Supplementary Online Content


eAppendix. The Person-Centred Dermatology Self-Care Index (PeDeSI): A Tool to Measure Education and Support Needs in Long-term Skin Conditions

This supplementary material has been provided by the authors to give readers additional information about their work.
eAppendix. The Person-Centred Dermatology Self-Care Index (PeDeSI): A Tool to Measure Education and Support Needs in Long-term Skin Conditions

From prototype to PeDeSI²

The prototype 23-item PeDeSI was developed by a group of dermatology specialist nurses.¹ To ensure face validity, that the tool appears to measure what it is intended to measure, the question set was developed using their own experience of the issues that needed to be addressed with patients to enable them to self-manage to the best of their ability. The prototype had been used in a secondary care dermatology centre by these nurses and found to be a useful tool for assessment; however, it had not been validated.

The PeDeSI¹ was developed by the research team and an expert panel of patient representatives with long-term skin conditions, practitioners and educationalists. The prototype was reviewed and content validity, the extent to which the measure represents all attributes, of the tool strengthened by drawing on the theoretical base using self-management theory, and in particular the self-efficacy construct,² and a model of concordance within prescribing practice.³ Evidence indicates that these processes are valuable elements in chronic illness self-management and have been used effectively in other fields such as asthma⁴ and diabetes⁵ management. One of the central elements of self-management is self-efficacy: this is defined as the belief that a person has about their ability to achieve a particular level of performance in a specific task.² Self-efficacy beliefs influence how people feel, think, motivate themselves and behave.⁶ The literature suggests that in order to enable people to self-manage chronic conditions it is necessary to help them develop their self-efficacy.⁷,⁸ This includes the need to ensure people acquire sufficient knowledge, skill and confidence. There
are four key sources of self-efficacy: 1) mastery experience; 2) vicarious experience; 3) social persuasion and 4) emotional regulation.²

Mastery experience is considered to be the most effective way of creating a strong sense of self-efficacy. In enabling people to master tasks it important that the tasks are pitched at the right level for the individual. If tasks are too easily achieved people will expect instant success and will be discouraged by failure. Mastery experience may be gained by breaking tasks down into component parts, for example if a person needs to learn to apply a range of topical treatments to different areas of the body they might first be taught how and when to use emollients. The person would need to practice this task repeatedly in different environments with the required support, encouragement and feedback. When they are confident in this element of the task further actions may be added. Vicarious experience is a weaker influencing factor than mastery but may be particularly useful in people with little experience or confidence. Watching someone successfully achieving a specific task can be an effective way of convincing individuals that they can master the skills needed to be successful, for example a practitioner demonstrating a particular skill such as applying a topical treatment to a plaque whilst avoiding healthy skin. Using social persuasion people can be persuaded verbally that they are able to master tasks and succeed. For this to be most effective the facilitator needs to expose individuals to situations where they can succeed and avoid situations too early in which they are likely to fail. It is well known that some dermatological treatments are messy and inconvenient to apply. It is possible that through effective communication and social persuasion patients may begin to understand and accept how seemingly difficult treatments can be incorporated into their lives. To achieve emotional regulation people need to be taught how to interpret their physical and psychological states accurately, especially those related to the influence of stress and anxiety. They may see physiological and emotional reactions as signs of inability to complete certain tasks. It is not
the degree of such reactions that is important but how these are perceived and interpreted. There are a range of strategies that can be taught or encouraged that may help people to cope with their responses to their condition; these include stress management and relaxation techniques.\textsuperscript{6} Assessment of the knowledge, skills and confidence required for self-efficacy are key to the value of the PeDeSI.

The second component of the theoretical base of the PeDeSI is the concordance process, the principle of medicine-taking based on partnership working\textsuperscript{3} which can enhance treatment adherence. There are three central pillars of concordance: (1) patients need to have enough knowledge to participate as partners and health professionals must be prepared to work in partnership; (2) prescribing consultations must involve patients as partners and (3) patients must be supported in using medicines.\textsuperscript{3} It is acknowledged that not every practitioner seeing people with long-term skin conditions will prescribe for them, however, they are likely to play a crucial role in supporting and educating people in the use of topical medications.

The principles of self-management and concordance were used to shape the question set ensuring an optimal range of assessment questions to ensure a high level of construct, content and face validity. Construct validity, the extent to which the Index was measuring the intended attributes, was addressed by the research team comparing the PeDeSI\textsubscript{1} with relevant theoretical and empirical research literature and clinical evidence. A panel of patients and practitioners assessed the face and content validity of the Index using their experience and expert judgement. The original PeDeSI\textsubscript{1} had 22 items (Table) with a score range of 0-3 indicating the level of support and education required.

The PeDeSI\textsubscript{1} was extensively tested in practice. Fifty indices were sent to seven UK dermatology units (n=350 distributed). The theoretical base of the tool and its significance was explained to practitioners in a concise accompanying user guide. 177 (51\%) indices were returned completed having been used in a range of skin conditions including chronic plaque
psoriasis, lichen planus, eczema and ichthyoses. The development methods used helped to ensure good face, content and construct validity. Cronbach $\alpha$ was .98, indicating high internal consistency and factor analysis extracted just one useful factor, with eigenvalues for all other factors being 1 or less. This implies the tool was measuring a unidimensional construct. The correlations between individual items and the single factor (factor loadings) ranged from 0.66 to 0.93. However feedback from practitioners indicated that whilst the PeDeSI1 was valuable in calculating education and support needs it was too lengthy for use in everyday clinical practice. We therefore developed and field tested PeDeSI2.
References


Table. Items in PeDeSI

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1. Do you have an understanding of your skin condition?
2. Can you explain how this condition affects you? (consider using DLQI to assess impact)
3. Do you know what things make your condition worse?
4. Do you know what makes your skin condition better?
5. What is this treatment(s) used for?
6. Can you explain how this treatment works?
7. Do you understand what may be achieved by using this treatment?
8. Are you aware of how long initial treatment will take to be effective?
9. Do you know what the common side-effects of your treatment(s) are?
10. Do you know how side effects may be minimised?
11. Do you know how to obtain a repeat prescription?
12. Can you explain how to store this treatment safely
13. Do you know how to use it without risk of causing infection
14. Do you know how much cream / ointment / lotion should be applied each time
15. Do you know how often and at what time(s) you should apply this treatment?
16. Do you know when you should apply this treatment in relation to other treatments?
17. Can you apply treatment to affected areas? (demonstrate)
18. Do you know in which direction to apply your treatment? (demonstrate)
19. Do you know how and when to adapt treatment / seek help if condition gets worse?
20. Do you know how to safely put medications into smaller containers for daily use?
21. Is the action plan you have developed with your nurse or doctor is realistic and achievable?
22. Do you feel confident to use treatment(s) at home yourself?