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Clinical Haemophilia

Physical Activity Awareness and Understanding of Treatment Protection Among People With Haemophilia and Their Caregivers in Central Europe

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ABSTRACT

Background: Physical activity is now considered generally beneficial for persons with haemophilia (PWH). However, the specific type and extent of activity and its impact on quality of life (QoL) and bleed protection during exercise is under-researched. This knowledge gap should significantly impact PWH's ability to manage their condition optimally.

Objective: To explore levels of physical activity and understand bleed protection during exercise among PWH as part of the Liberate Life project.

Methods: A web-based survey was conducted across eight European countries between August and September 2023. The online survey was developed by haemophilia treatment experts and patient association representatives according to the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) method. The 24-question survey, distributed to PWH or their parents/caregivers, covered topics such as demographics, the impact of haemophilia on daily life, bleed protection understanding and involvement in physical activities. An activity index was used to categorize PWH as 'more' or 'less' active.

Results: Of 374 respondents analysed, PWH engagement in physical activities, mainly low-impact activities like walking, swimming or cycling, was high (90.9%). Most respondents (74.9%) were 'less active' according to the activity index. There was a significant knowledge gap in respondents' understanding of bleed protection provided by factor and non-factor therapies. Joint health (68.7%), disease severity (69.3%) and capability for physical activity (62.3%) were indicated as key variables influencing PWH QoL.

Conclusion: These findings underscore the need for educational programs to improve PWH's understanding of protective factor levels and the role of non-factor therapies in managing haemophilia.

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1 | Introduction

Regular participation in physical activity is recognized as an essential component of optimal health management for persons with haemophilia (PWH), aids recovery after bleeds and improves joint function in the presence of arthropathy [1, 2]. The World Federation of Haemophilia (WFH) recommends physical activity to improve the quality of life (QoL) for PWH and to enhance clinical outcomes alongside advances in prophylactic treatments [1]. Although physical activity is encouraged for PWH to promote physical fitness and normal neuromuscular development, there may be a risk of bleeding due to trauma during these activities [1, 3]. Therefore, the WFH recommend tailoring physical activities to consider individual PWH interests, age, physical condition and capabilities to foster normal neuromuscular development and physical fitness [1]. A comprehensive systematic review to determine the relationship between physical activity among PWH revealed an inconclusive relationship between physical activity and bleeding phenotype, although there was evidence that recent advances in treatment, particularly in prophylaxis regimens, increased physical activity, especially amongst people with severe haemophilia [4]. As the general population ages, it is common for physical activity levels to decrease [5, 6]. However, older adults with haemophilia often have even lower activity levels, partly because when they were younger, less effective treatments led to more bleeding and joint damage, discouraging physical activity and fostering a lifestyle of low activity. In a systematic review, Kennedy et al. (2021) reported that the levels of physical activity vary markedly between individual adults and children with haemophilia [4, 7]. Other variables beyond age, such as socio-economic status, cultural aspects, environmental conditions, personality traits and behavioural influences, could contribute to the differing levels of physical activity observed among the various samples of individuals with haemophilia included in the systematic review [4, 8]. Thus, it seems the importance of physical exercise needs to be emphasized continually, and the pattern of activities among PWH needs to be analysed further [4].

Despite the documented benefits, the extent to which PWH engage in regular physical activities and their comprehension of the relationship between factor and non-factor protection against bleeds during physical exertion remains largely unexplored. Being informed about their condition and knowledge of improved treatment options can significantly influence PWH's ability to effectively manage their haemophilia, particularly regarding the adoption and maintenance of physically active lifestyles. We conducted a cross-sectional survey to investigate the patterns of physical activity among PWH and their level of understanding of protection against bleeding during exercise with current factor and non-factor therapies. Further, we sought to explore the perceived influence of joint health, disease severity and physical capability on PWH's ability to live well with haemophilia.

2 | Methods

A web-based, cross-sectional electronic survey was conducted across eight European countries (Bulgaria, Croatia, Czech Republic, Hungary, Poland, Romania, Slovakia and Slovenia) between August and September 2023. The Checklist for Reporting Results of Internet E-Surveys (CHERRIES) was followed [9].

2.1 | Study Design, Development and Pretesting

The survey was created by haemophilia treatment experts and haemophilia patient association (HPA) representatives from the Liberate Life Board affiliate expert group in Central and Eastern Europe (CEE). Topics and questions were formulated during an online CEE Liberate Life Steering Board Committee meeting in March 2023. The finalized questionnaire included 24 mandatory, self-reporting, non-adaptive questions and was distributed via HPA in each country (Table S1). An email link to the open survey allowed voluntary responses, and individual participants were not directly contacted. The estimated response rate was determined using viewer, participation and completion rates. The questionnaire covered the following topics: PWH characteristics and demographics (six questions), openness to disclose bleeding disorder (three questions), impact on daily life (three questions), relationship with Haemophilia Treatment Centres (HTC) (two questions), types of physical activities (one question), understanding of haemophilia severity and recommended factor levels for protection (four questions), knowledge of treatment protection levels (three questions) and reasons for additional dosing (two questions). All questions (except two open-ended question) were multiple choice and included a 'not applicable' option. The survey was translated into each local language and pretested with HPA representatives.

2.2 | Participants

HPA members received an open online survey link via email or another digital platform, with the option to complete it using a computer, tablet or mobile phone. Participants could be adults or children living with haemophilia making health-related decisions, defined as PWH or adults deciding on behalf of a child or senior with haemophilia (parents/caregivers). Participants were analysed according to age groups: paediatric (≤ 12 years), adolescent/young adult (13–25 years), younger adult (26–49 years) or older adult (≥ 50 years) and by treatment type (on-demand or prophylaxis).

