International Federation of Pharmaceutical



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Foreword

Psoriasis – time to act together to end the suffering

Psoriasis is a chronic, painful, disfiguring and disabling non-communicable disease for which there is no cure. It affects more than 125 million individuals across the globe, causing widespread suffering and putting an enormous psychosocial burden on those affected. Psoriatic arthritis is among the most disabling forms of arthritis known. Psoriasis also increases the risk of heart attacks and strokes. The associated economic costs lie heavy upon individuals, societies and healthcare systems.

And yet, psoriasis remains far down on the global, regional and national healthcare agendas compared with other non-communicable illnesses with similar impact.

In recent years, international organizations have begun to take notice of the seriousness of the suffering and the economic consequences of psoriasis. This is an extremely welcome development.

But global healthcare agendas are crowded, with limited resources available. It is easy for diseases to slip back into the shadows before a critical momentum has been achieved.

This document is a call to action. It is possible to reduce the burden of morbidity, mortality and disability from psoriasis world-wide. But it will need similar drivers as for other non-communicable diseases: leadership, coordinated multi stakeholder engagement and multisectorial action for health both at government level and at the level of local healthcare providers and patient organizations.

Psoriasis has been recognized as a disease since the early 19th century and there is a wealth of knowledge, expertise and experience available globally. Our industry is committed to continue researching new therapies to fight psoriasis as well as to work with partners to increase awareness and access to care through concerted action.

Eduardo Pisani

Director General, IFPMA

Executive Summary

Bringing Psoriasis into the light: A Call to Action

A hundred million people with psoriasis across the world remain undertreated, at increased risk for cardiovascular events and suffering social and work-related stigma and discrimination. This unmet need persists despite the widespread availability of a spectrum of treatment options. The result is prolonged, avoidable suffering; high rates of psoriasis-associated illnesses; and substantial costs to individuals and society in terms of lost productivity, cost of healthcare services and medications.

The suffering from psoriasis is often underrated: the disease is much more than its immediate, visible symptoms. Psoriasis can have a devastating impact on psychological well-being and social functioning, similar to that of cancer, arthritis, hypertension, heart disease, diabetes or depression. A person's lived negative experiences may be much more powerful that the clinical severity of symptoms would suggest.

The stigmatization of psoriasis is higher than for many other skin diseases with sometimes severe consequences in terms of depression, disability and dismal quality of life. Children or adolescents who develop psoriasis are hit particularly hard by the psychosocial impact of the illness.

There are a number of treatments available, but their full potential remains unrealized within healthcare systems. In consequence, many people with psoriasis do not have access to appropriate therapies. Patients' stories often recount an arduous, long and burdensome trial-and-error process trying out a number of medications.

In order to remove the barrier psoriasis poses to well being and socioeconomic development it is urgently necessary to raise the priority of psoriasis on global, regional and national agendas. Integrating psoriasis into global frameworks would help populations reach the highest attainable standards of health and productivity at every age. Such an achievement can only be attained through close co-operation and advocacy among all stakeholders.

Key needs and actions fall into three main priority areas: Awareness, Research and Access.



- Intensify and co-ordinate advocacy efforts to increase awareness of the public health impact of psoriasis
 - Support concerted efforts by public-health organizations at all levels, from supranational bodies such as the World Health Organization to national governments, local organizations and media
 - Emphasize the global nature of the problem and generate accessible information and education materials that can be easily adaptable to local conditions
- Facilitate the involvement of policy makers across areas of responsibilities
 - o Emphasize and communicate the wider impact of psoriasis on economic activity to policy makers in areas of labor markets, health and social policies
- Increase awareness of the nature of psoriasis by supporting the development of organizations and associations that connect people with psoriasis and other stakeholders
 - Facilitate efforts of patient organizations and self-care programs to link people with psoriasis and enable the sharing of experiences to help them and their loved ones manage and cope with the disease
 - o Widen the access to information within societies to reduce stigma and remove barriers to care
 - o Commit to education and training of healthcare providers in primary care and boost the development and awareness of treatment guidelines
 - Work towards closer involvement of people with psoriasis in continuing medical education efforts
 - o Encourage wider networking of professionals and between dermatologists and other stakeholders to increase access to expertise

