

Perception of vitiligo patients about their illness: A single center study in Egypt

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Abstract

Objective This study aims to describe the illness perception of vitiligo patients and its associated factors.

Methods In this cross-sectional study, the Arabic version of illness perception questionnaire was completed from 100 vitiligo patients. Patients were asked about their beliefs of the cause of vitiligo. The median score of the seven subscales (acute/chronic, cyclical, consequences, personal control, treatment control, disease understanding and emotional effects) were calculated and their variations with different parameters were compared.

Results Majority of patients believe that emotional state, family problems, altered immunity, heredity and infections are causes of vitiligo. The median scores of beliefs about chronicity, cyclical nature, consequences, personal control, treatment control, disease understanding and emotional effects are 18, 12, 17, 21, 18, 14 and 24; respectively. The median scores of beliefs about chronicity and cyclical nature are significantly higher among patients with above secondary education and in patients with more 36 months of disease duration. The median scores of beliefs about disease understanding is significantly higher among patients of younger age; unmarried and with younger age of onset.

Conclusion Patients have wrong beliefs about causes of vitiligo and believed that their life and emotions are strongly influenced by the disease. Health education and psychological counseling could correct these beliefs and influences.

Key words

Vitiligo, illness, perception, beliefs.

Introduction

Vitiligo is a common disease with unknown etiology and its course is not predictable. It is characterized by periods of remission and exacerbation.^{1,2} Vitiligo has been associated with many myths and misconception about its nature, risk factors and treatability.³⁻⁵

Illness perception is the reflection of individuals' beliefs and expectations related to a

disease.⁶ Since vitiligo is an episodic condition with an uncertain aetiology, the labeling and beliefs about its timeline, treatment and outcome are likely to be based less on substantive medical knowledge and more on cognitive representations of the patient.⁷ An understanding of patients' views about the cause of vitiligo can help healthcare providers to incorporate patients' beliefs into the care and improve patients' adherence to and benefit from treatments.⁸ There are no previous studies in Egypt that highlight the perception of vitiligo patients about their illness. This study aims to describe the illness perception of vitiligo patients and its associated factors.

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Methods

This is a cross-sectional descriptive study done in the outpatient clinic of Dermatology Department, Mansoura University Hospital, Egypt during the period from July to September 2020.

A convenience sample of 100 patients was recruited consecutively. Vitiligo patients aged 18 years or more with one year or more disease duration were included.

A questionnaire was completed during a direct interview with the patients. The questionnaire contains:

-Demographic characteristics e.g. age, sex, marital status, educational level and residence.

- Clinical data of the disease e.g. age of onset, duration, body surface area (BSA) affected and family history of the disease. BSA was calculated in hand units. One hand unit, which encompasses the palm plus the volar surface of all the digits, is approximately 1% of the total BSA.⁹ Extent of lesions was divided into <1%, 1-4.99% and $\geq 5\%$ of BSA.¹⁰
- The Arabic version of illness Perception Questionnaire (IPQ) translated and validated by Al-Ghamdi,³ from the original English version of Moss-Morris *et al.*,¹¹ was used with slight modifications. The IPQ was created to provide a theoretically derived measurement instrument suitable for use with any patient population. It has been used in patients with vitiligo in previous studies.^{3,12}

The scale consists of three dimensions; illness identity, probable causes and attributions concerning the disease.

The dimension of illness identity: is concerned with patients' ideas about the label and the

nature of their condition (i.e. associated symptoms). As vitiligo is an asymptomatic disease, the dimension of "symptoms" was not used.^{3,12}

The causal component: consists of 18 items that comprises the patient's ideas about the likely cause or causes of the illness. Patients' mental attitude, personality and behaviour are three causes listed in causal subscale that were excluded due to low content validity index in Arabic version. Additional items related to local culture were added to the "causes" part, including evil eye (in Arabic, Ayin Hasad, which means eye of envy), sorcery (any magical act intended to cause harm or death to people or property), Jinn (evil spirits), excessive sun exposure.³ Respondents were asked to respond to each of the listed causes as yes or no.

