



Well-Being in Psoriasis: Weighting its Components Using Best-worst Scaling Methodology

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Received: June 18, 2025 / Accepted: July 9, 2025 / Published online: July 18, 2025
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ABSTRACT

Introduction: The Inpsight Project, established in 2021, aimed to define the concept of well-being in patients with psoriasis from a holistic perspective. Well-being was defined as a

multi-dimensional concept that includes achieving emotional balance, having adequate overall health and control of the disease, enjoying positive social relationships, and being satisfied with disease care. However, while these components are recognized as integral to the concept, their relative contribution to achieving optimal well-being remains unclear. To address this gap, the present study aimed to determine the relative weight of each component in contributing

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s13555-025-01499-8>.

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to optimal well-being, focusing on a Spanish population.

Methods: An observational, descriptive, cross-sectional study was conducted in Spain using best-worst scaling (BWS). Two questionnaires were developed: one addressed to patients (33 item) and the other to healthcare professionals (HCPs) (18 item). The questionnaires collected sociodemographic and clinical (patients)/occupational (HCP) characteristics of the participants and the BWS scenarios. The 20 components of well-being were randomly distributed across 76 scenarios, with each component paired with others four times to ensure a comprehensive evaluation of all possible combinations. Participants assessed 9–10 randomly selected scenarios and identified the components they considered most (best) and least (worst) important for achieving optimal well-being.

Results: A total of 87 HCPs and 152 patients with psoriasis participated in the study. The five key components for patients were pain (P: 100.00), stress (P: 98.74), treatment satisfaction (92.21), itching (72.05), and lesions in functional locations (P: 69.09). From a HCP perspective, the most important components were mood disorders (100.00), pain (69.39), lesions in functional locations (49.34), self-esteem (49.24), and stigmatization/shame (45.22).

Conclusions: This study highlights the differences between patients and HCPs in their perception of the relative importance and relevance of the components contributing to the well-being of patients with psoriasis. Future research should focus on understanding the cumulative impact of psoriasis on patient well-being.

Keywords: Well-being; Psoriasis; Quality of life; Best-worst scaling

Key Summary Points

Why carry out this study?

The Inpsight Project defined well-being in patients with psoriasis and its components. However, the relative contribution of each component to achieving optimal well-being remains unclear.

This study aimed to assess the relative weight of each well-being component in contributing to optimal well-being, from the perspective of both patients and healthcare professionals (HCPs)

What was learned from the study?

Patients ranked physical aspects (pain, stress, itching) as most important, while HCPs emphasized emotional aspects (mood disorders, self-esteem). Clear differences emerged in emotional and social dimensions.

Our study identified disparity between what patients and HCPs consider most relevant to well-being in psoriasis, underscoring the need for more holistic, patient-centered approaches that align treatment with patients' lived experiences and priorities.

INTRODUCTION

Psoriasis is a chronic inflammatory skin condition with a global prevalence of 1%–3%, and an approximately 2.3% prevalence in Spain, significantly impacting individuals' health and quality of life (QoL) [1–4]. Similar to other chronic diseases, it is a multifactorial condition in which factors such as stress, physical visible lesions, anxiety, and other psychological problems can diminish health-related quality of life (HRQoL) [5, 6]. The cumulative effect of these factors can create increasing instability in patients' lives over the long term, affecting not only them but also their families [7, 8].

Well-being is closely related to HRQoL and has been approached from different perspectives

over the years [9–11], making it challenging to clearly differentiate the two concepts because of overlapping aspects such as social, physical, and emotional dimensions [10, 12]. Despite the similarities, HRQoL primarily focuses on health status from a functional perspective, emphasizing the impact of the disease on daily activities [12]. In contrast, well-being encompasses a broader and more subjective view, based on a more emotional and psychological response. It integrates social, emotional, and physical dimensions, while also addressing other aspects of the patient's life, providing a more comprehensive view [13–15].

The physical dimension includes specific characteristics, such as pain/discomfort, lesions in visible and functional areas, and quality of sleep, which patients associate with poorer social relationships and stigmatization [16]. These physical and social consequences may also trigger harmful emotional responses, such as anxiety or feelings of sadness, which, over time, can evolve into more persistent psychological effects, including stress, mood disorders, and other mental health issues. This makes the emotional dimension a critical one alongside the physical and social aspects that can affect patient QoL, addressing the immediate feelings and emotional responses of patients that arise from both physical symptoms and social challenges, which directly impact their overall well-being [16, 17].

