



Research Article

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## The challenges facing with vitiligo: a phenomenological research

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### ABSTRACT

Vitiligo is a chronic acquired skin disease in which epidermal melanocytes disappear. The disease is manifested as areas of depigmentation. Reason for destruction of melanocytes is uncertain but potentially pathogenic mechanisms, include genetic, neurological, biochemical, viral and autoimmune mechanisms. 0.5 to 2 percent of the world's population are infected with the disease and statistics about Iran is equivalent to global statistics. Thus, the aim of this study was to evaluate the participants' experiences with vitiligo regarding challenges of the future. It is a qualitative research with descriptive phenomenology approach. It was performed through semi-structured interview with 10 patients referring to dermatology clinic in Zabol and Zahedan hospitals using targeted sampling in 2015. Colaizzi method was used to analyze the data. The main themes describing experiences of people with vitiligo include: Permanent expectation for better treatment future, job prospects, hereditary disease, and forming a family. Results showed that some challenges threaten future of people with vitiligo and influence their life. Family and society are considered as main factors which influences future of people through culture making and increasing awareness. Also, psychiatrists, doctors and nurses should be aware of the patients' experience and attempt for greater understanding and try in raising the morale of patients and correction of body image and self-esteem and body care.

**Keywords:** Vitiligo, descriptive phenomenology, Colaizzi approach, concern for the future, live experiences

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### INTRODUCTION

Vitiligo is a chronic and progressive disorder which appears due to loss of pigmentation of the skin and mucous membranes. The disease is a chronic idiopathic disorder characterized by the occurrence of one or more depigmented spots due to loss of melanocytes in the skin. White patches create painful appearance for the patient [1]. Reason for destruction of melanocytes is uncertain but potentially pathogenic mechanisms, include genetic, neurological, biochemical, viral and autoimmune mechanisms [2].

About 0.5 to 2 percent of people in world are infected by vitiligo and this prevalence is identical for all races in all countries [3]. Prevalence of this disease in Europe and USA is 1 percent and it is estimated as 8 percent in some parts of Indian. Vitiligo prevalence varies in different communities and it is higher in developing countries. There is no much exact figures in Iran, however it is estimated that its figure is equivalent to global figures [3, 4].

About half of the patients with vitiligo developed their disease usually in childhood or adolescence, and clinical symptoms disease begin before age 20 (50%), while in 25% of cases it starts before the age of 14 years. Today, numerous studies mention significant prevalence of feelings of deformity, stigma, depression, anxiety, paranoia, agitation, obsession and Melancholic emotions, irrational negative thoughts, personal or sexual damaged relationships and quality of life in adult patients with vitiligo. It has a profound and permanent impact on the quality of life for these patients, especially young people [5-8].

Appearance of the skin can determine the status of each individual incarnation of himself and any pathological changes in it can result in psychological results [6]. Due to changes in a person's appearance, vitiligo patients often experience psychological stress and suffer from social stigma [9].

Khattari *et al.*, Firooz *et al.*, Ahmed *et al.* studied high level of complication disorders in people with vitiligo. About 31 percent of people with this disease considered major depressive episodes as a result of vitiligo, which is significantly more common in women than in men. This problem is more acute in younger women because of their age related properties. It is strongly felt among unmarried young women due to reaching the age of marriage. Because young women with symptoms of vitiligo are less likely to marry. The disease is extremely stressful for women. Marital problems, divorce and remarriage in in married women with progressive vitiligo have also been reported [10-12].

Patients with vitiligo are blamed in some cultures because of the unknown factors that affect the incidence of the disease [13]. According to some particular cultural values, family members of the person with vitiligo disease are not unable to work, marry or engage in social interactions and are ostracized from society [13]. Besides of social problems in Iran, these patients face with serious family problems and it seems that they do not receive sufficient support even from their families. So many these people are embarrassed and anxious because of their problems and are discriminated in many aspects of their lives, even many doctors downplayed the disease and increase the difficulties of these patients [14].

