ASSESSMENT OF HUMANISTIC OUTCOMES IN PSORIASIS RELATED DISEASES

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ABSTRACT
Psoriasis is a chronic condition with a recurring pattern which has been linked with undesirable influence on quality of life. The management using different treatments has shown to be expensive. Improving a patient’s humanistic aspect is one of the endpoint that is being considered in clinical practice. The effect of the disease on the patients has been evaluated using various questionnaires that have been validated. These questionnaires cover varied aspects of a patient’s life like the symptoms, emotional facets, day to day activities, and impact on work, effect on personal relationships and also on the adverse effects of the treatment.

KEYWORDS: Psoriasis, effect on personal relationships.

INTRODUCTION
The term Quality of life (QOL) if defined or standardized would not be a proper definition, as it is the perception of different individuals on that particular disease or condition. WHO defines QOL as “individuals’ perception of their position in life, in the context of the cultural and value system in which they live and in relation to their goals, expectations, standards and concerns”.
With the latest advances in therapy for those suffering from psoriasis, the endurance of these patients has been amplified and their humanistic outcome has grown into a significant focus for researchers and clinicians. Patients with psoriasis have to deal with various social problems like social stigma, poverty, depression and cultural beliefs especially in an Indian scenario. These aspects can have a major effect on their QOL in terms of physical, mental and social perspectives which in turn could cause a series of glitches in everyday activities and leisurely aspects of the patients. Evaluating health-related quality of life (HRQOL) will help in the documentation of the burden of chronic disease, subsequent to changes in health over a period of time, evaluating the effects of treatment and calculating the extent of expenditure falling on each individual.

Psoriasis is a complex disease in which there are erythematous, sharply demarcating papules and rounded plaques covered by silvery scales. Sometimes these lesions are pruritic and furthermore, other exterior factors can worsen psoriasis which includes medications, stress, and infections (lithium, beta blockers, and antimalarials). There is a lot of misunderstanding among general population which leads to discrimination and people keep away from patients, fearing of transmission of the disease. Psoriasis is a noninfectious condition and does not spread from person to person. It is also important to know that the discrimination and isolation of the infected persons carry a stigma and suffer humiliation leading to psychological depression, than physical morbidity. There is a need to remove myths regarding psoriasis from the community and the patient as well. Public attitude has to be changed from fear and hatred to sympathetic and sharing, this change in attitude can only happen through continuous education to the family, relatives and friends of these patients. The patients are supposed to be educated thoroughly regarding disease treatments and lifestyles which mend the humanistic aspect for the patients and it will also remove the apprehension and fear from the patient’s mind leading to improvement in QOL of the patients. The different instruments developed on validity to evaluate QOL are available through various web sources for utilization. The QOL instruments are generally of two types like generic and disease specific. These questionnaires cover varied aspects of a patient’s life like the symptoms, emotional facets, day to day activities, and impact on work, effect on personal relationships and also on the adverse effects of the treatment. The generic questionnaires focus on overall QOL whereas disease specific are designed to evaluate the QOL of patients in a particular condition.
The clinical assessment of psoriasis is performed by clinicians using Psoriasis Area Severity Index (PASI). The locations of affected area are, the head (h), upper limb (u), trunk (t) and lower limbs (l), are independently recorded by using these parameters, erythema, induration and desquamation, each of which is classified on a severity scale of 0 to 4, where 0 = nil, 1 = mild, 2 = moderate, 3 = severe and 4 = very severe. The percentage association can be calculated as: 1 = less than 10% area; 2 = 10-29%; 3 = 30-49%; 4 = 50-69%; 5 = 70-89%; and 6 = more than 90%. The changes in the PASI score are reflective of effectiveness of a particular clinical intervention and an easy way to follow the prognosis of psoriasis. The humanistic outcomes are mainly mirrored by the PASI score hence the humanistic outcome in patients with psoriasis can be assessed using various instruments. The merits and demerits along with limitations are summarized in the table:

