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Original Research Article

A cross-sectional content analysis of the psychosocial sequelae of vitiligo using Reddit

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ABSTRACT

Background: Vitiligo is a chronic autoimmune disorder associated with significant psychosocial burden, including depression, anxiety, and impaired quality of life. Despite this, providers frequently underestimate its psychological impact, and existing qualitative research has relied primarily on structured clinical settings that may limit candid patient disclosure. This study aimed to characterize the psychosocial sequelae of vitiligo as expressed organically by patients on an anonymous online forum.
Methods: A cross-sectional content analysis was conducted on posts from the Reddit forum r/vitiligo. Posts were manually screened by two independent researchers using predefined inclusion and exclusion criteria. Relevant posts were analyzed using an inductive grounded theory approach, with iterative coding until thematic saturation was reached.
Results: Forty-four posts published between January 2022 and August 2025 were analyzed. Six preliminary themes were identified: disease progression and development, treatment options and outcomes, excessive disease preoccupation, implications on mental health, implications on interpersonal relationships, and implications on self-confidence and vitiligo-positivity. Three emergent concepts were derived: heightened distress associated with lesions in visible areas particularly the face, frustration with suboptimal treatment outcomes, and broad psychosocial impairment coexisting alongside an emerging vitiligo-positive movement within the online community.
Conclusions: Anonymous online forums such as Reddit capture candid patient perspectives that may not surface in clinical encounters, revealing a substantial and under-recognized psychosocial burden in vitiligo. These findings highlight a persistent gap between patient experience and clinical recognition, and underscore the importance of integrating psychosocial assessment into routine vitiligo care.

Keywords: Vitiligo, Reddit, psychosocial, Quality of life, Dermatology, Social media

INTRODUCTION

Vitiligo is a chronic autoimmune disorder affecting approximately 0.5-2% of the global population.[1] It is characterized by melanocyte destruction and depigmented skin patches for which there is currently no known cure. Despite causing no direct physical impairment, vitiligo has been shown to carry a psychosocial burden, with depression and anxiety reported in up to 62% and 68% of patients, respectively.[2] Additionally, while many patients report experiencing stigmatization, diminished self-confidence, and disrupted interpersonal relationships, providers often underestimate the impact that vitiligo has on quality of life.[3,4] Addressing this discrepancy between patient and physician perspectives could facilitate improved communication, patient satisfaction, and overall care.

Qualitative research methods are ideal for capturing the patient-centered perspectives that standardized clinical outcome measures often fail to capture. In addition, previous qualitative studies examining the psychosocial

burden of vitiligo have primarily relied on in-person interviews and face-to-face focus groups – methods that, while informative, are limited by geographic reach, recruitment bias, and the possibility that patients may be less than forthcoming about their stigmatized condition.

Internet forums have emerged as a valid and increasingly utilized source of patient-generated data that address many of these limitations. Studies have shown that not only do a significant proportion of dermatology patients routinely use the internet to seek health-related information, but they are also more willing to share sensitive experiences online than in structured clinical settings.[5,6] Reddit, which currently receives over 2 billion visits per month, is one such platform where users engage anonymously or pseudonymously through posts and comments.[7] This anonymity allows the candid self-disclosure that is often absent in traditional research formats. Prior studies have shown that individuals with chronic conditions actively use Reddit to share personal experiences, seek support, and express emotions related to their illness.[8]

While prior studies have begun to explore patient perspectives through online platforms, existing literature remains limited in scope. Studies utilizing social media to examine the vitiligo patient experience have either focused narrowly on treatment outcomes, such as discourse surrounding topical ruxolitinib on Reddit, or have examined psychosocial themes across multiple dermatoses on non-anonymous platforms where candid self-disclosure may be less likely.[9,10] This study builds on that foundation through a cross-sectional content analysis of the vitiligo subreddit on Reddit, with a focus on characterizing the psychosocial sequelae of vitiligo as expressed organically in patients' own words. By leveraging the anonymity of Reddit to capture unsolicited, real-time patient discourse, this study extends beyond the treatment-focused emphasis of prior literature to offer a more patient-centered perspective that seeks to improve clinical understanding and care.

