome. When patients had satisfactory experiences, HCPs listened intently, immediately called an HTC/patient's physician, and provided care in consultation. Respondents highlighted the need for HCPs education on hemophilia. Conclusions: Patients/caregivers are aware of the need to treat an acute bleed fast, but sometimes delay their treatment, and experience delays when attending non-HTCs. The lack of experience of HCPs in managing acute bleeds contributes to these delays. Improved education of HCPs at non-HTCs and provision of protocols or guidelines would be beneficial for patients with CHwI.