

COMMENTARY

Movement behavior in hemophilia—from medicalized training approaches toward an active lifestyle

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In this issue of *Research and Practice in Thrombosis and Haemostasis*, McLaughlin and colleagues¹ explore ways to support persons with hemophilia in practicing nonmedicalized exercise approaches. In this study, 19 participants were included and were given an activity tracker and a free gym membership. In addition, half of the group were also offered a 12-week tailored, personal trainer-led fitness program. Researchers found both groups (those with only gym membership and those with gym membership and personal training) had increased activity. Adding a personal trainer enforced persons with hemophilia in conducting the training and demonstrated that this might help participants to maintain physical activity even after the study terminated. This is an example of the positive effect of facilitating behavioral change by providing resources and environmental support.

Improvements in the treatment of persons with hemophilia in the past 40 years have radically changed the impact of hemophilia in developed countries.² From a disabling condition that strongly affected life expectancy of persons with hemophilia, it now is a more easily treatable chronic health condition in which life expectancy is approaching that of people in the general population.² As a result of this improved treatment, the impact of non-hemophilia-related comorbidities such as cardiovascular disease and malignancy increases over time.^{3,4} Regular physical activity is important to maintain

muscular fitness, maintain a healthy weight, and reduce the risk of cardiovascular disease, type 2 diabetes, and malignancy.⁵ Although the World Health Organization released a report on the importance of regular physical activity in 2010,⁶ there is a rising number of people in the general population who have insufficient physical activity, especially in high-income Western countries.⁷

Guidelines for hemophilia care recommend supporting physical activity to enhance muscle strength and coordination, maintain a healthy weight, and support bone health in persons with hemophilia.⁸ Studies in the Netherlands and Australia showed sports participation in children with hemophilia is almost similar to that of the age-matched healthy peers.⁹⁻¹¹ Although sports participation in young persons with hemophilia is improving, a recent study showed that physical activity levels in adults with hemophilia are lower compared to age-matched healthy controls.¹² This might be an echo from the past as traditionally people with hemophilia were discouraged from participating in sports because of the high risk of bleeds when prophylactic treatment was not yet available. In addition, bleeding in the past leading to hemophilic arthropathy may have impaired the ability to perform activities such as running and biking.¹³ Moreover, the concerns regarding the risk associated with exercise or physical activity are still present in part of the adult population outweighing the benefits for them.¹⁴ This indicates the importance of studies that

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explore ways to overcome barriers and fears that might hinder persons with hemophilia from participating in sports or other forms of physical activity.

Movement behavior is a broader and more comprehensive concept than just sports participation or sedentary time. An integrated model (see Figure 1) that includes sedentary behavior, sleep, and physical activity is proposed.¹⁵ In this model, physical activity is further subdivided into light, moderate, and vigorous physical activity. As two persons with similar physical activity levels (eg, amount of moderate-intensity physical activity) might differ on other parameters (eg, amount of sedentary time), comprehensive profiles of movement behavior are recommended to capture the different dimensions.¹⁶ A recent systematic review showed that sedentary time is a predictor of deleterious health outcome independently from physical activity, highlighting the importance of this comprehensive model.¹⁷ We therefore believe that clinical practice and future research in persons with hemophilia should embrace this comprehensive definition of movement behavior and not be limited to focusing only on increasing the amount of moderate or vigorous physical activity. Particularly for patients with hemophilic arthropathy for whom moderate and vigorous physical activity might not be feasible, supporting light physical activity and limiting sedentary behavior has the potential to improve health outcomes. The hemophilia comprehensive care team as a whole should be aware of the role they can play in promoting healthy movement behavior, including regular physical activity and limiting sedentary behavior in persons with hemophilia.

To influence movement behavior (or behavior in general) in clinical practice health care for persons with hemophilia, theories about behavioral change should be taken into consideration. Providers should be aware of the various stages of behavioral change and techniques to use in the different stages (see Table 1).¹⁸ Often, there is a lot of attention to start behavioral change, but clinicians should be aware that interventions aimed to initiate behavioral change differ from interventions aimed to make a long-term behavioral change. A recent review identified the most important factors to take into account regarding the maintenance stage.¹⁹ The factors identified in this review and how to apply them in clinical care for persons with hemophilia are listed below.

1. Enlarge intrinsic motivation.

Health care providers should enlarge a person's intrinsic motivation by recurring, positive affirmation or reward. In caring for persons with hemophilia, it is essential to take into account physical abilities and risks and aim at participating in physical activities that a person enjoys and that suit a person's preference.

2. Facilitate behavior self-regulation.

To facilitate self-regulation it is necessary to make people aware of their old habits, take the time during consultation to compose a personal plan to reach daily or weekly goals, give support to prevent relapse to old behavior, and support them on how to return to changed behavior in case of a relapse. For example, if someone's goal is to perform a certain number of steps