2.3 | Physical Activity Index

Physical activity participation was subjectively grouped as 'less' or 'more' active for our study. Typically, the general standard for 'physically inactive' is defined as engaging in less than 30 min of moderate-intensity physical activity per week [10, 11]. Following a similar guideline, we created specific criteria for our survey. Respondents were grouped based on the number of physical activities they indicated in the past 2 weeks: respondents participating in ≤ 2 activities (participated in two or fewer physical activities lasting at least 30 min) were defined as 'less' active, and respondents participating in ≥ 3 activities (participated in three or more activities lasting at least 30 min) were defined as 'more' active. These activity cutoffs are consistent with the National Haemophilia Foundation (NHL) recommendations, which suggest gradually building up to 30 min of moderate-intensity exercise at least three to five times per week for individuals with haemophilia, including both children and adults [11].

2.4 | Survey Administration, Data Collection and Analysis

The online questionnaire was managed by Seesame s.r.o (Bratislava, Slovakia) using the online platform Survey Sparrow. Responses were collected, extracted and analysed by Seesame s.r.o. Only fully completed surveys were analysed.

2.5 | Ethical Considerations

All respondents provided informed consent at survey initiation. The survey was anonymous, with no personal details collected or stored. Data collection and analysis complied with EU General Data Protection Regulation 2016/679, local legislation and Ethics Committee approval (University Hospital of St. Cyril and Metod Bratislava Ethics Committee, No: EK2/10/2023).

2.6 | Statistical Analysis

Descriptive statistics were used to analyse the quantitative data collected.

3 | Results

Out of 955 unique visitors to the survey link, 387 completed it, resulting in a 40.5% response rate. Thirteen surveys were excluded for being related to von Willebrand's disease instead of haemophilia. The remaining 374 respondents were evenly split between PWHs and caregivers (Table 1).

3.1 | Respondent Demographics

Respondents differed in age and treatment types. For the paediatric group (≤ 12 years), 96.8% of responses, and for the adolescent/young adult group (13–25 years), 59.2% were completed by parents/caregivers. In contrast, 84.4% of younger adults (26–49 years) and 90.1% of older adults (≥ 50 years) completed the survey themselves. Most respondents (78.1%) either had severe haemophilia or were caregivers of someone with severe haemophilia. Prophylaxis was the main therapy type (74.9%) (Table 1). Among the 80.2% of PWH on factor therapy (factor VIII or IX), 77.0% received it as prophylaxis.

3.2 | Comfort With Disclosure, Treatment Reporting and Therapy Administration among PWH

Most respondents (71.1%) indicated they felt comfortable discussing their/their PWH's bleeding disorder, with 86.6% indicating they accepted their/their PWH's condition. Acceptance was consistent across all age groups. Nearly half (46.5%) of respondents indicated they/their PWH felt living with haemophilia defines who they are. The majority of respondents (84.5%) indicated they provide treatment reports to their/their PWH's HTC. Respondents indicated failing to report their/their PWH's therapy for various pre-defined reasons, including forgetfulness (36.0%), lack of trust of doctor (5%), data protection issues (2%),

TABLE 1 | Respondent demographics and characteristics.

Respondent, n (%)	
All	374 (100)
PWH	203 (54.3)
Parent/caregiver of PWH	171 (45.7)
Respondent country of residence, n (%)	
Bulgaria	17 (4.5)
Croatia	39 (10.4)
Czech Republic	82 (21.9)
Hungary	72 (19.3)
Poland	9 (2.4)
Romania	82 (21.9)
Slovenia	15 (4.0)
Slovakia	58 (15.5)
Haemophilia severity, n (%)	
Severe (< 0.01 IU/mL; $< 1\%$ of normal factor level)	292 (78.1)
Moderate (0.01–0.05 IU/mL; 1%–5% of normal factor level)	49 (13.1)
Mild (> 0.05 –0.40 IU/mL; 5%–40% of normal factor level)	33 (8.8)
Age distribution of PWH by age group, n (%)	
Paediatric	
≤ 6 years	55 (14.7)
7–12 years	40 (10.7)
Adolescent/young adult	
13–25 years	76 (20.3)
Younger adult	
26–49 years	122 (32.6)
Older adult	
≥ 50 years	81 (21.7)
Therapy type, n (%)	
On-demand	94 (25.1)
Prophylaxis	280 (74.9)
Treatment, n (%)	
FVIII (total)	
rFVIII	205 (54.8)
pd FVIII	61 (16.3)
Non-factor PPX	42 (11.2)
FIX (total)	
rFIX	26 (7.0)
pdFIX	8 (2.1)
Not applicable	32 (8.6)

Abbreviations: F, factor; IU, international unit; pd, plasma-derived; PPX, prophylaxis; PWH, person with haemophilia; r, recombinant.

