



Research Article

Exploring Pemphigus Challenges Based on the Patient Experiences: A Descriptive Phenomenological Research

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Abstract

Pemphigus, a life-threatening illness, is a chronic blister and autoimmune disease that affects the skin and mucus. The drugs used to treat pemphigus have high Adverse Drug Reaction. Therefore, the aim of this study is to explore patients' experiences and identify the challenges.

This study is a qualitative research with a descriptive phenomenological approach which was conducted through semi-structured interview on 10 male and female patients with pemphigus, using purposeful sampling. Colaizzi method was used to analyze the data. The themes for describing the Pemphigus Challenges are: challenges in diagnosing and treating the disease, individual's challenges and family challenges. The results of the study showed that people with pemphigus have some challenges that affect their lives. Increasing awareness of the family and society, as the main factors shaping the future of people through culture is possible. Psychiatrists, doctors and nurses by increasing awareness of patient's experience, should try to give physical and physiological care to patient.

Keywords

Pemphigus; Descriptive phenomenology; Colaizzi method; Patient experiences; Nursing

Introduction

The word pemphigus is derived from the Greek word 'pemphix', meaning bubbles and blisters. In this disease, for unknown reasons, antibodies are created in the body and eliminate the connections between the epidermis cells and cause blisters on the skin. The sizes of these blisters are different on the surface of the body and can range from one millimeter to more than twenty centimeters in diameter. These blisters are ruptured and cause very painful surface ulcers, some of which are bleeding [1,2]. Among different types of diseases, pemphigus vulgaris has a worldwide spread and ranges from 0.5 to 3.2 per 100,000 people in the world, and in Iran, it is estimated to be 1 per 100,000 persons every year [3,4]. Pemphigus vulgaris is also the most common type of the disease in Iran and many Asian countries [1]. Oral involvement is very common in more than 90%

of patients [5]. This disease is more common in Jews, people around the Mediterranean and Indians. Women infections, especially after the fourth decade of life, are more common [6]. In 140 cases of Pemphigus vulgaris in Iran, the age of the onset of the disease was reported to be 41(15.7) years and the ratio of male to female were 1.59 to 1. According to existing reports, the prevalence of this disease in Iran is more than that of other countries and the patients' ages are lesser [7]. On the other hand, in most Iranian patients (70%), there is a simultaneous involvement of skin and mucus, which causes more prognosis and mortality. Also, due to the chronic and recurring course of the disease, adverse reaction and treatment, most patients need to consume high amounts and frequent, corticosteroids and other immunosuppressant drugs that cause various Adverse Drug Reaction. Since the skin plays an important role in individual's confidence, any pathological changes in it can lead to harmful psychological outcomes [7]. Therefore, the apparent changes in the pemphigus disease cause a lot of psychological stress in people who are affected; [8] as the disease progresses, vital organs become involved, and cause harmful effects on the physical, psychological and social health of the individual. Living with signs of a disease for a long time, especially skin and appearance symptoms, can endanger personality and change in lifestyle; therefore, any treatment should be aimed at the physical, psychological and social compatibility of the individual and the family [9]. In Iran, these patients also have serious family problems in addition to social problems; they seem to receive no adequate support from their families and are discriminated against in many aspects of life [10].

Given the fact that pemphigus affects the appearance of patients and can cause many mental and psychological problems to them, their experiences are very painful in this regard.

In this regard, Pahwa et al. [11] in their study reported on severe social stigma associated with the illness other experiences of pemphigus patients include: Different aspects of treatment concerns, the provision of psychosocial and social needs, as well as waiting for the treatment and reduction of disease. Patients also expressed a wide range of concerns about their illness such as physical appearance, the development of white spots on the entire skin of the body, rejection, social constraints, and restrictions in dietary and employment in this study.

