

Vitiligo Patients Experience Barriers in Accessing Care

Teresa Chen; Carmen Grau, PhD; Maria Suprun, MPH; Nanette B. Silverberg, MD

PRACTICE POINTS

- Patients with vitiligo may experience difficulty receiving the care prescribed to them.
- It is best to identify barriers such as work schedule or distance before recommending a treatment plan.

Vitiligo is a loss of pigment occurring in approximately 0.4% to 2% of the worldwide population. The aim of this study was to determine and characterize barriers to access of care in US patients with vitiligo. An Internet-based, deidentified survey consisting of 82 questions about topics including demographics, recommendations for care, and/or barriers to receiving recommended care was designed and distributed to member participants in an online vitiligo support community consisting of patients (and parents/guardians of adolescents). Results indicated that treatment cost, relationships, work schedule, school schedule, number of sites affected, and female sex may be barriers to receiving prescribed care in some patients with vitiligo. Exploration of mechanisms by which these barriers can be reduced in the medical care

of vitiligo may allow more patients to successfully receive treatment.

Cutis. 2016;98:385-388.

Vitiligo is a disorder typified by loss of pigmentation. Worldwide estimates of disease demonstrate 0.4% to 2% prevalence.¹ Vitiligo generally is felt to be an autoimmune disorder with a complex multifactorial inheritance.² Therapeutic options for vitiligo are largely off label and include topical corticosteroids, topical calcineurin inhibitors, narrowband UVB (NB-UVB) light phototherapy, and excimer (308 nm) laser therapy.^{3,4} Therapies for vitiligo are time consuming, as most topical therapies require twice-daily application. Additionally, many patients require 2 or more topical therapies due to involvement of both the head and neck as well as other body sites.^{3,4} Generalized disease often is treated with NB-UVB therapy 3 times weekly in-office visits, while excimer laser therapy is used for limited disease resistant to topical agents.^{3,4}

Many barriers to good outcomes and care exist for patients with vitiligo.⁵ Patients may experience reduced quality of life and/or sexual dysfunction because of vitiligo lesions. The purpose of this pilot study was to identify barriers to access of care in vitiligo patients.

Methods

A survey was designed and then reviewed for unclear wording by members of the local vitiligo support

Ms. Chen and Drs. Grau and Silverberg are from Mount Sinai St. Luke's-Roosevelt Hospital and Beth Israel Medical Centers of the Icahn School of Medicine at Mount Sinai, New York, New York. Ms. Suprun is from the Icahn School of Medicine at Mount Sinai, New York.

The authors report no conflict of interest.

Correspondence: Nanette B. Silverberg, MD, 1090 Amsterdam Ave, Ste 11D, New York, NY 10025 (nsilverb@chpnet.org).

group at Mount Sinai St. Luke's-Roosevelt Hospital and Beth Israel Medical Centers (New York, New York). Linguistic revision and clarifications were added to the survey to correct identified communication problems. The survey was then posted using an Internet-based survey software. Links to the survey were sent via email to 107 individuals in a LISTSERV comprising Vitiligo Support International members who participated in a New York City support group (led by C.G. and N.B.S.). Only 1 email was used per household and only individuals 18 years or older could participate. These individuals were asked to complete a deidentified, 82-question, institutional review board-reviewed and exempted survey addressing issues affecting delivery and receipt of medical care for vitiligo.

Data were analyzed using the χ^2 test, analysis of variance, or Student *t* test depending on the type of variable (categorical vs continuous). Fisher exact or Wilcoxon-Mann-Whitney tests were used when distributional assumptions were not met. A type I error rate ($\alpha=.05$) was used to determine statistical significance. All analyses were performed using SAS 9.3 software.

Results

Respondents—The survey was completed by 81% (n=87) of individuals. The mean (SD) age of the treated patients about whom the respondents communicated was 33 (16) years and 71% (n=62) were women. The majority of respondents (64 [74%]) reported their race as white, followed by African American/black (12 [14%]), Hispanic (7 [8%]), and Asian (4 [5%]). Twenty-nine percent (22/76) of respondents reported a family income of less than \$50,000 per year, 34% (26/76) reported an income of \$50,000 to \$100,000, and 37% (28/76) reported an income greater than \$100,000, while 11 respondents did not report income.

