How to improve people-centred healthcare in dermatology?

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Conference
6th IFPA-WPPAC 2021

Keywords
patient-reported outcomes measures, shared decision making, wellbeing, people-centred health care, value-based care

Abstract

People with chronic skin diseases, such as psoriasis, experience multifaceted impairments that include physical symptoms, such as pain, psychological symptoms, such as anxiety, and social impairments, such as stigmatisation. To address this broad spectrum of impairments, a holistic healthcare approach is needed. The World Health Organization has established the people-centred model of care, in which health services adopt the perspective of people affected and their environment. The needs of patients are respected, and patients are put at the centre of care.

This model was also adopted by the global report on psoriasis, which aims to improve the wellbeing of the affected people. This paper gives a brief overview of the status quo and an outline of how to improve people-centred care and patient orientation in dermatology, specifically for people with psoriasis. This includes the application of shared decision-making. Although only a few patient decision aids for psoriasis have been published, promising results regarding the reimbursement of shared decision-making applications in the hospital setting by health insurances are available, which also refer to dermatology departments.

In addition, the use of patient-reported outcomes is of great importance to give patients a voice in their own healthcare. In accordance with the people-centred model, it is recommended to not only assess patients’ perspectives, such as their needs, goals, and treatment benefits, but also the needs and treatment benefits of the patients’ environment, such as their partner and treating healthcare professionals.

One recent example of such a people-centred approach is the POSITIVE-study, which is the first study assessing the treatment effect on the wellbeing of patients with psoriasis. Moreover, the treatment benefit on physicians’ satisfaction and patients’ partners’ lives is being evaluated. Therefore, it could act as a best practice example of how to integrate a people-centred approach in research.
BACKGROUND

Psoriasis is a chronic inflammatory skin disease characterised by extensive redness and thick scales on the skin, usually accompanied by a painful and itchy skin, leading to a high level of suffering and a decades to life-long course impairment. Its prevalence varies in different geographic areas from 0.14% to 2.5% [1]. Relevant cardiovascular and metabolic comorbidities have been shown in adults [2] and children [3]. The quality of life of patients is not only negatively affected by the physical symptoms and comorbidities of psoriasis but also by psychosocial factors. A study among dermatological outpatients in 13 European countries reported the presence of clinical depression in 10.1%, clinical anxiety in 17.2%, and suicidal ideation in 12.7% of all patients [4]. Studies have shown a considerable psychosocial effect with a major impact on social life, altering interpersonal relationships and feelings of stigmatisation, as well as impairments in sexuality [5]. In addition to physical and social consequences, affected people perceive a high psychological burden and have to deal with psychiatric comorbidities [6]. There is extensive research demonstrating high levels of external and self-stigmatisation [7, 8] and a higher risk of having body dysmorphic disorder symptoms [9]. Moreover, patients are significantly more likely to consider, attempt, and complete suicide [10]. These multifaceted impairments interact and may lead to cumulative long-term burden in the course of life, with non-reversible damage [11]. Cumulative life course impairment (CLCI) is a theoretical construct referring to persisting disease burden over time leading to non-reversible damage in the worst case. In a recent systematic literature review, risk factors for the development of CLCI were assessed [12]. Subsequently, measurement tools were developed to identify patients at risk for CLCI in routine care [13]. These new tools are currently undergoing psychometric validation. Their use in clinical practice and research may facilitate identifying patients at risk for CLCI, thus support preventing people affected from non-reversible damage in their disease course.

VALUE-BASED HEALTHCARE IN PSORIASIS

Value-based medicine is an approach to healthcare that prioritises the delivery of high-quality care that is aligned with patient values and preferences while minimising unnecessary costs. This approach focuses on achieving the best possible outcomes
for patients and ensuring that the resources used to provide care are used in the most effective way possible. It takes the patient's perspective and their individual preferences into account, as well as the best available evidence and clinical expertise. Value-based medicine emphasises the importance of measuring outcomes that matter most to patients and incorporating these measures into clinical decision-making. Ultimately, value-based medicine aims to improve patient outcomes and the overall quality of care while ensuring that resources are used efficiently and effectively. Considering the example of psoriasis, this means that to evaluate healthcare interventions, it is important to consider both input and output. However, in the case of psoriasis treatment, the output is not limited to just the percentage of drugs taken. More information is needed beyond just determining if the intervention has been completed. It is also essential to verify if the intended treatment goal has been achieved, such as a percentage reduction like PASI90 in psoriasis. Furthermore, it is of great importance to assess what is meaningful for the patient. The question "what is meaningful?" subsequently leads to what is called "value." Value refers to the importance of outcomes from the patient's perspective, such as gained wellbeing and achieved patient goals. Large-scale studies have shown that people with psoriasis can have a wide variety of relevant treatment goals. [2, 20]. It is notable that patient reported outcomes (PROs) translate the outcomes of our treatment decisions into values (figure 1).

