Photodynamic therapy (PDT) is a well-known, effective method for treating extensive areas of multiple actinic keratoses in the face and scalp. The main side-effect of PDT is the pain experienced during treatment. The objective of this study was to explore and describe patients’ experiences of PDT. The study used individual interviews, and analysis was carried out using phenomenography. The patients had all been treated with PDT for actinic keratoses on the face and scalp, and experienced PDT with and without nerve blocks. The results are presented in 3 themes and 10 categories. Most patients reported that the nerve blocks given prior to PDT altered their experience of pain. Alternative options are needed to reduce pain during PDT based on patients’ needs and body site. This study adds a patient perspective highlighting patients’ own voices as a qualitative complement to statistical analysis using the visual analogue scale. Key words: actinic keratoses; interviews; nerve blocks; pain; phenomenography; photodynamic therapy.

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Patients’ Experiences of Pain and Pain Relief During Photodynamic Therapy on Actinic Keratoses: An Interview Study

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The amount of sun to which our skin is exposed has increased in recent decades, as more people travel abroad to sunnier regions. This has resulted in a dramatic increase in skin cancer (1).

Non-melanoma skin cancer (NMSC) and actinic keratoses (AK) can affect large areas, a process known as “field cancerization” (2, 3). The condition can be treated in several ways, one of which is photodynamic therapy (PDT).

PDT is performed using a cream containing methylaminolaevulinate (MAL) to enhance the photoactive substance formation of protoporphyrin IX in the lesions. MAL cream is applied to the lesion and then occluded for 3 h. Subsequent irradiation with red light initiates the formation of reactive singlet oxygen, causing cell necrosis (4). AK are treated once with an illumination of 37 J/cm², while thicker lesions receive 2 treatments with PDT, 1–2 weeks apart. Erythema usually develops on treated areas after completion of irradiation and disappears over a period of 1–2 weeks. Oedema may occur, especially after treatment of the area around the eyes. After a few days, crusts form and scaling of the skin begins.

Since pain is the main side-effect during treatment (5–7) the risk of severe pain is immediate when treating AK, especially those located on the face and/or scalp. Studies have investigated the opportunity to predict the pain experienced by patients, with varying results (8–11). Common methods of reducing the pain are the use of water spray and using a fan to blow cold air; however, these methods are not very effective. An excellent option is to use nerve blocks (NB) (12, 13). In order to achieve anaesthesia of the forehead and scalp, the supraorbital and supratrochlear nerves are blocked in combination with the greater and lesser occipital nerves (13). One aim of NB is to enable pain relief also after completion of the PDT. The pain is expected to decrease after a few hours. Daylight-mediated PDT may be a less painful option, although this treatment is seasonal and weather-dependent (14).

The pain experienced during PDT is usually assessed using a visual analogue scale (VAS). To our knowledge, patients’ descriptions of their experience of PDT have not been investigated previously.

The objective of this study was to explore and describe patients’ experiences of PDT.

PATIENTS AND METHODS

Patients and treatment

Fourteen men, mean age 79 years (age range 65–87 years), and 4 women, mean age 68 years (age range 49–78 years), participated in the study. In the normal patient population receiving PDT, the majority are men, as is reflected in this study (15, 16). The patients had all been treated with PDT for AK on the face and scalp and experienced PDT with and without NB. All patients at the clinic with field cancerization on the face and scalp are offered NB as pain relief during PDT. The number of PDT treatments and time since the last treatment are shown in Table I.

The illumination lamp (Aktilite® CL 128 Galderma Nordic AB, Uppsala, Sweden) used in this study has a built-in fan, and an additional fan can be used. The staff attempt to engage the patient in conversation, in order to create some distraction so the treatment time is perceived as shorter.

Methods

This is a qualitative study with a phenomenographical approach (17). This approach deals with qualitatively different ways of...
determining how people experience and understand the various phenomena in, and aspects of, the world around them. In this case the phenomenon under study is experience of PDT. Interviews are a frequently used method to capture people’s conceptions of various aspects of the world. These conceptions are central to phenomenography (18, 19). In accordance with this approach, the participants were chosen in order to represent as many different experiences of PDT as possible (20). The interviews were tape-recorded and transcribed verbatim.

Data collection

A pilot study with 2 patients was performed to evaluate the interview question. These 2 interviews were not included in this study. After evaluation of the pilot study, the planned study was carried out.