Number of Physicians Seen—Respondents had reportedly seen an average (SD) number of 2 (1) physicians in the past/present before being offered any therapy for vitiligo and only 37% (32/87) of respondents reported being offered therapy by the first physician they saw. The number of physicians seen did not have a statistical relationship with years with vitiligo (ie, disease duration), sex, race, age of onset, income level, or number of sites affected.

Number of Sites Affected—The survey identified the following 23 sites affected by vitiligo: scalp, forehead, eyelids, lips, nose, cheeks, chin, neck, chest, stomach, back, upper arms, forearms, hands, wrists, fingers, genitalia, buttocks, thighs, calves/shins, ankles, feet, and toes. The average (SD) number

of sites affected was 12 (6). The number of sites affected was correlated to the recommendation for phototherapy, while the recommendation for excimer laser therapy was inversely associated with the number of sites affected. The median number of sites affected for those who were not prescribed phototherapy was 10 (interquartile range [IQR]=9; $P=.05$); the median number of sites affected for those who were prescribed phototherapy was 15 (IQR=11). The association between the number of sites affected and whether the patient proceeded with phototherapy was not statistically significant. The need for phototherapy was not related to years with vitiligo (ie, disease duration), sex, or race.

Excimer laser therapy was prescribed more often to patients with fewer sites affected (median of 9 [IQR=3] vs median of 15 [IQR=9]; $P=.04$). Respondents who had fewer sites affected were on average more likely to proceed with excimer laser therapy (median of 8 [IQR=4] vs median of 11 [IQR=5]). The association between the number of sites affected and whether the patient proceeded with excimer laser therapy was not statistically significant.

Access to Topical Medications—Forty-one percent (36/87) of respondents reported difficulty accessing 1 or more topical therapies. Of 52 respondents who were prescribed a topical corticosteroid, 12 (23%) reported difficulty accessing therapy. Of 67 respondents who were prescribed a topical calcineurin inhibitor, 27 (40%) reported difficulty accessing medication (tacrolimus, n=17; pimecrolimus, n=10). Calcipotriene prescription coverage was not specifically addressed in this survey, as it usually is a second-line or adjunctive medication. Difficulty getting topical tacrolimus but not topical corticosteroids was associated with female sex ($P=.03$) but was not associated with race, income level, or level of education. Difficulty obtaining medication was not related to race, sex, level of education, or income level.

Consequences of Phototherapy—Twenty-three of 34 respondents (68%) who were told they required phototherapy actually received phototherapy and reported paying \$38 weekly (IQR=\$75). The majority of patients who proceeded with phototherapy lived (17/23 [74%]) or worked (16/23 [70%]) within 20 minutes of the therapy center. Self-reported response to phototherapy was good to very good in 65% (15/23) of respondents and no response in 30% (7/23); only 1 respondent reported worsening vitiligo. Sixty percent (15/25) of respondents said they were not satisfied with phototherapy. Respondents who were satisfied with the outcome of phototherapy had on average fewer sites affected by vitiligo (mean [SD], 10 [8]; $P=.05$). The

association with other demographic and economic parameters (eg, sex, race, level of education, income level) was not statistically significant. Proceeding with phototherapy was not related to race, sex, level of education, or income level.

When questioned how many aspects of daily life (eg, work, home, school) were affected by phototherapy, 40% (35/87) of respondents reported that more than one life parameter was disturbed. Thirty-five percent (8/23) of respondents who received phototherapy reported that it affected their daily life “quite a bit” or “severely.” More respondents were likely to report that the therapy interfered with their life “somewhat,” “quite a bit,” or “severely” (76% [19/25]; 95% confidence interval, 55%-92%; $P=.01$) rather than “not at all” or “a little.”

Excimer Laser—Nine of 17 respondents (53%) who were recommended to undergo excimer laser therapy actually received therapy and reported paying \$100 weekly (IQR=\$60).

There was a trend toward significance of excimer usage being associated with lower age quartile (0–20 years) ($P=.0553$) and income more than \$100,000 ($P=.0788$), neither of which reached statistical significance.

