



The Lived Experiences of Persons with Vitiligo: A Phenomenological Research

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Authors' contributions

This work was carried out in collaboration between all authors. The preliminary research design, data collection and analysis and drafting of the manuscript were done by authors FS and AS under the supervision of author MF. Critical revisions of the manuscript for important intellectual content and supervision were the responsibility of authors MF, AA and MR who also contributed to the design and the final shape of the manuscript. All authors read and approved the final manuscript.

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ABSTRACT

Aims: This study was aimed to evaluate the lived experiences of vitiligo patients.

Study Design: Descriptive phenomenological approach.

Place and Duration of Study: Dermatology clinics of Zabol and Zahedan hospitals in southeast Iran, 1 years.

Methodology: Data were collected through semi-structured interviews with 15 male and female patients with vitiligo, who were selected through purposeful sampling method. Collected data were analyzed using Colaizzi method.

Results: The extracted themes were the challenging emergence of the disease; tirelessly patient in follow-up different treatments; true and false beliefs about the disease; difference in coping with disease in all patients; changes of lifestyle due psychosocial problems; stigma community gifts for patients.

Conclusion: The vitiligo patients faced with challenges that affect their lives. Enhancing knowledge and awareness of families and society as the fundamental factors in shaping the futures of these people is possible through mass beliefs changes. Moreover, healthcare providers should be aware of the suffering and experiences of these patients, and attempt to understand them when providing physical and mental health care and support.

Keywords: Vitiligo; descriptive phenomenology; Colaizzi's approach; lived experiences.

1. INTRODUCTION

Vitiligo is a pigment disorder of the skin and mucous membranes showing depigmented patches because of destruction of melanocytes. Although the reason for melanocytes' destruction is not known, pathogenic mechanisms may include genetic changes, neurological, biochemical, viral, and autoimmune [1].

Almost 0.5% to 1% of the world's populations have vitiligo with equal incidence rates. The vitiligo incidence varies in different countries, tending to be higher in developing countries. It is estimated that the incidence rate is equivalent to global statistics [2].

Vitiligo is often seen on the hands, feet, or face. It also affects the eyelids and hair. Frequent rapid progressive loss of pigmentation is seen on different areas of the skin, which are depigmented or hypopigmented, well demarcated, variable in size and shape i.e., round, oval, or linear, and having convex borders [3]. Half of the patients usually have clinical symptoms of the disease before age 20, including perceived deformity, disgrace, stress, irrational negative thoughts, depression, paranoia, agitation, obsession, and melancholic emotions, anxiety, impaired personal or sexual relationships and impaired quality of life [4-8]. The patients are also exposed to intense family and social problems. They probably do not receive support from their families. People may stare to their physical changes and referred them with rude titles [9].

Although several quantitative studies have been done on vitiligo, there are few qualitative researches. The present qualitative study is based on the descriptive phenomenological approach to gain a deep understanding of the experiences of vitiligo patients.

2. METHODOLOGY

2.1 Design

A descriptive phenomenological method was adopted applied to identify the lived experiences

of patients with vitiligo and expand nursing knowledge. Qualitative study is described as a systematic and mental method to demonstrate the meaning of life experiences. Phenomenological research method was obtained to perceive the nature of phenomena.

In the current study, bracketing was used based on the concept of Husserl. The researcher recorded his own assumptions regarding the phenomenon, before collecting the participants' experiences.

2.2 Data Collection

Fifteen vitiligo patients who visited in dermatology clinics of Zabol and Zahedan hospitals, Iran in 2015 participated in the study. Participants were five women and 10 men with mean age of 27 years; 60 per cent had college degrees and were married. Purposive sampling was adopted for sample selection and data were collected through a semi-structured interview. The inclusion criteria were being a vitiligo case, having ability to express and articulate their experiences, explanations were given to participants. Informed consent was achieved before interview. The time and place of the interview were set with the participants. The majority of interviews were conducted in the participants' homes. The average duration of interviews was 45 to 60 minutes. A total of 13 hours of interviews was conducted until data saturation. The researcher initially asked open questions such as "what kind of experiences have you had?" There were no right or wrong answers to this type of question, but the question enabled respondents to freely describe the phenomenon under study. The researchers also took notes to record the observed cases, interactions, communications, environmental conditions, and non-verbal gestures.

Interviews were recorded using a digital tape with the consent of the participants, which was then transcribed.