The dimension of attributions concerning the disease consists of 38 items, and it is a five-level Likert-type scale (ranging from "I strongly agree" to "I strongly disagree"). This dimension involves seven subscales. These are named timeline (acute/chronic), timeline (cyclical), consequences, personal control, treatment control, disease understanding, and emotional effects. The timeline subscale investigates the perceptions of the individual related to the duration of the disease and is grouped as acute/chronic (6 items) assess perceptions about how long the disease will last and cyclical changes (4 items) evaluate the patient's awareness of flare-up periods and remission of disease. The consequences subscale (6 items) reflects the individual's beliefs about the illness severity and the expected effects on the patients' life. Personal control (6 items) assesses patients' beliefs about their personal role in the control of their illness. Treatment control (5 items) evaluates the patient's beliefs about the efficacy of the medical treatment in recovery. Disease understanding (5 items) investigates to what

extent the individual understands or apprehends the illness. The subscale of emotional effects (6 items) evaluates the patients' perceptions about the impact of their illness on their emotions.^{11,13}

High scores on the consequences, timeline acute/chronic and cyclical subscales represent strongly held beliefs about the negative consequences, and the chronicity and cyclical nature of the illness. High scores on the personal and treatment control and understanding subscales represent positive beliefs about controllability and a personal understanding of the illness. High scores on the emotional representation subscale represent negative beliefs about how the illness affects one's emotional well-being.¹⁴

Protocol was approved by IRB (MS/16.02.77). Study 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). Kruskal-Wallis test and Mann-Whitney test were used for comparison between groups, as appropriate. $P \leq 0.05$ was considered statistically significant.

Results

Age of patients ranged from 18 to 67 years with a median of 31 years, 17% were males, 22% reported family history of vitiligo, median age of onset was 25.5 years, median duration of disease 36 months and median BSA affected was 2.5% (data not shown in tables).

Table 1 shows that patients emotional state

Table 1 Patient's beliefs about the causes of their illness.

Cause	Vitiligo patients agreed* N(%)
My emotional state	82 (82.0)
Family problems	74 (74.0)
Stress	71 (71.0)
Altered immunity	69 (69.0)
Heredity	61 (61.0)
Germ or virus	60 (60.0)
Evil eye/ sorcery/Jinn	49 (49.0)
Chance or fate	29 (29.0)
Excessive work	23 (23.0)
Pollution	21 (21.0)
Accident	20 (20.0)
Poor medical care	17 (17.0)
Aging	13 (13.0)
Do not know	11 (11.0)
Diet	8 (8.0)
Alcohol	3 (3.0)
Smoking	3 (3.0)

*Categories are not mutually exclusive.

(82%), family problems (74%), stress (71%), altered immunity (69%), heredity (61%), infection (60%) and evil eye/ sorcery/ jenn (49%) are the most common beliefs about causes of vitiligo among patients.

Table 2 shows that 60% and 27% of vitiligo patients believe that their vitiligo will improve in time and last long time; respectively. Less than two-thirds (63%) of patients reported that their vitiligo is very unpredictable and 45% of them reported that they go through cycles in which their vitiligo gets better and worse. More than half of patients (51%) believe that their vitiligo has strongly affected the way others see them. However, 49% of them said that their vitiligo does not have many effects on their life. About two-thirds (67%) of patients believe that what they (omit they) can determine whether their vitiligo gets better or worse. However, 14% of them believe that their actions will have no effects on the outcome of their illness. About two-thirds (66%) of patients believe that the treatment will be effective in curing their illness. However, 5% of them believe that there is nothing which can help their vitiligo.

Table 2 Subscales of patient’s beliefs about their illness.

