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## Lived Experience of Women Suffering from Vitiligo: A Phenomenological Study

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### Abstract

Vitiligo is a chronic skin disease, which through change of appearance and body image, exerts a devastating effect on people, especially women. The objective of this study is to explore lived experience of women with Vitiligo by the hermeneutic phenomenology method. The purposive sample consisted of 16 Iranian women. Data analysis followed Diekelmann, Allen, and Tanner (1989). The results showed four main themes: (1) Perceiving myself in a different light; (2) Vitiligo: Worry about others' perceptions; (3) Vitiligo, Being influenced by cultural beliefs; and (4) Accepting and fighting the disease; Variations in experiences of living with Vitiligo. The women affected with Vitiligo during their marriage-ready years face various psychosocial problems such as rejection by associates, isolation, divorce, and forced choice of a single life

### Keywords

Vitiligo, Phenomenological Study, Iranian Women, and Lived Experiences

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## **Lived Experience of Women Suffering from Vitiligo: A Phenomenological Study**

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*Vitiligo is a chronic skin disease, which through change of appearance and body image, exerts a devastating effect on people, especially women. The objective of this study is to explore lived experience of women with Vitiligo by the hermeneutic phenomenology method. The purposive sample consisted of 16 Iranian women. Data analysis followed Diekelmann, Allen, and Tanner (1989). The results showed four main themes: (1) Perceiving myself in a different light; (2) Vitiligo: Worry about others' perceptions; (3) Vitiligo, Being influenced by cultural beliefs; and (4) Accepting and fighting the disease; Variations in experiences of living with Vitiligo. The women affected with Vitiligo during their marriage-ready years face various psychosocial problems such as rejection by associates, isolation, divorce, and forced choice of a single life. Key Words: Vitiligo, Phenomenological Study, Iranian Women, and Lived Experiences*

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### **Introduction**

Vitiligo is a progressive condition and a relatively common depigmentary disorder that occurs in 1-4% of the general population, and for which no effective treatment or cure exists (Parsad, Dogra, & Kanwar, 2003). In Iran, there is no accurate statistical information, but 0.9 –1.2% of the total population have been estimated to be suffering from Vitiligo. Esfandiar-pour and Afsharzadeh (2002) found a high level of distress in Iranian people with Vitiligo compared to the general population. They explained that 30.83% of the informants reported an incident of essential depression as a result of their Vitiligo, which was significantly more pronounced in women rather than men. It is more acute in the case of young women because it is associated with some traditional beliefs. This is more seriously felt among young unmarried women, mainly because of arranged marriages. Thus, a young woman with Vitiligo has little chance of getting married. A married woman developing Vitiligo after marriage is likely to have marital problems, mostly ending in divorce (Parsad, Dogra, & Kanwar., 2003). Getting this disease is especially distressful to our women because of the numerous problems facing divorced and single women in our society. Thus, it is an important skin disease, having a major impact on the quality of life.

Although numerous research studies have been carried out on the curing methods, etiology, and the mutual effects of the skin and the soul in Vitiligo patients, most of this research has used a quantitative methodology. It seems that the quantification of a phenomenon, which is essentially qualitative in nature, has led to the neglect of some

aspects of patient care, which are deemed important by the patients. A few qualitative studies were found that reveal the meaning of Vitiligo and its effect on an individual's quality of life, but these were carried out in countries outside of Iran (Thompson, Kent, & Smith, 2002). To address these issues, the present study achieved an understanding of how Iranian women experience living with this chronic, and appearance altering, condition.

A review of the literature suggests that nurses know very little about how to face this phenomenon. In addition, this study is the first of its kind carried out in Iran. Therefore, exploring this phenomenon by using a qualitative method could change the nursing care of such patients drastically, because employing a deep qualitative study can produce some technical information on the process of coping with the altered appearance, resulting from a chronic disease with a lengthy prospect for cure from the perspective of the patient. Nurses recognize the value of this personal experience because the nature of a disease (i.e., the ways in which patients come to recognize and experience their disease) has an important effect on how to go about designing their cure (Price, 2003). Likewise, as this disease entails a cure has still not been discovered after the passage of thousands of years, therefore the responsibility of the nurses to help such patients and reduce their suffering becomes more pronounced. Where no effective cure and no prevention is possible, the role of patient care looms important.

