Pegem Journal of Education and Instruction, Vol. 14, No. 3 , 2024 (pp. 1233-1241)

RESEARCH ARTICLE WWW.PEGEGOG.NET

Growing Up With Hemophilia: Physical Activity, Bone Health, Pain, School Participation, and Transition

Shaimaa Hashem Abd El-Aziz [1], Mervat Atfy Mohammed [1], Hosam Fathi El-Saadany [1], Ahmed Mohammed Barakah [2]

Departments of 1 Pediatrics and 2 Clinical Pathology, Faculty of Medicine, Zagazig University, Zagazig, Egypt

Corresponding author: Shaimaa Hashem Abd El-Aziz

ABSTRACT

***Background*:** Bleed prevention has transformed the prognosis of children with hemophilia, but normal childhood cannot be inferred from a low bleeding rate alone. Physical inactivity, low bone mass, pain, school disruption, family overprotection, and difficulties during transition may persist even when hemostatic treatment is effective.

Aim: To present a developmentally grounded framework for whole-child hemophilia care from early childhood through transfer to adult services.

Methods: A focused narrative synthesis was conducted using international guidance, systematic reviews, pediatric observational studies, and qualitative research addressing physical activity, fitness, bone health, pain, education, quality of life, caregiver burden, adherence, and transition.

Results: Regular activity is generally beneficial when hemostatic cover, joint status, skills, and trauma risk are considered together. Children with hemophilia may develop reduced bone mineral density from childhood, making weight-bearing activity, nutrition, and avoidance of prolonged immobilization important. Pain requires mechanistic assessment because acute bleeding, post-bleed recovery, deconditioning, and chronic musculoskeletal pain demand different responses. School participation, peer relationships, caregiver confidence, and adolescent self-management are measurable health outcomes. Structured transition should begin years before transfer and should verify practical competence rather than rely on age alone.

Conclusion: High-quality pediatric hemophilia care should aim for a child who is physically capable, socially included, psychologically secure, and ready to manage a lifelong condition—not merely a child with fewer recorded bleeds.

Keywords: Hemophilia; Physical activity; Bone health; Quality of life; Transition to adult care

INTRODUCTION

The meaning of successful pediatric hemophilia care has changed. When recurrent bleeding was common, the immediate clinical objective was to prevent death and major disability. With effective prophylaxis, many children can now expect near-normal participation. Yet a low bleeding rate does not automatically produce fitness, healthy bone accrual, freedom from pain, school inclusion, or readiness for adulthood. These outcomes require deliberate pediatric care because childhood is not a waiting room for adult disease; it is the period in which movement, identity, confidence, and self-management are built. [1]

A whole-child model asks a different question at each visit: is this child able to grow, move, learn, play, and assume responsibility at a developmentally appropriate pace? The answer depends on hemostatic protection, but also on strength, weight, family behavior, peer acceptance, educational support, and equitable access to a comprehensive team. The pediatrician therefore serves as both hematologist and developmental advocate, ensuring that protection from bleeding expands life rather than merely narrowing risk. [1,2]

Review approach

This focused narrative review synthesizes international guidance, systematic reviews, pediatric cohort studies, and qualitative evidence on activity, fitness, bone health, pain, schooling, quality of life, caregiving, adherence, and transition. The literature was interpreted through a developmental lens from early childhood to transfer into adult services. The emphasis is on clinical function and participation rather than laboratory or imaging-based detection of joint damage.

From protection to participation

Historically, families were advised to restrict activity because trauma could cause bleeding. That protective instinct remains understandable, particularly after a frightening early bleed, but excessive restriction can create a second pathway to disability through weakness, impaired coordination, reduced bone loading, weight gain, social exclusion, and fear of movement. Current guidance supports regular physical activity with individualized consideration of bleeding phenotype, current prophylaxis, musculoskeletal status, motor skill, and the nature of the activity. [1,3]

Participation should be judged by what the child can do safely, not by diagnosis alone. A well-protected child with good strength and no active injury may undertake a broader range of activities than a poorly protected child with pain or recent bleeding. Conversely, a low-contact sport may still be unsafe during incomplete recovery. The decision is dynamic: protection, competence, surface, supervision, equipment, intensity, and rescue access interact to determine risk. [3-5]