The interviews were performed individually in a semi-structured way. According to Kvale, the research interview has a distinct power asymmetry, which may be reduced if the participant has the option to choose the location of the interview (21). In our study all patients but one decided to have the interview in the researcher’s office at the hospital. One interview took place in a café. The interviews lasted approximately 25 min (range 15–40 min). The main open interview question was: “Could you please tell me about your experiences of PDT?”

Data analysis

The tape-recorded interviews were carried out and transcribed verbatim by the first author (CH). The data were analysed according to the principles of phenomenography, as described by Alexandersson (22). The process can be divided into 4 phases: (i) becoming familiar with and obtaining an overall impression of the data; (ii) noting similarities and differences in statements; (iii) determining descriptive categories of conceptions; and (iv) examining the underlying structure of the system of categorization (22).

Two of the authors (CH and ML) analysed the descriptive categories and the underlying structure of the categorization. The analysis resulted in 3 themes and 10 descriptive categories. The categories represent qualitatively different ways of experiencing PDT. The patients’ perceptions are illustrated with quotes from the interviews.

Ethics

The study was approved by the regional ethics review board in Gothenburg, Sweden. All the patients gave their written informed consent to participate in the study.

RESULTS

The result of the analysis appears in a number of representative categories of experiences. Three themes emerged, viz. “Treatment without nerve blocks”, “Treatment with nerve blocks” and “Feeling the effects of the treatment on the skin”, each with its own categories. Each statement represents a different experience of being treated with PDT. The patients’ statements in the different categories are given in Table II and some conclusions and quotations are given below.

Table II. Distribution in 3 themes and 10 categories among the patients

<table>
<thead>
<tr>
<th>Themes</th>
<th>Category 1-10</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Treatment without nerve blocks</td>
<td></td>
</tr>
<tr>
<td>1.1 Burning, stinging pain</td>
<td>× × × × × × × × × × × × × × × × × × × × × 18</td>
</tr>
<tr>
<td>1.2 Getting professional help to ease the pain</td>
<td>× × × × × × × × × × × × × × × × × × × × × 14</td>
</tr>
<tr>
<td>1.3 Finding personal strategies to ease the pain</td>
<td>× × × × × × × × × × 8</td>
</tr>
<tr>
<td>1.4 It was worth the pain</td>
<td>× × × × × × × × 5</td>
</tr>
<tr>
<td>2. Treatment with nerve blocks</td>
<td></td>
</tr>
<tr>
<td>2.1 Feeling the sting of the injections</td>
<td>× × × × × × × × × × × × × × × × × × × × × × × × × × × × 15</td>
</tr>
<tr>
<td>2.2 Pain relief</td>
<td>× × × × × × × × × × × × × × × × × × × × × × × × × × × × 11</td>
</tr>
<tr>
<td>2.3 Duration of effect</td>
<td>× × × × × × × × × × × × × × × × × × × × × × 12</td>
</tr>
<tr>
<td>3. Feeling the effects of the treatment on the skin</td>
<td></td>
</tr>
<tr>
<td>3.1 Redness, crusts and scaling</td>
<td>× × × × × × × × × × × × × × × × × × × × × × 15</td>
</tr>
<tr>
<td>3.2 Anxiety when looking at the skin</td>
<td>× × × × × × × × × × × × × × × × × × × × × × × × × × × × 2</td>
</tr>
<tr>
<td>3.3 The experience of having a healthy skin</td>
<td>× × × × × × × × × × × × × × × × × × × × × × × × × × × × 2</td>
</tr>
</tbody>
</table>
at some distance from [the scalp]. It was burning horribly. Or close to a fire to feel the heat, it was that hard. It was like having a thousand pins in my head (No. 18).”

“Well, it might be true when they say it is like putting an iron on to [the skin], you know. I’ve never done that with an iron so it’s not quite true but … (No. 12).”

1.2. Getting professional help to ease the pain. Patients emphasized their need to reduce the pain during the 8–9 min during which the PDT was performed. To ease the burning sensation, staff sprayed cold water over the treated area and talked to the patient. If necessary, the irradiation was paused to give the patient time to recover from the pain.

“The stuff had to make some pauses, it was too much at one time. It felt lovely, really lovely when it cooled down and they blew cold air with a fan. Yes, it felt great when the cold water was sprayed (No. 4).”

“It is important that you know that they [the staff] are taking this seriously, even though you laugh and chit-chat and so on. I think this is a very good thing, because I notice that it is a way to divert attention from the pain (No. 6).”

1.3. Finding personal strategies to ease the pain. Even after irradiation was completed, some patients experienced pain that was difficult to handle. The patients developed various strategies to manage the discomfort and pain.

“I had to walk around, and be outside to get air. I could not sit or lie down for a long time. I had to walk (No. 2).”

