

Vitiligo is Not an Orphan Disease: Current Insurance Coverage Landscape and the Ethical Case for Coverage of Treatment



Moniyka Sachar BA¹, Vivian Wong MD,PhD², Lionel Bercovitch MD²
Warren Alpert Medical School¹, Brown University Department of Dermatology²

Abstract

Vitiligo is a chronic autoimmune disease characterized by the progressive development of white-colored macules and patches on the skin, and its progression commonly impacts the mental health and quality of life of patients. Over 50% of vitiligo patients suffer from depression and social anxiety due to progression of the disease, and 20% of patients have other autoimmune comorbidities. Despite this, many health insurance plans do not cover the treatment of vitiligo. In this study, we assessed current vitiligo coverage policies across major health insurance companies in the U.S to determine current patterns of coverage and gaps in coverage to evaluate the financial impact on vitiligo patients. In our study sample of 20 major health insurance companies in the United States, 55% do not cover laser therapy, 55% do not cover PUVA phototherapy, and 50% do not cover nbUVB phototherapy. The two most common reasons for denial of coverage was 1) vitiligo is considered a cosmetic condition and 2) certain therapies are not FDA-approved for vitiligo, though they may be approved for other skin conditions. In conclusion, 12/18 major insurance companies do not cover at least one major first-line therapy for widespread vitiligo. This lack of coverage not only worsens the financial impact and burden of vitiligo, but also further marginalizes patients with vitiligo, many of whom are patients of color.

Introduction

Vitiligo is a chronic autoimmune disease involving the gradual loss of melanocytes in the skin and associated with frequent comorbidities. Vitiligo affects over 5 million patients in the U.S.², but many insurance companies still do not cover treatments and consider it an orphan disease. Though men and women of all races are equally affected by vitiligo, depigmentation is more prominent in those with skin of color, and thus patients of color are more likely to seek insurance coverage for vitiligo treatments. There are topical steroid ointments, excimer laser therapy, phototherapy (psoralen with UVA light, i.e. PUVA), and narrow-band UVB (nbUVB) therapy available to treat this condition.

Vitiligo has psychiatric comorbidities:

- 50% of vitiligo patients report depression¹, 67% have social anxiety² and 90% report stigmatization³ due to progression of their vitiligo. There may also be a feedback loop, as 63% of patients indicate psychological stress as influential on the disease course⁴.
- Over 55% of patients report that vitiligo moderately to severely impacts their quality of life, specifically associated with self-consciousness, shame, decreased self-confidence, professional endeavors, fear of disease progression⁵.
- Vitiligo treatments can help alleviate psychiatric comorbidities by reducing the physical impact of the disease and the associated stigmatization, shame, and social anxiety reported by patients.

Vitiligo has medical comorbidities:

- 20% of vitiligo patients have another autoimmune condition, most commonly thyroid disease followed by alopecia areata and inflammatory bowel disease^{6,7}, 60% of vitiligo patients have cochlear dysfunction^{8,9}, 20-35% have pruritis and increased sunburn risk in affected^{10,11}.
- Vitiligo treatments cannot cure these medical comorbidities, but reducing the overall burden of disease increases the quality of life for patients.

Methods

- Inclusion criteria for health insurance companies in this study were significant regional or national market share as determined by publicly available data.**
- Coverage information was collected via both online database search for relevant medical policies and phone calls to customer service representatives to ensure accuracy of information.**
- State Medicaid policy information was collected by emailing providers in each state and inquiring about coverage policy, as this information is not publicly available.**

State Medicaid Policy on Vitiligo Coverage

State	Office Visits	Topicals	nbUVB	PUVA	Laser
AZ	1	3	3	3	3
CT	1	1	1	3	3
FL	1	1	2	3	1
GA	3	3	1c	1c	3
NH	1	3	3	3	3
NY	1	3	1	1	3
PA	1	1	1	3	1
RI	0	0	0	0	0
VT	1	0	0	3	3
VA	0	1	0	0	0
WI	1	1	2	3	0

KEY	
0	Not covered
1	Covered
1c	Covered after step therapy
3	Provider not sure
	Partial or no coverage

Results

- 55% of major insurance companies do not cover excimer laser therapy
- 55% do not cover PUVA phototherapy, 50% do not cover nbUVB phototherapy
- Of companies that cover therapies, up to 50% have stipulations on the provision of individual therapies, including anatomy specific coverage, step therapy, quantity limits.
- Most common reasons for denial of coverage: 1) vitiligo is considered a cosmetic condition 2) certain therapies are not FDA-approved for vitiligo, though they may be approved for other skin conditions.
- Preliminary data shows VT, VA, WI do not cover at least one major vitiligo therapy. In RI, no vitiligo treatments are covered.

