

RESEARCH ARTICLE

Exploring psychosocial adaptation among people with chronic skin disease: A grounded theory study

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Abstract

Aim: Chronic skin disease (CSD) often has devastating effects on the physiological, psychological and social aspects of patients, who must adapt to them. However, it is not clear how patients adapt, especially with regard to their psychosocial adaptation (PSA). This research explored a theoretical model of PSA among people with CSD.

Design: Following constructivist grounded theory methodology, a qualitative study was undertaken between August 2018 and June 2019.

Methods: Observation and semi-structured interview were conducted with included participants (n=19). Data were iteratively coded and analyzed by constant comparison following the key stages of initial, focused, axial and theoretical coding until saturation was achieved.

Results: When individuals face the impacts of disease, they try to adjust to adapt it. The findings showed the core category (self-cognitive) and the contributing categories (impacts of chronic skin disease, contextual factors, physiological experiences, psychological experiences, social experiences, and positive and negative psychosocial adaptations) of the PSA among people with CSD. The process of PSA among people with CSD was not linear throughout the disease and was instead entwined within a set of complexes (contextual factors-experience) interactions. The consequences of PSA included positive and negative aspects. The theoretical model of PSA among people with CSD will provide us with information needed to develop accurate assessment and effective intervention strategies. Understanding that PSA among people with CSD is a complex, dynamic, and interactional process may provide evidence for further assessing and meeting the needs of people.

KEYWORDS

chronic illness, grounded theory, psychosocial adaptation, qualitative research, skin disease

1 | INTRODUCTION

Chronic skin disease (CSD) has devastating effects on the physiological, psychological and social aspects of people, impacting on quality of life (Jafferany & Pastolero, 2018; Parna et al., 2015). And

the psychosocial and occupational effects of CSD are often comparable, if not greater, than those of other chronic diseases (Hong et al., 2008). The lifetime prevalence of skin diseases, including eczema (14.2%), urticaria (9.2%), atopic dermatitis (7.9%), psoriasis (5.2%), vitiligo (1.9%) and other diseases (11.3%), was reported for

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five European countries (Svensson et al., 2018). With the deterioration of the environment and various pressures, the prevalence of skin disease has increased in recent years (Zhang et al., 2019). CSD has become a global public health problem (GBD 2016 Disease and Injury Incidence and Prevalence Collaborators, 2017).

Chronic skin diseases, such as squamous diseases (e.g. psoriasis, vitiligo), allergy-related diseases (e.g. eczema) and bullous diseases, are different from one another, but all are related to different degrees of itching, its characteristics are recurrent, need long-term treatment (Zhai et al., 2014). CSD also requires the treatment of disease and help for patients to positively adapt (Jafferany & Pastolero, 2018). Roy defines adaptation as the process and result of individuals or groups choosing to establish the integration between individuals and the environment through cognitive (Roy, 2011). The British Association of Dermatologists (BAD) suggested that 85% of patients with skin disease have reported that the psychosocial impacts of their disease are a major component of illness, which is a concerning statistic (Services & WPRoMSfP-D, 2012). Therefore, attempts to understand the psychosocial impacts of CSD are limited to current demographic characteristics and measures of disease severity, which also requires us to manage the disease from a psychosocial perspective (Zhang et al., 2019).

1.1 | Background

In the 19th century, skin diseases were found to be associated with psychosocial factors, the mechanisms of which were gradually confirmed in the following decades, and the psychosocial assessment of patients with CSDs became the focus of researchers (Chouliara et al., 2017). Literature analysis was used by Londono & McMillan to form a mid-domain theory of the PSA concept, showing its multidisciplinary characteristics and attributes of variability, process, persistence, interactivity and individuality (Livneh & Antonak, 2005; Londono & Mcmillan, 2015). Most quantitative researches have focussed on the psychosocial status of people with CSD, such as anxiety/depression, self-esteem, stigma, body image, social support, social interaction, sexual life, social acceptance and optimism, and objective factors, adopting assessment scale methods to monitor patients' statuses and learn about related factors (Cazzaniga et al., 2016; Coneo et al., 2017; Dieris-Hirche et al., 2017; Kwan et al., 2018; Sampogna et al., 2012). Some qualitative studies have shown the experiences and adaptations of people with

CSDs, such as eczema, vitiligo and psoriasis (Ghio et al., 2020; Khoury et al., 2017; Pahwa et al., 2013; Rasmussen et al., 2018). It has been suggested that psychosocial interventions are an effective means to improve the quality of life (QOL) among people with CSD (Heratizadeh et al., 2017; Shah et al., 2014; Son & Lim, 2014; Zill et al., 2018), but a model of psychosocial adaptation for people with CSD has not been developed; such a model could provide schemas (Mizara et al., 2012) and explanations of behavioural mechanisms for psychosocial interventions.

2 | THE STUDY

2.1 | Aim

This study aimed to develop a model that shows the process and core category of PSA among people with CSD.

2.2 | Design

The study was conducted between August 2018–June 2019 both in the inpatient and outpatient departments of two hospitals, both designated by the Ministry of Health to provide care services in China. Grounded theory provides an ideal method for identifying categories and developing a theoretical model of psychosocial adaptation in people diagnosed with CSD to determine the relationship between psychosocial adaptation and CSD (Corbin & Strass, 2015). It is a method of induction, which deepens the understanding of social phenomena by analysing content, context and process. The COREQ was followed (Tong et al., 2007).