Although many studies have been conducted on methods of treatment, etiology and effects of vitiligo on skin and the soul of patients, but most of them have used quantitative methodology and qualitative studies are scant.

Very few studies are present regarding the psychological impact of the disease on quality of life in young patients with vitiligo. In these studies, more than half of people with vitiligo patients stated that strangers stare at them, 20 percent stated that they are titled and considered as rude and one third stated that to communicate with strangers is very difficult [14].

Borimnejad *et al.* in a qualitative study on experiences of women suffering with vitiligo introduced four main themes that include: finding yourself in a different viewpoint, vitiligo "worry about understanding others", vitiligo affected by cultural beliefs and acceptance, battle with the disease. Changes in life experiences of women with symptoms of vitiligo: these women during marriage face with a variety of psychological problems such as rejection by wife, separation, divorce and forced unmarried life [13]. Also Rafique conducted a research entitled as experiences and coping behaviors in adolescents with alopecia areata in Pakistan using interpretative phenomenological method. The study examined experiences of adults with ages 15-19 years with alopecia areata and introduced the factors leading to behaviors of acceptance of their disease under four main themes: deficiency (self / social), concerns (physical / future), negative (emotional / thoughts) and acceptance practices (tackling disease) (adaptive / deformity). Women have experienced more feeling of deficiencies, and were more worried about their future and reported more negative thoughts and feelings [15].

Considering that, after many years still no cure has been discovered for this disease, responsibility of nurses to help patients to reduce pain and suffering is greater [13]. Because there is no effective treatment and prevention for this disease, and permanent treatment of these patients is unclear, results can increase public, society and people awareness to the disease and influence planning in service organizations associated with the disease.

This qualitative study was conducted using descriptive phenomenological approach aimed at understanding the experiences of patients with vitiligo. Qualitative research methods have tried to emphasize on the belief that there is no just one truth and the truth is a combination of facts, they describe human complexity. These methods are sought to understand and explore the world of human experiences, because each person's experiences shape the structure of the truth to him. Thus, the researcher can discover meaning of phenomenon from their point of view just by entering the world of people's experiences. Therefore, to explore the phenomenon, he enters to the world of the participants and introduces the phenomenon from their live experiences from point of view [16].

Importance of understanding these experiences is so that expressing experiences obtained from working with patient helps science production and development of nursing knowledge. As stated by Banner, expressing experiences and facts of life is the main axis of learning through experiences and leads to clinical development and skill. Expressing experiences and facts causes that users apply them in the clinical activities [17]. Current study aims at evaluating understanding and perception of people with vitiligo so find their future challenges with different appearance and chronic conditions.

Considering reactions to diseases vary in different cultures and it is better to investigate these reactions in cultural texture of each country, current study was conducted aiming at understanding live experiences of people with vitiligo regarding their challenges.

## MATERIALS AND METHODS

Since current study aims at evaluating live experiences of people with vitiligo regarding their challenges, it is a qualitative research of descriptive phenomenological type. Qualitative research is an organized and mental method which is utilized for describing life experiences and obtaining their meaning. Phenomenological study is derived from descriptive and inductive and it is from the philosophy of phenomenology. The emphasis is on understanding the nature of phenomena. This emphasis of this philosophy is not only on understanding certain parts or part of a person's behavior, but its centrality is understanding total existing human responses [18].

Research population included 10 people with vitiligo referring to dermatology clinics of Zahedan and Zabol hospitals in 2015. 3 women and 7 men with average age of 27 years took part in the study. Targeted sampling method was used for sampling and in-depth interview was used for data collection. Average duration of interviews was 45 minutes to 1 hour. Overall 11 hours of interviews were performed to achieve data saturation. The items in in-depth interview provide an opportunity for higher freedom of action in the responses. Firstly such open questions as "what is your experience" were used. There is no specific answer for these types of questions, but they enable the respondent to describe the phenomenon under study freely. In addition, the author takes note to record observed cases, interactions, relationships, environmental conditions, and non-verbal motions. Following selection of participants based on inclusion criteria, such as having vitiligo, being literate and ability to express experiences, necessary explanations were given and their content for interview was taken. Then time and place of interview was determined with consulting with participants, and majority of interviews were conducted in the home of participants. Data collection and analysis was done simultaneously. Interviews were tape recorded with satisfaction of participants and then were transcribed totally. Axis of questions included life experiences since start of disease until now.

