

# Views and Beliefs of Vitiligo Patients in Online Discussion Forums: A Qualitative Study

Mary Beth Gadarowski, MD; Arjun M. Bashyam, MD; Amy J. McMichael, MD; Steven R. Feldman, MD, PhD

## PRACTICE POINTS

- Online forums provide invaluable insight on vitiligo disease management, psychosocial impact, and burden on quality of life. Patient care can be improved by inquiring where patients seek information and whether online forums are utilized.
- Commonly discussed topics in online forums were cosmetic concealment of vitiligo lesions and homeopathy or “cure” discussions. Health care providers can engage in honest conversations about evidence-based medical treatments for vitiligo. The interest in cosmetic management highlights a relevant research area in this field.
- Health care providers can better serve patients with vitiligo by providing online resources that are reputable and can help guide patients to credible internet sources such as the Global Vitiligo Foundation.

Individuals with chronic illnesses turn to online communities to engage in asynchronous peer-to-peer exchanges to better understand and manage their disease. Messages and advice exchanged by online users with vitiligo are not well characterized. We conducted a qualitative study to explore the content exchanged by individuals with vitiligo in online forums. An interpretive research paradigm was utilized to assess public online forum content. A systematic search using the phrases *online forum vitiligo support*, *vitiligo online message board*, and *vitiligo forums* identified 39 relevant forums; 9 of them met inclusion criteria, with 382 total anonymous users. Major themes and subthemes included vitiligo disease management, homeopathy/home remedies, psychosocial impact, public perceptions, and camouflage/concealment.

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Vitiligo is a chronic dermatologic condition that negatively affects quality of life (QOL), with substantial burden on the psychosocial well-being of patients.<sup>1</sup> There is no cure, and current treatment modalities are

From the Center for Dermatology Research, Department of Dermatology, Wake Forest School of Medicine, Winston-Salem, North Carolina. Dr. Feldman also is from the Wake Forest School of Medicine Department of Pathology and Department of Social Sciences & Health Policy, and the Department of Dermatology, University of Southern Denmark, Odense.

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The eTables are available in the Appendix online at [www.mdedge.com/dermatology](http://www.mdedge.com/dermatology).

Correspondence: Mary Beth Gadarowski, MD, Department of Dermatology, Wake Forest School of Medicine, Medical Center Blvd, Winston-Salem, NC 27157-1071 ([mbgadarowski@gmail.com](mailto:mbgadarowski@gmail.com)).

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aimed at controlling the chronic relapsing condition.<sup>1-3</sup> Despite topical and cosmetic treatments for stabilization and repigmentation, vitiligo remains unpredictable.<sup>3</sup>

All genders, races, ethnicities, and socioeconomic classes are equally affected.<sup>4</sup> The underlying etiology of vitiligo remains unknown to a great extent and is more poorly understood by the general public compared with other skin diseases (eg, acne).<sup>5</sup> Patients with vitiligo experience social withdrawal, decreased sense of self-esteem, anxiety, depression, and suicidal ideation.<sup>5,6</sup> Stigmatization has the greatest impact on QOL, with strong correlations between avoidance behaviors and lesion concealment.<sup>6-8</sup> Although the condition is especially disfiguring for darker skin types, lighter skin types also are substantially affected, with similar overall self-reported stress.<sup>6,7</sup>

Individuals with chronic illnesses such as vitiligo turn to online communities for health information and social support, commiserating with others who have the same condition.<sup>9,10</sup> Online forums are platforms for asynchronous peer-to-peer exchange of disease-related information for better management of long-term disease.<sup>11</sup> Moreover, of all available internet resources, online forum posts are the most commonly accessed source of information (91%) for patients following visits with their doctors.<sup>12</sup>

Qualitative research involving chronic skin conditions and the information exchanged in online forums has been conducted for patients with acne, psoriasis, and atopic dermatitis, but not for patients with vitiligo.<sup>13-16</sup> Although online questionnaires have been administered to patients with vitiligo, the content within online forums is not well characterized.<sup>2,17</sup>

The purpose of this qualitative study was to evaluate the online content exchanged by individuals with vitiligo to better understand the general attitudes and help-seeking behaviors in online forums.

