

Integrating advocacy and lived experience into psychosocial care for rare skin diseases

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ABSTRACT

Psychosocial care is vital for people living with rare skin diseases, yet in Malaysia it is often overlooked. These conditions affect more than health — they shape daily life, bringing stigma, isolation, financial stress, and emotional strain for patients and caregivers. As a caregiver to a child with Epidermolysis Bullosa (EB) a fragile skin disease and I share a lived experience perspective on why psychological and emotional support must be part of holistic care. Families affected by rare skin diseases often face limited access to trained professionals, fragmented services, and little understanding from the community. To help bridge these gaps, I have supported families through peer groups, caregiver training, and short-term accommodation support. The approach is very personal and family-centred. Psychosocial care often happens in small, trusted ways: hospital or home visits, online counselling, or informal family gatherings. In this role, I act as a mediator, helping families communicate with healthcare providers and other stakeholders, while also taking time to understand their social, cultural, and family circumstances. Families say they feel safer and more supported in these trusted, community-based spaces than in formal systems alone. By sharing these experiences, I hope to show how family-centred and culturally grounded approaches can reduce isolation and help families live with dignity and hope.

Keywords: Rare Skin Diseases, Epidermolysis Bullosa, Psychosocial Care, Family Support, Lived Experienced