Physical activity and sport

A systematic review found wide variation in activity among people with hemophilia, reflecting differences in treatment, measurement, culture, and opportunity. Pediatric reviews nevertheless consistently identify benefits from activity, including muscle strength, proprioception, cardiovascular fitness, weight control, confidence, and social participation. The appropriate clinical stance is therefore “plan activity” rather than “avoid activity.” [3,4]

Real-world data are reassuring when participation is supported. Dutch boys with hemophilia reported sports participation broadly comparable with peers, and injuries were not concentrated exclusively among those with severe disease. These findings do not imply that all sports are equivalent; they show that diagnosis alone is a poor substitute for individualized risk assessment. Skill development, conditioning, rules, protective equipment, and timely treatment remain crucial. [5]

Activity planning should begin with the child’s preferred activity, because a theoretically ideal exercise that the child dislikes will not be sustained. The team then evaluates collision risk, fall height, speed, repetitive joint loading, supervision, and the consequences of delayed treatment. Swimming, walking, cycling with appropriate protection, racquet sports, and structured strength work are often readily adaptable. High-collision activities require a more cautious, specialist-led discussion and may remain inappropriate for some children despite effective prophylaxis. [1,4]

Timing can be individualized. Children receiving factor replacement may benefit from scheduling higher-risk activity near a post-infusion peak, whereas children receiving steady-state non-factor prophylaxis require attention to the residual risk of trauma and the specific rescue plan rather than peak factor timing. School staff and coaches should know the child’s emergency contacts and first response, while avoiding unnecessary exclusion or public disclosure. The child should gradually learn to report symptoms early and to stop activity when pain, swelling, altered gait, or loss of function occurs. [1]

Table 1. A practical framework for activity planning

Domain	Questions to ask	Action
Hemostatic protection	Is prophylaxis current, and is rescue treatment available?	Align activity with the regimen and document the emergency plan. [1]
Current function	Is there pain, swelling, loss of motion, weakness, or altered gait?	Treat suspected bleeding and restore function before full return.
Activity characteristics	Does it involve collision, speed, height, hard surfaces, or repetitive loading?	Modify rules, setting, intensity, supervision, or equipment. [3-5]
Skill and conditioning	Can the child control movement and tolerate the required workload?	Build strength, balance, and technique progressively. [6,7]
Child preference	What activity is meaningful enough to sustain?	Select an acceptable option rather than prescribing an unwanted "safe" sport.
School and community	Do adults know the response to trauma without excluding the child?	Use concise, privacy-respecting written instructions.

Note: Activity decisions should be reviewed after a significant bleed, injury, treatment change, growth spurt, or new functional limitation.

Fitness, strength, and motor competence

Physical activity and physical fitness are related but not identical. A child may attend sport yet have weak stabilizing muscles, poor balance, or low endurance after periods of inactivity. In a multicenter Dutch cohort, children with hemophilia generally had normal aerobic capacity and muscle strength, but overweight was slightly more common and was associated with poorer walking performance and quality of life. This illustrates why routine pediatric assessment should include movement quality and fitness, not only sports participation. [6]

Therapeutic exercise should target identified deficits and progress from control to capacity: range of motion, isometric activation, closed-chain strength, balance, endurance, then sport-specific skill. A systematic review suggests that exercise can improve postural balance, although study quality and protocols vary. Rehabilitation after a bleed should restore pain-free function and confidence before full return, because premature return and prolonged immobilization are both harmful. [7]

Children benefit when physiotherapy is preventive rather than reserved for established disability. Periodic observation of gait, posture, joint motion, muscle strength, balance, and functional tasks can reveal deconditioning before the child describes limitation. Exercise prescriptions should be brief, age-appropriate, and linked to a valued goal, such as keeping up with classmates or returning to a chosen sport. [1,7]

Bone health during the years of peak accrual

Bone health deserves specific attention because peak bone mass is built during childhood and adolescence. Meta-analyses show reduced bone mineral density in people with hemophilia, with differences already detectable in children. Contributing factors include reduced weight-bearing activity, recurrent immobilization, low muscle force, vitamin D insufficiency, low body mass in some settings, and chronic inflammation or infection in older cohorts. The possibility of direct interactions between coagulation proteins and bone biology remains under investigation. [8,9]

