



Hemophilia Federation of America™

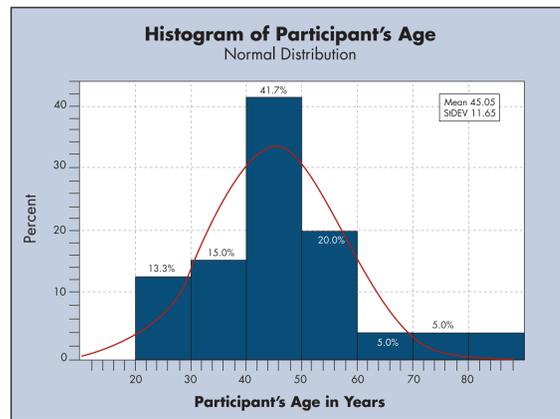
THE IMPACT OF PEER SUPPORT ON THE OVERALL QUALITY OF LIFE FOR AGING ADULT MEN WITH HEMOPHILIA

OBJECTIVE

To examine the impact of social support, educational and networking programs on the overall quality of life of aging adult men with hemophilia.

METHODS

A survey was conducted for adult men, 25 and older, with hemophilia to assess the impact of peer support/educational programs on the overall quality of life issues. Respondents' ages ranged from 25 - 72 years, with an average age of 45 years. The majority of participants were in their forties (41.7%) while a fifth were in their fifties (20%) and a tenth were in their sixties (5%) and seventies (5%). Slightly more than one quarter of participants were under 40 years of age. Of these participants, 15% were in their thirties and 13.3% were in their twenties.



Age distribution of participants who completed a baseline survey

Participants in the support groups answered questions regarding emotional/social support, hemophilia-related communications with peers, levels of stress, and sense of isolation. Peer support groups were implemented in both a face-to-face as well as online forums.

SUMMARY

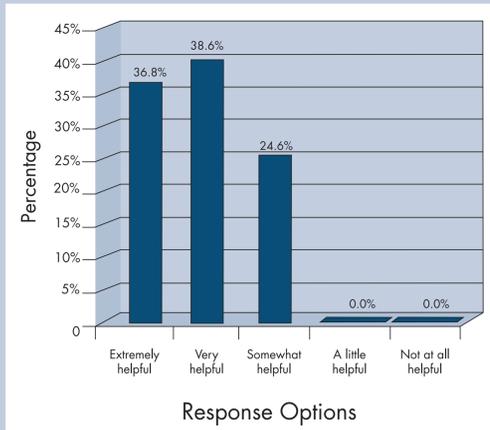
Research indicates that communicating directly with individuals who have similar diseases can significantly improve the quality of life for chronically ill people (Medical News Today, January 3, 2007).

Participants in the study were asked how helpful it is to be able to talk about issues related to their condition with other men with bleeding disorders. The majority of respondents (75.4%) reported that it is "very" or "extremely" helpful.

"SO TO THE NEW MILLENNIUM, I ASK TO BE ALLOWED THE "RISK" OF DISCOVERING WHAT WE CAN DO INSTEAD OF TRAPPING US WITH WHAT WE CANNOT DO. I AND OTHERS LIKE MYSELF SHALL ALWAYS LOOK TOWARD A HOPE FOR TOMORROW."

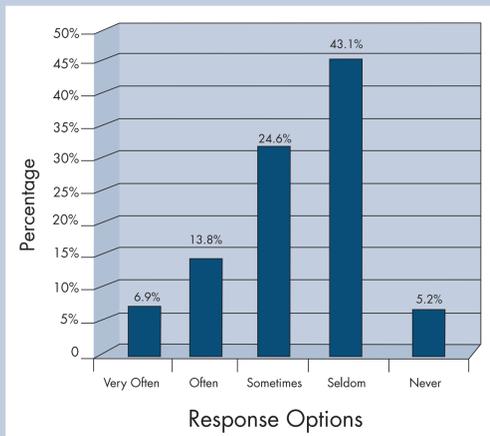
JOHN JARRATT, M. ED., L.P.C.

Percentage of participants who reported it is helpful to be able to talk about issues related to their condition with other men with bleeding disorders.



