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Original Article

Knowledge of patients, relatives and non-relatives and their attitude towards vitiligo

Abeer Mahfouz, Abdel-Hady El-Gilany*, Moheiddin Fakhry El-Ghobary#, Hassan Abdel-Rahim Fayed†

Resident of Dermatology, Meniat Al-Nasr Central Hospital, Ministry of Health, Egypt.
* Professor of Public Health, Faculty of Medicine, Mansoura University, Egypt.
# Assistant Professor of Dermatology, Andrology and STDs, Faculty of Medicine, Mansoura University, Egypt.
† Professor of Dermatology, Andrology and STDs, Faculty of Medicine, Mansoura University, Egypt.

Abstract

Background Deficient knowledge of and negative attitudes towards vitiligo are common. This study aims to compare the knowledge of and attitudes towards vitiligo between patients themselves, their relatives and non-relatives.

Methods This cross-sectional comparative study was done in the outpatient clinic of Dermatology Department, Mansoura University Hospitals, Egypt. One haundard vitiligo patients and equal number of both relatives and non-relatives were included. Demographic characteristics of the participants were collected. Knowledge and attitudes were measured using validated scales of 11 and 5 questions; respectively. The median scores of both scales were considered as cut of points.

Results Patients and their relatives have statistically significant more sufficient knowledge about vitiligo compared non-relatives (88% and 88% vs. 68%; respectively). Seventy-one percent of relatives versus 58% of non-relatives have positive attitude towards vitiligo patients. Medical personnels are the main source of information for vitiligo patients (47% vs. 39% and 6% in relatives and non-relatives). However, family and friends are the main source of information for non-relatives (49% vs. 23% and 29% in patients and relatives).

Conclusion Misconceptions and negative attitudes towards vitiligo are common especially among non-relatives. There is a need for both community-and hospital-based education about the disease for better adaptation of vitiligo patients within the community.

Key words
Vitiligo, knowledge, attitude, myths, misconceptions.

Introduction

Vitiligo is an acquired pigmentary skin disorder with unknown etiology.[1,2] It has been associated with many myths and misconceptions which differ from one area of the world to another. The common misconceptions are that the disease is contagious, related to a specific kind of food/drinks, due to bad personal hygiene, non-treatable, the disease is hereditable and may lead to skin cancers.[3,4]

The reasons for prevailing myths and misconceptions about vitiligo are multi-factorial. These include lack of knowledge about the disease, low education, cultural beliefs and

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Address for correspondence
Dr Abdel-Hady El-Gilany
Professor of Public Health,
Faculty of Medicine,
Mansoura University, 35516, Egypt
Ph:00201060714481
Email: ahgilany@gmail.com

social misconception. Such myths can influence others to act negatively towards the patients.[5] Arabian communities possess many misconceptions about vitiligo compared to Western ones.[6,7]

These false collective beliefs become part of cultural identity and used to justify a social behavior. They have a strong influence on the life of individuals and their way of living including seeking treatment during illness. Therefore, understanding the myths and misconceptions about vitiligo is important in providing better care and health education to both patients and healthy individuals.[4]

To our knowledge, there are no previous studies to address this topic in Egypt. Assessment of patient's and the public's perspective could uncover the overall state of population knowledge and attitudes about vitiligo that enable for future correction of these misconceptions. This study aims to compare the knowledge of and attitudes towards vitiligo between patients themselves, their relatives and non-relatives.

Subjects and Methods

This is a cross-sectional comparative study done in the outpatient clinic of Dermatology Department, Mansoura University Hospitals, Egypt during the period between September 2017 and September 2018.

Target population are vitiligo patients with more than one year duration of disease, their relatives and non-relatives aged 18 years or more. Relatives and-non relatives with vitiligo were excluded from the study.

Sample size was calculated online (https://www.dssresearch.com/KnowledgeCenter/toolkitcalculators/samplesizecalculators.aspx) with the following assumptions: The expected percent with deficient knowledge from previous study is 58.2% in general population. [8] The expected corresponding percent among patients is 40%, effect size 1, alpha error 5% and study power 80%, then the sample size =92 at least, in each group. Study participants attended outpatient clinic were recruited consecutively (100 in each group).

Participants were interviewed to complete an Arabic questionnaire containing:

1- Demographic characteristics of the participants including age, sex, marital status, educational level, occupation and residence.
2- Questions to elicit knowledge about vitiligo. Knowledge questions were collected from two Arabic questionnaires developed by Al-Ghamdi *et al*.[3] and Fatani *et al*.[8] and were tested for reliability with test-retest correlation co-efficient ranging from 0.7 to 0.87 and Cronbach's alpha was 0.71.