## Methods

**Study Design**—This qualitative study sought to investigate health beliefs and messages about vitiligo posted by users in US-based online discussion forums. An interpretive research paradigm was utilized so that all content collected in online forums were the views expressed by individuals.<sup>18-20</sup> An integrated approach was used in the development of the coding manual, with pre-established major themes and subthemes as a guiding framework.<sup>16,21,22</sup> We adhered to an inductive grounded method by means of de novo line-by-line coding, such that we had flexibility for new subthemes to emerge throughout the duration of the entire coding process.<sup>23</sup>

Individual posts and subsequent replies embedded within public online forums were used as the collected data source. Google was utilized as the primary search engine to identify forums pertaining to vitiligo, as 80% of US adults with chronic disease report that their inquiries for health information start with Google, Bing, or Yahoo.<sup>24</sup>

The institutional review board at the Wake Forest School of Medicine (Winston-Salem, North Carolina) granted approval of the study (IRB00063073). Online forums were considered “property” of the public domain and were accessible to all, eliminating the need for written informed consent.<sup>24-26</sup>

**Search Criteria**—We conducted our forum search in February 2020 with a systematic approach using predetermined phrases—*online forum vitiligo support*, *vitiligo online message board*, and *vitiligo forums*—which yielded more than 358,171 total results (eTable 1). Threads were identified in chronological order (from newest to oldest) based on how they appeared during each internet search, and all Google results for the respective search phrases were reviewed. Dates of selected threads ranged from 2005 to 2020. Only sites with US domains were included. Posts that either included views and understandings of vitiligo or belonged to a thread that contained a vitiligo discussion were deemed relevant for inclusion. Forums were excluded if registration or means of payment was required to view posts, if there were fewer than 2 user replies to a thread, if threads contained patient photographs, or if no posts had been made in the last 2 years (rendering the thread inactive). No social media platforms, such as Facebook, or formal online platforms, such as MyVitiligoTeam, were included in the search. A no-fee-for-access was chosen for this study, as the majority of those with a chronic condition who encounter a required paywall find the information elsewhere.<sup>25</sup>

**Data Analysis**—A total of 39 online forums were deemed relevant to the topic of vitiligo; 9 of them met inclusion criteria (eTable 2). The messages within the forums were copied verbatim into a password-encrypted text document, and usernames in the threads were de-identified, ensuring user confidentiality.

An inductive thematic analysis was utilized to explore the views and beliefs of online forum users discussing vitiligo. One author (M.B.G.) read the extracted message threads, developed an initial codebook, and established a finalized version with the agreement of another author (A.M.B.) (eTable 3). The forums were independently coded (M.B.G. and A.M.B.) in a line-by-line manner according to the codebook. Discrepancies were documented and resolved. Data saturation was adequately achieved, such that no new themes emerged during the iterative coding process. NVivo was used for qualitative analysis.

## Results

Nine forums met inclusion criteria, comprising 105 pages of text. There were 61 total discussion threads, with 382 anonymous contributing users. Most users initiated a thread by posting either a question, an advice statement, or a request for help. The psychosocial impact of the disease permeated multiple domains, including personal relationships and daily life. Several threads discussed treatment, including effective camouflage and makeup, as well as peer validation of

physician-prescribed treatments, along with threads dedicated to “cures” or homeopathy regimens. In several instances, commercial product endorsement, testimonials, and marketing links were reposted by the same user multiple times.

Inductive thematic analysis highlighted diverse themes and subthemes related to the beliefs and perspectives of users with vitiligo or with relatives or friends with vitiligo: psychosocial impact, disease management and camouflage/concealment, alternative medicine/homeopathy/cures, interactions with the public and health care providers, and skin tone and race. Quotes from individuals were included to demonstrate themes and subthemes.

