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Experience of rosacea and its treatment

Title: Experiences of rosacea and its treatment: An interpretative phenomenological analysis

Running title: Experience of rosacea and its treatment

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What's already known about this topic?

- Individuals with rosacea can experience social anxiety, depression and embarrassment, and decreased quality of life
- Relatively few people with rosacea receive specialist dermatology treatment or psychological support

What does this study add?

- This is the first qualitative study to use interpretative phenomenological analysis to examine the lived experience of individuals with rosacea; and their experience of treatment
- Results indicate that emotion-focused and behavioural/avoidant-focused coping strategies are used to manage the negative impact of rosacea on individuals' lives
- This study highlights the need for medical professionals to assess the psychosocial well-being of patients with rosacea, in order for them to be referred to psychodermatology services if necessary
- The study provides dermatology professionals with a nuanced account of the patient experience of rosacea. This knowledge should facilitate the discussion and identification of psychosocial issues affecting patients

Lay summary

Relatively few people with rosacea receive specialist dermatology treatment or psychological support. Despite this, individuals with rosacea can experience social anxiety, depression and embarrassment, and decreased quality of life.

Whilst questionnaire based studies have been used to investigate the type of distress that people living with rosacea might experience, there are not any studies that have sought to gain an in-depth understanding of the experiences of living with this visible skin condition. Further measures of quality of life do not provide an insight into self-management and of seeking treatment, and in order to access such information qualitative methods are required. Therefore this study used face-to-face interviews to ascertain participants nuanced individual experience of life with rosacea.

A qualitative approach called interpretative phenomenological analysis (IPA) was used to guide the interviews and analysis. This approach to research focuses on individual accounts and has been extensively used to investigate illness experience. In this study nine participants took part in detailed semi-structured interviews.

Three superordinate themes were gleaned from these interviews; self-consciousness, which focused on the fear of others' assigning blame to participants for having caused their own symptoms; avoidance, concealment, and hiding emotions, referring to the coping strategies participants employed in response to rosacea; and inconsistencies in treatment, which focused on the need for medical professionals to assess the psychosocial wellbeing of patients with rosacea.

The findings are consistent with qualitative findings from patients with other skin conditions that demonstrate that self-conscious emotions can be a significant part of the experience of life with a skin condition. Healthcare professionals need to take care to assess for the presence of such concerns in rosacea, and where unhelpful thoughts or beliefs are reported, patients may benefit from dermatology specific psychological support.

Abstract

Background Whilst rosacea is a chronic skin condition, the condition can often have a large psychosocial impact on the individual. There is therefore a need to understand the experience of living with rosacea from the patient perspective.

Objectives To examine the experience of living with rosacea and the experience of seeking and receiving treatment.

Methods Nine participants took part in semi-structured interviews, which were analysed using interpretative phenomenological analysis.

Results Three superordinate themes were identified within the data; *self-consciousness*, which focused on the fear of others' assigning blame to participants for having caused symptoms; *avoidance, concealment, and hiding emotions*, referring to the coping strategies participants employed in response to rosacea; and *inconsistencies in GP treatment and guidance*, which focused on the need for medical professionals to assess the psychosocial well-being of patients with rosacea.

Conclusions Rosacea can have a negative impact on the daily life of people with the condition, contributing to lowered self-esteem, embarrassment, and feelings of shame. Engaging in emotion-focused and behavioural/avoidant-focused coping strategies increased participant's confidence and reduced their avoidance of social situations. However, such strategies might still serve to maintain underlying unhelpful cognitive processes. Consequently, it is important for medical professionals to assess for the presence of cognitive factors that might contribute to maintaining distress in patients with rosacea, and where unhelpful thoughts or beliefs are reported, patients may need to be referred for psychological support.

Rosacea is a chronic facial skin condition characterised by flushing, erythema, papules and pustules, or dilation of capillaries¹. Limited epidemiological data suggests prevalence rates range from 2.2-22% across Europe^{2,3}. Current treatments for rosacea assist in alleviating symptoms, however no cure exists^{4,5}.