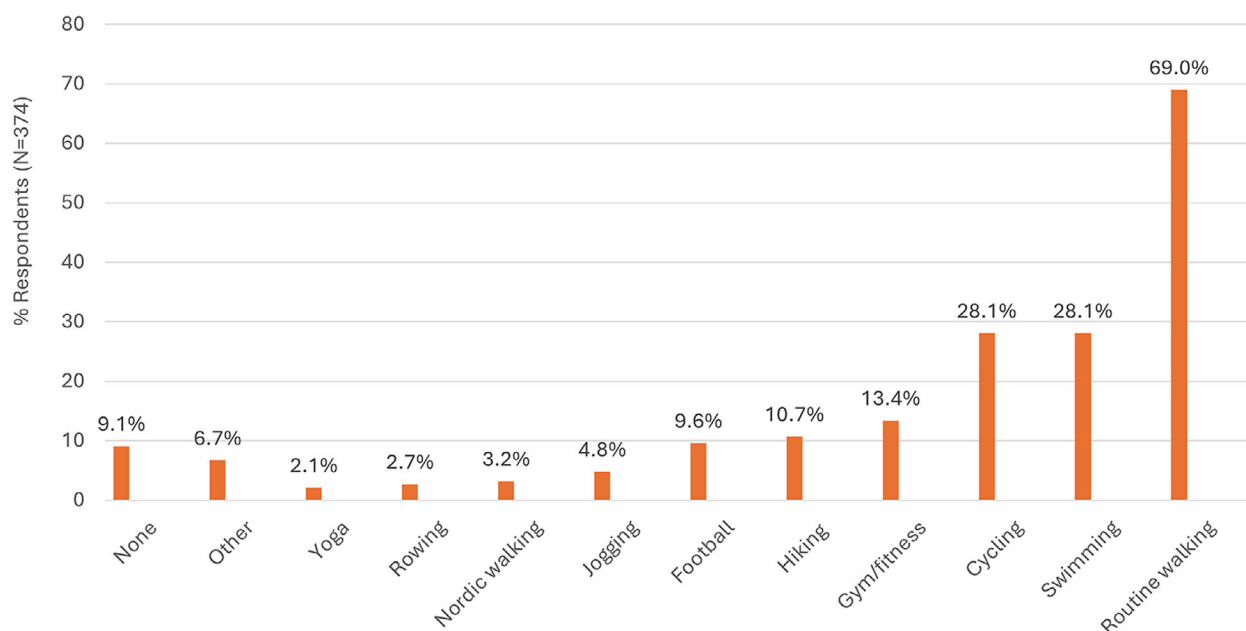


FIGURE 1 | Types of physical activities performed by respondents in the last 2 weeks (lasting ≥ 30 min).

non-compliance (7%) or other (not specified reason; 50%). The proportion of respondents in the paediatric group indicating failure to report their therapy was much lower (3.2%) than respondents in the other three age categories (adolescent/young adult 19.7%, younger adult 18.9% and older adult 21.0%, respectively).

Only 51.9% of respondents indicated they felt/their PWH felt comfortable during the administration of treatment, with discomfort highest among paediatric PWH (41%) and lower among adolescent/young adult, younger adult and older adult PWHs (18.4%, 21.3% and 16.0%, respectively). Of those respondents indicating they/their PWH was on factor prophylaxis (Table 1), 133 (44.3%) reported additional factor administration had been required in the past 3 months, with the primary reasons being trauma (47.4%), spontaneous bleeds (29.3%) and sporting activities (25.6%). Among respondents indicating they/their PWH was on non-factor prophylaxis (Table 1), 78.5% did not need additional factor therapy during the same period. Nine respondents indicated they/their PWH required additional factor therapy for trauma (33.3%), spontaneous bleeds (44.4%), sports (22.2%) and pain (22.2%).

3.3 | Types of Physical Activities for PWH

Most respondents (90.9%) indicated they/their PWH had participated in physical activities for at least 30 min within the last 2 weeks. Common activities included walking (69.0%), swimming (28.1%) and cycling (28.1%) (Figure 1). Older adults had a higher proportion of non-participation in physical activities compared to PWH from other age groups (Table S2).

An activity index was designed to classify the level of physical activity among respondents as less active (score of 2 or lower) versus more active (score of at least 3). The index revealed that most PWH tend to be less physically active (74.9% vs. 25.1%, respectively). This trend was consistent across all age groups (89.0%,

92.0%, 88.0% and 98%, for paediatrics, adolescent/young adult, younger adult and older adult groups, respectively) (Figure 2).

3.4 | Awareness of Individual Factor Level Changes and Understanding of Protection

The survey revealed that 68.7% of respondents believe they or their PWH on factor therapy fully understand post-injection factor level fluctuations (peak and trough levels), while 28.0% believe they have a partial understanding (Figure 3). Awareness was lower among those on non-factor therapy. Less than half (45.4%) of PWH on factor therapy know their target trough levels (factor VIII or IX) in concordance with their treating physician's treatment plan (Figure 4). Over half of PWH on factor therapy (56.7%) and most on non-factor therapy (76.2%) correctly identified that a $>50\%$ factor level ($>50\%$ – 150%) constitutes physiologically normal levels or a 41% to $<50\%$ factor level constitutes a near-normal level (Figure 5). Although many respondents believe they/their PWH taking factor therapy understand changes in factor levels (Figure 3), only 18.0% selected the recommended level (15%–30%) [12] for bleed protection during intensive sports (e.g., moderate-intensity cycling), approaching a zero joint bleed rate (Figure 6). More than half (54.7%) indicated they/their PWH taking non-factor therapy did not understand the haemostatic potential equivalence of current non-factor therapy ($\sim 9\%$ – 15%) [13–17] (Figure 7).