Evidence suggests that patients have unmet needs related to the three main dimensions [14], pointing to a lack of a comprehensive approach in the well-being of patients with psoriasis. In this context, some clinical trials using biological treatments have shown promising results in the improvement of well-being domains. A study carried out in different European countries, including Spain, assessing a therapeutic approach through the evaluation of well-being factors, determined that 40% of patients with psoriasis presented depressive symptoms at the beginning of the study. After 28 weeks of treatment, however, their levels of well-being were comparable to those observed in the general population [18]. The VOYAGE 1 and 2 studies reported that three-quarters of patients in the

treatment group declared that psoriasis had no negative impact on their lives [19].

The Inpsight project, launched in 2021 to promote a holistic approach to the management of psoriasis, aimed to reach a multidisciplinary consensus on the definition and components of well-being in psoriasis. Involving 261 Spanish panelists (patients and healthcare professionals [HCPs]), the project defined well-being as multidimensional. It includes achieving emotional balance, having adequate overall health and control of the disease, enjoying positive social relationships, and being satisfied with disease care [20]. However, while these components are recognized as integral to the concept, their relative contribution in achieving optimal well-being remains unclear.

To address this gap, the aim of the present study, conducted with a focus on the Spanish population, was to determine the relative weight of each well-being component in contributing to optimal well-being in patients with psoriasis. The study employed best-worst scaling (BWS), based on the idea that preferences for different selected choices, such as health-related attributes, can be measured by asking patients and HCPs to select both the best (most important) and worst (least important) aspects in different scenarios [21–23]. By quantifying what matters most to Spanish patients and HCPs, this initiative seeks to inform more effective strategies for healthcare provision, health communication, and outcome measurement in psoriasis management.

METHODS

A multidisciplinary scientific committee composed of ten HCPs (6 dermatologists, 3 hospital pharmacists, and 1 psychologist) and a patient representative led the project.

This was an observational, descriptive, cross-sectional, non-drug-related study based on BWS. The BWS methodology helps capture preferences from both patients and HCPs across different options [21–23]. This approach typically involves questionnaires designed to identify the best and worst characteristics in different scenarios composed of three or more features

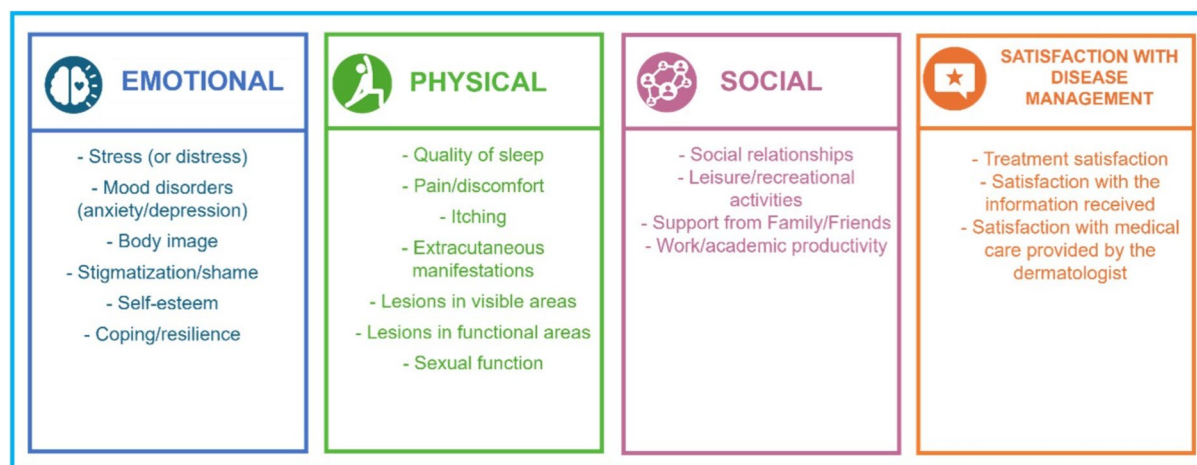


Fig. 1 Well-being dimensions (emotional, physical and social), disease management satisfaction, and their components

[23, 24], allowing each component to appear the same number of times.

