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Identifying Information Needs Among Children and Teens Living With Hemophilia

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Abstract

Introduction—Transitioning from one life stage to the next can be difficult, but for those living with a chronic condition, it can be even more challenging. Children and adolescents with hemophilia need help to manage transitions while dealing with the complications of their disorder. The National Hemophilia Foundation (NHF) headquartered in New York has an extensive information center on bleeding disorders, but it was unclear how much material existed on the topic of transition.

Aim—The objectives of this project were to (1) assess the availability of literature about transition for children and adolescents living with hemophilia, (2) determine which transition issues were the

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most relevant, and (3) develop and test information products that would address those transition issues.

Methods—An inventory of NHF’s resources and an environmental scan over the Internet was performed. Focus groups were conducted to determine messaging. Video prototypes containing messages were created, tested by focus groups, and revised.

Results—The literature search yielded limited information available on transition for children and adolescents with hemophilia. Results of the formative research indicated that adolescents wanted more information on sports participation and disclosure of their condition (e.g., to peers, teachers, coaches, health care providers). Video was found to be the preferred delivery format.

Conclusion—Children and adolescents living with hemophilia need information to help them transition through life. As a result of this study, two educational products were produced, but several more are recommended to guide these individuals in making healthy transitions into adulthood.

Keywords

Hemophilia; adolescents; children; disclosure; transition; sports

INTRODUCTION

Milestones signaling a transition in a young person’s life include switching schools, moving away from home and establishing a career. While transitions should be an exciting rite of passage, they often trigger fear or cause extreme stress. Many young people need support to make healthy adjustments during transitions.[1]

Transitions can be more challenging for those with a chronic condition. While changing schools and making new friends can be intimidating for any young person, for those with a disorder like hemophilia, apprehension is compounded by the worry of deciding who to tell about their condition. Stressors can vary greatly depending on cultural background; personal values; and access to, and level of, treatment. [2]

People living with hemophilia also deal with another set of transition issues, defined not only as a change in life’s developmental stages but also an alteration in health and social circumstance. [3] People with hemophilia go through additional life changes such as acceptance of the limitations of their condition, the shift from parental care to self-care, a move from a pediatric to adult treatment facility, and the search for employment providing adequate medical insurance.

The purpose of this study was to determine what type of informational products children and adolescents with hemophilia need to make successful transitions.

MATERIALS AND METHODS

Protocol Development

Experts in pediatric, adolescent, and adult health provided input to the research protocol, reviewed findings, and made recommendations on recruitment strategies. With their input, a mixed-method approach was designed that included an environmental scan and in-person and online/telephone focus groups. ICF's International Review Board (IRB) and the Centers for Disease Control and Prevention's (CDC) Office of Management and Budget (OMB) approved the research protocol and data collection instruments.

Environmental Scan

An environmental scan to assess existing materials and identify information gaps was conducted. A total of 427 documents were reviewed from the National Hemophilia Foundation's (NHF) Hemophilia and AIDS/HIV Network for the Dissemination of Information (HANDI) library. Two abstractors conducted the review which was validated by a senior researcher. After eliminating duplicate resources, literature published prior to 2000, and HIV/AIDS materials, 219 documents were retained for analysis.

Online searches were conducted from 200 hemophilia-related websites and databases hosted by support and advocacy organizations, pharmaceutical companies, government agencies, home care companies, and NHF chapters. Literature databases such as PsychInfo, ERIC, and Medline were also examined. As a result, several hundred items were reviewed including abstracts, journal articles, newspaper articles, books, book chapters, magazine articles, pamphlets, brochures, fact sheets, DVDs, and Web pages. A total of 181 items were selected for analysis using the following criteria:

- Focused on transition;
- Created for children ages 5–12 or adolescents ages 16–19;
- Targeted to individuals with hemophilia or other chronic conditions such as arthritis, diabetes, asthma or physical disabilities; and
- Published in English within the past 10 years (January 2000 to August 2010) from the United States and Canada. International documents were included if relevant for the target audience.

Qualified publications were entered into a database and each was assigned up to 5 descriptors, from a total of 68 possible descriptors, (See Table 1) to indicate its primary subject matter.

