

Knowledge, attitudes, perceptions, and misconceptions among vitiligo patients in Southwest, Saudi Arabia

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Abstract

Objective The study assesses the degree of knowledge possessed by patients with vitiligo in southwest Saudi Arabia regarding the disease's etiology, diagnosis, management, and prognosis. Additionally, the study identifies factors associated with patients' knowledge about the disease.

Methods The study administered a questionnaire in Arabic and English languages to measure the patients' knowledge about the causes of vitiligo, associated conditions, and available treatment options. The questionnaire was distributed among 293 patients diagnosed with vitiligo in the dermatology outpatient clinics at Khamis Mushayt General Hospital and King Khalid Hospital in Najran during the study period. Data analysis was conducted using χ^2 test for categorical variables.

Results 293 patients were recruited in this study. Of these, 124 (42.3%) were male, and 169 (57.7%) were female. Most patients were young, falling within the age group of 22–39 years. Approximately 156 (53.3%) of the patients possessed no awareness regarding causes of vitiligo. Only 52 (17.7%) patients demonstrated good knowledge related to vitiligo, while 241 (82.3%) had poor knowledge. Stress and fear were considered causative or aggravating factors by 68 (23.2%) patients. Additionally, only 138 (47.1%) patients were aware that the loss of pigment cells contributes to vitiligo. Herbal compounds were considered effective treatment agents by 56 (19.1%) patients. In addition, 211 (72%) patients were aware of vitiligo treatment with topical steroids, but 82 (28%) responded that they did not know about these treatment modalities.

Conclusion Erroneous beliefs, misconceptions, and myths surrounding vitiligo were uncovered in this study. These misconceptions often lead to delayed medical advice-seeking and poor adherence to medication. To address this, health education programs should be implemented by health authorities, focusing on mass disease education.

Key words

Vitiligo; Herbal compounds; Misconceptions; Perceptions.

Introduction

Vitiligo is a chronic, non-contagious skin condition that leads to loss of pigmentation¹ and

affecting about 1-2% of the global population.²

Numerous medical treatments are available, but no cure exists.³ The disease's unpredictability in terms of progression significantly impacts life quality for sufferers.⁴ And while vitiligo is not known to result in physical disability, it can severely affect psychological well-being.⁵ Indeed, many sufferers experience distress and

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social stigma.⁶

In Saudi Arabia, research has shown that a significant proportion of vitiligo patients feel that the condition significantly alters how others perceive them,¹ with nearly 50% reporting feelings of depression and anxiety.⁷

Our review of the literature indicates a lack of studies on public attitudes, knowledge, and reactions towards the disease and its sufferers. Gaining further insight into these could help address the issue.

Our study aims to investigate the knowledge, attitudes, perceptions and local myths about vitiligo among patients in southwestern Saudi Arabia. More specifically, we investigate the following two main areas:

1. Various epidemiological factors, such as age and gender distribution, disease duration, vitiligo type, and familial occurrence, and correlate these with patients' knowledge about the condition.
2. The co-occurrence of autoimmune disorders, and evaluate patients' understanding of vitiligo's causes, associations, and available treatments in regional hospitals.

Comprehensive management of vitiligo necessitates gaining the insights outlined in the study's aims. It is also expected that the results of this study contribute to the design of preventive and curative strategies, especially for the study community.

Method

The study comprises a cross-sectional survey of patients attending dermatology clinics of southwestern region hospitals in Saudi Arabia (Khamis Mushayt and Najran). This region has a population of around 1.2 million, according to a 2023 census.

Hospital dermatology outpatient clinics vitiligo patients were the population of our study during the period (January -December 2023). Data collection was carried out by a qualified research assistant and checked by the research team.

Inclusion criteria were adult patients >18 years who were attending the clinic with a diagnosis of vitiligo.

Exclusion criteria were those aged <18 years or those with no diagnosis of vitiligo.

All participants were provided a comprehensive explanation of the study purposes and told that the study results would be anonymized. The questionnaire was provided in both the Arabic and English languages and evaluated patient knowledge about the causes of vitiligo, associated conditions, and available treatment options (**Table 1**).

