

PHOTOBIOLOGY AND PHOTOPROTECTION

TELEPHONIC SURVEY FOR THE OUTCOME OF DESENSITISATION NARROWBAND ULTRAVIOLET B PHOTOTHERAPY IN ERYTHROPOIETIC PROTOPORPHYRIA

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Background: Erythropoietic Protoporphyria (EPP) is a rare inherited disorder of porphyrin metabolism, characterised by disabling photosensitivity to visible light, due to impaired activity of ferrochelatase enzyme. Management is based around providing information, photoprotection with visible light blocking sunscreen. There is a paucity of evidence for the efficacy of systemic agents. Recently, Afamelanotide, an alpha-melanocyte stimulating hormone analogue, has been used as subcutaneous photoprotective implant. Narrowband UVB (nbUVB) desensitisation therapy is used to increase tolerance to sunlight, although published evidence is sparse. The mechanism of reducing photosensitivity is uncertain, but may include photohardening and tanning. In our Porphyria clinics, the patients were very pleased with this therapy and reported increased tolerance to sunlight. We therefore performed a telephonic survey of patients with EPP who received nbUVB desensitisation. Our treatment regimen included 3 treatments weekly for 4 weeks and then once weekly for another 12 weeks (24 treatments per course).

Objective: We aim to define patient satisfaction, improvement in photosensitivity and quality of life with the treatment, identifying efficacy, adverse outcomes, improvement for the service and treatment protocol.

Materials and Methods: EPP patients seen in Porphyria clinics, having received nbUVB desensitisation in the past, were recruited for the retrospective telephonic survey of outcomes, using a paper proforma.

Results: Twelve patients (nine females, three males) were telephoned. Ten patients reported improvement in photosensitivity and quality of life, and recommended this treatment to other EPP patients. None experienced any adverse outcome except one who noted mild sunburn.

Conclusions: We recommend that nbUVB desensitisation be considered in the management of photosensitivity in EPP. Compared to Afamelanotide, nbUVB is more likely to be cost











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effective, has a known safety profile, is already widely available and could be made more accessible by home UVB machines, which can be purchased for £2500 and used for years.



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