2.3 | Sample/participants

According to the inclusion and exclusion criteria (Table 1), the potential participants were identified by the first author. Various variables, including demographics (sex, education level and marital status) and disease-related characteristics (clinical symptoms and localization), were thought to cause significant differences in the data (Table 2). To ensure the representativeness and typicality of the participants, purposive and theoretical sampling was used to collect data in different scenarios, adapting the questions when

Item	Content
Inclusion criteria	Being 18 years or older Diagnosed by dermatologists as chronic skin diseases, such as psoriasis, atopic dermatitis, vitiligo, chronic urticaria, eczema and bullous skin disease Willing to participate in the study
Exclusion criteria	Severe cognitive or mental disorders Serious cardiovascular disease and other diseases affecting the quality of life of patients

TABLE 1 Inclusion and exclusion criteria

TABLE 2 Demographic data of the participants

Characteristics	Number (%)
<i>Diagnosis</i>	
Psoriasis	10
Atopic dermatitis	3
Vitiligo	1
Chronic urticarial	1
Eczema	2
Bullous skin disease	2
<i>Gender</i>	
Male	11
Female	8
<i>Education level</i>	
Junior high school or below	7
High school/College	4
Undergraduate college or above	8
<i>Age years</i>	
Mean (SD)	42.6 (14.2)
Minimum	22
Maximum	67
<i>Marital status</i>	
Married	15
Unmarried	3
Divorced	1
<i>Years living with CSD</i>	
Mean (SD)	15.5 (10.3)
Minimum	0.5
Maximum	36.0
<i>Itching</i>	
Yes	17
No	2
<i>Localization</i>	
Visual position	8
Sensitive position	2
Both	4
Both not	5

needed and selecting cases, for example, by choosing both male and female participants (Charmaz, 2006). The interviewer and participants had not met before. The participants agreed to participate and signed informed consent with full understanding of the study protocol and process.

2.4 | Data collection

On the basis of literature, a semi-structured interview outline was developed by all the authors experienced in qualitative research, which included the context of, conditions of, variation in and

TABLE 3 Interview guide with which the interview was conducted

Questions	Cues
Can you talk about the diagnosis and treatment of CSD?	When was it diagnosed? How was it treated?
What changes have you faced since your skin disease?	How does the skin diseases influence on you?
What have you experienced since your skin disease?	How do you feel about these effects?
What efforts have you made to adjust or adapt to skin changes?	Have you tried to adapt to these effects? How?
What are your current psychological feelings and social relationships?	Can you talk about your feelings from the psychological and social parts?
What kind of your own factors have affected your adaptation to the disease?	What factors do you think are relevant to your adaptation?
What other factors do you think will affect your adjustment after illness? Stimulus or barriers?	What are the stimulus and barriers?
Can you talk about your own reviews on current psychosocial adjustment?	How do you rate your psychosocial adaptation?

experiences and consequences of PSA among people with CSD. After team discussion and interviewing 2 participants, the formal semi-structured interview outline was developed, as shown in Table 3. Face-to-face in-depth interviews were conducted by the first author in private offices or hospital wards and recorded. Data collection and analysis were carried out simultaneously. Theoretical saturation was reached when no new codes could be built, which was verified by all authors. For example, when the data of the 10 participants were constantly compared and the theory was developed, it was found that the topic of PSA was not separated from the perspective of positive psychology, so the 11th participant was selected by theoretical sampling method for data collection and analysis. The point of theoretical saturation was considered the termination of data collection.

2.5 | Data analysis

To record information and identify the next sample in a timely manner, the content of the interview and observation for each participant was transcribed and analysed without delay. NVivo 11.0 was used to manage and analyse all data. All authors participated in the three levels of grounded theory analysis: development, discussion and improvement of coding processes. Data analysis followed the guidelines for grounded theory by Strauss and Corbin, which consist of four steps: initial coding, focussed coding, axial coding and theory coding (Figure 1) (Corbin & Strass, 2015).

First, the initial coding was done word-by-word, line-by-line or event-by-event. To facilitate the participation of all authors, the

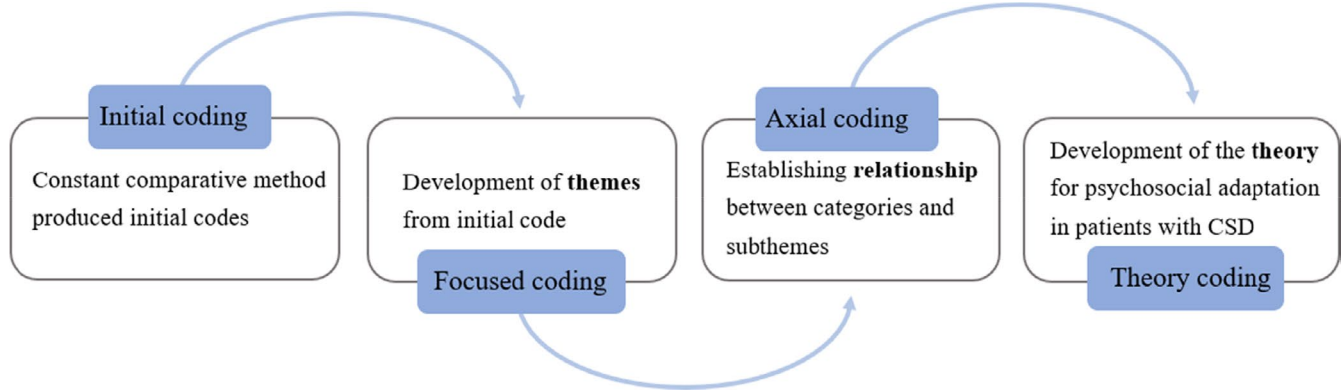


FIGURE 1 Steps involves in the coding

English codes were built (Johnson et al., 2012). The first six transcripts were independently coded by two Chinese authors fluent in both Chinese and English. Any disagreements were resolved through a larger group discussion. Data collection and analysis were conducted using the constant comparative method (Corbin & Strass, 2015). The initial coding included 174 codes. Further, 63 themes were developed by focussed coding from the initial code. For axial coding, we formed categories and subthemes and established their relationship (Table 4). Finally, selective coding was used to complete the integration process and refine the theory. A theoretical model was established through several group meetings (Figure 2). The codes must be central and relevant to all the others, appear frequently in the data, be logical and consistent, be interpretive and be able to explain variation (Corbin & Strass, 2015).