The questionnaire comprised inquiries about the presence of similar conditions within the family, awareness of the causes of vitiligo, knowledge of any curative treatments, and the effectiveness of herbal remedies. Patients were also questioned about factors that might worsen or alleviate their disease. A comprehensive list of all potential responses was included in the survey (true response, false response and not sure response, where any response of a correct answer compatible with the ideal questionnaire responses by the investigator was given a score of 1, and any other response that was not compatible with the proposed correct answer by the investigator was given a 0 score). All questionnaires were checked and assessed by the trained research assistant and the physicians themselves.

There were 37 questions in total with a maximum score of 37. The questionnaire opened with a short introduction explaining the purpose of the survey and offering a clear and succinct

description of vitiligo. Some questions were designed to uncover any misconceptions or to illicit knowledge of the participant regarding the disease and its related aspects. The anticipated outcome variables were to assess knowledge of variants of vitiligo and any association with other autoimmune disorders.

This questionnaire was designed and validated by a scientific team and approved by IRB Committee, College of Medicine, King Khalid University (REC# 2018–05–07).

All demographic information was gathered from the patients' medical records, which detailed their age, gender, occupation, age at vitiligo onset, initial site of the lesion, vitiligo duration, detailed medical history of the family, drugs or food allergies, and any related health conditions. The variant of vitiligo was documented according to the clinical assessment. Additionally, the disease distribution was documented according to a clinical examination.

Verbal agreement was received from each participant because there were no clinical interventions required by the study. All patients were guaranteed confidentiality of data. Security of data was ensured by placing it in a locked storage facility accessible by the principal investigator only. Manual checking was done via double data validation. Data analysis was conducted using χ^2 test for categorical variables.

Descriptive findings are presented as frequencies, percentages, data distribution means and standard deviations.

The statistical software SPSS program version 23 (SPSS Inc, Chicago, IL) was used for statistical analysis.

Numerical variables are presented along with various socio-demographic factors, including age, gender, education level, marital status and

employment status. For calculation of scores and grade of the knowledge, the scientific committee, which designed this questionnaire, agreed to classify the patients according to their responses as the following:

- If the patient achieved ≥ 21 as a score, they were labelled as having a good knowledge.

- If the patient achieved < 21 as a score, they were labeled as having a poor knowledge.

Results

Socio-demographic characteristics of vitiligo patients are presented in **Table 1**: 293 vitiligo patients responded to the study questionnaire; most of the cases were Saudi nationals (n=259, 88.4%), non-smokers (n=256, 87.4%), and 169 (57.7%) were females. Most of the patients were young (n=140, 48%), within the age group 23-39 yrs. The youngest patient was 18 years, and the oldest was 76 years. 142 (48.5%) of the patients were single, while 123 (42%) were married. Most of the patients (n=138, 47.1%) had graduated secondary school, while 90 patients (30.7%) held a university degree or higher. 65 patients (22.2%) had not received official academic qualifications.

Table 2 shows the clinical characteristics' data related to the disease among the study population. 104 patients (35%) possess a positive family history of vitiligo, and 189 patients (64.5%) had no history of vitiligo in their families.

Vitiligo vulgaris represented the most prevalent form of the condition, with involvement of both extremities (87.7%) and head and neck (53.2%) the most commonly associated distribution compared to other body sites. The sites which commonly affected at onset of the disease were both upper and lower extremities, head and

Table 1 Sociodemographic characteristics of vitiligo participants

Category	No.	%
Nationality		
Saudi	259	88.4
Non-Saudi	34	11.6
Sex		
Male	124	42.3
Female	167	57.7
Smoker		
Yes	37	12.6
No	256	87.4
Age group (yrs)		
18 -22	39	13.3
23 - 29	48	16.5
30 - 39	92	31.4
40 - 49	64	21.9
50 - 59	38	12.9
> 60	12	4.1
Total	293	100
Marital status		
Single	142	48.5
Married	123	42
Divorced	20	6.8
Widow	8	2.7
Total	293	100
Education level		
Primary or less	48	16.4
Intermediate	17	5.8
Secondary	138	47.1
College	78	26.6
High education	12	4.1
Total	293	100
Job status		
No job	68	23.2
Government	74	25.2
Private	91	31.1
Military	39	13.3
Retired	21	7.2
Total	293	100

neck, chest, back, and then genitalia in descending order of arrangement of distribution as a proportion.

