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REVIEW ARTICLE

Implementing well-being in the management of psoriasis: An expert recommendation

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Abstract

Psoriasis causes detriment in a person's physical, mental and social health which impairs their quality of life (QoL). However, the current psoriasis management may not adequately address all relevant health domains. Since the goal of healthcare is to restore or maintain health, health outcomes should include all areas of the patient's overall health. Life satisfaction, QoL and patient well-being are essential to a comprehensive approach to the disease. With the inclusion of more people-centred policies, care of patients with psoriasis should evolve towards a holistic and integrated assessment of the disease impact, including subjective measures of well-being in order to encompass all aspects of health. The main objective of this expert review is to give the concept of well-being a place as an entity within the holistic therapeutic approach for patients with psoriasis. Identifying and defining common goals beyond the skin with the patient and testing them throughout the course of treatment will benefit and enhance treatment success. We propose a series of recommendations for application in clinical practice, providing tangible clinical guidance for implementing well-being in the management of psoriasis. Among the recommendations are the need to initially listen to the patient, to know their level of empowerment or what they want to achieve, their preferences in decision making, the evaluation of not only the physical but also the emotional impact of the disease (well-being), the definition of the aspects that can generate a cumulative deterioration of the disease throughout life, and a continuous assessment of the patient's preferences with the opinion of the expert clinician and the integration of the knowledge of external clinical evidence.

INTRODUCTION

Psoriasis is a chronic immune-mediated inflammatory skin disease associated with other major medical conditions.[1] It consists of red, scaly lesions on the skin surface (plaques) that usually appear on the elbows, knees, scalp and lower back.[2] The prevalence of psoriasis varies worldwide depending on geographic location, from 0.14%[3]–0.17%[4] (East Asia) to 1.99% (Australasia)[3]–2.5% (Western Europe).[4] It has a global impact on all parties involved in its management, significantly affecting the lives of patients[5,6] and their relatives.[7,8] Healthcare professionals (dermatologists, nurses, psychologists, pharmacists, dieticians, etc.) are also affected, as clinical approaches to the disease are often restricted and generate frustration, discomfort and a sense of limited manoeuvrability for the medical professional.[9]

Patients' health-related quality of life (QoL) is not only adversely affected by physical symptoms, such as changes in physical appearance, itching and pain, but also by psychosocial factors. Up to one out of five patients are diagnosed and treated for depression associated with the inflammatory signature of psoriasis.[10] There is a major impact on social life, disrupting interpersonal relationships and resulting in feelings of alienation and social rejection. People affected by psoriasis also perceive a great psychological burden, facing psychiatric comorbidities such as anxiety and depression.[11,12] All the physical, psychological, social and economic facets that accumulate in psoriasis impair patients' well-being. This negative impact extends to external domains (i.e. social and family interactions, work absenteeism and lost productivity, and healthcare system costs)[13–15] that can accumulate over time. Because psoriasis is a lifelong disease with considerable comorbidity, it can induce sustained overall burden and Cumulative Life Course Impairment (CLCI).[16]

To adequately address the multifaceted impairments associated with skin diseases such as psoriasis, a holistic, people-centred perspective is needed. In its 2014 resolution, the World Health Assembly (WHA) stressed the importance of a comprehensive approach to healthcare for patients with psoriasis.[17] This includes recognition of psoriasis as a serious non-communicable disease and acknowledgement that many people around the world suffer unnecessarily from psoriasis due to incorrect or delayed diagnosis, inadequate treatment options and insufficient access to care. Following this resolution, the World Health Organization (WHO) published the Global Report on Psoriasis 2016, which proposes a general strategy on integrated and people-centred health services, adding the social environment of the individual patient to the disease management.[15] This paradigm implies a model of people-centred healthcare (PCHC) and integrated health services, in accordance with the ultimate healthcare goal of restoring patients' well-being and health.[18] In an attempt to provide a comprehensive and personalized care plan to improve patient disease management, 'people-centredness approaches' are increasingly gaining prominence in policy, research and general healthcare practice,[19–23] (and particularly in dermatology)[24–26] reflected in practice in different national initiatives.[27–30] However, initiatives such as the Global Psoriasis Atlas have demonstrated a wide variation in the approach to healthcare of patients with psoriasis, with different stakeholders, decision-making and pharmacological approaches globally.[4]

Therefore, the main objective of this expert review is to provide guidance on the concept of well-being as an entity within the holistic management of patients with psoriasis. We propose a series of practical recommendations, which include well-being focused on the patient's own needs and which are intended to apply to any patient with psoriasis.