<i>Belief about</i>	<i>Patients agreed* N (%)</i>
<u>Timeline (Chronicity)</u>	
My vitiligo will last a short time	23(23.0)
My vitiligo is likely to be permanent rather than temporary	24(24.0)
My vitiligo will last a long time	27(27.0)
My vitiligo will pass quickly	15(15.0)
I expect to have vitiligo for the rest of my life	13(13.0)
My vitiligo will improve in time	60(60.0)
<u>Timeline (Cyclical changes)</u>	
The symptoms of my vitiligo change a great deal from day to day	37(37.0)
My symptoms come and go in cycles	32(32.0)
My vitiligo is very unpredictable	63(63.0)
I go through cycles in which my vitiligo gets better and worse	45(45.0)
<u>Consequences.</u>	
My vitiligo is serious condition	14(14.0)
My vitiligo has had a major impact on my life	38(38.0)
My vitiligo does not have much effects on my life	49(49.0)
My vitiligo has strongly affected the way others see me	51(51.0)
My vitiligo has serious economic and financial consequences	46(46.0)
My vitiligo cause difficulties for those who are close to me	28(28.0)
<u>Personal control</u>	
There is a lot that I can do to control my vitiligo	57(57.)
What I can do determine whether my vitiligo gets better or worse	67(67.0)
The course of my vitiligo depends on me	48(48.0)
Nothing I do will affect my vitiligo	19(19.0)
I have the power to influence my vitiligo	55(55.0)
My actions will have no effects on the outcome of my vitiligo	14(14.0)
<u>Treatment control</u>	
There is very little that can be done to improve my vitiligo.	30(30.0)
The treatment will be effective in curing my vitiligo.	66(66.0)
The negative effects of my vitiligo can be avoided by treatment.	57(57.0)
My treatment can control my vitiligo.	62(62.0)
There is nothing which can help my vitiligo.	5(5.0)
<u>Disease understanding</u>	
My vitiligo is puzzling to me	52(52.0)
My vitiligo is a mystery to me	50(50.0)
My vitiligo doesn’t make any sense to me	26(26.0)
I don’t understand my vitiligo	50(50.0)
I have a clear picture or understanding my vitiligo	43(43.0)
<u>Emotional effects</u>	
I get depressed when I think about my vitiligo	69(69.0)
When I think about my vitiligo I get upset	71(71.0)
My vitiligo makes me feel angry	66(66.0)
My vitiligo doesn’t worry me	26(26.0)
My vitiligo make me feel anxious	72(72.0)
My vitiligo makes me feel afraid	54(54.0)

*Categories are not mutually exclusive.

Approximately half of patients do not understand their vitiligo and vitiligo is puzzling and a mystery to them. Lastly, 72% and 69% of vitiligo patients feel anxiety and depression;

respectively. However, 26% reported that their vitiligo does not worry them.

Table 3 shows that the median scores of beliefs about chronicity, cyclical nature, consequences

Table 3 Beliefs about chronicity, cyclical nature, consequences and personal control in relation to socio-demographic and clinical characteristics of patients.

