

Health for Hemophilia: A Family Wellness Intervention



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Background

There is a growing public health concern for increasing rates of obesity in children as well as concern for increasing rates of obesity in children with hemophilia. Currently, the prevalence of obesity in the general pediatric population is 18.5%.¹ 2015 data from the American Thrombosis and Hemostasis Network (ATHN) showed that of children with hemophilia in the 3-12-year-old range, 28.2% were considered obese/overweight and in the 13-18-year-old range, 31.6% were considered obese/overweight.²

Being physically active and involved in sports has also been linked with improvement in overall quality of life among children with hemophilia.^{3,4} Yet, there is a need for education on what physical activities are safe, as there are activity restrictions due to having a bleeding disorder.^{5,6}

A 2006 survey found that 60% of children with hemophilia managed their bleeding disorder by avoiding physical activity.⁷ Children with hemophilia have also been found to engage in high-risk, unsafe physical activities, such as football, lacrosse and rugby.⁸ Safe, low-impact activities recommended for children with hemophilia include swimming, golf, and hiking.⁹

A 2018 study found that 37% of children with hemophilia had a poor or a fair diet.¹⁰ This study highlighted the importance of more education on nutrition for children with hemophilia.¹⁰

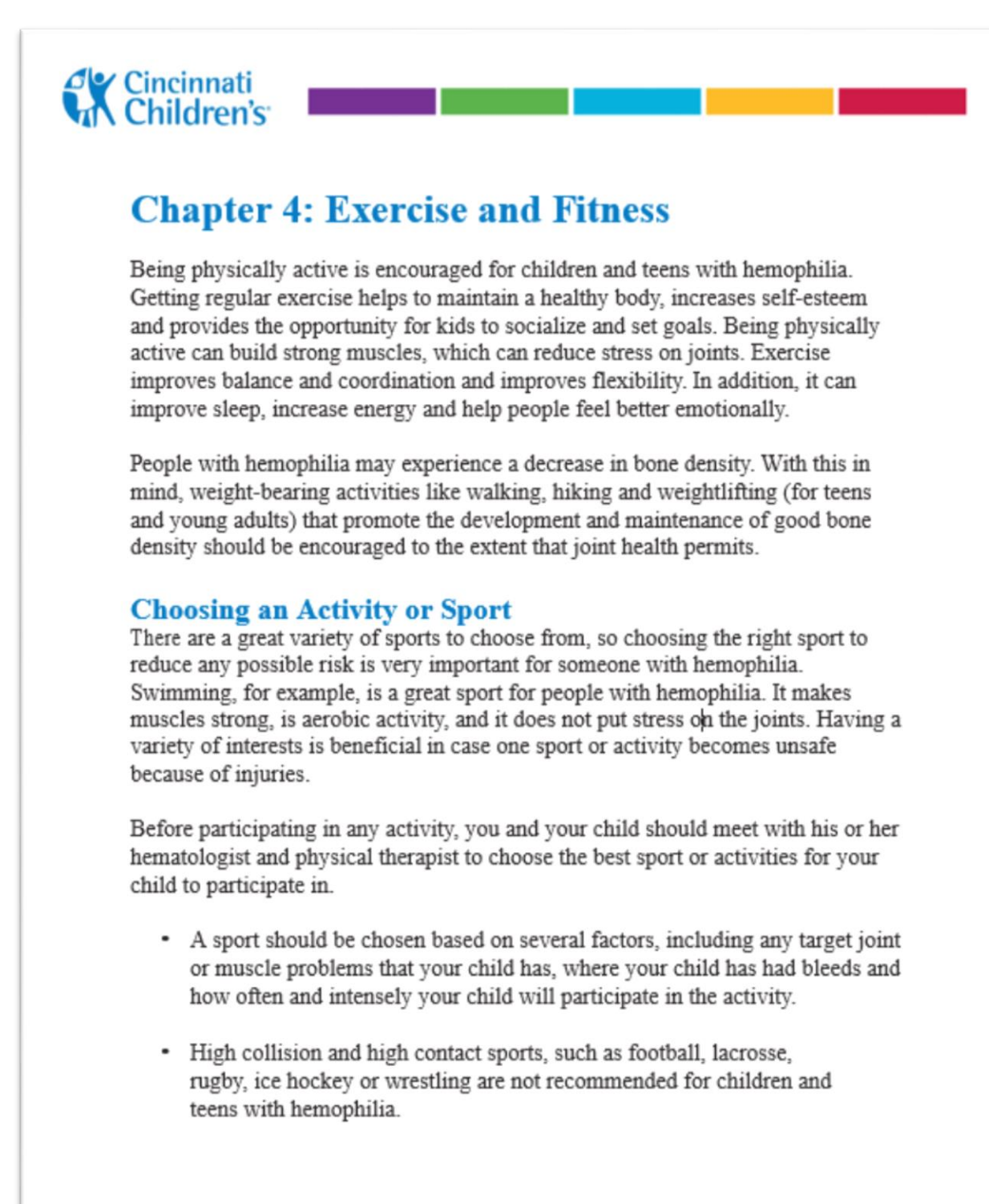
Given the growing rates of obesity in the hemophilia population, there is a need to create a family-based intervention that involves education about safe physical activities for children with hemophilia as well as education on nutrition.