The bracket was developed based on the concept of Husserl. Researcher recorded assumptions and hypotheses regarding the phenomenon under study before entering the study so that it has no effect on study during obtaining participants' experiences.

In this study, the analysis of data was done using seven-step Colaizzi method. First, descriptions of all participants were read to feel sympathy with them. Second, the protocols were referred to and important phrases were extracted. Third, the meaning or concept of every important phrase was shaped which was formed under the title of concepts by researcher. Fourth, set of concepts were organized into thematic categories. Fifth, the findings were integrated into a comprehensive description of the phenomenon. Comprehensive description of the phenomenon was formulated in the form of an explicit statement. In the final stage the results were returned to participants to verify and their ideas were taken regarding the findings [19].

In order to achieve validity and reliability of data, four criteria of data reliability and qualitatively findings via credibility, reliability, authentication and transferability were used. To increase credibility, researcher took long-term involvement and continuous observation. Some interviews were analyzed by research colleagues in a randomized study chosen by them and finally, compared with researchers as well as a review by the participants. To achieve reliability in the study, interviews were heard and transcribed and analyzed by another person. In order to achieve the information objectivity, external audit was performed. In order to increase transferability of data to other similar groups, the research utilized perfect research design introduction with selection of participants with highest difference [20].

In the current study, ethical considerations were taken into account with informing and gaining consent of participants for participation in the research and recording their interview and anonymity of interviewees, and secrecy and confidentiality of information and the right to withdraw at any stage of the research were presented.

## RESULTS

Following analysis of data taken from interviews based on Colaizzi method, major research themes included: Permanent expectation for better treatment future, job prospects, hereditary disease, and forming a family.

### **Permanent Expectation for Better Treatment Future**

The increasing development of science, stem cell therapy, expansion of day-to-day internet, the development of herbal treatments are the constituent elements of this theme. Despite of ineffective therapies available for the treatment of vitiligo, patients ever hope to escape this disease. A person who spots occur in childhood always hope for a new treatment for life for getting rid of the disease. Some patients gain hopes after hearing about the success in treating patients with stem cells to treat their disease. Another factor which always creates some hope in the patients is using the Internet. A lot of information that is published in the daily virtual space and the large number of internet users keeps patients as hopeful to think about new and decisive treatments. Also herbal treatments have been developed in Iran and some doctors are educated in the field of traditional medicine, and a few of them in the country has become famous and patients from far and near refer to them.

Participant 3, who is a 27 years old young person, states:

“After the onset of the disease, I read a lot of books and searched on the Internet, I went to different cities of Iran for treatments. I experienced laser therapy and used different solutions and tablets. But that was expensive and the result was too low. I always hoped life. I seek for being treated with stem cell therapy in Tehran. I saw the news on television introducing this method. I hope the day comes when a cure is found.”

“Not only there is no specific medical method for it, but also you have to tolerate so many drugs and experiments which are not effective. When I saw they are ineffective I did not use the medicines anymore. Because there was no impact. In addition, when I used them, my hand skin got thinner so that it seemed it is to be bleeding. However, I still live hopefully. Recently my spouse asked me to look at new treatments...” (Participant 2)

Participant talked about ineffectiveness of treatments and their high cost:

“...it is true that this disease has not much impact on the health, but I felt much sorrow. I wish I did not suffer it. The doctors say there is no treatment, but they prescribe some solutions and tablets for patient satisfaction. I have done many experiments up to now. As you see, the number of these experiments is high. That is, we spent considerable money for doctors in order to get well, but there was no result. (After a pause) anyway, they attempt, but nothing was obtained...”