2.6 | Validity, reliability and rigour

Several strategies were applied to ensure the validity, reliability and rigour of research. The interviews were transcribed verbatim, and the transcribed text was returned to the participants for verification. Researchers also analysed and verified participants' true feelings through observations and field notes. The data analysis panel invited dermatologists and psychologists to participate. The timely selection of literature and theory improved the refining and formation of the theory. All the results in this study were derived from the participants' data and illustrated by brief supporting quotes under themes. The theoretical model obtained from this study could explain the PSA process of people with CSD.

2.7 | Ethical considerations

The project was approved by the Ethical Committee. All participants were given detailed information about the content of the study and their right to choose freely, enabling them to voluntarily agree or refuse to participate at any time. The written informed consent was provided and confidentiality maintained.

3 | FINDINGS

The demographics of the 19 participants are shown in Table 2. The findings showed the core category (self-cognitive) and the contributing categories (impacts of chronic skin disease, contextual factors, physiological experiences, psychological experiences, social experiences, and positive and negative psychosocial adaptations) of psychosocial adaptation of people with CSD. The supporting quotes are shown in Table 4.

3.1 | Impacts of chronic skin disease

As a stressor, CSD generated individual physiological, psychosocial and other impacts. Itching is a major clinical symptom of CSD, leading to sleep deprivation and hypomnesia. Excessive dryness of skin lesions overlying joints often led to movement difficulties. The condition also affected mood, often resulting in a sense of loss, irritability, anxiety, depression and even misanthropy. The localization of the skin lesions, especially in visible or genital areas, often led to both a poor sexual life and poor social interaction. Most people with CSD reported that the condition seriously affected their study, work and choice of spouse or marriage and restricted both their diet and clothing. The cost of treating CSD also brought serious economic burden to families and society. Patients faced these impacts and had to adapt from a psychosocial perspective.

3.2 | Contextual factors

Most patients still remembered the time of diagnosis of the disease, while some patients did not want to recall it and selectively forgot the beginning of their painful experience. After diagnosis, patients usually mastered relevant knowledge of the disease through medical staff, network media, relatives and friends. CSD is an incurable disease that often recurs. Patients often thought that dermatologists have not mastered the treatment of CSD, because people do not study it as much as the deadly disease cancer. "Most dermatologists just told you to go back and apply the medicine, and they couldn't

TABLE 4 Supporting quotes of categories and themes for psychosocial adaptation in patient with CSD

Category	Theme	Supporting quotes
Chronic skin disease	Physiological impacts	"Itching badly affects sleeping, especially at night, results in insomnia, which makes me very sleepy during the day...Itching and scratching have become my habits and instincts. Sometimes it's strange not to scratch. For example, I keep scratching myself before going to bed at night. I can't fall asleep until tired (Involuntary scratching)" (P1) "Now often insomnia, memory is very poor" (P18) "The skin lesions at joints crack when you crouch... The crack is too serious. How big the skin damage, how big the crack... bleeding, terrible pain" (P10)
	Psychological impacts	"I feel better as soon as the rash goes away, and I feel worse if it comes back" (P12) "Most of the time, the effects of mood swings go beyond the illness itself..." (P17) "Mental torture is the biggest, even world-weary. When the disease is cured, the psychological problems will certainly be fewer..." (P18)
	Social impacts	"when I was at my high school time, I didn't know how to adjust. I had to concentrate on my study, while at the same time itching and insomnia seriously affected my study. Don't know how to vent... I couldn't sleep until midnight. I felt asleep only when I was tired after scratching. Now I am often late for work" (P1) "The disease grows from childhood to adulthood. I can't talk with other people at school. I can never expect all the teachers to take care of me. They looked at me differently... Because I knew my illness can be a drag on my family. Even if I get married in the future, I will drag my family down. For this reason, I just don't want to get married. There's no motivation to fight... When I go to work, if my boss knew my disease, I will be treated as an encumbrance. Boss won't fire me for this, but he'll say from other facets (sigh)..." (P17) "After the illness, I felt less enthusiastic about my work...Skin problems affect my relationships with colleagues and friends" (P18)
	Others	"I usually wear long-sleeved shirts... How do I wear skirts in summer? I can't even wear summer dresses except for long sleeves" (P15) "I can't wear short sleeves in summer...affecting family life...Chinese traditional medicine is at one's own expense! Can't travel... Can't have hot spring spa" (P5) "My skin problems have a serious impact on quality of life" (P11)
Contextual factors	Experiences in diagnosis and treatment	"When I was a kid, I didn't feel like... When you are heavy, you feel like you want to cure it, but as you grow up, sometimes you don't want to cure it and then you get sick and you want to cure it again and again. Others say there is a cure, then go immediately to try, acupuncture, red blood, cupping, etc." (P1) "I've been sick for more than 20 years. The doctor said that I could never overcome this disease. This is still fresh in my mind. Then the doctor let me go without doing any tests or prescription. I was very young at that time and thought: if this doctor in such a big hospital cannot do anything, no one would be able to heal it. After that it the journey of desperate treatment started. Even centipede, I tried all the strange drugs. My bone must be black for the drug poison. As the disease is on the surface of the body, it's not inside the body, so there's a time I was begging it can be just suppressed..." (P17) "...completely following the advices of doctors and nurses about how to enhance my immunity. I have protein hypoemia. So I took protein powder, milk, eggs, lean meat, seafood, but very few shrinks. Take all suggestions from my doctor, do what ever he told me to do." (P4) "Information on skin disease is scarce and not readily available...online...it's a disease that haunts people" (P18) "Chronic diseases... it's worse than high blood pressure and diabetes...because they don't have severe symptom...I didn't want to know about it. I don't have the courage to know." (P15) "Skin disease does not have apparent change in short term. It basically maintains a very standard condition, even more and more worsen...I have no hope" (P2) "Because it can't be cured at anywhere...I think my skin disease must be caused by shift work, fatigue and low immunity and anxiety. Skin care is important, such as moisturizing... Skin disease is not like other disease that can be cured. If you have a tumor, or other things that you can cut it off. But this disease is lifelong. It's not fatal. If it doesn't recur it doesn't matter. But it's annoying when it's serious... I feel it when I'm really anxious or nervous, and it comes back." (P3)
	Knowledge and cognition of disease	"I am an optimistic person who likes to make jokes at home and work. I forget this disease when laughing." (P14) "Moreover, I have a very bad personality, especially wants to be strong... My husband wasn't at home last night. I cannot cry when he is at home. I am very outgoing" (P11)
	Characteristics of personality	"I am slow heat personality, usually do not want to speak, but with friends also more willing to speak... Skin diseases have changed my character a little. I used to like to talk to people, but now I don't like to communicate with people. I don't want to look up at people because I'm blushing...(not willing to talk, more introverted personality)" (P16) "Since I was sick, I was not a very outgoing child. After having skin lesions on the face, I am more reluctant to contact with others. I gradually become introverted and not very willing to communicate with others. I spend most of my time reading, checking my mobile phone or sleeping." (P2)