Given that Pemphigus's disease is a variable and unpredictable disease, in the younger group, it makes progressive disability repeatedly. It also has intense psychological effects, not only on the patient, but also on health care providers. Dermatologists and caregivers who take care of them face many clinical challenges [12]. Therefore, the knowledge of patient experiences helps nurses to understand their real concerns, evaluate patients and explain the process of illness to them according to their place of treatment. In addition, they try to improve symptoms, teach their families, and improve the patient's life quality. Given that reactions to the disease vary in different cultures, it is better to examine these reactions in the cultural context of each country. Deeper studies are necessary, using a qualitative approach, to assess the experiences of those who are directly involved in this phenomenon.

From a general view, it is necessary to examine the various dimensions of patients' experiences, visible to invisible aspects, to help

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Received: December 15, 2017 Accepted: December 21, 2017 Published: December 29, 2017

the Health Department staff in a better plan. Therefore, the present study aimed to explore the experiences of patients with pemphigus in order to determine the challenges.

Methodology

Ethical approval

This study is extracted from master's thesis approved by the Zabul University of Medical Science's Ethics Committee (code: zbm.1.rec.1396.56). Also, by obtaining informed consent from the participants and recording their interviews, and not including the names of the interviewees on the texts, observance of secrecy and confidentiality of information, and maintaining the right of withdrawal at each stage of the research was ensured.

Study design

According to the aim of the study, the methodology of the study was chosen as qualitative and descriptive phenomenology, because the qualitative research is a systematic and subjective way to describe experiences in life. Phenomenology is the science of consciousness about essence and the nature of phenomenon. The emphasis of this philosophy is not only on understanding a certain part or some of the person's behavior, but its centrality is to understand the whole human response [13].

In this study, Husserl's concept of bracketing was applied. The researcher "bracketed" her preexisting knowledge to position herself to see the phenomenon through the eyes of the study participants.

Participants selection and data collection

The population in this study was 10 patients with Pemphigus, with up to saturation information. After interviewing 7 participants, new information was not obtained and saturation with information of 3 other interviews was obtained to improve the quality of the study.

Participants were 5 women and 5 men with an average age of 45.3 years and having Pemphigus. Participants were also single and married. Sampling method was "purposeful" sampling. A semi-structured interview was used to collect the data. The average duration of interviews was between 45 and 60 min. The questions posed in the semi-structured interview provided an opportunity for greater freedom in the responses given to the contributor. Initially, the researcher used open questions such as "What experience do you have?" There was no definite answer to this question; this question enabled the respondent to think freely about its answer. Meanwhile, the researchers used note-taking to record observations, interactions, communications, environmental conditions and non-verbal movements. Following the selection of participants, inclusion criteria used were, definite pemphigus, being literate and having reading skills, as well as the ability to conduct an interview; they received the necessary explanations. And with the satisfaction of the interview, the time and place of the interview with the opinion of the participants was determined and the consent letter was obtained. Most of the interviews were conducted at the participant's home. Collection and analysis of data were carried out simultaneously. The interviews, with the consent of the participants, were recorded by recording device and then fully transcript.

Data analysis

The focus of the questions included expressing life experiences from the time of the disease to the present time. In this study, seven-step Colaizzi's method was used to analyze the data: Step

one, each transcript was read several times to gain a sense of the whole content. Step two, extraction of significant statements and phrases, Step three, meanings were formulated from the significant statements (formulated meanings) and Step four, grouping of all these formulated meanings into categories with unique structure (categories, clusters of themes). Step five, all emergent themes were defined with an exhaustive description (exhaustive description of the phenomenon), Fifth, findings were integrated into a comprehensive description of the phenomenon. Step six, 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 them [14].

Rigor

In order to obtain the highest possible accuracy and reliability of the data, four criteria of data reliability and qualitative findings were met, including credibility, dependability, conformability and transferability [15]. In order to increase credibility, the researcher did long-term work and continuous observation. He used the partner research report for a random selection of interviews and analysis by them, and finally, compared the results of the researcher and review by the participants. In order to ensure reliability, the interviews were implemented and analyzed by a foreign person. In order to achieve the objective of the information, abandonment of external opinion and auditing was used. In order to increase the transmissibility of data to similar groups, the researcher also used the full introduction of the research project with the selection of participants with the greatest difference.