Formative Research Focus Groups

Twelve focus groups were scheduled in Atlanta, GA, Philadelphia, PA, Detroit, MI, and San Francisco, CA—cities in which NHF had active chapters. Three groups were scheduled at each site: adolescents ages 16–17 living with hemophilia; adolescents ages 18–19 living with hemophilia; and parents (mother or father) of children aged 5–12 and/or 16–19 living with hemophilia. For the latter, parents of young children were included with those of adolescents to obtain dual perspectives on the types of transition-related information

children need when young and how these needs might change as they undergo further periods of transition. Similarly, adolescents were asked to recall the types of information they needed at 5–12 years old and how their informational needs changed as they grew older. Adolescent participants were split into two groups to keep the minors separate from those 18 years and over who did not need parental consent.

Recruitment for In-person Groups

The recruitment strategy relied heavily on the local NHF chapters to promote the in-person focus groups. Promotional print and online flyers and Web banners were sent to all four chapters to post on their websites and Facebook pages. NHF also placed the materials on its website. All participants received a \$75 cash incentive. Two additional incentives were offered to adolescents: a \$15 gift card for the first 10 callers in each city and one MP3 player to be raffled at the conclusion of each adolescent group. These types of incentives have been shown to boost the recruitment of young men and women. [4]

Participants completed a consent form, with those ages 16–17 providing a signed parent/guardian consent form. Exclusion criteria for adolescents included individuals who did not speak English or who were either employed themselves or had someone in their immediate family working for a market research firm, CDC, NHF or a hemophilia research or treatment center.

For parents, exclusion criteria included persons younger than 18 years of age, parents of a child with a blood disorder other than hemophilia, those who did not speak English, or anyone employed by (and/or with an immediate family member working for) a market research firm, CDC, NHF or a hemophilia research or treatment center.

Recruitment Barriers

Initially, only four parents and one teen met the study's inclusion criteria. Therefore, the focus groups were cancelled and rescheduled. Suspecting additional barriers to recruitment, efforts were intensified. Regional chapter directors were encouraged to support recruitment with the chapters. The focus groups were also promoted at NHF's Annual Conference through posters and flyers, during sessions, and through other forums. Despite the expanded efforts, trained moderators were only able to conduct two in-person parent focus groups—one held with six parents in Philadelphia, and one with five parents in Atlanta. (See Table 2.)

Online/Telephone Focus Group Platform

Flexibility and adaptation are integral in recruiting adolescents as research subjects.[5] Based on limitations encountered while recruiting for the in-person focus groups, the formative research approach was modified to incorporate on-line/telephone focus groups to expand the universe for recruitment nationwide. By employing webcams and a special software platform designed for virtual focus groups, participants could be seen and heard live during sessions. The online platform allowed screen sharing, on-demand participant polling and a chat feature allowing observers to ask the moderator questions.

Recruitment for Online/Telephone Focus Groups

IRB and OMB approval were secured for the change in methodology and the following recruitment strategies were executed five weeks prior to the groups:

- An E-blast with a recruitment flier and Web banner for Facebook pages were distributed to all 46 NHF chapters. Follow-up calls were made to chapters to ensure receipt of materials and to encourage cooperation;
- An e-blast and recruitment flier were sent to about 10,000 people included in the HANDI database; and
- An e-blast and recruitment flier were sent to hemophilia treatment centers.

The strategies above were repeated two weeks prior to the groups. The groups were promoted on NHF's website and Facebook page and announcements were broadcast via Twitter and hemophilia blog sites. Promotional flyers were distributed at NHF chapter events, the Hemophilia Federation of America's annual symposium, and the NHF Inhibitor Education Summits.

Using the same inclusion criteria, participants were recruited for 10 online focus groups, resulting in seven with adolescents (four with 16–17 year olds and three with 18–19 year olds) and three with parents. A total of 60 people participated in the focus groups—40 adolescents and 20 parents. (See Tables 3 and 4.) All participants received \$50, a lower cash incentive than the in-person group participants since travel was unnecessary. Adolescent participants received \$15 gift cards for calling and a chance to win an MP3 player at the conclusion of the session. Participants were asked about the types of transition-related information needed, sources of information they deemed credible, where they received information, and how they prefer to learn about their disorder. A variety of transition topics, derived from the environmental scan, were probed. (See Table 5.)

Message Testing Focus Groups

Adolescents for three in-person focus groups were recruited and convened at the 2011 NHF conference to test messages developed based on the formative research. The same recruitment strategies and incentives used for the online/telephone groups were used for these focus groups, except that participants received \$75. A total of 19 adolescents participated. (See Table 6.) Participants were asked questions from CDC's Health Message Testing System Item Bank and addressed comprehension; impressions; audience and personal relevance; content and wording; images, visuals and illustrations; and a comparison of concepts, messages and materials.

