CHARACTERIZATION OF SKIN CLEANSING AND TOPICAL PRODUCT USE AMONG EPIDERMOLYSIS BULLOSA PATIENTS: AN UPDATE

PeDRA 2018 Annual Conference: October 26, 2018

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How do patients’ skin care routines play a role in colonization and patient outcomes?

- What are patients’ home skin care routines?
- Which organisms are colonizing EB patients’ wounds?

Jan 2018 Complete Data Collection

January - December 2018 Analyze one year data set

Future Analysis
- Identify resistance patterns
- Identify risk factors for SCC development
## METHODS

<table>
<thead>
<tr>
<th>EBCRC Participating Centers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children’s Hospital of Philadelphia*</td>
</tr>
<tr>
<td>Children’s Hospital of San Antonio*</td>
</tr>
<tr>
<td>Children’s National Medical Center</td>
</tr>
<tr>
<td>Cincinnati Children’s Hospital*</td>
</tr>
<tr>
<td>Columbia University*</td>
</tr>
<tr>
<td>Dell Children’s Medical Center*</td>
</tr>
<tr>
<td>Henry Ford Hospital</td>
</tr>
<tr>
<td>The Hospital for Sick Children*</td>
</tr>
<tr>
<td>Northwestern University</td>
</tr>
<tr>
<td>Phoenix Children’s Hospital</td>
</tr>
</tbody>
</table>

*Centers with questionnaires reviewed in this study*
METHODS

Patient-directed questionnaires regarding skin cleansing habits and topical product use captured between January 1, 2017 and December 31, 2017 were analyzed. These questionnaires were extracted from the database on September 10, 2018.

If a patient completed more than one questionnaire in 2017, only the first questionnaire was included.

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How often do you typically cleanse the skin?

- Never
- 1x/week
- 2x/week
- 3-4x/week
- 5-6x/week
- Daily/7x per week
- 7+ (More than once daily)

(Select one)

What method is used to cleanse the skin?

- Bath
- Shower
- Sponge Bath
- Skin is not cleansed
- Other (please specify)

(Select all that apply)

Specify the Other Method of cleansing

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Do you add products to the water when cleansing your skin and/or wounds?

- No. No additives (only water)
- Yes, Salt
- Yes, Vinegar
- Yes, Bleach
- Yes, Other

(Check all that apply)

Specify the Other Products or Additives

__________________________
RESULTS: RESPONDENT POPULATION

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>n</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dystrophic EB (DEB)</td>
<td>130</td>
<td>64.4%</td>
</tr>
<tr>
<td>RDEB</td>
<td>93</td>
<td>71.5%</td>
</tr>
<tr>
<td>DDEB</td>
<td>28</td>
<td>21.5%</td>
</tr>
<tr>
<td>Unspecified</td>
<td>9</td>
<td>6.9%</td>
</tr>
<tr>
<td>EB Simplex</td>
<td>51</td>
<td>25.2%</td>
</tr>
<tr>
<td>Junctional EB</td>
<td>15</td>
<td>7.4%</td>
</tr>
<tr>
<td>Kindler Syndrome</td>
<td>3</td>
<td>1.5%</td>
</tr>
<tr>
<td>Unspecified</td>
<td>3</td>
<td>1.5%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>202</td>
<td>100%</td>
</tr>
</tbody>
</table>
RESULTS: FREQUENCY OF CLEANSING

n = 202
RESULTS: CLEANSING ADDITIVES BY RESPONSE

n = 202 questionnaires

- No additives (only water) 78
- Salt 75
- Bleach 71
- Vinegar 36
- Other* 34

* Included Epsom salts, essential oils, baking soda, oatmeal.
<table>
<thead>
<tr>
<th>Additive</th>
<th>Minimum</th>
<th>Maximum</th>
<th>DEBRA recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Salt</td>
<td>“1/3 cup per 1/2 tub water”</td>
<td>“2 cups per 1/2 tub water”</td>
<td>2 lbs of salt to 1/2 tub (40 gallons)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“4-6 teaspoons per 32oz H2O”</td>
<td>5 teaspoons per gallon for infants</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vinegar</td>
<td>“1/2 - 1 cap full”</td>
<td>“4 cups white vinegar in 10 gallons of water”</td>
<td>1 part 5% acetic acid to 20 parts bathwater</td>
</tr>
<tr>
<td></td>
<td>“1/4 cup to tub”</td>
<td>“2 cups to half tub”</td>
<td>1 part 3% acetic acid to 12 parts bathwater</td>
</tr>
<tr>
<td></td>
<td>“4 oz per 1/2 tub of water”</td>
<td>“4 oz in 1 gallon of water”</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bleach</td>
<td>“1/4 cup per full tub”</td>
<td>“2 cups per tub”</td>
<td>1/4 cup bleach in 1/2 tub of water (40 gallons)</td>
</tr>
<tr>
<td></td>
<td>“the cap of the bottle in a full tub”</td>
<td>“1/2 oz per 32oz H2O”</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>“a few drops to a whole tub”</td>
<td>“a box of Aveeno oatmeal to a whole tub”</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>“a half a bottle of Hibiclens”</td>
<td></td>
</tr>
</tbody>
</table>
RESULTS: TOPICAL PRODUCT USE BY RESPONSE

ANTIMICROBIALS
- Mupirocin, 59
- Bacitracin, 58
- Polysporin®, 31
- Silver-Containing Product, 26
- Medical Grade Honey, 30
- Other Antifungal or Antibiotic, 26

EMOLLIENTS
- Other emollient, 69
- Petroleum Jelly/Vaseline®, 60
- Aquaphor®, 71

OTHER
- Other, 34

*Included topical steroids, study drugs, and powders.
RESULTS: TOPICAL PRODUCTS BY PATIENT

Combination*: 49%
Antimicrobials only: 21%
Emollients only: 17%
No topicals used: 11%
Other: 2%
RESULTS: TOPICAL PRODUCTS BY PATIENT

- At least one topical antimicrobial: 70%
- Emollients only: 17%
- No topical used: 11%
- Other: 2%
CONCLUSIONS

• Home skin care practices VARY WIDELY
  • Including washing with added salt, vinegar, and bleach.

