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Assessment vitiligo knowledge and burden among vitiligo patients

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Abstract
Background: Around 0.5% to 2% of people worldwide suffer with vitiligo, a chronic skin disorder marked by depigmented lesions brought on by the autoimmune loss of melanocytes.
Aim: The purpose of the study was to evaluate vitiligo patients' burden and level of understanding.
Research design: This study employed a descriptive cross-sectional research approach.
Sample: For this investigation, a convenient sample of 80 vitiligo patients was employed. Setting: Tools for gathering data: The data was gathered using three instruments, Tool (I): Questionnaire for structured interviews, Tool (II): Vitiligo disease knowledge evaluation sheet, The Vitiligo Impact Patient Scale is tool (III).
Results: 90% of the patients in the study had inadequate knowledge, while 10% had adequate knowledge. The largest percentage experienced significant burdens in the following areas: relationships & sexuality, economic constraints, psychological effects on daily life, and care & management of disease (50%, 61.2%, and 47.5%, respectively).
Conclusion: This study highlights the significant burden experienced by vitiligo patients across various aspects of their lives. It revealed that a considerable proportion of vitiligo patients suffered from a severe burden, particularly in domains related to psychological effects on daily life, economic constraints, care and management of the disease, and relationships & sexuality. Furthermore, it revealed a notable gap in patient' knowledge, as majority of the participants demonstrated an unsatisfactory level of understanding about vitiligo. Recommendations: Developing and implementing comprehensive patient education programs to improve patients' understanding of vitiligo and treatment options.

Keywords: Burden, vitiligo, knowledge

Introduction

Depigmented lesions are the hallmark of vitiligo, a persistent skin disorder caused by the autoimmune loss of melanocytes. This disease has a global frequency of 0.5 to 2% and affects people of all ages, races, and sexes (Sharkawy *et al*., 2025) [12]. There is currently no authorized medical therapy or cure for vitiligo, an autoimmune depigmentation condition. Lesions of vitiligo are characterized by a gradual loss of pigmentation brought on by the death of healthy melanocytes in the epidermis. Patients with vitiligo face substantial psychiatric comorbidity and a considerable burden on their quality of life (Picardo *et al*., 2022) [17].

Avoiding aggravating elements like stress, sunburn, and chemical and mechanical irritation seems to be the key to halting the spread of vitiligo. However, the key to effectively managing vitiligo is understanding the triggers and how to prevent them. Maintaining a positive outlook is also crucial for promoting proactive practice and avoiding concentrating on the disease's drawbacks. Patients should, in fact, be aware of their condition. Additionally, improved disease management may be linked to increased knowledge (Feng *et al*., 2025) [14].

Numerous studies show that vitiligo sufferers experience stigma, low self-esteem, and psychosocial load. There are numerous taboos around the term because of a lack of knowledge and attitude regarding this sickness. (Kumar *et al*, 2021) [10].

Significant burden occurs in normal activities, work, and psychosocial health for patients with vitiligo. According to earlier findings, patients who have visible lesions and a larger body surface area (BSA) involvement may also have a higher psychosocial load. Additionally, vitiligo patients are more likely to experience anxiety. Patients with darker skin tones, lesions on the face or hands, and more than 5% impacted BSA usually had the highest burden (Bibeau *et al*., 2023) [16].

Many myths exist around vitiligo. The disease is often misunderstood to be contagious, incurable, associated with specific foods or drinks, a kind of leprosy, always inherited, and capable of causing cancer. According to Tsadik *et al*. (2020) [19], all of these misconceptions are linked to a lack of knowledge about this otherwise benign and harmless illness.

Significance of the study

Vitiligo, a skin disorder that causes pigmentation loss, is thought to affect 0.36% of people worldwide in their lifetime. This means that about 28.5 million people are impacted globally. Vitiligo is a serious condition that affects both physical and mental health, and its prevalence is higher in adults than in children (Akl *et al*., 2024) [15].

Despite its prevalence, there is still a lack of public knowledge about vitiligo, including common misconceptions regarding its etiology or contagiousness. Public education is essential for filling in these knowledge gaps in order to improve social perceptions and the wellbeing of those who are impacted (Bibeau *et al*., 2022) [13].