Our recommendations are addressed to practising dermatologists, but it should be emphasized that psoriasis management encompasses a multidisciplinary team that includes other medical specialists, nurses, psychologists and social workers who also contribute to increasing patients' health-related QoL and well-being.

METHODOLOGY

This project consisted of a structured expert consensus following an extensive literature search on the topic of well-being in dermatological care. The starting point was a moderated expert workshop including dermatologists, psychologists, health researchers and dermatology nurses from several European countries. The groups identified the theory and issues related to well-being in dermatology. Consensus was reached on the need to better understand this topic. Subsequently, a literature search was conducted in Pubmed based on the search terms that were defined in the expert group ('biologics, dermatology, Dermatology Life Quality Index (DLQI), happiness, health, healthcare, management, Psoriasis Area and Severity Index (PASI), patient-centred care, people-centred care, person-centred care, psoriasis, QoL, shared decision-making, well-being'). The results of the literature were subjected to a group discussion and key conclusions were drawn. These key conclusions were translated into recommendations for clinicians based on the experts' experiences and choices. Decision processes were based on consensus.

RESULTS

Literature search

The literature search was conducted in August 2021 and updated in January 2022. The search terms (a) 'wellbeing/well-being/happiness…', (b) 'dermatology/skin diseases…' and (c) 'treatment/biologics…' revealed an intersection of $n = 1978$ hits which of $n = 122$ were considered relevant by two independent reviewers (MA, RS). The final selection

presented to the group consisted of $n=45$ publications. These publications were submitted to all co-authors for review and discussion. In total, three online rounds and one face-to-face meeting were performed. The extraction of items for the manuscript resulted in nine domains which by the group were condensed to nine themes in the first consensus process and five themes plus a conclusive part in the final agreement.

Expert consensus

The following results were obtained from the bibliographic search and the consecutive consensus of experts:

Unmet needs at the time of biological treatments: Does skin clearing automatically ensure 'well-being'?

The broad spectrum of patients' treatment needs goes beyond skin clearance and includes different goals such as reducing psychological, social or physical impact, impairments due to therapy and increasing confidence in therapy.[31–36]

Although some clinical trials with modern biologic agents in psoriasis offer promising long-term efficacy,[37,38] can we be sure that the impact of skin clearance on patient well-being is similar to that predicted by PASI? Changes in PASI do not necessarily translate into improved patient QoL and well-being,[39] and the relationship between disease severity (PASI) and impact on QoL-DLQI is weak.[39–42] Furthermore, despite new biologic drugs achieving PASI 90 and even PASI 100, which is equivalent to a 90% or 100% reduction from baseline PASI, respectively, there may not be a clinically meaningful difference in QoL and patient benefit between achieving different relative PASI responses.[39,43]

Patient satisfaction with treatment has gained special interest since the emergence of new biologic treatments.[44] However, even with the advent of biologics, psoriasis has a significant residual impact on mental health,[45] and subsequently on happiness (the latter involving positive emotions and life satisfaction).[46–50] According to the 2018 World Psoriasis Happiness Report,[51] almost 50% of patients feel that their healthcare professional does not understand the impact of the disease on mental health. Subjective happiness emerges as a key factor in this balance.[40]

Considering there is a discrepancy between the objective tools commonly used to assess treatment success and patient-reported outcomes (PROs),[40] it is essential to clarify the needs of each patient to guarantee a complete well-being beyond the mere PASI improvement through medical treatments, since a biologic or other medicine may not be sufficient to ensure a complete well-being according to the patient's perspective.

Which is the definition of 'well-being in healthcare'?

The WHO defines health as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'.[52,53] In general, the concept of well-being is considered a multidimensional notion.[54] Some definitions in the literature imply a multifaceted holistic orientation of well-being, which includes interdependent dimensions (i.e. body, mind, social, spiritual,[55] vital recovery,[56] economic or life satisfaction).[57] Schuster et al.[46] include positive affect as part of emotional well-being and life satisfaction. van Ee et al.[58] defined 'freedom from disease' in psoriasis as a multicomponent concept, which includes QoL and well-being, clinical symptom control, psychosocial elements, treatment and healthcare team support.

