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**To cite this article:** Lin-Lin Lee, An-Ping Huo & Shu-Ling Chen (2023) Experiences and coping behaviors of patients with psoriasis: a qualitative study, Journal of Dermatological Treatment, 34:1, 2193661, DOI: [10.1080/09546634.2023.2193661](https://doi.org/10.1080/09546634.2023.2193661)

**To link to this article:** <https://doi.org/10.1080/09546634.2023.2193661>



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Published online: 05 Apr 2023.



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# ArticleExperiences and coping behaviors of patients with psoriasis: a qualitative study

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## ABSTRACT

**Background:** Psoriasis is a complex, chronic, lifelong inflammatory skin disease characterized by the development of erythematous, indurated, scaly, pruritic, and often painful skin plaques, and it is currently incurable. It profoundly affects psychological wellbeing and social functioning and has significant associated co-morbidities. To improve clinical approaches, understanding of the experiences of patients with psoriasis is needed.

**Objective:** To explore the experiences and coping behaviors of patients with psoriasis.

**Methods:** A qualitative study approach was conducted. Through semi-structured interviews, 20 patients with psoriasis were recruited from general practices and specialist dermatology practices in a regional teaching hospital in Taiwan. Recorded interviews were transcribed and analyzed by content analysis.

**Results:** Three themes and nine subthemes were identified: (1) Symptoms distress: (a) trouble with scaling, (b) bothersome itching, and (c) complex pain experiences; (2) Psychological distress: (a) encountering discrimination and (b) feeling stigmatized; (3) Managing psoriasis: (a) coping with symptoms, (b) seeking alternative methods, (c) using biologic agents, and (d) changing thinking and coexisting with the disease.

**Conclusion:** The experience of patients with psoriasis has significant negative impacts on their lives.

The findings of this study can provide healthcare professionals with a reference for the care of patients with psoriasis.

## ARTICLE HISTORY

Received 13 February 2023

Accepted 14 March 2023

## KEYWORDS

Psoriasis;  
experience;  
coping behavior;  
qualitative research.

## Introduction

Psoriasis is a complex, chronic, lifelong inflammatory skin disease characterized by local or widespread, thick, white, scaly, pruritic plaques (1–5). Psoriasis affects approximately 2%–4% of the population in Western countries (2,5). Furthermore, plaque psoriasis, or psoriasis vulgaris, is the most common type of psoriasis in all populations of psoriasis cases (approximately 85–90%) worldwide (2,6). Psoriasis may occur at any age, but the highest incidence is usually observed in patients aged 20–40 years; the incidence is only slightly lower in those aged 50–60 years (7). Important factors in the variation of the prevalence of psoriasis include age, gender, geography, and ethnicity, probably due to genetic and environmental factors (2) or certain environmental triggers, such as infections (mainly streptococci), drugs (e.g., lithium, beta-blockers), emotional stress and smoking (7). Psoriasis manifests as well-demarcated papules and plaques covered with silvery scales, usually located symmetrically over the elbows, knees, sacroiliac area, and scalp. Besides skin involvement, patients with psoriasis may suffer from nail problems and joint involvement (i.e., psoriatic arthritis) (8). The associated itching can involve the entire body, although it predominantly affects the legs, hands, back, body, and especially the scalp (9). Due mainly to the visibility of the skin lesions, comorbidities, and

subjective symptoms including pruritus and pain, psoriasis also causes significant emotional stress, stigmatization, and suffering, and uncontrolled itching can significantly impact all aspects of the well-being and quality of life of the patient (9,10). It can have devastating physical, mental, and psychosocial consequences (11–13). Skin diseases often lead to social rejection of the patients due to their esthetic aspects and have negative impacts on their lives. Because of the obvious cosmetic side effects, such diseases in many cases influence the ways others deal with patients and the patients' feelings about themselves (14). The skin plays an important role in interpersonal relationships; therefore, skin diseases have obvious effects on patients' appearance and change others' attitudes toward them (15). Such skin blemishes may cause hatred, fear, and even intolerance, and others may avoid contact with the patient due to fear of contagion. Various studies report stigmatization and rejection as consequences of psoriasis (16–19). Psoriasis mainly affects the skin and joints and is associated with comorbidities such as cardiovascular disease and metabolic syndrome. Psychosocial comorbidities, including psychological distress, stigmatization, social isolation, and physical dysfunction, are also well recognized by the literature (11,14,20–22).

