The Person-Centered Dermatology Self-Care Index

A Tool to Measure Education and Support Needs of Patients With Long-term Skin Conditions

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Objective: To validate the Person-Centered Dermatology Self-Care Index (PeDeSI) as a tool for clinical assessment and for potential use in research evaluation.

Design: To date, no validated assessment measures exist to identify the education and support needs of patients living with long-term dermatological conditions and to enable them to self-manage as effectively as possible. The PeDeSI assessment tool was developed to meet this need using the self-efficacy construct and a model of concordance within prescribing practice. In total, 200 copies of the PeDeSI were distributed for validation, and 145 (72.5%) were returned completed. Data were analyzed using statistical software. Frequency distributions of all items were examined, and internal consistency was summarized using Cronbach α. Exploratory factor analysis was used to disclose any underlying structure among the data items.

Setting: Three specialist dermatology centers in acute care hospitals.

Participants: Dermatology specialist nurses treating patients with chronic dermatoses.

Intervention: A PeDeSI was completed with each patient during his or her usual outpatient consultation.

Main Outcome Measure: Cronbach α.

Results: Cronbach α was 0.90, indicating good internal consistency. Eliminating individual items in turn made little difference in Cronbach α (range, 0.89-0.90). Item total correlations ranged from 0.44 to 0.76 (median, 0.68). Exploratory factor analysis extracted just one factor (eigenvalue, 5.37), with no other factors having eigenvalues exceeding 1.00. Factor loadings on individual items ranged from 0.47 to 0.80.

Conclusion: The PeDeSI is a valid, reliable, and clinically practical tool to systematically assess the education and support needs of patients with long-term dermatological conditions and to promote treatment concordance.

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I N THE UNITED STATES, A NA-
tional data profile on skin disease has not been conducted since the late 1970s; however, it is estimated that about 66% of the population have a skin problem at any one time.[1] Survey results suggest that approximately 54% of the United Kingdom population experience a skin condition in any year.[2] Self-management of long-term conditions is a health policy priority.[3,4] Many patients with skin conditions, particularly those with chronic dermatoses, are expected to self-manage.[5] However, few studies[6,7] have examined self-management in dermatology, and they were small.

Self-management has a fundamental role in controlling skin conditions and in maintaining quality of life,[7] but the education and support required to enable patients to gain greater independence are often not systematically or adequately assessed, planned, or evaluated.[8] Specifically, tools to assess individual needs are lacking. The tools now used in dermatology are outcome measures, such as quality of life (eg, the Dermatology Life Quality Index[9]) or severity (eg, the Psoriasis Area and Severity Index[10]), and are not process measures that may assess key factors influencing such outcomes. Effective

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chronic disease intervention should begin with an assessment of prior knowledge,[11] personal competence,[12] and patient-identified outcomes.[13] Therefore, a tool to measure self-care ability could provide the basis for developing more tailored and effective programs of education and support.

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The objective of this research was to test the validity and reliability (internal consistency) of the Person-Centered Dermatology Self-Care Index (PeDeSI). The study examined the ability and usefulness of this tool in everyday clinical practice to assess the education and support needs of patients with chronic dermatological conditions.

METHODS

The prototype 23-item PeDeSI was developed by a group of dermatology specialist nurses (C.G. and her colleagues) based on their experience and expertise (C.G., unpublished index, 2005). It was used in practice but was not validated. The next iteration, the 22-item PeDeSI$_1$, was developed by the research team (F.C. and S.J.E.) and by an expert panel (including C.G.) of physicians and nurses, educationalists, and patient representatives (the patients had long-term skin conditions) using the robust theoretical underpinnings of the self-efficacy construct,[14] and a model of concordance within prescribing practice[15] (eAppendix; http://www.archdermatol.com). Field testing demonstrated that the PeDeSI$_1$ was valid and reliable but was too long for use in everyday clinical practice. Therefore, the PeDeSI$_2$ was developed and tested.

The PeDeSI$_2$ (**Figure**) was developed by reducing the number of items in the PeDeSI$_1$ from 22 to 10 using expert qualitative clinical judgment (face validity) of a panel consisting of 2 skin care researchers (F.C. and S.J.E.), 1 dermatology specialist nurse (C.G.), and a patient representative, together with feedback from the nurses who had field tested the PeDeSI$_1$. Particular emphasis was placed on removing items that had the least direct consequence for self-care. The final question on the PeDeSI$_2$ is a summary question that is intended to stimulate discussion and understanding between the patient and the physician or nurse.

