



Psychosocial and quality-of-life factors associated with depigmentation therapy for vitiligo

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Abstract

Background There is a paucity of data examining the psychosocial factors relevant to depigmentation therapy, an irreversible treatment for vitiligo. This study explores patients' perspective and experience while undergoing depigmentation therapy and quality-of-life effects of such therapy.

Methods An online instrument assessing the impact of depigmentation therapy on various psychosocial variables and including the validated Dermatology Life Quality Index (DLQI) were administered to two groups of participants with vitiligo: (1) those who are currently undergoing or have completed depigmentation therapy and (2) those with vitiligo who have not undergone depigmentation therapy but had considered it. Data were collected on psychosocial factors such as length of time until depigmentation therapy was offered, duration, financial burden, level of satisfaction, impact on life activities, and challenges faced during and after depigmentation therapy. DLQI scores were also measured.

Results Thirty-five vitiligo patients who did not undergo depigmentation and 42 patients who did undergo depigmentation therapy were included in the study. Baseline characteristics were comparable between groups. Mean DLQI was higher for patients who did not undergo depigmentation than for those who underwent depigmentation (10.2 versus 5.3, $p=0.002$), indicating worse quality-of-life in those not depigmenting. Patients who underwent depigmentation reported significantly less discomfort in various social situations after undergoing depigmentation therapy compared to how they felt before undergoing therapy and reported significantly less discomfort in these situations than patients who did not undergo depigmentation therapy.

Conclusions Despite potential challenges, depigmentation therapy appears to augment quality-of-life across various domains in individuals with vitiligo.

Keywords Quality of life · Vitiligo · Medical dermatology

Introduction

Vitiligo is an acquired pigmentary disorder that affects about 1% of the world's population [1, 2]. While there may be minimal physical consequences of vitiligo, many studies have shown that vitiligo can have a negative impact on mental health including correlations with anxiety, depression, and low self-esteem [2, 3]. Depigmentation therapy can be an

option for patients with treatment-resistant vitiligo [2] and may be indicated in the appropriately selected patient population. While few studies have explored the clinical aspects of depigmentation therapy [2, 4], none to our knowledge have examined the psychosocial factors relevant to this specific subset of vitiligo patients. Our study explores patients' perspective and experience while undergoing depigmentation therapy and quality-of-life effects of such therapy.

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Methods

Study design

This study was approved by the institutional review board (IRB) through the University of Texas-Austin. Online

questionnaires assessing the impact of vitiligo and depigmentation therapy on various psychosocial variables and the validated Dermatology Life Quality Index (DLQI) [5] were distributed to participants by the Vitiligo Support International (VSI) [6] organization. Study data were collected and managed using REDCap electronic data capture tools hosted at the University of Texas-Austin/Dell Medical School [7, 8]. Questionnaires were distributed to patients with any type of vitiligo for any length of time who (1) are currently undergoing depigmentation therapy or have completed depigmentation therapy or (2) have *not* undergone depigmentation therapy but have considered it. While both questionnaires were similar in many aspects, the questionnaire distributed to group one focused on questions specific to undergoing depigmentation therapy while the questionnaire distributed to group two focused on reasons why depigmentation therapy may not have been pursued. In addition, both groups completed the same DLQI.

Participants

Advertisements on the VSI online quarterly newsletters were initially placed to gather interest. Once IRB approval was attained, the survey links were distributed to both groups who met the inclusion criteria as mentioned above via a VSI email listserv. Participants were directed to click on a REDCap link to complete both the DLQI and the applicable survey created and produced by the authors (the structure was adapted from the United States Census Bureau [9]). The available data were de-identified for statistical analysis. Although participants were primarily members of the VSI organization, a minority of individuals were recruited from other de-identified vitiligo support groups through a central vitiligo support group listserv.

Outcome measures

The survey assessed factors such as length of time until depigmentation therapy was offered, commencement of therapy, duration, financial burden, level of satisfaction or regret at outcome, impact on life activities, and challenges faced during and after depigmentation therapy.