METHODS

Reddit is an online platform for public discussion organized into distinct forums called Subreddits that are dedicated to a specific topic where users engage through individualized posts. Reddit was selected as a source of public discourse because its widespread popularity and high user engagement renders substantive information across a broad range of topics. As an anonymous and voluntary forum, Reddit does not require users to provide demographic information, which encourages candid sharing of personal experiences and the seeking of tailored advice.

This cross-sectional content analysis was conducted using publicly available posts from the Subreddit "r/Vitiligo," a forum for vitiligo with over 9,900 subscribers and over 7,300 weekly visitors. Posts were manually selected from this Subreddit through an iterative screening process, rather than applying predefined keyword-based search criteria or extracting all available content. Two independent researchers screened the posts for eligibility. Each post was individually assessed for relevance according to predefined inclusion and exclusion criteria, and those meeting criteria were incorporated into the dataset. Posts describing perspectives, concerns and anecdotal experiences with vitiligo were included for analysis, whereas those not primarily focused on vitiligo or limited to informational content such as infographics or general disease facts were excluded. Only original posts were extracted and analyzed while comments and responses were not included in the data set. Some users voluntarily reported demographic information along with their diagnostic age and vitiligo characteristics such as location, appearance and extent. This information, however, was inconsistently provided and only available when self-disclosed.

Data collection was conducted in August 2025, capturing posts published between January 2022 and August 2025, using an inductive, purposive sampling approach. Relevant posts were identified through sequential manual review, with posts included until thematic saturation was achieved, defined as the point at which no new recurring concepts or themes emerged from additional data. This method allowed for the identification of a breadth of relevant patient-reported experiences without restricting the dataset to predefined search terms. Given the nature of manual sampling, the dataset represents a purposive sample rather than a comprehensive capture of all Subreddit content during the study period.

Sampling was continued until thematic saturation was reached. The relevant posts were then read and independently coded by both researchers. The analysis followed a qualitative grounded theory approach, as outlined by Kathy Charmaz, to inductively derive themes directly from the dataset.[11] Rather than testing a predetermined hypothesis, grounded theory situates findings within a research context and informs future investigation.[12]

Original posts were deconstructed into individual excerpts, which were then subjected to initial line-by-line coding using key phrases. Similar excerpts were compared and collated, and recurrent codes were developed into preliminary themes. These themes were further refined and organized to generate unique emergent concepts. The analysis was performed via multiple rounds of discussion on identifying concepts, categories and emergent themes to achieve consensus. Given the qualitative nature of this study, no statistical analysis was performed.

This study utilized only publicly available, anonymized data from the r/Vitiligo subreddit, and no personally identifiable information was collected or analyzed. This study was found to be exempt from Institution Review Board (IRB) approval.

RESULTS

Forty-four unique posts posted on Reddit between January 2022 and August 2025 were analyzed. These posts primarily discussed anecdotal vitiligo experiences, meeting the inclusion criteria for evaluation. The study population consisted of Reddit users experiencing vitiligo and the psychosocial implications of the disease within the Subreddit "r/Vitiligo." 42 (95.45%) of the 44 posts were composed by users discussing their own experience with vitiligo, whereas the remaining 2 posts (4.55%) were users commenting on their child's experience with vitiligo. Given that this was an anonymous and voluntary forum, demographic information was not available. Some users reported demographic information voluntarily, including their current age, age of diagnosis and vitiligo characteristics such as appearance, location, and extent.

Theoretical saturation of ideas, defined as the point at which no new concepts emerged from continued analysis of posts, was reached. Additionally, consensus was achieved on the themes and emergent concepts with minimal inter-observer variation. Qualitative analysis of these posts revealed six preliminary themes: disease progression and development; treatment options and outcomes; excessive disease preoccupation; implications on mental health; implication on interpersonal relationships; and implication on self-confidence and vitiligo-positivity. Table 1 provides illustrative quotes representing each of the themes.

