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# WHAT YOUR PATIENT IS THINKING

# Just another eczema case for you, but to me it's the world

Wei Chern Gavin Fong describes what it is like to grow up with eczema and how health professionals could have supported him better

Wei Chern Gavin Fong

I was diagnosed with eczema as a child and have lived with it for two decades. My journey has not been smooth sailing. The itch of atopic eczema was often debilitating, incessant, and intrusive. I remember clawing myself at night and struggling to sleep. At times I even physically hurt myself to distract from the itch. I was often told to simply "stop scratching," which was like being told not to sneeze.

# Take your time to explain to me

At most of my eczema clinic appointments I felt like I was being giving instructions rather than having a conversation. Any discussions were brief and mainly with my parents. No one truly spoke to me about my condition. I was involved only during a quick examination of my skin. The lack of explanation resulted in my parents and I not understanding the condition nor the treatment. We began to worry about becoming dependent on topical treatment, especially the steroids. I started refusing to use these sticky and uncomfortable therapies as I did not understand how they would help. This led to me being admitted to hospital to manage my condition and I missed three months of school. It also led us to explore expensive and unhelpful alternative therapies, some of which made my skin worse.

I wish health professionals had explained what caused the itching and why the topical therapy would help. Having a better understanding of the biology of eczema would have helped me learn how to manage it and improve my adherence.

#### Psychological impact

With my skin so visible, the eczema had a profound impact on my mental health. Growing up, I remember receiving glances that were a mixture of pity and disgust. I hated my appearance and would not even look people in the eye because of how ashamed I felt of my skin. I had persistent low mood, low self-esteem, and even had some suicidal thoughts.

I wish clinicians realised the full impact of eczema on mental wellbeing. I want them to consider assessing the mental health of people living with eczema as well as their skin. I would have appreciated my doctor asking me how I was coping psychologically with my eczema. I also wish they had signposted me to support groups, as knowing that I was not alone would have given me hope and made me feel less isolated.

# Setting realistic expectations

My parents and I were told by many clinicians that I would outgrow eczema. Yet with each "older" milestone, my eczema persisted. The unmet promises made me frustrated, desperate, and further distrust health professionals and their treatments. I wish our expectations had been managed appropriately. Knowing that—while my eczema could not be cured—I could control the condition and live a normal life would have helped me hugely.

#### My eczema now

As an adult my eczema is well controlled and has a minimal impact on my daily life. This is thanks to those health professionals who did take the time to educate me about the biology of eczema.

#### What you need to know

- Sharing details on the biology of eczema may help a patient accept and manage their condition
- Setting realistic expectations, such as explaining that creams won't work overnight, may help patients feel informed
- The impact of eczema is beyond just skin deep: the psychological burden of this highly visible disease is profound

#### **Education in practice**

- When might you explain the biology behind eczema to a patient and their family?
- How could you explore the concerns of a patient living with eczema?
- When might you ask a patient living with eczema about their mental health?
- How could you support someone living with eczema who is struggling with their mental health?

Competing interests: None.