Professionals should focus on 'what we want to achieve (patient well-being) rather than what we want to avoid (disease burden)'. Although well-being has been measured in research using many scales,[59] they may not capture the complexity of the concept.[60] The WHO developed a generic measure of current general mental well-being, the WHO-Five Well-being Index (WHO-5).[61] This measure has been recommended as the ultimate patient-related measure within the WHO international classification system for chronic diseases.[62] The applicability of the WHO-5 has recently been tested in a psoriasis sample, showing good psychometric properties.[63]

Subjective well-being as a result of psoriasis treatment from the patient's perspective, in addition to disease clearance, has rarely been measured in dermatology; however, it is necessary to fully understand the impact of psoriasis.[58,64]

Shortcomings of current standard measures of QoL in psoriasis

The clinical assessment of disease severity in patients with psoriasis has increasingly been combined with several patient-reported QoL instruments, including generic, dermatology-specific and psoriasis-specific indices.[65]

The DLQI[66] is one of the most widely used indices to assess the impact on QoL of psoriasis and/or its treatment. However, it has some biases, such as item inadequacy, differential item functioning by disease, age and sex, disordered response thresholds and inadequate measurement of patients with mild disease,[67] which underestimates emotional problems, psychological well-being and overall burden in people with psoriasis.[68,69] The DLQI does not fully capture the impact of disease, not just for psoriasis.[70] The index shows a failure to include both patient and clinician perspectives and requirements. Many DLQI items do not capture aspects of well-being, but focus on disease burden. Other psoriasis-specific QoL PROs,[71–75] some of which

are widely used,[76] may suffer from similar disadvantages and, if used, end up doing so in conjunction with other measures.

Therefore, current instruments for measuring QoL in psoriasis fall short in assessing psoriasis as a whole, underestimating patients' real needs for a comprehensive understanding of their health and well-being. It has been shown, for example, that adding happiness to the clinical assessment in addition to the DLQI contributes to a more global analysis of well-being.[77]

Paradigm shift: Importance of assessing well-being in the clinical management of psoriasis

The WHO has published relevant studies and a global policy framework that addresses the vision of PCHC[78] with an indicative list of evidence-based policy measures that can be used to put people at the centre of healthcare. The first step is to understand how the disease affects patients in all dimensions of their lives.[79] Thus, by redefining health in terms of people-relevant goals, healthcare could focus more directly on meaningful, not always disease-directed, outcomes.[80] A recent real-world survey including both expert and patient opinion on the impact of psoriasis on their well-being[81] reported that approximately 40% of patients felt that their dermatologist did not consider their well-being and that their current treatment was inadequate to improve their signs and symptoms. Patients placed equal importance on the three main areas associated with well-being (i.e. physical, mental and social) (mean scores of 4 on a 0–6 point scale). However, what patients want from their treatment and their perception of the disease are not aligned.[81] In this sense, one must consider the need for a multidisciplinary team that encompasses several disciplines, apart from the specialist dermatologist.

There are examples of national programmes that postulate that patients are jointly responsible for their health and, consequently, for their well-being, but physicians should also support patients' self-responsibility.[82–86] Although the 'people-centredness' approach has become particularly relevant in healthcare,[21,22] from the perspective of patients with psoriasis there are many unmet needs.[87]

Overall, a comprehensive people-centred approach using well-being as a primary goal in psoriasis can complement current standard outcomes, which do not fully reflect the impact of this disease on patients' lives, since: (a) total clearance of the skin disease does not necessarily represent complete well-being; (b) half of psoriasis patients do not feel understood by the medical professional as to the actual mental impact of the disease[51]; (c) well-being involves personal psychological, emotional and personality dimensions beyond curing the disease[88]; and (d) current outcome measures have many limitations and do not adequately capture patients' needs and priorities[89] (Figure 1).