Skin conditions, including rosacea, have been found to have a psychological impact including depression⁶, lowered self-esteem⁷, and feelings of shame and embarrassment⁸. There are also marked individual differences in the severity of impact of skin conditions^{9,10}, which does not correlate with clinical severity¹¹, and as a consequence individuals with severe distress may not be easily identified¹².

Moustafa et al.⁶ conducted a review of the psychosocial and quality of life (QoL) impact of rosacea, finding higher social anxiety, depression and embarrassment, and low QoL as compared to the rest of the populations studied¹³. A recent review by Van der Linden et al.¹⁴ found a negative impact on health-related QoL, with a small to moderate effect¹⁵. Measures of QoL do not provide an insight into the experience of life and self-management, and in order to access such information qualitative methods are required^{16,17,18}.

In a recent qualitative study, Cardwell et al.¹⁹ used content analysis to investigate experiences of rosacea. A large number of comments taken from a social support forum were categorized and depressive symptoms appeared to be the most commonly expressed psychological symptoms, with suicidal ideation also mentioned in a minority of posts. Some posts mentioned that physicians underestimated the impact. These results provide a novel insight into the types of distress present, however they do not provide an in-depth account of experience.

Qualitative studies collecting in-depth information may provide insights into the most appropriate target for psychosocial intervention and identify changes that might be required in dermatological practice²⁰. In light of this, this study uses interpretative phenomenological analysis (IPA). IPA is a specific form of phenomenological approach that focuses on individual experiential accounts²¹ and has been extensively used to investigate illness experience²². It is thus well suited to the aim of investigating the experiences of adults living with rosacea, and experiences of seeking and receiving treatment.

Methods

Participants

Experience of rosacea and its treatment

Nine participants took part in this study (an appropriate sample size for IPA²²). All participants were White British, eight participants were female, and the average age was 45.8 (range 23-64). IPA typically uses a purposive approach to sampling, with a small sample with relevant experience identified. Potential participants were screened for the following inclusion criteria; (a) diagnosis by a GP or dermatologist, (b) symptoms for more than 12 months, (c) consulted with a GP or dermatologist about treatment in the past 18 months, (d) over 18 years old, and (e) could speak English. Individuals were excluded if they had a diagnosis of another chronic health condition.

Procedure

Participants were recruited through two methods. Three participants were recruited from a previous survey that had consented to be re-contacted. Six participants were recruited through NHS primary care services. Potential participants were sent an invitation to participate, along with an information sheet. Participants were informed that the research goals were to understand the experiences linked with living with rosacea and undergoing treatment, in essence how rosacea affected their lives. Thirty individuals were contacted via the previous survey, 8 responded to the email. The GP service sent out letters to patients meeting inclusion criteria. Sixty patients from the GP service were contacted, and 11 responded. Participant's were not known to the research team. Three respondents were excluded from the study due to not meeting the inclusion criteria. Furthermore seven respondents were unable to either travel or participate during the time the study was recruiting.

Participants were given a £10 voucher to cover expenses. Interviews were conducted at either the Department of Psychology within a research room, or in participant's homes. Each interview took approximately one hour, and was recorded and transcribed verbatim. In order to provide additional contextual information the participants completed the Dermatology Life Quality Index^{23,24}. Ethical approval for the study was obtained from the NHS Research Ethics Committee (15/SC/0300).

Data Collection

Participants were asked questions about the psychosocial impact of living with rosacea, and the experience of seeking treatment. Questions were sectioned into four topics; personal and social experiences, symptoms, and experiences of treatment (e.g. *"Have you ever sought any professional help for your rosacea?"*; prompt: *"What are your experiences with that?"*). The first author conducted all interviews alone with participants. The full semi-structured interview guide is available in the supplementary files. In keeping with IPA, the semi-structured schedule enabled the use of a variety of techniques, such as paraphrasing, to ensure that participants' gave as elaborate responses as possible²⁵.

Data analysis

Initial notes were made on each transcript. This involved summarising the content, and recording any thoughts the first author associated with participant's statements, such as recurring

phrases, or comments on the language participants used to describe their experience²⁶. This process was conducted for each transcript before comparisons were made between transcripts. The analysis then proceeded to look at conceptualising the descriptive codes to bring out meaning; this was achieved by structuring the themes hierarchically into clusters. A master list of themes was eventually produced²⁶. As a means of quality control^{27,28}, an audit of the analytical process was conducted by the last author²⁵.