*Psychosocial Impact: QOL, Sources of Support, and Coping*—There was a broad range of comments on how patients cope with and view their vitiligo. Some individuals felt vitiligo made them special, and others were at peace with and accepted their condition. In contrast, others reported the disease had devastated them and interfered with relationships. Individuals shared their stories of grief and hardships through childhood and adulthood and their concerns, especially on affected visible areas or the potential for disease progression. Users were vocal about how vitiligo affected their daily routines and lives, sharing how they felt uncomfortable outside the home, no longer engaged in swimming or exposing their legs, and preferred to stay inside instead. Some users adopted a “tough love” approach to coping, sharing how they have learned to either embrace their vitiligo or “live with it.” Some examples include:

*“My best advice is go with the flow, vitiligo is not the worst thing that can happen.”*

*“I hate my life with vitiligo yet really I feel so selfish that there is much worse suffering in the world than a few white patches.”*

Other advice was very practical:

*“I hope it isn’t vanity that is tearing you apart because that is only skin deep. Make a fashion statement with hats.”*

Some users acknowledged and adopted the mantra that vitiligo is not a somatic condition or “physical ailment,” while others emphasized its pervasive psychological burden:

*“I still deal with this psychologically . . . You must keep a positive attitude and frame of mind . . . Vitiligo will not kill you, but you do need to stay strong and keep your head up emotionally.”*

*“I am just really thankful that I have a disease that will not kill me or that has [not] affected me physically at all. I consider myself lucky.”*

*Disease Management: Treatment, Vitiligo Course, Advice-Seeking, Camouflage*—The range of information discussed for treatment was highly variable. There were many accounts in which users advised others to seek professional help, namely that of a dermatologist, for a formal assessment. Many expressed frustrations with treatments and their ineffectiveness, to which the majority of users

said to consult with a professional and to remain patient and hopeful/optimistic:

*“The best thing to do would be to take an appointment with a dermatologist and have the discoloration checked out. That’s the only way to know whether it is vitiligo or not.”*

*“My way of dealing with it is to gain control by camouflage.”*

*“The calming effect of being in control of my vitiligo, whether with concealers, self-tan or anything else, has stopped my feelings of despair.”*

*Beliefs on Alternative Medicine: Homeopathy and Alternative Regimens*—Although some threads started with a post asking for the best treatments, others initiated a discussion by posting “best herbal treatments for cure” or “how to cure my vitiligo,” emphasizing the beliefs and wishes for a cure for vitiligo. Alternative therapies that users endorsed included apple cider vinegar, toothpaste, vitamins, and Ayurvedic treatment, among others. Dietary plans were popular, with users claiming success with dietary alterations in stopping and preventing lesion progression. For example, individuals felt that avoidance of sugar, meat, dairy, and citrus fruits or drinks and consumption of only filtered water were crucial to preventing further lesion spread and resulted in their “cure”:

*“Don’t eat chocolate, wine (made of grapes), coffee, or tea if you don’t want to have vitiligo or let it get worse. Take Vitamin B, biotin, and nuts for Vitamin E.”*

Other dangerous messages pitted treatments by health professionals against beliefs in homeopathy:

*“I feel that vitiligo treatment is all in your diet and vitamins. All that medicine and UV lights is a no-no . . . with every medicine there is a side effect. The doctors could be healing your vitiligo and severely damaging you inside and out, and you won’t know until years later.”*

There was a minor presence of users advising against homeopathy and the associated misinformation and inaccurate claims on curing vitiligo, though this group was small in comparison to the number of users posting outlandish claims on cure:

*“There is no cure . . . It’s where your immune system attacks your skin cells causing loss of pigmentation. The skin that has lost the pigmentation can’t be reversed.”*

*Interactions With the Public and Health Care Providers*—Those with vitiligo encounter unique situations in public and in their daily lives. Many of the accounts shared anecdotal stories on how patients have handled the stigma and discrimination faced:

*“I have had to face discrimination at school, public places, college, functions, and every new person I have met has asked me this: ‘how did this happen?’”*

Those with vitiligo even stated how they wished others would deal with their condition out in public, hoping that others would directly ask what the lesions were instead of the more hurtful staring. There were many stories in which users said others feel vitiligo was

contagious or “dirty” and stressed that the condition is not infectious:

*“I refer to myself as ‘camo-man’ and reassure people I come into contact with that it is not contagious.”*

*“Once I was eating at a restaurant . . . and a little girl said to her mom, ‘Look, Mom, that lady doesn’t wash her arms, look how dirty they are.’ That just broke my heart.”*

**Skin Tone and Implications**—The belief that vitiligo lesions are less dramatic or less anxiety provoking for individuals with lighter skin was noted by users themselves and by health care providers in certain cases. Skin tone and its impact on QOL was confusing and contentious. Some users with fair skin stated their vitiligo was “less of an annoyance” or “less obvious” compared with individuals with darker complexions. Conversely, other accounts of self-reported White users vehemently stressed the anxieties felt by depigmented lesions, despite being “already white at baseline.”