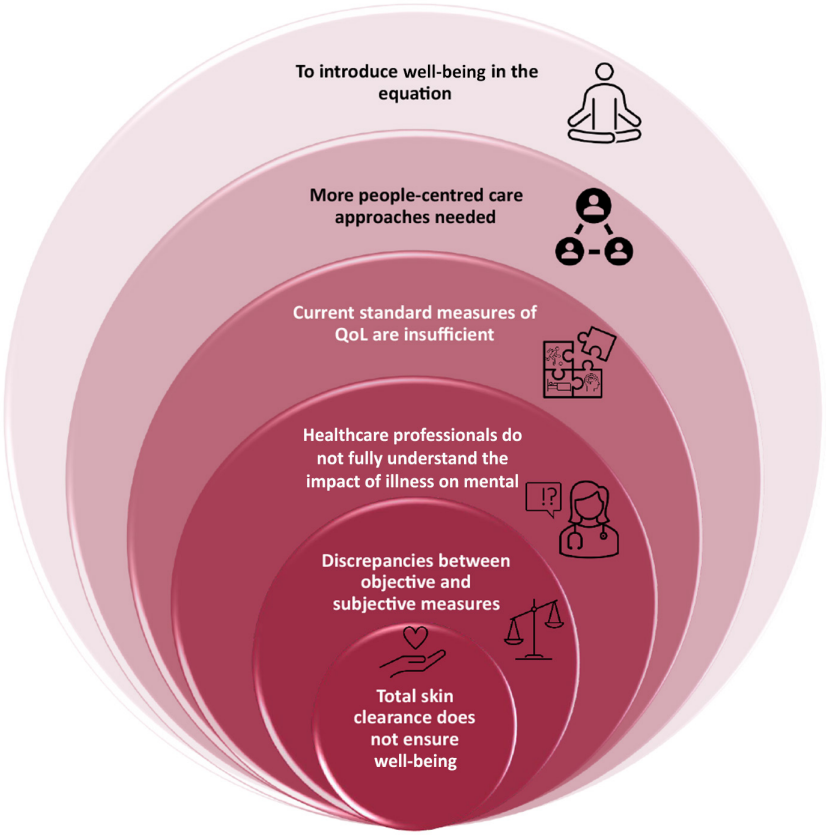

FIGURE 1 Determining factors in the comprehensive assessment of the patient with psoriasis. QoL, quality of life.

With the above in mind, an expert recommendation for implementing PCHC and well-being as an overarching treatment goal in routine psoriasis clinical practice is provided.

Implementing people-centred care and well-being as an overall treatment goal in psoriasis: An expert's recommendation

In order to implement the PCHC approach in practice, several activities are necessary. Firstly, favouring individual patient-physician (or other healthcare professionals) communication and shared decision-making (SDM).[90] Some healthcare professionals believe that it is necessary to improve their competencies to offer support in changing lifestyle habits and the possibility of providing patients with more specific strategies.[9] They face a dilemma between the lack of adequate skills and professional duty, which also generates discomfort for them.[9] In this regard, clinical collaboration in a multidisciplinary team involving not only dermatologists but also other professionals (e.g. nurses, psychologists and social workers) is increasingly emerging as a necessity in the PCHC approach covering all the needs of patients with psoriasis. Other success criteria are variables related to the patient's clinical treatment outcome,[91,92] which do not match the needs and challenges of the individual.[93]

Models of patient centricity have demonstrated that SDM and assessment of patient treatment needs, preferences and benefits are essential actions. Examples would be the use of high-quality decision aids, the existence of health service research on the effectiveness and implementation of PCHC, the increase in health knowledge and engagement skills[94] of all those involved in the treatment of patients with psoriasis (themselves, physicians and family members), and finally, the assessment of well-being and similar outcomes to evaluate the benefit of treatment from all points of view, as first done in the ongoing POSITIVE study in psoriasis.[95] Patient-oriented communication in medical practice plays a central role in strengthening PCHC.[96] To achieve this patient-oriented attitude, training should begin in medical school and continue thereafter.

