A qualitative study of knowledge, behaviour and attitudes regarding vitamin D acquisition among patients with photosensitivity disorders

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Abstract
Background: Cutaneous exposure to sunlight is a major source of vitamin D. Individuals with photosensitivity disorders have symptoms provoked by sunlight and may not achieve the brief sunlight exposures that convey vitamin D acquisition.

Objective: To explore knowledge, behaviour and attitudes towards vitamin D and its acquisition in patients with photosensitivity.

Methods: Patients (n = 19) diagnosed with solar urticaria, erythropoietic protoporphyria or polymorphic light eruption at a specialist photoinvestigation centre participated in semi-structured focus groups to discuss vitamin D knowledge, acquisition behaviours and attitudes towards vitamin D acquisition through sunlight and diet. Discussions were analysed by thematic analysis using MAXQDA11.

Results: Knowledge of vitamin D was variable. There was good awareness that sunlight exposure is an important source but knowledge of dietary sources was poor. Patients had little concern for their own vitamin D status prior to attending the photoinvestigation centre. Most patients avoided sunlight exposure, were unable to achieve the guidance on sun exposure for healthy individuals and were aware this could affect their vitamin D status. Use of oral vitamin D supplements was common, and all were willing to consider supplements if required. Patients recommended improving education of clinicians to increase patient awareness of vitamin D.

Conclusions: More targeted guidance is required on acquisition of vitamin D for patients with photosensitivity, supported by increased patient and clinician education.

Keywords
attitudes, behaviour, photosensitivity disorders, sun exposure recommendations, vitamin D

1 INTRODUCTION

Vitamin D is essential for bone health, playing an important role in regulating dietary calcium absorption and bone mineralisation. Cutaneous synthesis is the main source of vitamin D as only small amounts are usually obtained through diet.1-4 Ultraviolet B (UVB) radiation in sunlight converts 7-dehydrocholesterol to pre-vitamin D₃. This undergoes heat isomerisation to vitamin D₃ (cholecalciferol)
then hepatic hydroxylation to 25-hydroxyvitamin D (25(OH)D; calcidiol), the main circulating form and accepted indicator of vitamin D status. Further hydroxylation in the kidney produces the active hormone 1,25-dihydroxyvitamin D (1,25(OH)2D; calcitriol), which binds the vitamin D receptor in target cells to mediate its action.

Vitamin D deficiency, defined as a circulating 25(OH)D concentration of less than 25 nmol/L (10 ng/mL), is prevalent in the UK, affecting as much as 39% of adults in the winter months when UVB levels are negligible at UK latitudes. Low vitamin D status can cause rickets in children and osteomalacia in adults and children, while associations between low vitamin D status and several malignant and autoimmune disorders have been reported.

National guidance on sunlight exposure in the UK allows for brief exposures to achieve adequate vitamin D status while avoiding excessive exposure to reduce risk of skin cancer. In 2016, the Scientific Advisory Committee on Nutrition (SACN) revised its guidance on oral vitamin D intake to recommend 10 µg daily during the winter months for those aged 1 and over in order to avoid vitamin D deficiency, and year-round for “at-risk” groups including those aged 65 and over, those with darker skin and those with minimal sunlight exposure due to cultural or medical reasons.

Photosensitivity disorders are characterised by abnormal skin reactions to low levels of ultraviolet radiation (UVR) and/or visible light. Overall, photosensitivity disorders affect a large proportion of the population with the most common disorder, polymorphic light eruption (PLE), estimated to affect around 18% of the Northern European population. Photosensitivity disorders present with a range of symptoms and clinical features, in which some disorders appear rapidly upon sunlight exposure such as in solar urticaria (SU) and erythropoietic protoporphyria (EPP), or after a delay of several hours such as in PLE.

The mainstay of treatment of photosensitivity disorders is photoprotection with broad-spectrum sunscreens, protective clothing and sun avoidance. These photoprotective behaviours result in reduced sun exposure in patients with photosensitive disorders and increased risk of vitamin D deficiency. Previous studies have shown that patients with a range of photosensitivity disorders have levels of 25(OH)D which can be up to 18%-25% lower than healthy individuals. However, previously they were no more likely to take vitamin D supplements than healthy adults despite spending less time outdoors in the summer months. Thus, the aim of this study was to explore the current knowledge, behaviours and attitudes towards acquiring vitamin D among individuals with photosensitivity disorders, including conditions that manifest rapidly (SU, EPP) and after a delay (PLE) following sunlight exposure.