Prevention is practical even when the mechanism is incompletely defined. Children need adequate dietary calcium, vitamin D according to local pediatric guidance, weight-bearing movement, progressive resistance exercise, and avoidance of tobacco and unnecessary corticosteroid exposure in adolescence. Screening should be risk-based rather than automatic: recurrent fractures, prolonged immobility, marked underweight, delayed puberty, nutritional deficiency, or other secondary causes justify more detailed evaluation. [1,8]

A common clinical error is to protect bone by restricting impact indefinitely after bleeding. In fact, prolonged unloading accelerates loss of muscle and bone. The safer pathway is prompt hemostatic treatment, short protection when indicated, early

supervised restoration of motion, and graded return to loading. The goal is not maximal impact but sufficient mechanical stimulus to build a resilient skeleton without provoking recurrent injury. [1,7]

Weight and metabolic health

Weight influences hemophilia care through several routes. Excess adiposity increases mechanical load, can make venous access and physical activity more difficult, and may amplify pain and functional limitation. Families may inadvertently promote sedentary behavior because movement is perceived as dangerous. Weight discussions should therefore avoid blame and connect nutrition and activity to strength, energy, and participation rather than appearance. [6]

Routine pediatric growth surveillance should include body mass index trajectory, blood pressure, sleep, diet, screen time, and activity. Intervention is most effective when family-based: regular meals, accessible healthy food, active transport where safe, and enjoyable shared activity. Treatment should be adjusted to the child's current weight and pharmacokinetics, but increasing dose alone cannot correct deconditioning. [1,6]

Pain is a symptom, not a diagnosis

Pain is common across the hemophilia lifespan and can begin in childhood. In a Portuguese survey, pain was reported by most participating children and adolescents as well as adults, underscoring that pediatric pain should not be dismissed as an adult complication. The first task is to determine whether pain represents acute bleeding, post-bleed inflammation, mechanical overload, deconditioning, chronic musculoskeletal pain, or another pediatric condition. [10]

Acute suspected bleeding requires prompt hemostatic management and site-specific assessment. Persistent pain after bleeding has resolved requires a different strategy: graded rehabilitation, restoration of movement, sleep optimization, psychological support when fear avoidance is present, and analgesia compatible with the bleeding disorder. Repeated empiric factor dosing for every episode of pain may delay recognition of non-bleeding causes, while withholding treatment from a true bleed is equally unsafe. The family needs a shared decision pathway for uncertainty. [1,10]

Pain assessment should include intensity, quality, timing, function, sleep, mood, school attendance, and the child's own explanation. A numerical score alone cannot distinguish bleeding from chronic pain. Clinicians should watch for a cycle in which pain leads to avoidance, weakness, increased effort, and more pain. Breaking that cycle requires coordinated hematology, physiotherapy, and age-appropriate pain management, with clear reassurance that safe movement is part of recovery. [10]

School is a health outcome

School attendance and participation are sensitive indicators of whether care works in daily life. In the Academic Achievement in Children with Hemophilia Study, greater bleeding was associated with more absence and lower performance in selected academic domains. Later research across chronic illness similarly linked parent-perceived quality of life with absenteeism. These findings support routine documentation of missed days, early departures, incomplete physical education, and reduced concentration due to pain or treatment. [11,12]

A school plan should be concise and enabling. It should explain ordinary participation, medication storage if relevant, whom to call, first aid, and the response to significant trauma or suspected bleeding. It should not turn the child into a permanent patient at school. Privacy preferences should be revisited as the child matures, and exclusions from trips, sports, or practical lessons should be challenged unless a specific risk cannot be mitigated. [1,13]

Quality-of-life evidence shows that school attendance and sports participation are positively associated with better outcomes in children with congenital bleeding disorders. A systematic review and meta-analysis also found persistent impairment across pediatric hemophilia cohorts despite major treatment advances. Patient-reported outcomes should therefore complement bleed counts, particularly when the child appears medically stable but is withdrawing from peers or activities. [13,14]