2.3 Data Analysis

Data were analyzed after each interview using Collizzi's seven-step method [10]. First,

descriptions of all participants were read in order to reach a consistent and general sense. Second, every protocol was searched, and important phrases were extracted. Third, the meaning or concept of every important phrase was formed under the formulated concepts. Fourth, formulated meanings were organized into thematic categories. Fifth, the findings were incorporated into an exclusive description of the phenomenon under study. Comprehensive description of the phenomenon under study in the form of an explicit statement set was formulated; and as the final stage, the results were returned to participants to confirm and validate the findings.

In order to achieve the highest possible accuracy and reliability of the data, four criteria of data reliability and qualitative findings were met, including credibility, dependability, confirmability, and transferability [11,12]. The credibility of results increased through listening to the audios, and reading the transcript text several times. Some of interviews were randomly selected and the results were cross- checked. The participants revised the extracted meaning of the interviews. The dependability of results was increased through listening and transcriptions of a third party reviewer. In order to attain confirmability of the data, belief reduction and external audit were used. The transferability was increased through transferring data to similar groups although the research obtained the best results from the introduction of research design and selecting participants with the highest possible differences.

2.4 Ethical Approval and Consent

This study has been approved by the ethics committee of the Zabol University of Medical Sciences (Reference Num, 1395/03). In this study, ethical considerations were met through the following criteria: educating and gaining informed consent for participating and recording their interviews, coding instead of using interviewees' name in the transcription texts, observing the principle of privacy and confidentiality, and reserving the right to withdraw at any stage of the research process.

3. RESULTS

Analyzing the interviews led to six categories, including the challenging emergence of the disease; tirelessly patient in follow-up different treatments; true and false beliefs about the disease; different coping with disease for all

patients; changes of lifestyle due psychosocial problems; and stigma community gifts for patients.

3.1 The Challenging Emergence of the Disease

The incidence and progression of signs and symptoms of disease are the components of this theme. Emergence of the vitiligo is a challenge in patients. This disease appears as white patches with ability to change color on the hands and feet, behind the ears or on other open parts of the body such as the face. The disease progression can lead to the beginning of worry and stress in patients. From the emergence of the disease, patients and their families are involved in the disease consequences.

[...] It first appeared behind my left ear with a white visible border. My friends told me, "the back of your ear has become whitish" but I didn't pay any attention to them. One day ... I was driving my motorbike and my dad was riding behind me, and then he said, "the back of your ear is white," then after I checked it in the mirror and found out that yes, it's white.... And now, as you can see, all of the back of my ear and the back of my head have become white. After that, we tried to find out what happened to me; initially, we thought it was a fungal disease and visited the physician's office; he saw the lesions and examined me, then said you are suffering from vitiligo disease. (Participant 3, 27-year-old man)

3.2 Tirelessly Patient in Follow-up Different Treatments

Emergence of symptoms, spreading in open areas of the body, and family, cultural, and social issues in the lifespan of the patient all prompt the patient to pursue treatment and take action to cure it. The news of any particular treatment or advice of a famous physician tempts the patient to act. Recommending the use of hot springs, herbal, and chemical medications by people who have experienced the disease can motivate the patients to follow in their footsteps. Despite the ineffectiveness of treatments, the patients pursued new treatments.

Participant 1, a 37-year-old man, explained his search for a cure as follows:

[...] Every time I visited a doctor for curing my disease, it wasn't cured. Whenever

someone introduced a physician, I visited him in different cities. Some gave me hand-made drugs, some pills and other solutions, but no results, no effects, even biopsy of white spots was useless and again to no avail.

[...] Treatment modalities have no definite effects, they only reduce the symptoms. Implanting stem cells, using skin laser I don't know what to do most of the time. It fills my mind all the time, the treatment of my disease. (Participant 5, 30-year-old man)

3.3 True and False Beliefs about the Disease

The patients expressed different views about their own disease which resulted from others' reactions in the community. Some associated the onset of the disease with the death of a loved one, anxiety, looking at specific objects, eating certain foods, religious views, or doing some sorts of activities, and fate.

These beliefs challenge the person's life.

