TRANSIT 2.0
An online transition support tool for multidisciplinary care teams to engage, empower and impart knowledge of bleeding disorders to youth and their families

A COLLABORATIVE PROJECT WITH EMORY’S LIBRARY & INFORMATION TECHNOLOGY SERVICES, HEMOPHILIA OF GEORGIA, AND THE COMPREHENSIVE BLEEDING DISORDERS CENTER AT CHOA AND EMORY UNIVERSITY
OUTLINE

• Background
• Project Goal and Objectives
• Theoretical foundation
• Website content
• End users and Features
• Evaluation
• Progress update
• Next steps
• Future directions
• Website demonstration
BACKGROUND: TRANSITION

- **Healthcare focus:** Process of transferring care from pediatric to adult providers
- **Life stages focus:** Transition from childhood to adulthood with the capacity for self management of bleeding disorder
BACKGROUND: SUCCESSFUL TRANSITION

• Crucial to future health and psychosocial outcomes

• Self-management of medical condition improves treatment adherence, overall health and quality of life

• Transition readiness is associated with perceived self-efficacy in medical visits

BACKGROUND: INTERNET AND EHEALTH

• Youth use Internet as primary health education resource\(^1\)
• Effective in delivering healthcare messages to adolescents\(^1\)
• Interactive health educational tools are preferred by youth and improve knowledge, practical skills and confidence with healthcare providers\(^1,2\)
• Internet users are more self-efficacious in the healthcare arena than non-users\(^2,3\)

BACKGROUND: HEMOPHILIA-SPECIFIC RESEARCH

- Youth with hemophilia identify need for online education and support with life transitions, yet little exists\(^1\)
- Adolescents are comfortable with accessing medical information, social networking, and playing games online\(^1\)
- Needs identified: website with experiential videos, pictures, educational games and quizzes\(^2\)
- Youth recommend parent-specific education and support via website\(^3\)

CONSIDERATIONS

Knowledge and skills
• What is it that they need to know and be able to do in order to successfully self-manage?

Operationalize a process
• How to develop an effective transition support tool?
• How is information shared?
• How to implement a curriculum across multiple settings

Assessment
• How do we know that a child is on track?
PROJECT GOAL & OBJECTIVES

Goal:

• To create a website to be used by patients, family members, and healthcare providers to facilitate the acquisition- by patients with hemophilia- of the skills, knowledge and attitudes believed to be necessary for their transitioning to young adulthood along with a greater awareness of the importance of transition of care.

Objectives:

• Increase patient and family knowledge, skills and attitudes necessary for independent self-care and successful transition to adulthood.
• Increase patient and family member awareness of transition education.
TRANSIT™ TEAM

Comprehensive Bleeding Disorders Center at CHOA and Emory University

• Christine Kempton, MD, MSc Principal Investigator
• Jamilah Hill, LMSW, Social worker: Pediatrics
• Pam Bryant, Associate Director Emory HTC
• Shanna Mattis, MPH, Social Worker: Adults/Public Health Associate

Library & Information Technology Services

• Saundra Barrett, Lead web designer
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• Trisha Wilson, Project Manager

Hemophilia of Georgia, Inc.

• Deniece Chevannes, MPH, MCHES, Dir. of Health Promotion and Evaluation
EMERGING FRAMEWORK FOR SUCCESSFUL TRANSITION

Environment:
Community resources and schools

Health Care System:
Clinic, provider & accessibility factors

Family/Social Support:
Family functioning, social support, social environment

Individual:
Demographics, disease complexity & course, personality, self-management, self-advocacy

## THEORETICAL FOUNDATION

### Health Belief Model
- An individual’s health-related behaviors depend on their **beliefs about the benefits and barriers** of that behavior as well as their **self-efficacy** in performing the activity.
- Used in developing interventions to **increase healthcare compliance** and in **secondary prevention** efforts.