(Continues)

TABLE 4 (Continued)

Category	Theme	Supporting quotes
	Others	<p>"I was awarded as the best employer every year...is the leader's best assistant...my colleague also said this morning that you should come if you are in a bad mood at home." (P11)</p> <p>"I live well, I eat well, I earn so much. Why should I be depressed?" (P15)</p> <p>"I loved watching movies about special children when I was young. When they are unhappy with all sorts of difficulties, such as adolescent rebellion or bad exams, his parents will ask him what's wrong with you. He might not want to talk, so his parents would say: OK, I'll be here if you need me, you can come to me, and then he might come over after dinner or something..." (P2)</p>
Physiological experiences	Itching	<p>"The itching is so great that I can't sleep. It feels like a million ants crawling over me, scratching all the time even when I'm asleep. It's so painful. (crying)" (P11)</p> <p>"The itching was so bad that I couldn't sleep at night, and sometimes I slept sitting down." (P12)</p> <p>"Sometimes itching leads to a particularly heavy mental load." (P14)</p>
	Pain	<p>"When I first got skin disease in junior high school, it was really tough. Because I live in school in winter, I can only go back home once a week. Once relapse it can be very severe. There are white scales above skin lesion, sometimes crack especially long cut, extremely painful, also bleeding." (P3)</p>
	Mobility problem	<p>"Sometimes swollen legs cannot bend... The serious difficulties of mobility also hindered my work very much." (P12)</p>
	Insomnia	<p>"Sleep delays and wakefulness... Before I do not know what calls insomnia. Now I often insomnia." (P18)</p> <p>"The itching is tolerable during the day, but after taking off clothes at night it becomes special itching. It leads to insomnia." (P13)</p>
	Memory problems	<p>"Now often insomnia, the memory become particularly poor." (P18)</p>
Psychological experiences	Variability	<p>"It's been two or three years, but I haven't changed much in the past two or three years. After that, my mind can gradually calm down a little...My mood fluctuates with my condition. If it doesn't change or gets a little better during this time, I will feel relax a bit. But sometimes I frighten myself, and when I look in the mirror or look at myself once in a while, I will be very frightened when I suddenly find that the place has turned white." (P9)</p> <p>"I have a bad temper after the illness...I'm not emotionally stable. I was very good tempered myself, but not now. I'm a little cranky" (P19)</p> <p>"Normally, I am ok, but sometimes I feel depressed, just like last night when I saw the rash on my body, I cried and thought the life is unfair to me." (P11)</p> <p>"Now I wonder why I turn red skin? Why it is so serious?" (P11)</p> <p>"I thought I shouldn't have this disease. Why did I get it? Why me?" (P18)</p>
	Torment	<p>"I feel so tortured (weep)... One of the things I remember most is my mom taking me around for medical treatment. The financial at home was not very good (choking)... Then I used a 'Folk Remedies', which was made of rat poison. After eating it, it was worse than now. It was the worst, and then I wanted to kill myself... This illness has caused me distress... Just like last night, I cried and felt that life was so unfair to me... Now the corner of the mouth and the eye are bad, crying is fine, is a release. I felt like I couldn't look anyone in the eyes. After so many years of good work performance, I have to give up every chance to get an award or go out because of skin diseases." (P11)</p> <p>"Sometimes I can't help comparing myself to others. Why the others don't have this disease. So many treatments but still cannot cure this disease. It's that mentality... bad, extremely bad." (P14)</p> <p>"In fact, for me, it was very painful. On the one hand, I can understand their difficulties. On the other hand, myself... It's not just that... Your parents will worry about whether you can get a job, whether you will have a partner, whether you will have a good life because of your poor health. The parents will expect you to do the same as the other people do. But they overlook the physical situation. I may feel painful, and cannot sleep, so the next day will get up late. Then they think you are lazy. This is such a pain....</p> <p>People ask me if I feel better today, but I don't know what to say. I cannot say I feel bad, but I do not feel good. I'm frustrated, very. Why people put pressure on me? I cannot control this. I cannot make it better, even the doctors cannot make it better. When you get married and you don't have sexual life, you get more and more worried. You get worried about your husband. I couldn't do it, and I feel (sneers), I feel(sighing)...I'm a person with a lot of ups and downs in life.... I'm so tired, life is so hard (Crying)..." (P2)</p> <p>"...very upset, lost, sometimes there is a moment that I cannot let myself go..." (P15)</p>