Among the study cases, 78.8% (n=231) who had no history of any other associated diseases, 22% (n=62) had a history of other diseases, with diabetes accounting for the highest proportion observed (n=21, 7.1 %) along with vitiligo. The vitiligo duration when patients presented to the clinic was varied, with a minimum duration of the disease being one year and the maximum

Table 2 Clinical profile of vitiligo participants.

Variable	no.	%
Duration of the disease (yrs)		
< = 1	52	17.7
1-3	46	15.7
4 - 6	37	12.6
7 - 9	74	25.3
10 - 15	34	11.6
15 - 20	27	9.2
> 20	23	7.9
Total	293	100
Family history of Vitiligo		
Yes	104	35.5
No	189	64.5
Total	293	100
Site of disease (ordered according to its percentage)		
Extremities	256	87.7
Head and neck	156	53.2
Chest	116	39.6
Back	102	34.8
Genitalia	51	17.4
Clinical Variant (ordered according to its percentage)		
Vulgaris	143	48.8
Acrofacial	71	24.2
Localized	67	22.9
Segmental	7	2.4
Universal	5	1.7
Total	293	100
Associated diseases		
No associated disease	231	78.8
Diabetes mellitus	21	7.1
Hypertension	9	3.1
Anemia	11	3.8
Skeletal deformities	7	2.4
Tumors (fibroepithelial polyp, or skin tag keratoacanthoma, seborrheic keratosis, BCC, SCC)	17	5.8
Type of therapy		
Topical	183	62.4
Phototherapy	128	43.7
Systemic (prednisolone and aspirin during active disease)	19	6.5
Herbal	17	5.8

more than 20 years. More than 70% of cases (n=209) were within the first 9 years of disease onset.

Table 3 presents the statistical analysis of patients' responses to the questionnaires. The mean score was 14.5, the median was 15, and the standard deviation of 4.8.

We found that good knowledge related to vitiligo was represented by only 52 (17.7%) of our patients, while poor knowledge was shown by 241 (82.3%) of the patients. 156 cases (53.3%) had no knowledge at all of the nature of vitiligo causes, whether immunological, environmental, infectious or other influencing factors. Stress and fear were considered causative or aggravating factors by 197 (67.3%) of the cases. Only 209 patients (71.4%) knew that vitiligo caused by loss of pigment cells.

Herbal compounds were considered an effective therapeutic option by 79 patients (27%), while 172 patients (58.7%) were not sure of its efficacy. In addition, 211 patients (72%) knew of topical treatments for vitiligo using steroids, but 82 (28%) did not know of this treatment modality.

140 patients (47.8%) believed that vitiligo is caused by an infectious agent and can be transmitted to the normal population by contact with vitiligo patients' skin, while 47 (16%) were unsure of the truth of this statement. Overall, this study reveals a variety of common false beliefs the causes of vitiligo, including more than 23% (n=68) who thought it to be resulting from poor personal hygiene.

Discussion

Vitiligo is a hypomelanotic disorder resulting from the loss of functioning melanocytes, which lead to decreased pigmentation.¹

It is the prevalent cause of acquired depigmentation in the skin, hair and oral regions, with 0.5-2% of the population affected globally.⁸

This disorder manifests as circular patches and spots on the skin due to the eradication of melanocytes by auto-reactive cytotoxic T lymphocytes.⁸⁻¹⁰

Vitiligo is also classified as a psychodermatological disorder that does not cause physical harm or pain. However, it has a considerable effect on a person's personal and social life due to the cosmetic changes it causes.³⁴ This can lead to severe psychological distress, greatly affecting well-being and self-confidence,^{35,38} particularly those with darker skin.¹²⁻¹⁴ Additionally, vitiligo is strongly accompanied by other autoimmune diseases, notably thyroid conditions such as Hashimoto thyroiditis and Graves' disease.^{8,11,15,16}