Statistics

Descriptive statistics and responses to survey questions were tabulated and compared between patients who did and did not undergo depigmentation therapy. Categorical variables were compared using Fisher's Exact Test, and continuous variables compared using the Kruskal–Wallis Test. Proportions were compared using the two-sample test of proportions. Level of comfort performing various activities was compared between patients who did not undergo

depigmentation and those who did undergo depigmentation, both before and after depigmentation therapy. Analyses were conducted in Stata v17.0. All tests were two-sided with a *p*-value threshold of 0.05.

Results

A total of 77 individuals completed the surveys. Forty-two individuals who had either undergone or were undergoing depigmentation therapy completed the survey (approximately 57% response rate) and thirty-five individuals had considered, but not undergone depigmentation therapy (approximately 61% response rate).

Demographics

Patients undergoing depigmentation tended to be younger, with lighter skin types, though these trends were not statistically significant (Table 1).

Primary depigmenting agents used

The most common primary depigmenting agent was monobenzyl ether of hydroquinone (MBEH; 25/42, 59.5%), followed by monomethyl ether of hydroquinone (8/42, 19.1%).

DLQI

Average DLQI was significantly lower for patients who had previously undergone depigmentation compared to those who had not undergone depigmentation (5.31 versus 10.23, $p=0.002$, Table 1), indicating less impairment of QOL for those who had depigmented.

Activities considered uncomfortable for patients undergoing depigmentation

Patients who had undergone depigmentation were less likely to report discomfort with performing social activities after depigmentation compared to before undergoing depigmentation (Table 2). They were also more comfortable with these activities compared to patients who had never undergone depigmentation therapy. The only activities for which this was not the case were reading books and watching television.

Reason for not undergoing depigmentation

Of participants who did not undergo depigmentation, the most frequent reason was cost, cited by 26.1% as the primary factor (Table 3).

Table 1 Descriptive Status by Depigmentation Status ($n=77$)

	Underwent depigmentation				<i>p</i>
	No ($n=35$)		Yes ($n=42$)		
	<i>n</i>	%	<i>n</i>	%	
Current age (years)					0.072
≤20	0	0	2	4.8	
21–29	0	0	1	2.4	
30–39	5	14.3	0	0	
40–49	4	11.4	11	26.2	
50–59	9	25.7	10	23.8	
60–69	10	28.6	12	28.6	
70≥	7	20.0	6	14.3	
Sex					0.339
Male	4	12.9	8	19.5	
Female	27	87.1	33	80.5	
Race/ethnicity					0.267
White	26	74.29	30	71.4	
Black	4	11.43	3	7.1	
South Asian	1	2.86	5	11.9	
East Asian	1	2.86	2	4.8	
Southeast Asian	0	0	2	4.8	
Pacific Islander	1	2.86	0	0	
Other	2	5.71	0	0	
Where are you located?					0.165
USA	29	90.6	29	76.3	
Canada	2	6.3	0	0	
UK	0	0	3	7.9	
United Arab Emirates	0	0	1	2.6	
Vietnam	0	0	1	2.6	
Australia	1	3.1	1	2.6	
Oman	0	0	2	5.3	
Poland	0	0	1	2.6	
Percent BSA affected (prior to depigmentation, when applicable)					0.470
<5	3	8.6	2	4.8	
5–10	2	5.7	3	7.1	
11–30	13	37.1	11	26.2	
51–70	12	34.3	21	50.0	
71–90	3	8.6	5	11.9	
>90	2	5.7	0	0	
DLQI	10.23	7.98	5.31	6.03	0.002

The *p* values are from tests for significant differences in demographics between patients who did and did not undergo depigmentation

Cost

Of forty-one patients reporting estimated cost of depigmentation, six (14.6%) reported less than \$100, six (14.6%) reported \$100–\$500, eight (19.5%) reported \$500–\$1000, five (12.2%) reported \$1000–\$1500, one (2.4%) reported

\$2000–\$2500, and eleven (26.8%) reported a cost of greater than \$3000.