Several studies have used qualitative methods to explore the experiences of patients with psoriasis, including the impact of

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psoriasis symptoms (23), related skin pain (24), the impact of itchiness on quality of life (25,26), and social stigma and rejection (11). Despite similarities in psoriasis between ethnic groups, there are notable differences in the presentation, quality-of-life impact, and treatment of psoriasis, and these differences have important implications for the management of nonwhite individuals (27). However, in Taiwan, only a limited number of studies have used qualitative approaches to attain an in-depth understanding of the experiences of patients with psoriasis. Therefore, this study used qualitative research to explore the experiences of patients with psoriasis in Taiwan. These experiences can be used as a reference for healthcare professionals in providing better comprehensive care to patients with psoriasis.

## Methods

### Study design

A descriptive study with a qualitative approach was conducted. Purposive sampling was used to recruit patients with psoriasis who met the following criteria: (1) eligible adults ( $\geq 18$  years) with a physician's diagnosis of psoriasis ( $\geq 6$  months duration) (2) current or recent history (within 3 months) of moderate or severe involvement; (3) agreement to participate in this research, and (4) no current organic or mental diseases.

### Data collection

Each interview included two parts. In Part 1, patients were asked about their sociodemographic characteristics and clinical characteristics, such as the severity and course of the disease. Severity was quantitatively assessed with the Psoriasis Area and Severity Index (PASI) (28). PASI scores range from 0 to 72 and are often regrouped into three severity levels of psoriasis: PASI  $< 7$  (mild), PASI 7–12 (moderate), and PASI  $> 12$  (severe) (28). In Part 2, data were collected in semi-structured face-to-face interviews. The data on demographics and clinical characteristics were collected with the following guiding questions: Could you tell me about your initial experience with psoriasis? In your opinion, does psoriasis impact your life? If yes, in what aspects? In your perception, how do you cope with psoriasis? How could your life be improved in relation to psoriasis? Data collection

was completed using the data saturation criterion through the repetition of information in the statements from a total of 20 in-depth interviews. Patients were interviewed at a convenient location. From June to September 2022, interviews of approximately 2 h duration were conducted, audio-recorded, and transcribed verbatim.

### Data analysis

Data were analyzed with the qualitative content analysis approach from Graneheim and Lundman (29) by determining meaning units, condensed meaning units, codes, subcategories, categories, and themes.

### Trustworthiness

To ensure the trustworthiness of the study, our procedure followed the guidelines proposed by Lincoln and Guba (30). The credibility of the data was enhanced by the authors' expertise in nursing and qualitative research, which allowed us to fully understand patients' experiences of living with psoriasis. Transferability was facilitated through the use of a purposive sampling approach to obtain a broad representation of the patients with respect to age, gender, duration of psoriasis, and medical treatment. Dependability was enhanced by the authors meeting frequently to discuss the data analysis and by checking and rechecking the labeling, sorting, and naming of themes during data analysis for verification. Confirmability was ensured by describing the entire research process and procedures in detail, keeping a reflexive journal, and maintaining an audit trail (30). Patients' experiences were extracted as thick descriptions of the related phenomena.

### Ethical considerations

This study was performed in accordance with the principles of the Declaration of Helsinki. All the study procedures were approved by the Hospital Human Investigation Committee at the Regional Teaching Hospital (IRB No.11104-01). The participants' rights of anonymity, confidentiality, and withdrawal from the study were explained at the time of the interview.