The idea of starting this research followed from the personal involvement of the first author. Also, before conducting the research the first author of this article had spent six months, three day a week, with Vitiligo patients, listening to their experiences. From a hermeneutic viewpoint, having such a background and personal experience would most likely not interfere with the first author's adequate understanding of the phenomenon. In fact, the values which were adopted by the first author, brought forth the research dependent concepts for the people addressed in this study (Byrne, 2001). A review of the literature also helped the lead researcher choose an openness dialogue approach in her interviews with participants. She would start her dialogue with patients without hiding her previous knowledge and experience from them. This frank approach by the researcher resulted not only in bringing her previous knowledge to a conscious level, but also encouraged the research participants to ask candid questions, to air their inner anxieties and reveal to her (the lead researcher) their real experiences. In fact, the two-way communication between the researcher and the participants, and the merging of their vision and horizons, would become operational.

## **Method**

The hermeneutical approach used in this study to analyze interview texts is briefly summarized here. The phenomenological research based on Heidegger beliefs is known as the hermeneutic or interpretive research. The objective of this type of research is to understand the concept of human experiences (Cohen & Omery, 1994). Walters (1995) adds that in a hermeneutic research, the researcher is an active participant in the process of interpretation rather than a passive receiver of information.

Hermeneutic phenomenologists interpret human experiences not only from the viewpoints of individuals under study, but also from social and historical effects (Dempsy & Dempsy, 2000). The idea of attaining the daily experience of people is compatible with Heidegger's philosophy, which emphasizes that the understanding and interpretation of people's experiences are possible through their language, history, and cultural factors (Maggs-Rapport, 2001).

Reeder (1985), when talking about the special application of hermeneutics in nursing, declares it useful not only for the purposes of the research, but also believes that joining hermeneutics and nursing produces an active ontology that results from the dialectic nature of experience and the numerous conceptual levels of nursing in action. It seems that considering the nature of the phenomenon of Vitiligo experience (impressionable by society, race, and sex) and the purpose of this study, hermeneutic phenomenology is a strong methodological choice to study patients telling their experiences.

A critical survey of the various viewpoints on hermeneutic phenomenology suggests that despite its shortcomings, this method is the best choice to be used in this research because none of the other methods serves us adequately in attaining the following objectives:

- Understanding human experience in the context in which it happens.
- Deep and all a round analysis of the individual.
- Presentation of the essentials of care based on the true understanding and interpretation of beliefs, convictions, interests, and values of the patient, and true understanding of her experience (Robertson-Malt, 1999).

### **Participants**

Participants in this study were selected from patients referred to the two dermatology clinics affiliated with Tehran University of Medical Sciences. These patients would come to the said clinics three days a week. Patients from all over the country core referred to them because of the centralized and specialized nature of these clinics,. After the lead researcher contacted the participants and explained the objectives of the study, and after completion of necessary constant informs by participants, they would start participation in the research. Whenever a patient felt that she wanted to discontinue the interviews or even exit from the research she was allowed to do so.

Patients were considered for inclusion if they had been diagnosed with Vitiligo for two years or more, and excluded if they had any other chronic illness or prior psychiatric history. They underwent various medical/surgical interventions in the management of their disease: Sixteen women that suffered from Vitiligo were recruited for the study. Thirteen of them were under 30. The other three were aged 32 - 42 years. Three of them were married and the rest were single. Persian was their first language. These people were undergoing various therapies ranging from treatment with a solution and edible corticosteroids to surgery, UV therapy, and Laser therapy. The recruitment ended when interviews yielded no additional data and provided rich descriptions of the shared meanings. Saturation had clearly occurred by the time the sixteenth informant had been interviewed in this study.

## **Data Collection**

Approval was given by the Ethics Research Committee of the Nursing Faculty, Tehran University of Medical Sciences, and the patients gave their consent. After gaining ethics approval, one-on-one semi-structured tape-recorded interviews were conducted in a private room in the dermatology clinic by the principal investigator. Interviews began with open-ended questions about what it means to live with this condition. Participants were asked, “How have these white patches affected your life?” “What have been the reactions of those around you (i.e., meaning members of your family, friends, colleagues, and ordinary people in the street) when they notice your white patches?” “Please explain your inner feeling and reactions when confronted with others’ comments about your problem?”

