# Feeling uncomfortable in your own skin: a qualitative study of problematic skin picking in Italian women

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## Abstract

Skin picking disorder (SPD) is a body-focused repetitive behavior recently added to the DSM-V. It mainly affects women, with a prevalence ranging from 1.5 to 5.4%. Picking causes skin lesions that can lead to serious infections and permanent skin problems, usually on the face, scalp, arms, and legs. The behavior impairs quality of life and is associated with psychological distress and difficulties in managing emotions. The disorder causes social embarrassment, leading to avoidance and social withdrawal. As the literature on the perspectives of people with SPD is limited, our research aimed to analyze the meanings they attribute to the behavior and its consequences. A second aim was to explore how interacting with an online community can affect the management of the condition. Using a qualitative descriptive approach, we interviewed twenty-one Italian women (aged 18–50) who self-identified as having SPD and were recruited through an online forum dedicated to the disorder. Three themes framed our analysis: "A stick in the wheel of everyday life," "Other people's eyes make you realize what you are doing is wrong," and "The struggling search for control." These themes highlight the impact of SPD on different areas of life, the difficulties in accessing competent healthcare providers, the stigma experienced by participants, and the usefulness of the online group on an informative, emotional, and social level. A better understanding of these patients' perspectives can be useful for those providing professional care and those planning services for them in a Health Co-Inquiry approach that values patients' activation.

**Keywords** Skin-picking disorder · Patient's experience · Stigma · Peer relations · Qualitative analysis

## Introduction

Skin Picking Disorder (SPD) is a body-focused, repetitive behavior that has recently been included in the category of Obsessive-Compulsive and Related Disorders (American Psychiatric Association, 2013) due to the urgent, ritualistic aspects observed in patients during the act of picking. It is defined as pathological skin picking behavior that is recurrent and difficult to stop (American Psychiatric Association, 2013). The behavior causes skin lesions that can lead to severe infections and permanent skin problems (Odlaug & Grant, 2008). The picking behavior can be performed on different body parts, the most common being the face, scalp, arms, and legs (Hallion et al., 2017).

The rationale for including this condition in DSM-5 was twofold. First, skin picking often occurs as a primary disorder and has well-defined clinical features (including course) with accumulating data on diagnostic validators (Stein et al., 2010). Secondly, its incorporation would have enabled valuable research on its phenomenology, psychobiology, and treatment, ultimately resulting in enhanced clinical diagnosis and intervention. (Stein et al., 2010). However, some experts have questioned whether SPD qualifies as a distinct diagnostic category Jenkins et al. (2019) conducted a comprehensive review of articles on this topic published between January 2008 and May 2018. The review adhered to the five criteria proposed by Blashfield and colleagues (1990), which were followed to include the skin picking disorder in the DSM-5. The study found that the data met only one of the five criteria, specifically the presence of well-defined diagnostic criteria and assessment tools. Jenkins and colleagues' primary objection concerns the limited quantity of published studies and the limited validity of the data from these studies. Most of the studies were conducted online

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and depended upon self-reporting measures unchecked by researchers. Jenkins and colleagues (2019) suggest that SPD exhibits more similarities with related disorders than it does with being a distinct nosological category. Other authors have criticized the notion that SPD is a uniform disorder. In support of this stance, Schienle and Wabnegger (2020) argue that patients engage in skin picking for various reasons, accompanied by diverse emotional states. Some patients may pick their skin due to negative emotions such as anxiety, sadness, or stress, while others may be triggered by physical stimuli such as acne, scabs, or blemishes that trigger the act by sight and touch (Hallion et al., 2017; Keuthen et al., 2010). Some patients may feel relief while excoriating but also have a strong urge to control their behavior (Ring et al., 2014). Conversely, others may predominantly experience unpleasant emotions, such as embarrassment and self-disgust, when picking (Ring et al., 2014). The behavior can be intentional and focused on specific body parts (i.e., focused type) or unintentional (i.e., automatic type). In some patients, both patterns can be present (i.e., mixed type) (Pozza et al., 2020).

Overall, researchers are still debating this newly identified disorder, highlighting the need for further investigation in light of the heterogeneous picture of symptomatology and the limited overall research on SPD (Jenkins et al., 2019).

The prevalence of the disorder ranges from 1.5 to 5.4%, but several authors argue that it is underestimated because some patients do not recognize the pathological nature of their picking behavior (Malayala et al., 2021; Hallion et al., 2017). SPD appears to affect more women than men (Tucker et al., 2011), and there are three critical ages of onset: childhood (< 10 years), adolescence or late adolescence (15–21 years), and between 30 and 45 years. After onset, the disorder tends to follow a chronic course, with periods of ups and downs; the average duration of the disorder is around 20 years (Hallion et al., 2017; Odlaug & Grant, 2007). Comorbidities with SPD include obsessive-compulsive disorder, alcohol abuse/dependence, body dysmorphic disorder, mood disorder, anxiety disorder, borderline personality disorder, and obsessive-compulsive personality disorder (Malayala et al., 2021). Research on the effectiveness of medical treatments is limited (Jenkins et al., 2019; Tucker et al., 2011; Malayala et al., 2021). The preferred psychotherapeutic treatment is cognitive behavioral, which attempts to reduce or eliminate the habitual behaviors causing distress (Grant et al., 2014). However, some studies suggest that professionals' knowledge of the disorder is limited, leading to difficulty in obtaining appropriate diagnosis or treatment (Tucker et al., 2011; Hayes et al., 2009).

