White Paper
Psoriasis - Lifting the burden of stigma and changing lives
Psoriasis - Lifting the burden of stigma & changing lives
Policy for Action 5/2020

Galen Centre for Health & Social Policy

Abstract

Psoriasis is commonly described as a skin condition. However, research into psoriasis has discovered that it is a chronic and complex immune-mediated disease. The complications of psoriatic arthritis, cardiovascular disease, psychosocial disorders and other co-morbidities clearly show that damage extends beyond visible skin.

Despite recognition by the World Health Organisation as a chronic condition, getting appropriate care and treatment for people with psoriasis remains challenging. Due to inaccurate diagnosis, gaps in health services, and unmet treatment needs, patients face a lifetime of suffering and disability.

By 2017, the Malaysian Psoriasis Registry (MPR) captured an epidemiological picture of over 17,000 adults and children with psoriasis from 25 dermatology outpatient clinics, where more than one in four patients reported severe impairment of quality of life. The total number registered has now risen to more than 24,000.

It is critical that awareness and recognition of psoriasis as a serious medical condition that can significantly impact a person’s quality of life, is emphasised among healthcare professionals, particularly those at the primary care level.

Doing so will enable people with psoriasis to be diagnosed early and provided with the necessary care. Receiving quality, timely and effective treatment reduces the individual burden and wider economic impact of the disease.

However, management of this condition today is challenged by funding which falls short of ensuring access for all who are eligible for optimal treatment, particularly those deemed to be at a serious stage of their disease. People are being left behind.

With sufficient resources and investment to provide adequate access to manage psoriasis and its comorbidities, especially for patients with moderate to severe psoriasis, suffering and stigma can be reduced, and lives changed for the better.

The long-term objective for Malaysia contained within this Psoriasis White Paper should be to develop a model of patient-centered, coordinated care which ensures the delivery of comprehensive, individually adapted treatment for people with psoriasis over their lifetime.

Acknowledgements

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The findings of this policy paper were derived from a review of existing literature, consultations and discussions held in August & September 2020 with people living with psoriasis, patient groups, healthcare professionals, policy makers and payers.

Photo credits: Rocyie Wong. Rocyie is a young woman living with psoriasis. She is an inspiring and passionate advocate working to improve the lives of those with this condition in Malaysia.
Executive Summary

Despite an estimated 125 million people living with psoriasis worldwide, this condition is often not taken seriously.

Ten years ago, the Psoriasis Association of Malaysia estimated that at least 500,000 to 800,000 individuals in the country were living with the condition. Today, this number is estimated to be larger. However, only around 17,000 adults and children were registered on the Malaysian Psoriasis Registry from 2007 to 2016. This has now increased to over 24,000 in 2020.

Awareness of psoriasis is low, with the common perception that it is a skin condition needing only topical treatment.

People are unaware of the negative impact that psoriasis may have on a person, affecting one’s educational and employment opportunities as well as quality of life in general. Despite recent clinical advances, those living with psoriasis are largely undertreated and forced to settle with often sub-optimal treatment.

Despite the World Health Organisation declaring psoriasis as a serious non-communicable disease, there is an ongoing need to raise awareness of psoriasis as a serious medical condition that can greatly impact on a person’s quality of life.

Even though it is a common condition, psoriasis is still poorly understood even among health care workers. Medical professionals, especially general practitioners at the primary care level, need to be equipped with the latest clinical updates about psoriasis so that it can be diagnosed and treated at an earlier stage.

The long-term outlook for a person with psoriasis can be significantly improved by ensuring that there is access to quality care through effective and coordinated treatment. The goal of treatment should be to achieve what those with psoriasis want most, namely skin that is completely clear of psoriasis.

Treatment of this condition must also include addressing the stigma and discrimination that may come with it. The response to psoriasis can cause embarrassment, social stigma, discrimination, depression and sometimes, suicide.

A 10-year review of the Malaysian Psoriasis Registry (MPR) found that plaque psoriasis was the most common type of psoriasis, followed by guttate, erythrodermic and pustular psoriasis.

Around 94% of adults were prescribed topical treatments across dermatology outpatient clinics. Some were also prescribed oral systemic therapies (18.5%), biologics (3.3%), and phototherapy (2.9%). Nearly a quarter had moderate to severe disease, yet treatment outcomes from available follow-up data demonstrated that two in three patients did not improve or worsened.

Seen predominantly as a skin condition and subjected to competitive pressure from more well-recognised chronic diseases such as cancer, the burden of psoriasis is disproportionately borne by individuals living with the condition.

The following were found to be key challenges and unmet needs in managing psoriasis:

- **Lack of awareness among health professionals leading to late diagnosis:** Patients encounter barriers in healthcare settings such as a low level of knowledge about skin diseases among non-dermatology trained health professionals. As a result, people with psoriasis are being misdiagnosed or undermanaged.

- **Limited treatment options:** Dominant use of topical and conventional systemic therapies in the tertiary/specialist setting of care is concerning. Despite nearly 1 in 4 patients
classified as having moderate to severe disease, the utilisation of biologic therapy was much lower than expected, signifying delays in treatment escalation.

- **Low patient satisfaction due to inconsistent treatment standards and goals:** Health-related quality of life (HRQoL) for patients did not correspond consistently with the clinician’s assessment of disease severity, potentially leading to low treatment satisfaction. Patients ended up defaulting on treatment and spending on other therapies such as traditional medicine and supplements.