	Total	Median (min-max) score			
		Acute/ Chronic	Cyclical nature	Consequences	Personal control
Overall score	100	18(10-29)	12(6-20)	17(8-30)	21(8-28)
Age					
<30ys	41	18(10-29)	12(7-20)	16(8-28)	21(8-26)
≥30ys	59	17(10-28)	12(6-20)	18(8-30)	21(11-28)
Sex					
Male	17	18(10-27)	11(6-18)	15.5(8-27)	22.5(12-25)
Female	83	18(10-29)	12(7-20)	17.5(8-30)	21(8-28)
Marital status					
Currently married	60	17(10-29)	12(6-20)	17.5(8-30)	21.5(8-28)
Currently unmarried	40	18(10-26)	12(8-20)	16(8-28)	20.5(12-25)
Education					
Secondary or less	69	17(10-29)*	11.5(6-20)*	17(8-30)	21(8-28)
Above secondary	31	18(10-27)	13(9-20)	17(8-28)	22.5(12-27)
Occupation					
Professional/semiprof.	29	17(10-27)	13(6-16)	17(10-28)	23(12-27)
Farmer/manual worker	36	18(10-29)	12(7-20)	18(10-30)	20(8-28)
House wife	35	18(10-26)	12(8-20)	15(8-28)	22(12-25)
Student	10	18(16-21)	11(10-18)	18(8-26)	20(19-24)
Residence					
Rural	78	18(10-28)	12(6-20)	17(8-30)	21(11-28)
Urban	22	18(10-29)	12.5(8-17)	16(10-28)	22(8-25)
Family History					
Negative	78	18(10-29)	12(6-20)	17.5(8-28)	21(8-28)
Positive	22	17(10-27)	12.5(7-17)	15(8-30)	19.5(12-27)
Duration of disease					
12-36 months	44	17(10-28)*	12(8-20)	17(8-30)	21.5(8-28)
>36 months	56	18(10-29)	12(6-20)	17(10-28)	21.0(11-27)
Age of onset					
<25ys	50	18(10-28)	12(7-20)	16.0(8-28)	21.0(11-26)
≥25ys	50	17.5(10-29)	12(6-20)	18(8-30)	21.0(8-28)
BSA percent					
<1%	9	18(12-27)	13(10-16)	17(10-30)	19(14-25)
1-4.99%	72	17(10-28)	11(6-20)	16(8-28)	22(12-28)
≥5%	19	18(10-29)	12(9-20)	21(12-28)	20(8-25)

*P≤0.05

and personal control are 18, 12, 17 and 21; respectively. The median scores of beliefs about chronicity and cyclical nature is significantly higher among patients with above secondary education compared to those with secondary education or less (18 vs. 17). The median scores of beliefs about chronicity is significantly higher in patients with more than 36 months of disease

duration compared to those with 12-36 months duration (18 vs. 17).

Table 3 shows that the median scores of beliefs about treatment control, disease understanding and emotional effects are 18, 14 and 24; respectively. The median scores of beliefs about disease understanding is significantly higher

Table 4 Beliefs about treatment control, disease understanding and emotional effects in relation to socio-demographic and clinical characteristics.

	Total	Median (min-max) score		
		Treatment control	Disease understanding	Emotional effects
Overall score	100	18(8-25)	14(8-22)	24(6-30)
Age				
<30ys	41	18(8-24)	17(8-22)*	24(7-30)
≥30ys	59	18(12-25)	13(8-22)	24(6-30)
Sex				
Male	17	18.5(12-24)	16(10-21)	24(12-30)
Female	83	17(8-25)	14(8-22)	24(6-30)
Marital status				
Currently married	60	18(9-25)	13(8-22)*	24(6-30)
Currently unmarried	40	18(8-24)	17(9-22)	24(7-30)
Education				
Secondary or less	69	18(8-25)	14(8-22)	24(6-30)
Above secondary	31	18(12-21)	15(9-21)	24(12-30)
Occupation				
Professional/semiprof	29	18(12-24)	14(10-20)	23(12-30)
Farmer/manual worker	36	17(9-25)	17(9-25)	24(6-30)
House wife	35	18(8-24)	18(8-24)	24(7-30)
Student	10	17(15-21)	17(15-21)	22(12-30)
Residence				
Rural	78	18(12-24)	14(8-22)	24(6-30)
Urban	22	18(8-25)	14.5(8-22)	22(8-30)
Family History				
Negative	78	17.5(8-25)	15(8-22)	24(6-30)
Positive	22	19(12-23)	12.5(8-20)	24(10-30)
Duration of disease				
12-36 months	44	18(8-25)	14.5(8-22)	24(8-30)
>36 months	56	18(12-24)	14(9-22)	24(6-30)
Age of onset				
<25ys	50	18(8-24)	17(8-22)**	24(6-30)
≥25ys	50	17.5(9-25)	13(8-22)	24(11-30)
BSA percent				
<1%	9	15(12-22)*	15.0(11-20)	24(12-30)
1-4.99%	72	18(8-25)	14.5(8-22)	24(6-30)
≥5%	19	17(9-21)	12(9-22)	24(12-30)

*P≤0.05, **P≤0.01

among patients of younger age (<30 years) compared to those of older ages (17 vs. 13); unmarried than married patients (17 vs.13) and younger age of onset (<25 years) than later onset (17 vs. 13). The median scores of beliefs about treatment control is significantly lower in patients with <1% BSA than those with 1-4.99% BSA (18 vs. 15).