### 2 | PATIENTS AND METHODS

This was a qualitative study performed in 2014-2015 that used focus group research methodology to explore knowledge of vitamin D, vitamin D acquiring behaviours and attitudes towards sunlight exposure and vitamin D acquisition, in patients with photosensitivity disorders. This included patients both with conditions that manifest rapidly on sunlight exposure (SU, EPP) and with a more delayed onset (PLE). Ethical approval was obtained from the Greater Manchester West NHS Research Ethics Committee (ref. 14/NW/1100). All patients provided written informed consent and the study complied with the principles of the Declaration of Helsinki. Patients were recruited from the Photobiology Unit, Dermatology Centre, Salford Royal NHS Foundation Trust, Greater Manchester. Inclusion criteria were: ambulant adults, aged 18-85 years with a confirmed diagnosis of photosensitivity (including prior demonstration of an abnormal response on phototesting).

Patients participated in focus groups comprising individuals with the same photosensitivity disorder with individual group sizes approximating those suggested to be optimal for focus group research. The format and topic guide were based on those used previously for different ethnicity groups and patients with skin cancer. Discussions lasted 45-60 minutes, were facilitated by a trained researcher and were digitally recorded. Following a brief introduction to the study, the facilitator utilised a topic guide to assist the discussions. Initial open questioning explored pre-existing knowledge of vitamin D. The facilitator then verbally delivered information that highlighted the sources of vitamin D, its importance in health, and guidance for healthy people on acquiring vitamin D through brief, sub-sunburn sunlight exposures, of about 15 minutes duration, around lunchtime on most days of the week. A mix of open and closed questioning was then used to explore current vitamin D acquisition behaviours of the participants and to encourage discussion regarding their attitudes towards this guidance. Discussion continued until no new information was presented. Audio recordings were transcribed, coded and analysed qualitatively using MAXQDA11 (professional qualitative data analysis software, VERBI Software, Berlin, Germany) and the principles of thematic analysis. Participant comments were broadly classified into themes of knowledge, behaviour and attitudes.

### 3 | RESULTS

Nineteen patients were recruited into the study in 5 focus groups (4 male, 15 female; median age 48 years, range 19-65 years; Table 1). Three patients had EPP and 8 had SU, disorders that manifest rapidly on sunlight exposure (within minutes). A further 8 patients had PLE, a disorder with a more delayed onset (hours to days). Patients’ comments are classified according to diagnosis and numbers relate to individual patients (Table 1).

### 3.1 | Vitamin D knowledge

Nearly all patients had some knowledge of vitamin D, and this had been obtained from a variety of sources. Some patients reported that their own diagnosis of vitamin D deficiency was their cue to finding out more information. Contact with secondary or tertiary care
clinicians, particularly at the Salford Royal Hospital Photobiology Unit, was the most commonly cited source:

Q: Where have you heard/learned about vitamin D (family/friends/media/hospital)?

Salford Royal Hospital Photobiology Unit (n = 8); Media (n = 4); Friends/family (n = 3); School (n = 2); GP, job, rheumatologist, general reading (n = 1 each).

There was particularly good awareness among all patient groups that the sun is an important source of vitamin D, but the quality and depth of this knowledge was variable. While many patients were aware that food could be a source of vitamin D, there was a lack of knowledge of specific vitamin D-rich foods. Many patients were unaware that fruits and vegetables were a poor source of vitamin D:

Q: How do our bodies get vitamin D? (what are the sources)

PLE1: “You can get vitamin D from the sun.”
SU6: “My mum used to say when you go out in the sun, don’t have a wash straightaway because the vitamin D stays on your skin and is absorbed later.”
EPP1: “You can get small sources from food but your primary source is the sun.”
SU3: “I was going to say spinach but I don’t know why (maybe) because it’s really good for you.”
PLE7: “Vegetables and fruits.”

The majority of patients could state a health benefit of vitamin D, which mostly related to calcium and bone health. However, knowledge regarding the consequences of vitamin D deficiency was largely limited to the effects in children with several patients mentioning rickets:

Q: What do you know about the benefits of vitamin D?

PLE8: “Good for your bones isn’t it.”
SU5: “Does it help your body to absorb calcium?”

Q: Do you think vitamin D deficiency could be a health problem?

EPP2: “Rickets, I think isn’t it?”
SU2,6,7: “...rickets.”
PLE1,7,8: “Prevents/stops you getting rickets.”

Prior to attending the Salford Royal Hospital Photobiology Unit, the majority of patients had no pre-existing knowledge or concern about their vitamin D status or the potential impact of low vitamin D status on their health. Notably, only 1 patient reported obtaining information on vitamin D from their GP and many patients reported being unsupported by their GP with respect to their condition and potential for vitamin D deficiency:

Q: Have you ever been concerned about your vitamin D levels? Have you ever requested a blood test for vitamin D?

EPP3: “Well I hadn’t been concerned until I came here and my blood tests showed I was deficient.”
SU6: “I think it’s a lack of awareness. Slight ignorance is bliss. I wouldn’t know what it was in order for me to have a worry about it to be honest with you.”
PLE3: “I had never requested a blood test.”