The informants were interviewed from one to three times, each interview lasting up to 60 minutes, and terminated when the participants indicated they had no more to share or the agreed upon length of time had elapsed. In order to achieve a rich data set we made use of field notes and probes at the time of interview.

Often the researcher conducting the interview would ask a participant to go back and recount her experiences mentioned in her interviews before. Then, the interviewee would mention some new points, which she had not covered before. The researcher would ask questions such as, “What do you mean when you say that these patches become more important with the passage of years” or “Why do you think that your husband only pretended that your disease was not important?” Such newly discovered information was very helpful in revealing the real and heartfelt reactions of the patient. Through the process of the interviews, the researcher would record and document all the extraneous reactions by patients such as their voice tones, facial twists, and other non-recordable reactions like tearful eyes, rubbing hands in anguish, and putting on their gloves nervously. To ensure the candid revelation of every nook and corner of the patients’ feelings, they were asked to submit any recorded material related to their diseased condition such as pieces of prose, poetry, and painting. The results added up to three manuscripts, which were later utilized in this study’s analyses.

## **Trustworthiness**

A consistent interview technique, involving open-ended, non-leading questions was adopted. Credibility (internal validity) of the findings and their interpretation were assured through a prolonged engagement with the data, also to ensure authenticity as advocated by Diekelmann, Allen, and Tanner (1989).

During all the phases of the research, trustworthiness was our center of attention:

1. Before starting each interview the researcher would try to approach the participant with an open question and allow her, thence, to lead the interview, refraining from asking loaded questions based on her personal experience. As a team, the researchers carried out the interpretation and analysis of the results. This choice helped to reduce the effect of any particular researcher’s preconceived ideas on the final outcome.

2. After completing the documentation of an interview and discovery of themes, we would re-contact a participant and give her our actual manuscripts to make corrections or changes as she wished. In some texts this method is also known as “member checking” (Aigen, 1995; Creswell, 1998).
3. Utilizing the services of an outside observer was another method we used. Creswell (1998) stated that an outside observer acts as a tax analyst to test the product and examine the coordination of data and output with the interpretation and final results. To this end, colleagues familiar with the content of the study were approached to verify the interpretation and consistency of the themes found.

### **Data Analysis**

Data analysis followed Diekelmann, Allen, and Tanner (1989). They described a process for the analysis of narrative texts. This method has been used often by nursing researchers, and can help researchers produce the highest interpretation level and attain a constitutive pattern in the phenomenon under study (Draucker, 1999). The hermeneutic analysis began when each member of the research team first read the interview text and identified themes independently, and added or changed the question for the next interview. Then, in a common session they shared their interpretations. The first common meeting went over the critical analyses of the interview and method of observation by the researcher. Omissions or unclear points were identified, and discussions were carried out about the need for further explanations. The first interview was made with a single seventeen year-old girl in her senior year in high school. After the introduction, and determining the period of time elapsed since the start of the illness, the first question asked of the interviewee was, “How did you feel when you first noticed a white patch on your skin?” She would give only short answers to questions such as, “It is bad, of course. One doesn’t feel good for sure, well, nobody really likes it.” This interview lasted only 20 minutes, at the end of which the interviewer thanked the participant for sharing her experience, and set the time for the next interview for two days later. On the same day, the interviewer transcribed tape recording and reviewed it repeatedly with frequent stops. In each review a new question was added to the interview guide, or a former question slightly altered, and the next day members of the team reviewed the text of the transcript.

In the next stage, the research team would identify the important themes, which were revealed by the participants. Links between previous experiences and the present situation were discovered, and the processes of interpretation expanded repeatedly by the writing and rewriting the transcripts until the selected passage from everybody’s story was produced. These passages were put to discussion by the research team. In all the interviews we considered the movements from part to whole and whole to part. This was accomplished first, by a detailed study of the recorded text, and then all codes were determined. Then, the whole paragraph would be reviewed and a general theme would be derived. In case of any differences of opinion among researchers, the original text would be reviewed, or a new interview was carried out with the participant. At this stage common features of the participants’ comments would be determined. It was here that the process of assigning code names was accomplished. In accordance with the researching

team's views, the coding might change with every fresh review and interpretation of the codes. Repeating this trend would enable the team to come up with a comprehensive interpretation of the participants' comments.

