

Cultural nuances of skin shame: A qualitative study of skin conditions in Chinese women living in the UK

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the UK

## **Abstract**

**Background:** Qualitative studies demonstrate that whilst some people living with a skin condition report stigmatisation. However, little is known about the experience of stigmatisation of living with a skin condition from the perspective of individuals of Chinese ethnicity.

**Aims:** This study examined the experience of Chinese women living in the UK with a skin condition, and detailed their experience of adjustment, treatment, and the reactions of others.

**Methods:** The study used the qualitative method of Interpretative Phenomenological Analysis. Semi-structured interviews were conducted with ten Chinese women living with a range of skin conditions. The rigor of the analysis was ascertained via a process of secondary audit.

**Results:** Participants described themes related to (1) early naming and identification of the skin condition as shameful; (2) cultural views on the acceptability of concern about appearance; (3) shame and self-disgust internalised from the reactions of others; (4) adjustment taking place via reappraisal of others reactions and the personal value placed on appearance; and (5) treatment potentially being all consuming. The findings contain unique reference to subtle differences found between participants of a British-born-Chinese heritage and participants from Asia. These differences relate to differences in how the self is constructed and how this influences experience of self-conscious emotions.

**Conclusions:** The findings present an in-depth account of British Chinese women's experience of living with a skin condition. They support findings from other studies that skin conditions can be stigmatising and result in feelings of shame. This study demonstrates how the experience is also influenced by differences that may arise between "individualistic" and "collectivistic" cultures. The findings indicate the importance of conducting holistic culturally sensitive assessments.

**Declaration of interest:** None **Key words:** Psychodermatology; Interpretative phenomenological analysis; Culture; Ethnicity; Stigmatisation

## INTRODUCTION

People living with a visible skin condition may experience intrusive reactions from others, such as staring and name-calling<sup>1</sup>, and may be subject to stigmatisation<sup>2-5</sup>. Existing qualitative studies have illustrated that whilst stigmatisation is commonly reported in skin conditions, the impact of this may be different across countries<sup>6,7</sup>. For example, Thompson et al. (2010)<sup>6</sup> found that British South Asian women living with vitiligo commonly engaged in avoidance and concealment, which has also been reported in other populations. However, they also found that experiences of stigmatisation were tied up with cultural values related to the role appearance plays in status, marriageability, and to myths associated with the cause of the condition. Understanding such factors may be useful in developing psycho-educational interventions and in facilitating adherence to dermatological treatment.

There remain few studies that have examined socio-cultural factors associated with adjustment in skin conditions, and none that have examined this in Chinese communities (living in China or elsewhere). This is additionally problematic as there is evidence that skin conditions present a considerable health care burden in China where conditions such as scabies and dermatitis may be particularly prevalent<sup>8</sup>. Further, it has been established that there may be differences related to “individualistic” and “collectivistic” cultural values in relation to experiences of shame which might play out in experiences of skin related stigmatisation<sup>9</sup>.

Consequently, this study sought to explore the experience of women of Chinese ethnic backgrounds in the UK who were living with a recognised skin condition. The aim was to

understand their personal experience, their experience of treatment, and how their experiences might be shaped by socio-cultural factors.

## **METHOD**

The qualitative method of Interpretative Phenomenological Analysis (IPA)<sup>10</sup> was used because it has been specifically developed to focus on lived experience whilst acknowledging that there is a process of interpretation on the part of the researcher involved. IPA is deliberately idiographic and looks at accounts derived from small numbers of participants taking a case-by-case approach. IPA has previously been successfully used to explore the experience of living with specific skin conditions<sup>11</sup>.

### **Participants**

Ethical approval was gained from University of Sheffield, UK. Women diagnosed with a skin condition such as vitiligo, psoriasis, eczema and acne, who identified themselves as Chinese and over the age of 18 years old were recruited. Ten female participants from Chinese communities within the UK were recruited via the National Eczema Society and via University volunteer lists. The participants ranged in age from 22 to 42 (mean= 28, SD= 7) and were from various parts of the UK. All had a skin condition for over eight years. Participants described themselves as British-Born-Chinese (n=3) or Chinese-living-in-the-UK (n=7).

