

Responsiveness of People with Bleeding Disorders and Their Families to Educational Modules on Psychosocial Challenges



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INTRODUCTION AND OBJECTIVES

Psychosocial issues often impact people with bleeding disorders and their caregivers as they navigate life with a chronic condition. Bleeding disorders affect the way that people within families relate to one another, the social context in which people with bleeding disorders live and work, and how they envision their lives and their future. The HERO (Hemophilia Experiences, Results, and Opportunities) Study, conducted by Novo Nordisk, identified gaps in education on quality of life topics in the bleeding disorders community in the United States, indicating a need for programs in this area.

The National Hemophilia Foundation's Collaborating in Care modules were created based on the educational gaps shown through the HERO Study. These modules aim to educate people with bleeding disorders and their families about psychosocial aspects of life with a bleeding disorder.

MATERIALS AND METHODS

As part of the first-ever education program on psychosocial issues designed for National Hemophilia Foundation chapters, six one-hour educational modules were created for people with bleeding disorders and their families. Modules were rolled out in stages from 2014-2016.

Module Topics:

- Communicating With Your Provider About Pain
- Getting Unstuck: Overcoming Roadblocks to Intimacy and Relationships
- Out of the Woods: Skills for Coping with Anxiety and Depression
- Communicating in the Workplace
- To Reveal or Conceal: Navigating Disclosure of a Bleeding Disorder
- You Got This: The Art of Speaking Up

Each module is to be delivered a total of 10 times at National Hemophilia Foundation chapter events. Chapters select module topics to match community interests and needs. Module participants are asked to complete an evaluation at the event and can opt in to a follow-up survey 12 weeks later, to evaluate behavior changes as a result of the module activity.

Content development faculty and module speakers include healthcare professionals from hemophilia treatment centers across the United States, including nurses, physical therapists, social workers and psychologists.