In order to circumvent potential bias, the coding and analysis was undertaken by the first author, with subsequent discussion of results with the last author²⁹. The first author maintained a reflexive journal that was used to inform this process³⁰.

Results

DLQI scores for the nine participants are reported in table 1 within the supplementary materials. According to the DLQI coding guide²³, the majority of participants reported a small, or no, effect of rosacea on their lives within the previous week. Participant 2 reported a moderate effect, whilst Participant 3 was the only individual to report a very large effect of rosacea on their life.

Three super-ordinate themes emerged from participants' accounts. Each theme contained a number of subthemes. The number of participants contributing to each subtheme, and an overview of these themes (with illustrative quotes) is available in the supplementary files. Super-ordinate themes are presented in bold, with subthemes indicated in bold italics.

Self-consciousness

Fear of being blamed for causing the condition

Five participants believed that others would negatively appraise their symptoms as being the result of personal behaviour such as sun exposure or alcohol use:

"I sometimes think 'I bet you think I, I drink a lot' and I virtually drink nothing, because that's what people think, they don't think 'oh she's got rosacea.'" (P1)

These perceptions led to some participants seeking to ensure that they positioned themselves as not acting in a way that might have caused the symptoms, stating for example that they do not drink often or whilst on holiday they are "*always a shade person*" (P4). These fears as to what others might think appeared to be particularly present in encounters with new people:

"I think I'm conscious of the fact that people who don't know me, may look at me and... have that view of me."(P4)

Participant 2 indicated that this situation is exacerbated by an awareness that the general population do not know about rosacea:

“...but pretty much anyone that says ‘oh I’ve got rosacea’ they just say ‘oh what’s that’ or even ‘that’s a nice sounding thing...it sounds like roses’ (LAUGH), all sorts of weird comments [because] people don’t, have a clue about it.” (P2)

A range of self-conscious affects

The majority of participants discussed feeling embarrassment. Participants were concerned that the appearance of symptoms would undermine their desired image to others. Some expressed a desire to keep their symptoms a secret:

“Because I don’t want people to know that I’ve got it to be honest... I think it’s embarrassing just having a red face....” (P7)

Shame was also commonly mentioned amongst participants, however this emotion differed between participants. The majority of participants experienced external shame³⁰, involving fear of being judged by others. Participant’s 3 and 9 however, also displayed more internal shame, in so far as they held negative self-evaluations. For instance, Participant 3 appeared to be the most severely emotionally affected, expressing depressive symptoms, and often revealing self-critical thoughts:

“I don’t want him looking at me because it just, in some ways it’s sort of like worse than being naked. It’s like, I can’t explain it, it’s, just shame. Utter shame. That somebody’s looking at [you], it’s just ugly looking back...” (P3)

Participant 3 described feeling acutely vulnerable without concealing her rosacea with make-up. This relates to her belief that it was ‘ugly’. Previous experiences of bullying may have contributed to the emergence such beliefs: *“I got called a clown a couple of times... you hear a lot of negative comments when you’re younger and it sort of sticks with you” (P3).*

The tendency to place significant worth on appearance may have affected participants’ confidence in their own worth and abilities. For instance, Participant 1’s lowered self-esteem made her compare herself negatively to someone with whom she was competing for a job, someone she believed was *“slimmer, and she doesn’t look like a red face and then there was me” (P1).*

This caused the participant to expect not to be selected, despite her merits:

“...and I was chosen to be head of Uni my first thoughts were ‘why me’...and she said ‘you weren’t expecting that’ and I said ‘no why me’, ‘because you’re the best person to take over’” (P1)

Avoidance, concealment, and hiding emotions

Unsurprisingly, given the high levels of shame reported, participants used avoidant coping strategies in order to manage their reactions to the rosacea. Emotional and behavioural focused coping strategies were reported as being used. Whilst the emotional focused strategies appeared to be largely unhelpful, the behavioural strategies used appeared to have both positive and negative effects.