### **Job Prospects**

Natural limitations, imposed restrictions, and ignoring the interests are constituents of this theme. Threatening challenges are different in males and females with vitiligo. For not showing the symptoms, men and women are forced to hide spots and have to use more of clothing and grooming. When working outdoors exposed to more sunlight and air dust, they are forced to use more coverage which would surprise others in hot weather, and consider it as a kind of hiding symptoms. In job interviews for works in direct contact with customers, either they are not accepted by the employer, or if accepted, they prefer to work in areas that do not have direct contact with clients. Every person in life considers a job for the future career. But those who have symptoms from childhood are facing various social problems and isolation and they cannot think of any kind of job. For example, a physician if has this disease, his patients may not trust him. Or if the person would like to become a singer, he must have an attractive appearance. But with vitiligo, he have to ignore many wishes.

This is experience of job selection by Participant 8:

“...employers have special views regarding recruitment of people for the job which they pay. For example, I went to an airline agency to work, but they did not accept me because of spots on my face and they looked for a woman with beautiful face. These are limitations.”

Participant 1 states:

“Firstly it was not evident and it did not bother me. But in recent years, when I went to Chabahar or outdoor it was seen more and I was bothered. Especially I have to cover my head and face in hot weather. Others did not say anything, but I had told to coworkers in the workshop that it is not contagious disease. We worked in the same place and even ate food in the same dish. They did not have any problem, but I was not comfortable. I felt they think I cover my face because of them. I had to get retired after 20 years because of this issue and I followed farming because I work alone and I feel better.”

Regarding selection of future job, Participant 6 states:

"...selecting job is very difficult for the person that symptoms of disease appeared in childhood, because it is like to be a dermatologist who has no hair and is going to consult a person with hair loss. Of course that client does not ever trust in the doctor. Thus, you should be careful about destination which directs the one's life and influences job selection in the future."

### **Forming Family and Challenges**

Socialization and marriage is a great challenge of life and constituents of this theme. Socialization and be active as a member of the society is correlated with successful marriage and increasing couple's understanding toward each other. Considering the problems in socialization of people with vitiligo they may fail in marriage and its success in the future. People with vitiligo symptoms from childhood always have concerns on marriage. It is more serious regarding women so that they prefer to stay single for life time instead of frustration. However, men pursue marriage more serious and look for a wife which firstly can accept them. To this end, they prefer marriage with relatives and they feel they can deal with it better, and chance of marriage success is higher due to their previous familiarity. If it is accepted that inheritance also plays a role in disease, chance of disease emergence in the next generations is increased with relative marriage. The other issue which people with vitiligo have to tackle before and after marriage is future of the children. In the development period of children, the main concern of parents is emergence of disease in them, and they react with the slightest skin symptoms that appear in their bodies. This sensitivity is higher regarding female children, because the main preoccupation of family is their entry to the society and marriage.

Participants 5 explains about his marriage:

"...I did not face much problem regarding marriage and proposal, because my aunt's husband had also this disease and my wife and my cousin. Too early I got positive response. Because I think we completely knew each other. But I want to say that this was not so simply with my friends with this disease. The whole marriage and socialization process is so hard. "

Participant 6 states:

"Of course after proposal I talked about my skin problem with my future wife, and as I told you, spots were not still visible to cause frustration. Because the God does not take everything at once. He takes one thing in turn of another thing...it is not worrying for me, but inheritance from this disease may be very big problem, so that some people conflicted with this disease have new born child also with this disease. Or I think if it appears in the grandchildren, what their blame is, and they have to encounter many problems."

Participants 7 (female) states:

"I believe that one way for being successful in marriage is being active in the society so that people in contact get familiar to individual's characteristics. Considering negative views in the society, marriage issue is more difficult for women. My friends have very bad memories. They got proposals, but they were ignored after informing the disease. If the reality is hidden, even after marriage, men can act for divorce with the excuse of lie and fraud laws. Finally I believe that God had specified destiny for humans and at the end it happens."

