Viewpoint

Gender inequalities in inflammatory dermatoses and an unmet need for enhanced management in the Indian context

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Introduction

The well-being of female family members is intricately linked to the overall health and functioning of families. Prioritising the health of female members can yield positive benefits for both the family unit and society at large. Upon reflecting on our recent clinical interactions with female patients diagnosed with a diverse range of inflammatory dermatological conditions primarily affecting women, such as scleroderma, lupus, dermatomyositis, Sjogren's syndrome, overlap syndromes, hidradenitis suppurativa (HS), and lichen sclerosus et atrophicus (LSA),[1] a discernible pattern emerges regarding the physical, psychological, and social challenges affecting these patients, extending beyond the clinical manifestations typically addressed in clinics.

The term "disparities" denotes differences or inequalities, particularly in treatment, outcomes, or opportunities among various groups of people. These variations may stem from diverse biological factors such as race, ethnicity, and gender, as well as geographical and economic factors like geographic location and socioeconomic status. In the healthcare context, health disparities may encompass variations in inherent biological susceptibility to disease, access to care, quality of care, or health outcomes across different demographic groups, further influenced by multiple factors. This perspective sheds light on the daily struggles, disparities, and challenges faced by female patients affected by inflammatory dermatoses which disproportionately affect women, underscoring the urgent need for enhanced management strategies beyond pharmacological therapies, particularly in the Indian context.

Impact on physical health and functional limitations

Motor tasks

Several of the dermatoses mentioned above result in significant physical symptoms and accompanying functional limitations affecting both gross and fine motor activities. Cardio-pulmonary concerns, including pulmonary hypertension, interstitial lung disease and chest wall fibrosis further contribute to functional limitations.[1]

Sun-exposure

Particularly within the Indian cultural milieu, there may be a reluctance to acknowledge the possibility of photosensitivity, especially among married women, with families occasionally dismissing concerns by attributing symptoms to "malingering".

These disabilities can pose significant obstacles to performing everyday tasks, including handling cold objects, gripping and cutting vegetables, cooking, engaging in wet work, cleaning, and buttoning clothing. In the cultural context of India, where women are often expected to bear the responsibility of managing household chores and childcare, the gross motor limitations can lead to considerable distress and difficulty fulfilling societal expectations. Addressing these potential limitations beyond the scope of routine counselling by the physician therefore is of paramount importance, especially when performed in presence of the family members.

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Table 1: Remedial measures and practical strategies for addressing female-specific concerns in dermatoses