Knowledge scale includes 11 questions. Answers were scored as 1 if correct and 0 for incorrect or unknown answers. The total score ranged from 0 to 11. Scores below the median value (6) were considered as insufficient knowledge.[8]

3- Questions about attitude towards vitiligo (for relatives and non-relatives). Attitude questionnaire was a modified version the Arabic questionnaire developed by Fatani *et al.*[8] and were tested for reliability with test-retest correlation coefficient ranging from 0.8 to 1 and Cronbach's alpha was 0.92.

Attitude scale includes 5 questions. Questions were given a score of 2 if positive, 0 if negative and 1 if the participant was unsure. . The total score ranged from 0 to 10. Scores below the median value (8) were considered as negative attitude.[8]

A pilot study was done on 20 patients' relatives not included in the full scale study. The objectives of pilot study were to test the reliability of the tools, test clarity of Arabic versions of study tools and to train researcher for data collection.

The study protocol was approved by IRB (code no.MS/16.02.77). Participants gave informed consent to participate in the study and data confidentiality was assured.

Data were analyzed with SPSS version 23. Quantitative variables were tested for normality distribution using Kolomogrov-Smironov test and found to be non-parametric in distribution. They were described in median (minimum-maximum). Mann-Whitney test were used for comparison between groups. Qualitative variables were presented as number and percent. Chi-square test or Fisher's exact was used to test significance between groups, as appropriate. $P \leq 0.05$ was considered statistically significant.

Results

Table 1 shows that the three groups are matched in age, sex and residence. However, 36% of vitiligo patients are unmarried compared to 16% and 17% in relatives and non-relatives; respectively (P=0.001 & P=0.002). Sixty percent of non-relatives are above secondary education compared to 28% and 30% in patients and relatives; respectively (P≤ 0.001 & ≤ 0.001). Nineteen percent of patients are professionals and semiprofessionals compared to 34% and 36% in relatives and non-relatives; respectively (P≤ 0.001 & ≤ 0.001).

Table 2 shows, that 88% of patients and their relatives have sufficient knowledge about vitiligo compared to 68% of non-relatives with statistical significant difference between non-relatives and the other two groups (P= 0.001 & = 0.001).

Table 1 Socio-demographic characteristics of participants.

	Vitiligo patients N(%)	*Relatives N(%)*	*Non-relatives N(%)*	*P1/P2/P3*
Age				
Median (Min.-Max.)	31(18-59)	30(18-54)	32(21-57)	0.8/0.9/0.7*
Sex				
Female	80(80.0)	81(81.0)	77(77.0)	0.9/0.6/0.5
Male	20(20.0	19(19.0)	23(23.0)	
Marital status				
Currently married	64(64.0)	84(84.0)	83(83.0)	0.001/0.002/0.8
Currently unmarried	36(36.0)	16(16.0)	17(17.0)	
Education				
<secondary/ secondary	72(72.0)	70(70.0)	40(40.0)	0.8/≤ 0.001/≤ 0.001
Above secondary	28(28.0)	30(30.0)	60(60.0)	
Occupation				
Professional/ semiprofessional	19(19.0)	34(34.0)	36(36.0)	
Farmer/ manual worker	9(9.0)	8(8.0)	11(11.0)	≤0.001/≤0.001/0.7
House wife	47(47.0)	55(55.0)	48(48.0)	
Student	25(25.0)	3(3.0)	5(5.0)	
Residence				
Rural	72(72.0)	77(77.0)	78(78.0)	0.4/0.3/0.9
Urban	28(28.0)	23(23.0)	22(22.0)	

*Mann-Whitney test, otherwise Chi-square test

P1= between vitiligo patients and relatives groups

P2= between vitiligo patients and non relatives groups

P3= between relatives and non relatives groups

Table 2 Participants responses to knowledge questions about vitiligo$^{\#}$.

Questions	*Vitiligo patients N(%)*	*Relatives N(%)*	*Non-relatives N(%)*	*P1/P2/P3**
Vitiligo patients can infect others. (no)	92(92.0)	85(85.0)	62(62.0)	0.9/0.3/0.3
Vitiligo has serious health effects on the patients.(no)	55(55.0)	54(54.0)	47(47.0)	0.9/0.2/0.3
Vitiligo is more prevalent and exaggerated with exposure to psychological stress. (yes)	84(84.0)	80(80.0)	61(61.0)	0.5/≤0.001/0.003
There is treatment for vitiligo. (yes)	68(68.0)	60(60.0)	53(53.0)	0.2/0.03/0.3
Infection is a cause of vitiligo. (no)	40(40.0)	37(37.0)	30(30.0)	0.7/0.1/0.3
Hereditary is a cause of vitiligo. (no)	39(39.0)	51(51.0)	28(28.0)	0.1/0.1/0.001
Autoimmunity is a cause of vitiligo. (yes)	69(69.0)	52(52.0)	26(26.0)	0.014/≤0.001/ ≤0.001
Lack of hygiene is a cause of vitiligo. (no)	100(100.0)	97(97.0)	94(94.0)	0.1/0.013/0.3
Evil eye is a cause of vitiligo.(no)	55(55.0)	66(66.0)	72(72.0)	0.1/0.013/0.4
Sorcery is a cause of vitiligo. (no)	56(56.0)	68(68.0)	74(74.0)	0.1/0.008/0.4
Diet or eating habits is a cause of vitiligo. (no)	92(92.0)	91(91.0)	75(75.0)	0.8/0.001/0.003
Total knowledge				
Sufficient	88 (88.0)	88 (88.0)	68(68.0)	1.0/0.001/0.001
Insufficient	12 (12.0)	12(12.0)	32(32.0)	

