

'Easier said than done...' the challenges of living with cutaneous lupus and taking care in the sun



Many individuals living with lupus can experience the challenging symptom of skin rashes that are sensitive to sunlight - photosensitivity. skin involvement in lupus is common and termed cutaneous lupus erythematosus (CLE).

Measures such as regular application of sunscreen, covering up exposed skin areas and avoiding prolonged exposure to the sun can help reduce such photosensitive rashes and flare ups. However, evidence would suggest that, 'taking care in the sun' is easier said than done for many individuals living with CLE.

Research led by Queen's University Belfast medical student Bláithín McGarry (pictured) set out to explore what these challenges were. Importantly she and her research team also wanted to gain insights of how we may best help individuals living with CLE adhere to photoprotective advice. Together with her research team: Dr Collette McCourt, Dr Donal O'Kane, (Dermatologists from the Belfast Health and social Care Trust) and professor Gerry Gormley (Gp and academic at Queen's University Belfast) recently published their findings in the scientific journal 'Lupus': <https://journals.sagepub.com/doi/full/10.1177/0961203320958067>.

Bláithín performed in-depth qualitative interviews with individuals living with CLE about their photosensitivity and challenges of taking care in the sun. Aside from interviewing these individuals, she also used a research technique called 'rich pictures'. This is where she invited individuals to draw a picture that represented their experiences. In so doing, she was able to gain a greater insight into their experiences, and the participants were able to overcome the challenge of expressing all of their thoughts and feelings verbally ('I just can't find the words to express myself...'). Analysis of these personal experiences provided important insights into their lived experiences and photoprotective behaviours.

Taking care in the sun is not a simplistic process. photoprotective behaviours are complex and personal. There are many factors that can influence ability of an individual living with CLE to take care in the sun. Taking care in the sun may appear effortless to others i.e., 'just putting on sunscreen', but for individuals living with CLE they can be challenging, especially on a daily basis.

A main factor is the social dimension of photoprotective practice. On face value, photoprotective measures such as applying sunscreen, wearing long sleeve clothing or a wide brimmed hat appear to be relatively simple. Despite this, as evidenced in this study, carrying out such measures can be challenging and reinforce individuals feeling of being different. patients with CLE may already struggle with feeling different from other members of society due to the presence of their condition on exposed skin



sites. They recounted how their skin often drew attention from others, whether they were experiencing a disease flare or not. Certain photoprotective measures may exacerbate this sense of feeling different for example, wearing long sleeve clothing outdoors when it is sunny.

As recalled by one patient:

"I would just feel stupid walking along in the summer with an umbrella up. Just drawing attention to yourself even though I know it would help me."

They recounted how individuals who were aware of CLE could offer support in these circumstances. As mentioned by one patient:

“My manager...he has a lot of empathy. He would encourage me ‘come in if you don’t want to go out the shop front today and go out to the back to avoid the sun”



However, those who were not aware of CLE often did not understand - which led to participants taking measures to conceal their condition and isolate themselves from social situations:

“ ... if there’s a barbeque on everybody’s just going to be out in the back garden, and you think what’s the point in really going because I’m going to be sitting indoors if there’s no shade ... it can make you feel very isolated.”

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 the way they had prior to their diagnosis.

Participants experienced a number of factors that either promoted or inhibited their compliance with photoprotective advice. Advice from healthcare professionals, the provision of sunscreen on prescription and support from family and friends also facilitated participant’s adherence to photoprotective advice. As mentioned by one patient:

“They [doctors] always make sure that they give strict instructions when I’m leaving to make sure I’m putting my sunblock on.”

“I would get my sun cream on prescription ... which is really good because it’s pretty expensive, especially the one I do get.”

Many participants described factors which suppressed their motivation to practice photoprotection. For example the extra time and effort required to comply with photoprotective advice challenged their motivation to do so. Also, the texture of the sunscreen was a difficulty for some participants, as explained by one participant:

“The doctor gave me some stuff but this is like wallpaper paste so I didn’t use that.”

Overall, the study provided nuanced insights into the lived experiences of individuals with CLE and their photoprotective practices. Complying with photoprotective advice is far from a simplistic process. It is a highly complex and personal process, that can be subject to a wide variety of factors. Consistently complying with photoprotective advice requires sustained changes to one’s behaviours. Making these changes requires capability, motivation and opportunity, and is in no way easy. Complying with photoprotective advice is also highly influenced by the impact CLE has on an individual’s social life.

As well as being aware of the physical difficulties of complying with photoprotective advice, healthcare professionals have an important role. It is hoped by increasing their awareness of the psycho- logical and social difficulties of taking care in the sun for individuals living with CLE experience can help them in providing even greater person-centric care. Healthcare professionals must not underestimate these difficulties. This study provides an

opportunity for education in this regard from the patients to the healthcare professionals. Overall, the lived experiences of the participants of this study reinforce to us all that taking care in the sun with CLE is more than skin deep.

Our thanks to Prof Gerry Gormley MD FRCGP for providing this very interesting article and to Queen’s University Belfast medical student Bláithín McGarry and her research team for carrying out this very important study.