- **People living with psoriasis experience discrimination due to stigma:** The nature of illness, threat of disability, and fear of deformity, has led to social stigma and discrimination, making it difficult for persons with psoriasis to find their place in society.

- **Limited insurance coverage:** Psoriasis treatment is not covered by some health insurance providers, while psoriasis and psoriatic arthritis are not classified as critical illnesses.

- **Underutilisation of national registry:** Limited utilization of the registry data may undermine the value of the registry in the treatment of the condition.

In response, this White Paper calls for the following action points to be undertaken:

- **Support and empower people with psoriasis:** People with psoriasis in Malaysia and their networks should be involved and empowered to represent themselves and speak on their issues. They can play an important role in providing practical feedback towards the development of treatment guidelines and policies, as well as initiatives which address stigma and discrimination of those living with the condition.

- **Implement a National Psoriasis Programme:** Implementation of the Clinical Practice Guidelines (CPG) for psoriasis should be strengthened through a coordinated multidisciplinary approach which takes into account associated co-morbidities and works towards providing appropriate treatment at all levels of care. Last published in 2013, the CPG is due for an update in view of various clinical developments in the field of psoriasis that have taken place over the years.

- **Improve access to earlier interventions, therapies and care:** People with psoriasis should receive the optimal care that is necessary to clear their skin symptoms, treat their disease and improve their QoL, especially to improve physical functionality and bolster productivity. Separate public and private access needs and recommendations.

- **Improve access to funding and classify psoriasis under critical illness:** Existing insurance coverage should be reviewed to include psoriatic disease as a critical illness at the minimum, as well as the benefits under the Employee Provident Fund and Social Security Organisation.

- **Improve and strengthen the Malaysian Psoriasis Registry for patient-centred outcomes:** The effective use of a national patient registry improves the understanding of long-term prognosis and outcomes for psoriasis. It will help in the development of more effective therapies and improve the quality of service delivery and policies.
A common chronic disease

“Dealing with a chronic condition, we have to live differently. Our lives are different. In certain areas we do need help.” – Patient advocate

Psoriasis is a common autoimmune disorder which manifests itself as skin that is scaly and red leading to possible itching, burning or painful sensation, soreness and even bleeding. Its effects on the skin are highly visible.

People living with psoriasis may suffer from physical impairment and discomfort commonly associated with the condition. Nearly two-thirds have a mild form of the disease, with less than 3% of the skin surface of the body affected.5

However, it may be more extensive in others. Joints may become deformed, causing significant disability.

The onset of psoriasis is before the age of 40, for three quarters of those affected. In around a third, the condition appears before 20 years of age.5

Psoriasis, though lifelong, is not contagious

Though the cause of psoriasis is still not fully understood, the immune system and genetics are involved. There is no cure.

There are five types of psoriasis, namely plaque, guttate, inverse, pustular and erythrodermic. Each type may be mild, moderate, or severe in their degree, except for erythrodermic - which is a rare and severe type of psoriasis.

Psoriasis is not only a skin condition, it may also affect other organs such as respiratory, haematological, and cardiovascular systems. It increases the risk of developing co-morbidities including diabetes, hypertension, heart disease, and psoriatic arthritis. A diagnosis of psoriasis may also cause unhealthy behaviour change such as increased alcohol consumption, smoking and obesity.5

Though there is no cure, treatment options are available which can alleviate symptoms, improve the skin appearance, and address underlying causes.

125 million people are estimated to be living with psoriasis worldwide.4 Considering that psoriasis affects 2-3% of the global population, the Psoriasis Association of Malaysia estimated in 2010 that at least 500,000 to 800,000 individuals in the country were living with the condition.1 The Global Psoriasis Atlas estimated more than 90,000 live with psoriasis (0.3% prevalence), potentially up to 520,000.7

Though psoriasis is a common condition, it is poorly understood not only by the public, but also some health professionals.

Treatment of this condition must also include addressing the stigma and discrimination that may come with it.

However, studies in developed countries have reported higher rates on average of around 4.6%.5

Over the past 3 decades, the prevalence, incidence, and burden of suffering caused by the disease has increased significantly.8

In 2014, the World Health Organisation (WHO) through a resolution at its annual World Health Assembly, recognised psoriasis as a serious non-communicable disease (NCD). It called on countries to address issues of prevalence and incidence of the condition, access to treatment and care, associated co-morbidities, and its burden on healthcare.
How severe, is severe?

Defining psoriasis severity can be complex. Clinical assessment tools such as body surface area (BSA), psoriasis area and severity index (PASI), and Dermatology life Quality Index (DLQI) aid in treatment decision-making by classifying disease as mild, moderate, and severe.

The disease course of psoriasis is lifelong with periodic flare-ups and remissions.

About 1 in 4 individuals with psoriasis develop arthritis, which may affect the hands, feet, wrists, ankles, neck, and lower back. It develops in the joints and cause progressive damage, pain and deformity if left untreated.

The Malaysian Clinical Practice Guidelines (CPG) for psoriasis released in 2013 differs from international guidelines in the categorisation of disease severity. American Academy of Dermatology classifies severe psoriasis as BSA > 10%. Other guidelines place BSA above 10 as moderate to severe (to be interpreted alongside PASI). For Malaysia, BSA > 30% is considered severe (see Table 1).