**Table 1.** Patient demographics and clinical characteristics (N = 20).

Case	Age	Sex	Education level	Marital status	Occupation	PASI score	Duration of psoriasis (years)	Prior treatment			
								Topical	Medication	Phototherapy	Biologics
C1	43	F	Junior	Married	Employed	52.2	30	Yes	Yes	No	Yes
C2	46	F	Senior	Single	Employed	15.3	18	Yes	Yes	No	Yes
C3	33	F	University	Married	Employed	53.2	19	Yes	Yes	No	Yes
C4	44	F	University	Married	Employed	22.0	22	Yes	Yes	No	Yes
C5	43	F	University	Married	Employed	6.4	33	Yes	Yes	No	Yes
C6	42	M	Vocational	Single	Employed	21.9	33	Yes	No	No	No
C7	25	M	graduate	Single	Employed	10.0	5	Yes	Yes	No	Yes
C8	37	F	Senior	Married	Housekeeper	11.4	23	Yes	Yes	No	No
C9	50	F	Vocational	Married	Employed	12.0	45	Yes	No	No	No
C10	34	F	University	Married	Housekeeper	6.2	19	Yes	Yes	No	Yes
C11	27	F	University	Single	Employed	11.8	10	Yes	Yes	No	Yes
C12	26	M	Vocational	Single	Employed	37.7	12	Yes	Yes	No	Yes
C13	35	F	Vocational	Married	Employed	1.2	24	Yes	Yes	Yes	Yes
C14	54	M	Senior	Married	Employed	28.7	48	Yes	Yes	No	No
C15	39	M	Primary	Single	Employed	32.8	22	Yes	Yes	Yes	No
C16	32	M	University	Single	Employed	4.6	16	Yes	Yes	No	No
C17	36	M	University	Married	Employed	39.2	24	Yes	Yes	No	No
C18	37	M	University	Single	Employed	20.5	25	Yes	Yes	Yes	No
C19	32	M	University	Single	Employed	30.6	17	Yes	Yes	Yes	Yes
C20	46	M	Senior	Single	Employed	10.2	32	Yes	Yes	Yes	Yes

## Results

### Participants' characteristics and identified themes

The demographic and clinical characteristics of the 20 patients are presented in Table 1. There were 10 males (50%) and 10 females (50%), with a mean age of  $38.1 \pm 17.1$  years (range 25–54 years), and 50% were married. In the level of education, half (50.0%) had completed high school or vocational secondary school. With regard to occupation, 10 patients (50%) had jobs. The age of onset is less than 18 years. The mean duration of psoriasis was  $23.9 \pm 9.2$  years (range 4–48 years). The mean psoriasis severity assessed according to the PASI was  $21.4 \pm 15.44$  points. The majority of the participants (55%) had severe symptoms.

The findings were categorized into three major themes and ten sub-themes: (1) Symptoms distress, including the sub-themes (a) trouble with scaling, (b) bothersome itching, and (c) complex pain experiences; (2) Psychological distress, including the sub-themes (a) encountering discrimination and (b) feeling stigmatized; 3. Managing psoriasis, including the sub-themes (a) coping with symptoms, (b) seeking alternative methods, (c) using biologic agents, and (d) changing their thinking and coexisting with the disease.

The main themes and sub-themes are presented in Table 2.

### Theme 1. Symptoms distress

The symptoms of psoriasis include head erythema, scaly desquamation, itching, scratches, nail pits, and joint pain appearing on the scalp or joints, or even the whole body, accompanied by painful and recurrent inflammatory diseases. This theme included three subthemes: (a) trouble with scaling, (b) bothersome itching, and (c) complex pain experiences.

#### Trouble with scaling

Most patients reported that in the past few years, they had observed layers of silver-white scaling on their bodies. They reported large and small red desquamation plaques on the scalp, arms, trunk, and lower limbs. Occasionally, scratching would cause flaking, which would cause problems.

'I am quite troubled by the flaking everywhere in my house.' (C4)

'There will be a lot of flakes on my chair and on the floor. If you walk in with black socks, they will be white when you leave the room.' (C11)

'There are a lot of flakes on the floor and table in the room. Everywhere I walk, I leave traces, which will cause me trouble.' (C15)

Table 2. Themes and sub-themes.

Theme	Sub-theme
Symptoms distress	Trouble with scaling Bothersome itching Complex pain experiences
Psychological distress	Encountering discrimination Feeling stigmatized
Managing psoriasis	Coping with symptoms Seeking alternative methods Using biologic agents Changing their thinking and coexisting with the disease

In addition, recurrent skin lesions, most of which cannot be cured, affect patients for a long time and upset them.

'The whole body grows piece by piece, controlled for a year or two, and then it flares up again, without cutting the root, repeatedly, trying all methods. It is a very difficult disease.' (C9)

'My whole head is red and patchy, like a dysentery head. This disease will only be repeated and will not get better.' (C10)

'From behind my ears to the back of my head, it is flaky, and it will flake off. It gets better as soon as the medicine is applied, but after a while, it will relapse again, which is very annoying.' (C16)

#### Bothersome itching

Most patients reported that the most troublesome symptom was severe itching, which could be unbearable. When itching occurred, they would scratch it even to the point of bleeding, but they could not stop themselves from scratching. This chronic, long-term itching resulted in poor sleep quality and great physical and mental discomfort.