RESEARCH



- Invest in concerted new research efforts across specialties; from molecular science to psychology and economics, to address the halo of impaired physical and psychological health surrounding psoriasis
 - o Obtain more data on the epidemiology and socioeconomic impact of the disease, in particular in non-Western societies and in under-researched groups such as children

- o Intensify research efforts on the impact on long-term cardiovascular risk from moderate and severe forms of psoriasis
- o Invest in a greater understanding of the psychosocial consequences of psoriasis for affected individuals and caregivers
- Foster innovation to boost the development of new therapies with high efficacy and easy administration to improve compliance and reduce the long-term risk from comorbidities
 - o Invest in further research into the pathogenesis of psoriasis and the connection to the associated comorbidities, in particular psoriatic arthritis
 - o Support efforts to identify factors behind treatment dissatisfaction that make people go off their therapeutic regimens
 - Improve cross-specialty communication channels to expand access to scientific information
 - o Strengthen private-public research networks to leverage knowledge and drive the application of new therapeutic approaches

ACCESS



- Increase global access to current effective therapies and to wider healthcare services such as counselling and self-care programs
 - Work towards establishing partnerships to deliver greater patient benefits and patient support
 - o Identify and explore existing best-case examples of how the management of psoriasis has been successfully integrated in healthcare services for non-communicable diseases.
 - o Facilitate the exchange of experiences to leverage managerial expertise from a variety of stakeholders: from healthcare organizations to resource-efficient business practices
 - o Establish screening programs to identify comorbid risk factors, particularly cardiovascular, in patients with severe psoriasis
 - o Support the development, strengthening and harmonization of national and supranational evidence-based treatment guidelines
 - Work towards unified treatment strategies and defined treatment goals to increase access to treatments and help patients reach treatment targets and stay on therapies
 - Provide targeted information and support with life-style changes,
 psychological support, treatment goals and expectations, and other risk
 management tools

Understanding Psoriasis

Psoriasis: a non-communicable, treatable autoimmune disease

Psoriasis is one of the most common immune-mediated diseases world-wide: a chronic, non-communicable, painful, disfiguring and disabling disease for which there is no cure.

Psoriasis is an inflammatory skin disease in which the immune response is turned against the own body which leads to a rapid growth and destruction of skin cells. These mechanisms are similar to those in other serious immune-mediated diseases such as Crohn's disease, rheumatoid arthritis and multiple sclerosis (1).

The mechanisms of psoriasis are similar to those in other serious immunemediated diseases such as multiple sclerosis

Who gets psoriasis is a complex question and a large number of factors are involved. Genes are important: there is a family history in 71% of affected children (2). Environmental risk factors also play a role: bacterial infection, stressful life events, HIV infection, trauma, smoking and obesity have all been associated with psoriasis (3).

> 125 million

people worldwide have psoriasis

The early onset of psoriasis exposes people to lifelong suffering

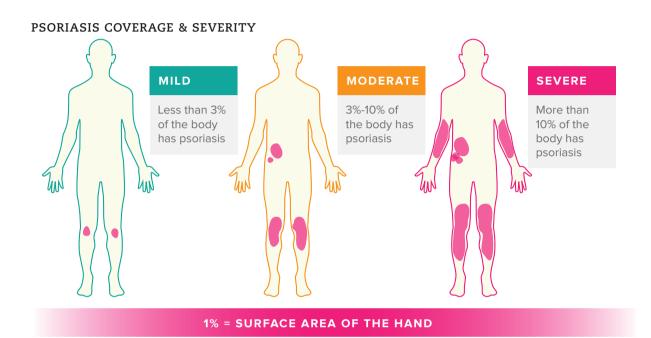
THE GLOBAL DISEASE BURDEN OF PSORIASIS

Psoriasis affects at least 125 million people across the world (4). Data from the US have indicated that psoriasis may be becoming more common (5). There are large variations in rates of psoriasis between geographical regions (6).

Psoriasis often develops early: one third of cases are diagnosed before the age of 20 (7) and most patients are under 30 years old at the time of the first outbreak (8). This early onset of illness exposes people with psoriasis to lifelong suffering, forcing them to live with a chronic, disabling, and potentially stigmatizing condition.