In this case, the 20 components that constitute well-being (Fig. 1) agreed upon during phase 1 of the Inpsight project [20] were combined in 76 BWS scenarios (5 components per scenario, with each component appearing 19 times and combined 4 times in pairs) (Fig. 2).

To ensure a response to all possible combinations of components ($n = 20$), a

balanced incomplete block design was used [25]. Each participant evaluated 9–10 randomly selected scenarios using the Alchemer platform. For each scenario, participants were asked to choose which component they considered most relevant (best) for achieving optimal well-being and which they deemed least important (worst).

Two questionnaires were originally designed for this phase of the project, one for patients and the other for HCPs. The patient questionnaire

Please indicate which of the following situations/circumstances is most important (BEST) and least important (WORST) for achieving optimal well-being:

Situation/Circumstances	Most important (BEST)	Least important (WORST)
Being satisfied with the psoriasis treatment I currently receive	☐	☐
Feeling supported by my family and friends	☐	☐
Sleeping well	☐	☐
Being able to engage in leisure and recreational activities without being limited by the disease	☐	☐
Not experiencing stress	☐	☐

Fig. 2 Example of a BWS scenario combining five components of well-being

comprised 33 items, structured in three sections: sociodemographic variables (3 items: age, sex, Spanish autonomous community), psoriasis-related variables (20 items: years since psoriasis diagnosis, presence of lesions in visible and/or functional areas, itching and pain scale, Dermatology Life Quality Index [DLQI], Patient Global Psoriasis Assessment [PGPA], comorbidities, current medication for psoriasis, and previous treatments), and BWS scenarios (9–10 scenarios). For HCPs, an 18-item questionnaire was developed, structured in three sections: sociodemographic variables (3 items: age, sex, Spanish autonomous community), professional variables (5 items: medical specialty, time practicing the medical specialty, availability of specialized clinics, multidisciplinary approach, and psychodermatology consultation), and BWS scenarios (9–10 scenarios).

A pilot test was conducted with 15 patients with psoriasis. Patients were identified and invited to participate by the Spanish patient association *Acción Psoriasis*. The inclusion criteria encompassed patients ≥ 18 years old with a confirmed diagnosis of psoriasis who had previously participated in the Inpsight teamwork initiative [20]. During the pilot test, the questionnaire was evaluated for clarity and length. Participants were asked about the complexity, comprehensibility, appropriateness, and length of the questionnaire. Based on their feedback, the final version of the questionnaire was developed.

Participants

Participants from phase I of the Inpsight project [20] were invited to take part in this phase of the project. All of them were invited via email, which included the informed consent and a link to the patient information sheet.

HCPs were identified and invited to participate by the study sponsor. All HCPs met the following inclusion criteria: they were HCPs specializing in dermatology or hospital pharmacy with experience in managing psoriasis patients, had provided an informed consent

form for the study, and had participated in the first Delphi consultation of the Inpsight project. Patients were invited to participate by *Acción Psoriasis*. The inclusion criteria for patients were aged 18 years or older, having a diagnosis of psoriasis, and providing informed consent for the study.

Data Analysis

A descriptive analysis of the study variables was carried out. Qualitative variables were described by relative and absolute frequencies, while quantitative variables were described by measures of central tendency and dispersion (mean and standard deviation).

The BWS methodology generates a score for each component based on how often it is selected as the best (B) or worst (W) option across all choice sets. Components were coded such that the most important was assigned a value of “1” and the least important a value of “– 1.” Specifically, the B score was calculated as the sum of the best scoring components and the W score as the sum of the worst-scoring components. Each component value was obtained through the formula $B - W$ [26]. The relative importance of each component was quantified by calculating the square root of the ratio of B to W ($\sqrt{B/W}$). The resulting coefficient represents the choice probability in relation to the most important component. The highest importance value was rescaled to an index of 100, with other values adjusted proportionally relative to this maximum [26]. All statistical analyses were conducted using Stata software, version 14.

Ethical Approval

Ethical approval for this study was obtained from the Clinical Research Ethics Committee (CREC) of Hospital La Princesa (Madrid) (reference no. LIB 14/2007) and complied with the Helsinki Declaration of 1975, as revised in 1983. All patients and HCPs provided informed consent for this study.