Insurance Coverage—Respondents were offered 7 answer options regarding the reason for noncoverage of topical calcineurin inhibitors. They were allowed to pick more than one reason where appropriate. For individuals who were prescribed topical tacrolimus but did not receive drug ($n=17$), the following reasons were cited: “no insurance coverage for the medication” (59% [10/17]), “your deductible was too high” (24% [4/17]), “prior authorization failed to produce coverage of the medication” (24% [4/17]), “your copay was prohibitively expensive” (24% [4/17]), “you were uncomfortable with the medication’s side effects” (18% [3/17]), “the tube was too small to cover your skin affected areas” (12% [2/17]), and “other” (29% [5/17]). Three patients selected 3 or more reasons, 8 patients selected 2 reasons, and 5 patients selected one reason.

Comment

It has been reported that patients with vitiligo may have difficulty related to treatment compliance for a variety of reasons.⁵ We identified notable barriers that arise for some, if not all, patients with vitiligo in the United States at some point in their care, including interference with other aspects of daily life, lack of coverage by current health insurance provider, and high out-of-pocket expenses, in addition to the negative effects of vitiligo on

quality of life that have already been reported.^{6,7} These barriers are not a function of race/ethnicity, income level, or age of onset, but they may be impacted, as in the case of tacrolimus, by female sex. It is clear that, based on this study’s numbers, many patients will be unable to receive and/or comply with recommended treatment plans.

A limitation of this analysis is the study population, a select group of patients who had not been prescribed all the therapies in question. The sample size may not be large enough to demonstrate differences between level of education, race, or income level; however, even with a sample size of 87 respondents, the barriers to access of care are prominent. Larger population-based surveys would potentially tease out patterns of barriers not apparent with a smaller sample. No data were generated specific to calcipotriene, and this medication was not specified as a write-in agent on open question by any respondents; therefore, access to topical calcipotriene cannot be projected from this study. Phototherapy was queried as a nonspecific term and the breakdown of NB-UVB versus psoralen plus UVA was not available for this survey. Data suggesting a burden of socioeconomic barriers have been reported for atopic dermatitis⁸ and psoriasis,⁹ which corroborate the need for greater research in the field of access to care in dermatology.

Despite some advancement in the care of vitiligo, patients often are unable to access preferred or recommended treatment modalities. Standard recommendations for care are initial usage of calcineurin inhibitors for facial involvement and topical high-potency corticosteroids for involvement of the body.^{3,4} Based on this survey, it would seem that many patients are not able to receive the standard of care. Similarly, NB-UVB phototherapy and excimer laser therapy are recommended for widespread vitiligo and lesions unresponsive to topical care. It would seem that almost half of our respondents did not have access to one or more of the recommended therapies. Barriers to care may have substantial clinical and psychological outcomes, which were not evaluated in this study but merit future research.

REFERENCES

1. Krüger C, Schallreuter KU. A review of the worldwide prevalence of vitiligo in children/adolescents and adults. *Int J Dermatol*. 2012;51:1206-1212.
2. Jin Y, Birlea SA, Fain PR, et al. Genome-wide association analyses identify 13 new susceptibility loci for generalized vitiligo. *Nat Genet*. 2012;44:676-680.
3. Silverberg NB. Pediatric vitiligo. *Pediatr Clin North Am*. 2014;61:347-366.

4. Taieb A, Alomar A, Böhm M, et al. Vitiligo European Task Force (VETF); European Academy of Dermatology and Venereology (EADV); Union Européenne des Médecins Spécialistes (UEMS). Guidelines for the management of vitiligo: the European Dermatology Forum consensus. *Br J Dermatol*. 2013;168:5-19.
5. Abraham S, Raghavan P. Myths and facts about vitiligo: an epidemiological study. *Indian J Pharm Sci*. 2015;77:8-13.
6. Silverberg JI, Silverberg NB. Quality of life impairment in children and adolescents with vitiligo. *Pediatr Dermatol*. 2014;31:309-318.
7. Silverberg JI, Silverberg NB. Association between vitiligo extent and distribution and quality-of-life impairment. *JAMA Dermatol*. 2013;149:159-164.
8. Silverberg JI, Hanifin JM. Adult eczema prevalence and associations with asthma and other health and demographic factors: a US population-based study. *J Allergy Clin Immunol*. 2013;132:1132-1138.
9. Hamilton MP, Ntais D, Griffiths CE, et al. Psoriasis treatment and management—a systematic review of full economic evaluations. *Br J Dermatol*. 2015; 172:574-583.