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EHPS 2017

Track 5: coping with chronic disease

Title: Using n-of-1 methods to understand a complex behaviour: Photoprotection in patients with xeroderma pigmentosum

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Introduction: XP is a very rare inherited disease, involving an inability to repair UV-induced damage and increased melanoma risk. The only treatment is complete avoidance or protection from UV. No research on the complexity of photoprotection behaviours in XP exists. The aim of this study was to understand this complexity by specifying a method to combine and profile multiple preventive behaviours used over time.

Methods: 14 adult XP patients completed an n-of-1 study over 50 days. They recorded time spent outside, context, photoprotection of the face (visor, hat, glasses, scarf/face-buff, hoodie), and sunscreen use in an activity diary, and self-reported their level of photoprotection and satisfaction. Analyses included summarising the proportion of outdoor time that each photoprotective behaviour was used, and the correspondence between self-report and clinical level of protection.

Findings: Photoprotection behaviour and sunscreen use varied considerably between- and within-participants. Protection was often inadequate (e.g., 10/14 participants used none/very poor protection >20% of time) and didn't correspond with self-reports. Covariation with satisfaction suggested varying levels of behavioural awareness. Initial protection was not always maintained for the duration of the outdoor occasion, and sunscreen was not reapplied frequently enough.

Discussion: This is the first attempt to measure and describe the photoprotection behaviour of XP patients. The detailed insights gained have implications for the selection of an appropriate primary outcome for further research and the specific behavioural target for planned interventions to improve photoprotection. The method of profiling multiple preventive behaviours may also be of use in other poorly-understood complex behaviours.

250 words