The first topic was related to disease progression and development, which was incorporated in nearly every post. Many users described a rapid progression and spread to visible areas such as the face, which was met with stronger contempt and urged users to pursue treatment. The majority of posts reflected significant worry about further spread of their vitiligo, especially to the face and other visible areas, with many users seeking advice on how to predict or prevent it. Notably, only one user expressed a desire for spread, contrasting with the anxiety prevalent across other posts, stating "I kinda want it to [spread]. I don't like it being exclusive to my groin area. I think its [sic] very pretty but having it only there is embarrassing to me." Several users stated that their vitiligo worsened during the summer. Other aggravating factors mentioned across posts included friction, tattoos, skin injury and scar formation. A few users mentioned associated symptoms other than skin hypopigmentation, with one user detailing heterochromia, conjunctivitis and photosensitivity in the context of ocular manifestations of vitiligo. Several users sought information on the risk of developing additional comorbidities including other autoimmune diseases and additional dermatologic manifestations, and some shared their concomitant diagnoses such as heterochromia and seborrheic dermatitis. A few users mentioned a notable family history for vitiligo and autoimmune disease and compared the onset and progression of their vitiligo to that of their relatives. Two posts were written by parents describing the development of their child's vitiligo and asked individuals who were diagnosed as a child to share how their disease progressed throughout their life.

The second topic was related to treatment options and outcomes. The majority of users took to Reddit to share their personal experiences with various treatments and measures with many reporting failed efforts and seeking alternatives, while several others documented their successful outcomes to instill hope and help their community. The most commonly mentioned prescription topical was Tacrolimus, followed by Ruxolitinib, then Tofacitinib, and Clobetasol, in which most users reported inadequate outcomes. Some posts mentioned using Ayurvedic creams and homeopathic therapies. Phototherapy was among the more favorably received interventions, with one user detailing an extensive multimodal regiment including phototherapy, dietary changes, and vitamin supplementation, reporting: "I have re-pigmented almost 85%." Several users reported holistic approaches, including sun protection, an anti-inflammatory diet, exercise, stress coping strategies, and vitamin supplementation (B12/D3), though with little reported success. A recurring theme was the frustration of maintaining long-term adherence to treatment regimens only to experience continued progression or no meaningful improvement. Many users revealed that they were only motivated to pursue treatment after their vitiligo had spread to the face, suggesting that visibility of their condition served as a catalyst for seeking help. Some users reported no intention to treat their vitiligo due to minimal or stable disease, lack of cosmetic concern, or barriers to dermatologic care.

The third topic was related to excessive disease preoccupation. Many users described a ruminative focus on their vitiligo, detailing constant self-research and over-analyzed self-examinations. Several users detailed a hyperfixation on their condition, with one user capturing this exhaustive pursuit plainly by stating "I spent a lot of time researching and trying out different treatments and practically visited every dermatologist in town." Users attributed these behaviors largely to a persistent fear of spread, which many described as consuming their daily thoughts and leaving them in an excessive state of panic and paranoia. Furthermore, some users have reported experiencing health anxiety regarding the likelihood of developing another autoimmune disease. These users were urged to complete comprehensive blood work, which they said alleviated some of their anxiety.

The fourth topic was related to the implications of vitiligo on mental health. Many users described experiencing anxiety and depression as a result of their vitiligo progressing, and some disclosed instances of substance abuse and suicidal ideations. These users reported anhedonia, feelings of helplessness, and severe emotional distress with several users endorsing a profound loss of sense of self and significant deterioration in overall quality of life. Some users attributed these mental health deficits to the exhaustion and defeat they felt after countless failed

treatment attempts, while others attributed anxiety and depression more directly to personal feelings about their outward appearance. Many users turned to Reddit seeking advice on how to manage their mental health in this context, with one user describing persistent distress despite professional intervention: "I also went to a psychologist but no help." Several posts highlighted the importance of prioritizing mental health as a central component of vitiligo care, underscoring that the psychological burden of the disease warranted the same attention as its dermatologic management.