3.5 | Variables Impacting a PWH's Ability to Live Well With Haemophilia

Survey respondents indicated disease severity (69.3%), joint health (68.7%) and capability for physical activity (62.3%) as the top three variables having significant/greatest influence on QoL for PWH (Figure 8). For older adults with PWH, joint health and physical activity had the greatest impact on QoL

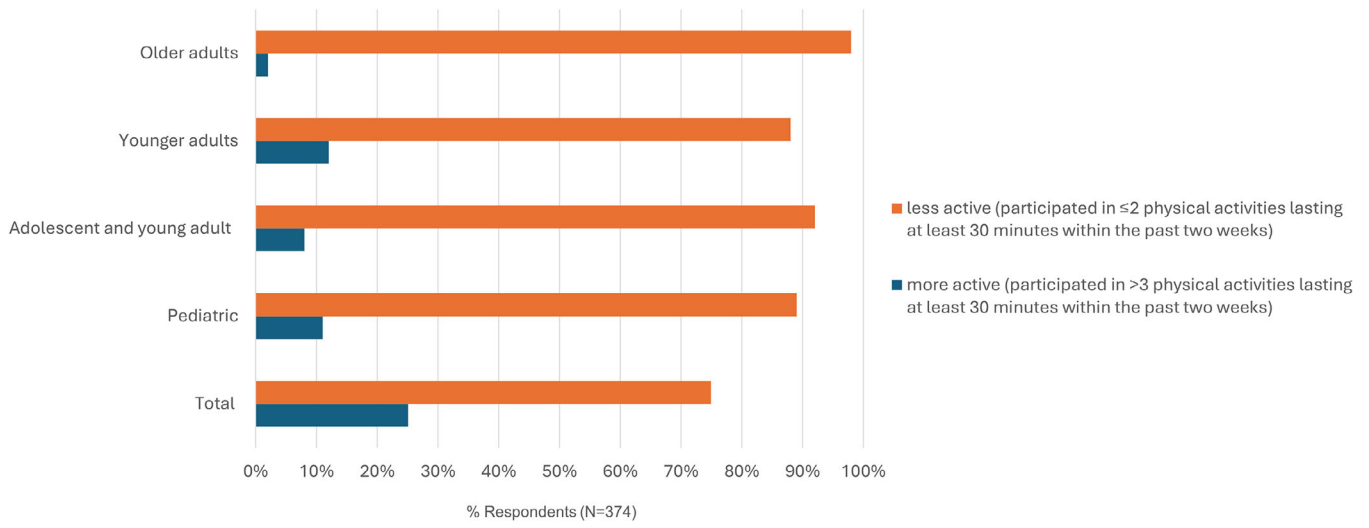


FIGURE 2 | Level of physical activity among respondents (less or more active).

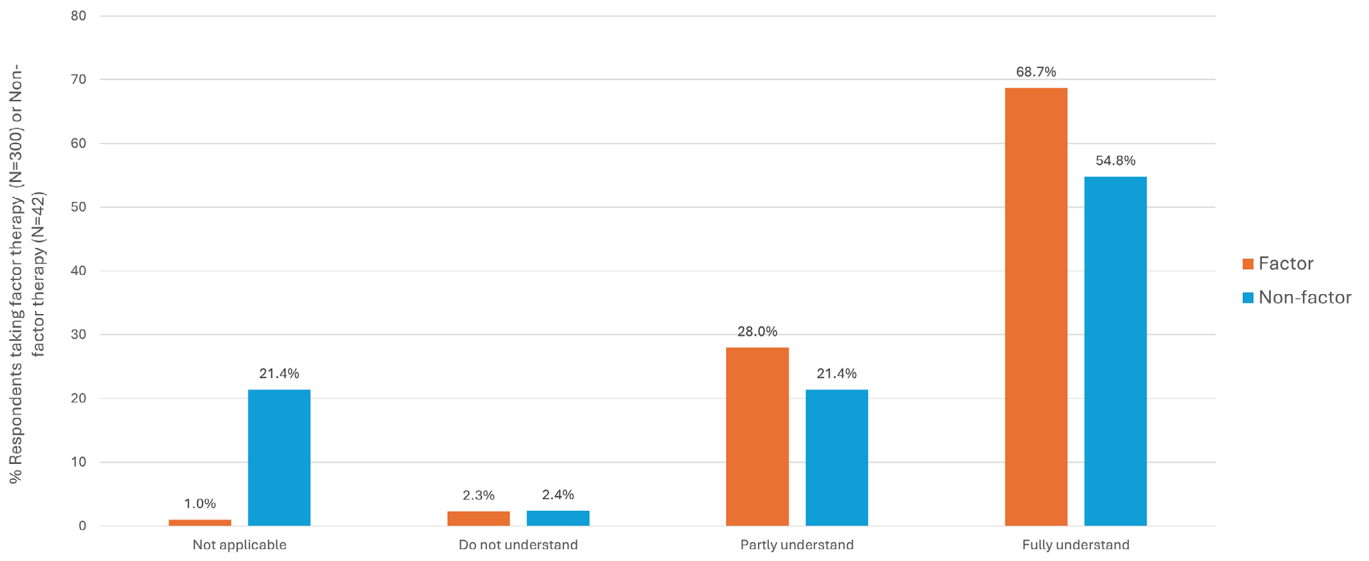


FIGURE 3 | Awareness of individual factor level changes over time by treatment type.