Body sites affected by vitiligo

Body sites affected by vitiligo were comparable between patients who did and did not undergo depigmentation therapy. People who underwent depigmentation were more likely to have neck involvement (14/42, 33.3%) compared to patients who did not undergo depigmentation (4/35, 11.4%; $p=0.022$).

Body sites affected by vitiligo and sites treated in patients who underwent depigmentation

Of the affected areas of the body in those who underwent depigmentation, the arms (64.3%), legs (52.4%) and the face (47.6%) were the most frequently treated areas (Table 4).

New challenges faced by vitiligo patients following depigmentation ($n=42$)

Seventeen (42.5%) of 42 patients who underwent depigmentation reported experiencing new challenges following depigmentation therapy. The most frequent challenges cited were protecting their skin from the sun (11/17, 64.7%) and repigmentation (3/17, 17.6%). Other challenges cited included adjusting to identity without vitiligo (1/17, 5.9%), pruritus (1/17, 5.9%), and looking different (1/17, 5.9%).

Side effects

The side effects reported by patients while undergoing depigmentation therapy were itching (13/42, 31.0%), dry skin (10/42, 23.8%), skin rash (9/42, 21.4%), hyperpigmentation of skin (3/42, 7.1%), and eye irritation (3/42, 7.1%).

Duration of vitiligo prior to offer of depigmentation therapy ($n=47$)

Forty-seven participants, including those who did and did not undergo depigmentation, reported the length of time between diagnosis and being offered depigmentation therapy. Eight respondents (17%) reported less than one year, nine (19.2%) reported 1–5 years, four (8.5%) reported 6–10 years, four (8.5%) reported 11–15 years, and twenty-two (46.8%) reported 16+ years. Out of the 35 patients who did not undergo depigmentation therapy (group 2), seven of them were offered such therapy as a treatment option.

Table 2 Activities considered uncomfortable for patients with vitiligo ($n=77$)

Activity	Nondepigmented ($n=35$)			Depigmented ($n=42$)				
	n	%	p value*	Before		After		p value**
				n	%	n	%	
Social events	14	40.0	0.002	24	57.1	4	9.5	<0.001
Playing sports	14	40.0	0.004	22	52.4	5	11.9	<0.001
Dining in restaurants	9	25.7	<0.001	12	28.6	0	0	<0.001
Going to bars or clubs	10	28.6	0.031	15	35.7	4	9.5	0.004
Visiting friends or relatives	12	34.3	<0.001	13	31.0	0	0	<0.001
Engaging in a hobby	11	31.4	0.036	17	40.5	5	11.9	0.003
Going to a religious service	4	11.4	0.024	5	11.9	0	0	0.021
Reading books	0	0	*	1	2.4	0	0	0.314
Watching TV	0	0	*	1	2.4	0	0	0.314
None of the above	15	42.9	0.036	12	28.6	28	66.7	<0.001

* p value of two-sample test of proportions of non-depigmented patients versus depigmented patients after depigmentation

** p value of two-sample test of proportions of depigmented patients before versus after undergoing depigmentation

Table 3 Reasons for not pursuing depigmentation therapy ($n=23$)

Reason for not undergoing depigmentation	Frequency	Percent
Cost	6	26.1
Hope for new treatments or cure for vitiligo	2	8.7
Did not want white skin	4	17.4
Health/safety concerns	1	4.3
Lack of knowledge	2	8.7
Not offered as treatment	2	8.7
Not bothered enough by vitiligo	1	4.3
Inconvenient to use depigmenting agent	1	4.3
Barriers to access	3	13.0
Still considering depigmentation	1	4.3

Table 4 Body sites affected by vitiligo and sites treated in patients who underwent depigmentation, prior to starting depigmentation therapy ($n=42$)

Body site	Areas affected		Areas treated	
	Frequency (n)	Percent (%)	Frequency (n)	Percent (%)
Face	38	90.5	20	47.6
Neck	30	71.4	17	40.5
Chest	25	59.5	14	33.3
Back	18	42.9	11	26.2
Arms	37	88.1	27	64.3
Hands	39	92.9	19	45.2
Legs	35	83.3	22	52.4
Feet	32	76.2	13	31.0
Buttocks	9	21.4	5	11.9
Genital area	22	52.4	5	11.9

Likelihood of recommending depigmentation to others

Twenty-four of 39 respondents (61.5%) answered that they would be “very likely” to recommend depigmentation to others; five (12.8%) “somewhat likely”, eight (20.5%) “neutral”, one (2.6%) “not very likely”, and one (2.6%) would not recommend depigmentation therapy to others.