Discussion

Perception of illness is a patients' cognitive appraisal and personal understanding of a medical condition and its potential consequences.¹⁵ This may include both positive and negative illness beliefs that can influence the ability to cope with the disease and to perceive it as manageable or threatening.¹⁶

The current study revealed that patients with vitiligo have many myths about the cause of their illness. Emotional state was the most common cause of vitiligo reported by patients (82%) followed by family problems (74%), stress (71%), altered immunity (69%) and heredity (61%). Evil eye/ sorcery/ jenn was reported by 49% of patients.

The same beliefs were reported from different culture with different percentages. Fate was cited by 84% of Saudi patients.³ Stress was believed to play a major role in the disease by 84% and 62.5% of Turkish and Iranian patients; respectively.^{12,17} Germ or virus was the most common cause assumed by Nepalese patients (64.4%), fate, poor medical care, diet, stress and heredity were reported as the other causes (56%, 27%, 24%, 23% and 16% of patients; respectively).¹⁸ These different findings could be attributed to differences in sample size, age, sex, race, educational level, residence, culture and sources of informations of studied patients.

The median total timeline acute/chronic and cyclical scores is considered relatively high (18 and 12; respectively) i.e. towards the negative side. Vitiligo patients experienced their illness as a chronic condition with cyclic nature.

The median scores are significantly higher in highly educated patients. This agrees with a previous Iranian study¹² but disagrees with Saudi and Turkish studies.^{3,17} Patients with longer duration of disease had higher median scores than those with shorter duration and this was in agreement with studies, in Saudi Arabia and Turkey.^{3,17}

Less than one-fourth of patients believed that their illness would last a short time. This is similar to the findings reported in Turkey¹⁷ but higher than results from Saudi Arabia and Iran (10% and 14%; respectively).^{3,12} This reflects

the state of hopelessness in chronic disease like vitiligo. On the contrary, almost half of Nepalese patients had this belief.¹⁸

On the other hand, 24% and 15% of patients perceived their illness as a long lasting condition rather than temporary; expect to have the disease for the rest of their lives. Previous studies reported much higher percentage up to 50% in different countries.^{12,17,18} However, a lower percent (19%) was reported in Saudi Arabia.³

This study revealed that the median of the total consequence score was 17. This means that the patients perceived that their illness has strong negative effects on their lives. No statistically significant difference was found between this score and sociodemographic and clinical variables and this agree with Firooz *et al.*, in Iran.¹² About half of patients belief that vitiligo strongly affected the way other see them, has serious economic and financial consequences and had strong impact on their lives. These ranged from 27% to 63% in previous studies from different countries.^{3,12,17,18} The present study found that only 14% of patients perceived their vitiligo as a serious condition. This agrees with a Saudi study³ but disagree with studies from Iran, Turkey and Nepal (35%, 84% & 36%; respectively).^{12,17,18}

The median of the total personal control score according to this study was 21 which is considered relatively high. This means that patients showed a more effective role for themselves in control of their illness. More than two-thirds of patients believed that their behavior could determine the improvement or worsening of their illness. This agrees with studies in Iran¹² and Nepal¹⁸ but considered high compared to the findings in Saudi Arabia and Turkey (38% and 10%; respectively).^{3,17} More than half of patients stated that there is a lot that they can do to control their illness and have

power to influence their disease. This is comparable to Iranian patients¹² but higher than results from Saudi Arabia and Turkey^{3,17} and lower than results from Nepal.¹⁸