Studies show a significant impact of the disorder at an individual and interpersonal level. SPD has a negative influence on quality of life and is associated with psychological distress, particularly anxiety, stress, tension, depression (Odlaug et al., 2010; Odlaug & Grant, 2011), and problematic management of emotions, which can be elicited or diminished by picking behavior, thus acting as positive/negative reinforcement (Flessner & Woods, 2006; Anderson & Clarke, 2019). The disorder causes shame and social embarrassment, leading to avoidance behavior and social withdrawal (Flessner & Woods, 2006; Tucker et al., 2011; Weingarden & Renshaw, 2015; Anderson & Clarke, 2019).

Research into the impact of skin picking is almost exclusively quantitative, which limits our knowledge of patients' experiences considerably as it cannot represent the nuances of individual voices, emotions, and perspectives (Anderson & Clarke, 2019). Few qualitative studies have investigated treatment interventions (e.g., Capriotti et al., 2015) or clinical characteristics of skin picking (e.g., Odlaug & Grant, 2008). Some single-case studies have focused on the patient's emotional experience (Martinson et al., 2011). However, although interesting, they do not allow us to compare people experiencing the same disorder to capture similarities and differences between them. Two recent studies are an exception to this scenario. In the first, Anderson and Clarke (2019) conducted a qualitative analysis of posts published in an online forum dedicated to the disorder. They found evidence of a self-perpetuating cycle in skin picking behavior, characterized by a range of negative emotions such as disgust, shame, avoidance, and the compulsive act itself. This result has clinical implications, as patients' shame and withdrawal could result in avoiding seeking professional treatment and exacerbating the condition in a self-perpetuating pattern. The second study included seventeen participants based in the UK who underwent interviews regarding their SPD (Anderson et al., 2023). Three main themes emerged from the analysis. One theme explores participants' explanations for their skin picking behavior, while the second delves into the dissociative aspects of this pathological act that offers emotional and mental relief. The third theme focuses on the distress caused by concerns about others' perception of skin picking appearance.

These two studies illustrate the complexity of participants' experiences, and they suggest that patients may be best understood by considering and responding to what is meaningful to the individual. They also indicate the necessity to deepen the social support that may be offered to these patients by understanding communities, such as the online groups that many of their study's participants praised or group psychotherapy.

Since these are the only two qualitative studies that have focused on patients' experiences, further research is needed to investigate this topic in various cultural contexts to shed light on additional aspects of patients' experiences and the potential role their social networks may play in relation to

their disorder. Our study aims to address this gap in the scientific literature. Culture can impact the development of psychopathology as beliefs about a disorder and its acceptance within a given culture, along with the availability of social support and healthcare systems, potentially contribute to the disorder's prevalence within that community. Additionally, culture can affect the manifestation of mental illness, especially in complex conditions like Obsessive-Compulsive Disorders (OCDs) (Wilson & Thayer, 2020).

For example, in Italy, where this study was conducted, religion's relevance and the cultural acceptance of superstitious beliefs and practices could potentially be factors associated with OCDs. Research indicates that people with superstitious tendencies are more susceptible to anxiety and obsessions than those without (Sica et al., 2002a). Individuals with high or medium levels of religiosity exhibit higher levels of obsessionality than those with low degrees of religiosity who share the same age, education, and gender (Sica et al., 2002b).

Moreover, certain features of the Italian healthcare system could affect the diagnosis and management of SPD. Studies suggest that Italy's utilization of mental health professionals is lower than that of similar countries due to expensive treatments, lack of reimbursement from national health systems, and low referral rates from general practitioners in the absence of collaboration guidelines among professionals (Dezetter et al., 2013). This problem is noteworthy as the longer obsessing and compulsive behaviors remain untreated, the less effective treatments may be (Perris et al., 2021).

## Research aims

Against this background, our research aimed to explore the experiences of people with SPD in order to analyze the meaning they attribute to the pathological behavior and its consequences. Privileging the perspectives of those affected by SPD can help to build knowledge that may also be useful to those working in health care, given the limitations of the current understanding of the issue.

A second aim was to analyze how engaging with an online community dedicated to this disorder might facilitate its management. As it is a challenge for patients to find professionals who are knowledgeable about SPD and to identify appropriate care pathways, it is worth exploring how and to what extent a mutual support group can contribute to improving the patients' management of the disorder.

## Methods

This study uses a qualitative description approach (Sandelowski, 2010). This methodology was chosen to give voice to participants and explore and describe their experiences, barriers, and facilitators in depth.

