

## UNDER MY SKIN

# Private Narratives

It's been said that 36 plot lines cover every dramatic situation. These include "Revenge: Avenger, Criminal" (no. 3); "Familial Hatred: Two Family Members Who Hate Each Other" (no. 13); and "Adultery: Deceived Spouse, Two Adulterers" (no. 25).

On the list of what motivates people to visit doctors, there is also a limited number of what you might call master narratives. As applied to dermatology, the following are some examples:

► **The beginning of the end.** My symptom, however slight, means the start of a process that will result in death.

► **Family ties.** My relative who had this problem suffered or came to a bad end, and since I take after him in my looks, personality, and skin type, I will, too.

► **Unclean! Unclean!** This rash means I am contaminated and will have to hide from polite society.

Finding which of these applies to a given patient is useful, because it helps explain why she actually showed up as opposed to why she says she has. A directed question or two plus a few seconds of open-ended conversation usually reveal

these master narratives, such as the following:

► "My aunt had exactly the same mole, and it turned cancerous and she died of brain cancer."

► "I haven't been to yoga in a year, because you lay right next to the next person's foot, and I can't have someone else stare at this ugly plantar wart."

Master narratives are easy to spot; there are just a few, and they apply broadly. Most every patient turns out to be worried that he is dying, allergic, contagious, or ugly. It's therefore helpful to address not just specific symptoms, but rather their implications, by saying that psoriasis is hereditary but doesn't manifest itself the same way in every family member, that warts and fungi are not as catchy as all that, and so forth.

More tricky are what I would term private narratives. These are a kind of subplot, not significant to all patients, but just to a particular one.

These narratives draw attention to concerns you might not guess unless you spend a couple of extra minutes (that's really all it takes) to hear people tell their

own story. Here are some examples from my own stock:

► Robert complains of a merciless itch that affects just his chest. Itchy people fill our days, of course; some have eczema, some scabies, others anxiety. But why did the itch affect just his chest? Well, the previous October Robert almost died of pericarditis. Just as many women worry that anything on skin near the breast may mean breast cancer, patients in general often ascribe symptoms on the skin to the organs they think are underneath them. Not everybody with a chest itch thinks he has recurrent pericarditis though, just Robert.

► Phil has a seborrheic keratosis sticking out of his scalp. Everybody worries about a new or changing growth, but the concern is not always due to the growth being situated right next to a scar from epidural hematoma surgery, as in Phil's case.

► Sally has warts on her left shin. She somehow seems more worried than most people about catchiness and spread via shaving. It turns out that Susie, Sally's sister with whom she is very close, had a melanoma removed from her left shin. Melanoma may not be on our wart differential, but it is on Sally's.

► Jeff was at a summer barbecue, netting an impressive collection of juicy mosquito bites on his legs. Why is he so anxious

about them? Five years earlier he had vasculitis on his legs, and the bites remind him of that episode. Palpable purpura is a pretty exotic thing for a layman to worry about, but not a layman who had a memorably bad time with it.

► The hemangioma on Ruth's face, present for years, looks banal, but not to Ruth. Her friend had internal hemangiomas that needed MRIs and surgery.

► Mike has a few folliculitis lesions in his groin area. He also has self-described "Irish-Catholic guilt" and a 92-year-old father recovering from a transurethral resection of the prostate, who Mike has been caring for and to whom he fears he's spread the folliculitis.

► Henry has extra pigment on his penis. Is he worried about an STD? Actually, no. He's worried because his grandfather "had polio or something and got mottled all over."

We all have the same story, yet everyone has his own. It's a good idea to pay attention to both.

If I weren't allergic to the word, I'd call that approach holistic. ■

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BY ALAN ROCKOFF, M.D.

## GUEST EDITORIAL

# Topical Calcineurin Inhibitors and Black Boxes

When the Food and Drug Administration posted a Public Health Advisory in March 2005 and then added a black box warning and medication guide to the labeling Jan. 19, 2006, to "inform health care providers and patients about a potential cancer risk from use of Elidel (pimecrolimus) and Protopic (tacrolimus)," it sent shock waves through the pediatric and dermatology communities.

These actions drew rapid media attention and caused widespread panic among eczema sufferers and caregivers.

But where's the evidence? Numerous professional and patient organizations have objected to the FDA-required warning and medication guide for these topical calcineurin inhibitors (TCIs). All have independently come to the same conclusions: The actions are unwarranted and there is no evidence from clinical trials, postapproval studies, or usage to suggest any causal link between the TCIs and development of cancer in patients treated with these agents. Indeed, even the new warning speaks of concern regarding a "potential risk."

While protection of our patients' safety is paramount, we depend on the FDA not only to make evidence-based deci-

sions but to communicate them in a responsible fashion to the public.

The FDA's label changes for TCIs are leading to consequences that, although certainly unintended, are having a profoundly negative impact on our patients and us. Many parents simply stopped treating their children's eczema. Some are now afraid that they have done irreparable harm to their children. Erosion of the physician-patient relationship by the FDA's actions is clear.

One mother of an 8-year-old boy said, "Dr. Orlow, how could you have done this to our child? Why didn't you tell us about the new studies?" (In fact, there had been no new studies considered by the advisory committee or the FDA). The mother of a 6-year-old boy with very severe atopic dermatitis, whose oral calcineurin inhibitor (cyclosporine) dose I'd been able to lower by utilizing TCIs ad-

junctionally, stopped his topical therapy and demanded that I increase his oral cyclosporine dose to control the subsequent severe flaring that occurred! (Oral cyclosporine is clinically linked to increased cancer risk in transplant patients).

In addition, among physicians, concerns far removed from any perceived risks associated with TCIs are exerting

undue influence. While some are prompted to act based on continued concerns about the risk of lymphoma or infections, it is fear of litigation and increased administrative burden, such as time spent reassuring patients and additional effort needed to secure preauthorization by third-party payers, that are cited to me by colleagues as the main reason for therapy changes.

Losing one of our treatment options—ironically the only class extensively studied in children and studied long term—means taking a giant step backwards for eczema management. We're moving back to the days of either overtreatment of patients with corticosteroids, including inappropriate use on the head, neck, and genital area, or undertreatment because of cortisone-phobia now combined with TCI-phobia.

I'm also very concerned over the negative impact these FDA actions have had on pediatric clinical trials. Public fears have had a profound effect on recruitment and retention, especially for infants. Development of new agents to treat children, in all specialties, is at risk.

Evidence-based evaluation of drugs is essential, and speculation-based communications are

dangerous, leading to harmful unintended consequences, as demonstrated by our experience with the TCIs. With the addition of a black box warning and medication guide by the FDA, physicians must be even more diligent in providing thorough, objective information to their patients. ■

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