Recognising distress in health care consultations: a qualitative study of people with psoriasis

P.A. Nelson¹, L. Cordingley¹,², C.E.M. Griffiths¹,³, C.A. Chew-Graham⁴

Affiliations:
¹Manchester Centre for Dermatology Research, Institute of Inflammation and Repair, University of Manchester, ²Manchester Centre for Health Psychology, University of Manchester, ³Salford Royal NHS Foundation Trust, Manchester Academic Health Science Centre, Manchester, ⁴Research Institute, Primary Care and Health Sciences, Keele University, Keele, UK

Presented at Society for Academic Primary Care Conference, Glasgow, UK, October 2012

BACKGROUND: Psoriasis is a life-long inflammatory condition affecting around 2% of the UK population. It is characterised by thick, red, heavily scaled plaques on the skin and scalp and can impact on a person’s quality of life, psychological and social functioning. There is some indication of patient dissatisfaction with psoriasis management, however, little is known about people’s specific experiences of health care consultations.

OBJECTIVES: The aim of the study was to gather in-depth perspectives about coping responses, self-care strategies and how consultations with health care professionals in both primary and secondary care are experienced.

METHODS: Face-to-face, in-depth, semi-structured interviews were carried out with 29 people with psoriasis recruited from community sources across the North West of England who had responded to advertising. An iterative, purposive sampling strategy gave rise to a diverse sample in terms of gender, age, ethnic/socio-economic background and self-assessed psoriasis severity, duration and treatment. Verbatim transcripts of interviews were coded using the Framework Analysis approach, resulting in a thematic framework incorporating all the key issues and concepts emerging from the dataset.

RESULTS: Respondents perceived that the reality of living with psoriasis went unacknowledged by health care practitioners. They reported physical, emotional and social stress and distress as a consequence of the condition, with its visibility having strong effects on self-confidence and relationships. Having low control over psoriasis was often reported, compounding feelings of stress and distress. Participants wanted practitioners to acknowledge the degree of impact psoriasis has on wellbeing and provide more opportunities to discuss the condition. In addition, practitioners were perceived as disengaged from psoriasis management because of appearing to lack expertise and failing to manage it as a long-term condition (LTC). Participants described a broad range of strategies to cope with psoriasis, however some responded by ceasing to consult about psoriasis or seeking alternative opinions outside the UK health service.

CONCLUSION: The study highlights that it may be problematic for patients to express within consultations in both primary and secondary care the extent to which psoriasis is a source of stress in their daily living and have this acknowledged by practitioners. It also indicates that the paradigm shift of the 1990s in experts’ understanding of psoriasis as a complex LTC involving the development of new treatments is not being currently reflected in routine clinical practice. Such emotional blocking and disengagement from psoriasis management may discourage people from consulting their practitioners about psoriasis. If the mismatch between patient and practitioner perceptions of the condition is to be aligned, people with psoriasis need to be managed in a way that addresses emotional and social need, with appropriate diagnosis, regular review of treatments and ‘stepping up’ of care when necessary.