### **Hereditary Disease**

Such factors as unhappiness of parents about the hereditary disease, hereditary as a tool for non-curability of disease, feeling guilt and hereditary remain for future generations. Participants believed that when there are no certain specified reasons for the occurrence of a disease always hereditary factor for disease also arises. When you go to a doctor, the first thing that is told to patients is that it is a hereditary disease and it is possible than one person was inflicted with it in previous generations and now you have it. Therefore, because it is hereditary and there is no reason for it, it does not have obvious treatment, and only a series of treatments can be done to control it. When the disease is diagnosed and it is informed to the family as well as the introduction of hereditary disease, psychological problems occur for parents. Because they blame themselves for the disease and creating problems for their children, and this issue affects the whole life. Individuals experience different events by growing older in the lie. One of these events is constituting family and creating new generation. But considering many problems and challenges which the conflicted individual dealt with since childhood regarding the disease, he may ask why to generate people who may get this disease in the future and face serious problems in this regard. These are factors which affect hereditary of the disease.

Participant 3 describes reaction of parents regarding emergence of disease:

"... My father died when I was a child. When I was in fifth grade, these spots appeared. One day I noticed three white spots below my knee. First I thought I might fell while playing soccer and my skin was torn, but as I looked at my skin I saw no sour. I came home and showed it to my mother. My mother reflected and said my son, these spots

are a bad sign and said some prayers ... But she said no one was inflicted by it. I felt that my mother is always upset with me and felt and guilty.”

“... Every doctor I went they said there is no particular reason and there is the possibility that someone in your family was suffering. But as long as the symptoms of itching and pain do not hurt you, why you follow it. They gave some synthetic drugs in order to help to control the symptoms better. They asked to control such things as food, stress and anxiety ... because there is no known cure nowhere in the world, because it is hereditary. These statements were repeated over and over. When the number of my questions and follow-up got more for doctors ... (participant 6)”

Participant 7 describes:

“...With a look at the past and the problems which I encountered after emergence of symptoms, thinking about marriage and creating new generation, which may also suffer from this disease if it is hereditary, bother me...”

## DISCUSSION

Current study showed future challenges of some people with vitiligo. Internal and foreign studies have addressed different issues of people with vitiligo, however, most of them are qualitative studies and there are a few number of qualitative studies. Considering religious, cultural and social backgrounds governing the society, problems and difficulties of people is more serious. Comparison of research findings showed that people encounter various difficulties which vary in different communities.

One of the themes of study is permanent wait for better treatment future for this disease. Patients expect that since is developed so much that it can eliminate their problem obviously. Despite of frustration and futility of treatments, they always look for new treatments. This issue has become the permanent expectation in their life. Following studies support this finding.

Sulochana et al. in their study entitled “Factors affecting life quality of people with vitiligo”, introduced treatment issue as one of the essential factors affecting life quality. All people with vitiligo experience Invasive and noninvasive methods, chemical and herbal medicines, traditional and non-traditional methods in the world. Considering characteristics of individuals, they have positive and negative impacts on their psychological, social and economic conditions. These reasons never frustrate them to follow-up the treatment and they expect that one day finally they can take advantage of these treatments [21].

Borimnejad et al. showed that follow-up of different treatments by individuals with vitiligo is one of the actions taken by them. They may suffer from different psychological harms due to different medical follow-ups which negatively influence their well-being and symptoms, and they may feel it as a chronic disease. Also, follow-up of different treatments influence spirit of patients [3].

Sokolova and Smith studied on the results of inconclusive treatments in chronic inflammatory diseases of the skin in children and suggest that while there is no effective treatment, taking different treatments has bad effects for the patient and his family as well. In such patients, there must be a regular schedule. Following treatments keeps alive the hope in the human, but can cause lot of physical and mental harm to humans [22].

The other finding of the study is worry for future job. These patients cannot choose their job based on their interests and have some limitations in this regards. Their life period is influenced and they sometimes are surrendered to the destiny. Various limitations affect their job prospects.

Grag and Sarkar stated that diseases which influence the skin and are visible by others influence many interests and favorites of the individual. One of the interests of patients which is affected is selection of job which also influences his future and parents will also face problems. They never can be successful in job selection similar to normal people. Thus, the patient needs considerable social and cultural supports [23].

