

Stigmatization in psoriasis vulgaris: a qualitative study

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Abstract

Background: Psoriasis vulgaris is an autoimmune chronic inflammatory disease of the skin, which has become a global problem, with at least 100 million people affected. Although not life-threatening, psoriasis vulgaris affects the patient's life regarding physical appearance which can lead to shame, stigmatization, as well as mental health, thus affecting the quality of life. **Objective:** Qualitatively analyze about stigma and its psychological impact in psoriasis vulgaris patients. **Research Method:** A case study of a qualitative study to observe at the problem in depth and thoroughly. Subjects were recruited through outpatient clinic at the Department of Dermatology and Venereology, dr. Soetomo Hospital, Surabaya, Indonesia, with snowball sampling techniques, and conducted by telephone call. **Results:** The six informants, three men and three women, with range of 37 to 49 years old, married, with various levels of disease severity, revealing stigma of psoriasis vulgaris, and its psychological impact. Psoriasis vulgaris is a complex condition, having challenges to the informants' physical, psychological and social conditions. **Conclusion:** Living with a chronic skin disease such as psoriasis vulgaris can affect an individual's life in different ways in certain cultural settings and situations. Understanding the stigma and psychological impact of psoriasis vulgaris will be able to help patients openly share their discomfort so that they can develop more efficient treatment strategies for psoriasis vulgaris patients.

Keywords: Psoriasis vulgaris; Stigma; Mental Health; Psychological impact; Qualitative study; Indonesia

1. Introduction

Psoriasis is a chronic skin inflammatory autoimmune disease, recurrent, characterized by erythematous plaques, well-defined and silvery white scales. (Boham et al., 2016). There are several types of psoriasis, and psoriasis vulgaris is the most common type of psoriasis, found in almost 90% of patients with psoriasis. (Goldsmith et al., 2012). Although psoriasis vulgaris is not life-threatening, the impact of this disease on a person's quality of life is just as severe as any other chronic disease. Because of the persistent shedding of the skin, the treatment is unpleasant, time-consuming and costly, has serious side effects and takes a long time to achieve remission, patients may perceive the lesions as stigmata and may even attribute guilt feelings to the disease. Then the stigma that is often present is that people may think of psoriasis vulgaris as an infectious disease. (Bhosle et al., 2006; Choi et al., 2017; Alexa B Kimball et al., 2005; Polat et al., 2012; Rieder & Tausk, 2012; Ros et al., 2014).

The physical and psychological effects of psoriasis vulgaris are attached in the disease itself: pain and itching, presence of facial or genital lesions, stigmatization, sleep disturbances, impact on self-esteem, impact

on self-image, impact on self-consciousness, depression, suicide ideas, sexual complaints, and anxiety (Carrascosa & Balleca, 2017; Ferreira et al., 2016; Gupta & Gupta, 1998; Richards et al., 2001; Rieder & Tausk, 2012; Uddin & Howman, 2011). In several studies it was found that psoriasis is responsible for unsightly physical appearance, disgrace, and shame, in addition to the visible symptoms of skin lesions that have a psychosocial impact that can result in increased body area closure, sexual inhibition and reduced sports activities and affect quality of life. (Khoury et al., 2014; Uddin & Howman, 2011). Therefore, the present investigation aimed to understand the stigma of patients living with psoriasis vulgaris. This study will explore the individual experiences of psoriasis vulgaris patients and, ultimately, to contribute to the knowledge in dermatology and psychiatry.

2. Methodology

This research is a qualitative study in the form of a case study which aims to see the stigmatization experienced by psoriasis vulgaris patients. The reason for using a qualitative approach is to look at the problem in depth and thoroughly, which cannot be done with a quantitative approach. Subjects were recruited through outpatient clinic at the Department of Dermatology and Venereology, dr. Soetomo Hospital, Surabaya, Indonesia and snowball sampling techniques. The study was conducted by telephone call. The characteristics of the subjects were patients with mild and moderate-severe psoriasis vulgaris, with a period of more than one year, who were married (have a partner), aged at least 18 years, with a minimum education of high school graduation and domiciled in Surabaya, for the past year, both as permanent residents and temporary residents, and listed as patients at outpatient clinic at the Department of Dermatology and Venereology at Dr. Soetomo, Surabaya. Inclusion criteria were the diagnosis of psoriasis vulgaris in patient data. Exclusion criteria were patients younger than 18 years of age. Patients were informed verbally about the purpose of the study and their rights, including anonymity and voluntary consent. They are registered after written consent has been recorded.