#% with correct answer, Correct answer in parenthesis,
*Chi-square test or Fisher exact, as appropriate
P1= between vitiligo patients and relatives groups
P2= between vitiligo patients and non relatives groups
P3= between relatives and non relatives groups

Table 3 Source of information about vitiligo

*Source of information**	*Vitiligo patients N(%)*	*Relatives N(%)*	*Non-relatives N(%)*	*P1/P2/P3*
Social media$^{\#}$	28(28.0)	27(27.0)	24(24.0)	0.9/0.5/0.6
Mass media$^{@}$	11(11.0)	15(15.0)	19(19.0)	0.4/0.1/0.5
Family or friends	23(23.0)	29(29.0)	49(49.0)	0.3/≤0.001/0.004
Medical personnels	47(47.0)	39(39.0)	6(6.0)	0.3/≤0.001/≤0.001

*Categories are not mutually exclusive. #e.g. facebook, internet search enginges, y-tube…etc
@Television, television, newspapers & magazine
P1= between vitiligo patients and relatives groups
P2= between vitiligo patients and non relatives groups
P3= between relatives and non relatives groups

Table 3 shows that medical personnels are the main source of information for vitiligo patients (47% compared to 39% & 6% in relatives and non-relatives (P≤0.001 & ≤0.001). However, family and friends are the main source of information for non-relatives (49% compared to 23% & 29% in patients and relatives with P≤0.001 & =0.004).

Table 4 shows that 71% of relatives versus 58% of non-relatives have positive attitude towards vitiligo patients with borderline statistical difference (P=0.055).

Discussion

In the current study 88% patients and their relatives had sufficient knowledge about vitiligo compared to 68% of non-relatives.

Table 4 Responses of relatives and non-relatives to attitude questions about vitiligo.

Questions	*Relatives N(%)*	*Non-relatives N(%)*	*P-value*
Do you accept to marry a vitiligo patient?			
Yes	31(31.0)	11(11.0)	0.001
No/I don't know	69(16.0)	89(37.0)	
Do you accept shaking hands with a vitiligo patient?			
Yes	87(87.0)	87(87.0)	1.00
No/I don't know	13(13.0)	13(13.0)	
Do you accept sharing food with a vitiligo patient?			
Yes	87(87.0)	84(84.0)	0.54
No/I don't know	13(13.0)	16(16.0)	
Do you accept eating food prepared by a vitiligo patient?			
Yes	74(74.0)	60(60.0)	0.04
No/I don't know	26(26.0)	40(40.0)	
As an employer, do you accept to hire a vitiligo patient?			
Yes	96(96.0)	82(82.0)	0.002
No/I don't know	4(4.0)	18(18.0)	
Total attitude			
Positive attitude	71(71.0)	58(58.0)	0.055
Negative attitude	29(29.0)	42(42.0)	

Patients and their relatives are more concerned with the disease, searching more for its causes, triggering factors and treatment and getting their information mainly from health providers. Also exposure to an affected person provides better chance to understand this disease.

The results regarding sufficient knowledge agree with Asati *et al.*[9] in India but is higher than the findings of Fatani *et al.*[8] and Alshahrani and Alamar[10] in Saudi Arabia who reported that only 41.8% and 56.7% of general population had sufficient knowledge; respectively. This difference may be due to differences in tools of assessments, sample sizes, cultures, participants' characteristics (age, sex, race, education and marital status) and sources of information.