Behavioural avoidance-focused strategies

With the exception of Participant 6 who felt symptoms were painful rather than cosmetic, all female participants discussed actively using make-up to conceal symptoms. The male participant also reported having considered wearing make-up. Such concealment, as well as hiding the face, is typical of shame driven coping behaviour:

“Once I started wearing the make-up I didn’t want to have to be going, I still don’t, I would still not go to the GP, take my make-up off to show him, because it means I would have to come back without it on. And I wouldn’t be able to leave the doctor’s office.” (P3)

Participant 3’s reliance on concealment might have hindered her ability to seek medical treatment.

Participants also reported using avoidant strategies, particularly as a method of reacting to other people’s comments often taking the form of using commonplace explanations for looking red:

“...it’s in the summer time better because I can just sort of say, ‘Oh, my big nose is closest thing to the sun so it always goes- it always gets burnt,’ sort of thing so I always pass it off as sort of sunburn... that’s an easy way of just sort of dismissing it.” (P5)

Such comments could allow Participant 5 to conceal the rosacea from others behind what she believed to be a more socially acceptable explanation. In contrast, Participant 8 chose to tackle comments head on, displaying a potentially more positive coping strategy. By correcting other’s perceptions of her symptoms, she was able to stop others assigning blame to herself:

“If they commented that I’ve caught the sun..., ‘oh you’ve caught the sun’, [I’d say] ‘well but I haven’t it’s rosacea’.... but I don’t go into detail and they don’t tend to ask.” (P8)

Emotional-focused strategies

Some participants discussed hiding themselves more generally. One participant described a metaphor of a brick wall inside her mind:

“I think I live behind a wall if I’m honest, people think I’m this really confident person but behind I’m not, I spend half my life worrying, but I have my wall, I put it up and that’s what people see.” (P1)

This coping strategy affords the appearance of functioning well to the outside world. Similarly this strategy appears to provide her with the confidence she needs in order to complete tasks: *“I was thinking ‘why me I can’t do this’ but then again build the little brick wall a little bit higher and then get on with it”(P1).*

Humour was also displayed as an emotional-focused strategy for coping. Whilst humour can be used positively the participants described using it in a potentially unhelpful way. For example, participant 5 cited going along with being called “Rudolph”, as this minimized his sense of vulnerability in front of friends yet he clearly did feel distressed by the interaction:

“...when I’ve been out socialising people have commented on, you know, red nose or big nose or [pause] you just sort of try and laugh it off really.” (P5)

Inconsistencies in GP treatment and guidance

Clinical vs. subjective severity

Participants recounted having had a range of different responses from their General Practitioner (GP), and the degree to which they were seen as helpful appeared to relate to whether the GP had taken into account the psychosocial impact, and the subjective severity of the rosacea. At one end of this spectrum, Participant 1's subjective severity was not taken into account, causing her to seek help from another GP instead:

"...his attitude was you know 'why on earth are you here for this little bit of redness on your face' ...yeah he was totally dismissive." (P1)

Similarly, Participant 8's clinical severity was compared with others in order to determine whether treatment should be provided:

"I do remember him saying 'Well there's people worse than you' like well maybe there is but to me that wasn't an excuse not to give me treatment or some kind of respect." (P8)

Participant 8 felt her symptoms were important to her and should therefore be acknowledged with more respect. She believed that if her rosacea was more clinically severe, the GP might have made more of an effort with her. At the other end of the spectrum, Participant 2's subjective severity seemed to be taken into account, therefore creating a more positive treatment experience:

"I think that I was really pleasantly surprised... I said to them... 'I think this is probably quite trivial and I don't want to waste your time', and the Doctor was incredibly supportive and said... 'its not true it is clearly a problem'." (P2)

Whether a GP recognises the subjective severity of rosacea is as important as its clinical severity, may mean the difference between a positive or negative GP experience.