The prevalence of vitiligo in southwestern regions of Saudi Arabia in a previous study was shown to be 1.98%,¹ but its prevalence shows regional variations.^{1,10,13} It ranges between 0.7-3.2%, with the highest prevalence for Makkah region.^{1,17-20} However, a new study claimed that its national prevalence in Saudi Arabia is of 3.5% of the population, considerably higher than the global average range 1–2%,^{21,22} providing some evidence for its genetic predisposition.^{23,24}

Our study reveals that vitiligo being in females than males (57.7% versus 42.3%), a finding in opposition to the most cited global studies that found equal prevalence in male and females.^{22,24-26} The present study does find agreement with the results of a study on a population in Riyadh though.²⁰ These findings may be explained by increased severity of the impact of the condition on women's social lives, personal relationships and sexual activities, meaning that they tend to undergo treatment earlier than men.^{19,20,25} It is also understood that reported quality of life for women vitiligo sufferers is lower than men.^{10,32,33} In a previous study, it was also noted that despite being covered by the Purdah (veil) and so having less exposure to sunlight, women in Saudi Arabia exhibited a higher prevalence of vitiligo compared to men. No notable the manifestation and locations of vitiligo between genders.²⁵

Table 3 Survey assessing the knowledge of the vitiligo participants regarding their diseases.

STATEMENT OF QUESTION (The ideal answer: T or F)	True	False	Not sure
Once you have vitiligo, the disease will be worsening or improving even without treatment. Ideal answer: (F)	198 (67.5%)	51 (17.4%)	44 (15.1%)
People with vitiligo can develop other chronic diseases (e.g., D.M.H.T.N or thyroid disease). Ideal answer: (T)	46 (15.7)	153 (52.2)	94 (32.1)
(3) The more vitiligo you have, the higher possibility to develop other autoimmune diseases. Ideal answer: (T)	34 (11.7%)	73 (24.9%)	186 (63.4%)
(4) Whitening of the skin is resulting from the destruction of pigment cells in the skin. Ideal answer: (T)	209 (71.4%)	16 (5.4%)	68 (23.2%)
(5) Have you noticed that medications taken for other health conditions had an effect on your vitiligo (i.e., improved or worsened your vitiligo symptoms). Ideal answer: (T)	81 (27.6%)	128 (43.8%)	84 (28.6%)
(6) Systemic infections can/may cause vitiligo. Ideal answer: (F)	21 (7.2%)	197(67.2%)	75(25.6%)
(7) A skin injury (e.g., scratching of the skin, wounds or surgery) can/may cause new vitiligo lesions. Ideal answer: (T)	122 (41.6%)	82 (28%)	89 (30.4%)
(8) Environmental pollution can/may cause vitiligo. Ideal answer: (F)	39 (13.3%)	179 (61.3%)	75 (25.6%)
(9) Do you think that sunlight exposure has a positive or negative effect on vitiligo. Ideal answer: (T)	209 (71.3%)	48 (16.4%)	36 (12.3%)
(10) Stress or worry or depression can cause, or may exacerbate, vitiligo. Ideal answer: (F)	197 (67.3%)	43 (14.6%)	53 (18.1%)
(11) Do you think that diet has a positive or negative effect on vitiligo. Ideal answer: (F)	80 (27.3%)	93 (31.8%)	120 (40.9%)
(12) Laundry powders and various types of chemicals touching the skin can cause or exacerbate vitiligo. Ideal answer: (T)	101 (34.5%)	69 (23.6%)	123 (41.9%)
(13) Treatment is the same for all vitiligo patients. Ideal answer: (F)	115 (39.2%)	138 (47.3%)	40 (13.5%)
(14) Treatment according to lifestyle, the severity of vitiligo, and the site of the lesions. Ideal answer: (T)	178 (60.7%)	4 (1.4%)	77 (37.9%)
(15) There are different types of topical steroids ointments/creams with different potency to treat vitiligo. Ideal answer: (T)	211 (72%)	49 (16.7%)	33 (11.3%)
(16) Do you think that there is an effective herbal treatment for vitiligo. Ideal answer: (F)	79 (27%)	42 (14.3%)	172 (58.7%)
(17) Daivonex (calcipotriol) ointment/cream is a component like vitamin D can be used for treatment of vitiligo. Ideal answer: (T)	99 (33.8%)	49 (16.7%)	145 (49.5%)
(18) Systemic steroids oral or injections can be used in the treatment of vitiligo lesions. Ideal answer: (T)	26 (8.9%)	43 (14.8%)	224 (76.4%)
(19) Phototherapy can be used as a long-term treatment for vitiligo (unlimited treatment sessions with UVB therapy). Ideal answer: (F)	168 (57.4%)	52 (17.7%)	73 (24.9%)
(20) Tacrolimus creams can/may reduce the symptoms of vitiligo. Ideal answer: (T)	92 (31.5%)	23 (7.8%)	178 (60.7%)
(21) Do you think that bad skin hygiene may cause vitiligo or increase its severity? Ideal answer: (F)	68 (23.3%)	159 (54.2%)	66 (22.5%)
(22) Vitiligo located on the face and hands is more difficult to treat than vitiligo on other skin areas. Ideal answer: (T)	197 (67.2%)	40 (13.7%)	56 (19.1%)
(23) Psoralin-containing creams can be used for treatment of vitiligo. Ideal answer: (T)	64 (21.8%)	43 (14.7%)	186 (63.5%)
(24) Biological treatment (e.g., humera injections) can treat vitiligo. Ideal answer: (F)	43 (14.6%)	81 (27.8%)	169 (57.6%)
(25) Nutritional deficiency (e.g., a significantly unbalanced diet with vitamin deficiency) can cause vitiligo. Ideal answer: (F)	83 (28.3%)	116 (39.7%)	94 (32%)
(26) Vitiligo is an infectious disease and can be transmitted by touching vitiligo patients. Ideal answer: (F)	78 (26.7%)	168 (57.3%)	47 (16%)