SYMPTOMS

More than 90% of people with psoriasis have plaque psoriasis. This is the kind of psoriasis usually referred to when healthcare professionals and patients use the term (9). It is characterized by round-oval or coin-sized plaques: patches of raised, red, flaky, skin covered with silvery scales. The skin can also become inflamed.



Mild psoriasis is when symptoms affect less than 3% of the body surface. Moderate psoriasis covers 3% - 10% and the classification of severe indicates that symptoms affect more than 10% of the body.

However, this standardized classification does not tell the whole story: a person's lived negative experience of psoriasis may be much more powerful that the clinical severity of his or her symptoms may indicate (10).

Psoriasis can cause extreme itching and scratching tends to make the symptoms worse. As psoriasis is an inflammatory disease, irritating the skin by scratching may trigger the development of plaques (known as the Köbner phenomenon). This can also happen in other situations, such as if people with psoriasis have a tattoo (11).

The most common site for plaques is the scalp: severe dandruff is one of the hallmarks or 'stigmata of psoriasis'. The scalp is also

A person's lived negative experience of psoriasis may be much more powerful that the severity of symptoms may indicate

where the first outbreak of psoriasis typically occurs. Other sites with high plaque frequency are the face, knees and elbows, genitalia, palms and soles. These sites are often seen as the 'high-impact sites' and count as the sites most difficult to treat (9).

Distinctive changes to fingernails and toenails, often pitting and oil spots, are also typical of psoriasis (12). The nails may thicken, become discolored and yellow and misshapen or split. Psoriasis can even make the nail detach from the nail bed (13).

Psoriasis symptoms tend to come and go in distinct episodes. Symptoms may clear up completely between outbreaks but they usually reappear. Symptoms are often more severe in the winter and improve in the summer months (13).

"I haven't been on holiday for several years because I don't know if I'm going to be clear"

The symptoms of psoriasis can be disabling, particularly when they occur on the palms and soles. At those sites, psoriasis causes greater pain and physical disability than similarly severe outbreaks at other body parts (14).

PSYCHOSOCIAL IMPACT

Psoriasis can have a devastating impact on psychological well-being and social functioning, similar to that of cancer, arthritis, hypertension, heart disease, diabetes or depression (15–18).

Almost everyone with psoriasis experiences shame and embarrassment. Particularly women and people with a long history of psoriasis report feelings of shame (19). Around half of people with psoriasis experience anxiety, depression, major difficulties at work or negative impact on sexual function (20,21).

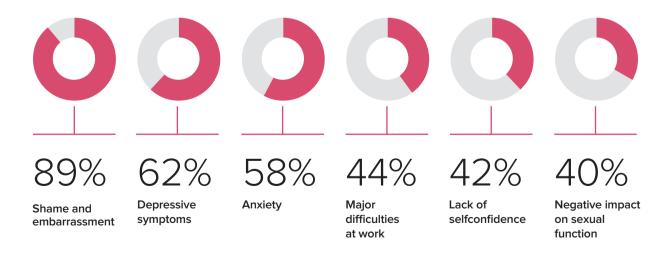


FIGURE 1. Impact of psoriasis on physical and social functioning.

Most people with psoriasis suffer feelings of stigmatization because of their highly visible symptoms. Stigmatization is defined as having a discrediting mark that leads to social discrimination and alienation (22). In psoriasis, this often shows as social rejection: people avoiding physical contact for fear of catching the disease or getting filthy.

The stigmatization of psoriasis is higher than for many other skin diseases and the consequences, on quality of life, depression and disability can be severe (23,24). For most people with psoriasis, difficulties in establishing social relationships are the most troubling consequence of their illness (25). Even relatively mild symptoms cause stigmatization which can lead to psychological stress and social withdrawal.

Children or adolescents who develop psoriasis are hit particularly hard by the psychosocial impact

"The name of the disease... ... is Humiliation."

John Updike

Children or adolescents who develop psoriasis are hit particularly hard by the psychosocial impact. First, children are still developing intrapersonal skills and are less psychologically equipped than adults to deal with the negative reactions of peers. Secondly, the illness strikes at pivotal events in a young life such as schooling, choice of profession, first social contacts and partnerships (26). Thirdly, developing psoriasis as a child exposes a person to a life-long struggle with the disease and accumulated suffering (27).

