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The Current Landscape of Vitiligo Support Groups: An International Survey of Support Group Leaders

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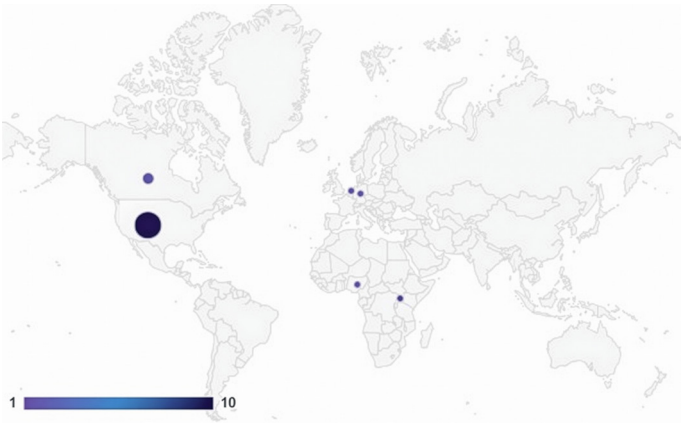
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INTRODUCTION

Vitiligo can significantly impact the quality of life of affected individuals and their family members. Support groups provide numerous benefits, including allowing individuals to give and receive emotional and practical support.[1,2] This prospective, international, cross-sectional study aimed to characterize the current landscape and needs of support groups.

The authors designed an online survey with input from international support group leaders from the Global Vitiligo Foundation (GVF) and the Vitiligo International Patient Organizations Committee, which are largely recognized as major umbrella organizations for organized support groups globally. The English-language survey was distributed to 66 support group leaders from their respective networks. Sixteen group leaders responded from 6 countries: the United States, Canada, Uganda, Nigeria, Germany, and the Netherlands (Figure 1).

FIGURE 1. Map of survey respondents.



Among groups surveyed, founding years ranged from 1990 to 2024. Most groups met quarterly (37.5%) or monthly (25%) through virtual and in-person meetings (68.8%). Meeting places included community centers, restaurants, offices, business conference rooms, and cultural centers. Half the groups had official officers (50%), including the roles of president, secretary, treasurer, or executive board. The majority did not have dues or other membership requirements (68.8%). Nearly all the groups had a social media presence (93.8%), and 87.5% of group leaders reported social media as the most common route of member referral.

The most common age group was 35 to 54 years (mean 39%). Among US-based groups, the average racial/ethnic makeup was 51.9% Black, 34.2% White, 10% Mixed race, 8.3% Hispanic or Latino, 6.7% Other, and 5% Asian. Race/ethnicity data were restricted to US-based groups due to legal restrictions on demographic data collection in Europe. Women comprised over half of most groups, averaging 63.5%. Individuals with darker skin may experience increased disease visibility, contributing to greater psychosocial burden and reduced quality of life.[3,4] Additionally, women with vitiligo have been shown to experience greater impact on quality of life.[5]

The most popular topics covered were vitiligo treatments, living with vitiligo, mental health, and sun protection. Nearly half of groups hosted events targeted at individuals outside the vitiligo community (43.8%), and half had events for parents of affected children (50%). The most common group goals included providing emotional support, spreading awareness, and sharing practical information.

While less than half of the groups were affiliated with an academic center or hospital (43.8%), most had medical professionals attend meetings (62.5%), of whom 70% were dermatologists, and of that group, 70% served in an official role.

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TABLE 1.

Umbrella Organizations for Vitiligo Support Groups	
Parent Organizations	***n***
Vitiligo International Patient Organizations Committee	3
VitFriends	3
Global Vitiligo Foundation	2
Global Skin Foundation	1
German Vitiligo Association	1
Vstrong	1
Litty Ligo	1

The overwhelming majority of support group leaders reported members developed a deeper understanding of their condition through participation (93.8%). While most reported feeling confident facilitating events, and three-quarters held other leadership positions, nearly all (93.8%) were interested in additional training to help run their support group. Many groups were chapters of larger vitiligo organizations (Table 1), and most were part of the Global Vitiligo Foundation Community (68.8%). The majority (75%) had members who attended the US World Vitiligo Day conference.

While over half of groups had funding (56.3%) from donations, member contributions, grants, health insurance, and government support, half still cited funding as their largest challenge. Half reported burnout and difficulty recruiting volunteers as their second greatest challenge. Other challenges faced include organizing meetings, lacking a medical advisor, and a lack of public awareness and supportive policies.

Overall, there was significant global heterogeneity in group membership and size, leadership structure, and meeting frequency. Commonalities included shared primary goals and the key role of social media in group functioning. Many groups had a predominance of Black and female members. This study was limited by survey nonresponse bias, reliance on group leader-reported data, and the potential omission of additional vitiligo support groups not identified. Factors contributing to the response rate include that the survey was only distributed in English, which may have limited participation from non-English-speaking regions, and some support groups may have been inactive at the time of survey distribution. Finally, as many support group leaders serve in a voluntary capacity, survey completion may have been limited by competing priorities. Findings from this study highlight several important findings, including the current benefits and needs of support groups, the need for increased funding to expand programming and leadership training for group facilitators, and lastly that dermatologists may assist vitiligo support groups by serving as medical advisors.

DISCLOSURES

Dr. Elbuluk has served as a consultant, advisory board member, and/or speaker for Arcutis, Incyte, La Roche Posay, Beiersdorf, Eli Lilly, Pfizer, Takeda, Abbvie, Janssen, Sanofi, L'Oreal, McGraw Hill, Dior, Medscape, Kao USA, Skinceuticals, Verademics, Canfield, Kenvue, Teva. She has grant funding from Pfizer and Eli Lilly, has received royalties from McGraw-Hill and has stock options in VisualDx. Dr Grimes has served as an investigator, consultant, advisory board member, and/or speaker for Galderma, Clinuvel, L'Oreal, Johnson & Johnson, LaserOptek, Versicolor Technologies, MERCK, Dermbiont, VYNE Therapeutics, RAPTTherapeutics, Incyte, Pfizer, AbbVie/Allergan, SkinBetterScience, Klotho Skincare, Mother Science, Medscape, and Beiersdorf. She is the founder and director of the Vitiligo and Pigmentation Institute. She has stock options in Versicolor Technologies. Dr Huggins has served as an investigator, consultant, and/or advisory board member for Arcutis, Avita, Clinuvel, Incyte, Novartis, Mitsubishi, Pfizer, and The Immune Tolerance Network. He is a board member of the Global Vitiligo Foundation (GVF) and chair of the GVF Community Committee. The remaining authors have no disclosures to report.

Ethics Statement: This study was reviewed and deemed exempt by the University of Southern California Institutional Review Board. Study ID UP-24-00832

Data Availability Statement: The data that support the findings of this study are available from the corresponding author upon reasonable request.

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