A National Health Service Research Ethics Committee approved the study. Fifty copies of the PeDeSI$_2$ were sent to 2 dermatology units and 100 copies were sent to a larger unit, with 200 distributed for validation overall in the United Kingdom. The theoretical basis of the tool and its significance were explained to physicians and nurses in a concise accompanying user's guide. In total, 145 copies (72.5%) were returned completed, having been used among patients with a range of skin conditions that included chronic plaque psoriasis, lichen planus, eczema, and ichthyoses. The development methods used helped to ensure good face, content, and construct validity (eAppendix). All the copies of the PeDeSI$_2$ were completed by dermatology specialist nurses in collaboration with patients. Noncompletion was reported as being due to workload and a lack of appropriate patients. No formal sample size calculation was conducted, although various rules about the ratio of patients to items (ratio, 14.5) and the ratio of variables per factor (ratio, 10.0) were satisfied.[16,17]

The primary outcome was Cronbach α, a measure of internal consistency and the degree to which the items measure the same thing. Cronbach α values of 0.70 or higher are acceptable for research purposes, and values of 0.90 and higher are acceptable for clinical purposes.[18] Exploratory factor analysis was used to disclose any underlying structure among the data items by identifying the number of underlying constructs (factors) using "rotation" to assess which items fall within each factor (if >1 factor) and then interpreting the factor. The number of factors was determined by inspection of the amount of variance explained by each possible factor in relation to the total variance of all items (eigenvalues). Factors with eigenvalues exceeding 1.00 explain more variance than the individual items and are considered useful. Factor loadings were calculated, and

loadings of 0.40 or higher are thought to signify items that contribute to the factor in a meaningful way.[19] Frequency distributions of all items were inspected to assess the extent to which respondents used the full range of the scale. Consideration of the scree plot and eigenvalues were used to determine the number of factors. Data were analyzed using commercially available statistical software (SPSS version 16; SPSS Inc).[20]

RESULTS

Apart from the data about obtaining repeat prescriptions, analysis of the PeDeSI$_2$ demonstrated that for each item the respondents used the full-scale range of items from 0 to 3, indicating the level of support and education required. The percentage of respondents with scores indicating at least sufficient ability to self-care ranged from 55.2% ("Do you know what the common side-effects of your treatment(s) are?") to 93.8% ("Do you know how to obtain a repeat prescription?"). Cronbach α was 0.90, indicating good internal consistency for research and clinical purposes. Eliminating individual items, in turn, made little difference in Cronbach α (range, 0.89-0.90) (**Table**). Item total correlations ranged from 0.44 to 0.76 (median, 0.68). Exploratory factor analysis extracted just one factor (eigenvalue, 5.37), indicating that the scale is a unidimensional construct interpreted as the self-care ability of patients living with chronic dermatoses. Factor loadings on individual items ranged from 0.47 to 0.80, indicating that all the items contributed to the factor in a significant way and that none needed to be discarded. The factor loading for the final question ("Do you feel confident to use treatment(s) at home yourself?") was 0.74, indicating good correlation between this summary variable and the overall factor. Nurses reported that the completion of the PeDeSI$_2$ could be incorporated into their usual appointment timescales.

COMMENT

The prototype PeDeSI was judged by nurses to be useful in practice but needed to be revised and tested to ensure validity and clinical manageability. The PeDeSI$_1$ provided useful assessment but was too lengthy to be of practical value. To be successful, measures must be feasible for use and be easy to understand, clear, and unambiguous.[21] In addition, a more robust theoretical underpinning of the prototype was needed. The self-efficacy construct[14] and the concordance model[15] provide an evidence base for interventions designed to support self-management and have been used successfully in their application to other long-term conditions.[22,23] Improving self-efficacy is vital to enhancing self-management, necessitating a more systematic assessment that positively facilitates agreement and understanding between the patient and the physician or nurse.

Including an action plan in which realistic patient-determined goals are agreed on, documented, and reviewed in true partnership interaction style ensures that the needs of patients are most likely to be achieved. It is useful to have a template for the action plan and to enable participants to consider carefully what they really

Person-Centered Dermatology Self-Care Index
A tool to assess the education and support needs that will enable people with long-term skin conditions to manage topical treatments on their own.