RESULTS

Participants

A total of 87 HCPs (99% response rate) and 152 patients (99% response rate) from diverse regions across nearly all Spanish autonomous communities participated in the study. Among the HCPs, more than half of the participants were women (55.7%) and most were > 40 years old (81.8%). All participating HCPs had extensive experience in managing the disease, with most having > 15 years of professional practice. Specialized consultations are conducted in the workplace of 80.7% of the HCPs, following a multidisciplinary approach, while 10.2% are performed by a specialist in psychodermatology clinics (Table S1) (see supplementary materials for more details).

Regarding patients, more than half of the participants were women and most were > 40 years old. Most (89.5%) had been living with a psoriasis diagnosis for > 5 years, reflecting a population with significant experience in coping with the condition. Moreover, patients exhibited severe disease involvement, with 70% of lesions located in visible and functional areas (Table S2). Nearly 44% of the patients experienced severe itching, while 26.2% presented severe pain. Most had severe psoriasis according to the PGPA. The most frequently reported comorbidities included psoriatic arthritis (39.2%), anxiety/depression (28.8%), and cardiovascular disease or metabolic syndrome (26.8%); 15% of the patients had no comorbidities. More than half of the patients (53.6%) were currently on non-topical therapy, including phototherapy, non-biological systemic therapy, and biological therapy, and 54% had more than one previous treatment (excluding topicals) (Table S2) (see supplementary materials for more details).

Best-worst Scaling Results

Patients with psoriasis and HCPs identified pain and dermatological lesions in functional areas as highly important components for achieving optimal well-being. For patients, the five key components were pain, stress,

treatment satisfaction, itching, and lesions in functional areas. For HCPs, the most important components were mood disorders, pain, lesions in functional areas, self-esteem, and stigmatization/shame (Table 1) (Figure S1) (see supplementary materials for more details).

Differences were observed between HCPs and patients in the perceived relevance of well-being components. In the emotional dimension, stress was a major concern for patients (98.74) but was rated much lower by HCPs (14.34). Conversely, HCPs placed greater emphasis on stigmatization/shame compared to patients (45.22 vs. 22.25) (Table 1). In the physical dimension, itching was highly rated by patients (72.05) but much lower by HCPs (33.81). Additionally, pain and lesions in functional areas were noted as major components by both groups. In social aspects, leisure and recreational activities were rated higher by patients (21.89) than by HCPs (6.10). Similarly, satisfaction with information received and medical care was valued more by patients than by professionals.

DISCUSSION

The definition of well-being in psoriasis has been previously described as an initial part of the Inpsight project, highlighting the main components to be addressed [20]. Continuing the previous work carried out and placing this study within the framework of the Inpsight project, this analysis aims to assess the importance of each component, exploring differences in perspectives between patients and HCPs. To the best of our knowledge, this represents the first attempt to evaluate the relative importance of these components from the perspective of both patients and HCPs.

Physical and emotional dimensions emerged as the most relevant for patients and professionals, with the social dimension being the least relevant. However, their relative importance varied: patients prioritized the physical dimension, while professionals emphasized the emotional factors.

This difference highlights a gap in perception between patients and HCPs. Although patients

Table 1 Best-worst scaling questionnaire results classified with its dimensions

Dimension	Components	Patients (<i>n</i> = 152)*	Professionals (<i>n</i> = 87)*
Physical	Pain/discomfort	100.00	69.39
	Itch	72.05	33.81
	Lesions in functional areas	69.09	49.34
	Sleep quality	51.64	17.07 [#]
	Lesions in visible areas	45.35	29.70
	Extracutaneous manifestations	46.23	27.51
	Sex life	36.22	24.06
Social	Support of family/friends	33.07	20.72
	Social relationships	31.01 [#]	20.29
	Academic/work life	20.87 [#]	11.05 [#]
	Leisure/recreational activities	21.89 [#]	6.10 [#]
Emotional	Stress	98.74	14.34 [#]
	Mood disorders	65.57	100.00
	Self-esteem	60.42	49.24
	Coping/resilience	36.74	24.12
	Body image	28.94 [#]	27.51
	Stigmatization/shame	22.25 [#]	45.22
Satisfaction with disease management	Treatment satisfaction	92.21	33.60
	Satisfaction with information received	43.01	9.07 [#]
	Satisfaction with medical care received	58.50	23.57