The fifth topic was related to the implications of vitiligo on interpersonal relationships. Many users described feelings of shame and embarrassment associated with their vitiligo that prompted them to self-isolate and avoid public interactions. Several users expressed paranoia of public perception, recounting stares and unsolicited remarks from strangers, thereby motivating social withdrawal and avoidant behaviors with many seeking advices on how to overcome the perception of others. The effect vitiligo had on personal relationships was also prevalent. Several users reported a lack of friends or romantic partners, which they credited to their vitiligo. A few users revealed hesitancy to pursue sexual relations because their vitiligo affected their genitals, with one user describing this vulnerability candidly saying "my vitiligo has really affected my private parts. I have always been incredibly distraught by this and thus, am scared of ever getting into a relationship." These users sought guidance on how to broach the subject with a partner.

The sixth topic was related to the implications of vitiligo on self-confidence and vitiligo-positivity. Many users revealed that their vitiligo made them feel insecure and self-conscious, especially after remarks by the general public, and they sought guidance on coping with this judgement. Some users reported a notable decline in self-image upon onset or progression of their vitiligo, especially when spread to more visible areas such as the face and genitals. Some users went as far as to share an utter lack of self-love, elaborating on self-deprecating behaviors and avoidance of mirrors or photographs, with one user writing: "not a day goes by where I don't wake up and look in the mirror wishing I looked how I used to." Several users expressed a strong contempt for their outward appearance, describing their vitiligo as "ugly," "awful" and "horrible," thereby motivating them to seek advice on concealment strategies. Many reported using cosmetics, hair dye and other cover-up techniques to conceal vitiligo for social outings, noting that doing so improved their confidence. Others expressed frustration with the limitations these strategies imposed, including the burden of frequent hair dyeing and restricted options for permanent cosmetic procedures such as microblading. A few users expressed no perceived flaw and therefore had no desire to conceal or treat their vitiligo. Many users shared an evolving relationship with their condition, describing an ongoing journey of self-acceptance. Several posts actively promoted self-love and vitiligo-positivity, framing the condition as a source of uniqueness and beauty, and encouraged others on the forum to embrace rather than conceal their vitiligo. A few users reported pursuing careers in modeling and social media, crediting the opportunity to their vitiligo. Two posts were parents sharing their child's experience with vitiligo and seeking guidance on fostering self-confidence in their child.

From these six preliminary themes, three emergent concepts were derived (Table 1). First, individuals with vitiligo expressed considerably greater concern when lesions extended to highly visible areas, particularly the face, with this often serving as the primary motivator for both seeking treatment and emotional distress. Second, those who pursued treatment frequently reported frustration with suboptimal results and a persistent desire for more effective therapeutic options. Third, vitiligo carried broad implications for mental health, self-confidence and interpersonal relationships. This was juxtaposed with the simultaneous emergence of a vitiligo-positive movement within the same community.

Table 1: Preliminary themes found in Reddit forum "r/Vitiligo".

Preliminary theme	Illustrative quotations
Disease progression/development	"I'm 26 and got my first spot about 2 years ago…I honestly worry if any will appear on my face as I have none…Is there any way to know and if they appear could I stop them/manage them from spreading?...I really want to prevent them from getting on my face."
	"Discovered vitiligo 2 years ago, it started as a small patch on my right hand…This summer it has spread all over, and also on my face. I don't mind having vitiligo all over my body, it's just the face that sucks. I hate it."
Treatment options and outcomes	"I have been treating it with opzelura and got about 50% to fill in but it's more noticeable now as the pigmented skin came back darker than my natural skin color. Does it even out with time? Are there ways to speed up repigmentation process so that the whole area gets its color back?"
	"Phototherapy, the only thing that actually worked for me in 7 years to get my skin color back and cover the vitiligo spots…It's been a year of phototherapy for me, and my spots are 80% smaller, some have completely covered up with my skin pigment. Even the white hair is starting to become black."

Continued.

