1.03 Health and social economics, organizational issues

ENHANCING SHARED DECISION-MAKING IN INHERITED BLEEDING DISORDERS: A SINGLE-CENTER QUALITY IMPROVEMENT INITIATIVE

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Background. Shared Decision-Making (SDM) is a collaborative process in which healthcare professionals and patients jointly make decisions based on clinical evidence and patient preferences. Adequate patient knowledge is essential for effective SDM. However, even in specialized Inherited Bleeding Disorders Centers, patients may have limited understanding of their condition and treatment, reducing active participation in care.

Aims. To describe a single-center quality improvement (QI) initiative aimed at improving patient participation through structured written informational materials supporting clinician–patient discussions and disease awareness.

Materials and Methods. A multidisciplinary team of physicians and nurses identified the need for improved patient education and developed a formal QI initiative. During a 4-month preparatory phase (January–April 2026), patient informational needs were assessed and materials drafted, reviewed, validated, and integrated into the institutional documentation system. A 2-year implementation phase followed (May 2026–May 2028). The initiative was approved by the Forensic Medicine Service. Outcome measures include percentage of available materials for each bleeding disorder and proportion of patients receiving them during visits.

Results. Twenty informational documents were developed covering hemophilia A and B, hemophilia carriers, von Willebrand disease and subtypes, rare bleeding disorders and platelet disorders. Documents include information on disease characteristics, treatment options, daily-life recommendations, management in surgical or emergency settings, drugs to avoid and follow-up schedules. Materials also encourage patient participation in SDM, include a section for patient notes or questions, and provide final signatures from patient and physician to formalize shared understanding. Materials are delivered at diagnosis or at follow-up visits, with distribution recorded in the medical record and copies archived in a dedicated repository. During the first month of implementation, 16 patients received the materials. Limitations include the short observation period and absence at present of a standardized tool planned to assess effects on patient empowerment.

Conclusions. This initiative highlights the value of structured informational tools in supporting SDM in inherited bleeding disorders. Nurse involvement was essential during both development and implementation, underlying a central role in patient education, facilitation of understanding, promotion of adherence, and communication with the team. A multidisciplinary approach in developing informational materials is a feasible strategy to improve patient awareness and participation in care, and may facilitate SDM in the clinical practice.