

Background

Cutaneous lupus erythematosus (CLE) is a chronic inflammatory autoimmune condition of which photosensitivity is a major symptom. Individuals living with CLE are advised to practice photoprotection. Despite the benefits for disease control, many individuals living with CLE do not practice optimal photoprotection.

Aim

The aim of this study was to gain a deep insight into the lived experiences of individuals with CLE and their photoprotective practices.

Methods

A hermeneutic phenomenological approach was utilised in this study. Ten individuals living with CLE were recruited and interviewed. The interviews were minimally structured to allow emerging themes to remain as true as possible to participant experiences. Verbal interview data was enriched by the use of rich pictures (Figure 1). Interviews were transcribed and analysed using a template analysis approach due to its fit with hermeneutic phenomenology.

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Reference: McGarry B, O’Kane D, McCourt C, Gormley GJ. ‘More extraordinary than mundane ...’ A phenomenological analysis of the experiences of individuals living with CLE and their taking care in the sun. *Lupus*. 2020;29(13):1773-1780.

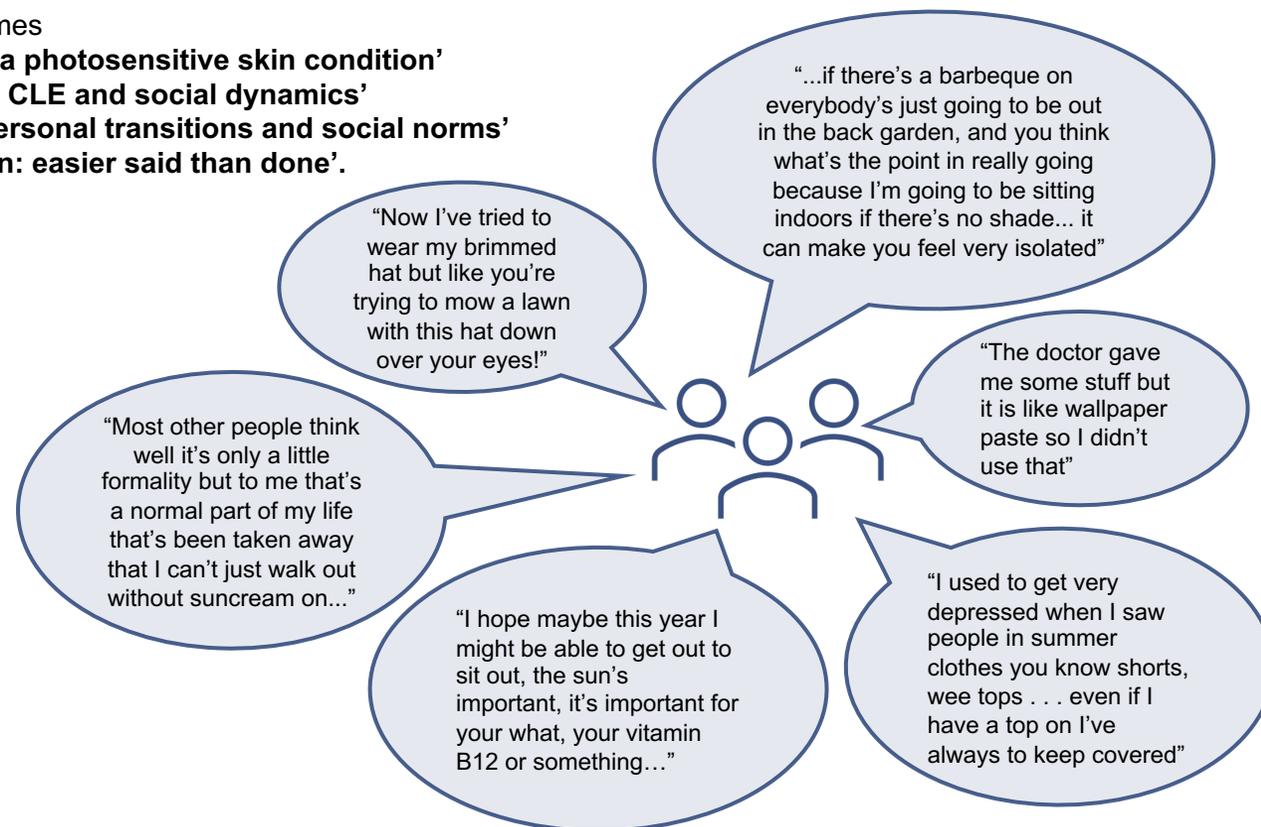
Results

Analysis revealed four themes

1. **‘Much more than just a photosensitive skin condition’**
2. **‘The impact of sun on CLE and social dynamics’**
3. **‘Drifting to the sun: personal transitions and social norms’**
4. **‘Taking care in the sun: easier said than done’.**



Figure 1. Example of a rich picture drawn by a research participant



Conclusion

For individuals with CLE, consistently complying with photoprotective advice is a highly complex, personal process and requires sustained behavioural change. Healthcare professionals must be cognisant of the physical, psychological and social difficulties experienced by individuals associated with complying with photoprotective advice. This will allow them to help individuals living with CLE optimise their photoprotective practices to reduce photosensitivity related disease flares.