### Diffusion of Innovations
- **Used to introduce an idea, behavior or product to target populations**
- **New or innovative** idea or behavior is key to adoption.
- Categorizes individuals as different types of adopters and provides strategies to introduce **innovation** to each type.
CONTENT DEVELOPMENT

• Current focus on ages 9-12 and their parents/caregivers
• 36 Learning modules mirror NHF Guidelines for Growing initiatives across 6 content areas:
  ◊ Social support ◊ Health and lifestyle
  ◊ Educational planning ◊ Self-advocacy and self-esteem
  ◊ Sexual health ◊ Independent health care behavior

• Mapped across topic, goal, age group, target audience, activity type
• Interactive content for patients and families
• Incorporate range of learning styles
• Links to existing community resources
<table>
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<tr>
<th>Health and Lifestyles</th>
<th>Goals &amp; Objectives</th>
<th>Strategies</th>
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<td>Parents/child understand consequences of activities and necessary adaptations due to bleeding disorder.</td>
<td>Discuss appropriate sports/activities/safety measures.</td>
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Discuss the importance of sports and exercise with members of your child’s HTC team. They will be able to help your child choose activities that are safe and beneficial for his or her physical and emotional well-being. Review with your child the NHF brochure “Playing It Safe: Bleeding Disorders, Sports, and Exercise”, available through HANDI.
SAFE SPORT

• Goal: Understand which sports are safe for participation and which are not

• Target audience: Both parents and children (9 years)

• Knowledge/Skill/Attitude:
  • Knowledge: Risk of each sport
  • Attitude: Bleeding disorder does not preclude participation in sports

• Tasks:
  • View CDC/NHF Playing it Safe Video and publication
  • Knowledge assessment
  • Match activity with risk:
    • High risk red light
    • Low risk green light

• Prior to annual visit, HTC team can assign the task and then see what has been done

• At the HTC visit, staff member will reinforce information through active discussion
INNOVATION

• Interactive

• **Collaborative approach** to transition education: youth, caregiver(s), healthcare providers and community supports

• Assessing **acquisition of knowledge and skills** needed to manage a complex medical condition

• Shared responsibilities and accountability for **monitoring and support**

• Can be used across the life stages

• Mixed methods needs assessment: stakeholder interviews, focus group, site interviews
### END USERS AND FEATURES

#### Patient
- Games: Motivation and concept reinforcement
- Rewards: Motivation and Engagement
- Learning Modules: Impart knowledge in age-appropriate format
- Tracks progress with assigned task

#### Parent/Caregiver
- Views child’s progress
- Joint completion of tasks
- Sign off on activities
- Learning Modules: Impart knowledge specifically for parents and caregivers
END USERS AND FEATURES

Providers

- Track patient progress
- Assign rewards to motivate and encourage
- Assign and grade learning modules
- Multidisciplinary communication

Administrators

- Manage users
- Assign learning modules
- Add new content
EVALUATION:
USABILITY AND PILOT TESTING

Usability Testing with 3 parent/child pairs completed early 2016
• Intuitive design
• Ease of learning
• Efficiency of use
• Memorability
• Error frequency and
• Subjective satisfaction

Pilot Testing 2.0 to start March/April 2017
• 3 month duration
• 10 to 13 parent/child pairs
• Usability of reimaged site
• Acquisition of knowledge: mapped to module content
• Changes in self-efficacy and transition readiness
  • Hemophilia Self-Efficacy Scale (HSES)
  • Transition Readiness Assessment Questionnaire (TRAQ)
DEVELOPMENT HURDLES

• **Personal Health Information (Security)**
• **Turnover and synergy**
• **Website and API design: Hosting the site and for whom?**
• **Gamification versus game**
Current project: 9-12 age group

- Further refine learning modules
- Audio recording for each module page
- Pilot testing
• **Roll out** the site to CHOA/Emory HTC patients 9-12 and their families
• **Expand** the scope of the project for 13-15 and 16-18
• **Refine** and further build out user experience for patients, parents and providers
• **Evaluate long term changes** in knowledge and skill acquisition
• **Expand access** to website to other sites within the region and later HTCs in other regions
Q&A
LET’S LOOK AT THE SITE!
REFERENCES


• Sterling LE, Nyhof-Young J, Blanchette VS, Breakey VR. Growing up with haemophilia: assessing teens’ experiences and needs during transition to adult health care. Univ Toronto Med J. 2012;90:146-51.


• Huang JS, Terrones L, Tompane T, Dillion L, Pian M, Gottschalk M, Norman GJ and Bartholomew LK. Preparing Adolescents With Chronic Disease for Transition to Adult Care: A Technology Program. Pediatrics. 2014;133:e1639.