The principal researcher reviewed and interpreted the literature continually through the analysis. Data collection and analysis were simultaneously carried out. As a result of the hermeneutic circle movement, part to whole and whole to part, they gained a comprehensive interpretation of the texts and themes analysis.

## **Findings**

After the final analysis of the disease experience in affected women, four main themes were identified: (a) Perceiving myself in a different light, (b) Vitiligo: Worry about other people's perceptions, (c) Vitiligo: Being influenced by cultural beliefs, and (d) Accepting and fighting the disease: Variations in experiences of living with Vitiligo.

### **Perceiving Myself in a Different Light**

All of the participants talked about their initial ignoring of the white patches appearing on their skin, and then the period of fear and anxiety, which they experienced, following the spread of the disease. They also mentioned their feeling of shame when they found out the white patches were noticeable. Their own self image, influenced by their cultural background and others' reaction, in addition to their way of thinking, was different before and after their affliction.

Participants explained their feeling of being different from others in these ways. "When you notice that some parts of your skin look natural while other parts look whiter you get a bad feeling because you always think that others are constantly staring at you."

This is a repulsive disease which you cannot compare with any other. Skin troubles are worse than other diseases, and among these, Vitiligo is the worst and the ugliest. I always disliked those affected; therefore, I do not expect others to accept me with such a repulsive appearance.

"The people calling me 'Piss<sup>1</sup> woman.' It definitely did hurt me." The belief that they were different from others had several emotional and social consequences; for example, seclusion, depression, and anxiety. "When I was invited to a party, I refused. I stayed at home and cried." "I loved to study in a university, but I was afraid of everybody staring at my hands."

Those problems of life that cause disquiet drive some to escape mentally from recognizing the problem or its causes, giving a false sense of self-confidence, one that cannot sustain itself.

### **Vitiligo: Being Influenced by Cultural Beliefs**

Review of historical studies show in Erodoto (480-425 BC), in the Clio, the foreigners who committed a sin against the sun had white patches and had lived removed

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<sup>1</sup> Equivalent with Vitiligo in the Persian language.

from society. Vitiligo and other skin-lightening diseases, and the stigma from these lesions, were seen as a punishment by God for sins, or at least, moral and spiritual impurity (Kopera, 1997).

Still most traditional beliefs were attached to the disease. Some cultural beliefs mentioned by participants in this study were,

I don't know why it happened to me. Some say that I have eaten pickles with my yogurt; some say I have slept in a bad location; personally I think I got this disease because I used to eat raw meat as a child. Some say that I will never get well.

"Once I donated some blood; I think that did it."

Others' behavior concerning this disease was due to their lack of information and was based on their cultural beliefs, which had no scientific or religious basis. "My sister-in-law (husband's sister) says that this disease is a form of uncleanness. A person who has this disease is surely unclean." "A neighbor came to our house. I offered her a cup of tea which she declined, saying later that she was afraid it might be catching." "My friend tells me how my children feel when I give them some food to eat. She wonders out loud how I can prepare food for my children with these hands."

I was about to get married but when my partner found out about my disease, he said: "I am confident about your chastity, your ladylike qualities, but I am afraid that I might catch your sickness. This was the worst calamity which befell me as a result of my disease.

This view of the patients form the basis of others' behavior towards the disease or what the disease means to others, and in turn what it means for the women experiencing it. For example, when a patient is labeled "unclean" by others, people will discontinue their relationships with her, and this will cause psychological problems in the patient. The participants had this to say about the effect of others' behavior on their lives.

"My aunt says her neighbor was affected and the white patches appeared on her face. Her husband felt sick whenever he looked at her, and finally he left her. When I hear such grim stories my nerves are shattered."

People say that during old age these patches turn cancerous and horrible wounds which are intolerable appear in their place. Some repeatedly ask what those patches are. But I would not answer because I don't even know the name of the disease. I became so nervous I had to take tablets for a while.

"Whenever my mother -in-law looks at me she heaves a sigh and mutters that God may cure all the sick!"