Loss of faith in treatment and guidance

Six participants discussed their concerns and disappointment in taking antibiotic medications and encountering a rebound effect when they stopped treatment:

"Well it's, it's awful. Well – the spots come out on my nose and just round the bottom part of my cheeks and it – it looks awful. I couldn't go out without covering them up." (P9)

Many participants discussed their disappointment in treatment, believing that nothing would help their symptoms, therefore leading to feelings of helplessness:

"...so it gets a bit dispiriting, I guess, because I – I just feel I've tried everything going –And nothing seems to work." (P4)

"it's-it-it kind of makes you feel a little bit helpless because what exactly am I supposed to do... ?" (P8)

Seeking a cure and self-management

For similar reasons to the previous subtheme, all participants attempted to use self-management strategies and buy over-the-counter products in order to treat or conceal their rosacea. There was often a trial and error method. However, this sometimes resulted in adverse reactions:

“...I went to work on the Monday with it on and I had a flare up. And I was mortified, I mean, I couldn't serve the customers, I couldn't, I was in tears.” (P3)

Such negative experiences may have exacerbated Participant 3's previous coping strategy of concealing symptoms, thereby leading to her motivation to continue wearing make-up. Many participants reported turning to the Internet for advice, with one participant trying Milk of Magnesia, a common laxative, as some commentators indicated it was helpful; however, it was not.

Some participants used anti-redness make-up in order to conceal symptoms. However participants expressed concern about the cost of these: *“will it make a difference or... just mask the redness or is it actually going to deal with the underlying issue?” (P8)*. Some participants conceded defeat in attempting to treat their symptoms after trying so many products, *“but my GP said, you know, ‘You just have to keep trying them, until you find something that works’...Erm, but I guess I gave up after six or seven” (P4)*.

Discussion

This is the first detailed qualitative study of the experience of living with rosacea, and of receiving treatment. The three superordinate themes identified appear to support previous literature that found there to be a risk of psychosocial distress associated with rosacea^{6,13,14,15,18,19}. Many of the findings were also consistent with qualitative findings from patients with other skin conditions^{31,32}.

There was some discrepancy between the psychometric measure of QoL and the contents of the interviews, as whilst the majority of the participants appeared to have good QoL there were very clear areas of psychosocial functioning affected by the condition. This suggests that assessment of psychosocial functioning should not rely solely on QoL measures.

The first superordinate theme “self-consciousness” focused on the fear of others' assigning blame to participants for having caused symptoms and the range of emotions felt by those with rosacea; such as embarrassment, lowered self-esteem, and shame were associated with this moral aspect of myths associated with the condition. So feelings of shame in rosacea are not simply associated with the visual aspect of the condition but with an awareness in those with the condition that they might be seen to have caused the condition through engaging in excessive behaviours. For two participants there was a strong sense of internal shame that appeared to stem from holding negative evaluations of themselves in relation to the changes in appearance resulting from rosacea³³. Participant 3 appeared the most severely distressed during interviews; and seemed that early experiences of bullying may have contributed the development of negative beliefs about appearance³⁴. Furthermore, Participant 3 was the only individual to describe depressive symptoms. This is in contrast to Cardwell et al.'s¹⁹ study of forum posts that found depressive symptoms to be commonly described; individuals writing posts may have discussed extreme disturbances, rather than day-to-day occurrences³⁵. The current findings are in line with the results detailing physicians' underestimation of the impact of rosacea¹⁹.

The second superordinate theme “avoidance, concealment, and hiding emotions” focused on the range of coping strategies participants employed to handle experiences associated with rosacea. Coping refers to the cognitive and behavioural management strategies employed in response to a stressor, which has been appraised as a threat or challenge to the self³⁶. Lazarus and Folkman’s transactional stress and coping model³⁷ describes two types of coping, emotion-focused and problem-focused coping. The former tends to occur when individuals feel they can change something to improve their situation, whereas the latter attempts to endure the emotional distress³⁸. Participant’s use of behavioural/avoidant-focused strategies, such as concealing and hiding their faces, are comparable to Lazarus and Folkman’s problem-focused coping; as participants were able to change how others saw them in order to potentially improve others’ perceptions of themselves, as well as their own. Furthermore, the use of emotion-focused strategies is also analogous to the emotional coping theorised previously, as participants were able to alleviate some distress by hiding their emotions from others, thereby hindering further psychosocial distress.