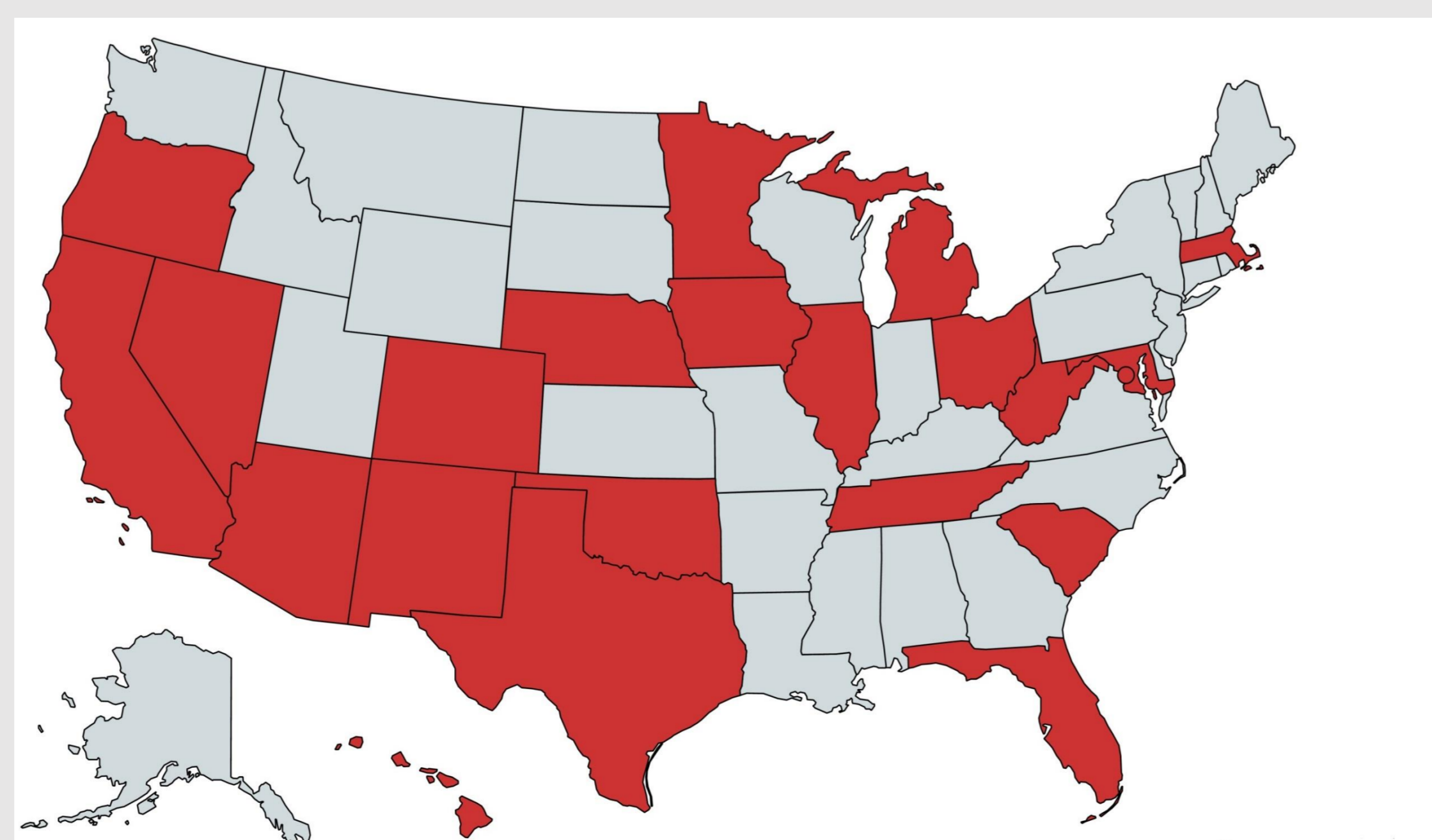
RESULTS

Since NHF began offering Collaborating in Care modules in 2014, 32 activities have been delivered to 1,541 learners.

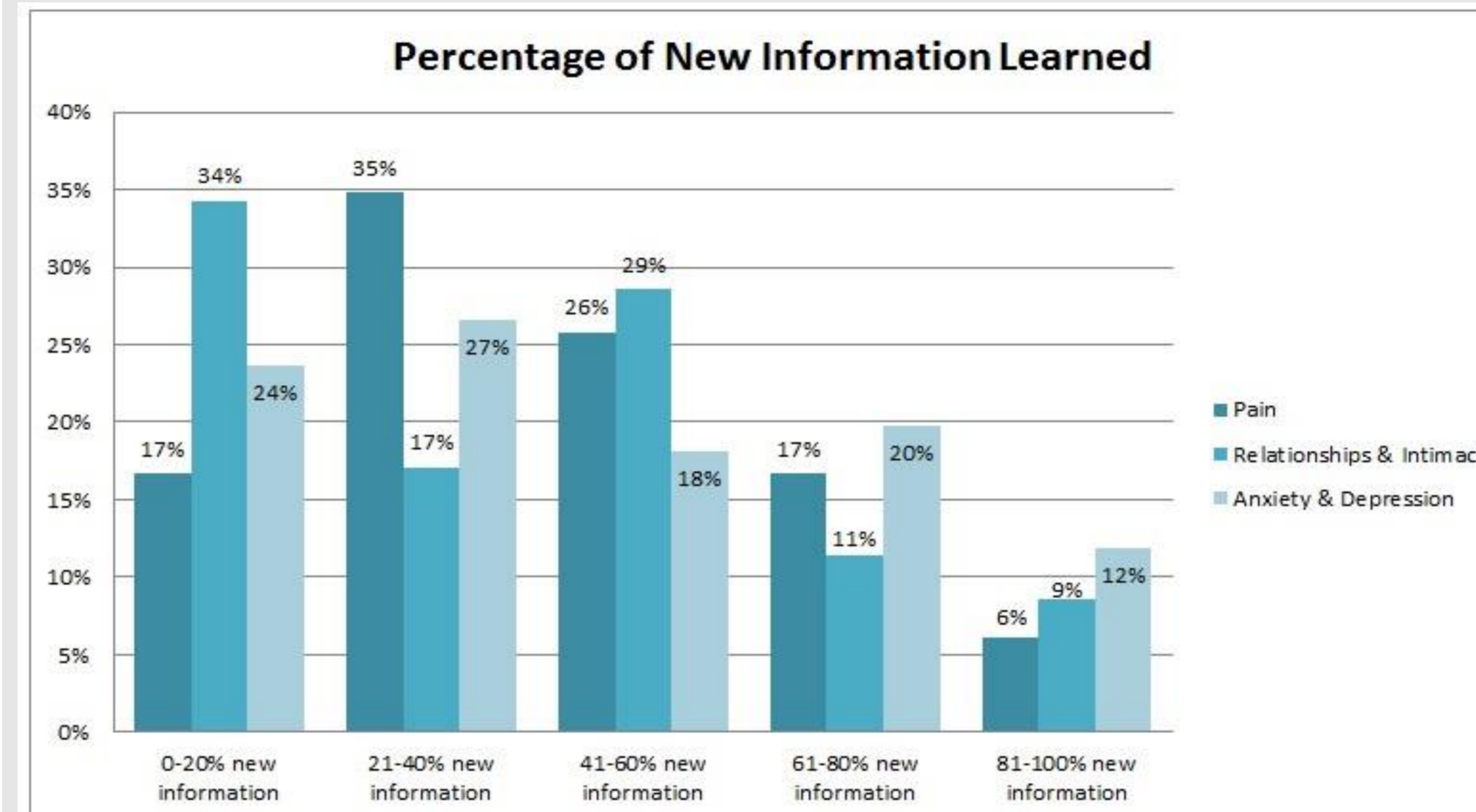
An additional 28 activities are anticipated for 2016, for an expected 840 learners.

Patients in attendance have hemophilia A and hemophilia B, as well as von Willebrand disease and other bleeding disorders. Support network members in attendance include mothers, fathers, siblings, spouses and significant others, grandparents and other direct caregivers, and friends.

Collaborating in Care Activities Delivered



Participants in the first three module activities reported that much of the information presented was new.



-“Great new insights on pain management.”