Psychological development and family adaptation

Parents must balance vigilance with permission. Early treatment demands, venous access, emergency visits, and fear of intracranial or internal bleeding can produce understandable hypervigilance. Yet when every bruise is treated as catastrophe, children may internalize fragility and avoid developmentally normal challenges. Family education should normalize uncertainty, teach graded risk assessment, and explicitly discuss how autonomy will expand over time. [15,16]

Education interventions can improve parental knowledge and quality of life, but information alone is insufficient when anxiety, financial strain, travel burden, or family conflict is prominent. Caregiver studies show that hemophilia affects time, employment, emotional well-being, and family routines, with greater burden when inhibitors complicate treatment. The comprehensive team should ask who provides care, who misses work, how siblings are affected, and whether the family has practical support. [15-18]

Psychological support should be offered according to need rather than reserved for crisis. Useful targets include needle fear, procedural trauma, pain coping, school anxiety, body image, disclosure, peer relationships, and parental overprotection. Adolescents need confidential space to discuss risk-taking, relationships, alcohol or substance use, sexual health, and the wish to be "normal" without losing access to expert guidance. [1,19]

Primary care, prevention, and ordinary adolescence

Specialist follow-up should not displace primary care. Children still need routine immunization, growth and pubertal assessment, dental prevention, vision and hearing review, sleep assessment, and counseling on nutrition, screens, injury prevention, and mental health. When every clinical encounter is organized around bleeding, modifiable pediatric problems can be missed. The comprehensive center and primary pediatrician should define responsibilities rather than assume the other is providing preventive care. [1,2]

Oral health is a participation issue as well as a bleeding issue. Dental pain affects eating, sleep, concentration, and school, while delayed preventive care increases the likelihood of invasive treatment. Families should receive early instruction in brushing, fluoride, diet, and regular dental review, with hemostatic planning for procedures. Normalizing dental attendance from early childhood reduces fear and avoids the pattern of presenting only when urgent treatment is required. [1]

Sleep and fatigue deserve direct questions. Pain, anxiety, late screen use, school pressure, and treatment routines can impair sleep even when bleeding is controlled. Fatigue may then reduce activity and concentration, producing a cycle that resembles disease progression. A brief sleep history and attention to mood, iron status when clinically indicated, and daily routine can uncover treatable contributors. [1,14]

Girls and women with hemophilia require explicit inclusion. Factor levels vary among carriers, and bleeding symptoms may become more visible with menstruation, dental work, surgery, or trauma. Adolescents should receive confidential menstrual and reproductive counseling, and heavy menstrual bleeding should not be normalized. Inclusive language also improves care for children whose gender identity or family structure does not match traditional assumptions about an X-linked disorder. [1,19]

Digital life, peers, and identity

Digital tools can support treatment reminders, activity tracking, symptom diaries, teleconsultation, and rapid contact with the center. They can also increase surveillance and conflict if parents use them primarily to monitor the adolescent. The young person should participate in deciding what is recorded, who can see it, and when parental access will narrow. Technology works best when it strengthens self-efficacy rather than functioning as an electronic substitute for trust. [19-21]

Peer relationships often determine whether safety advice is usable. A teenager may skip prophylaxis to avoid disclosure, continue activity through pain to remain on a team, or avoid travel because carrying medication feels conspicuous. Clinical conversations should rehearse short disclosure scripts, travel planning, and how to ask for help without surrendering privacy. Peer camps and patient organizations can reduce isolation by making competence with hemophilia socially normal. [1,19]

Identity development is healthiest when hemophilia is integrated rather than denied or allowed to dominate. Children need opportunities to experience mastery outside health care—sport, art, friendship, academics, volunteering, or work. The team can

support this by framing treatment as an instrument for chosen goals. This motivational shift is particularly important in adolescence, when adherence driven solely by parental fear becomes fragile. [20-22]

Adherence, autonomy, and the adolescent brain

Adolescence combines increasing independence with present-focused decision-making. Qualitative studies identify busy schedules, treatment inconvenience, venous access, stress, treatment fatigue, and a low perceived need for prophylaxis when bleeding is absent. Nonadherence is therefore rarely explained by ignorance alone. A clinician who asks "What gets in the way?" is more likely to find a workable solution than one who repeats instructions. [20-22]