The sources of information, which had influenced the patients' understanding of the disease, come from other patients, their own friends and associates and occasionally from doctors themselves. None of the patients knew much about the disease itself, treatment, or its side effects. Some patients even erroneously attributed the redness

resulting from a burn to a color change leading to a cure. For example, a woman who was showing her reddened white patches to the researcher happily exclaimed (Pointing to the reddish patches), “Look! Fifty percent of my patches have disappeared and the rest of them are getting better.”

After a periodic meeting with her doctor, she found out that to the severity of her burns she had to reduce the dose of her radiation. She became so upset she discontinued her therapy for a while.

The lack of information by patients, of the trend of their cure and side effects, was so pronounced that some of them preferred to tolerate their pain from burns and would not inform their doctors lest the latter might reduce their ray sessions, and thus prolong their cure process.

This problem among the participants in this research had reached such proportions that two of them had this to say, “My burns had become so severe that I discontinued my therapies. I was bedridden in my house. Nobody helped me with bandaging my burns. Everybody acted repulsively toward me.” “My back was so swollen with burns that I was forced to walk all through the night. You have no idea how much I suffered just because I wanted to get well.”

### **Accepting and Fighting the Disease: Variations in Experiences of Living with Vitiligo**

A different sensation and behavior appeared in patients after they were informed of their disease: anxiety, because of the lack of adequate information about their disease; depression due to their repulsive appearance; and fear of the spread of the disease. The patients’ reaction to the spread of the disease was also different and showed itself in the forms of acceptance or non-acceptance of the disease. One of the participants said, “Iran and Iraq fight for eight years, but I and this (Vitiligo) are fighting for thirteen years and anyone have not victor yet”

It seemed that some patients were able to accept their disease. Factors which led to their acceptance were based either on logic (so that they accepted the disease as one of the common occurrences in life, which they accepted appropriately) or they attributed the disease to God’s will, or even came to like their disease as a means of redemption of their sins.

I was affected during childhood and shed as much tears as I had plenty of, but as I grew older I came to believe that it was no longer important and I got used to it. I tried to look upon the disease top down. When you pass the submission state and come to yield to God’s purpose, then everything seems all right to you. I asked God to grant me the tolerance of this pain not its cure, because I was certain that current medical science offered no remedy for my disease.

First, I was frightened, but after the passage of some years I came to understand that getting sick was a part of life. All people moved on a spectrum of health and sickness, and the distance between the two was only a matter of seconds.

“I am a reasonable person and I think that whatever God chooses for me must be good. I have heard that when a person gets an incurable disease her sins will be forgiven.”

Religion was a supportive factor for the acceptance of the disease in some of the participants. Some considered their appearance repulsive, while others felt proud that God had chosen them for such ordeal. They said,

I tell myself that God has chosen me for this ordeal. I wish he had done so in my youth, but since he did it in my childhood, I suffered a great deal.... However, in exchange for this pain which he had bestowed on me he opened for me other vistas: He made me to know such great people.

“I think God liked me so much that He affected me with this disease lest I should meet with bigger miseries.”

On the other hand, some patients still had not been able to come to terms with their disease even after the passage of many years. They reported such behaviors as seclusion, deep sorrow, and aggression, and even decided to commit suicide. They declared,

This is the worst disease of them all. A person who has a heart condition or even cancer is in a much better state. A person with heart disease is more at ease with society. A person with Vitiligo is singled out by others. Since I got this disease I decline invitations to parties and always come up with excuses. When the rest of my family go out I retire to a corner and cry my heart out. Many a night have I kept crying until morning. Sometimes I felt so miserable from hearing others' incessant comments and questions that I had evil thoughts in my mind: I would pick up a knife to cut my hand's artery or pour some kerosene on me to set my- self on fire.

Patients classified their barriers to adaptation into three categories: the state of their disease, the availability of a mirror, and the negative reaction of others who surrounded them.

No way can you adapt yourself to this disease. When you look at yourself how can you adapt? No one can sympathize with you and say you never mind. Observing the society we notice that the majority of patients who get married develop serious problems. Tell me how you really feel when you walk about in society in your present condition.

Even if I wanted to ignore my condition the mirror wouldn't let me. I hate mirrors, and I hate being photographed. Even when I pass by shop windows and in advertently look at my image my nerves are shattered.

“Worst of all is the repeated questioning by others.... Oh, dear, Zahra, why have you become like this? Oh, what a pity! Why don't you get better? Go see a doctor...Nobody will propose to you, and...”

