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Social and familial impact of psoriatic disease

Psoriatic disease can significantly impact the social and familial life of people living with the condition in Asia. The visible nature of the disease and its social stigma can lead to embarrassment and social isolation, which can negatively impact a person's quality of life. People with psoriatic disease may also face discrimination and limited opportunities in education and employment due to the visible nature of the condition.

In Asia, where family and social connections are highly valued, the impact of psoriatic disease on social and family life can be particularly pronounced. Psoriatic disease can affect people at different life stages and impact their interactions with family, friends or co-workers and how they contribute to society.

THE CHALLENGES

Social stigma and discrimination

Psoriatic disease at a young age can leave damaging social, personal, and emotional scars.[1] Both the youth and their parents can be affected, and there is growing evidence that there may be an increased risk of developing childhood psychosocial and mental health problems in relation to having psoriatic disease.[1,2]

Family members, especially parents who have a child with psoriatic disease, may feel guilt towards their child, which can have negative emotional and/or psychological consequences for both the parent and child.[1]

Securing gainful employment due to prevailing stigma can be a challenge for people with psoriatic disease. The impact of stigma and discrimination is poorly understood, even by primary healthcare physicians.[3] Many people, due to social stigma and other personal reasons, have not come forward to seek treatment, and this may lead to a worsening of their condition.

Workplace opportunities and workforce engagement

Studies show that people with psoriatic disease are more likely to have fewer opportunities to be hired, and have missed work due to poor health and that the disease impacts productivity, burdening the economy and workforce.[4,5]

Lower levels of engagement at work: Poor health can negatively impact a person's capacity to contribute fully at work.
In a survey from the Philippines, 62% of respondents reported they had been prevented from fully engaging in work or school activities because of their psoriasis (38% frequently did so), and 69% have had work/school affected by psoriasis (45% frequently so).[6]

Lower earnings and unemployment: Missed days at work can seriously impact a person's wages and cause a person to be unable to work, affecting household income.[6] People with psoriatic disease also tend to have higher healthcare expenditures and sick days off from work and to be accompanied by family members to medical appointments or hospital visits.[7]

Impact on family members

Psoriatic disease is a chronic and sometimes disabling health condition that can greatly impact the whole family, especially in Asia, as caregiving responsibility is often kept within the family. Caring for a relative's chronic condition may affect family members in many ways, impacting their emotional and psychological wellbeing.

Social exclusion from stigmatization can be hard to cope with when it affects a close family member– it may even extend to the family caring for the person, causing stress and mental distress.

Caregivers may be family members, close relatives, or friends, which can strain relationships or the person caring.

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The financial burden of treatment and care can also affect families, especially in low-income households.[7] A family member caring for a relative may have to give up their job, change jobs or careers or reduce their work hours to care for a family member with psoriatic disease and manage hospital visits.

Women and their families

Women, in particular, may experience a higher disease burden than men, as psoriatic disease can have a greater impact on outcomes and quality of life. Women looking to start a family or caring for a young family tend to struggle most, with higher psychological implications reported with their disease than with men.[8,9]

PRIORITY ASKS

Employers: Provide a flexible work environment with accommodations such as flexible working hours, remote work options, and ergonomic equipment. Raise awareness about the disease and its impact on individuals to foster understanding among employees and their families.

Policymakers: Promote social and familial support by ensuring access to affordable healthcare and mental health services, promoting workplace accommodations, and allocating resources to reduce stigma and discrimination through support, for example, of activities by patient support groups and industry.

Patient organizations: Provide community and reduce social isolation for people with psoriatic disease. Offer opportunities for learning, sharing experiences, and emotional support with support groups for people with psoriatic disease as well as caregivers/family members.

Family and friends: Offer understanding, empathy, and emotional support, and encourage seeking professional help. Help reduce social isolation by inviting loved ones to social events and activities. Connect with other families to receive and offer support.

References

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IFPA FORUM ASIA THEME BRIEFS

This background document has been produced to provide an overview of one of the four themes that will be explored at the IFPA Forum Asia 2023. The four themes prioritized by IFPA patient association members in Asia are Access to care, Addressing and managing comorbidities, Mental health, and the Social and familial impact of psoriatic disease.

IFPA

Founded in 1971, IFPA is the international federation of psoriatic disease associations. We are the psoriatic disease community. Our members represent over 60 million people living with psoriatic disease. Together, we advocate for a future where all people living with psoriatic disease enjoy good health and wellbeing, free from stigma and preventable disability and comorbidities.

PsorAsia

Founded in 2012, PsorAsia is a regional organization in the Asia Pacific for psoriatic disease associations. PsorAsia is the regional arm of IFPA, and they represent the interests of millions of people living with psoriatic disease in the region.