(Continues)

TABLE 4 (Continued)

Category	Theme	Supporting quotes
Worry		"I'm afraid it may get worse... The biggest fear now is that it will spread... Constantly worrying about the food or other things that will aggravate... Worried that it may go to other places on my body... Worry about genetics... Observe skin lesions daily. This disease has no impact on longevity, but is most concerned about its spread. If it goes to the hands or face..." (P9)
		"If I am too severe to go to work, I may get crazy...I'm worried about passing it on to my children. Professor Lin, and another doctor, says the chance of passing it on to the child is 4%–6%. Now I'm worrying about my child's college. I persuade my child not to go to the south for its humidity, don't be like mum. The first thing when I gave birth to my child is to test the blood. Same type of blood and stated to worry." (P11)
Stress		"When I travel, what about itching? How to give blister to do? It's not cancer, but it develops... What should I do if the antibodies can't be controlled? I don't use hormones. But it's also scary, especially when you're sick... Think a lot." (P15)
		"I feel particularly bad when I worry about being a burden to my parents in the future." (P17)
		"We haven't had sexual life for a long time. He's afraid of contagion... The biggest worry is relapse and spending money but no cure" (P4)
		"There must be some pressure in my heart. Can I have no pressure this day?" (P10)
		"My main stressor is my hands. I wouldn't be stressed if I didn't have it. Because if I was lecturing, I used to be able to do that (pointing to the lecture with his hand), but now I don't even dare... There's a lot of psychological pressure." (P15)
Anxiety		"Another issue is my finance. Now I have lots of treatments and my money will run out." (P4)
		"There is a mental stress." (P7)
		"This year has been particularly struggling... One part comes from work..., when getting aged, one needs to consider a lot of problems, such as getting married and starting a career, which I can't do well(skin disease)... Will affect me invisibly." (P8)
Helpless		"I can always find a way to control the disease. But if one day I try everything and I can't control it, I will get anxious, extremely anxious..." (P3)
		"There is no hope for the future. I am very anxious now." (P2)
		"Skin disease definitely affects my mood...I'm a little anxious." (P5)
Self-image disorder		"I feel frustrated... Really frustrated. Because it can't be cured at anywhere...I think I'm getting used to it (laughter). It took me so long to adapt to it." (P3)
		"You have a bad mood and your skin disease can't be cured. You have to have a good mood. It doesn't help to have a bad mood." (P5)
		"There's just no solution... That's the best way." (P8)
Inferiority		"Often feel ugly and scared... Feel uglier...I used to like dressing up, but now I feel more and more...I feel like a monster just asking." (P18)
		"Avoid looking in the mirror... Looking in the mirror is stimulating." (P1)
		"I can't meet with anyone now (crying)." (P11)
Difference from the normal		"I do feel inferior. This is what the disease brings... Let me think about my childhood. No childhood. Never wore a dress because of low self-esteem. I feel inferior because of scales, others will abandon." (P11)
		"When I was young, from junior high school to college, I was quite... When I was in college, and lived on campus, when scaled, people laughed at me... First, low self-esteem." (P1)
		"My skin affects other people. At home sometimes also feel quite self-abased. Family member says this disease is not fatal, but...(musing) sometimes it's just a hassle to go... There is a sense of inferiority, which is not very normal psychology... As a friend, everyone envies my family happiness, but I still have a sense of inferiority because of skin disease." (P7)
Unhappy Sensitivity		"After puberty, all others get better but I got worse, spreading to my face and other places... More and more... That's when I got that different feeling. That different feeling was so obvious... You need to know that I am different from others. It is normal for others to see me differently." (P2)
		"I gradually find that there are many things to pay attention to. You are different from others. For example, diet should be very careful and this disease gets worse because of heat in summer, which I have to pay special attention. I must remind myself that I'm different with others." (P8)
Anger		"Moan (sigh)... Too many thoughts... Walking in the crowd or eating with other relatives and friends can be very upsetting." (P6)
		"When I wear long sleeves to cover my skin location, people sometimes ask whether I feel hot. In fact, it's a very normal conversation, but I would feel a little cynical to me. Do You know?...very sensitive... And when wearing short sleeves to expose skin location, people ask what's wrong with you. In fact, his words were extremely harmful to my soul... The next day I can't help changing my long-sleeve overalls... It feels like everyone is staring at me." (P18)
		"Sometimes annoying and irritable... Anger is a constant occurrence." (P6)

(Continues)

TABLE 4 (Continued)