### **Vitiligo: Worry about Other People's Perceptions**

Most of the participants believed their appearance was undesirable and became preoccupied with the disease, to the extent that it might be thought of as “saturating” their identity. They said, “I work in a hospital. The patients stare at my hands. Some of them think it is scar of burn but others asked me what it was.” “I was worried that I probably looked strange.” “I got concerned when visit new persons. I am not like everybody else. It is a very uncomfortable feeling” “If I went to a coffee shop, I would be thinking everybody was staring at my hands and I was really self-conscious.” “I was worried about what other people thought of me. I don't know, I just felt a bit ridiculous in a way but it changed how I felt about myself.” The reaction by people is the most important factor, which affects adaptation or non-adaptation to the disease by the patient.

The family is an important source of the social order in eastern culture, and the role of mothers, husbands, and mothers-in-law is the most pronounced. It seems that the special importance of the husband's role is due to his power to divorce. Because of the numerous problems facing divorced and single women in our society, getting this disease is especially distressful to our women, and their husbands' reaction and comments are fateful. This case has even affected a high percentage of single sick girls so that some of them avoid getting married for fear of an ensuing divorce.

"The worst thing that happens to you is the ridicule of people and their derisive looks, especially those of one's husband. Your husband might even hate you for it." "I am worried about my future! I dislike marriage because I am afraid of divorce!!" "I got the disease after I was married, and my mother-in-law put a great pressure on my husband to divorce me, saying that if I get pregnant my children will also be affected"

In summary, worrying about others' perceptions is a tremendous issue, which these women often face, that disrupts their everyday life.

### **Comprehensive Interpretation**

In a comprehensive interpretation the text was considered again as a whole. The general understanding, together with pre-understanding of the researcher and literature, were reflected and combined into a comprehensive interpretation. The interpretation reveals that a white patch has a major impact on the patient's experience. Body perception means “being an ill individual and being marked.” The patients' felt stigmatization caused differently from others was in line with the theory of self – awareness. Coleman (1997) stated that human differences are the basis for stigma and those individuals who have differences may feel permanently stigmatized in situations where their differences are pronounced, Coleman further asserted that stigma mirrors our social and cultural beliefs, which, if so, and unless social attitudes change, could mean that the stigmatized individual will continually be struggling against the grain. Picardi Abeni, Melchi, Puddu, and Pasquini (2000) stated that at first psychiatric disorders may often come up as a complication or a consequence of a primary skin disease, in reaction

to disfigurement, perceived social stigma, or undesirable changes in one's life-style resulting from a skin disease.

### **Discussion**

This study demonstrates the numerous problems facing Iranian women affected with Vitiligo. A number of similar problems are also recorded in some of the studies in western countries (see Thompson et al., 2002). Some of the problems facing western women appear more severely in Iranian women due to cultural and statutory reasons.

One of the findings in this study is "perceiving self differently from others." Thompson et al. (2002) uncover a similar theme in Caucasian patients with Vitiligo in England. The core issue for the sample was an awareness of being different from others. They said, "After an initial recognition of difference, and also recognition of it by others, the participants became preoccupied by its effects and on how they could manage to contain them" (p. 222).

Firooz et al. (2004) showed Vitiligo has strongly affected the patient's self-esteem in 57.5% of 80 Iranian patients. Similarly, studies have also investigated the psychosocial impact of Vitiligo. Balkarishnan et al. (2006) has pointed to the multiple studies of Porter et al., (1986, 1987, 1990) who showed the effects of Vitiligo on reducing self confidence compared with other patients, and problems such as social repugnance, problems with sexual relations, and embracement in patients affected with Vitiligo. Also perceiving self differently from others was reported in other chronic diseases (Monto, 2003, Van Brakel & Global, 1999). Priddy (1999) argued that one thinks, feels, speaks, and acts mainly in accordance with one's self-image. It follows from this that a change in self-image can initiate corresponding changes in behavior. If one has a weak, distorted, or inflated self-image progress will be affected. Confidence in oneself obviously builds on knowledge of one's actual nature and potential development, not in continually dwelling on failings or sins.