### **Data collection**

Semi-structured interviews were conducted by the first author, in either English, Cantonese, or Mandarin depending on participant preference. To ensure cultural sensitivity, the interview schedule was developed in collaboration with a community advisory panel<sup>12</sup>. The interviews focused on eliciting information on: (a) personal experience, (b) reaction of others, and (c)

treatment experience. Interviews lasted approximately 60 minutes and were recorded and transcribed verbatim.

### **Data analysis and interpretation**

The transcripts were analysed in accordance with principles of IPA<sup>13, 14</sup>. Transcripts were read several times alongside the audio-track to check for accuracy and to assist with engaging with the data. Initial responses to the data were recorded and then the transcripts were re-read. Preliminary themes were identified and analysed line-by-line from linguistic, descriptive and conceptual perspectives<sup>14</sup>. Emerging themes were identified that captured the meaning of the data and the researcher's interpretation of it. These themes were then further developed and restructured hierarchically to develop a list of super-ordinate themes. Connections between themes were then developed within and between participants using pictorial representation to facilitate interpretation. Final themes were checked against the original transcripts to ensure that the context from which they were taken was not lost during analysis. Several established strategies were used to enhance the rigour of the findings, including an audit of the analysis process.<sup>13</sup>

## **RESULTS**

The themes are presented in temporal order that show commonalities across different conditions - from the discovery of the condition, to feeling different, to detailed accounts of life with a long-term condition, and the experiences of treatment and support. Whilst the account of living with a skin condition were described in a temporal order (partially as an artefact of the interview schedule), the psychological processes involved were not linear and the participants' accounts contained references to unique cultural factors with subtle differences evident between participants who described themselves as British-Born-Chinese (BBC) and those that described themselves as Asian (international students).

### **Theme 1: Shame can be embedded in the name of the conditions**

The literal translation of some conditions was bound up with the meaning participants gave to the condition and consequently to the impact of it.

*P6 (has psoriasis): ‘...they describe it in Chinese (牛皮屑, psoriasis) it is like (牛皮, cow’s skin), the skin of the cow, it’s very thick and very hard and so you... will feel it is very horrible.’*

The diagnosis and associated meaning of the term in Chinese clearly contributed to a sense of self-disgust, a feeling of being dehumanised and becoming ‘animal like’. Some participants also talked about their skin condition as ‘an enemy’ which ‘creeps up on you’ (P7, has eczema); and some even feared it being seen to be caused by a ‘sexually transmitted disease’ (P2, has eczema).

### **Theme 2: Secondary shame associated with being seen to be vain**

Cultural views about appearance and the unacceptability of being seen to be overly concerned with appearance and thus vain were reported. This appeared to influence participants’ views of themselves and ran the risk of influencing adherence to treatment.

*P6 (has psoriasis): ‘if I’m at home I just, scratch it directly but if I’m in a public place I would, tolerate it... it’s not good manners to [scratch].’*

The quote demonstrates the importance of collectivist concepts and the importance of being seen to behave with good manners, mindful of others, without overly focusing on one’s own body and was more prevalent in the international student participants.

### **Theme 3: Shame and self-disgust internalised from the reactions of others**

Participants described experiencing negative social reactions such as staring, teasing, and bullying as has been found across other cultures.

*P1 (has eczema): 'I think the worst situation where it's ever been noticed where I cried ...I was seven ...they stopped me from going into the swimming pool because they were worried that my skin was contagious.'*

It is not surprising that such stigmatising experiences were reported as causing distress and occasionally shame.

*P3 (has psoriasis): 'I still feel ashamed, I feel kind of conscious of people learning that I have psoriasis because I think they're going to think badly about me or, you know, it's a flaw isn't it' ... I felt disgusting, I know that sounds a bit harsh but I, literally I felt disgusting... in my head when I say I'm thinking, god you know, that's quite vain'*

This quote was typical of participants' fears of receiving negative evaluation from others in connection with their appearance and a secondary sense of self-disgust or shame associated with being overly concerned with the self.

Participants described themselves as being different due to their skin condition. Being an ethnic minority group living in the UK, they described feeling doubly different; and this was particularly the case for participants born in the UK, some of whom had experienced racial abuse, making their experience of feeling different due to their skin condition more difficult.