Responsibility should transfer in observable steps. By early adolescence, the young person should increasingly know the diagnosis and severity, treatment and rescue products, schedule, allergy and inhibitor history, emergency contacts, and the rules for procedures. Later skills include ordering supplies, recording treatment, arranging appointments, communicating with school or employers, and recognizing when adult help is needed. Parents move from manager to coach, while the team confirms competence without abruptly withdrawing support. [19,22]

Subcutaneous and extended-interval therapies can reduce treatment burden, but they do not remove the need for self-management. Long intervals may make missed doses less visible, and a young person who has rarely bled may underestimate the condition. Digital reminders, shared records, and private adolescent consultations can help, provided they are integrated into a respectful therapeutic relationship. [19-21]

Transition is a process, not a birthday

Transfer to adult care is a single event; transition is a multiyear developmental process. Reviews and consensus work identify preparation, coordination, disease knowledge, self-advocacy, adherence, psychosocial support, and uninterrupted access as core elements. Programs should begin in early adolescence, set individualized goals, and reassess readiness rather than assuming competence at a fixed age. [23-25]

A transition visit should reconcile treatment, bleed history, inhibitor status, comorbidities, immunization, dental and surgical plans, pain, mental health, education or employment, insurance or financing, and emergency arrangements. A written portable summary prevents dependence on parental memory and is particularly important for students moving away from home. The first adult appointment should be scheduled before pediatric discharge, with a clear route back to the pediatric team if transfer fails. [23-25]

Success should be measured after transfer: attendance, continuity of prophylaxis, emergency use, bleeding, treatment knowledge, and patient experience. Young people with mild or moderate disease, girls and women with hemophilia, and those with few childhood bleeds may be at special risk of disengagement because their need for specialist care feels less visible. An inclusive transition program should address phenotype and life context rather than focusing only on boys with severe disease. [19,23]

Table 2. Developmental milestones for hemophilia self-management

Stage	Expected progression	Evidence of readiness
Early childhood	Names the condition in simple language; reports pain or injury; participates in treatment routines.	Can seek an adult and describe where it hurts.
School age	Knows basic safety rules, treatment days, and emergency contacts; begins supervised recording.	Explains the school plan and recognizes symptoms requiring help.
Early adolescence	Understands diagnosis, regimen, rescue therapy, and consequences of missed doses; practices private consultation.	Can give a concise medical history and demonstrate treatment tasks. [19,20]
Late adolescence	Orders supplies, arranges appointments, manages travel and disclosure, and communicates with clinicians.	Maintains treatment reliably with parents in a coaching role. [21-23]

Stage	Expected progression	Evidence of readiness
Transfer period	Uses a portable summary and attends the first adult-care visit with continuity of medication and insurance or financing.	No gap in prophylaxis, follow-up, or emergency access. [23-25]

Note: Chronological age guides expectations but does not replace individualized assessment of cognitive, emotional, and practical readiness.

Equity in whole-child outcomes

Whole-child care is impossible without access to basic hemostatic treatment. Global registry and humanitarian program data reveal large gaps in diagnosis, prophylaxis, and comprehensive services. In low-resource settings, school absence may reflect travel for treatment, untreated pain, disability, or family cost rather than a failure of motivation. Recommendations must therefore distinguish aspirational standards from feasible next steps while advocating for reliable diagnosis and prophylaxis. [26,27]

Comprehensive care can still be developmentally ambitious when resources are limited. High-value elements include family education, home treatment where feasible, school communication, low-cost strengthening and balance programs, nutritional assessment, vaccination, dental prevention, pain recognition, and structured transition. Global analyses show that prophylaxis uptake tracks national resources, reinforcing the need for policies that treat childhood participation and disability prevention as essential outcomes. [27,28]

A whole-child review at every visit

A practical consultation can be organized around six domains: bleeding and treatment; pain and physical function; activity and weight; school and peers; family capacity and mental health; and developmental self-management. Not every domain requires a long questionnaire. One or two focused questions, combined with observation of gait and movement and review of the child's own goals, can identify where deeper assessment is needed. [1,2]