Table 1 - Comparison of psoriasis severity classification

<table>
<thead>
<tr>
<th>Severity</th>
<th>American Academy of Dermatology</th>
<th>UK, EU, Clinical trials</th>
<th>Malaysian CPG 2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>BSA &lt; 3% PASI &lt; 5 DLQI &lt; 5</td>
<td>BSA ≤ 10% PASI ≤ 10 DLQI ≤ 10</td>
<td>BSA ≤ 10% PASI ≤ 10 DLQI ≤ 10</td>
</tr>
<tr>
<td>Moderate</td>
<td>BSA 3-10% PASI 5-10 DLQI 5-10</td>
<td>BSA &gt; 10% PASI &gt; 10 DLQI &gt; 10</td>
<td>BSA &gt; 10% - 30% PASI &gt; 10 - 20 DLQI &gt; 10 - 20</td>
</tr>
<tr>
<td>Severe</td>
<td>BSA &gt; 10% PASI &gt; 10 DLQI &gt; 10</td>
<td></td>
<td>BSA &gt; 30% PASI &gt; 20 DLQI &gt; 20</td>
</tr>
</tbody>
</table>

BSA=Body Surface Area; PASI=Psoriasis Area and Severity Index; DLQI=Dermatology Life Quality Index

Living with co-morbidities

The manifestations of psoriasis are not limited to the skin. It may be linked to cardiovascular, liver, respiratory and haematological conditions.

People with psoriasis can display a broad spectrum of symptoms and significant co-existing conditions. Moderate to severe cases may experience increases in relative risks of ischaemic heart disease, stroke, hypertension, dyslipidaemia, Crohn’s Disease and diabetes. Those with severe psoriasis also reportedly experience increased risk of strokes and heart attacks. These comorbidities can add to the impact that psoriasis has on a person’s QoL.

Therefore, early treatment of psoriasis may lower the risk of comorbidities as well as improve long term disease prognosis and quality of life.

Flare-ups are often the lowest points...

"For one year I was on medical leave and bedridden. I couldn’t move my limbs and torso. The plaques were so big when I twisted, they tore.”

Ryan*, 69 years old, patient advocate

...which can lead to desperation.

"The most terrible experience I had was wanting to jump down from my condominium.”

Leong*, 47 years old, patient advocate

*Name has been changed
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Invisible battles

“No one with this condition should feel alone or depressed because it is a common thing to deal with. Psoriasis is a type of chronic condition and can also include having heart disease and diabetes. It should be normalized.” – Young woman living with psoriasis

Psoriasis can have a major psychological impact on patients.

The functional and psychological effects of the condition may have bearing on the individual’s long-term physical and mental health. Depending on the severity and location of skin lesions, persons with psoriasis may experience significant discomfort and disability which interfere with basic functions, such as sleep.

Psoriasis manifesting on limbs cause impediments which negatively affect daily life, prevent working in certain roles and functions, reduce educational and employment opportunities, as well as cause distress to their general wellbeing. Among all age groups in Malaysia, the onset of psoriasis peaks between 21-30 years old.

People are generally unaware of the negative impact that psoriasis may have on an individual, particularly their quality of life. They may discriminate people with psoriasis out of fear and ignorance causing social marginalisation and isolation.

The Dermatology Life Quality Index (DLQI) is currently the most used method for evaluating dermatology-specific health-related quality of life (HRQoL). It helps measure quality of life (QoL) for patients with skin conditions. It allows for an assessment to be made on the impact of a disease on the physical, social, and psychological well-being of a patient.

Physical health: The most common type of psoriasis is plaque psoriasis, in which red, itchy and painful lesions covered with silvery scales appear on visible or sensitive sites like the scalp, elbow, knees, face, palms, soles, trunk, genital area and buttocks.

Nails and surrounding structures undergo abnormal changes that may cause secondary infections, pain and functional disability. In psoriatic arthritis, inflammation commonly affects joints of fingers and toes, large joints of the arms and legs, and the spine.

Individuals may experience fatigue, pain, tenderness, swelling, stiffness and limited range of motion.

Mental health: Depression, anxiety, and suicidality are mental health co-morbidities that are prevalent among people with psoriasis. They are 57% more likely to have depression and 26% more likely to attempt or complete suicide.

CASE STUDY
Juliana*, 31 years old, mother

“I have psoriasis and psoriatic arthritis. I’ve had psoriasis for the last 10 years and was misdiagnosed a few times. My skin was really bad and it started to affect my joints, because I didn’t get the correct treatment for it. I got misdiagnosed for eczema, tendonitis, and others.

In 2017, I managed to see a specialist at a government hospital and they diagnosed me with psoriasis and psoriatic arthritis (PsA). I have been on medication but there are so many side effects. Last year, I got pregnant and had my baby, so I had to be off meds for a year. But my condition became really bad because I was off medication. Finally, I got back on and the condition is now under control. With psoriasis, living in a pandemic situation like now, life has changed very much. This is an autoimmune disease, the mental and physical stress we have to go through is different from other people.”

*Name has been changed
Patients consulted for this whitepaper and studies have observed that there were higher rates of depression and anxiety among people with psoriasis compared to the general population, due to distress caused by stigmatisation. As a result, quality of life is severely impaired. In the Malaysian Psoriasis Registry, 11 out of 776 reported cases of death were attributed to suicide.

Significant psychological problems can be missed without integrated or coordinated mental health screening. More than one third of people who screened positive for major depression reported only ‘moderate’ quality of life impairment on the Dermatology Life Quality Index (DLQI).

Quality of life and daily activities: Those with skin lesions located on highly visible areas such as the face, hands and scalp, experience stigma and negative emotions in their daily and social lives. They may carefully dress covering affected parts of the skin, avoid certain sports and leisure activities (e.g. family gatherings), and isolate themselves from social opportunities.

