

Sex and the skin: A qualitative study of patients with acne, psoriasis and atopic eczema

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Quantitative questionnaire-based research has suggested a considerable effect of skin disease on the sexual life of sufferers. In this study, we explored the effects of acne, psoriasis and atopic eczema upon sexual functioning and sexual relationships in the context of a wider exploration of the psychological sequelae of these diseases. We employed a qualitative methodology employing in-depth semi-structured interviews and involving thematic analysis and constant comparison. Participants were patients with currently active acne, psoriasis or atopic eczema. Purposive sampling aimed to obtain a sample reflecting a wide range of participant characteristics including skin disease severity, age, sex, and care by general practitioner or dermatologist. Sixty-two semi-structured interviews were conducted. Acne had adverse effects on participants' self-perceived sexual attractiveness and self-confidence, as did psoriasis and eczema. But psoriasis and eczema also had marked effects on sexual well-being and on capacity for intimacy. These were related to issues of self-esteem and sexual self-image and were often pervasive, resulting in marked behavioural avoidance of intimate situations and continuing effects on sexual well-being even in long-established sexual relationships. Effects of psoriasis and eczema on sexual well-being and sexual relationships were mediated more by appearance and texture of non-genital skin than by involvement of genital skin. We conclude that, while recognising the distressing effects of acne on self-perceived sexual attractiveness, clinicians should be especially aware of the capacity of psoriasis and eczema to profoundly affect patients' psychological and sexual well-being.

Keywords: acne vulgaris; eczema; psoriasis; sexual behaviour

Introduction

There has long been an appreciation that skin disease may have a negative effect on sufferers' sexual lives (Heseltine, 1963). This effect is psychological and social as well as physiological dysfunction and impacts upon skin disease patients' quality of life (Ermertcan, 2009).

The skin diseases most often implicated in sexual dysfunction and effects upon sexual aspects of quality of life are psoriasis and atopic eczema. Subjects from a Turkish dermatology outpatients department have been found to have greater

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impairment of “sexual life” than control subjects (Gurel, Yanik, Simsek, Kati & Karaman, 2005). Impairment correlated with skin disease severity, and the greatest impairment of “sexual life” was in patients with eczema. In uncontrolled studies of psoriasis sufferers, 38% of subjects in a United States study reported problems with sexual intimacy (Young, 2005), 50% of Irish patients felt that psoriasis had inhibited their sexual relationships (Ramsay & O’Reagan, 1988), and 41% in a Canadian study attributed a decrease in sexual activity to the onset of psoriasis (Gupta & Gupta, 1997). In further uncontrolled studies of patients with atopic eczema, 19% of subjects reported that their sex lives were affected by the disease (Long, Funnell, Collard & Finlay, 1993) and 34% of subjects reported an effect on sexual relationships (Finlay, 1996).

The evidence for the effects of these skin diseases on sexual functioning and sexual relationships has mainly been derived from cross-sectional questionnaire-based studies – very often from single questionnaire items (Al-Mazeedi, El-Shazly & Al-Ajmi, 2006; Finlay, 1996; Gurel et al., 2005; Long et al., 1993; Young, 2005) or more than one simple item (Sampogna, Gisondi, Tabolli & Abeni, 2007). Single items might be thought to have very limited capacity to adequately capture as complex a construct as sexual functioning or sexual relationships. More recent cross-sectional studies have employed validated instruments to investigate sexual function in skin disease – the Female Sexual Function Index (Turel Ermertcan, Temeltas, Deveci, Dinc & Durkcan, 2006) and the Arizona Sexual Experience Scale (Mercan, Altunay, Demir, Akpinar & Kayaoglu, 2008) – and have found impaired sexual function (compared to control subjects) in psoriasis (Mercan et al., 2008; Turel Ermertcan et al., 2006) and neurodermatitis (Mercan et al., 2008). But even these studies are inherently somewhat limited in the depth of insight into the complex nature of skin disease effects on sexuality that they can provide.