*“Was told by my dermatologist (upon diagnosis) that ‘You’re lucky you’re not African American—it shows up on them much worse. You’re so fair, it doesn’t really matter.’”*

*“You didn’t say what race you are. I could imagine it has a bigger impact if you are anything other than White.”*

## Comment

**Patients Looking for Cures**—The general attitude within the forums was uplifting and encouraging, with users detailing how they respond to others in public and sharing their personal perspectives. We found a mix of information regarding disease management and treatment of vitiligo. Overall, there was uncertainty about treatments, with individuals expressing concern that their treatments were ineffective or had failed or that better alternatives would be more suitable for their condition. We found many anecdotal endorsements of homeopathic remedies for vitiligo, with users boasting that their disease had not only been cured but had never returned. Some users completely denounced these statements, while other threads seemed to revolve completely around “cure” discussions with no dissenting voices. The number of discussions related to homeopathy was concerning. Furthermore, there often were no moderators within threads to remove cure-related content, whether commercially endorsed or anecdotal. It is plausible that supplements and vitamins recommended by some physicians may be incorrectly interpreted as a “cure” in online discussions. Our findings are consistent with prior reports that forums are a platform to express dissatisfaction with treatment and the need for additional treatment options.<sup>15,22</sup>

**Concern Expressed by Health Care Providers**—Prior qualitative research has described how patients with chronic dermatologic conditions believe that health care providers minimize patients’ psychological distress.<sup>27,28</sup> We found several accounts in which an individual had explicitly stated their provider had “belittled” the extent and impact of vitiligo when comparing skin phototypes.

This suggests either that physicians underestimate the impact of vitiligo on their patients or that physicians are not expressing enough empathic concern about the impact the condition has on those affected.

**Cosmetic Aspects of Vitiligo**—Few clinical trials have investigated QOL and cosmetic acceptability of treatments as outcome measures.<sup>29</sup> We found several instances in which users with vitiligo had reported being dismissed as having a “cosmetic disease,” consistent with other work demonstrating the negative impact on such dismissals.<sup>22</sup> Moreover, concealment and camouflage techniques frequently were discussed, demonstrating the relevance of cosmetic management as an important research topic.

**Trustworthy Sources of Health Information**—Patients still view physicians as trustworthy and a key source of health care information and advice.<sup>30-32</sup> Patients with vitiligo who have been directed to reliable information sources often express gratitude<sup>22</sup> and want health professionals to remain an important source in their health information-seeking.<sup>31</sup> Given the range in information discussed online, it may be valuable to invite patients to share what information they have encountered online.

Our study highlights the conflicting health information and advice shared by users in online forums, complicating an already psychologically burdensome condition. Guiding patients to credible, moderated sites and resources that are accurate, understandable, and easy to access may help dispel the conflicting messages and stories discussed in the online community.

**Study Strengths and Limitations**—Limitations included reporting bias and reliance on self-reported information on the diagnosis and extent of individuals’ vitiligo. Excluding social media websites and platforms from the data collection is a limitation to comprehensively assessing the topic of internet users with vitiligo. Many social media platforms direct patients and their family members to support groups and therefore may have excluded these particular individuals. Social media platforms were excluded from our research owing to the prerequisite of creating user accounts or registering as an online member. Our inclusion criteria were specific to forums that did not require registering or creating an account and were therefore freely accessible to all internet viewers. There is an inherent lack of context present in online forums, preventing data collection on individuals’ demographics and socioeconomic backgrounds. However, anonymity may have allowed individuals to express their thoughts more freely.

An integrated approach, along with our sampling method of online forums not requiring registration, allows for greater transferability and understanding of the health needs of the general public with vitiligo.

