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WORLD PSORIASIS DAY REPORT-2022

By: Dakshayani and Amaravati Health and Education (DakshamA Health)



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Psoriasis is a non-communicable, common inflammatory skin disease that affects 2-3% of the global population, or approximately 125 million people. In India, the prevalence of psoriasis among adults ranges from 0.44 to 2.8%2. It is distinguished by an unpredictable course of symptoms, a wide range of extrinsic triggers, and severe comorbidities such as arthritis, metabolic syndrome, cardiovascular disease, inflammatory bowel disease, and depression.

The World Health Assembly recognised psoriasis as a critical NCD in 2014 and issued a resolution to improve the lives of those affected. As a result, the public health impact of psoriasis is highlighted.

Data on psoriasis prevalence in India currently comes from hospital-based studies rather than welldefined, large population-based studies. There is a deficit of data on the genetics, epidemiology, disease types, associations, and severity of Indian psoriasis patients. Risk factor studies are rarely conducted, which would aid in the identification of preventative strategies for chronic noncommunicable diseases. There is no cure for psoriasis diseases. This increases the burden on the patient's life and puts them in a vicious cycle of disease management without conclusive authenticated evidence.

Some of the key factors that must be addressed at all levels of healthcare in India to have a holistic and comprehensive approach to disease management. It is critical to comprehend how the disease affects people's lives.

On the occasion of World Psoriasis Day, 27th October,2022, Community of Psoriasis Supporters (Initiative by Dakshayani and Amaravati Health and Education) in collaboration with Indian Association of Dermatologists, Venereologists and Leprologists (IADVL) organised a virtual event with the theme **"Uniting for Action- Building A Voice for Psoriasis Patients in India"**, 04:00 PM IST onwards.

The panel discussion focused on the key issues surrounding psoriasis in India and the impact it has on patients' lives. The discussions focused on a few important aspects as well as potential solutions.

PANELIST:
Chairs:
Dr. Rashmi Sarkar, IADVL President
Dr. Sunil Dogra, Dept. Of Dermatology, PGIMER Chandigarh
Speakers:
Dr. Vibhu Mendiratta, Head, Dept of Dermatology, LHMC, New Delhi
Dr. Ramesh Bhat, Vice Dean, Father Muller Medical College, Mangalore Director, ILDS, President
IADVL (National)- 2018
Dr. Rashmi Kumari, Head, Dept. of Dermatology, JIPMER, Pondicherry
Dr. Vishalakshi Vishwanath, Head, Dept. of Dermatology, Rajiv Gandhi Medical College, Thane,
Mumbai
Mr. Varun Verma, Psoriasis Supporter
Dr. Ratna Devi, CEO and Co-founder DakshamA Health

Key takeaways from the discussion points:

Awareness:

• Patients must be provided counselling on the appropriate treatment regimen and informed about newer medications, along with their side effects and benefits.



- Patients and caregivers are unaware of the disease's aetiology, signs and symptoms, and life course. As a result, they have a poor understanding of how to manage their condition.
- In India, there is no easily accessible awareness material or resources on dermatological conditions for patients and caregivers. Patient education materials and leaflets can be created to help patients better manage their condition.
- Enhance disease awareness, patient-centred policies, and media coverage of the disease's impact on the lives of patients and caregivers.
- A lack of awareness leads to inadequate screening and delayed treatment, making them feel burdened, dissatisfied about their condition.

Trained Manpower:

- Training in counselling for medical professionals can improve patient care and compliance.
- One significant area of need is a lack of access to medical specialists including certified dermatologists. Specialists must have the necessary training to ensure the most effective diagnosis, care, and management of the condition.
- Continuous medical education on the updated treatment protocols and diagnostic tools.

Social and Mental wellbeing:

• Their mental health can have an impact on their professional development, social connections, and family dynamics. Inclusion of managing mental health as a holistic approach to treating patients, which increases patient adherence to treatment and medications.

Insurance:

- Involvement of insurance stakeholders to help them understand the significance and purpose of including dermatological disorders in the insurance package.
- The high cost of medicines, such as biologics, must be covered by insurance policies that allow patients to access better treatment options.

Standard treatment protocols and guidelines:

- Standardized treatment and diagnosis procedures are required for patients with dermatological conditions like psoriasis.
- Care continuum pathways and a clearly defined holistic approach to managing the condition must be designed with the assistance of professional organisations and subject-matter experts.

Research and Development:

- Behavioural and social research to understand the needs of the patients and caregivers.
- Alternative treatments for psoriasis should be researched and backed by convincing scientific evidence.
- Research on diagnostic tools, newer treatments, and cost-effective treatments to improve diagnostic outcomes and treatment accessibility for patients
- More research on the quality of life and economic impact of dermatological conditions is needed.
- There is a scarcity of scientific evidence on when biologics should be used to treat these conditions. More research is needed to determine how effective these are and when they should be used.
- Data is insufficient to help us investigate the economic impact of diseases on patients.
- Pharmacogenomics research would aid in understanding the appropriate treatment as well as the drug's effects on patients.



National registry for dermatological conditions

- Patient registries that will help determine disease burden, such as dermatological problems, as well as the burden of patients' quality of life, are an urgent priority.
- The NDHM has included psoriasis in the registry, but the disease's burden has not yet been estimated.

Recognition under National Health policy and schemes:

- Increasing awareness, creating patient advocates, collaborating with research institutes, and forming partnerships with patient organisations could all be seen of as strategies to initiate the inclusion stage under national health policy.
- The ILDS has advised WHO to include biologics to the essential drugs list. Some countries, such as European nations, have already adopted this. Ayushman Bharat Scheme must include at least one biologic under UHC.
- Representation of dermatological disease in NPCDCS programmes, which would aid in early detection, treatment access, and reducing stigma and discrimination among patients.

CONCLUSION

Psoriasis is more than just a skin condition; it has an impact on patients' quality of life. It is critical that we express our concern to policymakers about the disease's criticality. This is possible with sufficient research and evidence. This can also be accomplished through strong advocacy efforts and the strengthening of patient voices. The need of the hour is patient-driven policy and standard treatment and management guidelines. It is critical that we focus on strategies and roadmaps for psoriasis recognition in national health policy and universal healthcare schemes. This will ensure that patients benefit from improved access to treatments, higher quality care, and a reduction in stigma and discrimination.