Qualitative research methods offer a complementary approach and a particularly appropriate means of further defining and exploring the complexity of skin disease effects on sexual function and sexual relationships. But qualitative research is sparse in skin disease settings. It has been suggested that rigorous qualitative methodologies have much to offer dermatological research (McNally, Phillips & Williams, 1998). It has also been proposed, in the context of psoriasis, that qualitative research “is the first key to determining, unraveling, and understanding” complexities in the patient’s experience of skin disease (Jobling & Naldi, 2006) and that “the method allows the interviewer to obtain a more coherent picture of the subject as a person” (Metz & Jemec, 1996). One qualitative paper has reported (briefly) on sexual aspects of the wider patient experience of living with severe psoriasis and found some participants’ sexual lives to have been affected, mainly by the physical effects of psoriatic lesions but also by feelings of unattractiveness and disgust regarding lesions (Wahl, Gjengedal & Hanestad, 2002).

The current article reports in more detail the effects of three skin diseases (psoriasis, atopic eczema and acne) on sufferers’ sexual relationships. It reports qualitative findings from a wider qualitative and quantitative project examining the psychological sequelae of these three diseases (Magin, Adams, Heading, Pond & Smith, 2006, 2009; Magin, Pond, Smith, Watson & Goode, 2008). The effects of skin disease on sufferers’ sexual functioning and relationships should be considered in the context of considerable evidence for deleterious effects of skin disease on psychological well-being. Psychological sequelae of skin disease include depression, anxiety,

obsessionality, alexithymia, suicidal ideation, alcohol abuse, and stigmatization as well as anger and hostility (Gupta & Gupta, 2003). Of particular note are associations of skin disease with body image pathology and poor self-concept or self-image (Gupta & Gupta, 2003). Decrements of self-image and self-esteem in skin disease patients have been linked to embarrassment, self-consciousness and shame and, thence, to avoidant behaviours (Magin, Adams, Heading & Pond, 2009; Magin et al., 2006) and self-image is closely related to sexual psychological function in clinical (Basson & Schultz, 2007; Tindle, Denver & Lilley, 2009) and non-clinical populations (Ingersoll, Norvilitis, Zhang, Jia & Tetewsky, 2008).

Methods

The methodology has been described previously (Magin, Adams, Heading, Pond & Smith, 2008). Recruitment was via mailed invitations to participants from an earlier quantitative phase of the project (patients with acne, psoriasis or atopic eczema recruited by dermatologists and general practitioners (GPs) (Magin et al., 2008) as well as invitations to participate posted in waiting rooms of GPs who had participated in the quantitative study. This design aimed to obtain a sample reflecting a wide range of participant characteristics including severity of skin disease, care by GP or specialist dermatologist, age and sex.

Data collection consisted of 62 in-depth semi-structured interviews (duration 35 to 140 min) with participants with current acne ($n = 26$), psoriasis ($n = 29$) or atopic eczema ($n = 7$). Twenty-five were male. Age range was 13 to 71. Interviews were conducted by a single researcher (PM) and followed a topic guide drafted by the research team with topics reflecting the literature and study aim (to explore the psychological sequelae of acne, psoriasis and atopic eczema). Data collection continued until thematic saturation had been achieved. The study employed grounded theory techniques: allowing ideas and themes to emerge from the data, with discussions being informant-led as much as possible. As data collection and analysis progressed, additional topics for exploration were added as new areas of interest emerged, and negative cases were sought to compare and test propositions. The effect of skin disease on respondents' sexual lives was one of the main themes to emerge from this inductive process.

Interviews were recorded to audiotape with participants' consent and then transcribed to word file. Interview summary sheets were completed during each interview by the interviewer. Data collection and analysis were cumulative and concurrent throughout the data collection period and employed a process of constant comparison reflecting the study's grounded theory approach. Each transcript was separately coded by two members of the research team (PM and GH) and a codebook developed. Comparative coding was conducted by PM and GH and differences in researcher perspective were resolved by negotiation and fed back into the analysis to cross-check codes and themes and develop an overall interpretation of the data. Reflexivity was inherent in this process via awareness and consideration of the potential influence of the researchers' respective professional and academic backgrounds (PM a medical practitioner and GH a sociologist) on their interpretation of the data and PM's role as interviewer. Possible contextual influences of the researchers' backgrounds on their interpretations of the data were explored and analyses reviewed.

