

THE POSSIBLE ROLE OF THE PSYCHOLOGIST IN THE MANAGEMENT OF PATIENTS WITH CONGENITAL BLEEDING DISORDERS: THE EXPERIENCE OF A SINGLE HEMOPHILIA CENTER

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Background and Aims. Patients with Congenital Bleeding Disorders (CBDs) face numerous challenges throughout their lives: the management of bleeding episodes and prophylaxis, which, despite considerable progress, still requires continuous psychological engagement in daily life. Additional challenges include adapting to the different life stages, from childhood to old age, and maintaining participation in social activities. Psychological support therefore becomes crucial, however requiring ongoing specialist education and development for practice in the field of bleeding disorders. A psychologist could also be of benefit to healthcare professionals within the team, in particular physicians and nurses, by helping them to manage chronic conditions and enabling them to provide optimal support to both patients and caregivers.

Materials and Methods. In 2025 the University Hospital of Verona implemented a psychological support service for healthcare professionals working within the HC, with several objectives including group training in the communication with patients and caregivers. Following an initial meeting between the medical director and the psychologist assigned to the HC, a second meeting involved all physicians and nurses dedicated to the care of people with CBDs. Subsequently, monthly meetings were specifically organized to discuss issues related to selected patients with CBDs.

Results. During the first two meetings, the congenital bleeding disorders managed at the HC, treatment-related challenges and the difficulties experienced by patients in their daily lives, were explored. Simultaneously, the needs expressed by healthcare professionals in coping with congenital bleeding disorders and addressing patients' needs were discussed. In particular, the need emerged to identify tailored strategies for dealing with the different personalities and behavioural patterns displayed by patients. Over three dedicated sessions, 5 patients (4 with severe hemophilia and 1 with mild FVII deficiency) were discussed. The discussions focused on how patients presented themselves to the HC team, and on the needs that emerged in relation to their disease. The psychologist also highlighted the feelings experienced by professionals towards patients, including anger (for example in case of therapeutic non-adherence) or difficulty relating to the patient. Finally, the group work identified potential strategies to improve the relationship between the team and patients, as well as the individualized patient management.

Conclusions. The psychologist represents a key member of the multidisciplinary HC, supporting patients and their caregivers in disease management, and promoting the education of the team, with the aim of optimizing communication with patients and caregivers.