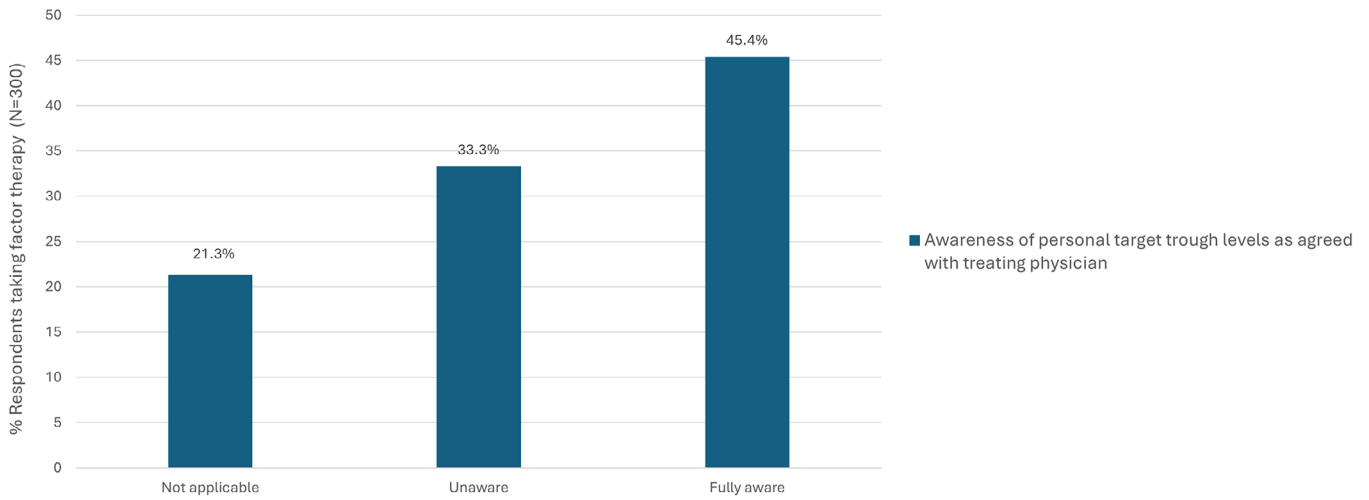


FIGURE 4 | Awareness of personal target trough levels for respondents receiving factor therapy in accordance with their treating physician's treatment plan.

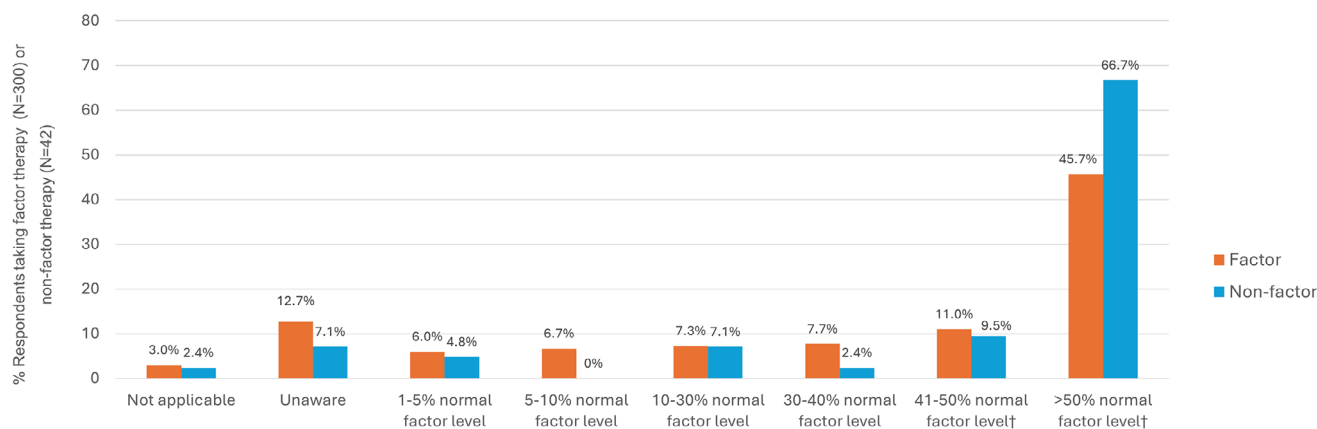


FIGURE 5 | Respondents' understanding of the factor levels that constitute normal levels of factor activity.

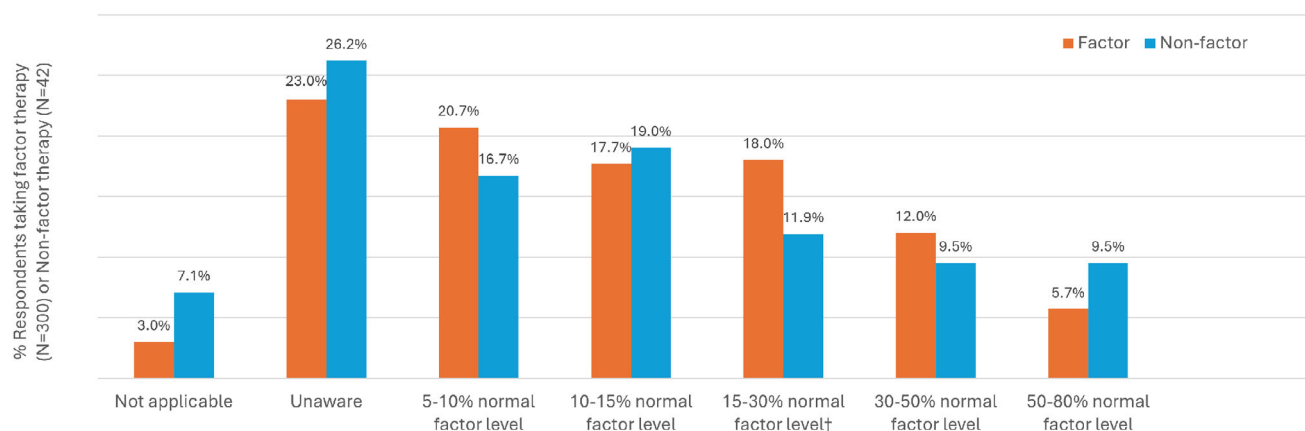


FIGURE 6 | Respondents' understanding of recommended factor levels required for protection during intensive physical activities (e.g., moderate-intensity cycling).