The study was approved by the Human Research Ethics Committee at the University of Newcastle, Callaghan, Australia.

Results

The experiences of participants with atopic eczema and psoriasis relating to sexual functioning and relationships were consistent, and these experiences contrasted markedly with those of participants with acne.

Participants with acne

The role of appearance and sexual attraction

There was a central role of appearance in participants' overall experiences of acne, and acne had considerable effects upon self-image and self-esteem. Not surprisingly, then, participants perceived acne as having adverse effects on their peer popularity and sexual attractiveness.

And of course it affected the way that I behaved socially. Like in as much as how I'd react to the opposite sex. I felt that no girl would want me because of my acne. (*Int. 21, Male, 41*)

The effect of acne on sexual relationships was primarily related to effects on sufferers' appearance. That this related primarily to sexual attraction in the early stages of sexual relationships is set in relief by respondents' experiences of no longer having to be "on-show" sexually – that is, having married or established long-term sexual relationships.

You are out of the pool for mating and for selecting partners so, again, you think it doesn't really matter. (*Int. 20, Female, 40*)

A caveat to these themes is that the effect on perceived sexual attractiveness may apply primarily to adolescents with more severe acne, especially nodulo-cystic acne, or to older (single) individuals with adult-onset acne or acne persisting well into adulthood – acne beyond "normal" adolescent experience.

No-one really cares because everyone knows that everyone gets pimples, unless like you have that real bad acne that's, like, welts. (*Int. 22, Female, 15*)

Gender differences

There was also a suggestion of gender differences in this adverse effect of acne on sexual attraction, with appearance being of more consequence among females.

I think girls are much more worried about it than guys are because I think it's important to have an appearance if you're a girl, if you know what I mean. [...] it's more about your strength and stuff when you are a guy, rather than your looks. (*Int. 24, Female, 13*)

Participants with psoriasis or atopic eczema

The role of appearance and sexual attraction

In psoriasis and eczema there was also a relationship of appearance and sexual attraction with sexual functioning and relationships. Sufferers told of their self-consciousness in being "on-show" in the sexual marketplace.

Probably when I was about twenty I started feeling more self conscious [...] more concerned with the way you look and how you are going to please the opposite sex. (*Int. 36, Female, 54, psoriasis*)

This is illustrated by the role of the media and advertising in setting (an unrealistic) standard of an “image” of sexual attractiveness.

You’ve only got to look at the women in FHM and Playboy, they don’t have skin diseases. [It] makes me feel less attractive sexually to people, because I’m not the ideal, I’m not the perfect image. (*Int. 37, Female, 43, psoriasis*)

Consequently, a fear of rejection on the basis of appearance seemed to underpin some of the respondents’ apprehensions regarding intimacy and exposure.

I know a girl who was only married six weeks and in those days you didn’t live with each other so she was new to him and he was new to her. He found all this [psoriasis] all over her and the marriage lasted six weeks, he couldn’t handle it. (*Int. 36, Female, 54, psoriasis*)

Effects on body image and self-worth

But the sexual effects of psoriasis and eczema were perceived to extend further than “superficial” issues of sexual attractiveness. Effects were on participants’ body image beyond simple attractiveness, and were subsequently effects upon their sexual self-image and had links to more pervasive feelings of self-worth. Intimacy was the area where psoriasis and eczema were most associated with profound self-consciousness and impaired self-confidence and self-image.

I felt like my femininity was compromised because of it. (*Int. 61, Female, 33, eczema*)

This was illustrated by the experiences of a respondent who felt her transition in sexual life-stage to that of marriage was compromised by her eczema.