![Figure 1. Concept of values in medicine](image)

Figure 1. Concept of values in medicine

Remarkably, evidence-based medicine (EBM), which is considered the core element of medical healthcare, has expanded its self-definition from being simply a combination of clinical experience and the best external evidence to include a third component: patient values [21, 22]. The current EBM concept, therefore, includes all three elements, forming what is called the EBM triad: the best external evidence, individual clinical expertise, and patient values and expectations. As a result, value-based care has become extremely important in healthcare from the perspective of evidence-based medicine, demonstrating that shared decision-making (SDM) is an essential dimension of EBM. [23] (figure 2).

![Figure 2. Concept of evidence-based medicine](image)

Figure 2. Concept of evidence-based medicine


PEOPLE-CENTRED HEALTHCARE IN PSORIASIS

This concept has been up taken in the global report on psoriasis by the WHO [14] and in the European White Paper for psoriasis [25] and psoriatic arthritis [24]. The people-centered health care approach from the WHO is an approach to healthcare that focuses on the needs and preferences of individuals and communities. This approach
recognises that healthcare is not just about treating diseases or conditions, but also about addressing the broader physical, social, and emotional needs of patients. The WHO’s people-centered approach to healthcare emphasises the importance of ensuring that health services are accessible, affordable, and of high quality. It also emphasises the importance of involving patients in their own care, as well as their families and communities.

Key principles of the people-centered approach include:

1. Respect for the dignity and autonomy of individuals and communities.
2. Recognition of the importance of social and environmental factors in health and wellbeing.
3. Empowerment of individuals and communities to participate in their own care and decision-making.
4. Collaboration and partnership between healthcare providers, patients, families, and communities.
5. Equity and fairness in the distribution of healthcare resources and services.

The people-centered health care approach from the WHO is a way to ensure that healthcare is patient-focused and responsive to the needs of individuals and communities. It is an important step towards achieving better health outcomes for all [15].

**Shared decision-making in psoriasis management**

Shared decision making (SDM) is an important dimension of patient orientation in healthcare. It is a process that involves healthcare providers and patients to work together to make informed decisions about healthcare options, based on the best available evidence and the patient’s preferences, values, and goals. The shared decision-making (SDM) model was defined in contrast to the paternalistic model, in which the clinician decides on treatment without patient involvement, and the informed model, in which clinicians provide information and the patient is the sole decision-maker [26]. In SDM, patients are considered experts in their illness and clinicians are considered experts in management of disease, allowing for an egalitarian partnership that supports patient autonomy. SDM is based on the idea that patients have the right to be fully informed about their healthcare options, and to be involved in making decisions about their care. It recognises that healthcare decisions can be complex and involve a range of options with different risks and benefits, and that patients may have different priorities and preferences that need to be taken into account. SDM involves a structured conversation between the healthcare provider and the patient, in which the options, risks, benefits, and uncertainties of different therapies or management options are discussed. The patient is encouraged to ask questions, express their preferences and concerns, and work with the healthcare provider to make a decision that is right for them. SDM has been shown to improve patient satisfaction, increase adherence to treatment plans, and lead to better health outcomes. It is particularly important for patients with chronic conditions, such as psoriasis, who may need to make ongoing decisions about their care over time. Overall, SDM is an important dimension of patient orientation in healthcare, as it helps to ensure that patients are involved in decisions about their care, and that those decisions are based on their individual needs and preferences.

Regarding psoriasis and psoriatic arthritis, there is a huge number of systemic drugs available for use in healthcare at the moment. For example, if dermatologists want to prescribe a systemic drug for psoriasis in Germany, there are more than 20 different choices of active substances. All together, including psoriatic arthritis, more than 30 single drugs are available that dermatologists need to consider and discuss with the patient to make the
best personalised treatment choice. Therefore, the next few years with such a large plurality of treatment options in psoriasis will be about choices and values, making shared decision-making crucial.

To facilitate SDM for physicians and patients, patient decision aids provide detailed, balanced, and evidence-based information about varying treatment options. These aids can be used before, during, or after a patient visit. However, a recent literature review found only five publications introducing SDM tools specifically for dermatologic conditions. In total, four of these tools referred to psoriasis. Time and a lack of training for clinicians were mentioned as barriers for implementation. However, all studies emphasised the value of SDM for both patients and physicians [27]. To address these barriers, it is important to train SDM skills from the early stages of medical education. There is encouraging progress in implementing SDM into the curricula of medical education [31]. In addition, there is promising progress regarding the reimbursement of applying SDM in the hospital setting by health insurances [32].