Results

Analyzing the participants' interviews led to three categories, including challenging in diagnosis and treatment of the disease; Individual challenges; Family challenges.

Challenges in diagnosis and treatment of the disease

This category contains subcategories: Patient's loneliness with the occurrence of unknown symptoms, inappropriate treatment by medical staff due to an unknown disease, "treatment constraints and complications".

With the sudden onset of illnesses and due to its rarity, there is little information about them on causing anxiety.

It starts when the person experiences pain in the morning due to oral pain or rash. At first, due to patient's loneliness and patience for self-healing, they do not respond to usual medications. In the onset of the illness, patient wakes up in the morning with pain of Canker sores or Exanthemas. At first, their loneliness and patience for self-medication and taking usual medications do not make them to respond to treatment. The disease progresses to the extent that it affects the patient's sleeping, awakening and eating pattern. Severity of the illness makes the patient to consult a doctor.

Patients experience more difficulties when they have a rare and unknown disease. Physicians prescribe medicines to control only symptoms. Patients' conditions deteriorate, and they need to be hospitalized. Physicians may suspect an infectious disease and healthcare providers cautiously approach the patients, which causes fear in the patients.

Long-term admission in small care centers, non-curative treatment, and even loss of hope makes the patient to visit more specialized treatment centers.

In the more specialized medical center, due to expertise (suspicion of having a definite illness), while performing diagnostic procedures the doctors diagnose the disease. Apart from therapeutic problem, other patient's problems are: the Adverse Drug Reaction, life limitations of daily routine, periodic follow-up of the disease and economic problems.

Symptoms began suddenly... I was eating until I felt my throat area was burning, which was relatively intense....it was not canker sores, I did not feel well. I felt something was drooping my throat...I saw myself in the front of mirror like a dangle gland and full of blood. (Participant 1 male)

My illness started with a very intense burning sensation at the tip of my tongue...it had a terrible itch and burning sensation. (Participant 3 Female)

After waiting and did not get better, I came to the emergency department, and the doctor said it was not important, but if it reoccurs, I should come back for checkup. A few days later, it reoccurred with the same symptoms as the blisters broke and bleed, then the wounds became scarred and reoccurred again. It developed exactly like a pattern, followed by bleeding and in the end, partial repair... and early illness, I was afraid to die...then I went to an ENT specialist and he told me that there was nothing special and maybe it's an allergy that has its effects in this form...I was injected with two corticosteroids, but it did not make any difference.... (Participant 1 male)

My symptoms became intense that I could not cover my mouth. The hospital staff put a bucket under my head to get out the secretions because I did not have control over myself...I was so scared and thought I was going to die... I made a will...the doctor did not hope for improvement either.... (Participant 2)

I was hospitalized in our city for nearly 30 days or more and was told that I had a fungal skin infection..... I was so annoyed. (Participant 3 female)

After a definitive diagnosis, I started taking Corticosteroid. On the other hand, the doctor said that taking corticosteroids weakens the immune system and care should be taken, for a while, I had Adverse drug Reaction following body edema. I was afraid if I got out of the house, I would have a viral illness. I was restricted.... (Participant 3 female)

Individual challenges

This category contains subcategories: Not understood by others, life with physical changes, the likelihood of death, matching with jobs and colleagues.

The sudden onset of patient's problems are not acceptable to the family and medical staff, others do not understand the patient's discomfort. The sick person has difficulty in doing work, leading to severity of the symptoms. Symptoms such as canker sore and Exanthemas cause unpleasant feeling in the patient, the patient repeatedly thinks about how others will think about him. Due to the inappropriate treatment by the medical staff and people around, the feeling of death is created in patients and this fear always threatens them.