Coping strategies such as concealment, hiding the face, and avoidance are thought to be signs of poor adjustment to the skin condition³⁹. The majority of participants reported that they had used, or considered using, make-up to conceal their symptoms. Kent³⁹ investigated the effects of camouflage use, and found that whilst engaging in such techniques increased confidence and reduced avoidance it did not change underlying negative cognitive processes or beliefs. This is in line with the current findings; some participants reported not being able to interact effectively in social situations without the confidence with which make-up brought them.

The third superordinate theme “inconsistencies in GP treatment and guidance” focused on the different interactions experienced with GPs, the loss of faith in treatment when multiple interventions and products appeared not to aid symptoms, and the journey in which participants travelled to seek a cure or self-management.

The many different experiences that participants received with their GPs illustrate inconsistency in treatment. Guidelines recommending the psychosocial assessment of rosacea could be highly beneficial. These could be made similar to the assessment guidelines used for psoriasis, which recommend routine psychosocial assessment^{40,41}. As the first point of contact in primary care, it is important for GPs to be aware that patients might minimise their symptoms and sensitive screening is needed to ascertain if psychosocial support might be required⁴². The patient.info website available to GPs briefly comments on the impact of rosacea on psychological well-being, and the need to refer patients to dermatology services should symptoms be causing psychological and social distress⁴³. However the current findings suggest that further information on how symptoms may be impacting patient’s lives is needed, as well as how this can be addressed effectively and sensitively during appointments.

One limitation of this study is that the interviews involved retrospective accounts and therefore are open to memory bias. Secondly, participants were self-selected by using letter responses

as a recruitment strategy, as with many other qualitative studies. Those who chose to take part may have had more negative experiences of care, or have been experiencing higher levels of emotional distress. Clearly, this study did not seek to be representative of the wider population with rosacea and the nuanced findings reported here warrant further investigation. To aid transferability, the study may have been improved with additional medical information on rosacea severity and type diagnosed. Furthermore, the majority of participants were female. Therefore there is a clear need to purposively seek male participants in future studies.

In conclusion, the behavioural/avoidance-focused and emotion-focused strategies employed to deal with individuals' self-conscious affects may perpetuate unhelpful beliefs about both appearance and the reactions of others.

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Supplementary Material

Title: Experiences of rosacea and its treatment: An Interpretative Phenomenological Analysis

Running Title: Experience of rosacea and its treatment

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1.0 Table 1: Demographics information including DLQI scores for each participant

Table 1. Demographics information including DLQI scores for each participant

Participant	Age	Gender	Employment status (employed/ not employed/ retired)	Recruitment Strategy	Interview Location	DLQI score*
1	50	F	E	Previous survey	University	4
2	31	F	E	Previous survey	University	6
3	23	F	E	Previous survey	Own home	12
4	64	F	R	GP service	University	1
5	62	M	R	GP service	University	2
6	42	F	NE	GP service	Own home	5
7	40	F	E	GP service	Own home	4
8	48	F	E	GP service	Own home	3
9	53	F	E	GP service	Own home	4

**DLQI scores ranged from 0-30, with higher scores indicating poorer quality of life¹⁶*

2.0 Interview Schedule

Experiences of people living with rosacea

Preamble

As I said earlier I now want to discuss your experiences associated with rosacea. I would like to find out more about whether it impacts on your life, and also your experiences of treatment with rosacea. Please feel free to stop at any point if you want to ask me a question or you feel uncomfortable answering any of the questions. Do you have any questions before we start?

Personal experience of living with rosacea

- See how much participant tells me to start with: The feelings, emotions and thoughts associated with rosacea
 - “Can you tell me a bit about what it is like to have rosacea?”
 - Prompts: “What effect has it had on your everyday life? Is there any way in which rosacea impacts on your everyday life or on how you feel?”

Social experience of living with rosacea

- Reiterate aims, and say now talk about personal and intimate experiences. Gain continuous consent.
- Rosacea and interacting with other people (friends, family, romantic partners, professional relations)
 - “Has having rosacea impacted in any way on your relationship?”
 - Prompts: “What effect has it had on your romantic relationships? How has it affected how you interact with other people?”
- Rosacea and everyday activities (e.g. socialising, work)
 - “Can you tell me a little bit about how your rosacea has impacted your social life? Has it affected you at work at all? How so?”
 - Prompts: “What effect has it had on you going out and socialising?”