Do you ever regret undergoing depigmentation?

Twenty-eight of 40 respondents (70%) answered “never”, five (12.5%) “rarely”, six (15.0%) “sometimes”, and one (2.5%) “all the time”.

Do you wish you would have pursued depigmentation earlier?

Twenty-nine (70.7%) of 41 patients reported wishing they had pursued depigmentation therapy earlier.

Discussion

This study provides insight into the psychosocial factors affecting individuals who choose to undergo depigmentation therapy. The average DLQI score was substantially higher for patients who did not undergo depigmentation than for those who did, indicating that depigmentation is associated with a reduction of impairment of vitiligo on quality of life. The most common barrier to pursuing

depigmentation was cost. As observed, from this study, this can be widely variable, which may depend on the location of the individual. Lack of access to depigmenting agents may further contribute to barriers to treatment (Table 3). Of the participants who completed depigmentation therapy about 70% wished they had pursued depigmentation therapy earlier, and most would recommend depigmentation to others with vitiligo. While twenty-eight of 40 respondents (70%) answered “never” when asked about regret in pursuing depigmentation therapy, it is important to note that there are still challenges that these individuals may face. Repigmentation is one such challenge that has been often reported in the literature that may be related to amount of sun exposure following cessation of depigmentation therapy or potentially as a reaction to the medication [10]. In a double-blind randomized study to compare effectiveness and tolerability of two concentrations of MBEH, the investigators reported repigmentation 3–6 months after MBEH discontinuation in 25.3% and 11.1% of patients who used a 20% and 40% concentration respectively [11]. This rate was higher than the reported 3% of individuals who completed the present online survey. Other commonly reported reactions that were also observed in this present survey include dermatitis, pruritus, and xerosis [2, 10, 11]. More studies would be helpful in quantifying the relative risks of side effects in relation to type of vitiligo, duration of therapy, and concentrations of depigmenting agents used.

Limitations

One limitation of this study is the relatively small sample size. Since the goal was to gather as much information as possible from each participant, all the questions were not mandatory to complete (outside of fulfilling the criteria needed to complete the appropriate survey). In addition, most responders were those who identified as “white” indicating that the responses may not necessarily be generalizable to all individuals with vitiligo. The surveys were administered during the Covid-19 pandemic; therefore, one could consider that responses to questions on participating in social activities may be influenced by the uncontrollable circumstance. Another limitation is the lack of data specific to each patient case, including baseline characteristics on the type of vitiligo of the individuals undergoing depigmentation therapy (acral, segmental, etc.). This may affect response to treatment and potentially impact quality of life scores both before and after therapy. Additionally, since the surveys were completed by presumed patients, there is no data that describes the medical providers experiences including assessment of patient appropriateness to undergo depigmentation therapy.

Conclusions

Depigmentation therapy is associated with augmented self-reported quality-of-life scores across various domains in individuals with vitiligo. While not all cases are good candidates for depigmentation therapy, clinicians treating individuals with vitiligo should be aware of the potential improvement in the psychological burden in the appropriate patient, as well as challenges related to this therapy.

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Data availability The data generated and analyzed during this study are included in this manuscript. Additional data is available from the corresponding author upon request.

Declarations

Conflict of interest None declared.

Ethical approval This study was approved by the institutional review board (IRB) through the University of Texas-Austin. The participants in this manuscript have given informed consent to publication of their case details. All authors have made a substantial contribution to the article including interpretation of data and revision and have approved this version to be published.

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