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Psoriasis: The Skin I'm In. Development of a behaviour change tool to improve the care and lives of people with psoriasis

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Summary

Background

Psoriasis is a long-term skin condition associated with considerable life impairment. Extensive literature regarding the needs of patients with psoriasis is not translated into clinical practice.

Aim

To explore and communicate the experience of living with psoriasis and interacting with healthcare professionals (HCPs).

Methods

In total, 21 patients attending a tertiary adult psoriasis service were interviewed individually. Interviews were recorded and transcribed, then the transcripts were examined and thematic analyses and qualitative content analysis performed. The results were communicated via a short film.

Results

Three key themes were identified: comparison with cancer, misalignment of response with need and fear of social exclusion. Cancer comparison subthemes included poorer services, lack of awareness and trivialization of psoriasis compared with cancer. Misalignment subthemes related to lack of knowledge and inappropriate response of HCPs and society towards psoriasis. Fear of social exclusion subthemes included erroneous belief of psoriasis being contagious and the expectation of rejection. Consequent emotions of fear, shame and anxiety resulted in avoidant behaviours, which perpetuated social exclusion. Participants valued active listening, shared decision-making and communication of hope regarding treatment by HCPs.

Conclusion

Despite extensive research into psoriasis and the availability of effective treatment for many patients, people with psoriasis live unnecessarily impaired lives and have unsatisfactory healthcare experiences. Storytelling techniques provide a method to communicate scientific information in a way that may drive change in delivery of healthcare and improve the lives of patients.

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