Preliminary theme	Illustrative quotations
Excessive disease preoccupation	"What frustrates me the most is not knowing what's causing this. I've seen 3 dermatologists…this is too overwhelming. I've read enough research papers and reviews, but I'm struggling to make sense of it all."
	"...my vitiligo had become more prominent and seriously bothered me…So I spent a lot of time researching and trying out different treatments and practically visited every dermatologist in town."
Implications on mental health	"I'm feeling like I'm losing myself and my depression has gotten worse to the point I'm feeling so paranoid in public and feeling like people stare of me because of it…I [sic] feeling so helpless like this has destroyed my life."
	"It hurts me so bad. I know it's harmless but it fills me with so much anxiety and depression… I don't even want to do the things I love… Please give me tips on how to deal with this mentally."
Implications on interpersonal relationships	"My vitiligo has affected my private parts…I have always been incredibly distraught by this and thus, am scared of ever getting into a relationship… if any of you, women (or even men) have experienced this, how did you tell your partner and how did they react?"
	"I work in retail and deal with a lot of people every day… It hurts having people I have known for years ask if I missed a spot of self-tanner on my face… When my family says things… then feel bad when I burst into tears… How do you guys deal with people commenting on your vitiligo? It hurts me so bad… I even struggle with eye contact now because all that is racing through my mind is 'they are looking at my skin."
Implications on self-confidence and vitiligo-positivity	"I hate it. I cannot take pictures or look at myself in the mirror…I tried to hide it by putting on different makeups…I hate myself for a while…I don't go out as much trying to hide it…I wasn't like this, I used to be confident and outgoing."
	"Have had vitiligo for quite a while since I was 12 or 13… still very self-conscious about it but I'm trying my best to make the best of it, it feels like a love hate relationship at times but I'm learning to embrace it the best I can!"

DISCUSSION

This study offers a unique perspective on the lived experiences of individuals with vitiligo that moves beyond the focus of clinical and treatment-centered approaches. Reddit, an anonymous and voluntary platform, proved to be a rich source of data that is centered around the patient's experiences rather than focusing on clinical metrics. This was apparent in the depth of the experiences shared by users who openly described suicidal ideation, sexual insecurity, and a profound loss and deterioration of self-worth. Without the pressures of a clinical setting, users were more candid in ways that are uncommon in structured clinical settings.

Consistent with existing literature, the psychological impact of vitiligo was far from uniform. In fact, location played a large role. Users who had stable and less visible disease often described a very different emotional experience than those whose vitiligo had spread to their face or genitals. When lesions reached these areas, the response was frequently of urgency where suddenly, treatment became a priority and mental health notably suffered. This is consistent with prior studies that demonstrated how facial involvement is independently associated with a poorer quality of life and a higher rate of anxiety and depression in vitiligo patients. Similarly, the theme of treatment frustration was prominent throughout the data. Many users had tried everything available to them, from topical agents and phototherapy to holistic regimens and combination approaches. It was evident that patients were not merely looking for efficacious solutions, but also desired normalization of their lived experience by their providers. This insufficient validation in clinical care prompts many users to turn to Reddit to fill this gap.

One notable finding of this study was the coexisting reports of psychological distress and an emerging vitiligo-positive movement within the same online community. While many users described anhedonia, self-isolation, avoidance of mirrors and photographs, and the abandonment of dating and family planning, others actively reframed their vitiligo as a source of identity and even opportunity. For example, some users leveraged their vitiligo into modeling careers and a presence on social media platforms. This duality reflects the deeply personal and variable nature of adjustment to chronic visible illness, and it suggests that a vitiligo-positive cultural shift is beginning to occur, at least within certain online spaces such as Reddit. Healthcare providers would benefit from awareness of the evolving narrative, as it could offer a meaningful avenue for supporting patient resilience and self-acceptance alongside medical management.

Preexisting research detailing patients' experiences synthesizes data from interviews and focus groups of individuals with an established vitiligo diagnosis, with similar themes and revelations reported across these studies. Teasdale et al. evaluated survey responses to reveal the frustration and dissatisfaction vitiligo patients had with help-seeking for their condition. Many believed that general practitioners (GPs) had inadequate awareness of available treatments and expressed a need for reliable, detailed information.[12] Furthermore, many participants felt