Several procedures were used to improve the trustworthiness of this study including triangulation of methods, peer debriefing, and the use of rich thick descriptions. During the study, investigators collected information from different sources (i.e., an environmental scan, in-person, and online/telephone focus groups). Following each focus group, research team members documented their first impressions and recorded similarities and differences observed from earlier focus groups. Ongoing peer review was used to provide an external

review of the overall research process. Finally, rich, thick descriptions were used to enable the reader to make their own decisions about the transferability of the findings.

RESULTS/DISCUSSION

Environmental Scan

Findings from the environmental scan revealed gaps in messaging about transition, for both children and adolescents. For children, the identified gaps were related to bullying, disclosure, peer pressure, siblings, and teachers. For adolescents, few materials focused on social support, dating, sexuality, peer influence, peer pressure, employment, financial issues, independent health care behaviors and health insurance. The findings from the scan are corroborated by a January 2011 study of persons with hemophilia that showed a lack of high quality life cycle research in early childhood, siblings' relationships, adolescents, relationships, and marital support.[6]

Formative Research

All focus groups were audio and videotaped and transcriptions used for the content analysis. Data were reviewed and coded and major themes identified. Two major themes emerged. First, adolescents expressed wanting to be active and participate in sports, but reported they were constantly being told what they could not do. Several participants said they were told not to engage in any sport. This theme's emergence was not too surprising since an earlier CDC-funded survey found 60% of youth managed hemophilia by avoiding physical activity. [7]

Participants said that imposed limitations made them feel frustrated, disappointed and marginalized by their peers. One comment which summarizes much of the lengthy discussion on sports was, "...when you hear someone say you can't do this, it just makes you want to do it more." On the topic of sports, participants repeatedly mentioned they just wanted to "feel normal."

Second, adolescents said they wanted information on disclosure, specifically how to explain their condition to different audiences (e.g., peers, medical professionals, employers, school personnel, coaches)—but especially to friends. Several participants said hemophilia was too complicated to describe, and a few participants said they would say they had another condition like asthma, to avoid a lengthy conversation.

On disclosure, one participant described a self-imposed filter depending upon who was asking the question. "It's definitely a different kind of story. There's the story that you give to your roommate, there's a story that you give to a doctor, there's a story that you give to an acquaintance. It's important to make that distinction between how much detail they really need and how much will freak them out. Tell your roommate about a fibrin clot...and he might just run away."

The findings from the parent groups were similar to those of the teen groups. But some additional themes surfaced with parents who saw a need for information to help their children become more self-sufficient and learn self-infusion. The parents of teens felt more

information was needed to guide their career choices and find employers that provide adequate health insurance.

Both adolescents and parents agreed that video was the preferred format to receive information—short in length, but long enough to communicate key messages—readily available through the Internet. Videos would assist adolescents in addressing difficult topics, and easily inform peers and the general public about hemophilia, and reduce stigma.[8]

Message Development

Based on these top two themes, two videos were produced: one on disclosure to middle school friends and one on selecting an appropriate sport based on the severity of hemophilia. Key messages were identified and scripts prepared for both videos. (See Table 7.) The videos focused on ways adolescents could increase their social, problem solving, and communication skills when dealing with their condition. Increasing interpersonal and intrapersonal skills is a key component to any successful health education program to adolescents.[9]

As one adolescent said, "...as you're entering seventh grade or middle school, you start changing and your friends aren't being made by your parent's associations anymore. It would be helpful to have tools on how to tell your friends." So disclosure to middle school friends was selected first in a potential series, with each video portraying a customized explanation of hemophilia to different audiences.

In the disclosure video, a pre-teen boy with hemophilia shares his health condition among a group of old and new friends. The light-hearted dramatization serves as a model of quick, simple responses to frequently asked questions and dispels some of the common myths about hemophilia. The video was designed to be short—less than 2 minutes—with a touch of humor to soften the serious content and hold viewer interest. Middle school students reported the use of humor in a serious subject is important to maintain attention to the topic. [10]

The sports topic was selected for the other video prototype. Participation in physical activity is important to the health of someone with hemophilia but also integral to developing positive self-esteem and social interaction.[11] However, parents and health care providers, with the best of intentions, often tell kids not to play a sport that could cause a serious bleed. Focus group participants repeatedly said they were tired of being told what sports they could not play. The video was carefully crafted to show a variety of recommended sports and a few to be avoided and highlighted the consequences of making certain choices such as playing contact sports. The video also gave examples of problem solving, the importance of infusing before playing, alternatives to playing sports, and featured friends, coaches, and parents being supportive.