When a person becomes infected with an unknown illness, he is not at fault...and others do not understand the condition and discomfort...loneliness. (Participant 7 male)

My wife did not understand me, the doctor said that I should be hospitalized, but my wife did not accept, he said the symptoms on my face are normal and I need to be hospitalized, but her opinion is important too...I was burning from within. (Participant 10 female)

My illness was severe and could not stay at home, lately, I could not breathe and I felt choking and at the hospital, the doctors also stopped hoping for me...when I got better, the doctor advised me to take care of myself so that the disease does not reoccur again. (Participant 3 female)

I wasn't well, but I went to work. My colleagues told I'm very well, but I replied I'm not well and I'm an introverted person and don't like to show my problem to others. (Participant 1 male)

Canker sore and exanthema were on my face, I could not go out with bad lips and mouths, even when I was wearing a mask, others asked me about it...I just answered that I had a herpes...it was interesting to others. (Participant 3 female)

Family challenges

This category contains subcategories: Doubts on family support, marital life and children, the implications of marriage and divorce, the views of others due to lack of awareness.

Occurrence of the disease sometimes makes the patient to always be alone. In some cases, the patient's family experiences ambiguity in how to protect the patient and cure the patient's illness. Even the material life of an individual is affected by the fear of the partner. The marriage life of the patient is affected by the fear of infecting spouse, and the relationship between mother and child is also affected by fear of illness. If the mother is sick, the problem becomes multifold. A single person loses the chance of marriage with the illness. Married patients divorce because their marital needs are not completed. The family's view of the husband and colleagues, due to lack of knowledge of the disease, affected the patients. The way people look at patients and their conversations will annoy the patient, making the person to stop.

The lack of knowledge on the disease made my wife to avoid me and our marital relationship was affected. I weaned my three-month-old child to prevent him from becoming sick. (Participant 8 female)

My husband stopped sexual relationship with me for fear of being infected...after my genital area was involved, and we became divorced (Participant 1 male).

I was very worried and depressed, I could not go anywhere, the behavior of others was good to me but I did not know if they talked behind me or not...I was scared of being contagious and my kids getting sick, I was very worried and I was crying privately. (Participant 3 female)

I separated my equipment, meal and sleeping place from my kids and my husbands... The kids were surprised at me and they were afraid of my unknown illness. (Participant 9 female)

I felt that people were surprised to see me, and they do not have a good idea. They think that I deliberately use mask and because of ignorance, they suggested an herbal medicine or a traditional physician. (Participant 8 male)

Discussion

The aim of this study was to explore the challenges of people with pemphigus. Due to the scarcity of the disease and the low awareness

of the medical staff on the disease, male and female patients encounter different challenges. The comparison of the results of this research shows this.

One of the results of this study is the challenge of the disease. Patients are confronted with an appearance of unknown symptoms, inappropriate treatment of medical personnel due to unknown disease, treatment, constraints and complications of the disease, which affects their lives. The appearance of symptoms suddenly causes the patient's concern. In small towns, the patient becomes confused and visits the hospital due to lack of awareness of the medical staff. The patient goes to big cities because he/she is not improving. Holtzclaw (2011) in his study on rare diseases, stated that when a patient is referred to a doctor with unknown symptoms, lack of experience and knowledge in the medical staff, lack of patient status and failure to perform specialized care from patients are observed. In fact, the cause is rooted in health and medical inequalities [16].

Also, various studies show that management of rare diseases is low. Sometimes due to lack of proper treatment and the prediction of complications, the patient's quality of life reduces, therefore restricting the patient [17,18].

Long-term treatment with corticosteroids and immunosuppressant can have adverse drug reaction and even death [19].