In addition to achieving patient well-being through a people-centred approach in terms of patient-oriented communication and participation, it should also be measured as a direct treatment outcome. In a recent qualitative study, people with psoriasis rated well-being as a relevant treatment outcome, if not the most important one.[97]

In this context, Figure 2 lists key points for clinicians to adapt to the challenges associated with the implementation of this people-centred approach in practice. These recommendations would also apply to other inflammatory skin diseases, such as atopic dermatitis. Both clinicians and patients will benefit from this approach to disease management, maximizing the potential of treatment to achieve the values the patient ascribes to therapy. The patient will be more satisfied by participating in the decision-making process, feeling more understood by the professional, and the clinician will not have the ultimate responsibility to seek a treatment that should achieve the patient's well-being without knowing the patient's needs.

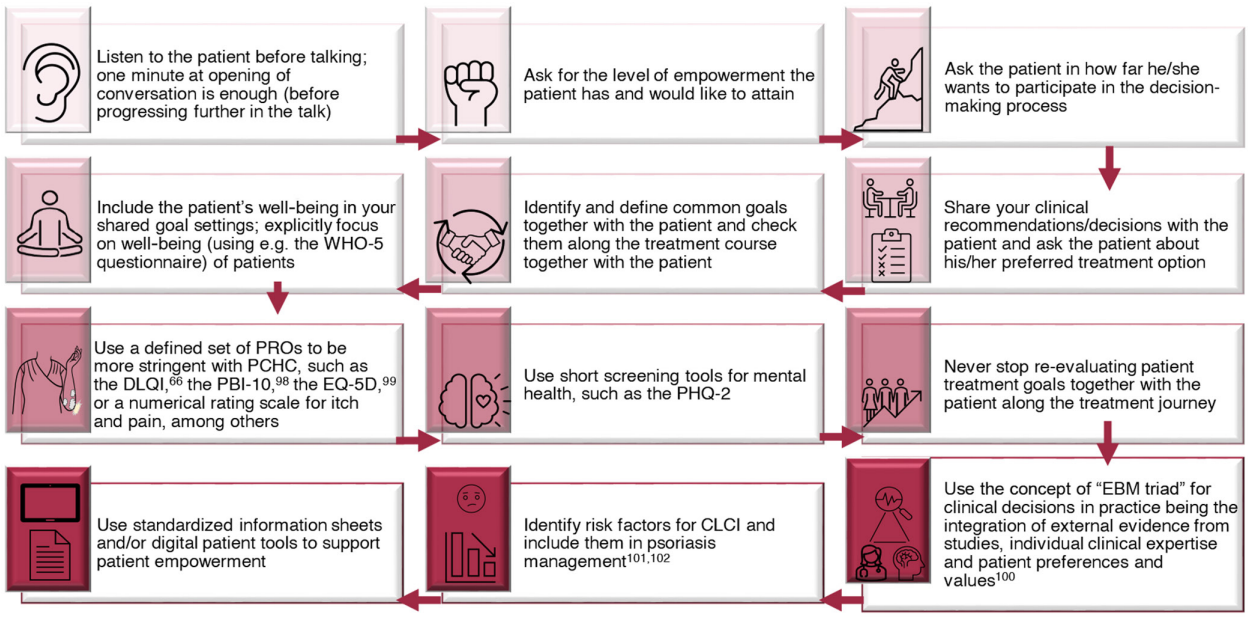

FIGURE 2 Key recommendations for implementing a people-centred approach to psoriasis treatment practice.[66,98–102] CLCI, Cumulative Life Course Impairment; DLQI, Dermatology Life Quality Index; EBM, evidenced-based medicine; EQ-5D, EuroQoL 5 Dimensions; PBI-10, Patient Benefit Index-10; PCHC, people-centred healthcare; PHQ-2, Patient Health Questionnaire-2; PRO, patient-reported outcome; WHO-5, WHO-Five Well-being Index.

CONCLUSIONS

Advanced healthcare in dermatology today requires an extended perspective related to the WHO concept of PCHC. People-centred healthcare is a healthcare approach that places the patient at the centre of care delivery. This means that healthcare providers must understand the patient's needs, preferences and values.

An important facet of PCHC is understanding the goals of healthcare, the ultimate goal of which is the patient's well-being. In routine care, there are several means of measuring well-being in a valid way. Several studies have shown positive associations of patient centricity with satisfaction, well-being, adherence, health behaviour, disease knowledge and recovery rate. These optimized outcomes may encourage dermatologists to apply this person-centred care in practice, including SDM and measurement of well-being.

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DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.

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