that GPs and dermatologists often dismissed their vitiligo as solely cosmetic.[12] This emphasizes the persistent discrepancy between patients' experiences and providers' impressions of those experiences. Pandya et al further explored this psychosocial burden of vitiligo through qualitative interviews, with participants reporting reduced self-esteem and social inhibition, especially with facial involvement.[13] Most respondents expressed that the noticeability of their vitiligo affected their behavior as well as a greater desire for facial repigmentation.[13] This is corroborated by the work of Ahmed et al., who utilized questionnaires to uncover the impact of vitiligo on body image dissatisfaction, self-esteem and confidence, determining that vitiligo on sensitive sites was associated with a greater psychological impact.[14] Prior online studies have examined related topics, including patient discourse surrounding topical ruxolitinib on Reddit, psychosocial themes across multiple dermatoses on broader social media platforms, and treatment resources and stigma management within a Facebook vitiligo community.[9,10,15] However, these studies were either narrowly focused on treatment outcomes or conducted on platforms where full anonymity is not guaranteed. The present study addresses this gap by capturing unsolicited, anonymous patient discourse on Reddit focused specifically on the psychosocial sequelae of vitiligo, rather than through structured interview formats or treatment-centered discussion.

One of the strengths of this study is the utilization of anonymous online forums as a data source. This differs from previous studies, which primarily incorporated focus groups and face-to-face interviews. While these interactions provide valid and nuanced information, the use of anonymous web discussions allow for open and honest discourse that may be difficult to emulate in face-to-face discussions.[16,17] Compared to focus groups and in-person interviews, online discussions have been shown to foster greater emotional support and increased self-disclosure among participants.[18] This was evident in the work of Kuhlman et al, who compared the themes that emerged from a focus group discussion with those identified in a social media group. The focus group themes were primarily focused on symptoms and management, whereas the social media group themes were more personal and vulnerable.[19] This reflects the comfort that anonymity provides when sharing private insights and experiences. Additionally, online discussions provide easy accessibility at all times.[17]

By capturing authentic emotional expressions through anonymous patient discourse, this study was able to reveal candid perspectives and effectively illustrate the decrease in quality of life experienced by those living with vitiligo. These insights can help providers develop a deeper understanding of the array of patient experiences, frustrations, and needs, ultimately informing patient-centered care.

The limitations of this research include self-selection of the participants into the forum from which the data was extracted. Due to the absence of systematic keyword-based retrieval or full dataset extraction, relevant posts may have been inadvertently omitted, and the findings may not be fully representative of all discussions within the Subreddit. Additionally, the majority of Reddit users (93%) are generally under the age of 50.[20] Although the age range of the participants of this specific forum is not entirely known, it is possible that the viewpoints and experiences of older individuals are underrepresented. Qualitative methods are subject to concerns of reliability and objectivity, and the subjective nature of these processes underscores the potential for investigator bias. To minimize this, two independent researchers analyzed the data and worked toward saturation of ideas. Consensus was reached when establishing preliminary themes and emergent concepts, yielding high inter-observer reliability. Despite the value of the anonymous format, there are some concerns regarding its effect on accuracy and validity. The anonymity prevents confirmation of each participant's clinical history and vitiligo diagnosis, as well as demographic information and relevant clinical data. Several posts included some of this information, but this was inconsistently reported across each post. The analysis was also limited to the information presented within each post, and clarification through follow-up questions was not possible. Additionally, anonymity raises questions regarding reporting bias and possible sampling error. While an anonymous online forum invites open and honest discourse, some argue that this enables users to post extreme emotions or reviews.[21] These concerns are known risks; however, they likely had a minimal impact on the overall findings given the volume of posts that were evaluated in this study.

CONCLUSION

This study leveraged patient-reported experiences from an anonymous online forum to provide a contemporary qualitative analysis of the psychosocial implications of vitiligo, offering unique insight into a widely used platform for candid public discourse. The anonymity of these discussions allowed for an unfiltered perspective, capturing patients' intimate symptoms, concerns, motivations, and perceptions of how vitiligo impacts their quality of life. Through this approach, preliminary themes and emergent concepts were identified that deepen the understanding of the patient experience as well as their needs. These findings highlight a persistent tendency to minimize or dismiss vitiligo as merely cosmetic, underscoring a fundamental gap between patient needs and the care they receive. By amplifying patient voices, this study provides clinicians with a broader and more nuanced perspective, emphasizing the importance of actively listening to patient concerns to optimize care. Future research should continue to explore patient perspectives, particularly focusing on patient-driven recommendations to further improve and personalize vitiligo management.

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