Category	Theme	Supporting quotes
Social experiences	Envy	"I look at other people's skin and I wonder why they're fine. For example, when I walk down the street and see someone wearing a sleeveless shirt, which makes me jealous." (P18)
	Suicide	"I want to commit suicide in the worst time of this illness." (P12)
	Selective amnesia	"I'm the one who has selective forgetting, that is, the memory of bad things is not so deep." (P3)
	Hope	"The future is bright. The disease will eventually be healed. For example, some biological agents can control the disease now...I really want to live a normal life." (P8) "Taking care of my baby is a very happy thing for me." (P2) "I just want to take flights, go out and see the world...I just want to get out...I'll be happy when I get out." (P4)
	Meaning-making	"I was determined to study hard, so I was always the first in my class... Then determined to go to college to study hard to earn money for curing skin disease... It inspired me... Must be better at learning than others." (P11)
	Benefit-finding	"Motivation...I think if I work hard to earn money, then I will get the best treatment, and the disease will be cured, the quality of life will be improved. This may be my only motivation. NI sometimes say that it is because of this illness that I am who I am and where I am today. Without this disease, I might be different now." (P11)
Social interactions	Stigma	"The skin problem affected me very badly. It also caused me embarrassment and attention to myself very badly... It's too social, when taking a shower in public. I don't like to do that." (P10) "Embarrassed... Red faces. Feel embarrassed to be in front of people. Skin and red face are more reluctant to be in front of people." (P13) "It's embarrassing... The skin lesion is on my hand. My sleeves are in here. No one can see them. It would be embarrassing to see them. The first reaction will be fear and disgust. Fortunately, it is not on the face... Very embarrassed...(silence)" (P15) "(.....) It's awkward... If I walk into a crowd or with friends, especially if going to a restaurant, when I stick chopsticks out, everyone will mind... Even myself will mind. Just eat half of it and hurry up. Don't spoil someone's appetite... I don't go to parties like I used to. Now I'm all dirty." (P6) "No one except my husband knew that I have a skin disease. Neither my parents know." (P9)
	Social interaction	"Skin diseases affect me a lot. Most of my relations break up because of this... Skin problems affect my social relationships and friendships. When you are in a bad mood, you are reluctant to talk to others." (P10) "Sexual life is not in the mood. How can you be in the mood? Jobs after graduation are also affected... Marriage is the same, I have always had this disease, really need to limit the range of selection. Mum doesn't like my husband. His education is lower than mine, as well as the body height." (P11) "The biggest impact is with people... Maybe from the moment I held out my hand, every time I said I couldn't shake hands today, I had eczema." (P15) "Now I don't want to find a partner, bad skin, bad face." (P16) "Skin diseases affect social interactions. Friends and classmates are going to a hot spring or travel, but I can't go together... That definitely affected sexual life. Only good skin can give good sexual life. Bad skin cannot...I can't go abroad. I was unable to go abroad because of this illness." (P5)
	Social support	"I would have felt better if the doctors and nurses had accepted it." (P6) "My husband is in charge at home. My husband knew I had it before he got married. He was really nice to me. I don't do anything at home." (P11)
	Self-regulation	Internal and external cause "Actually, I have a different mental state from others. I'm psychologically stronger, and I'm more resilient... It's that everyone in your family wants you to be actively treated. But it's not useful if you're not strong... Everything else is external, you are the internal cause... External causes do not determine... Still need to adjust... The key is that you play a role in your own study, work or life... No skin disease, you'll never feel it... The psychology of illness...I'm very strong inside." (P1) "Self-regulation... No matter how much others say, you still have to adjust yourself." (P3) "I'm adjusting now...I think it's just self-comfort... As long as you can mentally accept and adjust... It's better and can't affect normal life." (P9)
	Compare	"In fact, if we compare ourselves to those less fortunate than ourselves, we may be able to balance." (P18) "When you're in the hospital for a long time, you think you're lucky...I know friends who just work all day and stay up all night. Suddenly one day unit physical examination found urine protein 3+ and creatinine increase, soon dialysis. Bye... Less than six months... Bye... Who can you argue with?...I see more cases on the Internet and think I'm better than them... For example, when Hawking was at the peak of his life, his legs suddenly can't stand..." (P8)
	Self-control	"When you're really dark, it's to test you... Do you have courage or not? Courage is not to stab people with a knife... it's when you know something hurts...and you have to put up with it. And always use rationality to control to the greatest extent everything but rationality." (P8) "Some things are self-contained." (P12)

(Continues)

TABLE 4 (Continued)

Category	Theme	Supporting quotes
Positive psychosocial adaptation	Positive coping	"I am quite open-minded and positive about the changes which my illness brings to me." (P7)
	Virtuous circle	"For me, it's using illness as a motivation to motivate myself...A virtuous cycle." (P11)
Negative psychosocial adaptation	Negative coping	"Disappointed...more disappointed, no matter what you do will have psychological preparation... What should you do if you fail? So there wasn't much disappointment." (P17)
		"The enthusiasm is fading... In the past, I was willing to fight for the best thing to pull out the best thing. Now I'm just like that. I'm not willing to fight for anything." (P18)
		"No, not at all. I was just giving, and after I got it, it was even less fun. I feel terrible about my health. There is no difference living or not.... Especially want to give up, live boring." (P4)
	Vicious circle	"After I got this illness, my enthusiasm for work and life became less and less... In the past, I was willing to fight for the best thing to pull out the best thing. Now I'm just like that. I'm not willing to fight for anything." (P18)

Abbreviation: P, Participant.