Ibler and Jemec concerning total deficiency of life state that if skin disease is visible on the face, one’s eagerness for job selection in the future is affected. Considering the body image and self-confidence is reduced in the patient, selection of job in the future face problem. Because these people have defected socialization factor, which is an influential factor in selection of job. In addition, working capacity is also reduced [24].

The other finding of the study is inheritance of the disease. As stated by the participants, their main concern is inheritance factor which fails frequent follow-ups for treatment and lack of presence of obvious treatment for the

disease. After frequent visits to doctors, they are told that the disease is hereditary and since it does not bring about special physical problem, they are discouraged to follow the treatment. Because there is no treatment actually for it due to inheritance factor. Also transmission to future generations means involvement of other people in the future to the disease and creates many problems for patients who feel conscience.

In this regards, Esmaeili *et al.* studied 16 patients with alopecia areata which is a chronic skin disease. They considered that success and failure of treatment depends on various factors such as: age, extent of the lesion and the patient's personal preferences [25].

Also Fadaee and Firooz in their study entitled as "Clinical guide for evidence based treatment: vitiligo, success or failure" mentioned following factors: skin color, race, age at onset of disease, mental health, the halo nevus, a history of autoimmune disease, quality of life, disease situation in the past six months, history of pigmentation, the Koebner phenomenon, involving the genital area, photography, history family (vitiligo, premature graying of hair, autoimmune disease) and previous therapeutic interventions [26].

James *et al.* stated that in hereditary diseases, parents feel guilty for spreading the disease to their children and future generations. Concerns about the dangers of reproduction in disease transmission causes feeling guilty and sin in them. Feeling guilt and blame for emergence of disease problems in children is observed in parents who are suffering from genetic diseases [27].

Forming family is the other finding of the study which includes marriage sub-themes. It includes marriage as great challenge of life and genetic disease for children. According to statements of participants, every young individual wishes to get marry and marriage to a person with vitiligo is regarded as a challenge and affects one's life. Type of challenges in the female and male patients is different which is more observed in women. Anxiety and worry about confrontation and contact with the opposite sex, who may have different views and wishes, occupies one's mind. These factors causes many worries.

Fatani *et al.* introduced vitiligo as an obstacle in socialization of the individual. In addition, socialization problem is an obstacle for marriage. 42 percent of research subjects did not tend to marry. For successful marriage there is need for interactive relationships for better understanding of couples. In this regards, women have many problems, and thus they do not have much tendency to marry [28].

Rashidi *et al.* studied smoking in patients with vitiligo. They introduced inheritance factor and its impacts on the parents as problems of patients with vitiligo. Also, vitiligo influences life quality, self-confidence, marriage and employment, especially in people with darker skin color and it is more problematic in special cultures, which is consistent with research findings [29].

Findings of this study indicated the problems in life of people with vitiligo influences future of individuals' life. Future worries influences quality of all life periods, job, and marriage which are major life events. These events are wishes of every young person which have many plans for them. This disease causes defects in beauty, social exclusion, isolation, defeat in good job and failure in marriage and selecting singlehood.

One of the limitations in this study is lack of tendency of women to take part in interviews and expressing life problems. In addition, men also with difficulty expressed their challenges in private life and generally talked about the topic. Even expressing some materials was painful for some of them.

Findings of study can be applied in various disciplines which are involved with problems and issues of these patients. They can be utilized in the subsequent research works.

## CONCLUSION

Findings of the study showed some problems of patients with vitiligo. These problems influence future of these patients. Considering problems expressed by men and women with vitiligo entitled as experiences indicated that awareness of family individuals and society regarding this disease is low and needs informing. Also, giving Iran is a religious society, society individuals should be have religious attitude toward the disease and media can play significant role regarding raising awareness of public and culture making. Practitioners who are responsible for physical and psychological care for patients like psychologists, physicians and nurses should attempt more for increasing spirit of patients and modifying body image and self-confidence as well as physical care with awareness of patients' experiences.

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