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Review

Social impact of the burden of psoriasis: effects on patients and practice

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Abstract

The raised, scaly, and erythematous plaques associated with psoriasis can be cosmetically disfiguring, which may provoke disgust, fear, and aversion in others. Consequently, the social stigma of psoriasis can be devastating for patients, evoking feelings of shame and anxiety about how they are perceived. In recent years, appreciation of psoriasis as a disease that can cause social distress and impairment has increased. This review discusses the manifold social burdens of psoriasis; different and emerging therapies that may mitigate these burdens by improving outcomes associated with the underlying disease; and psoriasis management in the context of healthcare reform changes focused on assessing the quality and value of patient care. The social impact of psoriasis is substantial (eg, affecting interpersonal relationships, sexual function, intimacy, occupational success). Undertreatment of psoriasis continues, despite evidence that biologic agents may lessen the physical and social burdens and provide greater patient satisfaction than conventional therapy. Changes in healthcare place an even greater emphasis on measurable outcomes, including patient satisfaction. Increased understanding of the social burden of psoriasis may lead to provision of more comprehensive, holistic care that is in concordance with the evolving restructured reimbursement system.

Key words: psoriasis; burden; patient; physician; healthcare reform; treatment

Introduction

Psoriasis is a common dermatologic disease that manifests most frequently as raised, erythematous plaques on the most visible organ, the skin [1, 2]. As a consequence—and regardless of severity—psoriasis can be associated with significant physical and psychological impairment, both of which may contribute to substantially reduced patient well-being [1, 3]. The physical and mental impact of psoriasis on health-related quality of life (HRQoL) is similar that of other major chronic diseases, including cancer, arthritis, diabetes, and depression [4]. The medical community now largely views psoriasis as not just a cosmetic annoyance but as a chronic, systemic, inflammatory disease that can be both physically and emotionally incapacitating [2, 5]. Untreated moderate-to-severe plaque psoriasis is associated with psychological impairment similar to that observed with untreated breast cancer, coronary artery disease, congestive heart failure, and diabetes [5]. Prompt and effective treatment of the psoriasis restores the psychological well-being of patients to a level similar that of the general public [5].

The severity of psoriasis skin lesions does not always correlate closely with individual patients' subjective impairment [6, 7]. For example, a patient with psoriasis only on the hands (palms) would be considered to have only mild disease severity based on the body-surface area index. However, this patient might report significant functional impairment [6]. Moreover, psoriasis can affect so many aspects of patients' lives that assessing the social burden of the disease—the effects of the disease on how patients relate to other people—may be complex.

This review examines the multimodal effects of uncontrolled psoriasis on a patient's social framework. Treatment strategies for psoriasis will be discussed to examine how existing and emerging therapies may provide patients with options that may help improve both the physical and social burden of the disease. In addition, this review addresses the growing focus on assessments of the quality of healthcare, to determine the value for consumers, and how restructuring the healthcare system to pay-for-performance or value-based purchasing could affect the care of psoriasis [8]. As these new healthcare reimbursement practices are trending toward valuing measures of patient satisfaction [8], this review will also discuss how increased understanding of the social burden of psoriasis may lead to the provision of care in which treatment satisfaction is paramount.

Social Burden of Psoriasis

The common physical manifestations of psoriasis are well characterized and may include scaling, itching, bleeding, burning sensations, and pain of affected skin, which often cause considerable physical discomfort [9, 10]. Psoriasis is often associated with physical comorbidities, such as cardiovascular disease, inflammatory bowel disease, metabolic syndrome, obesity, and psoriatic arthritis [1]. Aside from the considerable physical burden of psoriasis, the social burden of the condition is similarly substantial.