• Concentrations of additives VARY WIDELY
  • Implications regarding efficacy and cytotoxicity?

• Topical antimicrobials are commonly used
  • Mupirocin was reported as the most frequently used topical antibiotic, followed closely by bacitracin
  • Implications for bacterial resistance?
Future Directions:

- Increased knowledge of how EB patients care for their skin may elucidate whether certain skin care practices are associated with the development of resistant bacteria, helping to guide individualized recommendations.

- Future longitudinal studies are needed to determine if wound microbiome interventions have the potential to inhibit or delay the development of SCC.
ACKNOWLEDGMENTS

Dr. Kimberly Morel

Dr. Laura Levin
REFERENCES

SUPPLEMENTAL SLIDES
### Table 7. CLEANSING SOLUTIONS

<table>
<thead>
<tr>
<th>Agent</th>
<th>Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sodium hypochlorite solution</td>
<td>High pH causes irritation to skin. Dakins Solution and Eusol (buffered preparation) can select out gram-negative microorganisms.</td>
</tr>
<tr>
<td>Hydrogen peroxide</td>
<td>Desloughing agent while effervescing. Can harm healthy granulation tissue and may form air emboli if packed in deep sinuses.</td>
</tr>
<tr>
<td>Mercuric chloride, crystal violet, Proflavine</td>
<td>Bacteriostatic agents active against gram-positive species only. May be mutagens and can have systemic toxicity.</td>
</tr>
<tr>
<td>Cetrimide (quaternary ammonium)</td>
<td>Good detergent, active against gram-positive and -negative organisms, but high toxicity to tissue.</td>
</tr>
<tr>
<td>Chlorhexidine</td>
<td>Active against gram-positive and -negative organisms, with small effect on tissue.</td>
</tr>
<tr>
<td>Acetic acid (0.5% to 5%)</td>
<td>Low pH, effective against <em>Pseudomonas</em> species, may select out <em>S. aureus</em>.</td>
</tr>
<tr>
<td>Povidone iodine</td>
<td>Broad spectrum of activity, although decreased in the presence of pus or exudate. Toxic with prolonged use or over large areas.</td>
</tr>
</tbody>
</table>
Table 9.
TOPICAL ANTIMICROBIALS USEFUL IN WOUNDS WITH OVERT AND COVERT INFECTION

<table>
<thead>
<tr>
<th>Agent</th>
<th>S. aureus</th>
<th>MRSA</th>
<th>Streptococcus</th>
<th>Pseudomonas</th>
<th>Anaerobes</th>
<th>Comments</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cadexomer iodine</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>Also debrides. Low potential for resistance. Caution with thyroid disease.</td>
<td>Low risk and effective</td>
</tr>
<tr>
<td>Silver</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>Some silver dressings can be moistened with saline. Low potential for resistance. Caution with sulphonamide sensitivity.</td>
<td></td>
</tr>
<tr>
<td>Silver sulfadiazine</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Polymyxin B sulphate/ Bacitracin zinc</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>Bacitracin in the ointment is an allergen; the cream formulation contains the less-sensitizing gramicidin.</td>
<td>Use selectivity</td>
</tr>
<tr>
<td>Mupirocin</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Reserve for MRSA and other resistant gram+ species</td>
<td></td>
</tr>
<tr>
<td>Metronidazole</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>+</td>
<td>Reserve for anaerobes and odor control. Low or no resistance of anaerobes despite systemic use.</td>
<td></td>
</tr>
<tr>
<td>Benzoyl peroxide</td>
<td>Weak</td>
<td>Weak</td>
<td>Weak</td>
<td>Weak</td>
<td>Weak</td>
<td>Large wounds. Can cause irritation and allergy.</td>
<td></td>
</tr>
<tr>
<td>Gentamicin</td>
<td>+</td>
<td>+</td>
<td></td>
<td>+</td>
<td></td>
<td>Reserve for oral/IV use—topical use may encourage resistance. Contains lanolin (except in the cream).</td>
<td>Use with caution</td>
</tr>
<tr>
<td>Fusidin ointment</td>
<td>+</td>
<td></td>
<td></td>
<td>+</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Polymyxin B sulphate/ Bacitracin zinc neomycin</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>Neomycin component causes allergies, and possibly cross-sensitizes to aminoglycosides.</td>
<td></td>
</tr>
</tbody>
</table>

Adapted from Sibbald RG, Osted HL, Schultz GS, et al.14
MUPIROCIN RESISTANCE TESTING

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- **City:**
- **State:**
- **ZIP Code:**
- **Business Phone No.:**
- **Fax No.:**

- **Accounts Payable Contact Person:**
- **Accounts Payable Telephone No.:**
- **Accounts Payable Fax No.:**
- **Accounts Payable Email Address:**

- Are You **Taxable?** (If no, please attach a copy of exemption certificate) Yes [ ] No [ ]

---

### Description of Business:

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<th>Hospital</th>
<th>Lab</th>
<th>Doctor’s Office</th>
<th>Manufacturer</th>
<th>Distributor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other (specify)</td>
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### Type of Business:

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<th>Partnership</th>
<th>Sole</th>
<th>Local Government</th>
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<td></td>
<td></td>
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</tr>
<tr>
<td>State</td>
<td>Federal</td>
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**Bundling Affiliation (GPO):**
Not applicable until LETTER OF PARTICIPATION is