South Asian perspectives about living with psoriasis: a qualitative UK study

P.A. Nelson1, C.A. Chew-Graham2, C.E.M. Griffiths 1,3, L. Cordingley1,4

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

Presented at the 6th International Congress of Psoriasis: from Gene to Clinic, London, UK, December 2011

BACKGROUND: Psoriasis affects around 2% of the UK population, including people of South Asian (SA) heritage. It can impact on a person’s quality of life, psychological and social functioning, however little is known about the experiences of SAs in relation to living with psoriasis.

OBJECTIVES: The aim of the study was to gather in-depth perspectives of SAs about their condition, their coping and self-care strategies and how they experience consultations with health professionals in both primary and secondary care.

METHODS: Face-to-face, in-depth, semi-structured interviews were carried out with 27 people with psoriasis, including 11 of SA heritage. Participants were recruited from community sources across the North West of England, responding to advertising or informal talks to community groups. An iterative, purposive sampling strategy gave rise to a diverse sample in terms of gender, age, socio-economic background, self-identified ethnicity 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 reported physical, emotional and social distress as a consequence of having psoriasis, with the visible nature of the condition having particularly strong effects on self-confidence and relationships. Many of these issues were common for all participants; however, for participants of SA heritage, they could be nuanced by particular cultural dimensions.

Stigmatisation was a particular concern for SAs, with consequences for loss of social standing to self and family. Participants identified difficulties accessing information about and understanding their psoriasis, with biomedical treatments often perceived as ineffective and accompanied by unacceptable side effects.

CONCLUSION: While health care practitioners in both primary and secondary care were perceived by all participants as failing to acknowledge the degree of impact of psoriasis on wellbeing, participants of SA heritage often identified their reluctance to discuss their skin problem as a culturally specific phenomenon. Participants described a broad range of coping strategies, however disengaging with biomedical treatments and/or an interest in alternative remedies were particularly common.

The stigma felt by SA people with psoriasis needs to be recognised and discussed within consultations to enable patients to engage more effectively with the management of the condition. Awareness of the cultural context in which individuals attempt to self-care, including seeking alternative approaches, will help professionals provide more effective and tailored support.