This video portrayed four boys with hemophilia as they experimented with different sports and extracurricular activities. Because kids start playing sports at a much earlier age than high school, it was decided to use an animated approach to appeal to a younger audience.

Animation allowed for incorporating interesting sound effects and arresting graphics to hold viewer attention during the 3-minute video.

Message Testing

The value of preproduction research and message testing cannot be underestimated [12] and, for this study, it helped increase the probability of acceptance for the two videos. Content development for each video was guided closely by the voices from the first set of focus group participants. Actual experiences reported by participants were incorporated and some comments included verbatim. As a result, most of the participants in the message testing focus groups reported that they easily understood the main message of each video.

Comments received were positive and in direct alignment with the key messages. For the disclosure video, one participant said, “I think it does a good job to portray that we’re normal kids, and having that feeling is important when you are thinking about telling others.” Another comment regarding the sports video made this point. “Kids with hemophilia can still be active and fit. They just have to do it smart.” Most participants agreed that both videos would have been helpful to them when they were younger and that the videos would encourage them to seek more information.

Message Revision

Valuable feedback from focus group participants was used to improve the videos. The background music in the disclosure video was altered to broaden its appeal to a middle school audience. For the sports prototype, participants recommended an older child’s voice as narrator, a minor script change, and additional color graphics. The videos were revised accordingly, and final versions were made 508-compliant and posted on the CDC website at www.cdc.gov/ncbddd/hemophilia and NHF’s Steps for Living website at www.stepsforliving.hemophilia.org.

Study Limitations

This study has several limitations. Participants were recruited through organizations that serve people with hemophilia, thus introducing a possibility of selection bias. Families who do not utilize the services of Hemophilia Treatment Centers, do not have access to a computer or lack the financial resources to attend national meetings, may have been less likely to participate in the study. The findings from this study are not quantitative and therefore cannot be generalized to the larger population of youth with hemophilia. Finally, given the qualitative nature of this study, research bias may have influenced the data analyses and interpretation of findings. Despite these limitations, the focus groups yielded valuable information and insights about transition issues facing youth with hemophilia.

CONCLUSION

Transitions are hard for everyone, but even more difficult for someone with a chronic disease like hemophilia. Little information exists to help persons with hemophilia with the many types of transitions they encounter in life.

Children and adolescents with hemophilia—especially those living in rural areas of the U.S.—are eager for information to assist them with the complex issues associated with their condition. Using online/telephone focus groups was well suited to the technologically-savvy younger generation. The environmental scan and experiences and opinions shared in the focus groups were invaluable to honing the messages for each video. Since the videos were well received, it can be concluded that the video format and messaging were on target with an adolescent audience. More videos are recommended to address the needs of young people growing up with hemophilia, especially with disclosure to college roommates, coaches, school administrators, medical professionals, and potential employers.

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Table 1

Topic Descriptors

1	Academic Achievement
2	AIDS
3	Bullying
4	Camps
5	Classroom Environment
6	Coaching
7	College Students
8	Continuity of Care
9	Dating
10	Dental Care
11	Diet
12	Disclosure
13	Discrimination
14	Doctor/Patient Relations
15	Elementary School Students
16	Emotional Adjustment
17	Employment
18	Exercise
19	Family Relations
20	Financial and Cost Issues
21	Health Behavior
22	Health Care Planning
23	Health Insurance
24	Health Knowledge, Attitudes, Practice
25	Hemophilia A
26	Hemophilia B
27	Hemophilia Treatment Center
28	High School Students
29	Higher Education
30	HIV Infections
31	Independence
32	Legislation
33	Life Changes
34	Medical Home
35	Middle School Students
36	Mild Hemophilia
37	Moderate Hemophilia
38	Pain

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39	Parent/Teacher Cooperation
40	Parents
41	Peer Influence
42	Peer Pressure
43	Peer Relationships
44	Physical Endurance
45	Responsibility
46	Rest
47	Retreats
48	Safety
49	School Attendance
50	School Personnel
51	School to Work Transition
52	School Transition
53	Self-Advocacy
54	Self-Care
55	Self-Esteem
56	Self-Infusion
57	Severe Hemophilia
58	Sexuality
59	Siblings
60	Social Support
61	Social Support Programs
62	Sports and Recreation
63	Student Financial Aid
64	Student Health Services
65	Teachers
66	Travel
67	Treatment
68	Vocational Education