Insurance Policy Details on Vitiligo and Coverage Area

Health Insurance Company	Geographic Coverage Area	Coverage of Vitiligo Treatments
Medicare	All states	Does not cover laser therapy, covers other therapies
United	31 states	Does not cover laser or phototherapy, covers topicals only
Tufts	2 states	Does not cover laser or phototherapy, covers topicals only
Humana	15 states	Does not cover laser or light therapy, covers topicals only
Cigna	14 states	Does not cover laser or light therapy, covers topicals only
Aetna	15 states	Covers everything, with limitations on light therapy
BCBS	48 states	17% cover laser therapy and 35% of states do not cover phototherapy and topicals
HealthNet	4 states	Covers everything
Capital Blue	1 state	Does not cover topicals, covers light therapy with limitations
Centene	13 states	Covers everything
Wellcare	All states	Covers everything, with limitations on laser therapy
Molina	16 states	Does not cover laser or phototherapy, covers topicals
Kaiser	9 states	Covers topicals, covers laser and phototherapy with limitations
Harvard Pilgrim	1 state	Does not cover topicals or phototherapy, covers laser therapy with limitations
VA	All states	Covers everything, covers phototherapy with limitations
Neighborhood	2 states	Does not cover pimecrolimus, nbUVB or laser. Cover tacrolimus and PUVA
Emblem	1 state	Does not cover phototherapy, covers topicals and laser therapy
Sentara	2 states	Does not cover any treatment

Conclusions

- Vitiligo is not an orphan disease and affects over 5 million in the U.S. and ~2% worldwide. Vitiligo has no cure and patients rely on a combination of treatments to manage their disease.**
- In the U.S, 12 out of the 18 largest health insurance companies by market share do not cover at least 1 of the major vitiligo treatments, and of the remaining 6 companies that cover all treatments, 4 have limitations on the coverage they offer.**
- This lack of coverage worsens the financial impact, associated psychosocial stress, and burden of disease, not to mention further marginalizes patients with vitiligo, especially for patients of color, who are more likely to seek treatment.**
- Important ethical arguments supporting vitiligo treatment include:**
- Beneficence: 1) Treatments have been shown to directly alleviate psychosocial comorbidities and improve the quality of life of vitiligo patients. 2) Insurance coverage of treatments results in easier access, affordability, and timely administration of treatments, resulting in better disease outcomes.**
- Justice: 3) Other skin diseases with a similar psychosocial impact on patients, like alopecia areata and acne vulgaris, are covered by insurance.**

Future Directions

- Future administrative efforts should be focused on legislation mandating health insurance companies to cover vitiligo treatments, as well as seeking FDA approval for certain vitiligo treatments.**
- Future research should be pursued into mechanisms by which targeted vitiligo treatments may also prevent or treat auto-immune comorbidities due to targeted action on inflammatory pathways.**
- There are many new biologics emerging as powerful, near “cures” for vitiligo, and thus coverage of current therapies is an important precedent and first step to guarantee equitable access of these therapies to patient populations of socioeconomic classes.**

Acknowledgments

Brown University Alpert Medical School for summer research funding.

References

- Al-Harbi M. Prevalence of depression in vitiligo patients. *Skinmed*. 2013;11(6):327-330.
- Kruger C, Schallreuter KU. (2012). A review of the worldwide prevalence of vitiligo in children/adolescents and adults. *Int J Dermatol*. 51, 1206-12.
- Stangier U., Ehlers A., and Giler U.: Measuring adjustment to chronic skin disorders. Validation of a self-report measure. *Psycho Assess* 2003; 15; pp. 532-549.
- Felipe Cupertino, João Paulo Niemeyer-Corbellini and Marcia Ramos-e-Silva, Psychosomatic aspects of vitiligo, *Clinics in Dermatology*, 35, 3, (292), (2017).
- N. Talsania, B. Lamb, A. Bewley. Vitiligo is more than skin deep: a survey of members of the Vitiligo Society. *Clin Exp Dermatol*, 35 (7) (2010), pp. 736-739.
- Sheth VM, Guo Y, Qureshi AA. Comorbidities associated with vitiligo: a ten-year retrospective study. *Dermatology (Basel, Switzerland)*. 2013;227(4):311-315.
- Gill L, Zarbo A, Isedeh P, et Al. Comorbid autoimmune disease in patients with vitiligo: A cross-sectional study. *J Am Acad Dermatol*. 2016 Feb;74(2):295-302.
- Anbar TS, El-Badry MM, McGrath JA, Abdel-Azim ES. Most individuals with either segmental or non-segmental vitiligo display evidence of bilateral cochlear dysfunction. *The British journal of dermatology*. 2015;172(2):406-411.
- B.N. Akay, M. Bozkir, Y. Anadol, S. Gullu. Epidemiology of vitiligo, associated autoimmune diseases and audiological abnormalities: Ankara study of 80 patients in Turkey.
- Silverberg JI, Silverberg NB. Association Between Vitiligo Extent and Distribution and Quality-of-Life Impairment. *JAMA Dermatol*. 2013;149(2):159–164. doi:10.1001/jamadermatol.2013.927.
- May W, Linthorst Homan, Phyllis I. Spuls, John de Korte, Jan D. Bos, Mirjam A. Sprangers, J.P. Wietze van der Veen. The burden of vitiligo: Patient characteristics associated with quality of life. *Journal of the American Academy of Dermatology*. Volume 61, Issue 3, 2009, Pages 411-420.
- Alkhateeb A, Fain PR, Thody A, Bennett D, Spritz R. Epidemiology of Vitiligo and Associated Autoimmune Diseases in Caucasian Proband and Their Families. *Pigment cell and melanoma research* 2003; 208-214.