Methods

Develop New Written Educational Material on Sports/Fitness with a Bleeding Disorder

Previous Cincinnati Children's Hospital Medical Center (CCHMC) Education on Sports/Fitness and a Bleeding Disorder

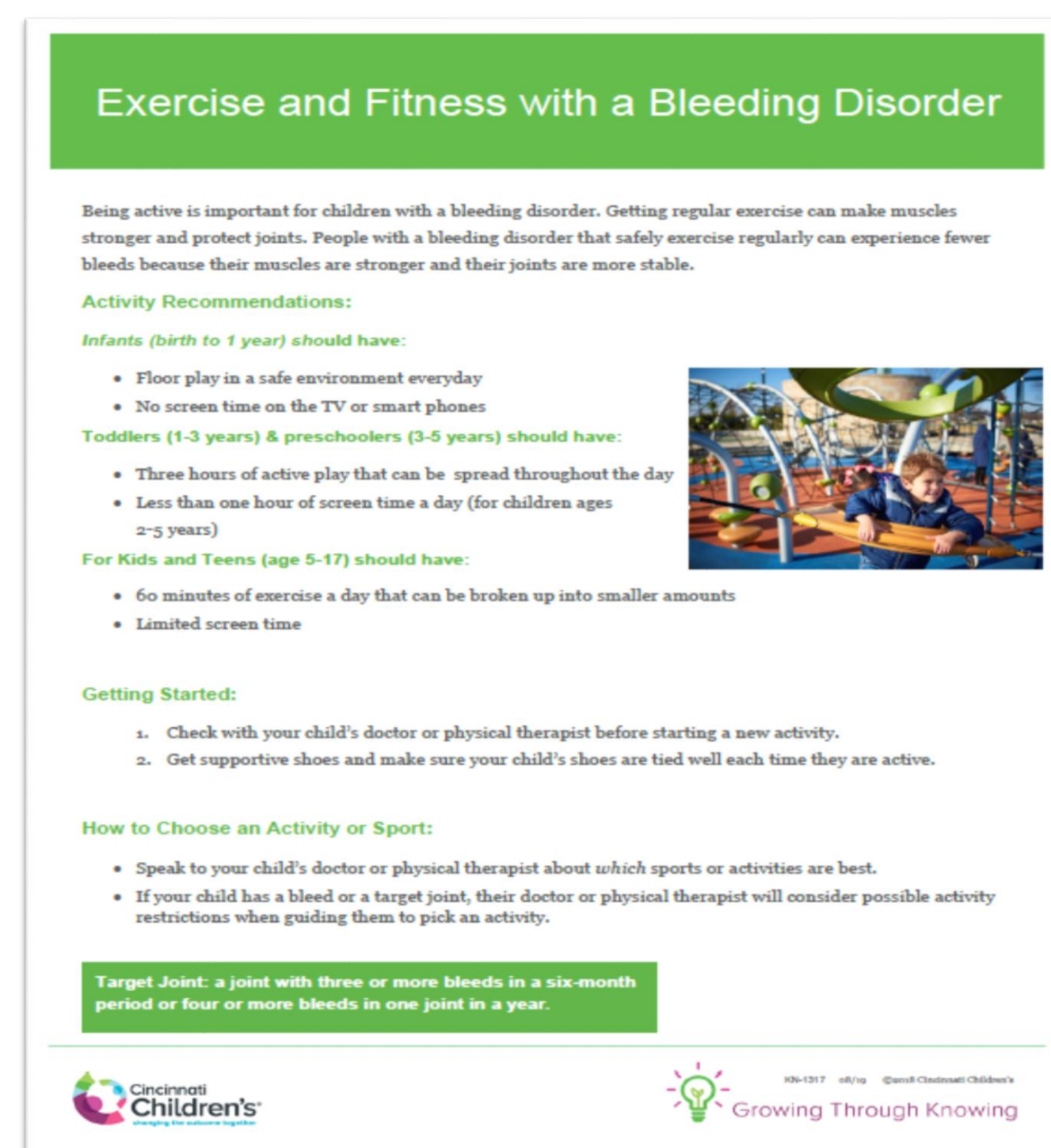
- Written at an 11th grade reading level
- More words and sentences than necessary
- Outdated terminology



Methods

New CCHMC Educational Material

- Written at a 7th grade reading level
- Conversational style of writing
- Plain language utilized



Social Cognitive Theory Constructs and their Application to the Health for Hemophilia Intervention

Reinforcement	<ul style="list-style-type: none"> • Parents/guardians serve as role models • Families featured in videos are examples of people that lead healthy lifestyles.
Observational Learning	<ul style="list-style-type: none"> • Children learn healthy lifestyle behaviors from their parents/guardians
Self-Efficacy	<ul style="list-style-type: none"> • The goal of the intervention is for families to feel confident to live a healthy lifestyle