[...] It doesn't have a good social and cultural view and perception, and everyone has a story and interpretation about it. One says that it has been told that passing the countersink (a place in the old bath house where water was warm and people bathed in it) can lead to this disease; and someone else says that it is hereditary. Some believed that the causes of this disease in religious books are the death of a loved one, staring at sea water, eating two incompatible foods or edible items. Now that I know the reason, I thank God that the disease is not contagious, I do not have itching and pain.... because word of mouth could kill you. (Participant 2, 23-year-old man)

[...] Anxiety is a factor affecting this disease, and I experienced intense anxiety at that age (10 years), and that's when my hands were afflicted with this disease, and then again, my elbow was affected and other spots appeared with my age ... so, most of the time my mind is busy with this disease. (Participant 5)

3.4 Coping with Disease is Different for All Patients

The adaptation process with vitiligo varies in patients. They spent hard time to deal with the

disease. Some denied, got anger, depressed, and finally accepted that there is no effective treatment for vitiligo. However, some cannot adapt to the disease at all and may wish to die.

Participant 1, a 37-year-old man who has been affected from childhood, explains:

[...] I believed it was God's will that I to live with such thing, and it was out of my control. Sometimes I cried, "O God, why are you bothering me this way, take me, kill me, give me death, I'm tired"; I controlled my food, and I would avoid hard working conditions. Often I don't eat rice because I think I'm suffering more by eating rice

[...] Now, so much time has passed, I have my own life, it doesn't matter to me anymore. Living long time with this disease made me adaptive and I dealt with it. At first, it was very hard on me, like others, I have a hard time but it became a habit. Because I was affected when I was young, I've adapted well to the situation; so, time is an important factor for my adaptation. (Participant 5, a 30-year-old man)

3.5 Changes of Lifestyle due Psychosocial Problems

This theme describes patients' perspectives on the effects of disease on their lifestyle, body image, and psychosocial problems. Their body image affects their lifestyle. They encountered a new sense of self in their social relationships due to feeling deformed and having a negative mental image of themselves. These feelings lead to and intensify their psychosocial problems such as anxiety, depression, disappointment, social isolation.

Participant 1, a 37-year-old man, described his psychosocial condition as follows:

[...] Human is faced with different actions and decisions in different stages of life in order to become the same as others; for example, you cannot wear sleeveless shirt, this makes you depressed; you cannot wear shorts or T-shirt or sportswear like your friends, instead you become a fan of football, why?... because the spots are exposed. Therefore, you choose things that make you isolated...

[...] Living with this disease is much more difficult for women. I cover the spots with a

dress or by wearing make-up; one day I should marry, work ... so, this awful face is exposed. This facial deformity resides in our mind and it cannot be excised that easily; therefore, we have the right to become anxious and depressed, and isolated. (Participant 9, 29-year-old single woman)

3.6 Stigma, Community Gifts for Patients

This theme shows frustrations, social failure, and negative reactions of society in the face of patients with vitiligo. They are often ridiculed in some form by their friends, classmates, colleagues, and even by society. They are labeled with different things that contribute to their academic, marriage or job failures.

[...] A friend called me "how are you musty"... [laughing]... It's true that he's joking, but it somehow makes you sad, it's hard to bear others' jokes at your expense. At the beginning, it affected me severely and distressed me. Or ... little by little, I thought to myself, it's not so bad, maybe they have seen something else from outside, or feel that my appearance is so and so ... or if they touch me or kiss me, they'll get the disease; or in my relationship with the opposite sex, I'll explain about the disease at first and ask them to study it, or me and my disease is so and so ... (Participant 3, 27-year-old man)

Participant 10, a 28-year-old woman, explained her social interactions as follows:

[...] When there is a bad attitude toward an illness in the community, nothing can be done. Some people are afraid and won't come close to the person (patient). I feel that my aunt does not like to greet me up close. Therefore, you may marry and encounter similar reaction from your husband. You do not know what to do. Although the issue is solved for the individual, it is not solved for others. I knew a woman with vitiligo who had a suitor that told her, you are great in every aspect, but I'm afraid of getting the disease.

4. DISCUSSION

This study shows some of vitiligo patients' experiences. Most of the studies on vitiligo are quantitative and there are few qualitative studies that evaluate in depth the experience of these patients. Considering the religious, cultural, and

social context of different societies, the vitiligo brings various problems and dilemmas for affected men and women.

One of the results of current study was challenging emergence of the disease. The patients experienced changes in their behavior after manifestation of the first symptoms and signs. Since the disease often appears in childhood, it affects the person's behavior in most cases. This situation leads to behavioral changes in the person. Psychosocial problems such as worry, anxiety, or social phobia appear when disease progresses and the skin changes are evident [13,14]. However, the patients' reactions are varied based on their personality [15].