A sign of the psychological impact is the high rate of depression in people with psoriasis. Up to 60% of people with psoriasis may show symptoms of depression (20). The risk of depression in people with severe symptoms is twice that of people with milder psoriasis (28).

It has been estimated that in the United Kingdom, >10,400 diagnoses of depression, 7100 diagnoses of anxiety, and 350 diagnoses of suicidality are attributable to psoriasis every year (28). The emotional impact of psoriasis is such that as many as 5-10% of patients wish they were dead or contemplate suicide (29). Low self-esteem and suicidal tendencies are associated with disfiguring skin conditions across geographical regions and societies (30).



>10,400

diagnoses of depression

7100

diagnoses of anxiety

350

diagnoses of suicidality due to psoriasis are made every year in the United Kingdom

Psoriatic arthritis is among the most disabling forms of arthritis



40%

of people with psoriasis have psoriatic arthritis

People with psoriasis are more likely to die of cardiovascular causes



CO-MORBIDITIES

Psoriatic arthritis develops in around 30% of people with psoriasis (31). It is among the most disabling forms of arthritis (32), causing pain, stiffness and swelling at the joints. Over time, psoriatic arthritis can lead to permanent disfigurement and disability.

Psoriasis is also associated with increased prevalence of other illnesses, such as chronic obstructive pulmonary disease (33). Pregnant women with psoriasis may be at increased risk for adverse pregnancy outcomes (such as preterm birth, low birth weight or placental complications) (34,35). Moreover, patients with psoriasis suffer from more sleep disturbances than people without psoriasis, both because of the itching and because of the negative impact of the disease on their mood (36). Insomnia increases cardiovascular risk and reduces quality of life further (37).

CARDIOVASCULAR RISK

In addition to the daily suffering, psoriasis causes long-term harm. People with psoriasis are more exposed to cardiovascular risk factors than the general population, including high blood pressure, diabetes, obesity, ischemic heart disease and dyslipidemia (38,39).

The increased prevalence of cardiovascular risk factors means that people with psoriasis are at high risk for cardiovascular complications. In addition, psoriasis itself increases the risk for cardiovascular events (40). Even mild psoriasis is associated with greater risk of heart attack and stroke, and the risk is higher in more severe psoriasis (39). Psoriatic arthritis almost doubles the risk of hypertension and angina (31). People with hypertension and psoriasis struggle more to control their blood pressure than their peers without psoriasis (41). The risk of dying from diabetes almost doubles if a person has severe psoriasis (42).

This increased cardiovascular risk means that people with psoriasis are more likely than the general population to die of cardiovascular causes. In the US, psoriasis is held responsible for >10,000 additional deaths, strokes and heart attacks every year (39).

14

ECONOMIC IMPACT

The economic consequences of psoriasis hit individuals as well as health care systems. The disease limits people's ability to work and leads to higher costs for healthcare services and drugs.

In Canada, 38% of patients reported that their psoriasis had affected their ability to find work or the career that they had chosen (43). In Germany 24.3% of people with psoriasis reported a reduction in their earning capacity because of their psoriasis. A person with moderate-to-severe psoriasis loses on average €1310 (in 2004) in annual productivity (44). On average, people with severe psoriasis take 26 days off sick per year (45).

In 2008, the annual cost from medical expenses and lost wages due to psoriasis in the U.S. was estimated at \$11.25 billion (46). For the same year, an Italian study reported that the average yearly total cost of psoriasis per patient was €8,371.61 (47). In a recent survey in the US, 92% of unemployed people with psoriasis cited psoriasis or psoriatic arthritis as the only reason for their not working (48).

These analyses did not take into account non-insured costs to patients. People with psoriasis carry a large part of the disease-associated costs themselves as lost earnings and out-of-pocket costs for over-the-counter medications. More than half of psoriasis drugs in the US are paid for by the patients themselves (49). Data from outside the US and Europe likewise show that patients spend a large amount of money on non-prescription products (18).

'I find the cost a great drain as I use several different treatments at one time.'