Overall, a patient's social acceptance—which is correlated with their population's awareness of the disease—determines their well-being, quality of life, and response to therapy. Studies that seek to learn more about vitiligo are therefore urgent and vital, especially in places where the condition is not widely known and has a substantial negative

impact on patients' quality of life. Thus, the purpose of this study was to evaluate the burden and knowledge of vitiligo among those who suffer from it.

Methodology

The study's objective

The purpose of the study was to evaluate vitiligo patients' burden and level of understanding.

Questions for research

Q1: How much do patients know about vitiligo disease?
Q2: How long does vitiligo affect a patent's life?
Q3: What is the relation between patients' educational level and their knowledge level?

Design of the research

The study's goal was accomplished through the use of a descriptive cross-sectional research design.

Setting

The investigation was carried out at dermatological clinic in clinic No.3 in Al-Bayda City.

Size of the sample

A selective sample of 80 vitiligo patients was included in the study based on their admissions between January 2024 and December 2024, totaling 101 patients.
Sample size were calculated according to the following equation:

N = [DEFF*N p (1-p)]/ [(d2/Z21-α/2*(N-1) + p*(1-p)]
DEFF (Design effect) = 1
N (population) = 101
P (Hypothesized %) = 50%+/-5
D (tolerated margin of error) = 0.05
Z (level of confidence) = 1.96
α (Alpha)= 0.05

By substituting the values, the final sample size was calculated to be 80 patients.

Criteria for Inclusion

1. Patients who are at least eighteen years old.
2. Vitiligo that was confirmed by a dermatologist after a clinical diagnosis.
3. Willing to take part and accessible for evaluation during data collection.

Exclusion Criteria

1. Patients with other pigmentary disorders that may confound the assessment (e.g., post-inflammatory hypopigmentation, albinism).
2. Patients with severe psychiatric or cognitive impairment that prevents reliable responses.
3. Patients who have recently undergone major dermatological procedures affecting skin appearance.

Tools for gathering data

The following three instruments were employed to gather the data:
Tool (I): Questionnaire for structured interviews: It was created by the researcher following a review of relevant literature and consisted of two sections.

Part 1: Data on sociodemographics: Age, gender, marital status, place of residence, degree of education, and occupation were all included.

Part two: Vitiligo disease history: It included duration of vitiligo, cause of vitiligo, localization of vitiligo and associated diseases.

Tool (II): Knowledge assessment sheet about vitiligo disease:

The researcher changed it from (Tsadik *et al*., 2020) [19] to gauge the patients' level of vitiligo disease knowledge. Eight multiple-choice and six true-false questions concerning the nature of the disease were included. These questions asked about whether Vitiligo was contagious, autoimmune, hereditary, related to hygiene, systemic, food, lethal, triggered by psychological distress, whether it was likely to result in death, whether there was a treatment for Vitiligo, and whether it was caused by magic or witchery.

System of scoring

Every question had a score of (0) for an erroneous response and (1) for a correct response. A percentage score was obtained by adding up the item scores and dividing the total by the number of things.

Ultimately, the following categories were assigned to the total knowledge score:

- Unsatisfactory (If the percentage score <50%).
- Satisfactory (If the percentage score ≥ 50%)**.**

Tool (III): Vitiligo Impact Patient Scale (VIPS)

The burden of vitiligo is measured using the Vitiligo Impact Patient Scale (VIPS), a patient-reported outcome tool tailored to the illness. Economic restrictions, care, and disease management (7 items), relationships and sexuality (3 items), and psychological affects on daily life (19 items) comprised its 29 items.

Scoring system

A Likert-type scale is used to assess each item, and dimension scores are determined by adding up the scores of each individual item and normalizing them to a range of 0 to 100. Additionally, the total of all items, represented as a percentage, is used to determine the global score. Higher scores indicate a greater burden of disease (Salzes *et al*.,2016) [18].

Validity and Reliability

Four community health nursing specialists evaluated the tools' content validity, and any necessary adjustments were made. The reliability of the instruments was evaluated using Cronbach's Alpha, which was (0.811) for the knowledge tool and (0.74) for the Vitiligo Impact Patient Scale.

Ethical and legal considerations

Patients gave their signed consent to participate in the study after being informed about its purpose and nature, which does not involve any injury or pain, prior to data collection. Additionally, they received assurances that the data would be kept private and utilized exclusively for research. They were made aware that their participation in the study is entirely voluntary and that they are free to leave at any moment.