This study also showed worrying about other people's perception is a difficult haze. The other studies confirmed this issue in persons with a skin disorder (Kleve, Rumsey, Wyn-Williams, & White, 2002). Humans are social in nature, and development of self-image and personal identity is influenced by interaction with other members of the society. The presence of a visible skin lesion perceived as abnormal on the face or body can result in significant psychological impairment (Lanigan & Cotterill 1989; Mills, Hughes, & Lanigan, 1994). For example, individuals with port-wine stains felt that their skin lesions exerted negative effects on self-esteem, social and sexual relationships, education, and their ability to get a job. (Troilius, Wrangsjö, & Ljunggren, 2000)

One important finding was the role of cultural beliefs in the perception of self and other concerns in these persons. They become part of the way that individuals' experience events both within their own bodies and beyond it –and the meanings that they give to these experiences. In dermatologic studies it explains that religious beliefs influence negatively the quality of life of Indian women with Vitiligo (Parsad, Pandhi, Dogra, Kanwar, & Kumar, 2003).

Mattoo, Handa, Kaur, Gupta, and Malhotra (2002) explained that most patients felt a deep sense of shame, which led to a drop in their self-confidence and social isolation. Affected patches on the face and hands, and open areas of the body, increased

the feeling of shame; and the resistance of these patches to treatment brings about a feeling of anger and detachment. To avoid being cast out by the society, such patients chose to stay away from the crowds. Sometimes even an encounter with their friend could be quite hurtful.

The effects of such factors are so great that attempts to commit suicide by these people have been reported (Cotterill & Cunliffe, 1997). The most significant provoking factor which emerged from this study is other people's behavior. The way patients are looked upon by others and other people's reaction to them, which is primed by their thoughts and erroneous beliefs about the disease. Beliefs such as the contagiousness of the disease, its changing into skin cancer, and the untouchability of the patient, which were not mentioned in any of the quantitative types of research carried out even in countries with a rather similar culture such as India (Parsad, Pandhi, Dogra, Kanwar, & Kumar, 2003).

Another significant point in this study is the role of religious beliefs. As seen in the comments by participants quoted in this research, patients who were able to adapt themselves to the disease believed in God's will and attributed their success in adaptation to their seeking help from the supreme will of God. On the other hand, humans as social beings need protection from society, the importance of which in stressful situations has been proved. The importance of social protection is that it leads to the acceptance of the individual in multiple groups (Baumeister & Leary, 1995). Important people can assist these patients in facing their problems by their proper approach and courses of action. Also, the revision of civil laws is necessary in view of the fact that Vitiligo causes no particular problem in marital relationships. Most affected persons were anxious of becoming lifetime bachelors or divorcees. The effect of this disease on the quality of life has been studied by Kent and Alebadi (1996).

The results have practical implications in nursing. Dermatology nurses need to become skilful in addressing these areas as part of a holistic assessment of the needs of the patients and their families. Nurses need to appreciate how the domains of culture should be used for data collection, with the purpose of identifying the specific cultural needs of patients and their families. They are also of particular significance to the field of dermatology nursing practice. Cultural assessment also offers the opportunity for identifying potential differences between the value systems of the practitioner and the patient.

As a limitation of this study we can mention that the affected divorcees showed no desire to participate in this study and said they were too distressed to recall their stories. This study may not be generalizable to all patients. Further research work is required to determine the living experience of divorced women with other cultural backgrounds and in Iranian women who live in other societies

### **Conclusion**

Women affected with Vitiligo during their marriage-ready years, in addition to their mental problems resulting from a skin disease and marred beauty, face various other social problems such as rejection by associates, isolation, divorce, and forced choice of a single life. On the other hand, such women do face some problems with their treatment. The result of understanding such problems can be utilized in the nursing care of these

patients. It seems necessary to combine psychotherapy with routine skin treatment. As there still is not a certain cure for Vitiligo, breaking the stress-disease-stress cycle with support and psychotherapy will help toward the improvement of the disease. A practical method of caring for these patients is increasing the awareness of society members, especially the patients themselves.

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### Author Note

L. Borimnejad, as principal investigator, co-designed the study, interviewed, analyzed, and interpreted the data, and wrote the first draft. Dr Parsa Yekta coordinated in the study design and data analysis, and contributed substantially to the revision of the article. Dr Nikbakht Nasrabadi contributed to the design of the study and assisted with data analysis and revision of the article. All the authors approved the final version submitted.

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