*P1 (has eczema): 'the only Chinese girl in an all white school you really have enough that makes you stand out, erm, you don't want something else that makes you stand out so I had two huge things that made me stand out, the fact that I was the only Chinese girl in the whole school and the fact that I had eczema'*

Being the 'only Chinese' child in the school may have heightened their sensitivity to prejudice, making the experience of having a skin condition more stigmatising.

Not wanting to be different, participants engaged in concealment or avoided social situations and intimate relationships for fear of being rejected.

*P10 (has vitiligo): 'because I can cover mine by clothes so nobody know it, only when I tell people... your appearance I think is more important, especially when I worked as a secretary I think, so I worry if one day it will spread to my face, I don't think the company will employ me'*

#### **Theme 4: Adjustment via reappraisal of others reactions and the personal value of appearance**

Cognitive strategies and behavioural management styles were commonly described. Despite facing very real risk of receiving negative reactions from others, one of the commonly described cognitive strategies was recognition (and thus correction) of a tendency to over-estimate the chances of encountering negative social reactions.

*P3 (has psoriasis): 'I think what's in your head is always so much worse than, you know, you invent things in your head when people look at you, you know, they, they could be looking at you for any reason, they're not necessarily looking, I mean when somebody, when I see somebody who has a skin condition I'll look at it but then that's it, I won't keep, and it's very difficult to think well when I do that I'm not judging anyone.'*

Participants reported having revised the value they placed on appearance in their self-



concept and reported that by putting less attention on appearance they were no longer in conflict with their physical symptoms, rather they sought to seek harmony between their mind and body. This in turn facilitated engagement in culturally-derived methods of maintaining wider health:

*P1 (has eczema): 'now my parents are making me soup because it's good for me not to get rid of [it]... '*

Emphasis for many participants was placed on establishing a healthy balance in life to prevent flares, which were linked to traditional Chinese understanding of wellbeing. However, some participants felt that it was an extra burden to maintain this.

*P3 (has psoriasis): 'I was living life at a ridiculously fast pace... it was only when I stopped to have that treatment (acupuncture) twice a week I realised... I realised that that's what I've got to start doing for myself, I need to have that time out... I need to slow down... I've learnt a bit about meditation and yoga... '*

Overall, acceptance of self with the skin condition was linked to feelings of acceptance by friends and family.

*P1 (has eczema): 'as you grow up older and older, and also become more accepting in your, you develop friendship groups, close friendship groups, you realise that they don't care, and as I sort of settled in to my friendship groups... the impact of having eczema has been less ... '*

### **Theme 5: Treatment can be all consuming**

Seeking treatment and advice on management of symptoms was reported as occupying a large part of the participants' lives, and social network support, where people share similar

experiences, was popular and balanced with seeking medical and traditional support. Participants described a sense of willingness to try anything that was perceived to be helpful despite also being sceptical. UK-born participants, who had experience of Western medicine, expressed scepticism about traditional treatments such as acupuncture and Chinese remedies, yet they were willing to try them. They reported that their engagement with traditionally-derived treatments was motivated in part by desire to avoid family confrontation.

*P1 (has eczema): 'I think my parents bathe me pretty much everything... the carrot is that you're getting rid of eczema so as disgusting as it was, you just do it, my grandmother would hold my nose and I would just down it (herbal medicine) all in one... I think any Chinese child would as well, you just do what your grandmother says'*

Dietary manipulation and restriction formed a part of the alternative treatment; however, this practice sometimes clashed with cultural concepts of the importance of eating what you are offered.

*P7 (has eczema): 'when we are eating stuff they will say, oh why don't you eat beef or why you don't eat prawns? And they will just keep questioning you and trying to force you to eat... I struggle because people give it to you and should I eat or not... because in Chinese culture you would...'*

The participants described other differences between Western medical models and Chinese beliefs. The Eastern medical model believes in organ function and the Yin-Yang principle; any symptoms of skin condition are seen as a sign of imbalance between Yin (陰) and Yang (陽) forces in the body, and the person's body, mind and spirit are treated as a whole to restore equilibrium. Hence, the diagnosis leads to a series of treatments aimed at achieving balance. The differences in conceptualisation of health had an impact on how the participants viewed their condition or how

they chose to live with it. For example, the participants of international origin focused on seeking balance within their bodies. For them, there was great importance attached to the concept of detox (cleansing of the inner organs) or 'getting rid of the heat' by adherence to a specific diet or remedy.