Malaysian caregivers of younger patients reported that their children were not permitted to go to kindergarten by their teacher, thus depriving them of an opportunity for early education. Others prematurely dropped out of their educational pathway to focus on their disease and wellbeing.

Debilitating pain, fatigue and intense itching disrupt daily functioning at work, school, and at home. People with psoriatic arthritis in finger or wrist joints may be unable to perform simple tasks such as tying shoelaces or using keyboards.

In response to which domain of DLQI was most impaired, 40% of Malaysian patients reported physical symptoms and emotional feelings affected them ‘a lot’ or ‘very much’. Nearly one third found their daily activities and leisure profoundly affected by psoriasis.

During one of the group consultations, several individuals with psoriasis spoke of isolation or withdrawal as a method of coping with their condition.

Socioeconomic burden

At the individual level, people with psoriasis experience functional impairment, lost opportunities in education, and missed work days. Over a lifetime, indirect and treatment-related expenditure can be significant. Coupled with the burden of physical and mental health stressors, the economic impact of psoriasis is growing significantly.

Canadian and German studies showed that patients who were employed lost a mean of 4-5 working days per year due to their condition. This loss in productivity increased with the severity of the psoriasis.

Nearly 40% of psoriasis patients surveyed across eight dermatology departments in Malaysia experienced productivity losses due to absenteeism from work or school.

For those experiencing a more severe form of the condition, the incidence of absenteeism and hospitalisation were far greater. Severe psoriasis patients missed 9.2 days (vs 3.7 days for mild to moderate cases) and 13.7% were hospitalised (vs. 0.8%). Having psoriatic arthritis increased the likelihood of not currently working or studying.
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Unemployment or early retirement from the workforce also increased the indirect costs associated with the condition.\(^2\)

Due to the chronic nature of psoriasis, patients require lifelong care resulting in lifetime expenses. Local estimates on the combined direct and indirect costs of psoriasis ranged between RM 1308 to RM 7763 per patient per year.\(^2\),\(^2\) This amount was far lower than other countries due to government subsidisation of healthcare costs in Malaysia, as well as patients choosing less expensive treatments due to affordability concerns.\(^2\)

Paying out-of-pocket to fund treatment is often ruinous for patients, especially when people living with psoriasis may not be able to take on work due to discrimination or health reasons.

Since lifelong treatment is needed either under outpatient or inpatient care, the resulting loss of income or underemployment is expected to increase socioeconomic burden.

With an increased yearly incidence of psoriasis in Malaysia, this financial burden, for both patients and healthcare providers, is also expected to grow.

The cost of therapies for chronic conditions like psoriasis will add a burden to overall yearly health expenditure. As psoriasis treatment is mainly provided through government facilities, which are funded through public funds, this expenditure will be significant.

A hidden burden in Malaysia

Even with a conservative estimate by the Global Psoriasis Atlas that more than 90,000 Malaysians have psoriasis\(^2\), the state of diagnosis, care delivery and outcomes is not known for the majority of these patients.

A 10-year review of the Malaysian Psoriasis Registry (MPR) data from 2007-2016 involving 15,794 adult patients from 25 dermatology outpatient clinics, found that plaque psoriasis was the most common type of psoriasis.\(^4\) It accounted for 85% of individuals, followed by guttate psoriasis (3%), erythrodermic psoriasis (2%), and pustular psoriasis (1%). Participating clinics were predominantly from public hospitals.\(^4\)

The majority of patients received topical treatment (94%), while 25% were also prescribed systemic, phototherapy and biologics. Despite therapies that were given, treatment outcomes indicated that 51% of patients followed up did not experience improvement in skin lesions while 18% worsened. Joint pain symptoms worsened or remained the same in 49% of cases.\(^7\)

Based on available data, 51% of patients followed up did not experience improvement in skin lesions while 18% worsened, despite therapies that were given.

Moderate to severe psoriasis patients, who have a larger disease burden, would be the most affected by suboptimal treatment outcomes. Nearly a quarter of patients attending the outpatient clinics had moderate to severe disease.\(^4\)

As a chronic relapsing condition, psoriasis requires long-term management which considers associated co-morbidities, high psychological burden, and functional impairment.

Malaysian patients with psoriasis experience quality of life impairment on the same level as other chronic medical conditions, such as ischaemic heart disease and diabetes.\(^2\)
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Seen predominantly as a dermatological condition, psoriasis is consequently placed low on the list of health priorities in Malaysia.

There is still limited information concerning the epidemiological and clinical data pertaining to psoriasis in Malaysia, especially patients in primary care and private hospitals.

Improving the availability and diversity of research into this area of dermatology would contribute to a better understanding of the disease burden, assess the effectiveness of treatment approaches, and guiding the development of health policies to increase access to more effective treatments.

Diagram 1 - Profile of Malaysian adult patients with psoriasis managed by dermatologists

Global commitment to reduce burden

A report by the World Health Organisation (WHO) on psoriasis published in 2013, followed by a World Health Assembly resolution in 2014, placed renewed emphasis on the condition as a serious noncommunicable disease (NCD). These interventions called on country-level actions to improve the care of people living with psoriasis.

Besides addressing issues of access to treatment and care, associated co-morbidities, the United Nations organisation has urged countries to increase efforts to improve awareness of the condition and alleviate the suffering caused by the discrimination of people with psoriasis.