Further personal experience of living with rosacea: Symptoms

- Symptoms (e.g. pain, changed appearance)
 - “Could you tell me what symptoms of rosacea you have?”
- The history of rosacea (e.g. when the symptoms first started and magnitude of rosacea over time)
 - “Can you tell me a little bit about the history of your rosacea, when did the symptoms first start?”
 - Prompts: “Has the severity of your symptoms changed with time? Have they gotten better/worse?”

Experiences of treatment for rosacea

And the final set of questions...

- **Really focus on this heavily:** Seeking help from health care professionals and views about the available help
 - “Have you ever sought any professional help for your rosacea?”
 - Prompts: “Could you tell me some more about the help you received? What are your particular experiences with that?”
- Self-help strategies (e.g. make up, not drinking very hot drinks) or over the counter products to manage rosacea

Experience of rosacea and its treatment

- “Is there anything in particular you do on a daily basis, or when you have a flare up to manage your rosacea?”
- Prompts: “Can you think of any situation that you used this technique?”
- What do you think about these techniques/products?”
- Ask about talking to other people and seeking support (e.g. looking for the information on-line) for rosacea
 - “Have you received support from anyone else? Have you talked to anyone else about your rosacea? Have you found any information from other sources?”
- Views on any prescribed treatment (if relevant)
 - “What are your views on prescribed treatments?”

Thank and debrief

- How did you find this interview?
- Is there anything that you would like to add or comment on?
- Is there anything that worries you about this conversation?
- Are you still happy for the recording to be used in the study?
- Ask if the participant would like to be sent (via post or email) a brief report outlining the main findings of the study
- Thank you for taking part in the interview

3.0 Contributions of participants to subthemes

Table 2. Participants contributing data to each subtheme

	Participants								
	1	2	3	4	5	6	7	8	9
Self-consciousness									
Fear of being blamed for causing the condition	●	●		●	●			●	
A range of self-conscious affects	●		●	●	●		●	●	●
Avoidance, concealment, and dissimulating emotions									
Behavioural/ avoidance-focused strategies	●	●	●	●	●	●	●	●	●
Emotional-focused strategies	●		●		●				
Inconsistencies in GP treatment and guidance									
Clinical vs. subjective severity	●	●		●	●		●	●	●
Loss of faith in treatment and guidance		●		●	●	●		●	●
Seeking a cure and self-management	●	●	●	●	●		●	●	●

4.0 Theme Overview

Table 3. Superordinate themes and subthemes identified including illustrative quotes

Superordinate theme	Subtheme	Participant	Quotes	
Self-consciousness	Fear of being blamed for causing the condition	P1 (pg. 7)	<i>"I think people will look at it and think "she's a drinker". a secret drinker because generally you don't see me drinking"</i>	
		P8 (pg. 3)	<p><i>"I: Mmm, okay. Erm so when people make those assumptions and say "have you been up all night", "have you had a good party", how does it make you feel when they say those comments?</i></p> <p><i>P: Erm [silence] mmm [silence] I think eh...I don't know what the right word is, not disappointed so much but the fact that I used to have such good skin and now I don't and-and it can be quite...oh I can't remember what the right word is, deflating maybe that-that my skin is bad enough for people to comment on... Well and once upon a time people used to comment on how clear it was."</i></p>	
A range of self-conscious affects		P1 (pg. 6)	<i>"...but I'm always conscious of "oh my god what am I looking like"</i>	
		P7 (pg. 8)	<p><i>"I: Okay and how do you feel when it flares up?</i></p> <p><i>P: Um just angry at why have I got it now when my skin used to be nice.</i></p> <p><i>I: Okay, so um when you say your skin used to be nice um what sort of things do you mean by that?</i></p> <p><i>P: It just used to be, there were no like redness or anything. I had spots when I were younger but not like redness there or anything like that.</i></p> <p><i>I: Okay. Um so when you think about how your skin used to be and how your skin is now, um and you think about the comparison, do you compare yourself to how you were?</i></p> <p><i>P: Er, a bit.</i></p> <p><i>I: Yeah? And how does it make you feel?</i></p> <p><i>P: Er, a bit low self-esteem."</i></p>	
		P3 (pg. 1)	<i>"Umm, and then I got into the make-up and stuff and started covering it up, and I've been doing that ever since, and it, it's, it just makes you feel so much better being able to just look like everybody else."</i>	
		P5 (pg. 3)	<i>"I don't take a good photo anyway but with having a red nose and everyone was, you know, it's always difficult to find a photo to stick in a photo frame sort of thing."</i>	
		P4 (pg. 18)	<p><i>"I: What do you believe your strategies are, to help you manage it, then?</i></p> <p><i>P: Erm... avoid... looking at myself, avoid having my photograph taken, especially outside..."</i></p>	
		Emotional focused strategies	P1 (pg. 9)	<i>"I: ...so you know when you said you were wearing a mask for most of the day do you think that helps or hinders how you feel about your Rosacea at work?"</i>

