

BEYOND CLOTTING FACTORS: NURSING AS A CORNERSTONE OF LIFELONG HEMOPHILIA CARE

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Background and Aims. Haemophilia is a rare inherited bleeding disorder requiring specialised, multidisciplinary, lifelong care. Despite major therapeutic advances, optimal outcomes depend on coordinated healthcare delivery, patient education, psychosocial support, and regular follow-up. Within Haemophilia Centres, nurses play a key role in education, care coordination, and treatment adherence. This study analysed the clinical, organisational, educational, and psychosocial aspects of comprehensive haemophilia care across the lifespan, focusing on nursing contributions and their potential impact on patient outcomes.

Materials and Methods. A narrative review of the literature and organisational practices adopted in specialised Haemophilia Centres was conducted. The analysis explored haemophilia management during childhood, adolescence, adulthood, and older age. Areas examined included nursing interventions, patient and family education, communication, treatment adherence, multidisciplinary collaboration, home care, psychosocial support, and the Italian legislative framework for rare diseases. Findings were synthesised to identify the main domains of nursing practice in haemophilia care.

Results. Comprehensive haemophilia management requires continuous, individualised care from diagnosis onwards. During childhood and adolescence, family education, promotion

of autonomy, safe physical activity, and prevention of complications were key elements of care. During the transition to adulthood, communication with healthcare professionals, self-management, and adherence to prophylaxis become increasingly important. Older adults often present with age-related comorbidities requiring more complex multidisciplinary management. The analysis identified major nursing domains, including therapeutic education, support for self-management and adherence, coordination of care pathways, psychosocial support, monitoring of complications, and facilitation of communication between patients, families, and healthcare professionals. Electronic communication tools and integrated care models may further improve continuity of care and patient engagement.

Conclusions. Haemophilia management extends beyond replacement therapy and requires a holistic, patient-centred approach integrating clinical, educational, psychological, and organisational aspects of care. Nurses are essential members of the multidisciplinary team, supporting patients and families throughout the disease course while promoting self-management, adherence, and quality of life. The identified domains may provide a basis for developing nurse-sensitive outcomes and strengthening specialised nursing practice within Haemophilia Centres.

1.03 Health and social economics, organizational issues

Table 1. Nursing contributions and potential nurse-sensitive outcomes in lifelong haemophilia care.

Nursing domain	Key nursing activities	Potential nurse-sensitive outcomes
Therapeutic education	Education of patients and caregivers on disease, treatment, bleeding recognition, and prevention strategies	Increased disease knowledge, improved treatment adherence
Self-management support	Development of autonomy, self-infusion skills, and home treatment management	Greater patient empowerment, increased independence
Care coordination	Coordination among Haemophilia Centre professionals, community services, and family caregivers	Improved continuity of care, enhanced care integration
Adherence promotion	Monitoring and reinforcement of prophylactic treatment adherence	Higher adherence rates, reduced treatment discontinuation
Psychosocial support	Assessment of emotional and social needs, counselling support, referral to specialists when required	Improved coping strategies, enhanced quality of life
Communication facilitation	Promotion of effective communication between patients, families, and healthcare professionals	Increased patient engagement, improved shared decision-making
Monitoring and early intervention	Identification of bleeding episodes, treatment-related issues, and age-related complications	Earlier management of complications, improved clinical stability
Transitional care	Support during transfer from paediatric to adult services	Better continuity of care, sustained long-term engagement
Healthy lifestyle promotion	Encouragement of safe physical activity and preventive health behaviours	Improved physical functioning, reduced risk of disability