## Recruitment and participants' characteristics

We obtained permission from the administrators of an online forum dedicated to SPD to post a message on the forum board in November 2019. The message presented the research objectives and invited forum users to participate in an interview regarding their skin picking experience. The study excluded participants under 18 or non-native Italian speakers to ensure adequate interview participation. From November 2019 to May 2020, twenty-one Italian women (ages 18–50; mean = 28.75, SD = 7.51) who responded voluntarily to our invitation (Table 1) were interviewed. The participant quantity was deemed sufficient to present a comprehensive narrative (Braun & Clarke, 2013) and encompass various skin-picking types, including automatic, focused and mixed.

The absence of men among the participants is not surprising, given the higher prevalence of the disorder among women (Odlaug et al., 2013). The participants' level of education was medium to high: eleven had a university degree, and ten had a high school diploma. Twelve participants were employed, seven were students, and two were unemployed. Nineteen participants lived with other family members or friends, and two lived alone. Thirteen had a partner, six did not, and two did not answer the question. Eight participants had consulted a psychologist to deal with SPD, and three of them had been or were undergoing pharmacological treatment (One participant was taking anxiolytics and antidepressants, while another was taking anxiolytics only. The medication intake of the third participant was not disclosed). Six participants had received or were currently undergoing psychotherapy for unrelated issues. Four participants said they would like to start psychotherapy to resolve their problem. Finally, three participants stated that they had no intention of starting psychological therapy to deal with this disorder, as they felt they could manage it on their own or for financial reasons. Seventeen participants reported having or having had other behaviors that fall into the category of body-focused repetitive behavior (BFRB) or can be placed on the obsessive-compulsive disorder spectrum (e.g., hair pulling, excessive washing).

To gain insight into our participants' characteristics and skin picking behavior, we asked them to complete the Italian version of the Milwaukee Inventory for the Dimensions of Adult Skin Picking (MIDAS) at the end of the interview

**Table 1** Demographic Characteristics of Participants

| ID Number | Age | Educational Level | Employment Status | Living condition | Relationship Status | Treatment | OCD's behavior |
|---|---|---|---|---|---|---|---|
| 1 | 18 | High school diploma | Student | With family/friends | Not declared | Psychotherapy for SPD and pharmacological treatment | Yes |
| 2 | 22 | High school diploma | Student | With family/friends | Partner | Psychotherapy for SPD and pharmacological treatment | Yes |
| 3 | 33 | High school diploma | Full-time/part-time | With family/friends | Partner | Psychotherapy for other reasons | Yes |
| 4 | 32 | Bachelor's/Master's Degree | Full-time/part-time | Alone | Partner | Interested in psychotherapy | Yes |
| 5 | 26 | Bachelor's/Master's Degree | Student | With family/friends | Partner | Psychotherapy for other reasons | Yes |
| 6 | 30 | High school diploma | Full-time/part-time | With family/friends | Partner | Psychotherapy for SPD | Yes |
| 7 | 25 | Bachelor's/Master's Degree | Student | With family/friends | Single | Psychotherapy for other reasons | Yes |
| 8 | 24 | Bachelor's/Master's Degree | Full-time/part-time | With family/friends | Partner | Psychotherapy for SPD and pharmacological treatment | Yes |
| 9 | 45 | Bachelor's/Master's Degree | Full-time/part-time | With family/friends | Partner | Psychotherapy for SPD | No |
| 10 | 25 | High school diploma | Student | With family/friends | Partner | Not interested in therapy / cannot afford therapy | Yes |
| 11 | 28 | Bachelor's/Master's Degree | Full-time/part-time | With family/friends | Partner | Psychotherapy for other reasons | Yes |
| 12 | 24 | Bachelor's/Master's Degree | Student | With family/friends | Partner | Not interested in therapy / cannot afford therapy | Yes |
| 13 | 26 | High school diploma | Full-time/part-time | With family/friends | Not declared | Psychotherapy for SPD | Yes |
| 14 | 22 | High school diploma | Student | With family/friends | Single | Interested in psychotherapy | Yes |
| 15 | 35 | Bachelor's/Master's Degree | Full-time/part-time | With family/friends | Partner | Psychotherapy for other reasons | No |
| 16 | 26 | High school diploma | Full-time/part-time | With family/friends | Single | Psychotherapy for SPD | Yes |
| 17 | 25 | Bachelor's/Master's Degree | Unemployed/other | With family/friends | Partner | Not interested in therapy / cannot afford therapy | Yes |
| 18 | 25 | Bachelor's/Master's Degree | Full-time/part-time | Alone | Single | Psychotherapy for other reasons | Yes |
| 19 | 50 | High school diploma | Full-time/part-time | With family/friends | Partner | Psychotherapy for SPD | No |
| 20 | 26 | Bachelor's/Master's Degree | Unemployed/other | With family/friends | Single | Psychotherapy for SPD | No |
| 21 | 33 | High school diploma | Full-time/part-time | With family/friends | Single | Psychotherapy for SPD | Yes |

(Pozza et al., 2016). The MIDAS is a 12-item self-report questionnaire, with ratings for each item ranging from 1 ("not true of any of my skin picking") to 5 ("true for all of my skin picking"). MIDAS is the sole tool created for assessing skin-picking subtypes, including a focused subtype that selects certain body areas and arises in reaction to negative emotions or physical sensations, an automatic subtype that appears unintentionally during unrelated activities, or a mixed subtype that combines aspects of the first two subtypes, such as selecting a specific body part without an emotional coping component.