'There are white places and then they itch, and you want to scratch and cannot sleep, which affects the quality of life.' (C3)

'The itching feels like a bunch of ants on my head, and I want to scratch them off; it's as if there are thousands of ants on my head, it is itching so badly.' (C5)

'It is always very itchy. I can scratch it irregularly, or lean my body against the wall or rub against the back of a chair. Rubbing it, I often want to scratch it, but if I scratch it too hard, it will bleed. It is really itchy, painful, and troublesome.' (C7)

'It's very itchy, itchy and uncomfortable, and it bleeds when scratched. It feels like being bitten by ants, like many ants are biting me.' (C12)

'It's like the itching of mosquito bites. I often scratch and scratch the broken skin.' (C15)

#### Complex pain experiences

Most patients reported that the psoriasis caused cracked skin pain in repeated attacks, which were as painful as lacerations, needle pricks or open wounds. They even reported having thoughts of self-harm and suicide. They described it as despairing to live.

'Because of this disease, I would like to ask, "Why can't I just die?" When I lie down, it will hurt when I press on the pustules.' (C1)

'Many people don't know that this skin disease is really painful, like an open wound.' (C2)

'The skin is hard. If you touch it, it's like a laceration pain. I cannot deal with it and want to hurt myself.' (C3)

'My symptoms are cracked skin pain. The dry cracked pain feels like needle pricks, and it was so severe that I gave up on myself.' (20)

## Theme 2. Psychological distress

The symptoms can affect anywhere from just the scalp to the whole body. The skin presents red plaques combined with dander exfoliation and emits a peculiar smell. When skin lesions recur, they can be clearly visible and easily lead to misunderstandings or rejection by others. These experiences can result in negative feelings such as embarrassment and low self-esteem, shyness, withdrawal, depression, hopelessness, and other psychological problems, and they seriously affect the patient's self-image, self-esteem, and sense of interpersonal relationships. This theme includes two sub-themes: (a) encountering discrimination and (b) feeling stigmatized.

### Encountering discrimination

Most people reported that they had red patches on the scalp and the whole body with exfoliated dandruff and odor. They would encounter curious and strange looks, misunderstandings, or rejection, and they develop feelings of inferiority, pressure, depression, and hopelessness in their hearts.

'I can't go swimming. Maybe when I jump into the water, everyone will get out when they see it, afraid of being infected, and they will give me strange looks. Because my symptoms are so obvious, a psychological sense of inferiority must be there, and it affects me negatively.' (C6)

'Psoriasis has grown above my eyebrows. It is very painful and ugly, and it cannot cover the eyebrows. Why does it grow on my face? I feel very inferior.' (C11)

'I have it on both my head and my body. It looks scary. My friend said my hands look like toad skin. I think it's just a joke. I've been discriminated against. I have very low self-esteem.' (C14)

'When my disease is very serious, I am afraid that other people will look at me differently.' (C15)

### Feeling stigmatized

Most patients reported that the skin is always prone to obvious erythema, rash, and odors and that layers of thick white dandruff stained their clothes, floor, and living room, etc. These problems made them feel stigmatized as 'dirty', 'unclean', and 'contagious'.

'The impression you give to others is that you are different from ordinary people, covered with dandruff and dirty; people will be afraid, and they will first reject you and keep their distance.' (C4)

'There are a lot of scalp flakes on my blue uniform. When my classmates see it, they think that I have not washed my hair and that I have poor personal hygiene. It is very hurtful to me.' (C5)

In addition to being considered unclean, the disease is also considered to be contagious, as the participants said below.

'I am not willing to disclose my psoriasis. Many people do not understand it, are afraid of being infected, and even think it is a dirty skin disease.' (C10)

'Because many friends don't know about psoriasis, they are afraid of being infected and give me strange looks.' (C15)

## Theme 3. Managing psoriasis

Most of the patients applied various methods to face the distress and discomfort caused by the disease. This theme includes four sub-themes: (a) coping with symptoms, (b) seeking alternative methods, (c) using biologic agents, and (d) changing their thinking and coexisting with the disease.

### Coping with symptoms

The patients reported coping with these symptoms (such as scalp flakes, scaling, bleeding, cracking, redness of the skin, pustules, and deformed nails) to reduce embarrassment and shame and to improve comfort. The patients' strategies included avoiding wearing dark clothes; avoiding going out; avoiding hot water and preventing dryness of the skin; and wearing long-sleeved pants to conceal the disease.

