

Applying individualized care to safe physical activity recommendations: an evidence-based resource for persons with bleeding disorders.

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INTRODUCTION

The benefits of physical activity for persons with bleeding disorders (PBD) are well recognized.¹ For every individual, the degree of risk associated with physical activity and sport depends on the interaction of many variables, including their health condition, personal factors and their environment.² Physical activity resources currently available for PBD are primarily didactic and based on an incomplete assessment of sport risk.^{3,4} They are inadequate for guiding individualized activity choices or for providing strategies to decrease personal risk during participation.³ This may lead a person to disengage from the recommendations and partake in activities with significant risk of trauma without a full appreciation of their susceptibility to injury or the opportunity to openly discuss plans for minimizing danger.

Vision: An engaging and interactive workbook designed to foster competence and autonomy in decisions about physical activity participation. It will be adaptable to each person's learning priorities and could be used independently or as a guide for collaboration.

METHODS

The need for an innovative self-management resource on the topic of physical activity for PBD was identified. The Canadian Hemophilia Society provided support for the project and members of Canadian Physiotherapists in Hemophilia Care formed a working group. A review of the literature was undertaken, focusing on patient-centered learning, theoretical concepts in health behavior change, sporting injury epidemiology and prevention, and the management of joint health in persons with bleeding disorders. Key findings and learning outcomes, established through the synthesis of clinical expertise and the available evidence, were incorporated into the vision for the project. A workbook-style paper booklet is being developed in consultation with learning design and health communication experts. Future plans include evaluation of the utilization and efficacy of the print-based tool and adaptation of the concept to an electronic platform, which would create the potential for a more customized, interactive and engaging learning experience.

Learning Outcomes

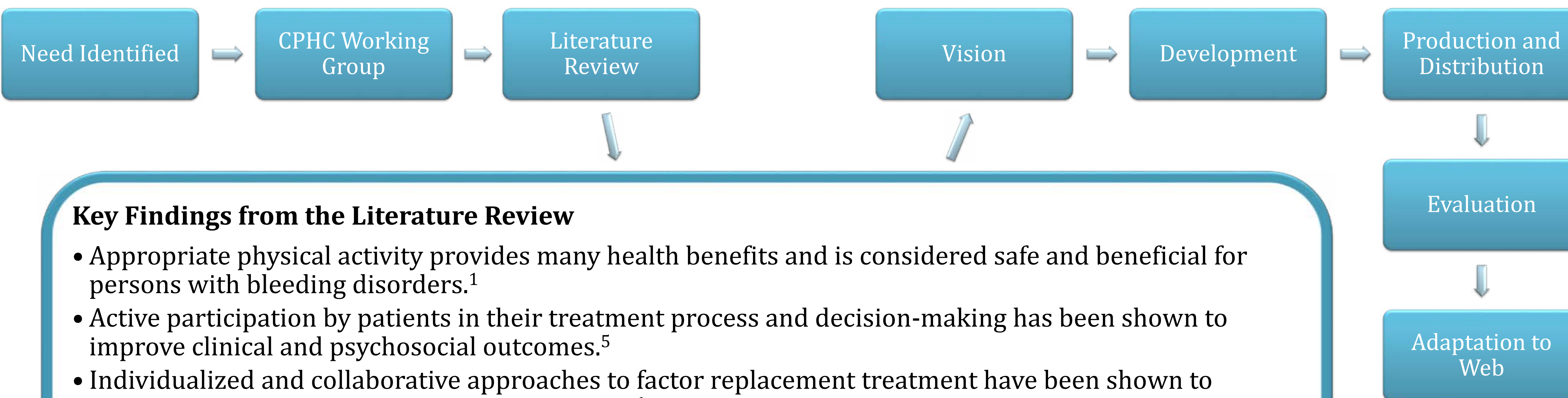
- ✦ Develop a realistic perception of personal risk for injury
- ✦ Become adept at evaluating the dangers associated with an activity of interest
- ✦ Weigh the benefits of an activity against the potential consequences
- ✦ Gain the skills to create a responsible plan for participation in a chosen activity

CONCLUSIONS

Similar to individualized factor prophylaxis, this approach will combine evidence with patient-specific goals and abilities to guide selection of appropriate physical activities and improve health outcomes for persons with bleeding disorders.

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Key Findings from the Literature Review

- Appropriate physical activity provides many health benefits and is considered safe and beneficial for persons with bleeding disorders.¹
- Active participation by patients in their treatment process and decision-making has been shown to improve clinical and psychosocial outcomes.⁵
- Individualized and collaborative approaches to factor replacement treatment have been shown to improve outcomes in patients with hemophilia.⁶
- Children and adolescents with hemophilia are participating in moderate and high-risk physical activities.^{7,8}
- An evidence-based and comprehensive risk-rating system for physical activity in PBD has not yet been developed.^{1,4}
- Modifiable risk factors for sporting injury, potentially targeted through a learning resource include activity choice, physical body function (balance, strength, proprioception, sport-specific training), skill development and protective equipment.²
- The most successful health education tools are structured, interactive and tailored to the individual.⁹
- Health communication should focus on positive views and feelings towards a health behaviour rather than threat-based messages.¹⁰

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