Bold numbers with gray shading: five most important for each group; [#]five least important for each group; *2 data lost: patient (*n* = 1) and professional (*n* = 1)

generally expressed satisfaction with their treatment, they highlighted factors relevant to their experience that professionals may undervalue. The difference in perceptions encountered in this study may be partly due to the easier recognition of physical symptoms, like pain and itching, by the patients. However, emotional issues like depression or stigmatization are harder to identify, even though they may impact patients' well-being. This misalignment warrants further examination, as it could hinder efforts to address the factors that most significantly impact patient well-being [27]. Moreover, these results suggest

that HCPs, at least in this study, appear to be more aware of the emotional impact of psoriasis than what is commonly reported in previous studies that also recognized this awareness in the case of the patients [28, 29]. This may reflect, at least in Spain, that HCPs are recognizing the emotional burden more than before. However, this may not be the case globally, and further research is needed to assess whether this shift is occurring universally or if it is specific to certain regions or healthcare system.

The physical burden of psoriasis plays a central role in patients' lives, as evidenced by

concerns about pain, discomfort, itching, and lesions in functional areas. These factors directly impair QoL and have been consistently associated with worse outcomes in previous studies [5, 20]. Patients indicated that they are most concerned about pain/discomfort, itching, and lesions in functional areas. Pain, discomfort, and itching have a direct negative impact on patients with psoriasis, being associated with poorer QoL [30–32]. Skin lesions, especially in visible or functional areas, have been identified as debilitating factors that generate a tremendous burden on patients with psoriasis [33]. These components can affect patients not only physically but also emotionally and socially, as their burden can affect different dimensions. They may also be associated with an increase in stress [34], as well as various psychiatric disorders such as depression [35], anxiety [36, 37], and sleep disorders [37], as previously reported by other authors.

The fact that patients are more impacted by these physical components, and that their perspective differs from HCPs, who focus primarily on the emotional dimension, may explain their importance for people with psoriasis. As patients, they see physical impairments as potential barriers to everyday life, affecting their mental health and well-being [36, 38]. In this context, different studies have highlighted the fact that skin lesions are an important source of stigmatization for patients, leading them to cover them up to avoid distress [39, 40]. Another study found that depressive symptoms increased as the QoL of patients with psoriasis became poorer [41], suggesting that patients may consider the idea that better physical health might improve their emotional and psychological dimensions. Physicians, however, recognize the long-term psychological burden of psoriasis, including stigma, anxiety, and depression, viewing emotional well-being as pivotal to overall QoL [38, 42, 43]. This difference highlights the need for a holistic approach that aligns patient and physician priorities in psoriasis management.

Self-esteem, mood disorders, and stigmatization/shame were the emotional components considered more critical by HCPs. These components could be directly associated

with physical impairments, contributing to increased disease burden. Different studies suggest that the severity of psoriasis, related to the visibility of severe lesions, low self-perception, and other psychopathologies, is associated with lower self-esteem [6, 44, 45]. The impact of these factors and low self-esteem in patients can also undoubtedly cause them to experience stigmatization and shame, also expected consequences of psoriasis [46, 47], further contributing to a decline in their QoL. As previously mentioned, several studies have shown the risks of having mood and psychiatric disorders for patients with psoriasis [35, 36, 43], affecting their psychological and emotional state, despite efforts to downplay them and the complications of psoriasis [42, 48]. The physical effects resulting from the patients' emotional state could be vital in understanding the outcomes reported by HCPs in this study. Assessing the emotional dimension could generate uncertainty among physicians, as they can quickly examine physical conditions, encountering more difficulties in evaluating the emotional components and prioritizing them over others. A more comprehensive approach from HCPs through improved specialized training and the ability to identify, understand, and provide patients with more emotional support could narrow this gap between patients and HCPs.

This study has some limitations. Despite the significant number of participants, all of them were required to have participated in the previous phase of the *Inpsight* project and to be members of the *Acción Psoriasis* group, preventing new participants from joining the study and limiting the range of answers.

The study was conducted in Spain, providing a comprehensive view of the Spanish cultural context, although variations might have arisen if the surveys had been conducted globally. Nevertheless, the responses obtained are likely to be similar, as no major differences would be expected.