Dermatoses	Disabilities and concerns pertaining to females owing to their expected work-profile	Support measures
Physical health		
Gross and fine motor functions, balance, bone health		
Systemic lupus erythematosus, dermatomyositis, scleroderma and morphea, particularly in the linear and pan-sclerotic variants, hidradenitis suppurativa, lichen sclerosus *et* atrophicus.	Small and large joint pain, muscle fatigue and weakness affecting the midline and proximal muscle groups along with skin fibrosis, panniculitis, lipoatrophy and dystrophic calcification result in reduced sense of balance and gross movement difficulties impacting basic activities like walking, climbing stairs, bending and lifting objects. Rarely, therapy and/or disease-associated avascular necrosis of hips also contribute to the discussed issues. HS causes painful lumps and abscesses, often in friction-prone areas, impacting mobility and making simple daily activities like sitting, walking and dressing extremely uncomfortable. LSA results in thinning, itching and erosions in genital and anal areas, causing discomfort, pain and limited mobility.	Physiotherapy is extremely important in addition to pharmacologic measures to maintain function. Support from family is essential in the Indian context from scheduling appointments to attending the appointments, thereby highlighting the discussion of these topics in the presence of family members.
Systemic lupus erythematosus, dermatomyositis, mixed connective tissue disease.	Outdoor activities which involve exposure to sun like gardening, drying clothes, farming and tending to animals, cleaning. Both patients and their families may hesitate to recognize the risks associated with sun exposure. This dynamic adds layers of complexity to addressing the importance of sun protection in such contexts.	Emphasis on the use of sunscreen and sun protective clothing, avoidance of going out in peak hours, addition of sheds and covers in balconies.
Systemic sclerosis, mixed connective tissue disease, also frequent in lupus and anti-synthetase syndrome associated with myositis.	Due to skin fibrosis, calcinosis cutis, Raynaud's phenomenon and fingertip ulcers, hand-functions are significantly impaired leading to a disability to perform simple chores like buttoning clothes, gripping objects and performing kitchen work.	Home-based physiotherapy like squeezing a ball, emphasis on moisturising hands, looking out for ulcer development, and using utensils with heat-proof handles for better grip. Use of warm water for daily chores, thermal gloves for handling cold objects.
Reproductive health		
Challenges preceding conception		
Systemic lupus erythematosus, dermatomyositis, scleroderma, mixed connective tissue disease, severe subtypes of morphea, hidradenitis suppurativa; all chronic dermatoses needing prolonged medical management.	Desire on the part of the patients and families to extend their families and bear children as soon as possible, coupled with immense societal pressure. Hormonal imbalances, irregular menstrual cycles, and fertility issues (like primary or secondary ovarian insufficiency) resulting from prolonged effects of immunosuppressive and genotoxic medications, and also from the autoimmunity associated with the primary disease that affects the gonadal function. APLAS can be associated, and significantly affects the outcomes of the already precarious and precious pregnancies. Physiological complications can arise from the disease per se that prohibit conception, sometimes forever. For example, the development of pulmonary hypertension in scleroderma creates great uncertainty about achieving motherhood ever.	Discussing the advantages of disease control prior to conception, partner involvement in discussion related to family planning, screening for APLA syndrome, and discussing the medication and disease effect on pregnancy and its outcomes. Guidance on fertility-preserving options such as sperm or egg freezing, and surrogacy.
Challenges during pregnancy and post-partum		
Systemic lupus erythematosus, scleroderma, mixed connective tissue disease, hidradenitis suppurativa.	Pregnancies in CTDs, particularly lupus and scleroderma, are often high-risk at baseline. Additionally, autoimmune diseases like lupus also have a tendency to flare-up during pregnancy, creating a fear of disease exacerbation and deterioration in an already demanding physiological state like pregnancy. Increased vulnerability to complications like preeclampsia, preterm birth, and low birth weight, alongside challenges like recurrent miscarriages in those with anti-phospholipid antibody (APLA) and issues with assisted reproductive techniques, can be intensely demanding. hidradenitis suppurativa can have flares during pregnancy, triggered by hormonal fluctuations or weight gain, add discomfort, and complicate lesion care during pregnancy, especially during the third trimester with the gravid uterus.	Multi-disciplinary management is of utmost importance.

(*Contd*)

Dermatoses	Disabilities and concerns pertaining to females owing to their expected work-profile	Support measures
Sexual health and well-being		
Systemic lupus erythematosus, scleroderma, Sjogren's syndrome, mixed connective tissue disease, Lichen sclerosus et atrophicus, hidradenitis suppurativa.	Negative impact on self-esteem and sexual relationships. HS, for example, can pose unique challenges as it affects intimate areas, influences menstrual hygiene, and strains sexual relationships. Vaginal dryness in Sjogren's syndrome and scleroderma, genital lesions in HS, and sclerosis and itching in LSA pose issues of dyspareunia and decreased sexual satisfaction.	Family counselling, involving partners in the discussion of the disease implication and management, early involvement of psychologists, and discussion about social support groups to facilitate discussion with people suffering from a similar disease. Multidisciplinary management and family and/or partner involvement is the cornerstone.
Impact on emotional and social health		
Emotional health		
Systemic lupus erythematosus, scleroderma, myositis, Sjogren's syndrome, mixed connective tissue disease, hidradenitis suppurativa.	Long treatment follow-ups and need for medical visits requiring extensive family support. Patients also experience emotional distress arising from disruption of daily activities and possible loss of functional independence, underscoring the vital need for medical support and family assistance in their treatment. Though detrimental for both genders, the effect on the emotional health of the females can be immensely disruptive because of precarious social disparities, expectations, and responsibilities, again important in the Indian context.	Scheduling follow-up based on both the patient and caregiver availability, identifying healthcare providers in proximity to their location, tele or video call visits, education about identifying high-risk features, and for early and emergent follow-up.
Social Health		
Systemic lupus erythematosus, scleroderma, myositis, Sjogren's syndrome, mixed connective tissue disease, hidradenitis suppurativa.	Social withdrawal and self-doubt are commonly faced due to the presence of active lesions, scarring, and post-inflammatory changes, many a times affecting the face and other cosmetically sensitive sites, given unrealistic beauty standards in the world of social media. The need to wear sun-protective clothing, and clothing to minimise friction affects daily wardrobe choices in people with CTDs and HS. Even with gender neutral diseases like vitiligo, the profound social stigma often leads to a detrimental impact on the marriage dynamics, especially if the affected patient is a female.	Support, multidisciplinary management, and a need to discuss these issues at follow-ups in order to address these comprehensively.