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Merits</th>
<th>Demerits</th>
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<tbody>
<tr>
<td>Psoriasis Index of Quality of Life (PSORIQoL)</td>
<td>Centered on concept and gauging the influence of the disease on QoL</td>
<td>25 questions not patient compliant</td>
</tr>
<tr>
<td>Psoriasis Life Stress Inventory (PLSI)</td>
<td>measure of the daily disturbances of psychosocial stress related to day to day activities</td>
<td>Focus is on the stress linked with psoriasis</td>
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<tr>
<td>Psoriasis Disability Index (PDI)</td>
<td>Reports self-reported disability wherein the focus is on everyday activities, occupation, relationships, and treatment effects.</td>
<td>Can be biased as its self-reported</td>
</tr>
<tr>
<td>Psoriasis Area and Severity Index (PASI) and Simplified PASI (SAPASI)</td>
<td>Gives an satisfactory depiction of the impact of the disease on patients' QoL</td>
<td>The impact of psoriasis on patients' QoL is not measured directly</td>
</tr>
<tr>
<td>Dermatology Life Quality Index (DLQI)</td>
<td>All the indications and emotional state, daily activities, work and school, personal relationships treatment is assessed</td>
<td>Self-reported</td>
</tr>
<tr>
<td>Short Form 36 (SF-36)</td>
<td>Covers all the aspects and the impact of psoriasis</td>
<td>36 item- can be too lengthy hence not patient compliant</td>
</tr>
<tr>
<td>EuroQoL 5D (EQ-5D)</td>
<td>Valuation of consequences associated to health conditions or their treatment</td>
<td>May not be sufficient to assess all the aspects</td>
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</table>

**Living with Psoriasis**

The dramatic presentation of psoriasis due to disfigured skin usually creates the mental trauma among patients and his relatives further, as there is lot of myths and beliefs influenced.
by ignorance, which makes the patient depressed and his relatives to look down on patient. The patient condition becomes more severe if not treated leading to spread of the disfiguration and sometimes the joints gets affected leading to psoriatic arthritis. The available therapies are empirical and the effectiveness cannot be definitive which frustrates the patient. The patients should manage the pruritis and the pain in the joints along with psychological trauma and face the stigma of isolation.\textsuperscript{[3, 4]} The manifestation of psoriasis is clinically classified as psoriasis vulgaris, palmoplantar psoriasis, guttate psoriasis, pustular psoriasis, plaque psoriasis, erythrodermic psoriasis and inverse psoriasis.

Psoriasis vulgaris appears as a rash with silvery scales, it may be associated with itching and pain. It can appear in any part of the skin including scalp, palms of hands and soles of feet. It is also called as plaque psoriasis as there is scaling of skin. There is a danger of opening of skin due to scratching the skin resulting in bleeding prone for skin infections. It is usually observed in patients with the age group of 18 and above.

Guttate psoriasis is a condition which is common in children. In this kind of psoriasis, looks like a small, red, with separate spots on the skin. Lesions typically appear on the trunk and limbs occasionally on scalp, face and ears.

Inverse psoriasis shows up as red lesions in body folds. It may appear smooth and shiny. The patients may also have plaque psoriasis, pustular psoriasis on the body along with inverse psoriasis.

Pustular psoriasis in characterized by white pustules (blisters of noninfectious pus) surrounded by red skin. The pus consists of white blood cells. It is not an infection, nor is it contagious. Erythrodermic psoriasis is characterized by erythema and scaling involving more than 90% of the body surface area. It is usually mistaken as contagious which is not true as there are no microorganisms involved in causing this condition. Some of the different kinds are shown below:
Comorbidities Associated with Psoriasis

There are well identified comorbidities associated with psoriasis like diabetes, obesity, hyperlipidemia, and metabolic syndrome. Apart from this the patient usually suffers from psychological stress, anxiety and depression. The chances of developing the cardiovascular disease are very high in psoriasis patients. The evidence for comorbidities like obesity, diabetes, hyperlipidemia, and the metabolic syndrome is available in literature and in a cross sectional study from Italy by Gisondi has established that the prevalence of metabolic syndrome was higher in patients who were not treated for psoriasis by systemic medications compared to the patients on systemic medications. [5] The occurrence of dyslipidemia was prevalent among psoriasis patients irrespective of being treated with PUVA or oral retinoids increased total cholesterol and triglycerides, decreased HDL, and no alteration in LDL in psoriasis patients compared to controls. [6,7] Type 2 Diabetes was also prevalent among psoriatic patients, however to consider diabetes type 2 as a risk factor the evidence is still elusive. [8,9,10] The cardiovascular disease like myocardial infarction is one of the serious conditions which appears in psoriasis patients due to association with atherosclerosis and thrombosis as comorbidities of psoriasis. [11,12]