			<p>P: I suppose to a certain extent you are in denial because you are behind you, your little brick wall so I don't try, I don't sort of make it a bit -think, I don't, I don't think about it cos if you've got a lecture to do you've got to sort of think about that or if you've got eight patients in the chair and you've got to supervise eight students you've got other things to think about other than my red face.</p> <p>I: Fair enough</p> <p>P: So I just come across as the happy, happy person that greets all the patients"</p> <p>"I: Okay erm if you feel uncomfortable with any questions please feel free to stop me</p> <p>P: I might go red</p> <p>I: Okay(LAUGH)"</p>
Inconsistencies in GP treatment and guidance	Clinical vs. subjective severity	P1 (pg. 4)	
		P8 (pg. 4)	<p>"P: Erm but...I don't know, I just felt like he was a bit dismissive that's how I felt, whether he was or not I don't know because it's not exactly like threatening and it's...and you're...and-and I know sort of like in time over a period of years you can end up quite disfigured with it...Erm but I just felt that...it didn't...it wasn't that important"</p>
		P9 (pg. 4)	<p>P: "I went to the GP and then she diagnosed with rosacea and told me a bit about it, that it was a symptom that could just appear and it could disappear just as quickly, erm, everybody that had rosacea different. Erm ... severity....Of it. Erm, some suffered for a long time, some it would come and go.</p> <p>I: Okay. Erm, and did you find her mannerisms helpful? Did – did you like the way the diagnosis happened in a way? Do you know what I mean?</p> <p>P: Yeah, yes. Erm, I were – I were satisfied with how she explained and, and, and what it was, yeah."</p>
	Loss of faith in treatment and guidance	P4 (pg.11)	<p>"P: I think... you know, really, you get the same advice, you know, "Don't drink alcohol, don't have spicy foods", erm... but really, it's hard... to avoid extremes of temperature.</p> <p>I: Mmmm.</p> <p>P: Because, you know, we live in a climate that's seasonal."</p>
		P6 (pg. 4)	<p>"So I went back again, er, and they said obviously I needed more antibiotics, er, and when I started taking the second lot, it just didn't seem to do a thing to it. Er, and then the third lot was the same. And since then I haven't been back.</p> <p>I: Erm, and is there any reason why you haven't been back, at all?</p> <p>P: To be honest, I don't want to be on antibiotics forever and a day."</p>
	Seeking a cure and self-management	P7 (pg. 15)	<p>"P: I think it was just on like a forum thing with what people did, um ...</p> <p>I: Okay and what did you think of that forum and that sort of ...</p> <p>P: Um it did help yeah and I mean it was the same symptoms as what I've got just, and I were reading like cut out spicy food, red alcohol, caffeine...um stay out of the sun</p>

P3 (pg. 13)

because that can make it worse...

I: Okay, um in what way did it help you in that way?

P: Um knowing, you know knowing what to do, um and knowing how to treat it sort of thing [sniff].

I: Okay, so it helped you to have a bit more control over it?

P: Yeah, yeah."

"Err, let's have, let's see if I can list them all. Right so my mother in her infinite wisdom suggested trying soap, that didn't work. She suggested trying charcoal facemasks, that didn't work. She suggested, you know like, moisturizing creams, that didn't work."