I was a bride covered in eczema. [It] made me feel really undesirable, very unsexy [...] I’m sure [my husband] wondered what sort of package he had. (*Int. 57, Female, 58, eczema*)

The unique context of nakedness and intimacy

It is evident from participants’ responses that removing clothing and sexual intimacy were perceived as egregious examples of being “on show” and subject to scrutiny. Nakedness was repeatedly cited as being stress-inducing and shaming. But the one-on-one scenario and the relationship to intimacy made this a very different context to being on-show and scrutinised publicly, even to being near-naked at the beach or pool.

I think the psychological build up and the stress [in a relationship] associated with thinking you’ve got to get your clothes off for anybody can be a bit daunting sometimes. Especially if you’ve got a physical image of yourself that isn’t up to par. (*Int. 42, Female, 31, psoriasis*)

The result was marked behavioural avoidance of intimate situations.

Well I didn’t really do anything [sexually intimate], if I had a breakout of psoriasis. I wouldn’t really go there [...] I think because if I’m being intimate with anybody it’s like I’m letting them past my barriers. (*Int. 35, Female, 42, psoriasis*)

While it is apparent that fears of “exposure” and attendant shame and embarrassment (and behavioural avoidance due to anticipation of these emotions) were prominent in new sexual relationships, the issues of self-esteem and sexual self-image were often pervasive and continuing. Even in well-established relationships (and unlike the scenario in acne) this led to problems with sexual aspects of the relationship.

I’m embarrassed with my husband and we’ve been married five years, been together ten years, and it’s “Don’t look at that, don’t touch that, don’t get that close”. (*Int. 33, Female, 31, psoriasis*)

The effect of psoriasis and eczema (unlike acne) on sexual self-esteem and sexual self-image and on capacity for intimacy is illustrated by a respondent with experience of acne as well as psoriasis.

First appearances with the acne, that is a bit of a problem. Being on display, that is a problem. You feel nervous about it, you are awkward. But the psoriasis – you don’t really think about it in that situation [being on display publicly], but in an intimate situation the psoriasis takes over from the acne. (*Int. 42, Female, 31, psoriasis*)

Physical aspects of skin lesions

While self-image, self-esteem and sexual attractiveness were the main determinants of psoriasis and eczema affecting sexual relationships, the physical aspects of skin lesions also played a role. Only occasionally, however, did this involve genital lesions.

I had it around my genitals, I had it around my backside. [] when I had it around my genitals I was so embarrassed, really knocked up about it. (*Int.32, Male, 53, psoriasis*)

More often it involved non-genital skin.

So sexually even that was a problem as well. I felt like I couldn’t have that intimacy because you know . . . I had these [eczema-affected] hands. (*Int. 58, Female, 44, eczema*)

But even here there was an appreciation that effects on sexuality went beyond the appearance of affected skin and manifested as a pervasive effect on sexuality. The appreciation amongst participants was that skin and sexuality were intrinsically linked.

Because skin is what you’re touching, it’s what you are seeing, so it’s that tactile and that sensory perception [. . .] and because the sexual thing is all a magnetic thing. (*Int. 41, Female, 44, psoriasis*)

Discussion

Principal findings

In the broader study from which these findings on sexual functioning and relationships emerged, appearance concerns were central to self-esteem and self-image, as well as mediating embarrassment and shame and prompting behavioural avoidance in participants with the three skin diseases (Magin, Adams, Heading, Pond, 2009; Magin et al., 2006). But in relation to sexual sequelae, while psoriasis or atopic eczema were related to appearance-related sequelae quite analogous to that in acne, there was also a much broader range of effects. Deleterious effects on sexual

well-being were essentially seen in respondents with psoriasis and atopic eczema rather than in those with acne. These effects upon the lived experience of sufferers of psoriasis and atopic eczema extended beyond issues of appearance-related perceived sexual attractiveness. For these participants their condition led to behavioural avoidance related to intimate and sexual activity and jeopardised their wider notions of sexual self-image and sexual self-esteem.