WHO’s Global Report on Psoriasis 2016 called for the following key actions to improve the care of people with psoriasis: commitment and managerial support from policymakers; improved access to services and medicines; education and training for healthcare providers, especially in primary-care settings; and advocacy efforts to raise awareness and fight the stigma suffered by people living with psoriasis.
Treating psoriasis

“Psoriasis is common and not just a skin disease. It is a systemic disease associated with comorbidities. Treatment needs to be tailored depending on severity. Patients need to understand the disease so that they are more compliant to treatment.” – Senior dermatologist

Early diagnosis and ensuring that access to treatment are patient-centred and coordinated with the management of co-morbidities, are critical to ensuring that people with psoriasis are able to be treated holistically and effectively. Therapies must not only be efficacious, but also safe over long periods.

The long-term outlook for a person with psoriasis can be significantly improved by ensuring that there is access to quality care through effective and coordinated treatment.

The goal of treatment should be to achieve what people living with psoriasis want most, namely skin that is completely clear of psoriasis.

Treatment is centred on the control of symptoms to achieve remission (a period when symptoms lessen or disappear). Several factors are considered namely, the type, severity, and location of the psoriasis; the patient’s age and medical history; and the impact the disease has had on quality of life.

In Malaysia, the bulk of psoriasis treatment is provided and administered through the public health system which provides for topical, phototherapy, conventional systemic and biologics therapies. However, treatment approaches in Malaysia may differ between public and private healthcare sectors.

Determining treatment

The International Psoriasis Council found that the existing classification of psoriasis severity (mild, moderate and severe categories) resulted in patients not receiving appropriate care and treatment. In 2019, a consensus proposed re-defining psoriasis into two categories: either candidates for topical therapy or candidates for systemic therapy.

Those who require systemic therapy (conventional systemic treatments and biologics) are patients who meet at least one of the following criteria:

- body surface area >10%,
- disease involving special areas (face, hand, palm, soles, genitals), and
- failure of topical therapy

Under those standards, if only 1% of the body surface area is involved but if affects special areas such as the face, systemic treatment would be appropriate as such a lesion is expected to have a severe impact on quality of life and daily functioning.

Over 90% of patients on the Malaysian psoriasis registry are on topical therapy, predominantly topical corticosteroids and emollients. Only 3% of adults and 1% of paediatric patients have been treated with phototherapy, while around 18% of adults are on systemic therapy, predominantly methotrexate, acitretin, cyclosporine and sulphasalazine (treatment of joint disease). Less than 3% are on biologic therapy.

While the CPG advises for stepwise treatment from topical to phototherapy to systemic and biologic options taking into consideration cost constraints and safety profiles, clinical judgement is also crucial. For example, a person with joint disease should not
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solely be treated by topical therapy or phototherapy, as it will not modify their joint symptoms.

The emergence and use of biologic therapies in the past decade have been found to be highly effective than other treatments. They bring hope, relief from pain and improvements in the quality of life of a person with psoriasis. As observed in the Malaysian context, it has realised the possibility of patients achieving PASI 90 or even PASI 100 (clear skin). However, the issue of cost often limits its use to select and very severe patients.

Management of this condition must also take into consideration the psychological and socioeconomic consequences of living with psoriasis without appropriate treatment.

A multicentre trial in the United Kingdom found that intensively treating to target for patients with early psoriatic arthritis improved joint and skin outcomes, as well as patient-reported outcomes.

Accessing and affording appropriate therapy and care

The journey for psoriasis patients towards finding treatment that is both effective and acceptable for them, has been described as long and arduous. Studies from several developed countries show that the average annual costs of moderate to severe psoriasis were between RM 14,000 and RM 43,000 per patient.

While this would include medication and hospitalisation, a substantial amount goes towards the management of comorbidities, estimated to be around RM 12,000 annually.

Psoriasis is associated with lower earnings and rates of employment. Indirect costs should also be factored in due to individuals needing to take days off-work or being unemployed due to accessing treatment. Most adult patients in the Malaysian registry had 1-5 clinic visits.

Treatment options

**Topical:** Topical treatment generally complements systemic treatment in moderate to severe psoriasis. While toxicity is lower, adherence, convenience, and satisfaction are challenges faced by patients with more extensive disease.

**Phototherapy:** Phototherapy can be chosen if topical treatment is inadequate, or be used in conjunction with systemic treatment. Effective treatment requires two to three treatments per week for a defined period, hence it may not be suitable for those who are working or cannot travel frequently.

**Systemic**

- **Non-biologic:** Oral treatment includes methotrexate, ciclosporin and acitretin requires monitoring for toxicity and is used for extensive or widespread disease. Apremilast, a newer agent that modulates inflammation, has not yet been made been available in the national formulary.

- **Biologic:** Eligibility under the CPG is limited to severe psoriasis who have failed or contraindicated for phototherapy and systemic therapy. Biologic therapy can be classified by molecular targets and method of administration (subcutaneous or intravenous).
The direct cost of treating psoriasis to providers in the public healthcare sector in Malaysia reportedly ranged from RM 957 to RM 5,583 per patient per year. However, this did not necessarily reflect the true cost of treating psoriasis including comorbidities, or the cost of private care in the country.

The majority of patients depend on accessing treatment via the public healthcare system, due to it being subsidised and easily available through the network of healthcare facilities across the country.

Topical creams and ointments are often prescribed as the first line of treatment for psoriasis and the most accessible through both the public and private healthcare systems.

However, patients reported feeling stressed from repeatedly needing to apply creams and ointments, while others experienced thinning of the skin and discontinued application. If there were extensive areas to be medicated, vitamin D analogue creams provided could quickly run out and need to be purchased out-of-pocket which could be expensive in the long term.