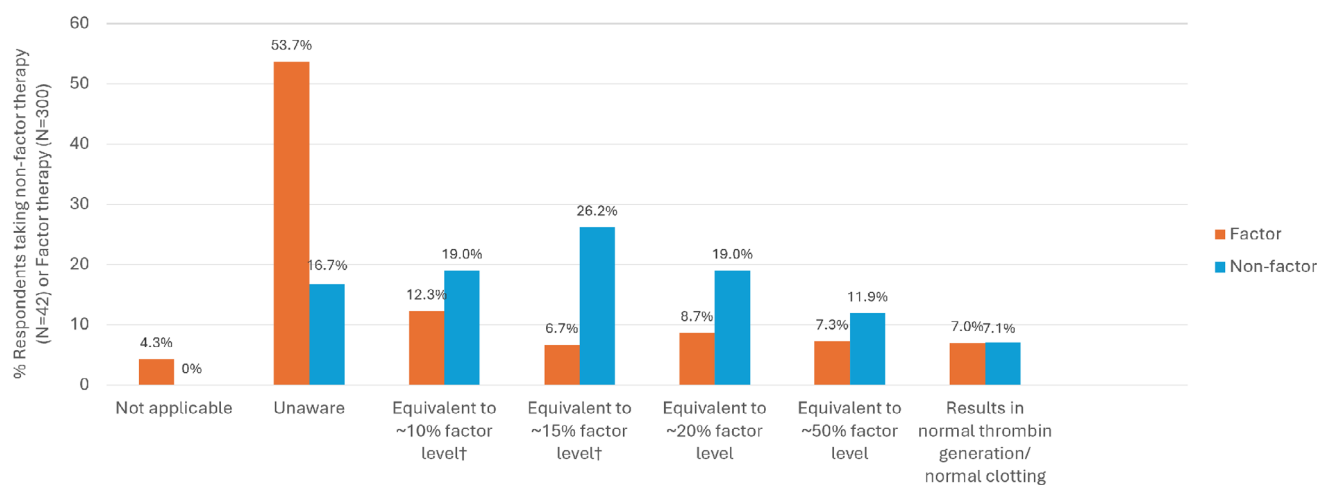


FIGURE 7 | Understanding of haemostatic potential equivalence achievable with currently available non-factor prophylaxis.

(88.9% and 82.8%, respectively; Table S3). Respondents indicated financial security, comorbidities and mental health as the top three variables having little or no impact on QoL for PWH, indicated by 65.2%, 60.9% and 59.1% of respondents, respectively; the QoL impact was the lowest for paediatric PWH (75.8%, 74.8% and 61.1%, respectively; Table S3).

4 | Discussion

Engaging in physical activities alongside appropriate treatment is essential for preserving joint health and preventing joint damage and hemarthrosis in PWH [18]. This survey indicates a high awareness of physical activity benefits among PWH,