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Table 2

In-person Focus Group Participant Profile—Parent

Parents	Group 1 Philadelphia, PA 01/18/2011	Group 2 Atlanta, GA 02/08/2011
Total number of participants	6	5
Number of parents with child ages:		
5–12	5	4
16–17	1	1
18–19	0	0
Type of hemophilia their child is living with:		
Hemophilia A/Factor VIII deficiency	5	4
Hemophilia B/Factor IX deficiency	1	1
Severity		
Mild	0	1
Moderate	1	0
Severe	5	4
Race of parents		
Asian	0	0
Black or African American	0	1
White	6	4
Ethnicity of parents		
Hispanic or Latino	0	1
Not Hispanic or Latino	6	4

Table 3

Online Focus Group Participant Profile—Adolescents

	Group 1 05/18/11	Group 2 05/19/11	Group 3 05/24/11	Group 4 05/25/11	Group 5 06/06/11	Group 6 06/28/11	Group 7 06/29/11
Total number of participants	7	6	6	5	5	5	6
Ages							
16–17	7	0	6	0	5	0	6
18–19	0	6	0	5	0	5	0
Type of hemophilia							
Hemophilia A/Factor VIII deficiency	6	5	6	4	4	5	6
Hemophilia B/Factor IX deficiency	1	1	0	1	1	0	0
Severity							
Mild	0	1	2	1	0	0	0
Moderate	1	2	2	1	1	0	2
Severe	6	3	2	3	4	5	4
Race							
Asian	0	0	0	0	1	0	1
Black or African American	1	0	3	5	0	0	1
White	6	6	3	0	4	5	4
Ethnicity							
Hispanic or Latino	0	0	0	0	0	1	0
Not Hispanic or Latino	7	6	6	5	5	4	6

Table 4

Online Focus Group Participant Profile—Adults

	Group 1 05/16/11	Group 2 05/23/11	Group 3 06/08/11
Total number of participants	7	7	6
Number of parents with child ages:			
5–12	2	1	2
16–17	4	3	4
18–19	1	3	
Type of hemophilia their child is living with:			
Hemophilia A/Factor VIII deficiency	6	6	6
Hemophilia B/Factor IX deficiency	1	1	0
Severity			
Mild	0	1	0
Moderate	1	1	1
Severe	6	5	5
Race of parents			
Asian	1	0	0
Black or African American	1	1	1
White	5	6	5
Ethnicity			
Hispanic or Latino	1	0	1
Not Hispanic or Latino	6	7	5

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Table 5

Transition Issues Addressed in Formative Research

Transition Topics Addressed in Formative Research
<ul style="list-style-type: none">• Social Support• Exercise• Peer pressure• Education/vocational/financial planning• Self-advocacy/self-esteem• Sexual health• Independent health care behaviors

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Table 6

In-person Message Testing Focus Group Participant Profile

	Group 1	Group 2	Group 3
Total participants	6	6	7
Ages	11/10/11	11/11/11	11/11/11
16–17	3	5	4
18–19	3	1	3
Type of hemophilia			
Hemophilia A/Factor VIII deficiency	6	6	7
Hemophilia B/Factor IX deficiency	0	0	0
Severity			
Mild	0	0	0
Moderate	0	0	1
Severe	6	6	6
Race			
Asian	1	0	0
Black or African American	1	2	0
White	4	4	7
Ethnicity			
Hispanic or Latino	0	0	0
Not Hispanic or Latino	6	6	7

Table 7

Key Messages for Videos

Key Messages and Message Framing for Disclosure Video	
1	It's OK to tell your friends about your condition.
2	Friends will understand. They just have a lot of questions.
3	You can provide short, straightforward responses to define hemophilia and infusions.
4	Acknowledge myths like "paper cuts will cause one to bleed to death" and show how to dispel them.
5	Children with hemophilia need to feel "normal," like other children.
6	Positive responses communicated from friends can boost the confidence of children with hemophilia.
Key Messages for Sports Video	
1	It's OK for children with hemophilia to want to play <i>and to play</i> sports.
2	Children with hemophilia need to be smart about what they play.
3	See what happens to children who didn't make smart choices (and the consequences) and recommended precautions.
4	There are alternatives to playing sports. Other children with hemophilia solved the dilemma of being told they couldn't play.
5	Children with hemophilia can be successful athletes.
6	Children should talk with parents/doctors/nurses about their choices.

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