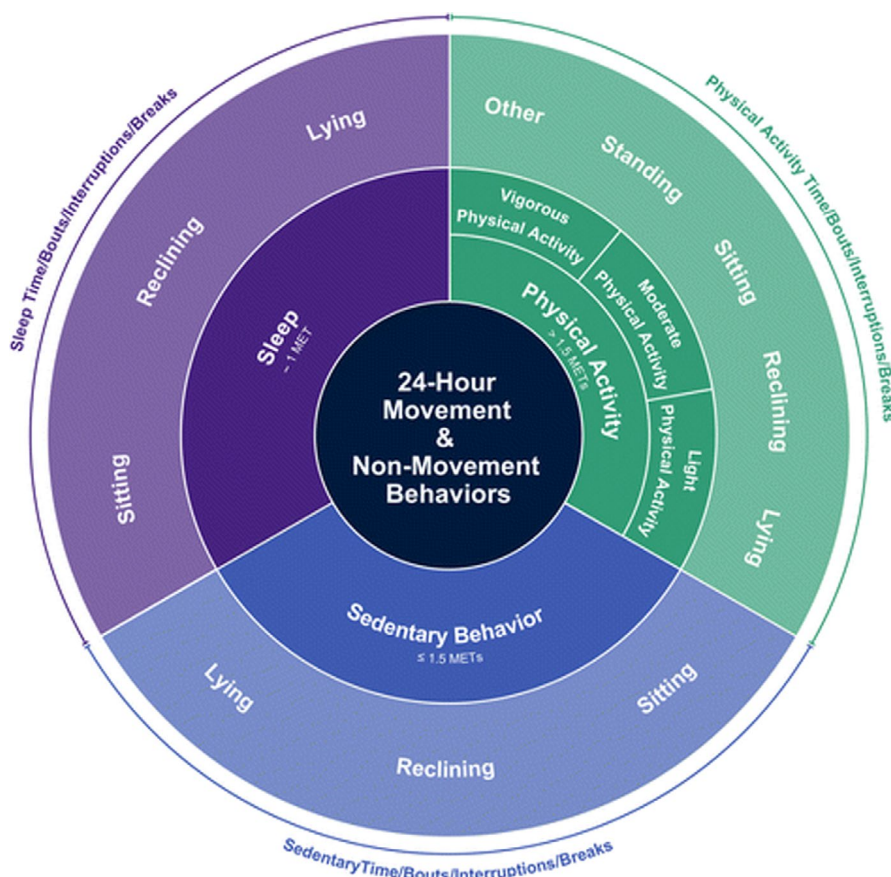


FIGURE 1 Integrated movement behavior model. Source: Tremblay et al.¹⁵

TABLE 1 Stages of behavioural change

Stage	Characteristics	Actions
Precontemplation	Not intending to change behavior in near future. When people are in this stage they are either not informed enough about the consequences of their behavior or they have tried numerous times and have become demoralized.	<ul style="list-style-type: none"> • Education on risks • Increase emotional experience • Make someone aware of impact on environment
Contemplation	Intending to change in the near future. More aware of the pros of changing but also conscious of the cons. People in this stage are ambivalent about changing behavior.	<ul style="list-style-type: none"> • Education on benefits • Stimulate reevaluation of self
Preparation	Intending to take action in the immediate future. Often, people in this stage have a plan how to change behavior.	<ul style="list-style-type: none"> • Develop realistic goals and timeline • Provide positive reinforcement
Action	People in this stage have taken action to change their behavior. However, in this stage, people are frequently tempted to relapse into old behavior.	<ul style="list-style-type: none"> • Provide positive reinforcement • Increase awareness of achieved results • Provide resources • Provide support
Maintenance	In this stage, people have applied change for a period of time and are working to prevent a relapse to old habits. They aim to move to a state in which they are not tempted to perform old behavior, and their new behavior is part of daily life.	<ul style="list-style-type: none"> • Help individuals to maintain positive behavior • Facilitate behavior self-regulation • Reshape environment and use cues • Provide resources • Provide support

per day, make a specific plan together of how to reach this goal (eg, what time of the day is most suitable to perform the activity, what to do when someone experiences a bleed or flare-ups of arthropathy).

3. Utilize cues and reshape environment.

Maintaining old habits takes time and repetition and can be supported by cues in daily life (eg, gather your sports outfit the night before, use digital notifications) and by reshaping the environment (eg, make sure sports equipment is easily accessible, trainers or physiotherapists are informed about hemophilia).

4. Provide necessary resources.

Provide resources that are needed to maintain new behavior; these could be both physical (eg, look for suitable sports facilities during consultation, provide orthopedic footwear) and psychological (eg, knowledge about joint structure and pain, goal setting).

5. Social support.

Be aware of the social support (or lack of support) a person receives on an individual, social, and community level. Involve the social environment in the process of behavioral change. When someone's support is deemed not sufficient, you can recommend seeking help from a local physiotherapist or personal trainer that could support him or her to maintain the behavioral change. Health care providers in a hemophilia comprehensive care team should identify whether parents or a partner are hesitant about physical activity due to perceived risks or habit to take over tasks of patients who are less physically active.

These techniques should help people to adhere to physical activity and limit sedentary behavior in the long term and to incorporate this into daily life. The selection of these techniques was described in a recent study on the potential of blended care in hemophilic arthropathy.²⁰ In their study, McLaughlin and colleagues¹ also explored ways to support persons with hemophilia

in participating in nonmedicalized physical activity. They found providing resources and support from a personal trainer helped persons with hemophilia to increase and maintain activity. The study was performed on a small selection of young adults with low bleeding rates and good joint health. Future studies should explore whether these techniques also apply to a wider population of persons with hemophilia of different ages and levels of joint disease. These future studies should evaluate the potential of behavioral change techniques to enable persons with hemophilia to reduce sedentary time and include physical activity as a standard part of their lifestyle.

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AUTHOR CONTRIBUTIONS

All authors were involved in the concept of the manuscript. JB wrote the first draft of the manuscript. All authors critically reviewed the manuscript and approved the final version.

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