Skin health, skin care and dermatology nursing worldwide: evolution of a clinical research programme

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Context: the significance of skin health, skin care and skin disease worldwide
Historical continuity of nursing interest concerning care of the skin

Bathing patients

Supporting skin barrier function

Empirical evidence of systemic disease
Skin health, skin care and dermatological nursing

• Key distinction between dermatological nursing and universal skin care and skin health
• Skin care interventions are extensive and ubiquitous across clinical fields
• But an undeveloped field for nursing related research and development
Dermatological need-scope for nursing intervention

**Scale**

Primary care: dermatology- one of the commonest reasons to consult. 13m (20%+) present; 6% referred in UK

- 54% UK population experience a skin condition in a 12-month period: most (69%) require self-care
- Specialists most commonly see people with chronic dermatoses (35-40%): e.g. eczema, psoriasis

Schofield et al (2009)

- Similarly - extensive community based in needs in many other countries
Care of the skin has universal nursing significance

Extensive hygiene practices in care settings (often clinical routines)

Protection and thermoregulation

Significance:
Psychological
Socio-cultural
Health economic
Stimulus: 20 years ago undertook a commissioned review of the dermatological nursing literature for Department of Health (England) revealed need for a nursing focused research programme in this clinical field.

Few research studies, including those supporting self-management

**Impact:** skin conditions may have a significant psychological and quality of life impact

- Comparing health-related quality of life (HRQL) in psoriasis with 10 major chronic conditions
- Psoriasis patients reported reduction in physical and mental functioning comparable to those seen in cancer, heart disease, diabetes and depression

Rapp, Feldman et al (1999) Psoriasis causes as much disability as other major medical diseases
*Journal of the American Academy of Dermatology* 41:401-7
Impact: skin disease is a leading cause of premature death worldwide.

DALY = disability adjusted life years

Table 1. DALY ranks when considering skin conditions collectively

<table>
<thead>
<tr>
<th>Cause</th>
<th>Global DALYs</th>
<th>DALY rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ischemic heart disease</td>
<td>129,800,000</td>
<td>1</td>
</tr>
<tr>
<td>Lower respiratory infections</td>
<td>115,200,000</td>
<td>2</td>
</tr>
<tr>
<td>Cerebrovascular disease</td>
<td>102,200,000</td>
<td>3</td>
</tr>
<tr>
<td>Diarrheal diseases</td>
<td>89,523,909</td>
<td>4</td>
</tr>
<tr>
<td>Malaria</td>
<td>82,688,806</td>
<td>5</td>
</tr>
<tr>
<td>HIV/AIDS</td>
<td>81,549,177</td>
<td>6</td>
</tr>
<tr>
<td>Low back pain</td>
<td>80,666,896</td>
<td>7</td>
</tr>
<tr>
<td>Preterm birth complications</td>
<td>76,979,669</td>
<td>8</td>
</tr>
<tr>
<td>Chronic obstructive pulmonary disease</td>
<td>76,778,819</td>
<td>9</td>
</tr>
<tr>
<td>Road injury</td>
<td>75,487,102</td>
<td>10</td>
</tr>
<tr>
<td>Major depressive disorder</td>
<td>63,239,334</td>
<td>11</td>
</tr>
<tr>
<td>Neonatal encephalopathy (birth asphyxia and birth trauma)</td>
<td>50,162,510</td>
<td>12</td>
</tr>
<tr>
<td>Tuberculosis</td>
<td>49,399,351</td>
<td>13</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>46,857,136</td>
<td>14</td>
</tr>
<tr>
<td>Iron-deficiency anemia</td>
<td>45,349,897</td>
<td>15</td>
</tr>
<tr>
<td>Sepsis and other infectious disorders of the newborn baby</td>
<td>44,236,488</td>
<td>16</td>
</tr>
<tr>
<td>Congenital anomalies</td>
<td>38,890,019</td>
<td>17</td>
</tr>
<tr>
<td>Skin conditions</td>
<td>36,921,995</td>
<td>18</td>
</tr>
<tr>
<td>Self-harm</td>
<td>36,654,590</td>
<td>19</td>
</tr>
<tr>
<td>Falls</td>
<td>35,405,935</td>
<td>20</td>
</tr>
</tbody>
</table>

Impact: skin conditions are the 4th leading cause of disability (non-fatal disease burden) worldwide.