Q: Have any of you heard anything (about vitamin D) from your GP?

EPP1,2,3: “No, nothing.”
SU3: “(The) GP has never raised it as a possibility of being a problem.”
PLE3: “They (the GP) questioned me as to whether I really needed it or not. They were very sceptical.”
PLE4: “One of the things I said was ‘Can we just check it?’ They replied: ‘There’s no need, don’t worry about it.’”
PLE8: “My friend is a GP and he knew about vitamin D but on a very superficial level.”

3.2 | Behaviours

Most patients avoided sunlight exposure by various means including spending little time outdoors, wearing clothing covering most of their skin and using sunscreen. Patients with EPP and SU also reported
seeking shade when out in the sun, using umbrellas and applying UV film to windows of their houses. All patients had some understanding that sun avoidance behaviours may affect their vitamin D status. Most had concerns regarding the vitamin D sun exposure guidance of about 15 minutes sun exposure around lunchtime on most days of the week in summer. Only 2 patients, both with PLE, stated that they would be able to achieve this:

Q: On average, how much time do you spend outdoors between 11am and 3pm in the summer?

PLE5: “I would avoid it as much as possible... I can't go out and do the things in the sun because of the consequences.”

SU3: “I would be in hospital even if it is for 5 minutes. Just not a chance...”

EPP1: “11am to 3pm Those are the times we avoid the sun the most.”

Q: Do you protect your skin when you are outdoors? How?

EPP1: “All I have to do is wear a long sleeved shirt, cotton gloves and a wide brim hat. So you are getting very little direct sunlight.”

EPP2: “Generally I follow the shadows. You can spot shade at three miles.” “I've got Dundee cream.”

SU3: “I have got huge hats, clothes, umbrellas so the sun doesn't touch my skin. I have UV film all over my house and car." “I wear Dundee Suncream.”

PLE3: “Factor 50, that's what I buy.”

PLE6: “The only part of me that ever really shows in the summer are my hands, and obviously my face and neck.”

With respect to dietary behaviours, many patients believed they were getting a good amount of vitamin D from food because they had "a healthy diet." However, when specifically questioned, few patients consciously sought to eat vitamin D-rich foods, reflecting their lack of knowledge:

Q: Do you consciously eat any particular foods?

EPP1: “I generally eat vitamin D-rich food, I eat a lot of lean meat, eggs and dairy.”

EPP2,3: “No.”

SU5: “I eat a healthy diet.”

PLE8: “I think we have a healthy diet, we eat lots of fruit and veg.”

Most patients reported taking vitamin D supplements with two patients taking them only intermittently. The type of supplement used varied and included prescribed tablets, over-the-counter preparations, supplements designed for children and in one case a spray bought online:

Q: Do you take vitamin D supplements?

PLE1: “Yes I take mine all year round. They are just over the counter vitamin D.”

EPP2: “I come off them [supplements] in the summer and take them through the winter.”

PLE3: “The only one I found is children's supplements.”

PLE5: “I spray Dlux, and it comes with 1000 units...I found it through the internet”

3.3 | Attitudes

All patients were willing to take oral vitamin D supplements if required but some voiced concerns including the taste of supplements, lack of monitoring while actively taking supplements, intolerance or side effects, cost, and a perceived risk of overdose:

Q: Would you be willing to take vitamin D supplements?

PLE8: “I am happy to take supplements if it is a once a day tablet.”

SU2: “I would be willing to take supplements if it is going to make a difference.”

PLE1: “I can't tolerate the tablets, I can't digest them.”

SU2: “I would be happy to take them if it’s something that is going to be monitored.”

SU4: “If you take too much, does it affect your liver?”

At the end of each focus group discussion, patients were invited to give their thoughts on how to increase awareness of vitamin D including its function and sources. Several strategies were suggested but in particular educating clinicians, especially GPs, was popular (Figure 1). Furthermore, they stated that attempts to improve awareness needed to be targeted and unambiguous:

SU3: “Targeting information better would work rather than general information for the whole population. You need to target those who are more at risk, for example people who stay out of the sun like us.”

![Figure 1](image-url) Strategies suggested by photosensitive patients to improve vitamin D awareness
EPP2: “You are telling people to put sunblock on and then saying they are not producing enough vitamin D, it is mixed messages. So maybe there should be a clear message.”

