

Assessing Programming Needs of Patients and Clients of the Hemophilia Center at Oregon Health & Science University and the Hemophilia Foundation of Oregon

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Objectives

- To determine:
 - (1) Patient awareness of our educational programming
 - (2) Frequency of participation
 - (3) Barriers impacting participation
 - (4) General feedback

Conclusions

- Understand the barriers identified by patients will allow the HC and HFO to better plan for the educational needs of individuals and families with a bleeding disorder.
- Strengths and weaknesses programs identified: value to the community, applicability of educational programs, access of programs based on demographics and geographic locations of patients and clients.

Future Actions

- Planning future educational programming including outreach programs to encourage greater participation on the part of community members.
- Continue feedback survey in the future to include: Survey Monkey, Phone Calls, Paper Surveys at Events, Separate HFO and HTC, Spanish Options

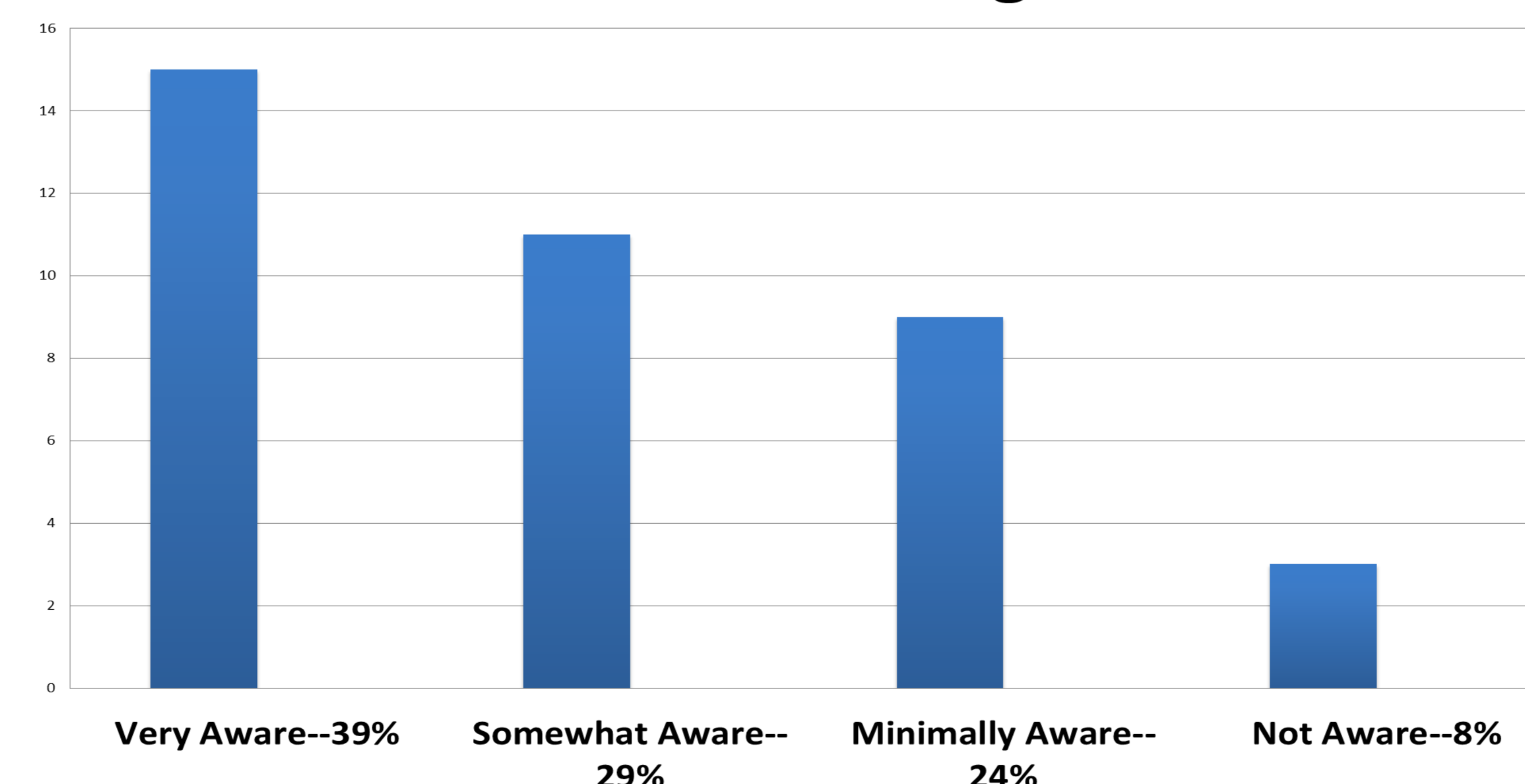
Methods

- Data collected via structured phone survey or by an Internet-based survey tool.
- On a 1-5 Likert Scale (1 = do not agree; 5 = very much agree), 39 questions were developed by the HC and HFO staff.
- All parents of children affected by bleeding disorders as well as patients ages 15 and up from the HC were approached to participate.

Results

- A total of 109 respondents participated, 23 on the phone and 86 via the Internet-based survey tool.
- Respondents with bleeding disorders included 62 males and 31 females. In addition, 16 parents of a child with a bleeding disorder participated.
- Thirty-nine percent of respondents were very aware of the programs offered by the HC and HFO, while 20% regularly attended programs.
- Major barriers to attending the program were: transportation (gas), proximity (event was too far), time constraints (date/time of event did not fit schedule), lack of interest or program did not apply to individual/family, and unawareness or limited understanding of resources provided.

Awareness of Programs



Barriers to Attending Programs