Pilot study

At the start of the study, 10% of the entire sample was used to evaluate the tools' applicability and feasibility, and any

necessary adjustments were made. The entire sample did not include the pilot research.

Data collection procedure

Actual fieldwork was carried out in a period of six months from December 2024 to May 2025. The study proceeded using the following phases:

- **Phase of preparation**

To gain a thorough theoretical understanding of the several facets of the issue, the researchers studied historical and present literature that was pertinent to the study topic. To evaluate patients' understanding of vitiligo and the effects of the condition on their lives, the researcher created the study's instruments. The competent hospital authorities granted permission to conduct the study after being informed of its purpose and design.

- **Assessment (interviewing phase)**

After receiving official approval to conduct the study. Three days a week, from 9 am to 1 pm, the researcher gathered the data. The researcher conducted individual interviews with each patient, explained the purpose of the study, and got their verbal consent to participate. Then, socio-demographic data, knowledge level about vitiligo and vitiligo burden on patient life were assessed using the predesigned tools. This took from 20 to 30 minutes.

Statistical analysis

Version 23 of the statistical package for the social sciences (SPSS) was used for data entry and analysis. Numbers, percentage means, and standard deviation were used to display the data. The t-test and chi-square were employed to demonstrate the relationship between the variables. When $p < 0.05$, the P-value is deemed statistically significant.

Results

Table 1: shows the sociodemographic data distribution for the 80 patients under study

Socio demographic characteristics	No	%
Age groups:		
25-35 years	20	25
36-45 years	36	45
46 -60 years	24	30
Mean ± SD	40.34 ± 8.85	
Gender:		
Male	52	65
Female	28	35
Residence:		
Urban	37	46.3
Rural	43	53.7
Marital status:		
Single	24	30
Married	48	60
Widow	8	10
Educational level:		
Illiterate	13	16.2
Basic education	8	10
Secondary school	43	53.8
University	16	20
Occupation:		
Non-working	16	20
Farmer	34	42.5
Machinery	16	20
Office work	14	17.5

Table 2: Distribution of vitiligo disease history among the studied patients (n=80)

Patients medical data	No	%
Duration of vitiligo:		
2-8 years	48	60
9-16 years	28	35
17-25 years	4	5
Duration Mean ± SD	7.72 ± 3.51	
Causes of vitiligo:		
Stress	18	22.5
Altered immunity	12	15
Hereditary (genetic)	22	27.5
Evil eye	9	11.2
Jinn (evil spirits)	10	12.5
Excessive sun exposure	9	11.2
Localization of vitiligo:		
Face and Neck	34	42.5
Hands and Arms	18	22.5
Legs and Feet	14	17.5
Chest/Trunk and Back	11	13.7
Genitals	3	3.8
Associated diseases:		
No associated disease	16	20
Hypertension	15	18.7
Pulmonary disease	18	22.5
Kidney disease	12	15
Endocrine disease	19	22.8

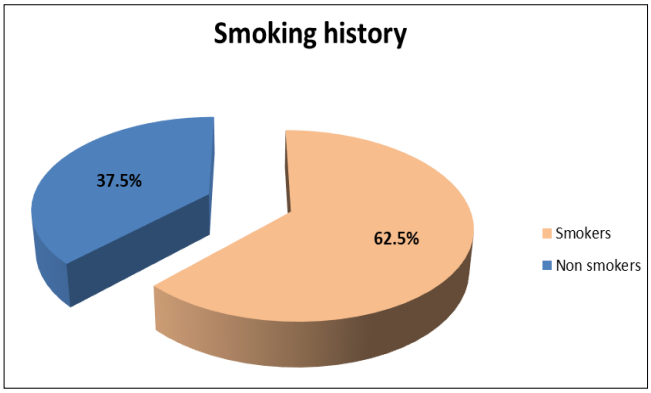

Fig 1: Smoking history among studied patients (n=80)

Table 3: Distribution of Vitiligo Burden among studied patients (n=80)

Variables	Mild Burden	Moderate Burden	Severe Burden
	No (%)	No (%)	No (%)
1- Psychological effects on daily life	15 (18.7)	25 (31.3)	40 (50.0)
2- Economic Constraints, Care & Management of Disease	10 (12.5)	21 (26.3)	49 (61.2)
3- Relationships and Sexuality	12 (15)	30(37.5)	38 (47.5)