The use of measuring tools is not carried out because the assessment aims to reveal what is experienced by the informant. Data collection was based on semi-structured individual interviews. Open questions were used to give participants the opportunity to vary their statements (See. **Table 1**). Verbatim transcripts in this study were analyzed using template analysis style. This method is used to analyze qualitative data thematically. Verbatim transcripts are read thoroughly to find recurring themes through distinctive patterns. Data saturation is considered to be reached when data collection does not show new data and results in meaningful interpretations.

Table 1. Examples of open questions

Understanding Psoriasis Vulgaris
How do people view your illness?
What they thought about psoriasis vulgaris?
Psychological impact of stigma
How does this view affect your life?
How do you cope with this view?
How does psoriasis vulgaris affect your self-confidence?

3. Results

Six interviews were conducted in Surabaya during May 2020 at outpatient clinic at the Department of Dermatology and Venereology dr. Soetomo Hospital, Surabaya, Indonesia. All participants fulfilled the inclusion criteria and none of the exclusion criteria. Mean age was 43 years (range 37–49), disease duration between 6 and 30 years (See. **Table 2**). The duration of the interviews ranged from 45 to 100 min. One investigator conducted the interviews and subsequently made transcriptions. The abbreviations “I” are used for “informant” respectively.

Table 2. Demographic data concerning psoriasis vulgaris

	Informant 1	Informant 2	Informant 3	Informant 4	Informant 5	Informant 6
Age	49	37	47	41	37	49
Gender	Male	Female	Male	Female	Female	Male
Education	Bachelor Degree	Highschool	Bachelor Degree	Highschool	Bachelor Degree	Bachelor Degree
Occupation	Private Employees	Housewife	Private Employees	Private Employees	Government Employees	Private Employees
PASI Score	2.5	24	18.5	8	15	25
Duration of Psoriasis Vulgaris (Years)	6	8	17	26	30	27

3.1. Understanding psoriasis vulgaris

According to question about “How do people view your illness?” regarding other people's views about psoriasis vulgaris experienced by informants, there were two themes obtained regarding the understanding of others about the patient's illness.

Incomprehension

Some informants admitted that many people did not know their illness and they had difficulty in explaining their illness.

I1: “No, people don't understand what psoriasis is.”

I2: “What is psoriasis, because they do not really understand about psoriasis.”

I5: “they don't know anything”

I6: “some people asked what's happen to my back, I finally tried to explain psoriasis”

Stigma being disgusting

Some informants described the views of others as disgusted by the condition of their skin. Thus, making informants reluctant to meet other people.

I3: “So his face, his gaze looks disgusted, maybe infectious skin disease is a contagious disease, which makes us reluctant to meet people.”

I4: “the problem is my nails, the condition of my nails is peeling and peeling down, it’s just the skin, right, they look disgusted like this, don’t I feel good, you know.”

Stigma being infectious disease

Some informants described the views of others as infectious disease.

I2: “They say the disease is due to witchcraft, then allergic disease, also said to be a contagious disease.”

I3: “maybe infectious skin disease is a contagious disease, which makes us reluctant to meet people”

3.2. Psychological impact of stigma

Supportive

Then the influence of the stigma on the lives of informants, informants answered not affected to their lives. Because of the informants' explanations about their illness, over time people were able to understand and support them.

I1: “No, I’m just worried, I’m worried whether this can still be cured. I was afraid that I wouldn’t recover, but it turns out to be taken to enjoy, to exercise, to take it, to finally reduce by itself.”

I2: “After participating in the exercising, then my friends understand, sometimes my friends also explain to other friends, so they can accept me.”

I4: “Thank God, there’s no such thing, they’re just the asking “oh it’s an itchy disease.”

I5: “No, thank God there is no problem.”

I6: “Yes, I am fine, the easiest for me to say that it’s allergies.”

Body coverage

From interviews conducted by researchers, it was found that psoriasis vulgaris makes informants used clothing to cover their psoriasis. They worry about people's views on the condition of their skin.