In France, average yearly out-of-pocket expenses for the disease were estimated at €543 per patient (50). However, costs vary greatly between different countries and between different severities of psoriasis (51). The out-of-pocket expenditures for patients with severe psoriasis can be several-fold those of people with milder versions: In Switzerland, yearly out-of-pocket costs for ambulatory care per patient in 2005 could be up to CHF 9900 (USD 10,750) (52).

Psoriasis limits people's ability to work and leads to higher costs for healthcare services and drugs

26 days

sick leave are taken by the average person with psoriasis every year Psoriasis also increases the use of medications for other, associated ailments. In a survey of treatment patterns across Canada, a large proportion of people with psoriasis reported taking prescription medications for depression (61%), anxiety (54%) or insomnia (47%) (53).

However, people with psoriasis often try out a number of medications through a long and burdensome trial-and-error process. Such disappointments color their attitudes to medications and increases the sense of helplessness (54). As a result, people with psoriasis may lose faith in both treatments and doctors, and stop seeking help from within the healthcare system altogether (55).

CURRENT TREATMENTS

Available treatments for psoriasis range from very simple remedies to highly sophisticated biomolecular agents, from century-old cures to new pharmacological treatments still undergoing clinical development. The effectiveness varies and different patients respond differently to therapies.

The basic fact remains for all treatments: while they may reduce the symptoms, they cannot cure the illness. One consequence of this is that treatments need to be taken regularly for a long time; there is no 'magic bullet'. Treatment regimens for chronic diseases are very difficult to maintain over the long term and people with psoriasis are in need of support to increase adherence to therapies (56).

Psoriasis treatments are divided into three kinds: topical therapies that are applied to the skin directly, phototherapy, and systemic and biological therapies that are taken by mouth in liquid or pill form or given by injection.

'Please be careful when using the word disease. It brings to mind a contagious catching ailment.'

TOPICAL THERAPIES

For up to 80% of patients, topical treatments are prescribed for home use to self-manage psoriasis. Among common topical therapies are moisturizers, vitamin D and analogues, corticosteroids or a fixed combination of vitamin D and corticosteroids, and coal tar preparations to combat itching and reduce the skin dryness experienced with psoriasis.

Moisturizing creams or lotions contain oils or fats and often replace soap, which can irritate inflamed skin (57). Vitamin D analogues or topical steroids as creams are often the first active treatment (58). Both are easy to apply, cosmetically acceptable, do not stain the skin and rarely cause irritation. The combination of Vitamin D analogues and steroids is more effective than each on its own (59).

Coal tar sensitizes the skin to UV light and is often used to enhance the effect of phototherapy. However, it has been largely replaced by preparations containing corticosteroids and vitamin D analogues.

Topical therapies work well particularly in people with mild to moderate psoriasis: response rates are up to 80% (60). In more severe cases, topical therapies are often used in combination with systemic therapies. With regard to tolerability, overuse of topical corticosteroids can lead to skin thinning (61).

In spite of their effectiveness, people with psoriasis often struggle to keep up with their topical treatment regimens in everyday life (54). Commonly reported reasons for low adherence are unrealistic expectations, inconvenient and time-consuming application or fear of side effects (62,63). An improved dialogue between patients and physicians to manage expectations, set realistic goals and determine the most suitable treatment option for each person's individual life style can help (64), as can patient education, through training programs or involvement in advocacy groups (65–68).

PHOTOTHERAPY

Healing effects of sunlight have been used to treat skin diseases throughout recorded human history (69). The medical concept of phototherapy is more than 100 years old and ultraviolet (UV) light in combination with tar or oils has been used to treat psoriasis since the mid-20th century (70). Phototherapy is an effective, relatively safe treatment for individuals with moderate or severe disease. People who are not helped by topical therapies can also receive phototherapy.

There are typically three variants of phototherapy: broadband UV-B (BB-UVB), narrowband UV-B (NB-UVB) and psoralen plus UV-A (PUVA). NB-UVB is more effective than BB-UVB and safer than PUVA, while PUVA is the most effective of the three therapies (71). Typical regimens for NB-UVB involve treatment 3 times per week for at least 3 months. But all phototherapy must be independently developed to suit individual needs.