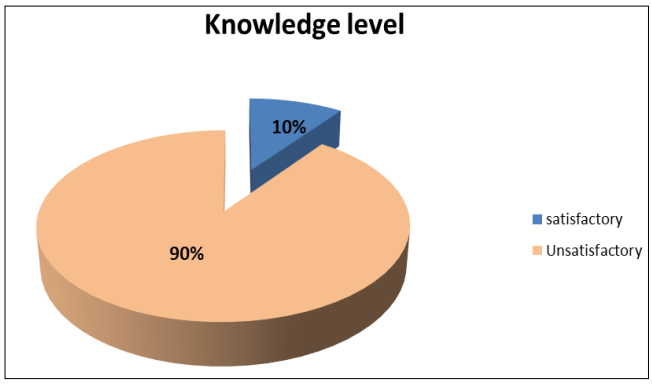

Fig 2: Distribution of total knowledge level of studied patients regarding vitiligo (n=80)

Table 4: Relationship between patient's educational level and their knowledge level (n=80)

Educational level	Patients knowledge				p-value
	Satisfactory N=72		Unsatisfactory N=8		
	No	%	No	%	
Higher education	39	54.2	1	12.5	0.001**
Secondary school	17	23.6	1	12.5	
Read and write	9	12.5	1	12.5	
Illiterate	7	9.7	5	62.5	

Table 1: Shows the sociodemographic distribution of the vitiligo patients under study. It explains that 45% of the patients were between the ages of 36 and 45, with a mean age of 40.34, 65% were males, 53.7% resided in rural areas, 53.8% had secondary education, and 42.5% were farmers**.**

Table 2: Shows how the individuals in the study were distributed according to their history of vitiligo and explains that roughly 60%, have experienced the disease for 2-8 years. Genetic factors are implicated in 27.5% of cases, while stress is noted in 22.5% of them. The most common localization areas include the face and neck (42.5%) and hands and arms (22.5%).

Table 3: Shows the distribution of vitiligo burden among the patients in the study and explains that the largest percentage experienced severe burden in the following areas: relationships & sexuality, economic constraints, care & management of disease, and psychological effects on daily life (50%, 61.2%, 47.5%) respectively.

Figure (1): Shows smoking history of studied patients with vitiligo, and clarifies that, (62.5%) of them were smokers.

Figure (2): Illustrates the overall amount of information that the patients in the study had about vitiligo. It makes clear that 90% of the patients in the study had inadequate knowledge, while 10% had adequate knowledge.

Table (4): Describes the extremely statistically significant difference between the patient's educational level and their knowledge level using the p-value (.001) and illustrates the relationship between the two.

Discussion

Vitiligo burden affects a person's thoughts, feelings, and day-to-day activities. Along with the patient's demographics, personal traits, and unique life circumstances, the severity of this detrimental effect is correlated with patients understanding and attitudes about the illness (Rangegowda *et al*., 2023) [2]. Accordingly, the purpose of this study was to evaluate vitiligo patients' burden and level of understanding.

Approximately three-fifths of the patients in the current study had vitiligo for two to eight years, according to the study's findings. Stress and genetic factors were the most frequent causes. The face and neck are the most frequently localized locations, followed by the hands and arms. These findings are consistent with those of Abuhalimeh *et al.* (2024) [3], who discovered that stress and hereditary factors were the main causes of vitiligo, which affected about three-fifths of patients for two to eight years. The hands and arms were the most frequently localized locations, followed by the face and neck. Additionally, Harris *et al*. (2022) [4] found that the majority of individuals had vitiligo for two to eight years, with stress and hereditary factors being the most common causes. The hands and arms were next in line, then the face and neck.

From researchers' point of view, these results suggesting a strong hereditary component, with a higher prevalence among individuals with a family history of the disorder. Stress, identified as the second most common contributing factor, for its role in triggering or exacerbating vitiligo, by disrupting the neuroendocrine-immune balance. Due to their frequent exposure to environmental stressors and physical trauma, the face, neck, hands, and arms are the most typically affected areas.

But, incongruent with Gupta, (2019) [5] who found that more than half of patients had a disease duration of 12-60 months. The most affected site was the lower limb, not the face and neck.