*P4 (has acne, and eczema): '... it reminds me to think about what is the best, what is the most healthy lifestyle and I realise that I have to eat healthy food and drink water as many times a day to 排毒 (detox) just the Chinese concept, my mum would say don't eat beef 燥熱 (it carries heat)'*

Some participants felt responsible for their skin condition as the Chinese medical model implied that skin disease resulted from lifestyle issues.

*P4 (has acne, and eczema): 'they said "it is just because you have some problem with your organs it will effect your face"... so I just like pay attention not sleeping too late, not eating hot and spicy food'*

*P5 (has acne): '... in China they would say that there is a heat in your body, and it revealed on your face, like different areas on your face, present different problems with your organs in your body'*

Another cultural difference was described in the meaning of treatment. For example, participants described the process of preparing herbal remedies as serving to bring the family closer together.

*P1 (has eczema): '... they're convinced it's something about the heat inside me, getting rid of it...making soup... I'm in my thirties, he's (father) sixty and he still does it for me.'*

## **DISCUSSION**

This study found that aspects of the experience of living with a skin condition such as feeling different and struggling with a fear of negative evaluation to be similar to those in previous studies, which further highlights the common psychosocial difficulties people living with skin conditions may face,<sup>11, 15-19</sup> and the relevance to models of shame, stigma, and social anxiety<sup>5</sup>. This adds weight to the suggestion that cognitive behavioural therapies may be useful in treating some of the distress associated with appearance concern linked to self-disgust and body image disturbance<sup>5</sup>.

Whilst there were similarities with the existing literature, culturally-specific factors unique to the sample of Chinese women were found and which may be overlooked in clinical practice. Thompson et al. (2010)<sup>6</sup> also found subtle differences in the way that stigmatisation might operate in their sample of British South Asian women. The women in this study did not make direct reference to their condition influencing marriage or status as reported by Thompson et al., however, the findings of the current study demonstrate that participants concerns about the meaning of the skin condition were influenced by cultural values and wider concepts of wellbeing derived from Eastern cultures.

Most interviews illustrated participants' experiences of being stigmatised due to their skin condition, but also a fear of being seen as vain if they became overly concerned with the condition. The emphasis on collectivism within Chinese culture may provide some explanation as to why dietary habits and behaviours such as scratching presented an additional challenge for participants. Interestingly, the translations of some diagnoses were also influential in stigmatisation as they linked conditions to animal traits.

The current study illustrated that cultural differences were associated with dilemmas around self-management. Some of the participants described believing that Western medicine lacked a holistic and contextual view of skin disease, whilst others were sceptical about traditional remedies.

Dilemmas in relation to cultural practices and healthcare have been found in other studies with Chinese women<sup>9</sup>. This study demonstrates that the pursuit of treatment involves sensitive balancing between different belief systems, that in turn adds complexity to self-management with the potential to influence adherence to prescribed treatments. Being aware of subtle cultural factors might be useful for clinicians in discussing engagement with treatment.

Clearly, these findings suggest some avenues for exploration when conducting holistic dermatology assessments, and healthcare professionals should look to ask about what it might 'mean' for a specific patient to be seen to be scratching or worrying about their appearance. Where this meaning is associated with low levels of distress simple reassurance may be sufficient, however where higher levels of distress are present referral for psychological support is indicated. It can also be useful to explore culturally based understandings of causation as understanding these may present opportunities for patient education. Finally, it remains important to check for the need for support in managing actual discrimination that might be associated with both skin diseases related prejudice and in some cases experiences of having suffered racial abuse.

There were some interesting inter-cultural differences between the participants based on whether they were born in the UK, although given the small sample size some caution must be expressed in drawing conclusions from this. Further, this study acknowledges that as it sought to present a detailed idiographic account it is not generalisable, so further research with a larger, more homogenous sample of participants is required. Whilst this study does not allow wider generalisation to the Chinese population with skin conditions, it does serve to demonstrate some of the specific cultural factors that may impact on psychosocial adjustment and has demonstrated the complex relationship that exists between these and wellbeing.

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