ARTICLE IN PRESS

International Journal of Women's Dermatology xxx (2017) xxx–xxx

Contents lists available at ScienceDirect

International Journal of Women's Dermatology

Psychosocial adjustment to skin conditions resulting in visible difference (disfigurement): What do we know? Why don't we know more? How shall we move forward?☆

N. Rumsey, PhD *

Centre for Appearance Research, University of the West of England, Bristol, United Kingdom

ARTICLE INFO

Article history:
Received 29 August 2017
Received in revised form 18 September 2017
Accepted 21 September 2017
Available online xxxx

Keywords:
psychological adjustment
psychological intervention
health care provision

ABSTRACT

This article offers an overview of the current understanding of the psychological factors and processes that play a part in the continuum of distress and positive adjustment in people who are affected by dermatological conditions that affect appearance. Despite research demonstrating the significant psychosocial challenges posed by visible difference and mounting evidence of the role played by psychosocial variables in the etiology, exacerbation, and treatment of skin conditions, current healthcare provisions focus predominantly on the amelioration of physical manifestations. Impediments to progress in the understanding of psychological adjustment, blocks to the development of effective interventions, and challenges to the implementation of integrated psychological and medical care are reviewed. A route map to advance current understanding and care provision is proposed.

Contents

Background

We live in a society in which considerable importance is attached to an attractive, healthy appearance. A variety of forces, including social media, the Internet, and advertising funded by the ever-expanding cosmetics industry, have conspired to produce and fuel unprecedented levels of dissatisfaction, worry, and anxiety with appearance in most segments of the population (Nuffield Council on Bioethics, 2017). In our daily lives, we are surrounded by images of appearance ideals, replete with explicit or implicit messages that suggest that our bodies are malleable. To a greater or lesser degree, we internalize the imperative to reduce the gap between our own appearance and these ideals, often motivated by the belief that this will enhance our relationships, social lives, and occupational

---

☆ Conflicts of interest: None.
* Corresponding Author.
E-mail address: nichola.rumsey@uwe.ac.uk.

https://doi.org/10.1016/j.ijwd.2017.09.005

Please cite this article as: Rumsey N, Psychosocial adjustment to skin conditions resulting in visible difference (disfigurement): What do we know? Why don't we know mor..., International Journal of Women's Dermatology (2017), https://doi.org/10.1016/j.ijwd.2017.09.005

achievements (Halliwell and Diedrichs, 2012). The value that is placed on outward appearance is becoming greater and more disproportionate to other aspects of self-esteem and self-worth.

Most societies attach considerable importance to the complexion. Beauty ideals in all cultures include an even skin tone that is free from blemishes. Yet skin conditions are very prevalent. In the United Kingdom, more than half (54%) of the population is affected by a skin disease each year, and 15% to 25% of primary care consultations relate to skin disease (Bundy, 2012). In addition to patients with diagnosable skin conditions who seek to normalize their appearance, a dermatologist's caseload will include patients who are motivated by the prospect of psychosocial gains to seek cosmetic enhancement (e.g., remove blemishes or reduce visible signs of ageing).

In this article, I focus on the current understanding of wellbeing in those with skin conditions that result in a visible difference. Readers who are interested in the psychological care of patients who seek esthetic enhancement are referred to the Nuffield Council in Bioethics' recent report on Cosmetic Procedures (2017). Because self-esteem has been defined and operationalized in very variable ways in research in this field (see the section entitled "Why do we not know more"), this article considers psychological adjustment more broadly.

What do we know about adjustment to skin conditions?

Psychological challenges

A condition that results in an appearance that is visibly different from current norms and ideals is widely acknowledged to result in significant psychosocial challenges (Rumsey and Harcourt, 2012). Despite the diverse range of etiologies, symptoms, and severity, skin conditions are very similar in the psychological issues they present (Bundy, 2012). Whether transitory, progressive, or episodic, the majority of conditions are associated with a range of significant psychosocial symptoms that affect key areas of daily living and quality of life (QoL), including emotional, cognitive, and behavioral impacts on self-systems, relationships, and social and occupational functioning. Many of the challenges are common to those experienced by people with a range of disfiguring conditions, and researchers who specialize in dermatology are likely to find this broader literature helpful (see, e.g., Clarke et al., 2014 in relation to intervention). It should be noted, however, that skin conditions with unpredictable trajectories (e.g., alopecia and psoriasis) have been reported to be particularly distressing, with recurrence after an improvement particularly challenging (Bundy, 2012; Sharratt et al., 2017).