Another finding of the current study is the tirelessly patient in follow-up different treatments. After the emergence of disease and its spreading over the open parts of the body, the patients eagerly pursue follow treatments regardless of their ineffectiveness and high costs. In this regard, Boorse [16] pointed out there is no cure for all diseases, therefore frequent visits to health centers, trying various treatments, and follow-ups are psychological reaction to adapt to the disease. Contrary to the views of participants in this study who did not access the effective treatments, Ohguchi et al. [17] believe that effective treatment of vitiligo depends on the type of vitiligo and underlying diseases such as diabetes. Therefore, the patient should thoroughly be assessed before treatments.

True and false beliefs about disease are another finding of this study. Depending on the educational, cultural, social, and economic background the patients had different views. The results of a study by Mishra et al. [18] in a Nepalese shows that low literacy index, there are different scenarios for vitiligo patients that affect their quality of life. Factors such as age, gender, education, and family history affect these kinds of beliefs. In another study in India by Pahwa et al. [19] attitude and false beliefs about vitiligo in the society increased the mental and emotional stress in patients, which impacts the trend of incidence and future of patients. This supports the findings of the current study. However, the results of this study are contradicted the results of the study by Thompson et al. [20] because they believed that the society has an impact on people's views of the skin diseases. People who live in developed countries are different from those who live in developing countries.

Coping with disease was different in the participants. The presence of disease can lead to undesirable effects and thoughts. Abreu et al. [21] believe that coping is different for vitiligo patients, for example, a patient with a problem around the eyes has more difficulty coping with the disease compared to a patient with a problem of the body skin. Kumar and Naveen have stated that vitiligo is known as “white leprosy” in the Indian community. As a result, affected individuals become intensely nervous and cannot adapt easily, and hence are forced into isolation. These unhealthy opinions in the community lead to aggressive behaviors [22]. Kumar and Rao [23] in their study demonstrated that when children are affected by vitiligo, it impacts their families and their psychological state as well. The problems that occur during a person’s life intensify and cause psychological disorders and interfere with individual adjustment to the disease.

Another factor that these people faced with was changes of lifestyle due psychosocial problems. The patient’s problems begin with the emergence of the first spots. Unwanted dependency of disease, hiding signs, and symptoms, anxiety, concerns, depression, and social isolation happens in the individual. Vitiligo leads to a change in relations and interactions in men, and changes in emotions and feelings of women. When the disease appears the people experience changes in their character such as nervousness, embarrassment, depression [24], impairment of social relations, anxiety, sleep disturbances, and personality disorder in these patients. These changes marked a deep change and consistency in their personality, quality of life, and self-esteem [25]. Garg and Sarkar [26] believe that lifestyle change is affected by the severity of disease, location of symptoms, gender, age, and marital status. Our findings suggest a social stigmatization. The disease signs and symptoms remained a mark and labeled on the patients and attracted public attention, and some sort of frustration and failure was seen in the patients’ life and social activities. Premkumar et al. [27] have evaluated the social stigma of vitiligo in various communities and according to demographics of different patients. Their findings suggest the impact of education, age, and affected areas on social stigmatization. Khouja and Corrigan [28] attributed stigmatization of skin disease to various cultural prejudices toward a group of people. They react to the changes in the face skin according to their beliefs. Stigma is the greatest obstacle to

achieving the objectives in patients with skin disorders. In social stigma, discrimination is common, so they may be considered dirty, so that they may be isolated from community and experience mental problems. Unlike the study by Thompson et al. and some studies that reported that stigma are dependent on culture and ethnicity, psycho-social problems [29-32].

Our findings showed that vitiligo patients faced with considerable challenges in their lives. The intensity of these problems is higher in women than in men; it affects their employment and marriage, which are the most important wishes of any young adult. Among the strengths of the current study, compared with similar researches, is experiencing challenging phases of disease by participants such as job and marriage problems that show the dilemmas of these patients very clearly.

5. CONCLUSION

The results of this study revealed some of the problems of vitiligo patients, which affect the future of them. The findings suggest a lack of knowledge of families and society about vitiligo and a necessity for educating and informing them. People should be aware of the religious perspective towards disease, and media should contribute to the development of public awareness and shaping of general culture. Healthcare providers should be trying harder in raising the morale of patients, and improving their body image, self-esteem, and physical care along with understanding patients’ experiences.

CONSENT

As per international standard or university standard, patient’s written consent has been collected and preserved by the authors.

ETHICAL APPROVAL

As per international standard or university standard, written approval of Ethics committee has been collected and preserved by the authors.

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COMPETING INTERESTS

Authors have declared that no competing interests exist.

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