Methods

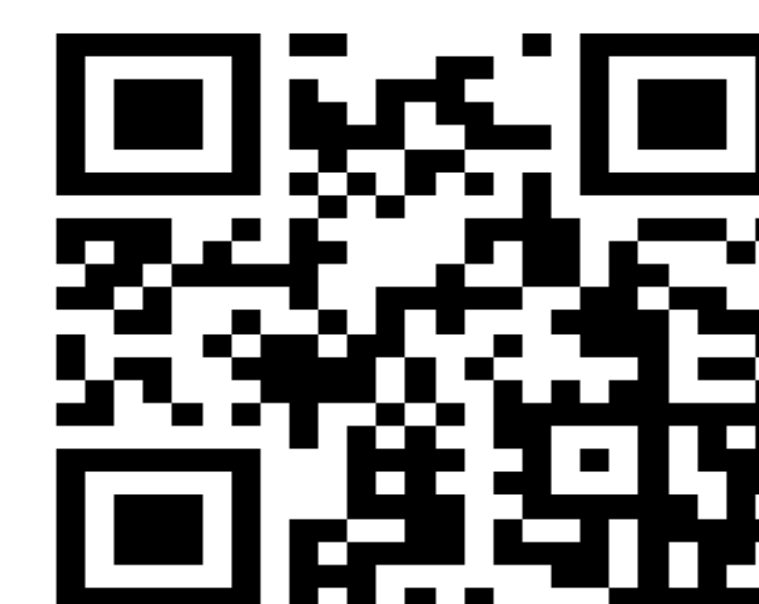
Develop Three YouTube Videos on Sports, Fitness and Nutrition and Hemophilia

- Featured on CCHMC's YouTube page
- Videos are in English and in Spanish
- Videos feature CCHMC physical therapist and dietician
- CCHMC patients and families featured in videos
- Video education used as form of education that appeals to different age groups and literacy levels

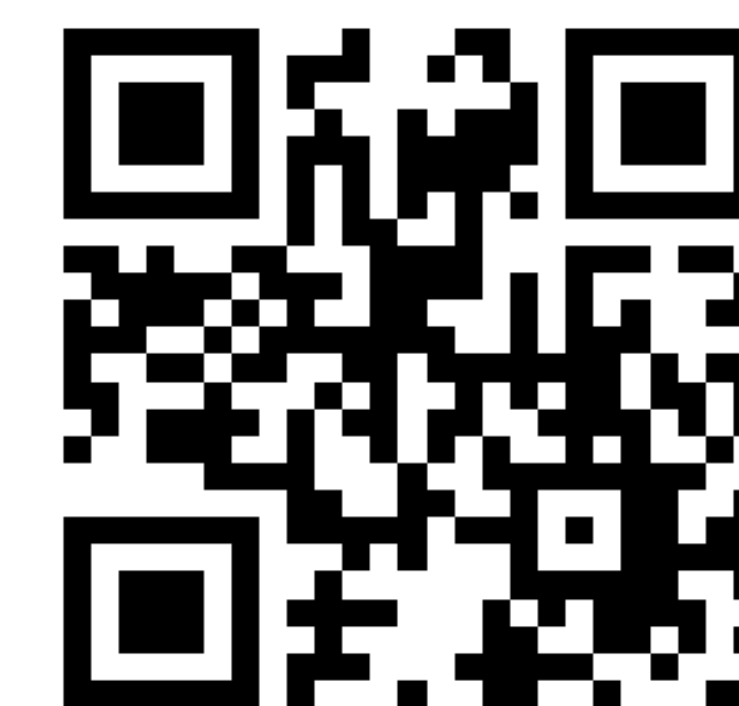


Video Themes and QR Codes

Making healthy choices as a family/leading a healthy lifestyle



Safe sports and fitness with a bleeding disorder



Keeping the motivation up for living a healthy lifestyle



Conclusion

Due to Covid-19, only preliminary pre- and post-outcome evaluations for the Health for Hemophilia YouTube videos have been obtained. The survey will remain open following the pandemic to gather future outcome data.

Healthy Choices	<ul style="list-style-type: none"> • Pre-test score:100% • Post-test score:100%
Sports and Fitness	<ul style="list-style-type: none"> • Pre-test score:95% • Post-test score:100%
Keeping up the Motivation	<ul style="list-style-type: none"> • Pre-test score:95% • Post-test score:100%

Future Directions

A website will be developed in 2020-2021. This last phase of the family wellness intervention will have eight different learning modules. The content will have different themes including safe sports for children with bleeding disorders, decreasing screen time and healthy eating-on-the-go.

The YouTube videos will be integrated into the content. The web content will also feature other videos on exercise and nutrition. The educational content of the website is written at the 7th grade reading level. By featuring video-based education, this intervention will appeal to all health literacy levels.

References

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