'I dare not wear dark clothes. If my hair moves, the skin will fall off in flakes.' (C5)

'I don't wash my hair with overly water and or let my skin get dry, or it will be very itchy.' (C9)

'I'm very concerned about pitted and deformed nails and try to keep my nails from being seen or getting manicures.' (C11)

'I am very reluctant to go out with friends. I always claim to be busy as the reason for turning down their invitations. Because others would be afraid of my appearance and think that it was an infectious disease.' (C12).

### Seeking alternative methods

The treatment of psoriasis is mainly based on steroid drugs, oral drugs, and light therapy. When the treatment reaches a certain level, the effects will stagnate or the disease will even recur, severely affecting sleep. Many patients become discouraged and are unwilling to continue treatment, so they choose folk therapies. These therapies include soaking in sulfur, drinking toad or snake soup, taking herbal medicines, and seeking divine aid. Most of the patients reported that they were concerned about the serious side effects of the long-term use of steroids and other drugs.

'My mother would urge me to bathe in herbal sulphur to see if it would heal my skin, and my friends would take me to the temple to be healed by Master Jigong.' (C2)

'We went to the temple to ask questions. The temple master said that I it was karma. I killed chickens in my previous life, so I have to pay for it in this life.' (C3)

'My family took me to see the old Chinese doctor, who took my pulse and prescribed Chinese medicine to help me clear the toxins from my body, but there was still no improvement.' (C11)

'I believe in Christianity and pray to God. I hope he can heal my body.' (C13)



'I drank snake or toad soup when I was in my 20s. I drank it for about two months. It didn't work, so I gave up.' (C14)

### *Use of biologic agents*

Over half (60%) of the patients used biologic agents. They stated that, after using them, their skin recovered and their confidence in life was restored. They were finally rid of the nightmare of psoriasis and saw a glimmer of hope in the darkness.

'The biologic agents improved the symptoms a lot, and now there is not much scaling, only a little bit left on my legs. It's the difference between heaven and hell. I feel like I have become normal. I am very satisfied, and I was really in too much pain before.' (C4)

'In the past 10 years since I got psoriasis, my entire life has been gloomy, hopeless, and very inferior. At present, my condition is much better. I don't need to deliberately cover my forehead, and I can choose a lot of clothes to wear.' (C11)

'I have a new future. I'm happier than if I'd won the lottery. I don't want to relapse again, because I don't want to live in the dark days.' (C12)

'I think biologic agents are very powerful. They can treat psoriasis, and my skin is much better. I am confident my skin is completely back to normal.' (C13)

### *Changing their thinking and coexisting with the disease*

Most of the patients were diagnosed with 'psoriasis' by the doctor and told that there was no way to cure the disease. The entire course of the illness is quite painful. After many experiences, patients found that they could only change their thinking and accept the facts.

'I feel that it has already happened, and it is also an established fact, so I want to say that I accept it and coexist with it.' (C5)

'When I got psoriasis, my parents were very worried and took me to see doctors everywhere since I was a child, but it couldn't be cured, and it would follow me for the rest of my life. When life throws you a curve ball, recognize it and accept it.' (C9)

'This disease made me very inferior. I saw a girl with psoriasis like me on the road before. She was not afraid of being seen by others. If she is so brave, then I should be as brave as she.' (C11)

'I think psychological self-construction is also very important and a daily routine is also very important. Don't stay up late, don't eat food that is too stimulating, and control your weight well. Because obesity is an inflammatory reaction, it is better to control your weight like this.' (C13)

'This disease will be with me for the rest of my life, and I have let it go, because there is no cure, but at least it can be alleviated a lot.' (C15)

During the long and torturous treatment process, most patients turn to encouraging themselves and regard anti-psoriasis as a practice in life. They come to the realization that they must 'face it, accept it, deal with it, and let it go.'