All participants completed the questionnaire using the online link provided by the interviewer. On average, the participants reported a total score of 41.64 (SD = 5.99), well above the mean score of 30. The highest mean score was obtained on the automatic skin picking subscale (16.50; SD = 4.58), followed by the mixed-picking subscale (13.64; SD = 2.17) and the focused subscale (mean 11.53; SD = 2.24).

## Data collection

We developed an ad hoc semi-structured interview based on previous literature and research objectives. The interview topics were divided into five sections to explore each relevant aspect of the participants' experience (the interview guide is available as Supplementary material). The first part of the interview reconstructed the participants' clinical path (e.g., When and how did you realize that SP was a problem for you?). A second set of questions explored the

experience of skin picking: antecedents, context, emotions, and thoughts (e.g., Tell me, in as much detail as you can, an episode that you think is typical of SP). This was followed by a third set of questions about treatments and strategies used to counteract the act of picking and its consequences (e.g., Is there anything you do to avoid picking?). Other questions explored the impact of SPD on social relationships and the presence of supportive networks of family or friends (e.g., Have you ever discussed SP with your family members? If so, please tell me about your experience of talking to them). A final set of questions concerned the experience of using the online forum for people with SPD (e.g., What made you apply for access to this group?). Finally, the demographic data of the participants were gathered. The interviews were conducted by one of the authors, a woman with a Master's degree in psychology trained in qualitative interviewing, who did not know any of the participants. The other author, a senior researcher with expertise in health psychology, served as the supervisor. The interviews, conducted in Italian through online communication platforms, lasted an average of 60 minutes. The full transcript of the interviews was emailed to each participant with a request for feedback on whether they felt the interviews adequately reflected their experience of the disorder or if they had any suggestions for additions or edits to the text (Birt et al., 2016). Sixteen participants responded by email, giving positive feedback (e.g., thanking the interviewer), and five participants did not respond even after a second reminder. No changes to the transcriptions were requested.

## Data analysis

Data analysis followed the model of inductive thematic analysis (Braun & Clarke, 2006) to identify broad thematic patterns within the data. Analysis was conducted from a critical realist perspective that views language as constructing social realities under the influence of cultural, linguistic, and social factors that operate within the material world (Willig, 2012, 2016).

In the first phase of familiarisation with the data, the two authors read all the interviews and identified concepts and linguistic expressions that seemed relevant to the research aims. To develop a shared perspective on the data in a logic of collaborative data analysis (Cornish et al., 2013), the two authors then identified three interviews that they agreed were representative of the diversity of participants' experiences. They conducted a preliminary inductive analysis of these interviews using the N-vivo software and, thanks to a series of research team meetings, compared codes, discussed differences, and arrived at a common overall approach to coding (Coates et al., 2021). The purpose was not to obtain an objective reading of the data but to promote

a deep engagement with them and a situated, reflexive interpretation (Braun & Clarke, 2016). This result was achieved through productive discussions among the coders, which encouraged them to explain and deepen their perspectives and reflections on the interviews. Based on this coordinated approach, the two authors then coded all the other interviews and, through further meetings, discussed a final list of codes and meaningful quotes for each code. The next step was organizing the codes into themes, facilitated by graphic maps. After several rounds of revisions and a review of their internal homogeneity and mutual heterogeneity, three main themes have been identified. This systematic approach to the analysis established an audit trail from the transcripts of raw data through to the final interpretation. Results are reported according to the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Tong et al., 2007).

## Results

The analysis identified three themes that articulate respondents' experiences in the individual and social spheres, their daily problems, and their strategies for dealing with them. The first theme, "A stick in the wheel of everyday life," outlines a vicious cycle in which individuals act on their perceived or actual skin imperfections to regulate problematic emotions. This results in significant skin damage, usually not recognized until the individual stops the behavior. The second theme, "Other people's eyes make you realize what you are doing is wrong," highlights the emotional consequences of the disorder, which are identified in the pairing of guilt and shame: guilt for not stopping the act of picking, shame for the damage done to the skin. The third theme, "The struggling search for control," highlights the patients' efforts to cope with their disorder, using various sources, such as psychologists and social groups of patients, and employing various behavioral strategies that produce only partial results.

In the following paragraphs, after each citation, the number in parentheses indicates the participant to whom the citation should be attributed. This number makes it possible to identify the participant's characteristics as described in Table 1.