Many misconceptions about vitiligo especially among non-relative to patients were found in this study. Only 65% of non-relatives were aware that vitiligo patient is non- infectious (patient can not infect others) compared to 92% of patients and 85% of their relatives. Comparable percentages were reported among patients and non-relatives in Saudi Arabia, Turkey and Thialand. However, higher rates of correct knowledge were reported among relative and non-relatives in one Saudi study and an Indian study.[3,7-12] Despite the above findings, less than half of patients and about one-third of relatives and non-relatives stated that infections are not the cause of vitiligo. Previous studies in other countries revealed that the majority of patients, relatives and non-relatives realized that infection is not a cause for vitiligo.[3,9,12-15]

About half of patients, relatives and non-relatives of the current study had the same concept in terms of seriousness of vitiligo. This was in line with the findings reported by Al-Robaee *et al.*[6] and Al-Ghamdi *et al.*[3] in Saudi Arabia but lower than results reported by Fatani *et al.*[8] Alshahrani and Alamar[10] and Alshammrie *et al.*[13] in other Saudi studies who reported that 62.9%, 64.7% & 71.9 of non-relatives; respectively realized that vitiligo is not a serious disease.

The current study revealed that knowledge about psychological stress as an aggrevating factor for vitiligo was lower in non-relatives (61% vs. 80% in patients and 84% in relatives). This result was higher than the results reported by Fatani *et al.*[8]

and Alshahrani and Alamar,[10] in Saudi Arabia and Juntongjin *et al.*[11] in Thialand (52.7%, 52.2% and 16.8% of non-relatives; respectively).

About two-third of patients and their relatives recognized that vitiligo is a treatable disease compared to half of the non-relatives. This reflects the experience of patients with treatment. The awareness of non-relatives about treatment was similar to results from Saudi studies.[8,10,13] However, a higher result was reported in another Saudi study[6] and much lower awareness was reported in Thialand.[11]

A significantly higher propotions of patients and their relatives are aware about the autoimmune nature of the disease compared to non-relatives. Previous studies in different countries reported lower awareness about the autoimmune nature of the disease among patients with higher awareness among public.[7,8,10-12]

This study revealed that misconception of poor hygiene is uncommon as all patients and majority of relatives and non-relatives reported that lack of personal hygiene is not a cuase of vitiligo. On the contrary, poor hygiene was reported to be a cause of vitiligo by 22.5% and 42.6% of the public in Saudi Arabia and Thialand; respectively.[3,11]

Half of patients recognized that vitiligo is not an inherited disease compared to 39% of relatives and 28% of non-relatives. Fatani *et al.*[8] and Alshahrani and Alamar[10] in Saudi Arabia reported that about one-third of the public did not believe in heredity as a cause of vitiligo.

Local beliefs as evil eye and sorcery were not uncommon in the current study. Only about 55% of patients reported evil eye and sorcery are not a cause of vitiligo compared to slightly less than 70% of relatives and more than 70% of non-relatives. This reflect the deeply ingrained belief in local culture that evil eye and sorcery is a common cause of illness. Much lower percent of patients and public reported that sorcery and evil eye as causes of vitiligo in Saudi Arabia and Turkey.[3,7,12]

This study found that non-relatives had lower knowledge as regard the non-association of vitiligo with diet or certain foods compared to relatives and patients. These results were better than the findings from different countries.[7,8,10-12,14,15]

The main source of information for patients and their relatives were medical personsels and social media while family/ friend and social media were the main sources of information for non-relatives. These findings agree with studies in other countries.[8,10,12,14] This highlights the importance of health professionals, who should transfer the right information to the population.

This study showed that 71% of relatives vs. 58% of non-relatives have positive attitude towards vitiligo patients. These results agree with Fatani *et al.*[8] in Saudi Arabia but much higher than Asati *et al.*[9] in India. Contact with patients and health care providers improves the knowledge and attitude of relatives towards patients.

The presence of vitiligo may act as a barrier for the patients mixing into the society and may hinder their marriages, sharing food and participation in workforce. Compared to non-relatives, significantly higher proportions of relatives accept to marry patient with vitiligo, eat food prepared by patients and hire a vitiligo patient. This explains the high proportion of the unmarried patients in the current study. Saudi studies reported that lower rates of the public accept marrying a vitiligo patient, eat food prepared by patients and hire them.[6,8,10,13] A woman with vitiligo may have less chance of getting married and married woman developing vitiligo may have marital problems ending in divorce. The majority of relatives and non-relatives accept sharing food and shaking hands with vitiligo patients. These results were much higher than the findings among general public in Saudi Arabia[8,10] and India.[9] This goes in line with the high percent knowing that vitiligo in non-infectious.

In conclusions there are various misconceptions and negatives attitudes towards vitiligo, including the belief that vitiligo is a serious disease or that vitiligo patient is infectious. Patients and relatives have a relatively adequate knowledge about vitiligo, while non-relatives have lower knowledge and more misunderstanding about this disease. Also, relatives and non-relatives have common negative attitudes about vitiligo.

There is a need for accessible, accurate, community-and hospital-based education about the natural history of vitiligo, the effectiveness of treatment and its expected duration to clarify the wrong misconceptions. A better understanding of the disease would result in better adaptation of vitiligo patients within the society.

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