YLD = years lost due to disability

Table 2. YLD ranks when considering skin conditions collectively

<table>
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<tr>
<th>Cause</th>
<th>Global YLDs</th>
<th>YLD rank</th>
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<tbody>
<tr>
<td>Low back pain</td>
<td>80,666,896</td>
<td>1</td>
</tr>
<tr>
<td>Major depressive disorder</td>
<td>63,239,334</td>
<td>2</td>
</tr>
<tr>
<td>Iron-deficiency anemia</td>
<td>42,505,250</td>
<td>3</td>
</tr>
<tr>
<td>Skin conditions</td>
<td>33,717,725</td>
<td>4</td>
</tr>
<tr>
<td>Neck pain</td>
<td>32,650,797</td>
<td>5</td>
</tr>
<tr>
<td>Chronic obstructive pulmonary disease</td>
<td>29,420,262</td>
<td>6</td>
</tr>
<tr>
<td>Other musculoskeletal disorders</td>
<td>28,247,230</td>
<td>7</td>
</tr>
<tr>
<td>Anxiety disorders</td>
<td>26,847,326</td>
<td>8</td>
</tr>
<tr>
<td>Migraine</td>
<td>22,362,507</td>
<td>9</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>20,791,397</td>
<td>10</td>
</tr>
<tr>
<td>Falls</td>
<td>19,479,581</td>
<td>11</td>
</tr>
<tr>
<td>Osteoarthritis</td>
<td>17,148,545</td>
<td>12</td>
</tr>
<tr>
<td>Drug use disorders</td>
<td>16,434,052</td>
<td>13</td>
</tr>
<tr>
<td>Other hearing loss</td>
<td>15,824,531</td>
<td>14</td>
</tr>
<tr>
<td>Asthma</td>
<td>13,843,163</td>
<td>15</td>
</tr>
<tr>
<td>Alcohol use disorders</td>
<td>13,838,157</td>
<td>16</td>
</tr>
<tr>
<td>Road injury</td>
<td>13,489,949</td>
<td>17</td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>12,975,089</td>
<td>18</td>
</tr>
<tr>
<td>Bipolar affective disorder</td>
<td>12,878,832</td>
<td>19</td>
</tr>
<tr>
<td>Dysthymia</td>
<td>11,091,105</td>
<td>20</td>
</tr>
</tbody>
</table>

Understanding impact through the life-world of those with chronic skin disease: eg: a life lived with psoriasis
Global impacts: many skin diseases are hidden public health concerns on a global scale - yet opportunities for nursing

‘500 million Indians get pill to wipe out killer bug’ The Times 15.2.14

Skin disease creates global public health challenges

- Chronic illness versus infections/infestations
- Key public health issues
  - skin cancer
  - lymphatic filariasis (NTD)
  - scabies
  - chronic wounds
- Nursing opportunities to:
  - prevent and alleviate the above
  - minimise socio-economic impact
  - alleviate impact on vulnerable groups

A man treated for elephantiasis (lymphatic filariasis): a neglected tropical disease (NTD) of scale – affecting 120 million people globally
## Developing a nursing research programme: some illustrations of existing work

1. Studies examining unmet or poorly met **skin-health related need** – especially self-management ability to improve wellbeing, amenable to nursing intervention

2. Studies developing and evaluating responsive (mainly) **nursing interventions** and **models of service delivery** (based on research evidence and theory) to meet such needs and improve wellbeing

3. Studies developing robust **patient-orientated measures** to enhance intervention evaluation (both clinical and research)
Identifying needs: skin care patients make up a major proportion of the NHS patient mix

GP (family practitioner) consultations: 1 in 6 patients (Schofield et al 2009)

NHS walk-in centres: nurse-led primary care and open access - a case analysis:

- skin/wound issues - most common reason for child presentation and second most common reason for adults
- the need for self-management support

Developing interventions to enable nurses to support the wellbeing of people living with chronic dermatoses
Interventions- building on existing evidence: developing structured education for eczema management
a Cochrane systematic review

What is the effectiveness of psychological and educational interventions for children with atopic eczema? — identified the importance of nurse-led interventions

Applying evidence to improve intervention: developing evidence-based guidelines

National and international guideline development to support key nurse-led skin care interventions

Ersser, Maguire, Nicol, Penzer, Peters (2012) Best Practice in Emollient Therapy; A Statement for Health Care Professionals 3rd Edition. Dermatological Nursing (supplement) 11(4) s1-s19
Types of interventions to supporting effective self-management

1. Strategies to improve self-management

2. Behaviourally and biologically based interventions for primary and secondary prevention:
   - Reducing vulnerability of skin barrier function
   - Supporting health behaviour

Eg: Culturally specific skin care education material for Lymphatic Filariasis morbidity control in Tanzania by International Skin Care Nursing Group –ISNG (Ersser & Penzer) in support of the World Health Organisation Lymphatic Filariasis Morbidity Control Programme)

Building interventions: application of theory e.g.