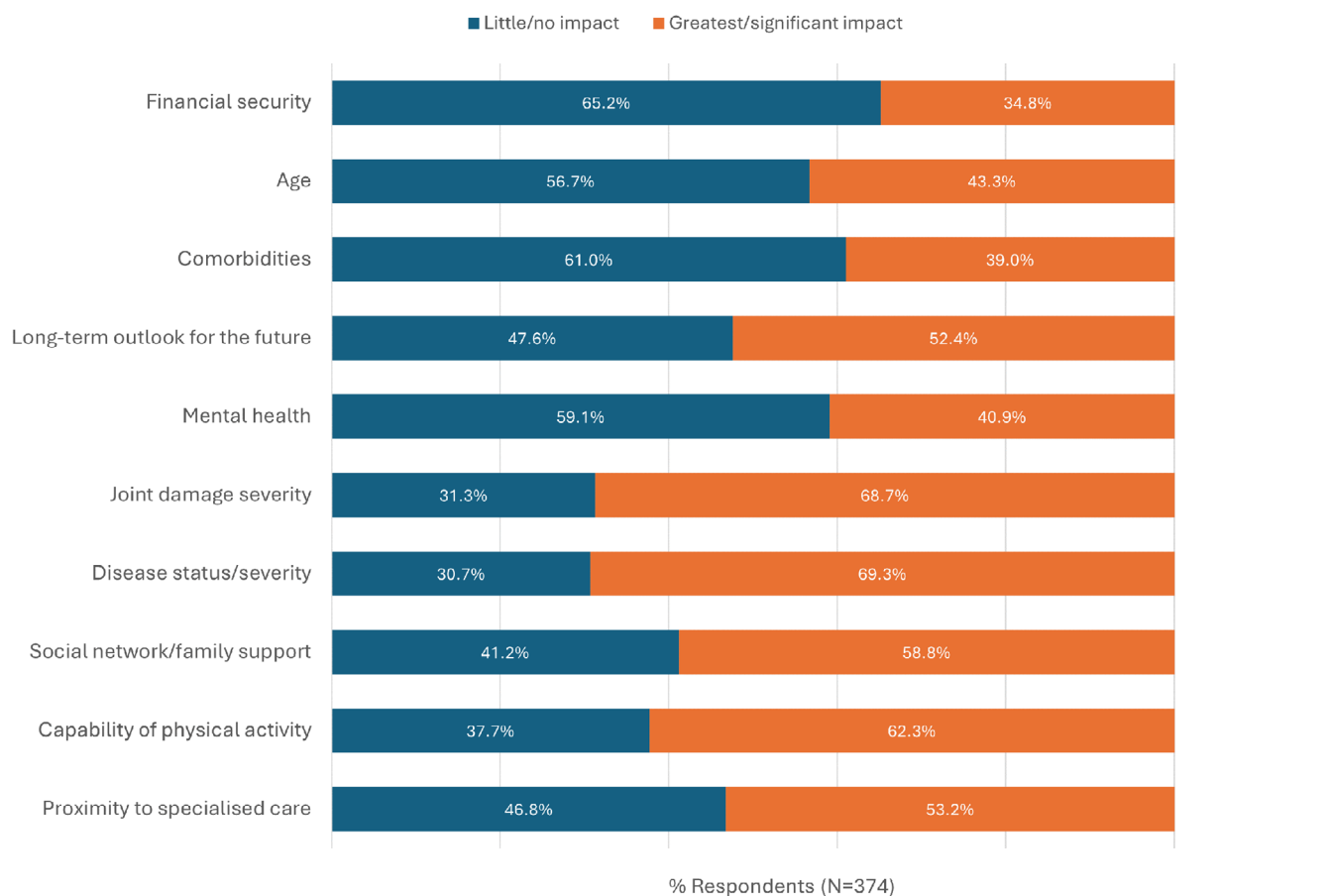


FIGURE 8 | Variables significantly impacting the quality of life for respondents.

but a gap exists in understanding protective factor levels during varying activity intensities. Education programs could help PWH and their caregivers/parents understand the bleed protection provided by factor and non-factor therapies in managing haemophilia.

4.1 | Clinical Implications of Physical Activity Levels in Haemophilia Management

Our survey emphasizes the need to educate and motivate PWH and caregivers to engage in age-appropriate activities. The activity index revealed that PWH are less physically active than recommended levels for the general population [10]. Reasons for lower activity levels amongst PWH are complex [19]. The trend is consistent across all age groups, with the highest rates of inactivity among older adults with haemophilia, similar to the general elderly population, who may face additional challenges such as joint pain or mobility issues. Tailored interventions are needed to promote regular physical activity among PWH, particularly older adults.

A recent systematic review reported that PWH has lower exercise capacity than the general population [20]. Historically, children and adolescents with haemophilia exhibited lower fitness levels, diminished aerobic exercise capacity and higher obesity rates compared to their peers without haemophilia [21], potentially leading to worse health outcomes in adulthood and a higher risk

of injury due to bleeding propensity [21]. Prophylaxis therapy now enables children with haemophilia a QoL comparable to their peers without haemophilia, enhancing their involvement in sports, including team activities [22].

4.2 | Clinical Implications of Additional Factor Requirements in Haemophilia Management

More than half of respondents receiving factor prophylaxis required additional factor in the last 3 months. We can speculate that these PWH had additional factor requirements as they engaged more in physical activities. Nearly one-third needed extra dosing on 1–2 occasions, and it is plausible to speculate that for these PWH, current factor prophylaxis regimens may not be sufficient for high-risk periods. Better education of requirements during physical activities of varying intensities and personalized prophylaxis regimens considering individual activity levels and bleeding patterns are necessary.

4.3 | Awareness and Understanding of Factor Level Changes during Physical Activity

PWH should be educated on the bleeding risk associated with specific sports and the protection levels provided by factor or non-factor therapy. Consistent with the literature [13, 23], PWH in our survey reported engaging more frequently in lower-risk

activities like routine walking, with less than half aware of their personal target trough levels. While most respondents believe that they/their PWH understand variations in factor level activity post-administration, only one-fifth knew the recommended factor level to prevent bleeding during moderate-intensity cycling. We might speculate that this lack of understanding may explain why most PWH opt for lower-risk activities like routine walking.

The variability in non-factor therapy trough levels and inconsistent assays make determining FVIII equivalence challenging [13, 24, 25]. The phase 3 HAVEN 3 trial reports steady-state plasma levels equivalent to 9–15 IU/dL (~9%–15%) of FVIII for emicizumab [13–15]. A recent *in vitro* study reported that factor VIII bioequivalence with an emicizumab analogue ranges from 4.7%–16.4%, depending on thrombin generation assay conditions [25].

Most respondents indicated they/their PWH couldn't identify the protection levels achievable with currently available non-factor therapy (emicizumab). It is crucial to educate PWH and their caregivers that non-factor therapies like emicizumab do not provide peak protection during high-risk periods such as during contact sports or physically intense exercise [13, 26]. The lack of understanding highlighted in our survey should prompt efforts to improve education and effectively communicate the necessary knowledge.

Experts suggest factor VIII levels of 15–30% may be needed for near-zero joint bleeding during intensive sports, though the optimal level is debated [12, 26, 27]. Tomschi et al. (2024) observed 1011 physical activity sessions in PWH to determine FVIII starting levels for various activities [27]. Prophylaxis should be individualized, as active individuals might need more frequent infusions [1]. Newer factor VIII treatments with extended half-lives may reduce therapy burden and enhance protection during physical activities [28].

4.4 | Clinical Implications and Variables Impacting QoL in PWH

The majority of respondents indicated they/their PWH report treatment to their HTC, emphasizing the importance of patient-provider communication. Barriers like forgetfulness, lack of trust, data protection issues and non-compliance affect reporting. Strategies to improve accuracy and reliability, such as implementing reminder systems, fostering patient-doctor trust and addressing data privacy, are essential. Parents/caregivers of paediatric patients show better reporting habits, possibly due to concern for the long-term impact of haemophilia on their child's health and well-being.

