The bigger picture: Changing understanding of psoriasis with new patient resources and identifying perceived mechanisms of change

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BACKGROUND: Psoriasis is a complex skin condition associated with psychological distress, social withdrawal and co-morbidities. Patients believe the disease is trivialised by others; their understanding of psoriasis is low and condition-specific self-management support is lacking. The Common-Sense Self-Regulatory Model (CS-SRM) emphasises the role of illness/treatment beliefs on coping and self-management. New patient resources (IMPACT ‘Pso Well®: Psoriasis and Wellbeing) informed by the CS-SRM addressed: psoriasis as a long-term condition; medication management and lifestyle behaviours. We investigated whether the resources: a) broaden understanding of psoriasis without increasing anxiety; b) are acceptable/usable and whether patients c) identify any potential mechanisms of change.

METHODS: The Revised Illness Perceptions Questionnaire (IPQ-R modified for psoriasis) and the Hospital Anxiety and Depression Scale (HADS) were administered pre- and post-exposure to the new resources in patients with psoriasis recruited from primary care. Visual Analogue Scales (VAS) assessed patients’ perceptions of change in understanding and anxiety. Qualitative interviews using Framework Analysis with a subset of participants explored acceptability/usability and any perceived active ingredients of the resources.

FINDINGS: 55 patients completed the pre-/post-intervention questionnaires (56% female; mean age 58 years). Post-exposure, a large effect size was indicated in two IPQ-R domains: illness coherence (t [55] = -3.48, p=.001 [two-tailed], eta² =0.19) and personal control (t [55] = -2.98, p=.004 [two-tailed], eta² =0.14); and a medium effect size in one domain: treatment control (t [55] = -2.08, p=.042 [two-tailed], eta² =0.08). HADS anxiety scores did not change. For VAS scores, 80% of participants reported increased understanding of psoriasis and 16% reduced anxiety. Interviews with 19 patients indicated the resources were acceptable and usable. Factors reported to broaden understanding and encourage change included: coherent linking of disease aspects; perceived personal relevance of content and high quality design. Patients reported these features promoted feelings of self-worth and a desire to engage with self-management.

DISCUSSION: This study suggests that carefully designed, high quality, theory-based psoriasis resources are acceptable to patients and can improve their understanding, coherence and sense of control without a corresponding increase in anxiety.