Prior to implementation of face-to-face and online forums, nearly half of respondents (48.3%) reported that, in the last month, they seldom or never talked to anyone other than their doctors and family members about their condition. Another 31% of participants stated that they talked to others about their condition only sometimes during the last month.

Percentage of participants who reported how often they talked about their condition to people other than their doctors and family in the last month



In addition, 14% of the respondents indicated they were socially isolated, 25% were isolated with low support and 10% indicating some level of support. *

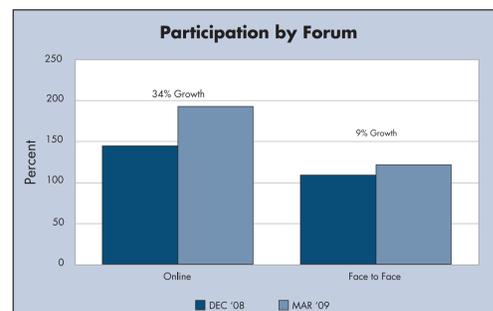
Items	Almost Always (0)	Most of the Time (1)	About half of the time (2)	Occasionally (3)	Never (4)
1. It has been easy to relate to others	32.1	46.4	16.1	5.4	0.0
2. I felt isolated from other people	7.3	1.8	12.7	45.4	32.7
3. I had someone to share my feelings	34.5	25.4	14.5	18.8	7.2
4. I found it easy to get in touch with others when I needed to	30.3	41.1	8.9	16.1	3.6
5. When with other people, I felt separate from them	7.2	7.2	9.1	30.1	45.5
6. I felt alone and friendless	5.3	0.0	10.7	12.5	71.4

*Scoring involves reversal of items 1, 2, 3, and 4 followed by summation across all items. The score range is 0-24. A high score represents social connectedness and a score of "0" complete social isolation.

Participants were asked to indicate what hemophilia-related organizations or groups they interact with on a regular basis and what mode of communication they commonly use during these interactions. Many participants reported that they interact regularly with organizations like the National Hemophilia Foundation and Hemophilia Federation of America by Internet. However, even more participants indicated a preference toward face-to-face interaction with their state or local hemophilia chapter or association, hemophilia treatment center, and/or other men with hemophilia. Participants reporting that they regularly interact with their home care company indicated that they did so most often by telephone.

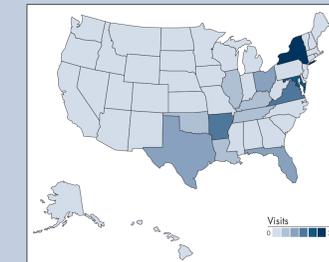


"IT IS THE BEST PILL IN MY BAG, THE BEST FRIENDS I COULD HAVE, THE HEALTHIEST THING TO COME MY WAY IN A WHILE."
A Blood Brother (2009)

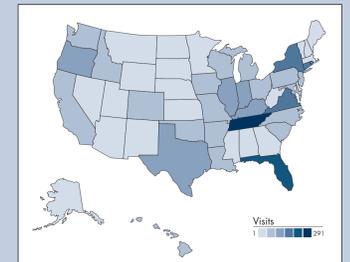


Since initial study inception, both face-to-face and online peer support forums have demonstrated significant growth. Participation in face to face events grew 9% in a 3 month period, where 120 members participated in 33 face to face events. Registration for the online forum grew 34% in a 3 month period, where 192 online members contributed to 317 discussion topics and over 4,000 posts of peer to peer communication.

Chat Site Participation by Region— 115 visits/13 Regions (December, 2008)



Chat Site Participation by Region— 258 visits/28 regions (March, 2009)



CONCLUSION

Analysis of quantitative baseline data and qualitative data collected to date indicate that participating in social networking (face-to-face and online) opportunities that support adult male peer relationships are desired and needed for aging adult men with bleeding disorders. Further study is needed to determine whether offering social support programs will positively impact the overall quality of life for adult men with hemophilia.



THE PROGRAM OFFERS THE CHANCE TO MEET OTHERS THAT FEEL AND HAVE BEEN THROUGH THE SAME THINGS; LISTENING TO EVERYONE, NOW I KNOW I AM NOT ALONE.

A Blood Brother (2009)

Acknowledgement

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