Besides the implementation of SDM in clinical practice, the use of PROs to assess patient preferences, values, goals, and treatment outcomes is an important step in order to improve patient orientation in psoriasis care. However, there are many PROs available, and they need to be selected carefully to assess topics that truly matter to patients and their lives, in accordance with a holistic, people-centered approach.

**Patient-reported outcomes measures in psoriasis**

Patient-reported outcomes (PROs) are an important dimension of patient orientation in healthcare. They provide a direct measure of the patient’s perception of their own health, quality of life, and treatment outcomes. PROs are collected through questionnaires or interviews that ask patients to report on their symptoms, physical functioning, emotional wellbeing, and overall quality of life. By incorporating PROs into clinical practice and research, healthcare providers can gain valuable insights into the patient’s experience of their illness and treatment. This information can help to identify areas of unmet need, inform treatment decisions, and improve communication and shared decision-making between the patient and healthcare provider. Moreover, PROs can be used to evaluate the effectiveness of healthcare interventions and to compare the outcomes of different treatments or healthcare providers. This can help to identify best practices and improve the overall quality of healthcare. In summary, PROs are a key component of patient-centred care and can play a vital role in improving the health outcomes and quality of life of patients.

Figure 3 provides a brief overview of the most commonly used clinician-observed outcomes, such as the Psoriasis Area and Severity Index (PASI) [28], which measures disease severity in psoriasis, and patient-reported outcome measures, such as the Dermatology Quality of Life Index (DLQI) [29]. However, other instruments have also emerged, such as the Patient Benefit Index (PBI) for identifying patient needs and treatment benefits [30]. The PBI is available in several disease-specific versions, including psoriasis, and is often used in international practice for clinical and health services research.

There are many more generic, skin-specific, and disease-specific measurements that can be used in psoriasis. PROs can be divided into outcomes that assess clinical characteristics, such as the self-administered Psoriasis Area and Severity Index (SAPASI), functionality-related measurements, quality of life-related instruments, instruments that assess the impact on patients’ families (FamilyPso), symptoms (such as pain numeric rating scale), psychosocial impact, and the impact on economic issues such as work productivity. Given the wide range of choices, it is important to focus on selecting the most suitable outcome measures.
In order to select the most appropriate measurements, it is necessary to first clarify whether it is needed to measure both clinician-observed and patient-reported outcomes. This question is supported by data from routine care in Germany, which reveals a discrepancy between objective and subjective outcomes (see Figure 4). The X-axis displays the Psoriasis Area and Severity Index (PASI) score calculated by the physician, while the Y-axis displays the DLQI score derived from the patients. The data clearly show that there is no correlation between objective and subjective outcomes in the cross-section, which supports the conclusion that both should be measured as one cannot predict the other. However, over the course of treatment (as demonstrated by the red line in Figure 4), the deltas correlate, demonstrating that an improvement in PASI is correlated with an improvement in DLQI. This indicates that, to make sound clinical decisions, both clinician-observed and patient-reported outcomes should be measured.

Figure 4. Discrepancy between objective and subjective outcomes

Correlation between PASI and DLQI in real world care:

$r=0.39$ (not significant) $n=1,511$ ($r=$Spearman correlation coefficient)

Given the limitations of the DLQI, the question arises as to whether we can obtain value-based information on what matters to patients from such instruments. The DLQI is one of the most widely used PROs for assessing the impact of skin diseases, including psoriasis, on quality of life. However, it has certain biases, such as inadequate items, differential item functioning based on disease, age, and gender, disordered response thresholds, and inadequate measurement of patients with mild disease [33], which underestimate the emotional problems, psychological wellbeing, and overall burden experienced by people with psoriasis [34, 35]. Furthermore, a recent study investigated whether the DLQI is a sufficient indicator of wellbeing according to the WHO's holistic definition of health. The study concluded that the DLQI primarily measures physical impairment associated with negative emotions and, therefore, provides only a limited assessment of wellbeing [36].