CONCLUSIONS

The present study reflects the differing perspective of patients and HCPs regarding the components that are relevant to the well-being of patients with psoriasis. Patients identify the physical dimension as critical to their well-being, as it can have a serious impact on their emotional dimension, while HCPs consider the emotional dimension as more important than others, perhaps because they can easily identify physical impairments. Additionally, patients may feel that HCPs do not fully understand the impact of the condition on their QoL and well-being, or their dissatisfaction with current treatments. The cumulative effects of psoriasis on patients also must be considered. Future research into this area should be undertaken to assess its progressive impact on the life and well-being of patients with psoriasis.

ACKNOWLEDGEMENTS

This study was endorsed by the Academia Española de Dermatología y Venereología (AEDV), Sociedad Española de Farmacia Hospitalaria (SEFH) and patient advocacy group *Acción Psoriasis*. The Spanish version of the DLQI questionnaire was carried out by Adolfo G de Tiedra et al.[49]. This publication authorizes AEDV and the Institute of Public Health to use, reproduce, and distribute the Spanish version of the DLQI questionnaire in all Spanish-speaking countries.

Medical Writing, Editorial, and Other Assistance. Medical Writing assistance was provided by Álvaro González Bris, PhD, employee of Outcomes'10. Outcomes'10 was contracted by Almirall SA to support the development and dissemination of the project.

Authorship. All authors meet the International Committee of Medical Journal Editors (ICMJE) criteria for authorship for this article, had full access to all the data in this study, take responsibility for the integrity of data and accuracy of the data analysis, and

have given their approval for this version to be published.

Author Contributions. Esteban Daudén, Isabel Belinchón, Elena Colominas-González, Pablo Coto, Pablo de la Cueva, Fernando Gallardo, Jose Luis Poveda, Esther Ramírez, Sandra Ros, Ricardo Ruíz-Villaverde, Isabel Cabezas and Luis Lizán contributed to the study conceptualization and design, and to the review and approval of the final manuscript.

Funding. The project was funded by Almirall SA. The sponsor was not involved in the study design, collection, analysis, or interpretation of data, the writing of this article, or the decision to submit it for publication. Rapid Service Fees were funded by Outcomes'10, contracted by Almirall SA to support the development and dissemination of the project.

Data Availability. All data generated or analyzed during this study are included in this published article as supplementary information files.

Declarations

Conflict of Interest. Esteban Daudén has served as advisory board member and consultant, and reports grants, research support, participation in clinical trials and honorarium for speaking, for AbbVie, Abbott, Almirall, Amgen-Celgene, Johnson & Johnson/Janssen-Cilag, Leo-Pharma, Novartis, Pfizer, MSD-Schering-Plough, Lilly, UCB, Bristol-Myers and Boehringer-Ingelheim. Isabel Belinchón has received fees as a consultant and/or speaker and has participated in clinical trials sponsored by the following pharmaceutical companies whose therapeutic arsenal includes drugs used to treat psoriasis: Janssen Pharmaceuticals Inc, Almirall, Lilly, AbbVie, Novartis, Celgene, Biogen, Amgen, Leo-Pharma, Pfizer-Wyeth, BMS, UCB, and MSD-Schering-Plough. Pablo Coto has served as speaker and consultant, and has participated in educational and scientific projects or clinical trials for AbbVie, Amgen, Almirall, Incyte, Leo-Pharma, UCB, and Sanofi. Pablo de la Cueva

has served as a consultant, speaker and investigator for AbbVie, Almirall, BMS, Boehringer-Ingelheim, Celgene, Johnson & Johnson, LEO Pharma, Lilly, MSD, Novartis, Pfizer, Roche, Sanofi, and UCB. Isabel Cabezas and Luis Lizán work for an independent research entity (Outcomes'10) that received funding from Almirall to coordinate and conduct the project. Elena Colominas-González, Fernando Gallardo, Jose Luis Poveda, Esther Ramírez, Sandra Ros, and Ricardo Ruíz-Villaverde have nothing to disclose.

Ethical Approval. Ethical approval for this study was obtained from the Clinical Research Ethics Committee (CREC) of Hospital La Princesa (Madrid) (Reference number: LIB 14/2007) and complied with the Helsinki Declaration of 1975, as revised in 1983. All patients and HCP's provided informed consent for this study.

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