According to the current study, the majority of patients with vitiligo experienced severe burden in the following areas: relationships, sexuality, economic constraints, psychological effects on daily life, and care and management of the disease. This outcome is consistent with the findings of Alhumam *et al*. (2024) [6], who discovered that the largest proportion of patients felt embarrassed, faced impacts on daily activities, reported significant effects on relationships, and on sexual problems, indicating a substantial burden across various domains of life. Similar to Ezzedine *et al.* (2021) [7], who emphasized that vitiligo patients have substantial psychosocial challenges, especially in regard to psychological consequences on everyday life, relationship issues, and sexual dysfunction.

From researcher 'point of view, Vitiligo is not merely a cosmetic issue; it often leads to visible skin changes that can significantly affect patients' self-esteem, emotional stability, and social interactions. The unpredictable course of the disease and lack of a definitive cure contribute to ongoing stress and uncertainty, which can intensify psychological distress. Financially, long-term treatment costs, cosmetic products, and frequent medical visits pose a substantial economic burden, especially in low- to middle-income populations. Additionally, managing vitiligo often requires lifestyle adjustments, adherence to treatment regimens, and dealing with public misconceptions—all of which add to the care burden. Relationship and sexual issues may stem from altered body image and social stigma, leading to reduced confidence and strained interpersonal connections.

Regarding the overall level of knowledge that the patients in this study had on vitiligo, the results of this study show that

most vitiligo patients knew very little about their illness, with just a small percentage showing adequate comprehension. This result is consistent with that of Agrawal & Rathore (2020) [8], who found that only a small percentage of individuals showed satisfactory understanding of vitiligo, while the majority had inadequate knowledge. Similarly, the majority of the patients in the study had a moderate level of expertise, according to Murshidi *et al*. (2023) [11]. These consistent findings suggest that limited awareness and understanding of vitiligo remain a widespread issue.

However, this is contrary to El-Gilany *et al*. (2020) [9], who found that most patients had a statistically significant greater level of vitiligo knowledge, indicating that patients knew enough about the condition. This disparity could be explained by variations in the study populations, educational backgrounds, or accessibility to health information and services in various geographical locations or medical facilities.

In terms of the correlation between patients' educational attainment and their level of awareness about vitiligo, the present study found a highly statistically significant difference between the two. This result is consistent across various studies, highlighting a significant gap in awareness and understanding of vitiligo among patients and the general public. For instance, Zhang *et al*., (2023) in China found that patients with higher education levels had better knowledge about vitiligo, which was linked to a lower disease burden and higher willingness to pay for treatment. Similarly, in Egypt, El-Gilany *et al*., (2020) [9] reported that patients and their relatives, who generally had higher education levels, demonstrated significantly more knowledge about vitiligo**.** These findings, which hold true in several cultural contexts, imply that education is a key factor in determining health literacy and how people see illness.

Contrary to Murshidi *et al*. (2023) [11], however, who could not discover any meaningful correlation between educational attainment and vitiligo knowledge scores. This disparity could be explained by variations in research environments, participant demographics, or knowledge assessment instruments.

Conclusion

This study highlighted a significant burden experienced by vitiligo patients in many facets of their lives. It was found that a significant percentage of vitiligo patients experienced significant burdens, especially in areas of relationships and sexuality, economic constraints, care and management of the disease, and psychological effects on day-to-day living. Additionally, this study highlighted a significant knowledge gap among vitiligo patients where the majority of participants showed an unsatisfactory level of knowledge regarding vitiligo. These findings demonstrate the urgent need for targeted educational programs and comprehensive support strategies to improve patients' comprehension and reduce the stress caused by this condition.

Recommendations

1. Designing patient educational programs to help vitiligo patients better understand vitiligo and their treatment options.
2. Integrating mental health services and psychological counseling into dermatology clinics and offer support groups for individuals living with vitiligo to share experiences and coping strategies, reducing feelings of isolation and stigma.
3. Support initiatives that lower the cost of living, like subsidised treatment, insurance that covers skin and mental health services, and including vitiligo care in public health programs.
4. Launch community and media campaigns to raise public awareness about vitiligo to reduce social stigma and misinformation.
5. Future studies should be carried out to explore the evolving burden of vitiligo and evaluate the effectiveness of implemented interventions on improving awareness and burde of vitiligo.

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