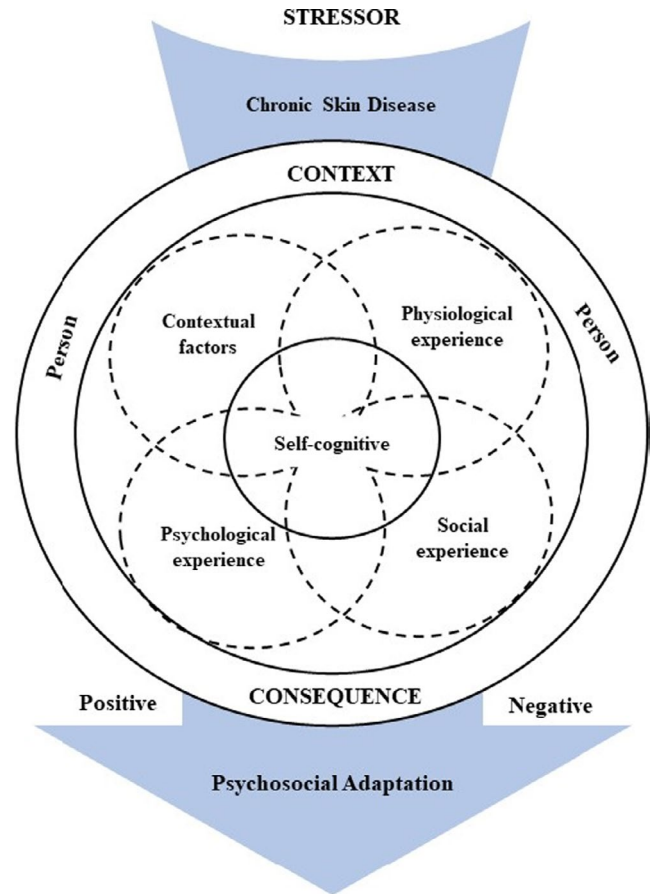


FIGURE 2 Theoretical model showing the core category and their contributing categories from psychosocial adaptation of patient with CSD

feel our torment." Most people with CSD embarked on a journey of "grasping for salvation." They began to believe in "folk remedies" (no rigorous drug clinical trials, spread through folk treatment methods), which often led to aggravation and relapse. Some patients had changes in personality, even describing themselves as "gloomy people" or "negative people." Contextual factors such as being strong in heart, having a stable job, having a better financial condition and having family support, were important for some patients' positive psychosocial adaptation.

3.3 | Physiological experiences

People with CSD experienced different levels of itching, insomnia and memory changes. Skin lesions on or near the joints became large or open, which often resulted in pain and movement difficulties.

3.4 | Psychological experiences

The psychological experiences of people with CSD were divided into positive and negative aspects and changed constantly over time. All participants reported their negative emotional experiences, and only

some described positive psychological experiences. When patients were first diagnosed, they asked themselves: "Why am I the one who gets sick?" Gradually, patients began to worry about disease progression, genetics, transmission and relapse. They were constantly under stress and pain and felt unable to talk and that others would not understand. They became sensitive and irritable and unable to control their temper. Some patients also felt a sense of helplessness brought on by the illness. Often due to self-image disorder, they felt deeply inferior and described themselves as special people who often felt "different from the normal." Some patients reported suicide attempts. When the condition abated, some patients resorted to selective forgetting in an effort to experience happy things in life. Some participants thought that CSD would be conquered in the future. Healing was their hope. What most touched us was that one participant turned the disease into a driving force to motivate herself to move forward. She worked and lived hard, which made her career and family fruitful, and her positive psychological experiences outnumbered her negative psychological experiences.

3.5 | Social experiences

Most people with CSD become reluctant to go out and reduce participation in group activities. Some patients felt that they would be rejected by others, especially when the disease recurrence or the skin lesions were located in the exposed locations, resulting in stigma. These were serious barriers to social interaction. Unmarried patients said that they did not have the courage to fall in love, because they were afraid of dragging others down and were unwilling to lower their standards. Married patients reported that their sexual lives were severely affected by CSD, either decreasing or ceasing entirely. However, patients with good family support, as the core of social support, were more optimistic and positive. Support from healthcare workers, colleagues, loved ones, friends and even religious officials could help patients have positive psychosocial adaptation.

3.6 | Self-cognitive

Self-cognitive appeared to be the core category of this research. Patients with more positive psychosocial adaptation or psychological experience were further interviewed. They believed that self-cognitive was crucial and attributed it to an internal cause; other factors were attributed to external causes, and external causes have an impact on internal causes, but internal causes play a decisive role. Patients were encouraged by comparisons with fellow individuals diagnosed with CSD or those with more serious illnesses, even by stories of celebrities who are physically disabled. One of the participants described an extreme case of girls with eczema killing their parents, suggesting that self-control is crucial in the presence of negative emotions. Without self-control, patients could do things to hurt themselves or others. Patients achieved positive self-cognitive by comparison and self-control.

3.7 | Positive psychosocial adaptation

Optimistic people with CSD quickly accepted their illness through positive self-cognitive. They accurately recognized the disease and reduced relapse through active compliance. Even the disease was given meaning, as a motivator, so that patients could achieve better results in life and minimize the impact of the condition.

3.8 | Negative psychosocial adaptation

Pessimistic patients did not acquire relevant knowledge of the disease through correct channels, leading to incorrect recognition of the disease. In addition, they lacked support and had a series of negative physiological, psychological and social experiences. At this time, patients could not adjust, and negative psychosocial adaptation could occur. Over time, it could lead to personality changes, even world-weariness and so on. The vicious cycle would adversely affect patients' compliance and psychosomatic health.