As phototherapy is only available in major government hospitals and during working hours, very few patients who are working or studying are able to access this option. This explains the low number of patients on phototherapy under the registry.

Biologics are the last line of treatment in Malaysia. In the national formulary, patients must have failed conventional treatment – topical, phototherapy and systemic treatment options (methotrexate, cyclosporine, or acitretin).

However, the cost of biologics for a single patient can range from RM23,000 to RM50,000 per year. Newer biologic treatment options can even reach between RM50,000 and RM60,000.

Under the public healthcare system, a mix of financing mechanisms enable clinicians to treat a small pool of patients on biologic injections. If this pool is to be widened and this option be available for more people with psoriasis, innovative funding mechanisms are needed.

CASE STUDY
Azman, 47 years old, legal professional

Azman (not his real name), 47 years old, was first diagnosed with psoriasis 15 years ago.

Initially treated as having a dandruff problem which later developed into dry skin with pus-filled pustules, Azman was unable to move his lower limbs due to extensive patches on his calves and thighs.

He is currently on a monthly biologic treatment on the recommendation of his doctors through a patient assistance programme at a public hospital and is responding well to the therapy.

Azman considers himself 90 percent cured with his outward physical appearance showing none of the earlier painful symptoms of psoriasis.

The challenges of treatment access and affordability have brought on conundrums for patients in Malaysia.

A person with both psoriasis and psoriatic arthritis was documented as saying during one of the organised consultations that she should not have to wish herself “to be sicker in order to get better treatment.” In other countries, she may have already qualified for biologic treatment.
However, the full cost of treatment, if unsubsidised, would be beyond the out-of-pocket affordability of the average patient.

Despite the availability of effective biologic treatments and great need, they remain out of reach of most patients. This is a cause of frustration for many. However, it is also an opportunity to develop innovative funding solutions which could bridge the gap and provide access to treatment for those who need it.

Dermatologists who were consulted during the development of this paper held the opinion that psoriasis being a systemic inflammatory disease which could progress to irreversible changes if left untreated, needs early and intensive treatment.18, 24

Treating early with systemic agents is being studied at the current time. It is hoped that an aggressive approach would lower the risk of onset of psoriatic arthritis, and reduce the risk of cardiovascular co-morbidities, as these cause further complications and increase the burden of treatment.

Some dermatologists advocated that the first therapy should be the most effective, rather than adopting ”saving the best for last” approach. This could instead potentially prolong remission, prevent the onset of psoriatic arthritis, lower the risk of cardiovascular co-morbidities, and even painful disability or deformity.15

The cost of biologics for a single patient range from RM23,000 to RM50,000 per year. Under the public healthcare system, a mix of financing mechanisms enable clinicians to treat a small pool of patients on biologic injections.

Patients’ Dilemma18

Dissatisfaction and frustration about existing treatment (e.g. perceived efficacy, side-effects, high dosing frequency, and affordability) have resulted in patients, despite being knowledgeable about the range of treatment available, resorting to complementary, traditional, or herbal remedies and supplements. These have ranged from Indian medicine, traditional Chinese medicine, and imported supplements, many of which have been promoted as “cures” or alternative treatments on social media.

Some medication such as methotrexate, were unacceptable by patients, as it had been indicated for cancer and causes significant side effects. The results of conventional treatment seen to be ”temporary”, manifesting with the return of flare-ups or symptoms when treatment was discontinued, was highlighted as a major concern.

Many persons with psoriasis found themselves having to choose, resorting to traditional remedies or herbal supplements, when they are unable to secure viable options in orthodox medicine.
Challenges and unmet needs in managing psoriasis in Malaysia

Lack of awareness among health professionals leading to late diagnosis

- Among adults, the gap between average age of disease onset and diagnosis was 2 years, signifying a delay in help-seeking, doctor-shopping, or failure of health professionals to provide an accurate diagnosis. Symptoms of psoriasis are first diagnosed most frequently between the age of 21-30 years old.²
- Patients may encounter barriers in healthcare settings such as knowledge gaps about skin diseases among non-dermatology trained health professionals. For whatever reason, there may also be delays in referring them to dermatologists. General practitioners (GPs) and primary care physicians need to be better informed and supported about the disease.
- Healthcare professionals are often missing the link between psoriasis and other illnesses, such as psoriatic arthritis, cardiometabolic diseases and mental health problems.
- This lack of knowledge or misinformation about psoriasis as a chronic disease among health care administrators and insurers could negatively affect the overall medical treatment of psoriasis and its reimbursement.
- Psoriasis patients consistently indicated that the best and most reliable way of getting a diagnosis of their condition was through the public health service.