Also, Condon et al. [19] did not describe the patient-medical staff interaction well in a study on vitiligo sickness. In some cases, doctors do not have faith in patients; sometimes they even humiliate the patients [20] reported that hospitalization; inactivity and secondary infections threaten the health of people with skin disease and presents a major problem to the health system, which requires more awareness by the community, healthcare providers, patients and their families on this issue. Chee et al. [21] also introduced Pemphigus disease as a fatal illness. Restrictions on persons with the disease include restrictions on physical activity due to health problems, social constraints, physical or emotional problems, restrictions on activities common in life due to health, physical pain, public mental health, and normal work activity due to emotional, vital and impairment of overall understanding of health. The results of the studies are consistent with the current study. Participants' experiences in this study also showed that, at the same time, with the advent of symptoms, patient becomes confused, causing limitations for them, and also, the therapeutic systems, because of anonymity, are challenging to the patient and even endanger the patient's life. Also, when the patient is treated, there are many adverse drug reaction and restriction in her/his life.

Another result is the individual challenges. Patients suffer from sudden symptoms of illness and face new challenges because of ignorance. Their illnesses are considered by their family and relatives, they express that the illness itself is improving and does not require medical treatment, but the patient's problems get worse. Also, due to the symptoms, the patient needs to use masks or coatings. As the disease progresses, medical staff recommends the use of no other medication due to the risk of death. These problems also make the patient to lose his/her job.

Heelan et al. [22] also stated that Pemphigus disease causes job loss, because there is a problem matching the disease with the job. Losing a job from an individual or public perspective is very important and has a significant impact on the individual's financial and social dimension. The result of the study shows that on one hand,

patients cannot cope with their occupation, and on the other hand, managers and other staff do not cooperate with them.

Kridin et al. [23] and Huang et al. [24] described Pemphigus as a fatal illness, and a mortality rate is reduced with corticosteroids. But infections, blood poisoning, heart disease and peptic ulcer disease are the main causes of death in these patients which should be prevented. In general, death is always threatening. Participants in this study also had similar experiences.

Another aspect of this study is family challenges. The patients face uncertainties with issues such as ambiguity in family support, marital life and children, the consequences of divorce and ignorance of others. In some cases, the patient has problems due to ignorance of family members, like in the early stages of the disease; others do not pay attention to the apparent symptoms of the disease. Also, due to genital infection, there might be divorce and inability to get married by the single people. Sebaratnam et al. [25] stated that relatives and colleagues have a negative effect on the patient due to insufficient information on the disease. Together with these results, marital conflicts were caused by genital skin diseases and immunodeficiency due to ignorance and not having proper sex relations. Also, Elbuluk & Ezzedine in their study on vitiligo patients showed that marital problems are encountered by couples, and the opportunity for marriages in the case of single people becomes very difficult; and spouses get divorced due to illness [26]. Edwards [27] considered important support for patients with rare diseases. Family members with their support increase the patient's hope and improve social relationships and ultimately increase treatment success. Also, the results of the Saeedinezhad et al. [28] qualitative study on vitiligo showed that married patients with sexual problems face divorce, and the single patients lose their chance of marriage. The bad thoughts of family and friends are due to ignorance about the disease. The results of this study are in line with existing ones. Meanwhile, vitiligo is also a rare disease that has the same characteristics as pemphigus. The limitations of this study are the difficulties in finding Pemphigus patients due to the lack of records in a particular health Centre. For some patients who had died, their families and professionals were reluctant to say anything. Also, the low number of participants reduced the ability to generalize the study. One of the strengths of the study is the selection of female and male participants, single and married, employed and unemployed, which resulted in good experiences.

Conclusion

Pemphigus is a serious illness with physical, emotional and social consequences. Dermatologists and medical staff should be aware that treating the symptoms and skin surface is not a cure. In fact, patients still suffer from the consequences of the treatment and face many constraints. There are many concerns about the recurrence of illness, family and work. Their experiences of illness are very bad; therefore, they need psychological rehabilitation and strong family support so that they can adapt to their new circumstances. Doctors, nurses and probably psychologists, family and partners should provide continuous support and comfort to maximize the benefits of successful clinical treatment for the patient.

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