Relation to previous research

Previous quantitative studies have established effects on sexual life as a common accompaniment of skin diseases (Al-Mazeedi et al., 2006; Finlay, 1996; Gupta & Gupta, 1997; Gurel et al., 2005; Long et al., 1993; Mercan et al., 2008; Sampogna et al., 2007; Turel Ermertean et al., 2006; Young, 2005) but have often been limited in scope and for the most part have not explored the implications for sufferers and their sexual relationships. Some quantitative results are, however, of relevance to our findings. A Singaporean study's finding of concern regarding acne appearance and its effect on sexual attractiveness being correlated with personality structure (Lim & Tan, 1991) reflects the strong nexus of appearance and perceptions of sexual attractiveness found in acne in our study.

Of the 50% of subjects who reported effects of psoriasis on sexuality in a UK study, 65% had genital lesions (Ramsay & O'Reagan, 1988). Presence of genital lesions has been associated with impairments in sexual life in hospitalised Italian psoriasis patients (Sampogna et al., 2007). The role of genital lesions was also prominent in the limited reporting of sexual sequelae in Wahl et al.'s qualitative study of the experience of living with severe psoriasis (Wahl et al., 2002). In our study this was the exception rather than the rule. This is consistent with findings from an Indian study of psoriasis (Gaikwad, Deshpande, Raje, Dhamdhare & Ghate, 2006) in which 21% of subjects reported sexual dysfunction and/or effect of psoriasis on sexual life despite none of these subjects having genital lesions. In our study, more common than direct genital effects was a pervasive effect on sexual self-image and an inhibition of sexuality based on the appearance and texture of non-genital skin and the resultant avoidance of disclosure or exposure of affected skin.

A cross-sectional study has suggested a relationship of sexual dysfunction and depression in psoriasis and neurodermatitis (Mercan et al., 2008). In our qualitative study there was evidence of psychological morbidity (Magin, Adams, Heading, Pond, 2009; Magin et al., 2006) as well as sexual sequelae of skin diseases, but the precise relationship between the two was not clear.

Strengths and limitations of the study

The strengths of the study lie in the broad range of disease severity of the respondents (having purposively sampled respondents who had been treated by GPs as well as by specialist dermatologists – unlike previous psychodermatological studies which have almost exclusively sampled the patients of specialist dermatologists) and the study's qualitative methodology. This afforded a rich and nuanced appreciation of this complex research question – one that has not been previously reported.

In terms of limitations, the study was conducted in a single geographic region and respondents were predominantly Australians of European cultural background. While quantitative studies have demonstrated sexual dysfunction in, for example,

Turkish patients with psoriasis and dermatitis (Mercan et al., 2008; Turel Ermertcan et al., 2006), given the singular religious and cultural dimensions of sexuality, studies in other ethnic and cultural populations may have found quite different experiences of sexuality in respondents with skin disease.

Implications for clinical practice and further research

Psoriasis, eczema and acne are common diseases and morbidity associated with them is consequently of relevance for clinicians. The results of this study should be considered in the context of the wider psychiatric and psychological sequelae of skin disease. The psychological aspects of living with skin disease may often be underappreciated by clinicians (Magin, Adams, Heading & Pond, 2009). The results presented here suggest that dermatologists, GPs and other clinicians should be cognizant of possible effects on sexual relationships in their assessments of the psychological impact of skin diseases, especially psoriasis and eczema. This should inform the advocated biopsychosocial approach to skin diseases (Feldman, Behnam, Behnam & Koo, 2005; Gupta & Gupta, 2003).

The role of skin disease in sexual function and relationships in wider cultural settings requires elucidation. The relationship of sexual effects and psychiatric morbidity in skin diseases also needs closer definition. It has been suggested that trials of psychological interventions in skin disease are indicated (Hoare, Li Wan Po & Williams, 2000). This study suggests a consideration of sexual well-being may be appropriate in such interventions.

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