I2: “Yes, I ended up wearing long sleeves. Yes, what makes me sad is that I used to like to wear clothes that were a bit revealing. Then when I’d go to the market, there are many models of clothes, they’re all good. Yes, I’m really like the clothes, it’s sad, it’s just like that. I can’t wear clothes like that anymore.”

I4: “I basically always wear long clothes and a headscarf, it means that no one knows.”

I5: “I’m wearing a headscarf daily.”

I6: “Yes, I used to wear the short sleeve in 2000... Maybe 7 years ago I was still wearing the short sleeve, I still brave to wear it because it’s not in my arm yet. Now it’s on my arm. so, it’s long sleeves now.”

Confidence

Psoriasis vulgaris affect self-confidence, thus making informants reluctant to meet other people.

I2: "That's right, I feel inferior, so on the hand, on the back of the hand or the parts that can't be covered, it makes me feel really inferior. If you continue to pay for shopping, it looks red, people will ask my skin."

I3: "I'm more into something routine, yes, I'm really reluctant to meet new people, feel inferior and don't have confidence."

I4: "Yes, I feel insecure, I am afraid if someone finds out. But thank God no one knows."

I5: "I feel inferior, but not so inferior."

I6: "I feel inferior, but I try to put it aside."

4. Discussion

In this study, we focused on identifying the stigma experienced by informants with psoriasis vulgaris. The main reason for doing so is our assumption that it negatively affects the patient's self-image. Patients in our study expressed concern about being stigmatized by their environment if the affected skin was seen by others. In the present study, we have found aspects of the impact of psoriasis vulgaris similar to those found in previous studies. The qualitative methodological approach used in this study provides a more holistic, dynamic, and contextual picture of stigma in psoriasis vulgaris patients than the previous one. The results confirm the viewpoint on life of a person with a chronic disease not only affects physically but also psychologically, and socially contextually, dynamically, and individually.

It is found in the literature that problems encountered in daily life include experiences of humiliation and rejection, negative impact on work capacity, career prospects and earning potential, so that these contribute to the cumulative impact of psoriasis vulgaris on patients' lives. (Ayala et al., 2014; A. B. Kimball et al., 2010; Łakuta et al., 2017; Warren et al., 2011). Social rejection or its anticipation can have profound psychological consequences. Psoriasis vulgaris patients with such experiences become less confident and feel angry, frustrated, and embarrassed (Feldman et al., 2005). Many misconceptions about psoriasis vulgaris, such as thinking that the disease is contagious or infectious, can cause other people to reject patients with psoriasis vulgaris in various social circles. Then patients with psoriasis vulgaris may face discrimination in public places, such as being rejected from gyms, swimming pools, and hairdressers, because of the general public's fear that the disease may be contagious. (Chen et al., 2018).

In another study, some participants wore clothes that covered their skin lesions so they didn't have to explain them. Then another study showed that the majority suffer from social discrimination due to illness, which causes some individuals to lie about it and keep it a secret (Meneguín et al., 2020). Psoriasis vulgaris can affect a person's life in many ways. It can affect the way a person feels about himself or herself, the clothes one chooses to wear, the way one manages symptoms and the way one cares for one's overall health (National Psoriasis Foundation, 2020). A survey conducted by the National Psoriasis Foundation found that about 40 percent of people with psoriasis vulgaris choose their clothes to hide their skin condition. For everyday activities where one does not want to deal with the reactions of strangers and being stared at, they will wear a long-sleeved shirt, long pants, and a well-placed scarf. (American Association for the Advancement of Science, 2004). According

to a recent study, 79% of patients with severe psoriasis vulgaris reported a negative impact on their lives (Goldsmith et al., 2012).

5. Conclusion

Based on the findings of the study, various kinds of experiences were obtained by the informants, including misunderstandings about psoriasis vulgaris, then the stigma of psoriasis vulgaris as a disease that makes people feel disgusted and a contagious disease. Then the psychological impacts experienced include being supportive, covering body parts, and changes in self-confidence. So, it can be concluded that living with a chronic skin disease such as psoriasis vulgaris can affect an individual's life in different ways in certain cultural settings and situations. Understanding the stigma and psychological impact of psoriasis vulgaris will be able to help patients openly share their discomfort so that they can develop more efficient treatment strategies for psoriasis vulgaris patients.

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