Limited treatment options

- Topical therapies alone are often insufficient to achieve skin clearance in moderate to severe psoriasis. They are often prescribed as concurrent therapy. Oral systemic therapy, phototherapy, and biologic therapy are recommended.²⁹ However, the predominant reliance on topical therapies in the country is a cause for concern.
- Despite nearly 1 in 4 patients classified as having moderate to severe disease, the utilisation of biologic therapy was much lower than expected at 3%.⁴
- Another study reported that only 57.3% of patients surveyed with severe psoriasis received phototherapy and/or systemic therapy, and 56.6% of those with joint involvement were on systemic therapy.²²
- The limited availability of biologic therapy has constrained dermatologists in Malaysia wanting to treat patients earlier.³⁰ The tighter Malaysian definition of severe psoriasis (BSA >30%) when compared to international guidelines also means that such therapies will only be considered when other systemic treatments cannot be tolerated or have failed. Despite this, many patients receiving biologic treatment in public hospitals were reportedly at BSA >50%.
- Based on a 10-year review of MPR data, existing coverage of biologic therapy appears sufficient only for very severe psoriasis patients with extensive lesions. To provide a general comparison, 131 and 43 patients at first visit and follow-up respectively had BSA > 90%. However, only 90 patients and 34 patients respectively were on biologic therapy.⁴

The limited availability of biologic therapy has constrained dermatologists in Malaysia wanting to treat patients earlier.
Diagram 2 – Initiating treatment for patients with psoriasis in Malaysia

Prescribed treatment at first visit in dermatology clinic

- Topical: 94%
- Oral: 19%
- Biologic: 3%
- Phototherapy: 3%

Source: Affandi et al, 2018

Low patient satisfaction due to treatment standards and goals

- Skin clearance is important for patients with psoriasis. ‘Get better skin quickly’, ‘recover from all skin lesions’, and ‘have confidence in the therapy’ were top-ranking patient needs in a German study. The impact is not merely cosmetic but improves quality of life, functioning and psychological burden.

- However, quality of life for patients did not consistently correspond with the clinician’s assessment of disease severity. A third of mild-to-moderate patients in one study reported significant impairment on their lives (DLQI>10).

- Patient-physician discordance on treatment goals can lead to low treatment satisfaction. In a Malaysian study, 1 in 4 patients surveyed wanted more intensive treatment and spent out-of-pocket on other therapies such as traditional medicine, supplements and vitamin D analogue creams.

- In the public sector, the limited access of treatment options for dermatologists is a hindrance to achieving treatment goals.

People living with psoriasis experience discrimination due to stigma

- The impact of stigma and discrimination on patients is little understood, even by some dermatologists and family members.

- As a result of stigma, it may be challenging for persons with psoriasis to secure gainful employment as a result of stigma. Job seekers, despite medical letters indicating that they did not have an infectious skin disease, are treated as if they were risks or liabilities, or persons with disabilities.

- When skin lesions are less obvious due to remission, employers disbelieved or lacked empathy when told that job seekers were living with a chronic condition.

- Without educating the public on the burden of being on chronic medications, the nature of illness, threat of disability, and fear of deformity, stigma and discrimination lead to isolation and marginalisation of people with psoriasis.
Psoriasis was described by some persons with psoriasis as worse than cancer because uncontrolled disease spelled a lifetime of suffering – with no way out.\textsuperscript{18} Progression to psoriatic arthritis led to members of their community being unable to walk, pick things up with their fingers, or even move their neck.

**Limited insurance coverage**

- There was consensus among persons with psoriasis interviewed that their condition is not being taken seriously or even understood by private medical health insurance providers.\textsuperscript{15, 24}

- As psoriasis was seen largely as an aesthetic disease, limited medical insurance providers cover treatment including for biologics. Patients indicated that "some insurance companies just barely cover biologics, and some do not at all."\textsuperscript{15}

- The Employee Provident Fund (EPF) provides partial withdrawal Account 2 facilities for persons diagnosed with psoriatic arthritis (PsA) only, while the Social Security Organisation (SOCSO) also provides benefits under its Invalidity Scheme for those with PsA.\textsuperscript{15}

**Underutilisation of national registry**

- Established in 1998, the Malaysian Psoriasis Registry (MPR) helps to provide real-world insight into clinical practice, describe patient outcomes and measure quality of care. However, gaps in the reporting and utilisation of the registry threatens to undermine its value in the treatment of the condition.

- The registry is over-represented by those accessing government healthcare facilities as clinicians in the private sector are less likely to report their data into the registry.

- Out of 15,635 cases notified to the MPR from 2007-2016, 5701 cases had follow-up data, representing a loss to follow-up of 63.5%.

- The registry obtained information on whether prescribed treatment fulfilled therapeutic goals. Findings identifying areas for improvement deserve more attention than given currently.

- Patients should not be maintained on ineffective treatment or suboptimal care, especially for moderate to severe psoriasis.

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**CASE STUDY**

*Aminah*, 64 years old, retiree

“I am a senior citizen who is both a patient and a caregiver. I already have psoriasis arthritis, as well as heart problems. But if you look at me now, I feel very healthy for my age. I use topical treatments and other medications. I have a 30 years old son who is also with psoriasis. He has stopped working for three years as no employer wants to employ him. His conditions is controlled on methotrexate. He wants to work but employers are not willing to accept him.”

*Name has been changed*
What can we do to address treatment gaps and improve patient-centred care?

Support and empower people with psoriasis

- The role of patient advocacy groups is expanding and growing stronger, as patient-centred approaches in healthcare becoming increasing important.

- People with psoriasis in Malaysia and their network such as the Psoriasis Association of Malaysia should be involved and empowered to represent themselves and speak on their issues. They can play an important role in contributing their feedback in the development of treatment guidelines and policies, as well as initiatives which address stigma and discrimination of those living with the condition.

- The government should initiate the creation of patient support frameworks which aim to include patient voices in the provision and evaluation of their care.

Implement a National Psoriasis Programme

- Implementing standards for patient-centred care is essential for a lifelong disease with associated co-morbidities. A multidisciplinary team that consists of pharmacists and mental health professionals is integral to care for the patient with moderate to severe psoriasis.

