Addressing the Emotional Support Needs of Individuals with Hereditary Cancer through Virtual Peer-Led Meetings

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FORCE
Facing Hereditary Cancer EMPOWERED

BACKGROUND

People with pathogenic variants (PV) associated with hereditary cancer risk face psychosocial challenges, including anxiety about risk-management, family communication, and feelings of isolation. While clinical guidelines are well-established for many genes linked to cancer risk, emotional support remains an unmet need (Figure 1).

Women with hereditary cancer risk experience significant emotional distress, and value referrals from their doctors to social support networks3. Perceptions of low social and emotional support predict increased distress and poor mental health outcomes in this population. However, structured support groups, peer connections, and family-based emotional support improve coping, anxiety levels, and patient experience[1-3].

Integrating emotional support into hereditary cancer care meets a critical need and can improve patient outcomes. To that end, FORCE, a national nonprofit organization serving people affected by hereditary cancer risk, provide virtual support meetings tailored for the hereditary cancer community. The meetings are organized by topic (e.g., mastectomy), situation (e.g., survivor, previvor, caregiver), gene (e.g., BRCA1/2, Lynch syndrome, others), and other factors. The meetings are co-led by genetics experts and trained FORCE peer volunteers. We evaluated participant feedback to better understand the impact of these support group offerings.

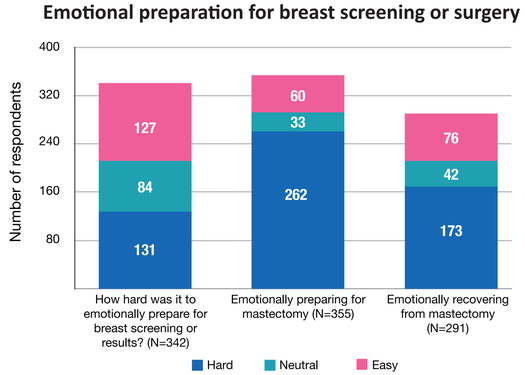


Figure 1. Previous survey data demonstrating emotional support need for respondents preparing for breast screening or surgery.

METHODS

Between February and September 2025, 1,532 people attended 65 FORCE virtual support meetings for people affected by hereditary cancer risk. Feedback was collected from 201 attendees via a post-meeting survey to assess satisfaction, emotional support, and perceived value of information gained (Figure 3). Participants could also provide open-ended feedback.

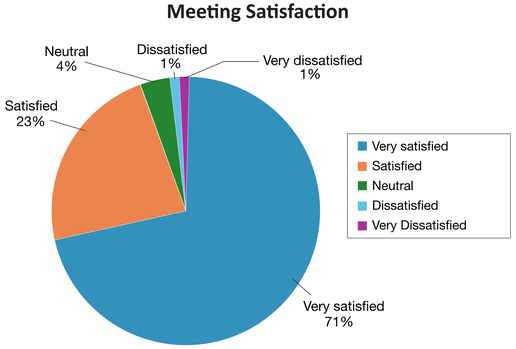


Figure 2. Meeting satisfaction results.

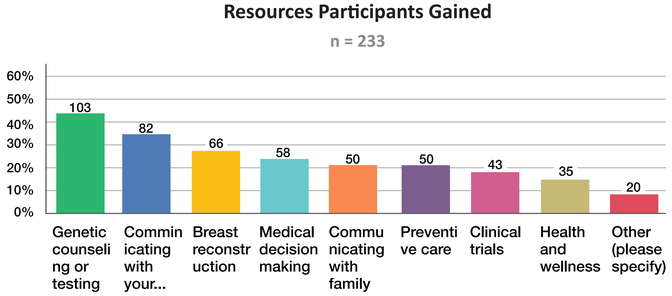


Figure 3. Resources or information gained due to meeting participation.

RESULTS

Participants expressed that the meetings provided a safe, inclusive space to connect with others facing similar challenges, helped reduce feelings of isolation, and validated participant's emotions:

- 66% felt less anxious or worried.
- 89% felt more supported or less alone.
- 83% felt more confident in their knowledge.
- 70% felt more confident about their decisions.
- 71% were "very satisfied" and 23% were "satisfied" with meetings (Figure 2).
- Attendees received support on various topics including genetic counseling/testing (44%), breast reconstruction (28%) and communication with healthcare providers (35%).

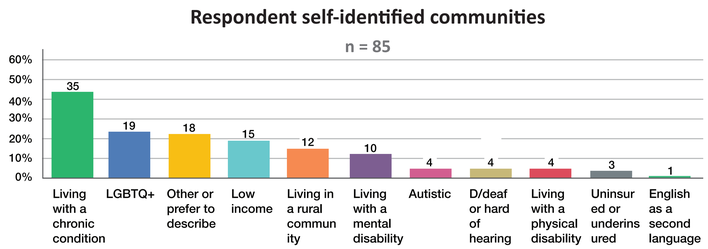


Figure 4. A subset of total respondents (42%) provided information on communities they identified with. Respondents were able to skip this question if they did not want to answer.

Qualitative Themes:

- **Greater sense of community:** "The support group is the only outlet for me to express my hopes, frustrations and fears."
- **Empowerment in medical decision-making:** "I am definitely going through with my mastectomy and am so happy I met new friends to help me through my journey!"
- **Improved representation:** Specific groups (e.g., LGBTQ+, young previvors) felt especially seen when breakout sessions included people who shared their lived experiences.

> *"The volunteer leaders were supportive and managed the discussions very well."*

> *"I'm so happy I've found a way to meet with people going through similar experiences. Part of what's been challenging about this is the feeling of being alone in all of it... This was my first meeting and I definitely plan to attend more in the future. Thank you so much for offering these spaces."*

DISCUSSION

The emotional burden of navigating hereditary cancer risk can be substantial. Survey responses demonstrated that FORCE's peer-and-expert-led virtual meetings create a needed space for people with hereditary cancer risk to process complex emotions, build resilience, and make informed decisions. Organizing meetings by topic highlights the diversity of attendees and the importance of tailored support meetings.

CONCLUSION

Virtual support meetings represent a scalable, low-cost, and high-impact intervention to address the emotional needs of people with hereditary cancer risk. The positive reception underscores the value of integrating psychosocial support alongside clinical care.

1. https://doi.org/10.1080/10410236.2016.1250187
2. FORCE. (2024, October 21). Results from FORCE's 2024 Survey Highlighting the Needs of People at High Risk for Breast Cancer. FORCE Blogs.
3. https://doi.org/10.3389/fpsyt.2019.00208

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