Nevertheless, the DLQI is very easy to use in practice. However, it has some biases, such as item inadequacy. The question is how patient needs can be measured directly rather than translating this from the DLQI. The global report on psoriasis has provided guidance on how to measure those patient needs. Patient needs can be directly
assessed through standardised questions, using the PBI. It was shown that patients with psoriasis largely have several needs, the most frequent being "to get better skin quickly." Other important goals include "to be free of itching," "to experience a greater enjoyment of life," and "to feel less depressed" [37]. Remarkably, most of the goals cannot be measured by the PASI but need to be measured and asked from the patient directly. Thus, there is a large number of patient needs leading our way to the treatment of choice and then leading to value-based care if the goals have been achieved (see Figure 1). However, how can the achievement of the goals be measured? The answer is "goal attainment scaling," which means measuring the patient needs and goals before treatment and then re-evaluating after some period of treatment to determine whether these goals have been achieved by treatment.

But how can we promote positive outcomes thinking and people-centred care beyond goal orientation and patient benefit measurement? There is a second approach that relates to the WHO definition of health. According to the WHO, "health is a state of complete physical, mental, and social wellbeing" [38]. This demonstrates that wellbeing is an essential and powerful component of health. Wellbeing as a holistic outcome, in turn, comprises several dimensions, such as psychological wellbeing and life satisfaction [42].

The wellbeing of patients has rarely been measured in dermatology, even though the ultimate goal of disease management should be to live a healthy life. This highlights the need for a paradigm shift away from hard clinical measures towards a more holistic approach that encompasses overall wellbeing. Considering this, a recent study has shown that positive affect, as part of emotional wellbeing and life satisfaction, can complement the information provided by the DLQI, contributing to a comprehensive evaluation of wellbeing in accordance with the WHO's holistic definition of health [36]. Furthermore, the importance of wellbeing as a treatment outcome from the patient's perspective was recently assessed. Patients were asked to reflect on the importance of wellbeing as a treatment goal and on its importance compared with other treatment outcomes. All patients confirmed that changes in wellbeing reflected treatment benefit. Wellbeing was evaluated as a central aspect of treatment benefit by the majority of participants. In addition, positive associations of wellbeing with other outcomes that were considered relevant were reported [39]. However, only a few studies have assessed disease-related wellbeing in psoriasis so far [40, 41], and none of them were therapeutic studies. This presents a particular gap in the literature since the rising number of highly effective innovative drugs [43] increases the need for differentiated choices and shared decisions based on patient-relevant outcomes. Identifying drugs with a particular positive effect on wellbeing may be a useful decision aid. Therefore, to assess wellbeing in psoriasis in research and clinical practice, valid measurements need to be available. The WHO-5 questionnaire, an internationally recommended questionnaire on health-related wellbeing, was recently psychometrically validated in a psoriasis sample [44]. The WHO-5 showed excellent reliability, with Cronbach’s alpha for the WHO-5 total score at baseline and at the second measurement time point. Responsiveness was proven acceptable, demonstrating that the WHO-5 is ready for use in clinical practice in psoriasis to facilitate a holistic care in terms of treatment outcomes.

CONCLUSION

Summarising how people-centred care can be integrated into dermatological practice includes the following recommendations:

- The patient should be actively included in all steps of healthcare practice; this requires listening to the patient
- The perspective of patients through patient-reported outcomes measures should be assessed. Supporting the acquisition of patient-reported data by digital devices can
be of great help. This first series of information, including patient needs and therapy goals, is gathered in a structured way independently from the physician.

- After this, there should be direct interaction between the patient and physician (as well as other healthcare professionals, such as nurses and psychologists), allowing for a participatory and shared decision-making process.

Altogether, in line with the SDM model, patients should be considered experts in their illness, and clinicians should be considered experts in the management of the disease. There is a clear need for a paradigm shift away from hard clinical measures towards a more holistic way of considering patient wellbeing. Thus, measuring wellbeing can contribute to a more comprehensive understanding of health. In addition, wellbeing is bidirectional and includes the patient, physician (and other healthcare professionals, such as nurses and psychologists), and the patient’s environment, contributing to a people-centred healthcare environment.

One recent example of such a people-centred approach is the POSITIVE study, which is the first study assessing the effect of tildrakizumab on the wellbeing of patients with moderate to severe psoriasis. Moreover, the long-term benefit of tildrakizumab on patient wellbeing and patients’ partners’ lives will be evaluated [45]. For the first time, the WHO-5 will be used as a primary endpoint in patients with psoriasis to investigate the improvements that a systemic treatment can achieve on patients’ wellbeing in a real-world setting. This study will provide novel insights into the dimensions of patients’ perspectives and their overall state of wellbeing using a holistic patient-partner and physician-centred approach, ultimately helping to improve not only patients’ wellbeing but also the wellbeing of their environment. Thus, it could serve as a best practice example of how to integrate a people-centred approach in dermatological research.

REFERENCES


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