'During the treatment, the doctor told me that it would not be good, and I just want to live in peace with it. So I accept it, make good friends with it, and live in peace with it.' (C4)

'I will accept it, because psoriasis is born to be accepted, and then live in peace with it.' (C5)

'I can only try to get along with it in the process of repeated illnesses, because there are many people who are in a more serious condition than mine and suffer more than I do. I feel that I am still lucky, and I can still wear short sleeves and shorts, so I think positively.' (C10)

'The doctor said that I can only maintain the status quo. I am going to live with it for the rest of my life and accept it.' (C17)

## **Discussion**

Understanding the experiences and coping behaviors of patients with psoriasis is fundamental to providing effective patient-centred care. In our study, patients most commonly reported bothersome scaling, itching, and pain. These findings are similar to those of previous reports. For example, in a survey of 100 patients, intense epidermal scaling was rated as the most burdensome symptom of psoriasis by 60% of the patients, followed by pruritus (65%), skin redness (51%), burning sensation (44%), dandruff (38%), and nail abnormalities (37%) (31). Besides scaling, the itchiness was also the most frequently cited symptom. Pruritus is the second most (79%) reported symptom in patients with psoriasis (32). Unlike atopic dermatitis, pruritus is the defining feature of the disease, with chronic pruritus reported in 87% to 100% of patients (33). Indeed, itchiness affects 60–90% of patients with psoriasis (8,23,31,34,35), and relief from itchiness is a primary treatment expectation in patients with psoriasis (36). The majority of patients with psoriasis consider pruritus as the most bothersome symptom of the disease. Many patients also ranked pruritus as annoying or unbearable. This finding is similar to those of previous reports (31,37,38). Lebowitz et al. (38) reported that this sensation is described by patients as one of the most relevant factors contributing to perceived disease severity. The intensity of pruritus is correlated with the severity of quality of life impairment (39), and pruritus negatively affects the quality of life (37). In our study, the itching was described as feeling like numerous ant bites or mosquito bites and as long-term tolerable itching that caused great physical and mental discomfort. In contrast, Amatya et al. (37) reported that many subjects reported such features of pruritus as stinging, pinching, tickling, or crawling sensations. It may be that everyone's perceptions are different, and the feelings presented are also different. In addition, patients recognized and avoided triggers as a primary strategy for coping with pruritus, such as avoiding hot water and skin dryness. This is in accordance with previous findings (25,32). The most important factors that exacerbated itching were heat, skin dryness, hot water, sweating, and emotional stress, while sleep and cold showers most often alleviated itching.

The experience of psoriasis-related skin pain is complex. Pain has a major negative impact on patients' emotional and psychological health. Most patients reported that psoriasis caused cracked skin pain in repeated attacks, which were very painful, and even had thoughts of self-harm and suicide. In this regard, as Ljosaa et al. (24) found, psoriasis-related skin pain reduced their physical

activity levels, impaired their sleep, and made them irritable, depressed, distracted while performing tasks, and withdrawn from other people and social activities. Although their lives were largely affected by the pain, patients stated that they chose tolerate it rather than taking analgesics for symptom relief. However, the pain was described as feeling like lacerations, needle pricks, or open wounds. Ljosaa et al. (24) reported several metaphors for painful skin: like the skin is ripped off of you or the skin feels like an open wound. The patients also reported encountering discrimination and feeling stigmatized, so their social interactions were disrupted or they became socially withdrawn. In this regard, Reich et al. (31), who conducted a study on 100 patients with psoriasis, suggested that the stigmata cause disturbances in social interaction; disappoint the person; create feelings of hatred, inferiority, isolation and worthlessness in the individual; and reduce the social status of the individual in the family and society.

Psychological distress was also found to be associated with psoriasis. Encountering discrimination by others was another unpleasant experience of the patients in our study. The majority of them expressed that, not only did they deal with the symptoms, but they also endured curious and strange looks, misunderstandings, or rejection by their friends and others, which further complicated their problems. As Richards et al. (19) found, perceptions of stigmatization were significantly related to both psychological distress and degree of disability. In this context, the results of Ghorbanibirgani et al. (11) showed that some patients felt a sense of rejection and labeling, which was consistent with the results of our study. Given the negative effects of stigmata in social interactions, patients' narratives showed that their feelings were related not only to their appearance but also to the feeling of being stigmatized as 'dirty', 'unclean', and 'contagious'. As a result, they were not willing to disclose their disease. In their statements, patients expressed that many people did not understand psoriasis, were afraid of being infected, and even thought it was a dirty skin disease or contagious disease. As Jacob et al. (40) stated, social aversion to skin disorders has promoted ostracism of individuals with those skin disorders, and this aversion still plays a role in current society. In addition, feelings of inferiority or low self-esteem were also the most common psychological reactions in our study. Similarly, the markedly visible appearance of lesions has a negative impact on body image, leading to decreased self-esteem, as reported in patients with psoriasis in previous studies (41–46). Our study found that patients might avoid going to public places and meeting friends due to psoriasis, and many of them might be concerned about curious and strange looks, misunderstandings, or rejection. This finding revealed that psoriatic patients can experience discrimination and stigmatization, mainly due to the visible nature of skin lesions. The visibility of psoriatic lesions makes social stigmatization and rejection common experiences for these patients. Furthermore, the public is often inadequately educated about psoriasis and may think the disease is contagious, so people tend to avoid contact with patients with psoriasis. Thus, the lack of education in the public is another factor which causes society to reject the patients (11,47,48). Therefore, public education is very important for psoriasis.