Patients may experience symptoms of sunburn following long-term phototherapy. (72) Long-term use of phototherapy can increase the risk of developing skin cancer (61) and routine skin examinations are usually recommended as a safety precaution (73).

Although it is relatively inexpensive phototherapy can be inconvenient: as it is generally offered in an outpatient clinic it requires patients to travel to the hospital during working hours two or three times a week. People who live in remote areas often lack access to the therapy.

Home phototherapy is an attractive alternative. But it is not always reimbursed, which limits access to treatment and perpetuates suffering for people who would have been helped by the therapy (70,74).

The suffering caused by psoriasis on palms and soles is completely out of proportion to the small areas affected

SYSTEMIC THERAPIES

Broadly, systemic therapies can be divided into non-biological and biological therapies. The first systemic therapy, methotrexate was approved for psoriasis in 1971 (75). Other therapies are cyclosporine, acitretin and fumaric acid esters. Most systemic therapies target the immune system to slow the growth of skin cells. They have a good track record for moderate to severe psoriasis. The downside is that systemic therapies all have potentially serious side effects (61) and treatment needs to be highly individualized, with benefits and risks weighed carefully and monitored for each patient (12) to minimize the risk of toxicity.

Systemic therapies are usually not given to people with milder forms of psoriasis, but there are exceptions. The suffering caused by psoriasis on palms and soles is completely out of proportion to the small areas affected. In consequence, people with palm and sole psoriasis are considered for systemic therapies even if the symptoms do not cover wide body areas (76).

'The ability to treat oneself properly is very important; this way it can at least be kept under control.'

BIOLOGICAL AGENTS

Biological agents are molecules engineered to target specific mechanisms in the development of psoriasis. The largest groups are agents that modulate the inflammatory response, such as tumor-necrosis factor alpha inhibitors or anti-interleukin antibodies. A number of biological treatment options are licensed for patients with severe disease (12,77) and more are in development as a result of increased understanding of the biology and mechanisms that lead to psoriasis.

Biological therapies are generally well tolerated in the majority of people but as with all medications there are associated risks and all biological therapies have potentially serious side effects (61,78). Patients should be monitored for long-term risk of infection, cardiovascular events or developing tumors (79).

Figure 2. Overview of treatment options for the different severities of psoriasis. Based on references (80,81)

	PHOTOTHERAPY (plus retinoids) - PUVA (Systemic, local) - UVB (311 nm) - UVA/UVB	SYSTEMIC THERAPY - Biologicals - Cyclosporine A - Methotrexate - Fumaric acid esters	Severe Psoriasis 12% of patients
			Moderate Psoriasis 36% of patients
TOPICAL THERAPY			
- Fixed combination of betamethasone dipropionate and calcipotriol			
Vitamin D3 analoguesSteroidsRetinoidsDithranol			Mild Psoriasis 52% of patients

makers: Awareness, Research, Access

Focus areas for policy

Awareness raising

Hundreds of millions of people with psoriasis across the world remain undertreated, at increased risk for cardiovascular events and suffering social and work-related stigma and discrimination. This dismaying situation is largely caused by insufficient communication and a resulting lack of awareness within societies and among decision makers, physicians and patients.

Greater awareness in general-practice settings would reduce the risk that doctors view psoriasis as a straightforward skin condition

People with psoriasis experience stigmatization everywhere: in the US, Europe, Asia, Africa as well as in the Middle-East (82–85). There is thus a huge potential benefit to people with psoriasis from greater public awareness of the nature of the disease. Moreover, greater access to counselling and improved networking opportunities would help people with psoriasis cope with their everyday lives.

Insufficient understanding of the illnesses and risks associated with psoriasis also mean that patients are not receiving the care they need. While many primary care physicians recognize psoriasis for the complex systemic disease that it is, efforts to raise the level of information in general practice settings would reduce the risk the illness is seen as a straightforward cosmetic skin condition (86). By the same token, increased availability and awareness of treatment guidelines for psoriasis among primary care physicians would increase the benefits to patients.