4 | DISCUSSION

Patients with photosensitivity disorders suffer unpleasant symptoms following sun exposure and are medically advised to practise photoprotection including use of protective clothing and broad-spectrum sunscreens, and avoidance of sunlight exposure. Consequently, these patients are at higher risk of vitamin D deficiency, and they have been shown to have lower serum 25(OH)D levels than non-photosensitive individuals in the same geographical location. However, patients with photosensitivity may not be aware of this risk and there is a paucity of information pertaining to their knowledge of vitamin D, and their behaviours and attitudes towards acquiring vitamin D. Our qualitative focus group study has provided new insight into this which can inform guidance and recommendations for this at-risk group. Key findings were that patients’ knowledge of vitamin D, in terms of quality and depth, was highly variable and was obtained from a number of sources. Only 2 patients—with both the delayed onset disorder PLE—and none of the patients with EPP or SU could achieve the brief sunlight exposures recommended for vitamin D acquisition via skin synthesis. All were willing to consider oral vitamin D supplementation, albeit with concerns over monitoring and safety.

The focus group is an effective research methodology that is commonly used to explore the factors that influence individuals' beliefs, attitudes and behaviours. We limited potential bias and increased the reliability of analysis through digital recording of each focus group session and by having these recordings transcribed by an independent researcher. The number of patients involved in our study (n = 19) was appropriate, with individual group sizes approximating those suggested to be optimal for focus group research. The gender balance of patients represented the fact that there is a higher prevalence of these photosensitivity conditions in females.

Our finding of substantial variation in the quality and depth of patients’ knowledge is in line with findings from studies of other patient groups and the general population, including our study of patients with skin cancer which used an identical study design and similar topic guide. Lack of knowledge of vitamin D-rich food sources was particularly evident with many patients wrongly believing that a “healthy diet” of meat, fruit and vegetables could provide adequate vitamin D. Furthermore, while many patients related vitamin D with bone health, awareness of the effects of vitamin D deficiency was limited to occurrence of rickets in childhood. This was also found in our previous study and is likely due to the emphasis the media puts on rickets in relation to vitamin D deficiency. The lack of knowledge of complications that arise from vitamin D deficiency in adulthood may explain why few patients in our study had pre-existing concern about their vitamin D status and its impact on their health. Our data highlight the need to educate people with photosensitivity disorders on the importance of vitamin D for health, consequences of deficiency and their need for increased oral intake of vitamin D, including supplements. Enhancing awareness supports the SANC recommendation to have a dietary vitamin D intake of 10 μg daily, whether this is from food or supplements, and could encourage people with photosensitivity disorders to follow this.

We found the most common source of information on vitamin D was from contact with the Salford Royal Photobiology Unit, a tertiary care service. Patients reported a particular lack of knowledge of vitamin D among general practitioners and therefore a feeling of being unsupported in the primary care setting. The perceived lack of knowledge and support from general practitioners is reflected in findings from a recent review of clinical management of low vitamin D worldwide, which showed that confidence in vitamin D knowledge among primary care physicians was varied, with 9%-40% being “not at all confident” in their knowledge. Studies from Australia and New Zealand have also shown that over 50% of general physicians believe that clear information about vitamin D is not easily available and would be useful. Data from the UK are limited, but similar findings of limited advice from health professionals (primarily GPs) have been reported. Thus, there is a clear need among healthcare professionals for improved vitamin D information. This could be incorporated and delivered as part of training and continued professional development, as suggested by some participants in our study.

While knowing that sunlight exposure was an important source of vitamin D and that limiting exposure may affect their vitamin D status, the majority of patients practised sun avoidance behaviours, particularly those with EPP and SU where symptoms of photosensitivity manifest rapidly on sun exposure. This follows the “perceived susceptibility” dimension of the health belief model, with patients considering the risk of photosensitivity to be greater than the risk, and potential negative health consequences, of vitamin D deficiency. This mirrors our findings in skin cancer patients who perceived the risk of developing further skin cancers through sunlight exposure to be greater than their risk of vitamin D deficiency, and they therefore practised photoprotective behaviours. Consequently, the majority of patients with photosensitivity were unable to meet guidelines for healthy people regarding sunlight exposure and vitamin D, further highlighting the need for targeted, unambiguous information specifically directed to this group.

All patients were amenable to taking oral vitamin D supplements and the majority were taking them since visiting the photoinvestigation unit. Nevertheless, many voiced concerns regarding taking daily supplements, including toxicity and monitoring, which were similar to those reported by non-photosensitive patients attending a UK general practice. This suggests there is a need to better educate and support patients that have been advised to take vitamin D supplements. Patient education activities have been demonstrated to significantly improve medication compliance across a broad range of conditions.

Low vitamin D status is a significant issue in patients with photosensitivity and must be managed appropriately and effectively. Our findings highlight the value of qualitative research that explores patients’ knowledge, behaviour and attitudes, in order to identify gaps in understanding and clinical care. Recommendations on vitamin D
supplementation should specifically target patients with photosensitivity disorders, supported by education of patients and primary care providers.

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