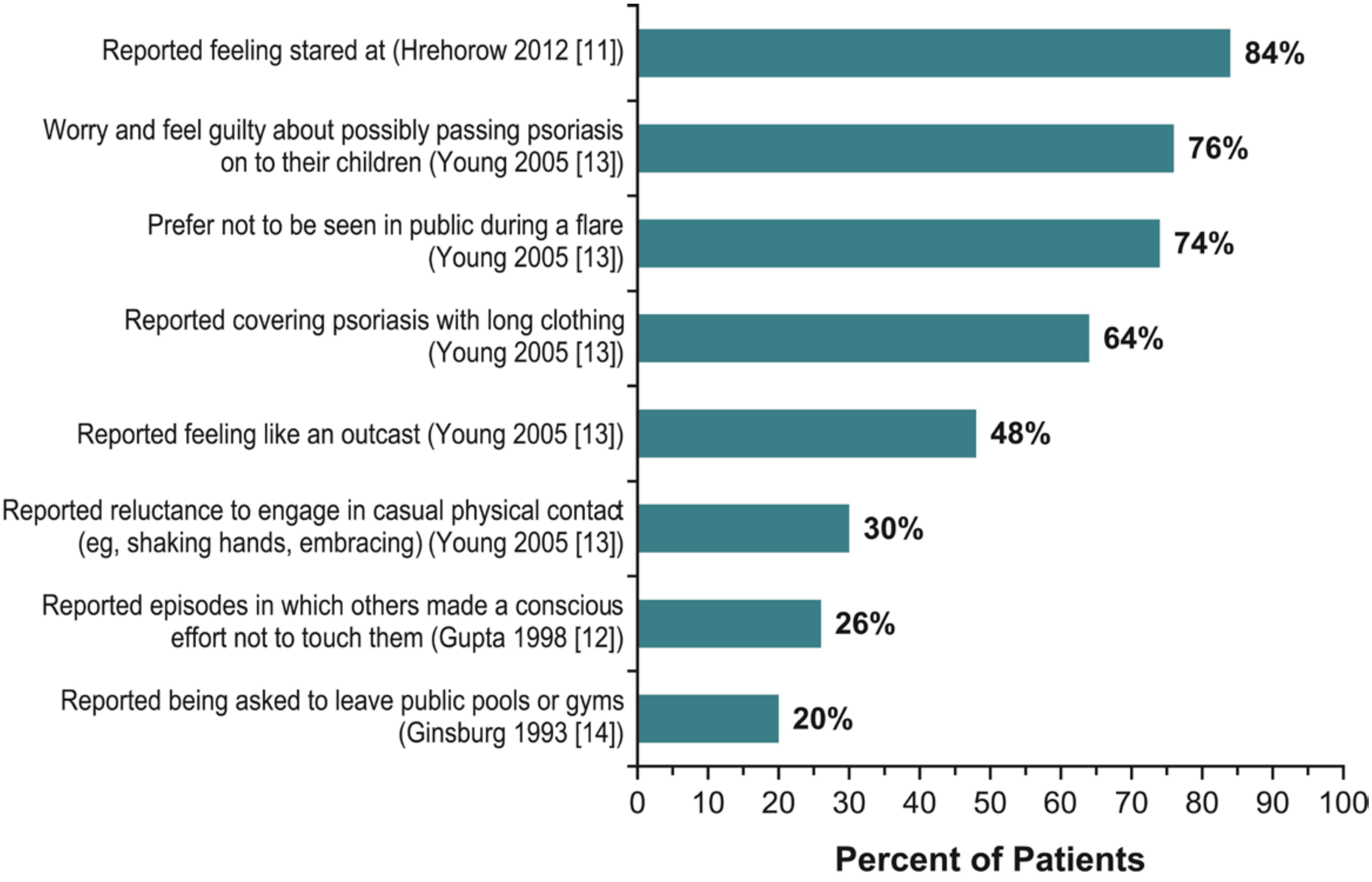

Figure 1. Social burdens of psoriasis, as indicated by patients [11-14]

A majority of patients with psoriasis feel that they are stigmatized by the disease; the major aspects of the social burden of psoriasis include anticipation of rejection and feelings of shame and guilt [11]. Other individuals may avoid touching people with psoriasis out of fear of contagion or filth [12]. A variety of other aspects of the social burden of psoriasis have been identified by patients (Figure 1) [11-14].

Psoriasis also has detrimental effects on affected patients' interpersonal relationships [10], although limited data are available on the impact of psoriasis on sexual function and intimacy [10, 15]. The impact of psoriasis on sexual well-being and the capacity for intimacy are primarily related to poor self-esteem and sexual self-image [16]. A 2005 survey study of patients with moderate-to-severe psoriasis found that 38% reported problems with sex or intimacy; the effects were greatest for younger, unmarried patients [13]. Skin and sexuality are intrinsically linked, so avoidance of intimate situations among patients with psoriasis is common [16]. Sexual distress is highest among patients with psoriatic lesions affecting their genitals, and women are typically more adversely affected than men [15]. One-third of women with psoriasis stated that the pain associated with their condition interfered with sexual activity [17]. These women also reported other complaints on how psoriasis affected sexual activity, including itchiness (19%), the need to adjust sexual position (10%), and bleeding (9%) [17]. Relationships are common in which both partners have psoriasis; an estimated 11% of married people with psoriasis have a spouse with the disease [13].

The negative social impact of psoriasis is also apparent in the workplace (eg, discrimination, difficulty finding employment or working outside the home, and financial hardships and/or lost income) [18-23]. Other occupational burdens related to psoriasis are increased patient absenteeism and reduced productivity [18, 23]. Nearly 60% of employed patients with severe psoriasis reported lost time from work in the previous year due to psoriasis; among those not working or retired, approximately one-third attributed this to psoriasis [18]. In patients with psoriasis, health-related work productivity loss is predicted not by severity of disease but by HRQoL [21], underscoring the importance of understanding each patient's self-experienced burden of the disease.