The child should speak before the parent whenever developmentally possible. Asking what hemophilia stopped the child from doing since the last visit often yields more useful information than asking only about bleeding. The parent's perspective remains essential, particularly for adherence and family burden, but discrepancies between child and parent reports are clinically meaningful rather than errors to be reconciled away. [14-17]

A brief functional screen can include pain during the previous week, recent limping, ability to run and climb stairs, participation in physical education, and any activity avoided because of fear. The response can direct physiotherapy, treatment review, or reassurance. Repeating the same compact screen over time makes change visible and allows the team to distinguish a transient recovery period from progressive restriction. [3,6,7]

The visit should finish with one agreed developmental goal as well as the medical plan. For a young child this may be naming symptoms; for a school-age child, carrying an emergency card; for an adolescent, ordering supplies or leading part of the consultation. Small verified steps build the competence required for successful transition more reliably than a large information transfer immediately before discharge. [19,23,24]

Research priorities

Future pediatric studies should measure movement, fitness, bone accrual, pain interference, school participation, mental health, family burden, and transition success alongside bleeding. Longitudinal research is needed to determine whether children beginning contemporary non-factor prophylaxis achieve normal peak bone mass and remain active without accumulating subtle functional limitation. Trials should report socioeconomic context and include regions where disability remains driven by delayed diagnosis and limited access. [14,26]

Intervention research should test developmentally tailored activity coaching, early physiotherapy, family-based weight programs, school support, digital adherence tools, and readiness-based transition. The field also needs consensus on a compact whole-child

outcome set that is practical in clinics and meaningful to families. Without such measures, care may appear successful while important restrictions remain invisible. [2,23]

Conclusion

The pediatric endpoint of hemophilia care is a capable young adult, not merely the absence of hospitalizations. Hemostatic prophylaxis creates the possibility of ordinary childhood; comprehensive pediatric care turns that possibility into strength, healthy bone, manageable pain, school inclusion, family confidence, and self-management. The most successful program teaches the child to respect hemophilia without allowing hemophilia to define the boundaries of childhood.

How to cite this article: Shaimaa Hashem Abd El-Aziz, Mervat Atfy Mohammed, Hosam Fathi El-Saadany, Ahmed Mohammed Barakah (2024). Growing Up With Hemophilia: Physical Activity, Bone Health, Pain, School Participation, and TransitionVol. 14, No. 3, 2024,1209-1221

Source of support: None.

Conflict of interest: Nil.

Accepted: 26.03.2024 **Received** 03.03.2024

REFERENCES

1. Srivastava A, Santagostino E, Dougall A, et al. WFH Guidelines for the Management of Hemophilia, 3rd edition. Haemophilia. 2020;26(suppl 6):1-158.
2. Ruiz-Sáez A. Comprehensive care in hemophilia. Hematology. 2012;17(suppl 1):S141-S143.
3. Kennedy M, O'Gorman P, Monaghan A, et al. A systematic review of physical activity in people with haemophilia and its relationship with bleeding phenotype and treatment regimen. Haemophilia. 2021;27(4):544-562.
4. Moretti L, Bizzoca D, Buono C, Ladogana T, Albano F, Moretti B. Sports and children with hemophilia: current trends. Children (Basel). 2021;8(11):1064.
5. Versloot O, Timmer MA, de Kleijn P, et al. Sports participation and sports injuries in Dutch boys with haemophilia. Scand J Med Sci Sports. 2020;30(7):1256-1264.
6. Douma-van Riet DCM, Engelbert RHH, van Genderen FR, et al. Physical fitness in children with haemophilia and the effect of overweight. Haemophilia. 2009;15(2):519-527.
7. Chimeno-Hernández A, Querol-Giner F, Pérez-Alenda S, et al. Effectiveness of physical exercise on postural balance in patients with haemophilia: a systematic review. Haemophilia. 2022;28(3):409-421.
8. Paschou SA, Anagnostis P, Karras S, et al. Bone mineral density in men and children with haemophilia A and B: a systematic review and meta-analysis. Osteoporos Int. 2014;25(10):2399-2407.
9. Iorio A, Fabbriciani G, Marcucci M, Brozzetti M, Filipponi P. Bone mineral density in haemophilia patients: a meta-analysis. Thromb Haemost. 2010;103(3):596-603.
10. Pinto PR, Paredes AC, Almeida A. Pain prevalence, characteristics, and impact among people with hemophilia: findings from the first Portuguese survey and implications for pain management. Pain Med. 2020;21(3):458-471.
11. Shapiro AD, Donfield SM, Lynn HS, et al. Defining the impact of hemophilia: the Academic Achievement in Children with Hemophilia Study. Pediatrics. 2001;108(6):E105.
12. Emerson ND, Distelberg B, Morrell HER, Williams-Reade J, Tapanes D, Montgomery S. Quality of life and school absenteeism in children with chronic illness. J Sch Nurs. 2016;32(4):258-266.
13. Limperg PF, Joosten MMH, Fijnvandraat K, Peters M, Grootenhuis MA, Haverman L. Male gender, school attendance and sports participation are positively associated with health-related quality of life in children and adolescents with congenital bleeding disorders. Haemophilia. 2018;24(3):395-404.
14. Azeredo-da-Silva AF, Zanotto BS, Kuwabara YS, Mata VE. Quality of life in children and adolescents with hemophilia A: a systematic review and meta-analysis. Res Pract Thromb Haemost. 2023;7(1):100008.
15. von Mackensen S, Myrin Westesson L, Kavakli K, et al. The impact of psychosocial determinants on caregivers' burden of children with haemophilia. Haemophilia. 2019;25(3):424-432.
16. Lindvall K, von Mackensen S, Elmståhl S, et al. Increased burden on caregivers of having a child with haemophilia