### "A Stick in the Wheel of Everyday Life"

This theme encapsulates the respondents' accounts regarding the vicious circle of skin picking in which they feel trapped. Picking at one's skin involves two components: an ongoing preoccupation with one's own skin and a challenge in managing emotions that are regarded as troublesome.

Therefore, picking is a way of "channeling" these emotions by working to resolve the imperfections one sees or feels on one's skin. However, it is a vicious circle because repeated picking causes severe damage to the skin, which becomes further evidence of its imperfections and renews the compulsion to remove them.

Interviewees spoke about many different emotions and situations that act as triggers for SP, ultimately making it a recurrent behavior and a pervasive disorder. The act may be performed to vent or cope with boredom, anxiety, fatigue, nervousness, or overstimulation. Other events that may lead to the initiation of the pathological behavior include waiting for something to happen, procrastination, and feelings of compulsion. A search for some form of pleasure or relief may also drive skin picking: "It often happened to me when I was nervous and even when I was excited. I mean in a positive state that I had to calm down somehow. But especially when I had feelings of emptiness and boredom" (P20).

The participants' accounts emphasized the magnitude of their inner drive and the extreme character of their actions. Using militant language, they asserted that they must "fight" and "destroy" any sign of skin that they deemed problematic. Additionally, blemishes on the skin were described as "impurities" to emphasize the moral implications of their actions:

"There is a strong urge to remove the impurities, and you say, 'I have to remove this stuff,' like a compulsive search for all the imperfections and things that might look like them. There is this urge to remove everything you can" (P13).

The mirror is a threat because seeing one's own image determines "that frustration that I vent by touching myself even more, so it is difficult to get out of it" (P10). This vicious cycle is upheld by the patient's self-confirmation logic about his or her aesthetics: "It confirms to me that I am of little value, that I am ugly. So by ruining myself, it is as if I am putting it into practice" (P4). Furthermore, the "pleasure" that participants claim to derive from the practice, "the satisfaction of expelling impurities," brings them instant but ephemeral relief. In this context, the metaphor with which skin picking is described is indeed that of "a trap" or "a snare," the promise of a solution that turns out to be illusory but into which one tends to fall.

The issue is that once the interviewees start picking their skin, they feel powerless to stop as the action becomes repetitive and beyond their control. Various interviewees described this state as trance-like or suggest that it feels as though a "monster" is inside them. Due to this lack of control, individuals may experience a momentary loss of awareness of the consequences of their behavior: "I always find this imperfection that I want to get rid of and then I

can't stop, I go into a kind of trance and I think about getting rid of these feelings and then I destroy my skin" (P3).

Participants indeed reported that they only became aware of the "damage" to their skin after doing it. These thoughts hurt the person's mood and fed a cycle of reactions that contributed to the disorder. Juxtaposed with the wheel that propels you forward, the circular path of SP is obstructing – "a stick in the wheel of everyday life" (P13). It is all encapsulating, "absorbing everything around you" and depriving you of your presence in everyday life so that you are unaware of "whether it is raining or sunny outside, you don't notice the passing of time, and you don't see the things you are missing" (P18). Skin picking was described as an all-absorbing and pervasive disorder also because it occupies much time in participants' lives, even to the point of interrupting one's sleep – "I remember I used to go to bed very late because I spent hours scratching myself" (P16). This disruption is debilitating – "a real tragedy" that negatively affects the person, even at work or school: "This pathology hurt all aspects of my life. It made me insecure, anxious, fragile and fearful, which I was not before the first rash" (P8).

In this context, the metaphors used by the participants to talk about the disorder were concrete expressions of its omnipresence: a "bubble [that] engulfs you to such an extent that it absorbs everything around you" (P18) and distances the person from their environment or a shelter that completely encloses the person to hide them from the problems of life.

### "Other people's eyes make you realize that what you are doing is wrong"

This theme encompassed the interviewees' discourses on the feeling of guilt and shame they experience due to skin picking and its resultant outcomes. Shame results from exposing wounds or scars caused by picking at one's face or body – "If others see me with my damaged face, I feel bad and I feel judged" (P6) – and this is linked to the guilt participants experience regarding their own actions. They believe that skin picking is a "vice" and that they should exert more effort to avoid scratching.

Shame pertains to social interactions. Participants reported both actual and imagined experiences that either augmented or assuaged their sense of guilt and shame. In the former case, negative comments about their skin caused them anger and humiliation, leading to increased feelings of shame: "I was ostracized and bullied because of the condition of my skin" (P8). In other instances, they expressed concern about the possibility of others holding negative opinions of them or making offensive remarks toward them: "He didn't say anything to me, but his eyes spoke and that

hurt me. I mean, other people's eyes make you realize that what you are doing is wrong. It adds an extra burden" (P20).

The issue was worsened when participants received accusatory comments from their dermatologists. According to participants, many professionals did not recognize the psychiatric factors contributing to patients' behavior and instead attributed it to their ill-will:

"I went to a number of doctors to have my skin looked at and so many of them said: 'How did you get like this? If you go on like this, you could get a serious infection. Why aren't you more delicate? There's nothing we can do, you have to stop'" (P16).

