

Psoriasis and Beyond: Interim results of the Global Psoriatic Disease survey capturing patient perspective

12. Patient organization projects/Patient research partners

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Introduction

Although scientific research in psoriasis (PsO) and psoriatic arthritis (PsA) has grown significantly, patient perspective remains insufficiently explored. Psoriasis is a systemic multifaceted disease¹, but the complexity of PsO and PsA and related manifestations are not yet widely understood, and it is unclear to what extent patients are aware about psoriatic disease and its comorbidities.

Objectives

The joint research initiative between the International Federation of Psoriasis Associations (IFPAs), dermatology experts and Novartis evaluates patients' understanding of psoriatic disease, associated comorbidities, and the humanistic and physical burden of living with the condition.

Methods

A cross-sectional, quantitative online survey, was conducted in patients with moderate to severe plaque PsO with or without concomitant PsA. The questionnaire was a combination of validated tools such as the Dermatology Life Quality Index and Work Productivity and Activity Impairment. The remainder of the questionnaire comprised non-validated questions used in previous 'Clear about Psoriasis'² survey to allow comparability, as well as newly defined questions (tailored to the objectives of this new survey). As of January 2021, 1678 responses were analyzed across 11 countries from Europe, North/South America and Asia. Final results are expected in the second half of 2021.

Results

Interim survey results demonstrated that 73% and 63% of all patients heard of "systemic disease" and "psoriatic disease" respectively, a high proportion of PsO patients remained unaware of PsA (71%) and all patients of axial symptoms (82%). High proportion of all patients also remained unaware of associated comorbidities like obesity (79%), high cholesterol (83%), cardiovascular diseases (82%), diabetes (83%) and axial disease (86%). Further, 30% of PsO patients have PsA, 70% of PsA patients experience swollen and tender joints, especially in finger(s) and/or toe(s).

84% patients experienced social stigma and discrimination in public. Mostly they were asked if it was contagious (36%), stared at in public (32%). 82% patients felt that their disease impacted past or current relationships (**Figure 1**).

Conclusions

The findings indicate that, while high percentage of moderate to severe plaque PsO patients with/without concomitant PsA heard about the terms systemic disease and psoriatic disease, they remain unaware of the systemic nature of the disease and the increased risk of associated comorbidities. Additionally, psoriatic disease has a profound negative impact on patients' quality of life, including psychosocial

wellbeing. The interim results underscore the need to recognize the systemic nature of psoriatic disease and its various manifestations and comorbidities. There remains a need for an awareness of human and physical aspects of all manifestations of psoriatic disease to ensure optimal management of patients.

References

1. Lebwohl M.G., et al. Clin Dermatol 2014;32(3):343-50.
2. Lebwohl M.G. et al. J Am Acad Dermatol. 2014;70(5):871-81.e1-30.