complicated by inhibitors. Pediatr Blood Cancer. 2014;61(4):706-711.
17. Myrin Westesson L, Sparud-Lundin C, Baghaei F, et al. Burden on parents of children with haemophilia: the impact of sociodemographic and child's medical condition. J Clin Nurs. 2019;28(21-22):4077-4086.
18. Phadnis S, Kar A. The impact of a haemophilia education intervention on the knowledge and health-related quality of life of parents of Indian children with haemophilia. Haemophilia. 2017;23(1):82-88.
19. Königs C, Motwani J, Jiménez-Yuste V, Blatný J; Factor Think Tank. Teenagers and adolescents with hemophilia: need for a specific approach. J Clin Med. 2024;13(17):5121.
20. van Os S, Troop N, Ryder N, Hart DP. Adherence to prophylaxis in adolescents and young adults with severe haemophilia A: a qualitative study with patients. Health Psychol Behav Med. 2018;6(1):277-300.
21. Hoefnagels JW, Kars MC, Fischer K, Schutgens R, Schrijvers LH. The perspectives of adolescents and young adults on adherence to prophylaxis in hemophilia: a qualitative study. Patient Prefer Adherence. 2020;14:163-171.
22. Lee Mortensen G, Strand AM, Almén L. Adherence to prophylactic haemophilic treatment in young patients transitioning to adult care: a qualitative review. Haemophilia. 2018;24(6):862-872.
23. Breakey VR, Blanchette VS, Bolton-Maggs PH. Towards comprehensive care in transition for young people with haemophilia. Haemophilia. 2010;16(6):848-857.
24. Sun HL, Breakey VR, Straatman L, Wu JK, Jackson S. Outcomes indicators and processes in transitional care in adolescents with haemophilia: a Delphi survey of Canadian haemophilia care providers. Haemophilia. 2019;25(2):296-305.
25. Brand B, Dunn S, Kulkarni R. Challenges in the management of haemophilia on transition from adolescence to adulthood. Eur J Haematol. 2015;95(suppl 81):30-35.
26. Coffin D, Gouider E, Konkle B, et al. The World Federation of Hemophilia World Bleeding Disorders Registry: insights from the first 10,000 patients. Res Pract Thromb Haemost. 2023;7(8):102264.
27. Pierce GF, Adediran M, Diop S, et al. Achieving access to haemophilia care in low-income and lower-middle-income countries: expanded Humanitarian Aid Program of the World Federation of Hemophilia after 5 years. Lancet Haematol. 2022;9(9):e689-e697.
28. John MJ, Stonebraker J, Jindal A, et al. Global prophylaxis trends in hemophilia: a macroeconomic analysis and its association with world development indicators. Expert Rev Hematol. 2024;17(12):947-956.