Self-efficacy construct
An individual’s belief in their capacity to successfully execute a health related behaviour

Social learning theory
People learn by observing others

More likely to engage in behaviours when they believe they are capable of carrying them out successfully
Using the self-efficacy construct to develop nursing empowerment strategies

- **Personal accomplishment** (achievement)
- **Vicarious experience** (modelling)
- **Verbal persuasion** (reinforcement)
- **Regulate emotional behaviour** (stress management)
The Eczema Education Programme (EEP): one of largest in Europe - a service innovation evaluation study

**Project Goal:** educate parents of children with eczema to manage their child’s condition more effectively and thereby improve the child and family quality of life and evaluate the model of intervention.
Eczema Education Programme (EEP)

Service access

Quality of life impact

Parental self-efficacy / empowerment

Service user and trainer learning

EEP evaluative summary:

- Overall **parental satisfaction** very high
- Parental **self-efficacy** increased
- **Quality of life** and **disease severity** significantly improved
- Service impact data analysis- indications that **primary care demand** may be reduced
- Preliminary **exploratory study** to inform design of a multi-centred primary care randomised controlled trial

Psoriasis self-management study: the need for intervention development work

How do psoriatic patients self-manage – what is their knowledge, skills and limitations?

How do we develop an effective nurse-led educational intervention to improve self-management?

Phase 1
Qualitative
Exploratory focus groups

Phase 2
Quantitative
A pilot trial evaluating
• quality of life
• disease severity
• self-efficacy impact

Improving psoriasis self-management through intervention feasibility testing

- Intermittent and erratic usage of topical therapy
- Low expectations of interventions and services

- Indications of how to support self-manage more effectively
- Built a feasible, promising group intervention supported by multimedia and social learning

Developing person-centred measures applied to dermatology
Developing measures 1: a tool to assess and promote self-management: **PeDeSI: Person-Centred Dermatology Self-Care Index**

- **Systematic assessment of self-management ability** re topical therapy
- Improve measurement *and* concordance with treatment
- **Focus:** *adults* with long-term skin conditions
- Developing tool translations

Developing measure II: Parental Self-Efficacy with Eczema Care Index (PASECI)-identifying support needs

Domains: likert scale questionnaire
1. **Managing medication** sub-scale:

2. **Managing eczema** symptoms sub-scale

3. **Communicating** with health care professionals
   - Tested through the EEP study
   - Further development taking place – exploring correlations and translations

Complex intervention development and evaluation in nursing through research programmes
Framework for trials of Complex Interventions: phases

1. **Theory**
   - Identify component of intervention & underlying mechanism by which influence outcomes

2. **Modelling**
   - Describing the constant variable components of a replicable intervention & a feasible protocol to compare to a suitable alternative

3. **Exploratory trial**
   - Compare a full defined intervention to an appropriate alternative that is theoretically defensible & reproducible and adequately controlled in a study of adequate statistical power

4. **Definitive RCT**
   - Determine whether others can replicate your intervention & results in uncontrolled settings over the long term

Increasing evidence
Eg 1: Programme: complex intervention development: on early detection of Skin Cancer via effective skin self-examination (SSE)

- **Workstreams include**: 1) CI development 2) feasibility study and then 3) an effectiveness RCT
- **Development**: building on our systematic review and meta-analysis of interventions on early detection of skin cancer
- **Target group**: community based delivery- to those > 40 years targeting some high-risk vulnerable sub –groups—older men and those with a skin cancer history
- **Intervention**: Supported by internet based ‘app’ development including images, video demonstration to enhance self-examination (vicarious learning) and MOLES Index to tailor education to relevant behavioural change theory
- **Primary outcome**: seeking to increase the rate of urgent referrals for skin cancer to dermatology and improve disease stage/prognosis

Eg 2: Programme: to examine the relationship between skin care practices, skin vulnerability using skin barrier function (SBF) as proxy measures and pressure ulceration risk

- **Skin status domain and specifically the moisture risk sub-domain** - a key factor in pressure ulcer (PU) risk (Coleman et al 2013)- distinction between skin moisture and incontinence related.
- Meta-analytic evidence suggests vulnerable skin caused by **incontinence acquired dermatitis** raising PU risk (Beeckman et al 2014)
- We wish to explore link to **skin barrier science**
- **Hypothesis to be tested:** the relationship between skin care practices, skin vulnerability, as reflected in skin barrier function (SBF) status, and pressure ulceration risk
- **Worksteams:** exploring routine skin care practices; developing an evidence-based skincare intervention supporting SBF, then trial evaluation against usual care to appraise impact on PU risk

Developmental work on skin barrier function measurement in clinical settings

- Intervention development on regular skin care and that to support specific needs - informed by current exploratory work in the UK and in Africa

- Currently exploring feasibility of skin barrier function measurement in the clinical setting using wireless probes, (trans-epidermal water loss and skin hydration) in acute primary and secondary care settings

- Informing a programme of work to test the foregoing hypothesis
The scope for a global nursing response
Nursing’s capacity to benefit in the dermatology field worldwide

Developing and evaluating interventions promoting wellbeing in resource-poor communities: the case of skin care for people living with neglected tropical disease

- Examples: former PhD students working in Africa
- Dr. Alex Effah: examining the support needs of people with Buruli ulcer in Ghana
- Dr. Jill Brooks: RCT to develop an effective skin care intervention (emolliation) to enhance skin barrier function (SBF) and quality of life for people with podoconiosis in Ethiopia

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