

***‘More extraordinary than mundane . . . ’***

**A phenomenological analysis of the experiences of individuals living with CLE and their photoprotective practices.**



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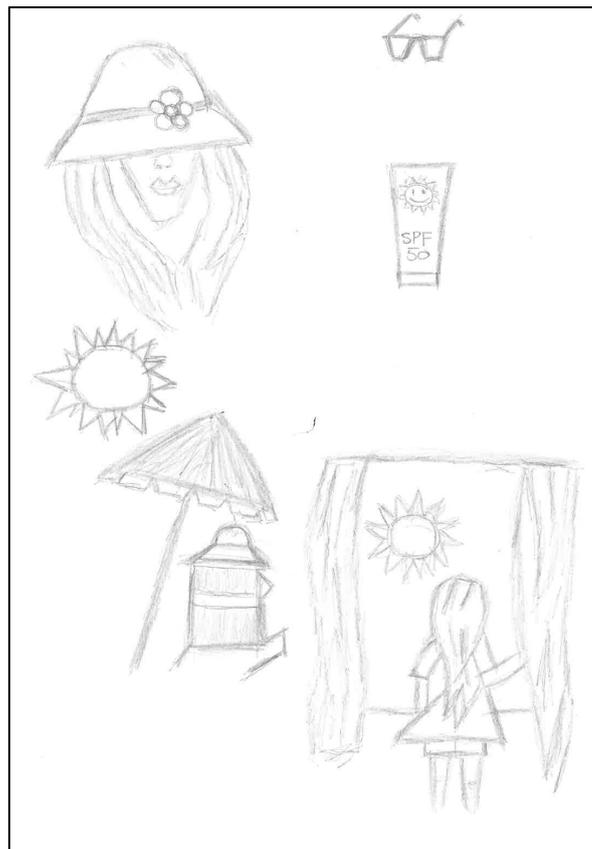
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## **Introduction and Aim**

Cutaneous lupus erythematosus (CLE) is a chronic inflammatory autoimmune condition of which photosensitivity is a major symptom. Individuals living with CLE are therefore advised to practice photoprotection. Despite the benefits for disease control, many individuals living with CLE do not practice optimal photoprotection<sup>1,2</sup>. Therefore, the aim of this study was to gain a deep insight into the lived experiences of individuals living with CLE and their photoprotective practices.

## **Methods**

A hermeneutic phenomenological approach was utilised in this study. Ten individuals living with CLE were recruited and then interviewed, either face-to-face or via telephone. 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. Rich pictures provided individuals with the opportunity to express their experiences visually (see Figure 1 for an example). Interview transcripts were then transcribed verbatim and were the focus of analysis. The rich pictures were not analysed directly but supported analysis of the interview transcripts. Analysis was conducted using a template analysis approach because of its fit with hermeneutic phenomenology.



Example of a rich picture drawn by a research participant (Kate\*) \*pseudonym

## Results

Analysis of the interview transcripts revealed four overall 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*' and 4) '*Taking care in the sun: easier said than done?*'. In this results section, each will be discussed in turn in more detail.

### Theme 1: 'Much more than just a photosensitive skin condition'

Many participants recounted that CLE was often perceived by others, including healthcare professionals, as 'just a photosensitive skin condition'. For these participants, exposure to the sun not only exacerbated their cutaneous symptoms but also systemic symptoms if they had co-existing systemic lupus erythematosus (SLE). Additionally exposure to UVR could trigger mental health and wellbeing issues.

### Theme 2: 'The impact of sun on CLE and social dynamics'

Participants reported how living with CLE greatly impacted on their social interactions. They recounted how their skin often drew attention from others, whether they were experiencing a disease flare or not. Participants reported how they often felt *different* from others. They recounted how individuals who were aware of CLE could offer support in these circumstances, however those who weren't aware of CLE often didn't understand which led to participants taking measures to conceal their condition and isolate themselves from social situations.

### Theme 3: 'Drifting to the sun: personal transitions and social norms'

Prior to developing CLE, many participants had a positive relationship with sun exposure, as is the social norm. Receiving a diagnosis of CLE marked a transition in how participants could experience the sun. Some participants accepted this transition, however some still longed for a time that they could enjoy the sun in the way they had prior to their diagnosis. Some even 'tested the limits' of their condition in the sun.

### Theme 4: 'Taking care in the sun: easier said than done'

Participants experienced a number of mediating factors that either promoted or inhibited their compliance with photoprotective advice. Previous negative experiences of sun exposure related to their condition motivated participants' compliance with photoprotective advice. Both advice and practical assistance (in the form of sunscreen on prescription) from healthcare professionals as well as support from family and friends had a similar effect. Many participants described factors which suppressed their motivation to practice photoprotection. Participants with co-existing SLE recounted how the burden of their systemic symptoms often reduced their motivation to comply with photoprotective advice. Participants also recounted how the extra time and effort required to comply with photoprotective advice challenged their motivation to do so. For some participants, the unpleasant feeling of wearing sunscreen or long sleeve clothing was a prominent inhibitory experience. For others, using an umbrella to provide shade attracted unwanted attention and intensified their feelings of feeling *different* from others.

## **Conclusion**

The findings of this study provide a rich, nuanced insight into the lived experiences of individuals with CLE and their photoprotective behaviours. Complying with photoprotective advice is far from a simplistic process. It is a highly complex, multi-layered and personal process, that can be subject to a wide variety of mediating factors that can change with time and circumstance. Consistently complying with photoprotective advice requires sustained changes to one's behaviours. Making these changes requires capability, motivation and opportunity, as indicated in the 'behavioural change wheel' model<sup>3</sup>. Individuals living with CLE may experience mediating factors that challenge their ability to meet these requirements. Beyond the biomedical model of illness, the social impact that CLE has on individuals has a dominant influence on their photoprotective behaviours. Individuals living with CLE may already feel different from others in society due to the presence of their condition on exposed sites, and complying with photoprotective measures may further exacerbate these feelings. Individuals may experience stigma, and may make efforts to conceal their condition to appear 'normal' to society.

Healthcare professionals must not underestimate the complex and multifaceted nature of sustaining photoprotective behaviours. Furthermore, they must be aware of the physical, psychological and social difficulties associated with complying with photoprotective advice and how these difficulties challenge compliance. Being cognisant of these difficulties will guide health professionals in providing patient-centred care to help individuals living with CLE optimise their photoprotective practices to reduce photosensitivity related disease flares. Overall, the lived experiences of the participants of this study reinforce one's understanding that taking care in the sun with CLE is more than *skin deep*.

**Word Count:** 909

## **References:**

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