In fact, in these cases, the legitimacy of the expert was a significant obstacle to effective treatment of the problem, relegating the patient to guilt and shame for her behavior.

A shame-relieving factor, on the other hand, has been the experience of attending the internet group on skin-picking, in which they could share their experience of the disorder without worrying about being judged as "these are all people with the same pathology, so no one can ever point a finger" (P8). Sharing in the group allowed participants to talk about themselves rather than "holding in" their thoughts about the condition, knowing they would not face the stigma they had experienced in other situations.

The shame that participants experienced in their daily life contexts led them to adopt two seemingly opposite behaviors. Hiding is by far the most common, using a variety of strategies: not going out or only going out when they thought no one could see them; using clothes, make-up, and hats that hide and disguise wounds or scars; lying to those who ask about their condition; or avoiding talking about the condition in the belief that others "won't understand": "Three-quarter sleeves up to the elbow were not enough to cover the disaster in my forearm, and I had to spend the summer wearing make-up and trying to even out my skin color" (P3).

In some cases, the decision to come out of hiding was based on an intense reflection on oneself or on others, which enabled the person to overcome the shame they had habitually experienced. For example, they decided to talk about their disorder and its consequences with the people they considered closest to them, and this gave them a sense of 'relief' as hiding was experienced as an unbearable burden: "I told them: 'I'm talking about this now but for years I didn't talk to anyone about it'" (P4).

In other cases, the "mountain of shame" was crossed when participants felt they had enough self-esteem or saw fewer signs on their skin and showed up with less make-up and less disguise, feeling more confident:

"I rarely go out without make-up because it gives me the confidence I need to face the day. But there have been, and still are, times when I go out with a tank top and all the marks are visible, or no make-up at all. It depends on how confident I feel at the time" (P7).

As this quote clarifies, the choice to show or hide depends on a decision-making process whose outcome is variable and difficult to predict. The perceived threat of the context and one's ability to cope with it play an essential role in this process.

## The struggling search for control

This theme encompasses the participants' accounts of the complex process they went through to identify the nature of their disorder and to manage it while interacting with other patients or psychologists.

At some point in their lives, participants felt that the act of picking was abnormal and a source of discomfort. However, they lacked understanding of their situation and how to improve it. The desire to make sense of this discomfort led them to use the Internet and discover a disorder that could explain what they were experiencing:

"The skin picking got much worse as I was preparing for a very demanding exam. I was exhausted and wanted to find a way to stop touching my skin. So I literally wrote on the Internet: how to stop scratching. Because I couldn't take it anymore. I found the online group and it only took me two posts to realize that it was not up to me" (P14).

Thanks to the online group and other online resources, participants developed an awareness of their condition by reading the stories of others. The discovery of this diagnostic label had the first positive effect of naming the problem and making them feel less guilty about their behavior and its consequences. In a liberating sense, the focus shifted from 'it's just me, it's my thing' to 'I'm part of a group, I'm not alone':

"The group has made me more aware of what picking is and that mine is not a vice. I realized that a lot of people have this problem, so whereas before I felt like I was the only one who was weird about picking these pimples and then feeling bad about it, I realized that there were other people like that. So it changed my approach to the condition" (P5).

Participants also aimed to understand their condition by identifying the root causes of the disorder. For some, this proved impossible; SPD remained "an incomprehensible disorder," while others attributed the disorder to various factors: psychological traits such as a tendency to perfectionism, control mania or insecurity, past traumas, a family history of relatives with similar disorders, hormones or various physical problems. These different explanations demonstrate the attempt to understand the disorder and its implications through a familial, personal, or life narrative lens.

The finding that skin picking is pathological has also opened up an opportunity to manage the behavior, "I diagnosed it myself. And that led me to the psychologist" (P2). A mixed picture emerged from the participants' accounts regarding the efficacy of their relationships with their psychologists: about half of those who had consulted a psychologist described a positive experience, but for the others, critical elements predominated because of the lack of support due to perceived insufficient knowledge of this condition: "I always felt that they were discovering it for the first time and knew less about it than I did" (P9).

Participants identified two modalities through which the online group assisted in managing the disorder. The first was to provide emotional support while sharing success stories of similar patients who were actively working to reduce or overcome their condition: "When a girl or a guy writes: 'I've been to a psychologist, I've understood this and that, I'm getting out of it…'. I think, oh my God, they made it. It gives me hope" (P6).

The second way the group proved helpful was by providing "practical things and advice" about possible valuable resources and coping strategies. Over time, participants learned to use a variety of tricks to control their picking. These included manicured nails, patches to deter the compulsion to remove the blemishes, and exercise or meditation to distract the compulsive thoughts. Counter-behaviors to avoid relapse were also mentioned, such as touching oneself or writing down thoughts instead of scratching. These strategies worked only partially, and few respondents reported successful control of the disorder.

Reflecting on their inability to control this condition fully, they identified what allows them to live with it. One participant, for instance, has been regularly practicing mindfulness "for a few months now, so when I feel the urge to pick my skin, I concentrate on my breath and often manage to redirect my attention" (P4).