STATEMENT OF QUESTION (The ideal answer: T or F)	True	False	Not sure
(27) Vitiligo is a disease of the immunity. Ideal answer: (T)	181 (61.7%)	21 (7.2%)	91 (31.1%)
(28) Vitiligo is an allergic disease like eczema and dermatitis. Ideal answer: (F)	83 (28.4%)	121 (41.3%)	89 (30.3%)
(29) Women are more prone to vitiligo than men. Ideal answer: (F)	69 (23.7%)	109 (37.1%)	115 (39.2%)
(30) Vitiligo can pass between generations (i.e., is an inherited disease) Ideal answer: (T)	169 (57.6%)	82 (28.1%)	42 (14.3%)
(31) Vitiligo occurs most frequently in old people but is not common in children or young people. Ideal answer: (F)	63 (21.6%)	157 (53.8%)	73 (24.9%)
(32) Topical treatment and phototherapy are the only treatments for vitiligo. Ideal answer: (F)	115 (39.2%)	80 (27.3%)	98 (33.5%)
(33) Laser therapy and surgical treatment (e.g., melanocyte surgical transfer grafting) are other new modalities for vitiligo treatment. Ideal answer: (T)	155 (52.8%)	47 (16.1%)	91 (31.1%)
(34) Treatment of vitiligo with local treatments or phototherapy for prolonged periods (unlimited duration or doses is safe with no side effects to the patients. Ideal answer: (F)	69 (23.7%)	80 (27.2%)	144 (49.1%)
(35) The traditional name for vitiligo is mahag or baras. Ideal answer: (F)	121 (41.3%)	115 (39.2%)	57 (19.5%)
(36) The traditional name for vitiligo is bahag. Ideal answer: (T)	64 (21.8%)	123 (42%)	106 (36.2%)
(37) In the case of vitiligo in married patients, it can be transmitted between couples by regular sexual contact. Ideal answer: (F)	27 (9.3%)	181 (61.7%)	85 (29%)

Although it is believed that the occurrence of this disorder is not related to sex, vitiligo sometimes runs in families. Indeed, many studies have reported a genetic link, at a range of 6-38% of vitiligo patients possess a family history of vitiligo.^{20,27-29} Our study showed 35.5% of the total cases presented a family history of vitiligo. Al Robaee (2007) stated that 27.5% of the Saudi vitiligo patients in his study were first-degree relatives.²³ This refers that many people are born with genetic predisposition for developing vitiligo, and the finding also draw attention of genetic possibility even in typical vitiligo cases.²⁴ Moreover, Jarallah *et al.* (1993) and Al-Mutairi *et al.* (2005), found that the family history of vitiligo was positive in 12% and 27.3% of patients respectively, compared with 35.6% in our study.^{21,30}