## Conclusion

Individuals with vitiligo continue to seek peer psychosocial support for the physical and emotional management of their disease. Counseling those with vitiligo about



cosmetic concealment options, homeopathy, and treatment scams remains paramount. Directing patients to evidence-based resources, along with providing structured sources of support, may help to improve the psychosocial burden and QOL experienced by patients with vitiligo. Connecting patients with local and national support groups moderated by physicians, such as the Global Vitiligo Foundation (<https://globalvitiligofoundation.org/>), may provide benefit to patients with vitiligo.

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APPENDIX

**eTABLE 1. Search Strategy for Online Forums Related to Vitiligo<sup>a</sup>**

Search term phrases	Total hits and results	Search engine
Online forum vitiligo support	102 total results, 11 Google searches	Google, US domains
Vitiligo online message board	69 total results	Google, US domains
Vitiligo forums	358,000 total results, 20 total Google hits	Google, US domains

<sup>a</sup>All results systematically reviewed in chronologic order.

**eTABLE 2. Online Forums Meeting Inclusion Criteria (N=9)**

Identified forum	Date range	Thread title	No. of subthreads	No. of users	No. of excluded threads within identified forum
The Straight Dope Message Board	2005-2018	Vitiligo experiences anyone?	1	10	0
Patient Info Forum-Vitiligo	2007-2019	Vitiligo	33	164	25 (no posts within past 2 y)
Digital Spy Forums-Albinism	2018-2019	Albinism	0	2	0
MedicineNet	2019-2020	Vitiligo article (patient comments)	4	95	9
Scars 1 Acne Forum	2010-2018	Vitiligo treatment	1	7	0
HearingTracker	2015-2018	Anyone else develop vitiligo?	1	7	0
What to Expect	2016-2019	My baby has vitiligo	9	43	19 (identifying photographs within these subthreads)
LGBT Chat & Forums	2018	Would you date someone with vitiligo?	1	17	0
DailyStrength Vitiligo Support Group	2016-2019	Vitiligo support groups thread	11	37	0

Abbreviation: LGBT, lesbian, gay, bisexual, transgender.

**eTABLE 3. Code Structure: Understanding the Beliefs and Content of Information Exchanged by Individuals in Online Forum Discussions on Vitiligo**

**Code and subcode**

- 
1. Reason for vitiligo onset
    - a. Random
    - b. Genetics
    - c. Stress
    - d. Pregnancy/following birth
    - e. Comorbid disease/autoimmunity
- 
2. Disease management
    - a. Advice-seeking from peers on treatment/management
    - b. Personal experiences of effective/ineffective treatments (including makeup, tattoos, self-tanners, sunscreen, lasers/phototherapy)
    - c. Treatments: cost/insurance
      - i. Obtaining medication abroad
    - d. Vitiligo diagnosis/course/progression/general disease curiosity
      - i. Accurate or inaccurate information shared
    - e. Sun protection
    - f. Location on body (eg, visible areas, genitalia)
    - g. Users suggesting to see a dermatologist or speak with a physician
- 
3. Homeopathy/curing vitiligo
    - a. Seeking information on finding a cure/natural treatment
    - b. Users endorsing a cure
    - c. Users explicitly stating no cure
    - d. Categories of “cures” (eg, herbs, alternative medicine, vitamins, diet)
- 
4. Psychosocial impact
    - a. Emotional support/encouragement from other users/sources of support
      - i. Putting disease in perspective
    - b. Disbelief/denial (whether self, family member, or friend)
    - c. How to cope/users offering coping skills/users asking for coping mechanisms
    - d. Acceptance
    - e. Self-esteem/stress/depression/hopelessness
    - f. Impact on relationships with others/impact on work/daily life
    - g. Anonymously reveal personal story
    - h. Skin tone (lighter vs darker)
- 
5. Experiences in public/public perceptions
    - a. Negative
      - i. Insensitivity and reactions of others
    - b. Positive
    - c. How one explains vitiligo to others
- 
6. Interactions with health care providers
    - a. User consulted with physician and/or information received from physicians
    - b. Negative experiences and opinions on health care providers (eg, dissatisfied)
    - c. Positive perception/experiences with and opinions on health care providers
    - d. Misdiagnosed/written off/told “cosmetic”
- 
7. Camouflage/concealment
    - a. Advice-seeking/general information-sharing
    - b. Reasons for covering up vitiligo lesions
    - c. Reasons not to cover up lesions
-