Realizing they had limited control was empowering for some:

"I am happy with the balance I have found. I say to myself: I have to live with this. I know this disorder, if I put a lot of effort into it I can control it, it's happened to me more than once, I've gained confidence and that makes me happy" (P9).

The search for a way out was configured in their stories as a spectrum of possibilities, from the hope of total recovery for some to the belief that it is impossible to get rid of it for others because "you can never fully recover. There have been relapses and they will come back at more difficult times" (P12).

Participants oscillated between these two poles, hoping to be cured and fearing they would fail.

## Discussion

This study aimed to explore the experiences of people with SPD by analyzing the meaning they attribute to the pathological behavior and the impact of the disorder on their personal and relational lives. A second aim was to understand how interacting in an online support group affects how people cope with the disorder.

Three themes were identified: "A stick in the wheel of everyday life," "Other people's eyes make you realize that what you are doing is wrong," and "The struggling search for control." These themes are interconnected: the pervasiveness of the disorder described in the first theme affects the social relationships described in the second theme, and the feelings of shame and guilt described in the second theme contribute to the difficulties in labeling and managing their problematic behavior, which are described in the third theme.

The first theme, "A stick in the wheel of everyday life," highlights the strong impact of SPD on personal life. The disorder's pervasiveness is evident through its compulsive fixation on the skin, often resulting in pathological picking during challenging emotional or circumstantial situations. Similarly, Anderson and colleagues speak of thoughts and attention focused on the skin that both trigger SP and make it difficult to stop once started (2023). The pervasiveness is also evident in the variety of situations and moments of the day in which the disorder manifests itself and in the different triggers that fuel it, so that it requires a considerable amount of time, both devoted to the pathological act and to the strategies enacted to cope with its consequences. Finally, the pervasiveness is related to the high emotional valence of picking: a feeling of intense temporary pleasure followed by profound sadness. Therefore, combining these elements makes the disorder difficult to manage and an obstacle to everyday tasks. This finding is echoed in Flessner and Woods' (2006) research, which highlights how SPD is an obstacle at work/school and a disorder that occupies many hours in a person's life. In our study, the pervasiveness of the disorder was also expressed by participants' metaphors: the vicious circle in which SPD seems to have no end, the trap that one falls into and is challenging to escape, and the all-absorbing bubble. Self-blame also fuelled this cycle: participants devalued themselves because of the pathological behavior and felt guilty for not controlling or stopping it, leading them to re-enact the behavior. This self-blame is analogous to the feeling of disgust with oneself that comes from knowing that one is responsible for one's self-destruction, as Anderson and Clarke (2019) reported.

The second theme, "Other people's eyes make you realize that what you are doing is wrong," deepens the relationship dynamics between the participants and their social

network. This theme highlights the relevance of shame, managed by avoiding social encounters in which the participants might feel uncomfortable or by masking themselves with clothes and make-up to conceal the skin lesions caused by the pathology. Thus, in a different social and cultural context, we confirm some of the findings from previous studies. In particular, Anderson and Clarke (2019; 2023) identified shame as a key factor in skin picking experiences among patients. It was found to be associated with social avoidance and substantially detrimental to patients' quality of life. Weingarden and Renshaw (2015) argue that shame is not limited to skin picking but is frequently experienced by OCRD patients, affecting personal relationships and leading to social withdrawal. It is critical to address this issue in order to comprehend and treat these disorders fully.

Other relational dynamics were also notable in our participants' reports: mentions of being stigmatized in various settings or being accused by dermatologists on the one hand and the presence of supportive relationships on the other hand. Experiences of stigma confirmed participants' fears and fed a vicious cycle of self-loathing. On the contrary, when social relationships acted as a positive source of support, as in the online forum of patients, participants experienced a social context that fostered hope and positive self-esteem. The presence of peer support sources, such as the one experienced through participation in the online forum group of patients, although crucial for people with this condition, has received little attention in the literature.

The third theme, "The Struggling Search for Control," describes how participants gradually learned about the disorder, its potential causes, and treatments through different sources. Nevertheless, their access to mental health and medical professionals was frequently limited. The patient's ability to actively seek out multiple sources to comprehend their malaise, identify coping strategies through interaction with other patients, and engage in new social and emotional support networks is especially pertinent in the context of chronic conditions like skin-picking disorder (Baucke et al., 2021). It has been framed as a health Co-Inquiry utilizing various techniques to converge on meaning, understanding, and cooperation and to progress toward better health outcomes (Seifert et al., 2019, p. 1773). In our research, most respondents discovered the label 'skin picking disorder' through internet searches that they carried out after observing their own behavior and deciding that it was abnormal in some way. Searching for information about illnesses and symptoms online, a growing phenomenon in the relationship with health, is now very common (Jacobs et al., 2017), and the use of health forums has also become part of the daily online diet as part of this trend (Seifart et al., 2019). Online activities play a crucial role in Health Co-Inquiry by promoting disease management and integrating various aspects of care through research, information sharing, and support (Seifert et al., 2020). The information found online, by allowing participants to name a behavior that they had previously seen as a bad habit for which they felt guilty, led participants to be convinced of the usefulness of medical and psychological support. This trajectory was influenced by the sense of guilt and shame described in the second theme. Similarly, Weingarden and Renshaw (2015) showed that shame and fear of stigma could act as barriers to seeking medical help for OCD and related disorders, which include SPD.