APLA: Anti-phospholipid antibody syndrome, CTD: Connective tissue diseases, HS: Hidradenitis suppurativa, LSA: Lichen Sclerosus et Atrophicus

Impact on sexual and reproductive health

Challenges preceding conception

Most of these diseases impact females during their child-bearing years and require long-term medications that may impair their reproductive health.[2] Several medications otherwise used in the treatment of these diseases like methotrexate, acitretin, thalidomide cannot be used among reproductive age group females due to genotoxic and embryotoxic nature. The challenge of delayed parenthood and societal expectations, especially significant in India, can have a significant emotional toll on the patients, and highlights the careful balance women have to navigate when deciding when to start their motherhood journey.

Challenges during pregnancy and post-partum

The need for intensified monitoring, specialised care and additional medications coupled with potential risks for conditions like neonatal lupus and congenital heart block further amplifies the challenges.[3] Caring for a newborn becomes especially daunting, given functional limitations discussed before such as ulcers, joint pain and Raynaud's causing significant emotional strain and anxiety.

Sexual health and well-being

The impact on sexual health and relationships varies across these diseases.[4,5] The physical and psychological repercussions of these diseases significantly impact women's overall sexual well-being, often contributing to instances of intimate partner violence (any behaviour in an intimate relationship that causes sexual, psychological or physical harm to the partner), abandonment threats and divorces.[4]

Impact on emotional, social and financial health

Emotional health

Chronicity of these diseases and unpredictable nature of the flares creates uncertainty about one's health. This, added to chronic pain, fatigue and neurological complications, can lead to emotional distress, including anxiety and depression. High levels of stress may exacerbate symptoms and negatively impact overall health.

Social health

In India, female patients grappling with inflammatory dermatoses also contend with pervasive social disparities, including unequal access to healthcare resources, cultural stigmatisation, limited educational and economic opportunities, and gender-based discrimination, all of which exacerbate the challenges they face in managing their conditions effectively.

Financial health

Due to physical limitations and unexpected flare-ups, absenteeism at workplace is common, leading to loss of job and financial independence. Additionally, the continuous

medical follow-up and the need for household helps or child-care increases the financial burden.

Significance of physical examination, open dialogue and the role of female physicians

The physical examination often entails a meticulous inspection of sensitive body areas, including the breasts, genitals and the perianal region. Some female patients may harbour preferences for female physicians, influenced by cultural, religious or personal beliefs, particularly when discussing sensitive topics such as sexual health and pregnancy. Female dermatologists often exhibit enhanced proficiency in ensuring patients' comfort during examinations, coupled with a personal understanding of female-specific concerns. Recognizing and honouring cultural differences, patient preferences and understanding their impact on healthcare decisions are imperative for delivering culturally competent care. Impact of various inflammatory dermatoses on women along with respective remedial measures has been summarised in Table 1.

Conclusion

Inflammatory dermatoses, notably CTDs, LSA and HS, primarily affect females, and significantly impact various spheres of health including physical, emotional, reproductive, social and financial well-being. Addressing these challenges necessitates a comprehensive approach that extends beyond medical management. Initiating open discussions from the outset, covering not only disease-specific concerns but also addressing reproductive health, psychological and social implications specific to females, and systematically addressing these concerns while involving the patient's family for comprehensive support are essential. Recognising the significance of physical examination, promoting open communication, and acknowledging the contributions of female physicians are crucial steps toward providing culturally competent care and improving the overall quality of life for women affected by these dermatoses.

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