Measuring Patients' Psoriasis-related Distress

Many clinical instruments are available to evaluate the impact of psoriasis on quality of life [24]. A recent review by Heller and colleagues [24] provides a comprehensive description of these instruments, with advice about the clinical usefulness of each. Some instruments, such as the 36-item Short-Form Health Survey, are valuable tools in clinical research, but may be less useful for clinical practice. Others were not developed as a measure of quality of life, but include items assessing emotional and social/physical functioning [25].

Table 1. Quality of Life Components in the Koo-Menter Psoriasis Instrument [24, 26].

Each of the following measures is rated by the patient on a scale of 0 (not at all) to 10 (very much)
How **self-conscious** do you feel with regard to your psoriasis?
How **helpless** do you feel with regard to your psoriasis?
How **embarrassed** do you feel with regard to your psoriasis?
How **angry or frustrated** do you feel with regard to your psoriasis?
To what extent does your psoriasis **make your appearance unsightly**?
How **disfiguring** is your psoriasis?
How much does your psoriasis impact your **overall emotional well-being**?
Overall, to what extent does your psoriasis interfere with your **capacity to enjoy life**?
How much have each of the following been affected by your psoriasis during the past month?
Itching?
Physical irritation?
Physical pain or soreness?
Choice of clothing to conceal psoriasis?

The Koo-Menter Psoriasis Instrument (KMPI) was designed to assist practitioners in making treatment decisions and avoiding undertreatment when quality of life is significantly impaired [24, 26]. A portion of the KMPI is specifically dedicated to determining the impact of psoriasis on the patient's quality of life (Table I) [24, 26]. The KMPI can be easily incorporated into daily dermatology practice to aid in decisions about the need for treatment intensification (eg, use of systemic or biologic agents) [24, 26]. The KMPI was carefully developed with detailed input from the medical advisory board of the National Psoriasis Foundation, which later endorsed the widespread use of this instrument [24]. The KMPI has been peer-reviewed and published in its entirety in the *Journal of the American Academy of Dermatology* [26]. KMPI results have been used to overturn the decisions of payers to deny coverage of systemic or biologic therapy by demonstrating meaningful reductions in patient quality of life [24].

Clinical Studies Evaluating Patient-reported Social Outcomes

Few studies have used validated instruments to assess the impact of older oral treatments for psoriasis on patient-reported outcomes associated with HRQoL or social burdens; however, these types of assessments are increasingly being incorporated in clinical trials of biologic agents. Treatment with these agents (etanercept, adalimumab, infliximab, ustekinumab) improve Dermatology Life Quality Index and SF-36 scores [9, 27-32]. For example, ustekinumab improves HRQoL, sexual dysfunction, anxiety, depression, and occupational factors [10, 33, 34], and adalimumab improves psychological general well-being, depression, and work productivity [5, 35, 36]. Three new biologic agents (secukinumab, brodalumab, ixekizumab) are in clinical development for the treatment of moderate-to-severe plaque psoriasis [37-41]. These agents provide high rates of clearance and improvements in HRQoL, which could have a substantial impact on the social burden of psoriasis if improvements in patient-reported outcomes are confirmed in larger scale studies [37-41].

Unmet Needs in Treating the Social Burdens of Psoriasis

Nontreatment and undertreatment of psoriasis is common, and patients' dissatisfaction with treatment is widespread [42]. Despite the availability of a number of effective treatment modalities for psoriasis, an estimated 30% of patients with severe psoriasis and 53% of patients with moderate psoriasis receive no treatment or only topical medications as opposed to systemic therapies [42]. Unfortunately, patients often report negative opinions of and poor adherence to topical medications because of disappointing efficacy results and poor physician communication of treatment expectations [43]. A Dutch survey of 1293 patients with psoriasis found that, overall, patients were only moderately satisfied with their current form of treatment [44]. In this survey, patients receiving biologic treatment were more satisfied with their treatment, whereas patients receiving topical treatment were least satisfied [44]. In a survey of 1884 patients taking prescription medications for psoriasis, 78% of patients were eager to try new medications [43]. One-third of these patients reported feeling like their doctors do not take psoriasis seriously [43]. Patients often feel that the impact of psoriasis on their sexual health is often underappreciated [15]. A possible explanation may be that dermatologists do not regularly encounter situations that would require them to diagnose and treat sexual dysfunction, while patients and physicians may also be uncomfortable discussing this sensitive topic [45].