However, our interviews indicate that patients often had negative experiences with healthcare providers due to their perceived lack of knowledge about the disorder. The literature regarding this condition confirms that patients perceive clinicians to have limited knowledge and treatments for skin picking to have limited efficacy (Tucker et al., 2011). Confirming patients' perspectives, Hayes et al. (2009) note that skin picking is often incorrectly diagnosed. Furthermore, a recent study by Capel et al. (2023) found that American mental health providers had outdated or inaccurate knowledge of the diagnostic criteria for skin picking and inaccurately identified evidence-based treatments. Participants in Capel et al. (2023) acknowledged that their training was inadequate to address this specific condition and expressed a need for additional training opportunities. There is no research on this topic in the Italian context. However, given the limited research on SPD in Italy, as noted by Pozza et al. (2017), and the lack of services for identifying and addressing OCD in the country (Perris et al., 2021), this issue of clinicians' inadequate knowledge could be particularly significant within this specific national context.

In this situation of overall difficulty for patients, the relationships with others who have undergone a similar experience appear to meet various needs. The online group was a crucial reference point in the Health Co-Inquiry framework (Seifert & Seifert, 2019). First, the group fulfilled the patients' requirement for information regarding the potential development and treatment of the condition. Secondly, the group fulfilled patients' emotional needs by providing a platform to share similar experiences, which helped them see their symptoms as common and promoted positive processing and acceptance of the disorder (Montali et al., 2022). Additionally, the group met patients' social needs by allowing them to establish or expand their social network with others who understood their situation (Burns et al., 2009), fostering hope for finding a solution to the shared problem.

Similarly, the participants in Anderson and Clarke's (2019) study found the online dialogue about their disorder to be liberating. They felt more comfortable discussing a subject crucial to them in the examined online forum than with friends or relatives who did not suffer from the

disorder. Furthermore, as shown in the study by Naslund and colleagues (2016), the decision to participate in an online peer group helps to cope with stigma while allowing people to seek and access more treatments that can improve psychophysical well-being.

Our analysis points to some clinical implications of the research. First, the interviews showed that the Internet was an essential resource for coping with the disorder. This result indirectly suggests that online self-help programs can be somewhat valuable for treating SPD in conjunction with psychotherapy. Prior research has shown that internet-based self-help programs have the potential to alleviate symptoms of SPD. However, additional studies in controlled settings must confirm their effectiveness (Mehrmann et al., 2023). Considering the typical early onset of SPD, the users of these programs might view them as a convenient tool that aligns with their daily experience of the world, including their disorder.

A second implication is related to the role of the peer group, specifically the other patients with whom our participants interacted in the online forum. They normalized the disorder and provided emotional support. This result suggests the potential usefulness of therapeutic group settings, where patients can share their problems and experience opportunities for confrontation and change, as highlighted by other researchers (Nakell, 2015). The third clinical implication involves fostering collaboration with dermatologists while increasing knowledge of the disorder among all health professionals. This approach is paramount in promoting timely referral of patients to mental health professionals. It is vital as delays in diagnosis and treatment initiation are associated with unfavorable treatment outcomes for patients with OCD (Perris et al., 2021).

## Limits

A limitation of the research was that participants were recruited through an online support group. Therefore, only people who use the Internet to cope with the disorder were included. On the other hand, this recruitment strategy made it possible to involve a population that is usually difficult to engage and to explore how an online group can provide the support that people with the disorder feel is appropriate. Another limitation is that recruiting participants outside a clinical setting makes it unclear whether their declared comorbidities could have played a role in their SPD. In addition, the participants were all women. The higher prevalence of the disorder in women has been highlighted in the literature, although no studies have thoroughly investigated gender differences (Calikusu et al., 2012). Future research could include male participants or other gender identities. This approach would allow for a wider range of cases.

Our participants were all Italian; further studies in different contexts will add to our knowledge of patients' experiences. Furthermore, as the participants in our study were aged between 18 and 50 years, a future study could include more participants across a wider age range to observe any age-related differences. A final limitation is that this study examined picking as a homogeneous phenomenon. Future research could explore the processes and experiences associated with the different picking types (focused, automated, and mixed). This approach is in line with the hypothesis proposed by Schienle and Wabnegger (2020) about the different emotional valence of the subtypes of picking.

**Authors' credentials, as requested in the Coreq checklist** Lorenzo Montali, Phd, is a Professor of Social Psychology. Sara Garnieri holds a Master of Science in Psychology. She is currently attending a psychotherapy specialization school.

## Declarations

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