Psychological Comorbidities

The psychological trauma faced by the patient is a major cause for all conditions like depression anxiety and stress. Significant higher levels of anxiety and depression are observed among patients who find it difficult to face society and family members who usually think the condition is infectious and isolate the patient from family and society. The isolation and humiliation usually makes the patient more submissive and tries to keep away from the eye of the public as a result of fear of being criticized and mocked. As they are viewed as marginal special population they get a differential treatment, as far as the employment opportunities it is worse for female patients and with younger patients as they face the society in a hostile manner as they grow for differential treatment. [13]

The influence of psychiatric comorbidities, explicitly depression, on the humanistic aspect of patients with psoriasis has not been well recorded. The occurrence of a foremost psychiatric disorder was connected with a negative impact on the humanistic aspect of mental wellbeing, societal functioning, and general health observations but not on physical health, or pain. [14]
Psoriasis and Unemployment
People with psoriasis have to cope with not just the chronic illness on a day to day basis but also the effect psoriasis has indirectly on work related issues. For patients who are employed their occupation provides them with not just the financial assistance but also a basis of social support, individuality, and significance in life. These patients always have this constant fear and uncertainty about the extent of effect psoriasis will have at their economic and occupational end. Some of the patients who have the options to take benefits stating their ill health choose to voluntarily leave the work front, while some others remain employed depending on the financial and societal issues they are facing in their personal front. These patients do face problems due to factors associated with psoriasis like stress, external appearances, if the job involves continuous exposure to sun, medication schedules and side effects, and frequent appointments with doctors. [15]

Studies have shown that the extent of reporting symptoms like depression, anxiety, social isolation, and low self-esteem have been observed more in unemployed than employed individuals. Suicide, attempted suicides are multifaceted clinical matters connected with conditions like psoriasis. Suicide in personnel with psoriasis has been stated in most scenarios to be related with a associated psychiatric disorder. [16]

Social Sustenance
There is an improvement in quality of life seen which has been associated with demographic features such as male gender, individuals who are younger, higher socioeconomic status, and employment. Furthermore, patients who have been put on regimens which has lower number of pills, patients who are adherent to therapy have better QOL following the treatment has shown to improve QOL.

Many people existing with psoriasis find it challenging to do their daily tasks of living, or involve in modest to energetic physical activities, or participate in a lively social life along with the management of psoriasis. [17,18,19]

Stigmatization
Studies have shown that psoriasis patients experience significant stigmatization than do other patients, and that these experiences that they have, facilitate a connection between the disease severity and the QOL measured on patients. Psychosocial intervention tolls would help in the betterment of these patients. [20]
CONCLUSION
Humanistic outcomes are multifaceted parameters whose definition and assessment remains elusive. Psoriasis causes a high burden on economic sphere of patients which is reflected as high societal impact. The humanistic outcomes can be represented as global and individual perception. The global parameters involve aspects which reflect the day to day quality of life and individual perception parameters are due to ADR’s due to drug therapy. As wellness of the patient is generally cited as one of the most imperative determinants of overall QOL, it has been suggested that the humanistic outcomes may be uniquely affected by specific disease pathology. There is lack of clarity in defining the humanistic outcomes and concomitant functional difficulties in it but still there is urgency in evaluating the humanistic outcomes in psoriasis patients. Future studies should encompass the evaluation of more determinants of humanistic outcomes in psoriasis patients. The group of psoriasis-related symptoms negatively affects the humanistic outcomes among the psoriasis patients. Effective management of symptoms is important for improving humanistic outcomes and probably for maintaining a complicated daily drug regimen. As this disease is among the most devastating of illnesses, having multiple and profound effects upon all aspects of life, hence the evaluation of humanistic outcomes is very important. Although research has suggested relationships among various psychosocial and spiritual factors, symptomatology, and physical health, extensive research is still needed to document their potential influences on immune function, as well as health status, disease progression, and humanistic outcomes among patients with psoriasis. It is important to underline the stress management interventions for psoriasis as they are paving a way to facilitate positive adjustment.

REFERENCES