This study revealed that there is a strong belief by patients in the role of medicine to control their illness and they were hopeful about cure and control of vitiligo. The median of control score is relatively high (18). This agrees with Topal *et al.*¹⁷ in Turkey, but disagrees with Firooz *et al.*¹² in Iran. A lower median score were reported in lesions affecting <1% of BSA. Patients with lesions affecting small BSA are more likely to had acrofacial vitiligo which is resistant to treatment than other clinical types. About two-thirds of patients believed that the treatment would be effective in curing their illness this is comparable to the findings reported in Iran¹² but higher than results from Saudi Arabia and Turkey.^{3,17} However, a study in Nepal¹⁸ reported higher result (76%). This study revealed that 30% of the patients believed that there is very little that could be done to improve their illness compared to 39% of Saudi Arabian patients,³ 41.3% of Iranian patients,¹² 64% of Nepalese patients¹⁸ and 18% of Turkish patients.¹⁷ Such negative impressions may decrease compliance with treatment which usually takes months. It is believed that recent development in medicine and new drugs in therapy may have affected patient's opinions and success rate of vitiligo treatment and low expectations regarding prognosis may be related to this belief.

This study revealed that the patients had a relatively acceptable understanding of their illness with a median score of 14. This score is significantly higher in younger age, unmarried and early age of onset. Younger patients had more sources of information as internet, TV and newspapers and this gave them more knowledge about vitiligo. Earlier disease onset is associated

with more motivation to know more about the disease. Vitiligo acts as a barrier and may hinder marriage and this may enforce unmarried patients to know more information about their illness to understand it. As regard disease understanding, approximately half of the patients of this study stated that vitiligo was puzzling to them, mystery to them and they did not understand their illness compared to about two-fifths of Saudi patients.³

This study revealed a strong negative impact of disease on patients' emotions with a median emotional effects score was 24 which is considerably high. This score showed no significant differences with sociodemographic and clinical variables. This agrees with a Turkish study that found no association between emotional effects and educational level or sex.¹⁷ Female patients tend to have lower scores of quality of life and more impairment of psychological health. This may be explained by women's greater awareness of disfigurement because it impairs their social life and personal relationship.¹⁹

The current study showed that 69% of patients reported depression when they think about their illness; lower figures than this study were reported in Saudi and Turkish patients (54% and 12%; respectively).^{3,17} A higher percent of patients of this study (66%) stated that their vitiligo made them feel angry compared to 34% of patients in Saudi Arabia³ and 29% of patients in Turkey.¹⁷ Also 72% of patients reported that having vitiligo made them feel anxious which was higher than the findings reported in Saudi Arabia and Turkey (57% and 46%; respectively).^{3,17}

Of patients in this study, 71% and 54% compared to 59% and 39% of Saudi patients³ reported getting upset on thinking about their vitiligo and their vitiligo made them feel afraid;

respectively. This means that patients of this study had more negative emotions. This could be explained by patients of other studies receiving more psychological support from their physicians, family and friends.

Interestingly, this study revealed that the extent of vitiligo did not affect patient's illness perceptions, this parallels the findings reported in Saudi Arabia and Iran.^{3,12} Thus the assumption that the objective severity of the illness will be associated in a linear fashion with patients subjective experience in terms of beliefs, coping or distress may not be correct.

Conclusion

Patients have correct perceptions about chronicity and recurrence of vitiligo. They believed that their life and emotions are strongly influenced by the disease but have positive ideas on cures and disease control. Health education and psychological counseling of patients should be routine part of the management plan to correct the false myths and misconception about vitiligo.

This study has some limitations; first it is a single center study on small non-representative sample of patients in a hospital-setting so its results cannot be generalized to patients in the community; secondly the possibility of recall bias cannot be excluded; lastly the possibility of social desirability bias cannot be excluded. Social desirability is the tendency of some respondents to report an answer in a way they deem to be more socially acceptable than would be their "true" answer. They do this to project a favorable image of themselves and to avoid receiving negative evaluations.

Study limitations a single center study on small sample of patients. Recall bias and social desirability image cannot be excluded.

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