‘Pso Well’ Patient Materials: Broadening patients’ understanding of psoriasis

K. Kane¹, C.J. Pearce¹, P.A. Nelson¹, A. Chisholm¹, C. Bundy¹,³, C.E.M. Griffiths¹,², L. Cordingley¹,³

Affiliations:
¹Manchester Centre for Dermatology Research, Institute of Inflammation and Repair, University of Manchester, ²Salford Royal NHS Foundation Trust, ³Manchester Centre for Health Psychology, University of Manchester, Manchester Academic Health Science Centre, Manchester, UK

Presented at the Manchester Academic Health Science Centre ‘Our Impact on Health’ Conference, Manchester, UK, December 2014

BACKGROUND AND OBJECTIVES: Psoriasis is a complex, relapsing-remitting, long-term inflammatory skin condition affecting around 1 in 50 people in the UK. Co-morbidities of psoriasis include psoriatic arthritis, Crohn’s disease, cardiovascular disease (CVD) and low mood. Psychological distress is higher in people with psoriasis when compared with other long-term conditions including diabetes, is associated with unhealthy lifestyle behaviours (such as smoking, over-eating), and reduces capacity to engage in health promoting activities. Furthermore, unhealthy lifestyle behaviours are particularly common in people with psoriasis and have a role in psoriasis onset, exacerbation and treatment response as well as being risk factors for CVD. Furthermore, people with psoriasis are often dissatisfied with the management of their condition, disengage from health services and find medicines self-management very challenging.

Previous research by the IMPACT team (Identification and Management of Psoriasis-Associated ComorbiditiTy) has shown poor understanding amongst people with psoriasis (and some practitioners) about the relationship between psoriasis and co-morbidities, treatment and lifestyle behaviour. The ‘Pso Well’ intervention draws on an evidenced-based, theoretical model (Leventhal's Self-Regulation of Health and Illness;SRM) as the basis for the design of patient-centred materials to promote better self-management. The materials target core belief domains identified in the SRM (identity, cause, timeline, consequences, and control) that cluster together to form a person’s ‘internal model’ of their condition. Illness representations are amenable to change and may be an antecedent to behaviour change and treatment adherence. The current objective is to develop and test materials with people with psoriasis in order to broaden their understanding of their condition and treatments, promote a coherent personal model of this long-term, relapsing-remitting condition. The ultimate aim is to increase intention to engage with effective psoriasis self-management strategies.

METHODS: Materials have been designed in a series of iterative phases. In Phase 1 key concepts were mapped against components of the SRM. Phase 2 (materials refinement) was undertaken in collaboration with clinicians and patients (Research User Group). Evaluation in Phase 3 involves up to 50 people with psoriasis recruited from primary care. Participants will be sent materials covering three areas: psoriasis as a long-term condition; medication management and lifestyle management. The Revised Illness Perceptions Questionnaire (IPQ-R; modified for psoriasis) will be completed pre- and post- exposure to the material to identify changes in psoriasis beliefs and illness coherence. Up to 20 of the participants will be interviewed in-depth to explore any perceived influence from reading the leaflets and the future development of the materials.

RESULTS: Will inform future development of both paper and electronic tools that encourage both self-monitoring and collaboration with a health care practitioner.

CONCLUSION: Once evaluated, these theory-based patient materials will be used in a randomised, controlled trial of an intervention to improve provision of psoriasis care and health outcomes.