The high proportion of those with a family history of vitiligo in this study can be explained by the high rate of parental consanguinity, which

is very common in the southern region.³¹

In another study, it has also been shown that 20-40% of the vitiligo patient relatives also have the disease, with children and siblings being the most common relatives in these cases.²⁸

While various theories have been proposed to explain the onset and progression of vitiligo, the autoimmune hypothesis is currently the most widely supported based on clinical and experimental evidence.^{1,8,11}

Our results revealed that stress, fear, and sun exposure were considered main causes of onset and aggravating factors for vitiligo by 23.2% and 68% of the cases, respectively, which indicates poor and incorrect knowledge of the real causes of vitiligo.^{37,38} Despite most patients (77.8%) had secondary school or higher education, unfortunately, they had a poor overall knowledge regarding their vitiligo, results which are reflected in numerous previous studies.^{17,37,40}

Of our cases, 26.7% of patients related the cause of vitiligo to nutrition, with 76.8% believing that vitiligo is infectious. Interestingly, Kerari *et al.* (2022) found in a population in Jazan region that most participants knew that vitiligo was not caused by either nutrition or infection, but they were not aware of its autoimmunity. For this reason, participants were comfortable interacting socially and physically with vitiligo patients, but they expressed an unwillingness to marry sufferers.¹⁷

Numerous misconceptions about vitiligo differ across various regions of the world. These include beliefs that the disease is contagious, incurable, related to certain foods or beverages, is a form of leprose, is always inherited, and can lead skin tumors.^{39,40} The false beliefs become part of cultural identity and used to justify social behavior.^{40,41} This has a huge impact on people's lives and attitudes, including how the management of the disease is handled by sufferers. For these reasons, it has been noted that a fuller comprehension of the various misapprehensions surrounding vitiligo is necessary to enable improved healthcare provision and better educate patients and the wider public.^{37,41}

In summary, the results of our study disclose the generally poor knowledge of the causes of vitiligo by participants. For this reason, we need more programs and activities that enhance and improve the patient's knowledge through a multidisciplinary effort by many ministries, including health, education, media and social.

Recommendations: In accordance with the results of our study, the subsequent admonitions are presented to enhance knowledge of the causes and treatment of vitiligo in Saudi Arabia:

- Patient education programs should be designed with the collaboration of specialists and authorities within health centers, including

dermatology departments, public health clinics, and social workers. These programs should be delivered at all levels of education, including high school education institutions.

- The dissemination of information regarding vitiligo should be placed on screens and monitors in hospital corridors of outpatient department waiting areas.
- Vitiligo education printed documents and flyers should be designed, printed, and distributed to various clinics, hospital departments, waiting areas, phototherapy units, and PHCs.
- Educational content should also be prepared for dissemination via commonly used social media applications such as WhatsApp and Snapchat.
- Vitiligo patients should be offered the opportunity to join support groups in person and online to gain the needed knowledge and emotional help regarding their disease.

Conclusion

Numerous myths and misconceptions about vitiligo persist, leading to delays in patients accessing healthcare for the condition. These misunderstandings must be combatted via targeted educational initiatives by relevant authorities. Public education regarding vitiligo would likely enhance patients' self-confidence, lead to increased social integration, and also improve the psychological well-being of sufferers.

In terms of extending the significance of the findings of this present study, future studies should recruit a larger, more representative sample of the entire Saudi population. Follow-up studies are also necessary to assess the validity of educational initiatives and to explore alternative methods of enhancing public perceptions and knowledge of vitiligo and its sufferers. It should be noted here that following the application of such educational programs, a

follow-up study will be conducted to assess their impact.

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Authors' contribution

HA,SMA,WA: Substantial contributions to study design, acquisition of data, manuscript writing, has given final approval of the version to be published.

SAA,MAA: Substantial contributions to manuscript writing, critical review of the manuscript, has given final approval of the version to be published.

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EAH: Substantial contributions to study design, acquisition of data, critical review of the manuscript, has given final approval of the version to be published.

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