The seriousness and prevalence of psychological problems secondary to a skin condition should not be underestimated. It is consistently reported that 25% of people experience significant challenges in several key areas of living. In a 2012 survey by the British Skin Foundation (BSF; reported in APPGS, 2013), the top three areas of concern for the 729 respondents were a "fall in confidence," the "negative effects on working life," and "making friends." QoL among those with skin conditions is frequently reported as lower than that in the general population, with approximately 25% to 50% of adult patients experiencing heightened levels of psychological distress (Evers et al., 2005). Schmit-Ott and Steen (2010) reported that the impact of psoriasis on the quality on patients' lives was just as pronounced as the impact of other chronic and possibly life-threatening diseases, including cancer, heart attack, or chronic pulmonary diseases.

Reports of negative emotional impacts include enduring states of anxiety, depression, and social anxiety, as well as more transitory states of shame and embarrassment from the stigma of feeling different, negative body image, anger, guilt, and self-consciousness. The loss of eyebrows and eyelashes can radically change a person's facial appearance and contribute to issues of identity (Hunt and McHale, 2012), and the loss of skin pigmentation in a patient with vitiligo may threaten an affected person's ethnic identity (APPGS, 2013).

Bundy (2012) has summarized reports of psychiatric disorders associated with some conditions. The prevalence of body dysmorphic disorder among people with acne ranges from 14% to 21%. People with disorders that involve significant hair loss have been reported to be at a higher risk for developing a range of psychiatric disorders, including a serious depressive episode, anxiety disorder, social phobia, or paranoid disorder. The presence of psychiatric disorders is significantly higher in patients with alopecia areata than in those without skin conditions. In addition, suicidal thoughts have been reported in up to one in 10 people with psoriasis (Psoriasis Foundation, 2012).

As with other disfiguring conditions, visible skin disorders can create a considerable social burden, particularly in relation to forming friendships and forging and maintaining relationships. Unwanted reactions from others, including questions, comments, staring, or avoidance, can be taken very personally, exacerbating the negative effects on the QoL associated with the physical symptoms. Fears of contagion and/or lack of hygiene may lead to social avoidance by others (Papadopoulous and Walker, 2003) and may contribute to a sense of social isolation. Avoidance of social situations (e.g., swimming pools and public changing rooms) has been widely reported.

In the BSF survey (APPGS, 2013), 29% of respondents felt that their condition was an active barrier to finding a partner. In some cultures, beliefs, myths, or taboos may affect the marriage prospects of the affected person. Sharratt et al. (2017) have noted that the cumulative effects of negative social experiences can be considerable, and disruption to relationship development, physical intimacy, and sexual activity may be influenced by embarrassment, shame, or fear of this in others. Twenty percent of respondents to the BSF survey felt that their skin disease was the driving factor behind the breakdown of their most recent relationship or a previous one. Fragile skin in conditions such as epidermolysis bullosa can interfere with touch and thus affect key psychological functions of affiliation, friendship formation, and support.

There have also been reports of limits on occupational functioning for people with visible skin conditions. In a survey of people with psoriasis, 67% claimed that their condition limited their job opportunities (APPGS, 2013), and discrimination from potential employers in relation to front-of-house jobs was reported by the Changing Faces (2014). A skin condition may also limit performance in some aspects of an existing role, such as the avoidance of invitations to appear in public for those with hyperhidrosis.

Lifestyle choices with the potential to negatively affect self-esteem and QoL have also been described in the literature, including clothing choices for those trying to prevent the exacerbation of itch, avoidance of social situations, limits on holiday choices for those with photosensitivity, or the need to avoid allergens that might exacerbate the condition (Bundy, 2012).

Wellbeing and physical health may also be affected by a sedentary lifestyle that results from the avoidance of exercise due to the possibility of excessive sweating, exacerbation of itch, or the need to wear particular types of clothing. The incidence of obesity has been reported as higher in people with psoriasis than in the general population (NICE, 2012). Rates of engagement in other unhealthy lifestyle behaviors, including alcohol consumption and smoking, have also been reported (Bundy, 2012). Reasons for these increases are unclear but are likely associated with psychological distress. In addition, sleep deficits that result from itching and scratching with some skin conditions may result in behavioral and cognitive deficits that affect wellbeing as well as social and occupational functioning (APPGS, 2013; Evers et al., 2005).

Individual differences in adjustment

Recent research on the impact of conditions that result in a visible difference over the past decade has demonstrated a wide range of

Please cite this article as: Rumsey N, Psychosocial adjustment to skin conditions resulting in visible difference (disfigurement): What do we know? Why don't we know mor..., International Journal of Women's Dermatology (2017), https://doi.org/10.1016/j.ijwd.2017.09.005