- In order to reduce under-treatment of patients with moderate-to-severe psoriasis, it is recommended to use treatment goals for each patient. Establishing clear treatment goals, including choice of treatment options, regular evaluation of outcomes, and endpoints on when to modify therapy, improves psoriasis management.

- Pharmacists delivering Medication Therapy Adherence Clinic (MTAC) services should be well-trained in management of patients on systemic and biologic therapy, including when to recommend modifying or intensifying therapy.

- Early detection of psoriatic arthritis is vital to prevent progressive complications. The Malaysian Clinical Practice Guidelines (CPG) for psoriasis does not recommend any screening tools for routine use. Validation of existing tools for the Malaysian population is important for wider screening by clinicians at all levels of care.

Improve access to earlier interventions, therapies and care

- Despite the availability of options for the treatment of psoriasis, existing surveys have indicated that people with psoriasis do not receive the optimal care that is necessary to clear their skin symptoms, treat their disease and improve their QoL.

- Interventions to identify and manage psoriasis should be part of existing health care services at the primary care level.

- The use of biologic therapies has been found to be highly effective than other treatments resulting in improved physical functionality, better productivity and significant improvements in the patient’s QoL. There must be deliberate effort to increase access and availability of such treatments for people with psoriasis.

- Services for psoriasis should be patient-centred and coordinated drawing on a multidisciplinary approach to ensure the best possible patient care, encompassing patient education, counselling, and the availability of different treatment options.
All eligible patients should be provided with access to treatment, as indicated under the existing CPG. No one should be left behind.

**Improve access to funding and classify psoriasis under critical illness**

- Psoriatic arthritis should be included as a critical illness under private health insurance schemes. It should also be one of the conditions covered under the critical illness covered by the Ministry of Finance’s MySalam protection scheme.

- Patients speak of being in limbo and left out where one is not severe enough to qualify for benefits and services under the Employee Provident Fund (EPF) or Social Security Organisation (SOCSO), but not well enough to be hired by employers. The provisions under the schemes for both the EPF and SOCSO should be reviewed with input from psoriasis patient groups.

- More private health insurance should also consider covering psoriasis treatment under their policies due to the episodic and recurrent nature of the condition, as well as progressive complications that could lead to higher healthcare costs. Patients frequently highlighted that outpatient treatment for psoriasis is not covered under insurance policies. Despite being similar to haemodialysis, where the medical condition (e.g. kidney failure) is lifelong and treatment not necessarily needing hospitalisation, psoriasis is excluded from coverage. Treating psoriasis similar to haemodialysis treatment, could mean thousands of patients being able to access biologic therapies through their insurance policies.

- Public funding for psoriasis needs, particularly allocations under the Ministry of Health, should be harmonised with current patient needs and allocated accordingly to ensure that the treatment gap can be narrowed. Patients are being left behind due to limited access and prioritisation.

**Improve and strengthen the Malaysian Psoriasis Registry for patient-centred outcomes**

- A national patient registry for psoriasis, when used effectively, not only helps in data gathering, it also promotes a better understanding of both successful and unsuccessful strategies and supports exchange of information and communication among health care providers.

- As psoriasis is a lifelong condition, the national database plays a role in ensuring that psoriasis is recognised by payers and policymakers.

- Dermatology care providers and clinicians should prioritise data entry, especially for follow-up data, to ensure outcomes are captured nationally. Treatment and care patterns in the registry provide policymakers with rigorous evidence to raise priority for funding.

- Improving the clinical picture of long-term prognosis and outcomes for psoriasis will help in the development of more effective therapies and improve quality of service delivery.
Conclusion

With an estimated 500,000 in Malaysia living with psoriasis, recent developments in the treatment of the disease provide opportunities for policymakers to deliver on WHO’s call for action to improve the care of people living with psoriasis.

Much more can be done to improve the lives of people living with psoriasis in Malaysia.

Despite significant advances in clinical medicine, unfortunately people with this condition are still undiagnosed, undertreated and face significant hurdles which affect their physical, social, and psychological well-being.

They face social exclusion and stigma which are devastating for them and their families. It undermines their ability to realise their full potential, and negatively impact their life.

Empowering people with psoriasis to represent themselves, speak on their issues, and take part in improving the quality of their treatment should be an essential ingredient of any effort.

It is critical that awareness and recognition of psoriasis as a serious medical condition that can significantly impact quality of life is emphasised among healthcare professionals, particularly those at the primary care level. Doing so will enable people with psoriasis to be diagnosed early and provided with the necessary care.

There are currently many patients in Malaysia who are not gaining the benefits of early access to high-quality care. This is due to several factors, including low prioritisation, non-standardised treatment goals, and limited funding.

Investing in ensuring that people with psoriasis receive quality, timely and effective treatment reduces the individual burden and wider economic impact of the disease.

Better understanding of the effectiveness of treatment strategies as well as communication among health care providers can be done by increasing utilisation and strengthening of the Malaysian Psoriasis Registry.

The long-term objective for Malaysia should be to develop a model of healthcare which ensures the delivery of comprehensive, individually adapted treatment for people with psoriasis that involves a multidisciplinary team working in a co-ordinated and integrated way.

Patient-centred, co-ordinated care is the most effective way to manage psoriasis and its comorbidities.

With sufficient resources and investment to provide adequate access to care, especially for patients with moderate to severe psoriasis, suffering can be reduced, and lives changed for the better.
References


The Galen Centre for Health and Social Policy is an independent public policy research and advocacy organisation based in Malaysia dedicated to discussing health and social issues through the lens of public policy.

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We work to improve health and social conditions through research, advocacy, networking and relationship-building.