

Skin Picking and Prader-Willi Syndrome

by *The Pittsburgh Partnership*



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The “skin picking” behaviour of PWS has a wide range of severity from patient to patient and sometimes in the same patient over time. A stability over time is more typical, however, as Wigren reported in 1999. Some patients have occasional minor skin picking while others maintain large open wounds. In the “PWS Personality” presented in 2006 we separated *skin picking as a habit behaviour* and *self mutilation* associated with extreme emotional distress, which is far less common. Here we will only address the former and leave the latter and rectal picking for another day.

Why do they pick? Some speculation.

Much of PWS behaviour makes more sense when we view it as a failure to inhibit. The eating behaviour is largely due to defective “brakes” called satiety. The drive to skin pick may be a normal drive (who has not picked a scab or other bodily irregularity?) designed to free us of unwanted parasites. But in PWS the limiting signals are weakened. We speculate that these signals are pain and disgust, both neurologically based (not just cultural) phenomena and apparently reduced in PWS.

Skin picking as a habit behaviour

Here, skin picking is defined as an activity that goes on when the patient is calm and does not appear to be expressing emotional distress by the behaviour. It has been related to boredom and anxiety, but objective evidence for this is difficult to establish. Features include:

- Opportunistic topography (i.e. location is convenient to reach)
- Arms, face, scalp
- Nose, nasal septum
- Picking cuticles
- Pulling out toenails, teeth
- Peeling skin from soles of feet

Points on management

No specific intervention has been uniformly effective. The behaviour often extinguishes if healing of the wound is achieved. There has been limited success using protective dressings and an intense program of alternative activity until wound healing occurs. Behavioural interventions have been effective in some cases (see box on next page).

Because skin-picking behaviour occurs intermittently and secretively, behavioural interventions targeted at the activity itself are difficult to implement.. A basic principle is that no attention, positive or negative, should be paid to the behaviour itself other than to require the patient to observe social conventions and good hygiene.

Obsessional, but not OCD

The behaviour appears to be “obsessional;” however, this is not an obsessive-compulsive behaviour and medications targeting OCD (Obsessive-Compulsive Disorder) or anxiety have not been specifically helpful. If the behaviour is clearly related to other signs of anxiety, then the anxiety should be addressed first with environmental changes. Remember that anti-anxiety medications all carry the risk of increasing irritability or of triggering abnormal mood elevation.

Use of Topiramate

Topiramate (Topamax) in low doses has been effective for some patients and should definitely be considered in persons with severe picking. In 2004 Shapira¹ and others used 25-50 mg daily and reported that some patients responded and some did not. Clinical experience with higher doses of topiramate as a treatment for mood disorder or appetite suppressant have been disappointing, but impressive improvement in picking behaviour was also noted. Higher doses

(100-200 mg/day) are associated with more side effects (irritability and renal tubular acidosis), but these are dose dependent, and reversible. These issues should not deter a trial of the medication, only guide the physician in what to monitor. Presumably if lesions heal, a trial off the medication makes sense. Allow 2-3 months on the medication to evaluate. Anecdotally, sensory stimulation has been quite effective for some severe picking behaviours. Sensory modalities have included vibration or massage administered on a schedule multiple times per

day. The sensory stimulation should not be linked verbally or temporally with the picking behaviour, as this could result in rewarding the behaviour. More information on using sensory integration techniques has been assembled by Janice Agarwal, P.T. and is available on www.pwsausa.org.

1 Shapira, N.A., Lessig, M.A., Lewis, M.H., Goodman, W.K. and Driscoll, D.J.: Effects of Topiramate in Adults with Prader-Willi Syndrome. Am. J. MentalRetardation, 109:301-9, 2004.

(Reprinted from the Gathered View)

A Program to Address Typical Skin Picking *Pittsburgh Partnership*

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1. *Tell the child that you want to help her sore to heal. Do not talk about the "picking".*
2. *Tell him that when the sore heals you will celebrate with a special reward.*
 - *This reward should be motivating, but not too motivating; rewards that are too motivating can create anxiety. Also there is the risk that an older, more clever individual will deliberately create wounds to heal to earn the reward!*
 - *Be prepared to offer the same reward on multiple occasions.*
 - *Try to anticipate the situations when picking tends to occur, and before he starts to pick, remind him that he is working to gain this reward.*
 - *Once the reward is earned, offer it weekly (for very young or low functioning children or for severe pickers) or monthly for "no new sores."*
 - *If a reward must be withheld because of a continued open sore, express your disappointment that the reward was not earned and your optimism that he can achieve it very soon. Most superficial sores show considerable healing in a matter of 2-3 days if there is no picking going on.*
3. *Tell her that you have medicine to help the sore to heal.*
 - *Plastic surgeons use Polysporin [Bacitracin/Polymyxin] Ointment on healing wounds to minimize scarring. Also, it has the effect of keeping the area soft, slippery, and less tempting or less easy to pick.*
 - *Use Polysporin ointment on the sore as frequently as possible (every ½ - 1 hour while awake) and apply thoroughly at bedtime.*
4. *Use a dressing or some other barrier where anatomically possible. Your purpose is to make the picking less convenient.*
 - *The ideal dressing is NOT airtight but is difficult to remove. On arms and legs this can be gauze wrap covered with cling wrap.*
 - *If there is no evidence of picking during sleep leave the area open to the air. Socks or mittens taped at the wrist have been used for nighttime picking.*
 - *Other covers have been effective barriers: "Onesies"; tight fitting clothes e.g. Scuba suit or leotard for trunk; Panty hose for legs; can be cut and redesigned for arms or scalp.*