-“Learned how anxiety/depression pertains to bleeding disorder diagnosis and how it can affect the entire family.”

-“Enjoyed openness between individuals and lessening level of taboo on the discussion of depression.”

-“I like that it covered impact on both patients and caregivers.”

-“People could speak freely.”

-“Session was funny and interactive.”

Across all modules, approximately 73% of participants expressed intent to change the way they manage life with a bleeding disorder, using information learned in the module activities.

-“Learned useful ways to understand pain and different aspects of emotional health.”

-“Loved the statement about needing to get out and live life, enjoy and help others, and not let anxiety steal that.”

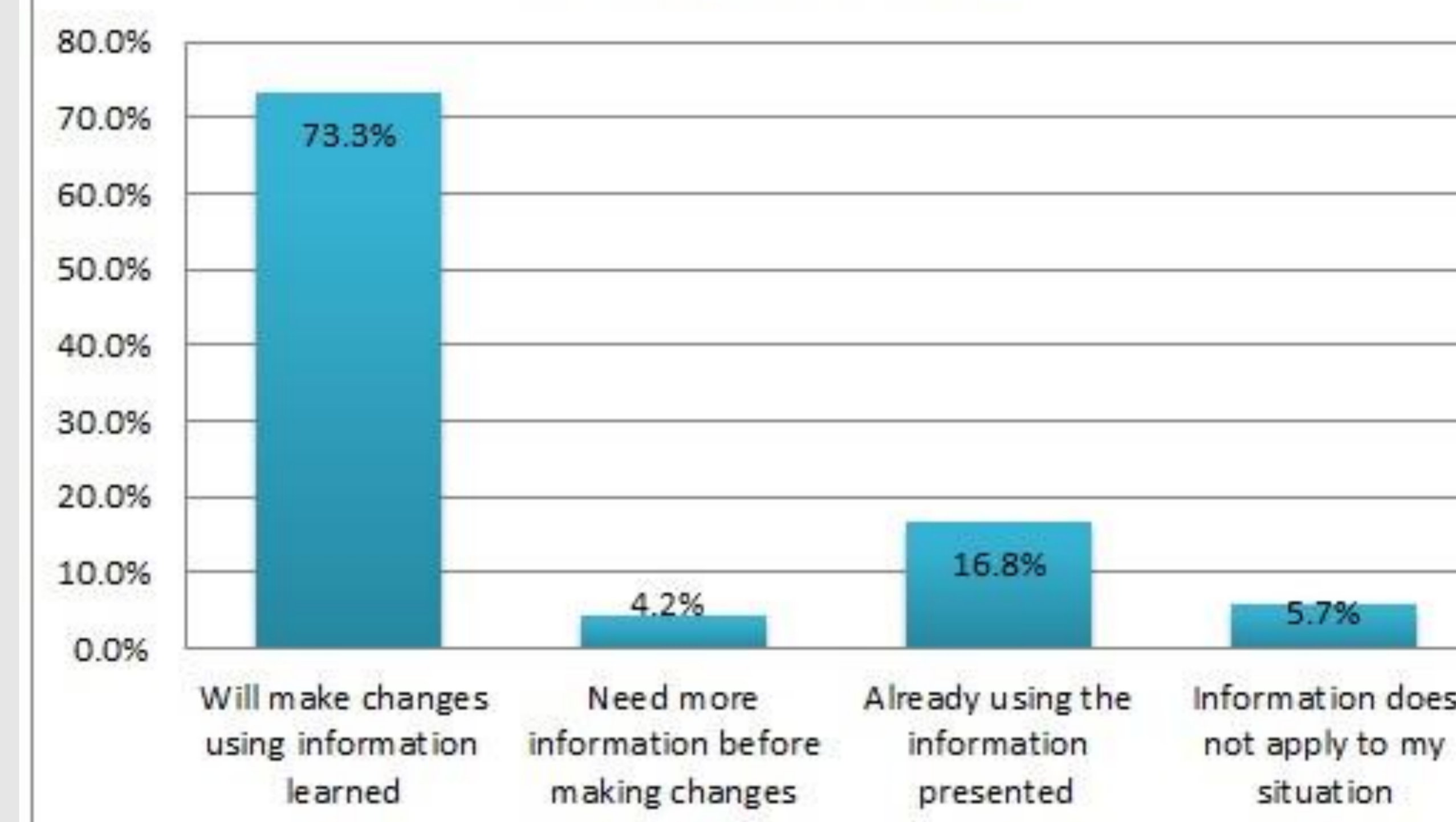
-“I will be more open regarding difficulties.”

-“I will educate myself to help my family members, and find a social worker to talk to for support.”

-“I liked learning how to build a relationship to make it stronger.”

-“Enjoyed learning to speak up for yourself in different ways.”

Intent to Change



Final outcome data will be analyzed and reported after module activities are completed at the end of 2016.

CONCLUSIONS

A large number of people with bleeding disorders and their families choose to participate in educational activities that focus on quality of life and psychosocial issues. The widespread appeal of these activities indicates that there would be an audience for more in-depth exploration of these and other quality of life topics affecting the bleeding disorders community.

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Educational and Communication Models
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