4 | DISCUSSION

Our findings provide important insights into the concept, experiences and model of psychosocial adaptation for people with CSD. When patients face the impacts of CSD, they try to adjust themselves to adapt to it. The process of psychosocial adaptation for people with CSD was not linear throughout the disease and was instead entwined within a set of complex (contextual factors–experience) interactions. Based on previous theories and studies, when individuals have CSD, the individuals will make different primary assessments due to their different contextual factors. If individuals think they can cope with it, they will adopt a positive attitude and behaviour, which refers to positive psychosocial adaptation. In contrast, when individuals think they cannot cope with it, they will suffer from psychosocial maladaptation or conduct a secondary assessment. The above two situations continued to occur after the secondary assessment. If we can carry out targeted psychosocial intervention before the individual experience invalid adaptation, we can help patients positively deal with CSD and then promote patient PSA (Figure 2). The consequences of PA include positive and negative aspects, which also have been proven in previous research (Londono & McMillan, 2015; Zhang et al., 2019), and researcher have tried to develop assessment tool (Zhang & Wang, 2011).

4.1 | Psychosocial adaptation is the result of the dynamic change

Whether people with CSD can achieve positive psychosocial adaptation depends on contextual factors and physiological, psychological and social experiences. Accurate cognition of the condition and positive experiences could help optimistic people with CSD adjust

themselves to achieve positive psychosocial adaptation. These results are consistent with previous studies (Livneh & Martz, 2016; Martz & Livneh, 2016), which focus on human strengths and virtues in the lives of people with chronic illness and disability (optimism, hope, benefit-finding, resilience, meaning-making and post-traumatic growth). Many factors change dynamically over time, so the status of psychosocial adaptation also dynamically changes.

4.2 | Self-cognitive is the core category of psychosocial adaptation

Self-cognitive, as an internal cause, is the adjustment of the individual's negative experience over time through comparison and self-control. Self-control is crucial in coping with negative emotions from the patient's perspective. It is the ability to control impulses in the face of challenges or temptations, and is robustly related to physiological and psychological well-being (Willems et al., 2019), which predicts better psychosocial outcomes (Miller et al., 2015). Healthcare consultation has to recognize the needs of patients (Nelson et al., 2013) and improve self-management (Rasmussen et al., 2018).

4.3 | Contextual factors of psychosocial adaptation

In this study, the contextual factors of psychosocial adaptation for people with CSD included knowledge and cognition of disease, characteristics of personality, family support, and working and financial status. Cognition is the process by which knowledge and understanding is developed in the mind, which is the basis of psychosocial adaptation for people with CSD. Some researchers have documented the effects of message framing, structured patient education and cognitive behaviour therapy on people with CSD (Heratizadeh et al., 2017; Jha et al., 2016; Keyworth et al., 2018), which emphasizes the importance of knowledge and cognition. Psychosocial adjustment to disease is mainly associated with personality traits (Bonotis et al., 2016). Previous studies have also reported the psychosocial effects of family support and working and financial status on people with CSD, which is consistent with the findings of this study (Dieris-Hirche et al., 2017; Nayak et al., 2018; Schmitt & Kuster, 2015).

4.4 | Experiences of psychosocial adaptation

This study described the physiological (itching, pain, mobility problems, insomnia and memory problems), psychological (denial, torment, worry, stress, anxiety, helpless, self-image disorder, inferiority, difference from the norm, unhappiness, sensitivity, anger, envy, suicide, selective amnesia, hope, meaning-making and benefit-finding) and social (stigma, social interaction and support) experiences of psychosocial adaptation of people with CSD. Most of the themes are similar to those of previous studies (Bonotis et al., 2016; Cazzaniga

et al., 2016; Coneo et al., 2017; Dieris-Hirche et al., 2017; Ghio et al., 2020; Khoury et al., 2017; Kwan et al., 2018; Nayak et al., 2018; Sampogna et al., 2012; Schmitt & Kuster, 2015), but this study is the first to explore patients' positive experiences from the perspective of positive psychology, providing references for interventions.

4.5 | Limitations

This study has several limitations. First, although two hospitals were selected that included inpatients and outpatients, the study participants most in need of help were more likely to participate, which could have resulted in selection bias. Second, participants were more inclined to describe current or memorable experiences. Compared with longitudinal studies, this study lacked follow-up and observation of participants to verify the accuracy of patient descriptions, which could have led to missing information. Finally, the conclusions of qualitative research are relatively subjective, so the theory and model established still need further study to verify and adjust.

5 | CONCLUSION

In conclusion, this research explored the construction of model of psychosocial adaptation among people with CSD. The psychosocial adaptation of people with CSD was dynamic, as it was both positive and negative. If healthcare professionals could provide timely interventions before or after the development of a patient's negative psychosocial adaptation, negative adaptation could be transformed into positive psychosocial adaptation, which could significantly reduce the impact of disease and improve the quality of life among people with CSD. Therefore, there is a need to increase the development of accurate assessment tools and intervention strategies for the PSA of people with CSD.

Understanding that the psychosocial adaptation among people with CSD is a complex, dynamic and interactional process may provide evidence for further assessing and meeting the needs of patients.

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CONFLICT OF INTEREST

The authors report no actual or potential conflicts of interest.

AUTHOR CONTRIBUTIONS

XJZ and APW designed and analysed. XJZ, HX, LF and DQW performed the search. XJZ wrote the manuscript. XJZ, HX, LF, DQW and APW read and revised the manuscript. All authors read and approved the final manuscript.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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