In disease management, treating the symptoms is as important as treating the skin disease. In our study, patients reported that to cope with these symptoms (such as scaling, bleeding, cracking, and deformed nails), they avoided wearing dark clothes; avoided going out; avoided hot water and prevented skin dryness; and wore long-sleeved pants to reduce embarrassment and shame and to improve comfort. As previous studies (8,24,25) have found, the most important factors that exacerbated itching were heat, skin dryness,

hot water, sweating, and emotional stress, lifestyle/activities (e.g., exercise, clothing), and self-care activities. However, the treatment of psoriasis is mainly based on steroid drugs, oral drugs, and light therapy. When the treatment reaches a certain level, the symptoms do not improve further, and patients will seek out various methods, such as alternative methods (folk therapy, such as drinking toad or snake soup, herbal medicine, or asking for divine aid). As some studies (49,50) have reported, spirituality can give a higher and deeper meaning to a person's life and inspire a person to transcend the ordinary. Spirituality can reduce stress, create feelings of wellbeing, and generate a personal sense of inner healing and peacefulness. In our study, patients sought relief from their psoriasis through religious rituals (such as seeking divine aid or praying to the Christian God). In addition, 60% of the patients used biologic agents. They described that, after they used them, their skin recovered and their confidence in life was restored. They had finally escaped the nightmare of psoriasis and saw a glimmer of hope in the darkness. However, the effectiveness of biologic agents in our patients was similar to that in prior reports (51–53). Biologic agents are effective for treating psoriasis. They provide physicians with additional options for patients who cannot tolerate traditional therapies. However, Lorenzin et al. (54) reported the reasons for the failure of biologic therapy and possible predictors of subsequent treatment switching, identifying causes such as smoking, body mass index, and female gender. No statistically significant demographic or disease characteristics were found in the study by Mastorino et al. (55), possibly due to the small sample size. To date, no failure experiences have been reported in the 12 patients using biologic agents in this study. In the future, drug-resistant patients will be an increasing challenge for clinicians. In addition to the above methods, after the medical journey, our patients also began to learn to change their thinking and coexist with the disease. The findings of these two methods are unique to this study and can be used as a reference for other studies.

### Limitations

The first limitation of this study is that data were collected at only one outpatient regional hospital, which may undermine the generalizability of the findings. However, the qualitative approach provided rich, unique descriptions of the experiences of patients with psoriasis in Taiwan. Furthermore, the results provided new knowledge on how to improve effective patient-centred care. Second, 20 psoriasis patients (10 males and 10 females) were recruited. It is recommended that future studies examine the question of whether different genders have different experiences of psoriasis and manage it in different ways. Finally, the majority of the patients (80%) had moderate to severe symptoms, so they could not offer the perspectives of those with milder psoriasis or nonplaque psoriasis.

### Conclusions

These analyses suggest that the experience of symptoms of psoriasis is complex and that the most frequently reported symptoms were silver-white scales, red plaques, and pimples on the skin, along with continuous scratching due to severe itching. This scratching could easily cause wounds, even those with bleeding and pus, and very painful skin cracks. The symptoms also cause psychological distress to the patients, including experiences of discrimination and stigmatization, which can lead to suicidal ideation. Most of the patients reported that they were concerned about the serious side effects of long-term use of steroids and

other drugs. To eradicate psoriasis, they tried various methods, to no avail. It was only the use of biologic agents that restored their self-confidence. Furthermore, education of the public is also very important to inform people that psoriasis is not a contagious disease, which would reduce the stigmatization of patients.

## Acknowledgments

We would like to thank the participants of this study.

## Disclosure statement

No potential conflict of interest was reported by the author(s).

## Data availability statement

Deidentified datasets are available from the corresponding author upon reasonable request.

## Funding

This study was funded by the Jen-Ai Hospital, Dali, Taichung. The funding organization had no role in the design, conduct, interpretation, review, or approval of the manuscript.

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