Name label: Condition: Topical treatment(s):

Please score each area of ability in discussion with the person using treatment(s) by ticking the relevant boxes.

PeDeSI number:	Degree of independence				
Ability	0 = No ability	1 = Some ability	2 = Sufficient ability	3 = Full ability	Agreed action plan
1. Do you have an understanding of your skin condition?					
2. Do you know what things make your skin condition better and worse?					
3. What is this treatment(s) used for?					
4. Are you aware of how long initial treatment will take to be effective?					
5. Do you know what the common side-effects of your treatment(s) are?					
6. Do you know how much cream/ointment/lotion should be applied each time and at what time(s)?					
7. Can you apply the treatment(s) to the affected areas? (demonstrate)					
8. Do you know how and when to adapt treatment/seek help if condition gets worse?					
9. Do you know how to obtain a repeat prescription?					
10. Do you feel confident to use treatment(s) at home yourself?					

Total Score/30 (maximum total score)
Total scores in range: 0-10 needs intensive education and support to develop knowledge, ability and confidence
Total scores in range: 11-20 needs some education and support to develop knowledge, ability and confidence
Total scores in range: 21-29 needs limited education and support to develop knowledge, ability and confidence
Total score of 30 has sufficient knowledge, ability and confidence to manage on their own

Signature   Date

Person-Centered Dermatology Self-Care Index
Action Plan to Meet Identified Learning/Support Need

Name   Date

Abilities that you need to achieve.	Initial Score	Actions agreed by partners	By whom	1st review: score Date	2nd review: score Date

Patient signature: Clinician signature:

Date:

Figure. The Person-Centered Dermatology Self-Care Index 2.

want to achieve; these goals often differ substantially from those anticipated by physicians and nurses.

The process of using the PeDeSI₂ helps to integrate the principles of self-management and concordance in

Table. Cronbach α and Factor Loading for Each Item of the Person-Centered Dermatology Self-Care Index 2

Item	Domain	Cronbach α With Item Deleted	Factor Loading
Do you have an understanding of your skin condition?	Knowledge and understanding of skin condition	0.89	0.77
Do you know what things make your skin condition better and worse?	Knowledge and understanding of skin condition	0.89	0.71
What is this treatment(s) used for?	Knowledge and understanding of treatment	0.89	0.80
Are you aware of how long initial treatment will take to be effective?	Knowledge and understanding of treatment	0.89	0.72
Do you know what the common side-effects of your treatment(s) are?	Knowledge and understanding of treatment	0.90	0.66
Do you know how much cream/ointment/ lotion should be applied each time and at what time(s)?	Application of treatment	0.89	0.70
Can you apply the treatment(s) to the affected areas? (demonstrate)	Application of treatment	0.90	0.62
Do you know how and when to adapt treatment/seek help if condition gets worse?	Application of treatment	0.89	0.74
Do you know how to obtain a repeat prescription?	Application of treatment	0.90	0.47
Do you feel confident to use treatment(s) at home yourself?	Summary question	0.89	0.74

consultations. Each question is designed to address the key issues of knowledge, skills, and confidence, and the action plan encourages the patient and the physician or nurse to agree on realistic goals. The concordance process is supported because optimal use of the tool requires collaboration through discussion of a patient's self-management understanding and capacity.

The PeDeSI$_2$ is unidimensional, has good content and construct validity, and demonstrates high levels of internal consistency. This shorter index can readily be integrated into clinic consultations, and anecdotal feedback suggests that patients, physicians, and nurses found it to be a useful tool to guide outpatient encounters. Indeed, it has been adopted by the study centers included herein and other clinical areas following dissemination. The objective of the use of the index is to help patients, physicians, and nurses work collaboratively to assess the education and support required to enhance self-management. Further research will be needed to evaluate whether accurate assessment of education and sup-

port needs translates into the behavioral change required for improved self-management.

Limitations to this work include logistical factors that prohibited the collection of detailed demographic data from patients and workload pressures of participating physicians and nurses that prevented assessment of test-retest reliability. Both of these elements require further testing.

The PeDeSI$_2$ may allow physicians and nurses to make timely, systematic, and accurate assessments of the education and support needs of patients with long-term dermatological conditions and act as a vehicle for actively engaging patients in the concordance process to improve adherence with treatment recommendations. The index also provides a basis for evaluating the effectiveness of measures to support self-management: a crucial factor in treatment efficacy.