Patients want their health care practitioners to acknowledge the stress and distress that psoriasis imposes on daily lives (55). Deepening the understanding among physicians, both in primary care and among dermatologists, of the psychosocial dimension of psoriasis would remove a barrier to the provision of appropriate psychological interventions. As the patients at greatest risk of depression and suicidal tendencies are those with more severe psoriasis, dermatologists might play

an important role in suicide prevention in this population (87). Therapies such as cognitive behavioral therapy have been shown to reduce anxiety and depression; disability and stress; and also the clinical severity of psoriasis (88).

Achieving all this would require changes to medical curricula as well as facilitated exchange of experiences. Psoriasis is diagnosed and treated both in primary care settings and in specialist dermatologist environments. Efficient communication and clinical networks would help physicians to work within teams with greater support of colleagues. This potential for improvement exists in most areas of medicine (89) and learnings from, e.g. primary care could be implemented in the field of psoriasis (89,90).

Integrated standardized care pathways and protocols are critical. When agreeing on structures for patient journeys, all stakeholders should be consulted, taking into account patients' expressed needs and experiences of the disease, to ensure consistent high standards of care everywhere.

FOSTERING RESEARCH

There is a continual research effort towards new and improved molecular therapies for psoriasis. A number of clinical trials are ongoing on agents that target different steps in the pathogenic cascade (91). Such work remains critical. But the need for research ranges across specialties: from molecular biology to psychology and economics. There is a lack of tools that capture all aspects of impact on life including physical, psychological and social well-being, and factors that may influence this impact, such as distress and beliefs about psoriasis.

Most work on the epidemiology of psoriasis has been carried out in Europe and the US. Wide-ranging international data are mostly lacking. More research collaboration internationally would help to address global knowledge gaps on the disease and potential trends over time (92).

Children and pregnant women are two insufficiently researched groups. Although children with psoriasis suffer particularly from the psychosocial impact of psoriasis, greater knowledge of the psychosocial effects in this vulnerable group is necessary to

The need for research ranges across specialties: from molecular science to psychology and economics

elevate care. We also need to learn more about the effect of psoriasis on pregnancy outcomes such as preterm birth, low birth weight or placental complications.

Despite its serious effect on patients, it is not well understood why patients with psoriasis often develop psoriatic arthritis and the true burden of this complication remains insufficiently researched.

To help patients stick with their therapies, it is necessary to identify the factors behind dissatisfaction that make people go off their treatment regimens (93). Additional work is needed to establish how different aspects of quality of life are affected by the disease and how they change with the clinical effects of therapies (94).

Many people in the world suffer needlessly from psoriasis due to incorrect or delayed diagnosis, inadequate treatment options and insufficient access to care

INCREASING ACCESS

Too many people in the world suffer needlessly from psoriasis due to incorrect or delayed diagnosis, inadequate treatment options and insufficient access to care (68,95). Non-treatment and under-treatment is almost universal: even the US almost half of patients with mild psoriasis, one-quarter of patients with moderate psoriasis, and almost 10% of patients with severe psoriasis were not receiving any treatment at all in 2011 (96). The situation is similar in Europe (56). The consequences are prolonged suffering and increased societal costs.

The availability of treatment guidelines can improve access to appropriate therapies by providing physicians (and patients) clear advice on initiating and optimizing therapeutic interventions (56). Defining achievable treatment goals and managing expectations can help patients reach treatment targets and stay on therapies. To be effective guidelines need to be aligned with evidence-based clinical consensus while at the same time reflecting local policies and practices. Hence, both supranational and local guidelines are necessary.

Psoriasis has a wide variety of severity of symptoms and often multiple comorbidities. This leads to complex needs for health care. It is difficult to find the appropriate balance between care provided by generalist and specialist professionals. Generalists are better able to see the whole individual and provide holistic services. Specialists can target specific problems, but need good systems for cross-referrals to ensure all aspects of a patient's disease are covered.

'I often feel a little bit helpless trying to help' GP

Patients' experiences have become steadily more important in healthcare policy in recent decades and patient-reported outcomes are gaining widespread acceptance as valid measures of treatment effects (97). Individuals with psoriasis are in the best position to know about the impact of their disease on their own lives and on the attitudes of other people, including the medical profession, to the condition (98,99)

There is also a need to develop and evaluate tools that can be used by patients and healthcare professionals to assess disease severity to facilitate modern healthcare delivery models such as remote monitoring of disease activity (9).

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