Our survey identifies disease severity, joint health and physical activity capability as key variables influencing QoL in PWH. Effective haemophilia management should prioritize minimizing severity and maintaining joint health. Older adults indicated the importance of joint health and physical activity, highlighting the need for tailored interventions. Early and continuous physiotherapy, along with individualized exercise programs, are crucial in mitigating long-term impacts on joint health and physical capabilities. While financial security, comorbidities and mental

health were reported to have less impact on QoL, these areas shouldn't be neglected. Comprehensive care models need to address mental health and comorbidity management to support overall well-being and long-term health outcomes.

Today, PWH are anticipated to live as long as the general population [29]. The disease's influence extends beyond physical discomfort, impacting the mental well-being of patients as well. Indeed, living with a 'haemophilia-free mind' is emerging as a new ambition of haemophilia care [30]. Nearly half of individuals with haemophilia feel it defines who they are, highlighting the psychological and social impact of the disease. This necessitates a holistic approach to care that addresses mental health, self-identity and QoL issues.

The European Haemophilia Consortium (EHC) survey highlights that these countries now offer comparable standards of haemophilia care and treatment access [31]. At the time of the 2023 survey, the treatment levels, factor supply and proportion of patients on prophylaxis (76%–100%) in Croatia, Czech Republic, Hungary, Slovenia, Slovakia and Poland (representing two-thirds of respondents) were comparable both among these countries and with other EU nations. According to the WFH Annual Global Survey 2023 (www.wfh.org), Bulgaria and Romania reported slightly lower factor supply during the same period. Still, we cannot rule out subtle differences in treatment approaches and/or access, shaped by each nation's specific healthcare systems, economic resources and historical paths [31]. The roles of HPAs might vary significantly across countries due to cultural differences, healthcare systems and policies. These groups can shape policies, build capacity, educate and provide peer support [32]. This diversity may explain the significant differences in our survey recruitment across different countries. However, further studies would be required to confirm this hypothesis.

Our cross-sectional survey provides descriptive data on PWH's engagement in physical activities and their believed understanding of factor and non-factor protection against bleeds during these activities. However, the limited number of survey respondents and the imbalance of PWH numbers between factor and non-factor treatments necessitates a cautious interpretation of the results. The respondents may not be representative of the general population of PWH in Europe. For example, the relatively high number of patients with severe haemophilia could impact the lower physical activity of respondents in our survey. Another possible bias could be that PWH who are completely inactive may have chosen not to respond due to disinterest or feelings of embarrassment. Additionally, some respondents might have avoided certain questions by selecting 'not applicable'. The lack of a standardized validity assessment for the questionnaire and activity index is a limitation. While self-reporting of physical activities was used for simplicity and cost-effectiveness, future studies could benefit from activity monitoring, which allows for goal setting and quantified tracking [33].

5 | Conclusions

This survey shows that while awareness is high, a significant knowledge gap exists regarding the protective role of factor and non-factor therapies against bleeds during physical activities.

Our data revealed an opportunity to encourage PWH to increase their physical activity levels, as many currently engage in low-risk activities due to understandable concerns about bleeding. Additionally, enhancing education and support could boost the confidence of PWH with their treatment regimen, as only half of those surveyed currently feel comfortable during treatment administration. Haemophilia significantly affects daily lives, causing physical discomfort and impacting mental well-being. Holistic care addressing both physical and psychological needs is crucial. Future research should focus on comprehensive educational programs and promoting safe physical activity among PWH.

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Ethics Statement

The research protocol was submitted to the Ethics Committee of the University Hospital of St. Cyril and Metod Bratislava for review prior to the initiation of the survey (proposal no. EK2/10/2023). The Ethics Committee determined that this research was exempt from ethics review under compliance with EU General Data Protection Regulation 2016/679 and relevant local legislation.

Conflicts of Interest

Angelika Batorova received speaker fees from Grifols, Novo Nordisk, Octapharma, Pfizer, Roche, Sobi and Takeda, and travel grants from Novo Nordisk and Sobi; Atanas Banchev received consultancy fees from Novo Nordisk, Sobi and Roche, and speaker fees and honoraria from Novo Nordisk, Sobi, Roche and Takeda; Ana Boban received speaker fees and honoraria from Bayer, CSL Behring, Novo Nordisk, Pfizer, Roche, Sobi and Takeda; Brigitte Brand received consultancy fees from Sobi in the early preparation of this manuscript; Melen Brinza received speaker fees from Novo Nordisk, Roche, Sobi and Takeda; Barbara Faganel Kotnik received consultancy fees from Licentis, Roche and Sobi; Csongor Kiss received funds from a NKFIH OTKA K143021 Grant, Foundation for Children with Leukemia, speaker and reimbursement fees from Octapharma AG, consultancy fees for AOP Orphan Pharmaceuticals GmbH Magyarorszag, CSL Behring Magyarorszag Kft., H-W-H Kft., Novo Nordisk Hungarian Kft., Octapharma AG, Roche Magyarorszag Kft., Sobi and Takeda; Gediminas Puras and Jan Rajnoch are employees of Sobi; Ester Zapotocka received consultancy fees from Novo Nordisk, Roche, Sobi and Takeda.

Data Availability Statement

The data that supports the findings of this study are available in the Supplementary Material of this article.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.