Discussion: The Future Landscape of Psoriasis Treatment Practices

In recent years, the medical literature has reflected a shift in how psoriasis is regarded; accordingly psoriasis is categorized as an inflammatory disease that causes both significant physical and psychological distress and impairment [4]. Still, patients' self-experienced burden of psoriasis may be underappreciated by healthcare providers [43]. As a result, patients with psoriasis may be undertreated and may become frustrated with their poor outcomes. Dissatisfaction is common among patients with psoriasis [42-44]. Trends in healthcare reform are placing more emphasis on pay-for-performance reimbursement models in which providers are rewarded for achieving prespecified measures of quality and effectiveness of healthcare delivery to patients [8, 46]. Patient satisfaction is an integral aspect of such pay-for-performance or value-based-purchasing [46-49].

The Consumer Assessment of Healthcare Providers and Systems (CAHPS) program, consisting of a series of nationally standardized patient survey tools, is a multiyear initiative by the Agency for Healthcare Research and Quality to promote the appraisal of consumers' (ie, patients') experiences with healthcare [50]. Once assembled, CAHPS results will be in the public domain, accessible to prospective patients, other providers, and payers [50]. Medicare.gov now reports data from Hospital CAHPS surveys and other sources, allowing consumers to compare hospitals based on patient perspectives regarding key domains of care [51]. Accountable Care Organizations under the Centers for Medicare and Medicaid Services (CMS) already use CAHPS surveys and will continue to use them yearly to assess quality of care for Medicare patients [52].

The Clinician and Group CAHPS (CGCAHPS) survey, most applicable to dermatologists, assesses patient experience and perception regarding the following domains: overall rating of provider or doctor; how well doctors communicate with patients; getting timely appointments, care, and information; and courtesy and helpfulness of office staff [50]. The CMS has partnered with the CAHPS program since 1996 [50]. In 2006, the CMS implemented the Physician Quality Reporting System (PQRS) which uses a combination of incentive payments and payment adjustments to promote reporting of quality of care information by providers who participate in the program [53]. The PQRS program has since been made permanent under the Medicare Improvements for Patients and Providers Act of 2008 (MIPPA), and MIPPA has mandated that CMS post a website detailing the names of providers and group practices who have satisfactorily reported under the PQRS [54]. Similarly, the Affordable Care Act (ACA) of 2010 requires that information regarding healthcare providers enrolled in the Medicare program be made available to the public [54].

Consequently, all of that combined information is now contained in the searchable Physician Compare database of the Medicare.gov website [54].

Physician Compare will also soon contain data obtained from quality measures (eg, CGCAHPS) for all providers participating in Medicare [54]. Beginning in 2015, the ACA will begin assigning PQRS payment penalties to providers who do not satisfactorily report data on quality measures for covered healthcare services during the 2013 year [53]. Providers will note that these reimbursement changes involve a movement towards the use of a provider's patient satisfaction rating to determine the level of payment. This behooves dermatologists to improve patients' perceptions of psoriasis care, management, and treatment. Thus, it is vital to understand the factors that affect patients' self-experienced burden of psoriasis (including social burden), and to address these issues within the medical community and at the patient–physician level.

To enhance the experience patients with psoriasis have with their care, and accordingly increase patient satisfaction with that care, physicians should be encouraged to do what is necessary to be perceived as a caring doctor by their patients. By making the effort to empathize with the individual needs of each patient, physicians could build a stronger relationship with their patients. This would allow them to provide more comprehensive, holistic, individualized treatment plans that address the possible need for treatment intensification if patients experience worsening psychosocial symptoms, even if objective lesional severity is stable. To accomplish this goal, it may be helpful to incorporate quantitative tools such as the KMPI into daily practice to help identify patients who experience an increased psychosocial burden and to help guide decisions about optimal aggressiveness of treatment [24, 26]. This tool is freely available and can be easily completed during a dermatology office visit, as it takes approximately 5 minutes for patients and physicians each to populate.

Patients should be offered and educated about the range of available treatments, including new treatment options as they become available if data indicate these therapies can safely ameliorate patients' experience with the disease. Furthermore, as new and highly effective treatments are developed, advocacy and education will be needed to ensure medications are accessible and patients are informed of benefit–risk profiles, including the possibility of reduced psychosocial burdens [42]. Such changes will likely be of significant benefit for patients, providers, and payers.

List of abbreviations:

ACA, Affordable Care Act

CAHPS, Consumer Assessment of Healthcare Providers and Systems

CGCAHPS, Clinician and Group CAHPS

CMS, Centers for Medicare and Medicaid Services

HRQoL, Health-related quality of life

KMPI, Koo-Menter Psoriasis Instrument

MIPPA, Medicare Improvements for Patients and Providers Act of 2008

PQRS, Physician Quality Reporting System

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