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PRACTICE GAPS

Practice Gap in Patient Education

Patients clearly have education and support needs in the management of chronic conditions. Are those needs being met? Cowdell et al[1] describe the development of an instrument that assesses these needs. While not the primary focus of their article, the study clearly identifies a gap in practice: the percentage of patients reporting less than sufficient ability to perform basic aspects of care—such as what the treatment is for, how to obtain a prescription refill, how much cream or ointment should be applied, and how to minimize adverse effects, among others—ranged from 7% to 44%. If this is generalizable to other dermatology practices, the practice gap in this area is large.

In responses to an online patient satisfaction survey,[2] patient education issues were among the more influential factors affecting patient satisfaction. Patients regard their physicians' communication skills, including their willingness to provide information and their ability to listen to the patient, as highly important to quality health care. Patients were more likely to give their physician a poor rating if this communication was lacking. The survey also found that informing patients about diagnosis and treatment, specifically educating patients about treatment options and medications, including adverse effects and cost, contributes to patient satisfaction. In a study[3] that focused specifically on US dermatologists, findings were similar in regards to communications skills of the physician and patient satisfaction. While many physicians scored well for including patients in decision making, providing clear instructions, and adequately answering questions, there was room for improvement.

In a qualitative study by Uhlenhake and colleagues,[4] discrepancies between patient and physician expectations in the treatment of psoriasis and a need for better communication were identified. In general, patients seek more education about their condition and desire more compassion and enthusiasm from their physicians. The study described a psoriasis encounter checklist that includes physician reminders to cover the key patient education issues during patient visits. Incorporating such checklist tools may help narrow the patient education gap. In some dermatology practices, this gap may be large.[5]

The development and validation of the Person-Centered Dermatology Self-Care Index by Cowdell et al[1] to measure the education and support needs of patients with long-term skin conditions gives us a way to evaluate these requirements, to assess whether they are being met, and to test the effectiveness of interventions to deal with gaps in dermatologic practice. Such a tool may enhance dialogue between the patient and the physician or nurse and address the needs and expectations of the patient. Even if used only among a sample of patients at intervals, such a tool may better guide the physicians' and nurses' approach to their individual patients with chronic conditions and strengthen overall adherence and treatment outcomes. Barriers to success include time constraints for additional counseling and health plan reconciliation.

Maintenance of certification in dermatology requires that surveys on patient experience of care should be obtained twice during each certification cycle. Not only will critically appraising patient experience scores help document the quality of care, but also practice gaps may be

identified and targeted for improvement. Working to improve an identified patient communication deficit could also potentially satisfy the practice assessment and quality improvement requirements for maintenance of certification. Identifying and improving dermatologist-patient communication is not just good medical care; it has the potential to improve treatment adherence and, ultimately, patients' treatment outcomes.

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The Best of the Best

Top Accessed Article: Propionibacterium Acnes and the Pathogenesis of Progressive Macular Hypomelanosis

Westerhof W, Relyveld GN, Kingswijk MM, de Man P, Menke HE. *Propionibacterium acnes* and the pathogenesis of progressive macular hypomelanosis. *Arch Dermatol.* 2004;140(2):210-214.

Progressive macular hypomelanosis is a common entity and is often mistaken for tinea versicolor and pityriasis alba; however, it is unresponsive to medications for these conditions. The authors of this interesting article had previously noted a red fluorescence of the follicles of affected skin in affected patients. Using biopsy specimens of lesional and healthy follicular skin as well as lesional and healthy interfollicular skin in 8 patients, they demonstrated gram-positive rods in the affected follicles but not in the unaffected follicles or the interfollicular skin. Culture of the affected follicles yielded *Propionibacterium acnes* in 7 of the 8 patients, while the unaffected follicles and the nonfollicular skin did not yield this organism. No spores or hyphae were visible in any biopsy specimens (stained with periodic acid–Schiff).

Westerhof and colleagues' astute observational skills and subsequent study of affected and control skin led to the discovery of *P acnes* as the etiologic agent. Also, they provided a useful method to make the diagnosis using a simple Wood lamp. Subsequently, articles have been published from all over the world confirming their findings and reporting good results using topical and systemic antimicrobial agents as well as phototherapy. This article is a good example of how a thorough examination and curiosity can stimulate research, leading to improvement of the lives of patients.

From October 2010 to August 2011, this article was viewed 1651 times on the *Archives of Dermatology* website.

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