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## NOVELTIES IN DERMATOLOGY

# Cumulative Life Course Impairment: The Imprint of Psoriasis on the Patient's Life<sup>☆</sup>

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### PALABRAS CLAVE

Psoriasis;  
Estigmatización;  
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**Abstract** We now realize that moderate to severe psoriasis takes a toll on the patient's overall health beyond the effects on the skin itself, and so we use quality of life (QOL) measures to assess how the individual perceives both the impact of disease and the response to treatment. However, available instruments give us a cross-sectional assessment of QOL at a specific moment, and we lack longitudinal studies of how a disease affects each and every aspect of a patient's life over time—including physical and psychological wellbeing, social and emotional relationships, vocational and employment decisions and how they change the individual's outlook. A new concept, cumulative life course impairment (CLCI), captures the notion of the ongoing effect of a disease, providing us with a new paradigm for assessing the impact of psoriasis on QOL. Unlike conventional measurement tools and scales, which focus on a specific moment in the patient's life, a CLCI tool investigates the repercussions of disease that accumulate over a lifetime, interfering with the individual's full potential development and altering perspectives that might have been different had psoriasis not been present. The accumulated impact will vary from patient to patient depending on circumstances that interact differently over time as the burden of stigmatization, concomitant physical and psychological conditions associated with psoriasis, coping mechanisms, and external factors come into play and are modulated by the individual's personality.

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### Discapacidad acumulada en el transcurso vital: la cicatriz de la psoriasis en la vida del paciente

**Resumen** Hoy en día se acepta que la psoriasis moderada-grave repercute de forma global en la salud del individuo mucho más allá de la clínica cutánea, y se emplean medidas de calidad de vida relacionada con la salud (QoL) para evaluar tanto la afectación percibida por el paciente como la respuesta de la misma al tratamiento. Sin embargo, las medidas de QoL disponibles se refieren a un momento o período concreto de la vida del paciente, de forma transversal, y

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no disponemos de estudios longitudinales que evalúen en qué medida el impacto de la enfermedad va condicionando todas y cada una de las vertientes de la vida del paciente —bienestar físico, psicológico, relaciones sociales y emocionales, decisiones vocacionales y laborales, etc.— modificando sus perspectivas. Para referirnos este impacto continuado y acumulativo se ha introducido un nuevo concepto, que se conoce como discapacidad acumulada en el transcurso vital (*Cumulative Life Course Impairment* [CLCI]) y constituye un nuevo paradigma de evaluación del impacto de la psoriasis en la QoL del paciente. A diferencia de las medidas y escalas convencionales, que focalizan la evaluación en un momento o período concreto de la vida del paciente, de forma transversal, en el CLCI se tiene en cuenta el impacto acumulativo que la afectación provocada por la psoriasis tiene longitudinalmente a lo largo de la vida del paciente, interfiriendo con el máximo desarrollo potencial del paciente y con su perspectiva vital si la psoriasis no hubiese existido. El resultado final será distinto para cada paciente, en función de las circunstancias que interactúen en cada momento, derivadas de la interacción entre la carga de la estigmatización, las comorbilidades físicas y psicológicas asociadas a la enfermedad y de las estrategias de afrontamiento y los factores externos que puedan intervenir, modulados por los estilos de personalidad de cada paciente.

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## Introduction

Psoriasis is a multifactorial disease with effects that go beyond the physical symptoms to compromise the patients' psychological and emotional wellbeing. The physical and psychological impact of the condition, which has been a subject of study for some decades, extends into all areas of these patients' lives, affecting both their personal lives—emotional wellbeing, relationships, sexuality, and leisure activities—and their relationships with others—work, social life, family, and financial status.<sup>1–10</sup> To date, studies in this area have focused on quality of life (QOL), quantifying the impact of psoriasis using cross-sectional data—in many cases retrospective—to provide a profile of the disease burden at a specific point in the patient's life. What this method does not take into account is the progressive impairment these patients accumulate over the course of their lives.<sup>11,12</sup> Recently, a new approach—called cumulative life course impairment (CLCI)—has been proposed as a way to take into account the cumulative effect of psoriasis and the way physical and psychological comorbidities and the stigma associated with the symptoms of the condition progressively affect the patient's life over time.

The concept of CLCI as described in this article arose from the work of an international committee of dermatologists, psychologists, and experts in psychometrics undertaken to develop a multidisciplinary approach to the management of psoriasis. The concept, which had already been applied in other disciplines, such as medical psychology and sociology, is based on analysis of the mechanisms and interconnections that influence the life course of patients who have a chronic disease and explores how protective factors and risk factors interact throughout the course of the disease. CLCI has been used in numerous chronic diseases.<sup>13–19</sup> The ultimate goal of this approach is to achieve a better understanding of the overall cumulative impact of psoriasis, helping to identify individuals who are more vulnerable to this cumulative damage, and facilitating more appropriate treatment decisions tailored to the needs of each individual.<sup>11</sup>

## The Concept of Cumulative Life Course Impairment

The concept of CLCI takes into account the cumulative impairment acquired by the psoriasis patient over a lifetime. The purpose of this concept, which has only recently been applied to the management of psoriasis, is to reflect the chronic nature and cumulative effects of the disease as well as the well-known repercussions, including stigmatization and numerous physical and psychological comorbidities. The concept of CLCI also incorporates other important components, factors that can play a moderating role or make the patient less vulnerable to such impairment. These include external factors (for example, a supportive environment), coping strategies, and personality style. The interaction between all these factors could explain the variations we observe between patients and how each individual experiences life with psoriasis.

As illustrated in Fig. 1, CLCI is the cumulative result of the balance between (A) the burden of the physical and psychological comorbidities and stigma associated with psoriasis and (B) the external factors and coping strategies modulated by the patient's personality. The relative weight of each of these components in each individual explains the inconsistencies we see in how different patients experience psoriasis of similar severity. Assessment of these components can also help us to determine each patient's vulnerability to the impact and detrimental effect of the disease (Fig. 1).

The negative impact of this cumulative impairment on different areas of the patients' lives is progressive and influences its course, undermining their aspirations and personal fulfillment and influencing major life-changing decisions that will mark their identity as well as their personal, professional, social, and family development. Patients with psoriasis believe that their lives would have been substantially different without the chronic and visible impact of the disease. This cumulative impairment over time can prevent patients from achieving their personal life goals and substantially alter the course of their lives. In such cases their

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