“When I was driving home after the last treatment I had brought 2 small soaked towels which I put by the windscreen. In addition to the air conditioner in my car, I was able to hold these towels against my forehead while driving (No. 7).”

Other personal strategies to ease the pain were:

- Cooling the treated area with ice
- Painkillers
- Trying to sleep away the pain
- Focusing on things other than the pain

1.4. It was worth the pain. This category contains statements that emphasize the patients’ feelings about undergoing a PDT session without adequate pain relief.

“For me, PDT is the superior form of treatment. I do think the result is better and lasts longer. You want to have the procedure done and you are grateful for the opportunity so I manage the pain, I do (No. 14).”

“I am wise enough to realise that I have to get through this to get well. If there is no other option I will have to endure this and then I might look nice. For this, I am grateful (No. 5).”

Theme 2: Treatment with nerve blocks

The second theme consists of the 3 categories:

2.1. Feeling the sting of the injections.

“I did not feel much. I could feel it, but many people who don’t tolerate pain probably experience the pain more intensely (No. 17).”

“Yes, the NB therapy with syringes they put into … they were damn painful. But it’s just a matter of seconds, and then the syringe is gone, you know (No. 11).”

2.2. Pain relief. The majority of patients felt a considerable difference in experienced pain. Some mentioned that the NB did not cover the whole treated area, for example passing over the temples, because of the distribution of the nerves.

“Oh, like night and day. If you can imagine a sunny summer and I could be lying on the pier feeling this wind and nothing else. It was fantastic (No. 15).”

One patient did not like injections, even at the dentist. This patient had declined NB therapy previously due to this aversion to injections. Describing his experience of PDT with NB, this patient said,

“But the third time, I tried the NB and it was more or less a complete turnaround. So it was clearly much, much better. Not at all hard to cope with (No. 13).”

2.3. Duration of effect. This category relates to the duration effect of the NB.

“I think now when they anaesthetize, it [the pain] disappears immediately when they remove their lamps and everything. Then it is almost back to normal, you do not become dizzy, you do not feel anything afterwards (No. 9).”

On the other hand, one patient stated that the anaesthesia was too strong and took a long time to wear off.

“Very unpleasant. I touched my hair and felt, wow this part feels strange. Half my head was almost numb for a long time afterwards. [I would] rather suffer for 8 minutes and have it over with than [feel numb] for so many hours (No. 8).”

Theme 3: Feeling the effects of the treatment on the skin

The third theme consists of 3 categories:

3.1. Redness, crusts and scaling. This category consists of statements describing how the patients experienced the effect of PDT on the skin after treatment.

“This redness disappears after a few days. When the crusts come you can see where you have been treated. I don’t know if I told you how ugly the scaling looks? It’s about 2 weeks or even more before the crusts and the scaling have disappeared (No. 2).”

Sometimes a large amount of crusting falls off at once:

“Last night, I had them [crusts] in the bed. My husband takes the blankets, sheets and pillows out for airing every morning. This morning he said there were some biscuits in the bed and he asked if I had been eating in bed? No, but there were a lot of crusts (No. 5).”

3.2. Anxiety when looking at the skin. Some patients said that the way their skin had looked after the treatment had caused them anxiety. In particular, they were worried that they may have misunderstood the information about the PDT process and its effects on the skin.

“And then on Thursday morning there was a swelling under my eyes, real bags. But then on Friday they had gone. It felt as if the skin was 2 sizes too small for my head. Each morning you are curious to see how it looks. At the beginning you literally took a step back, it looked awful (No. 4).”

Sometimes, the patients were worried that the skin condition would remain unchanged.

“Then I thought I will never look good again after this. When [the skin] was smooth, I was surprised that it could heal (No. 14).”

3.3. The experience of having healthy skin. Once the scaling process is complete the skin is almost back to normal. Some erythema may persist but it usually disappears gradually.
"Still, this is a treatment that doesn’t leave a lot of marks. [It’s an] advantage that you can see some marks here and there for a few months but after a while they fade away, don’t they? (No. 6)"

"Yes, I used to say that, after a week your facial skin is as smooth as a baby’s bottom (No. 7)."

DISCUSSION

One of the most important aspects of a patient’s perspective when undergoing PDT is the pain experienced during and after treatment. Patients may interrupt a treatment session or refuse to accept further treatment as a result of pain experienced previously during PDT (23).

The main purpose of this study was to describe patients’ experiences of PDT in their own words. Interviews provide a good addition to pain assessment using a VAS. Eighteen interviews were conducted in order to study patient perspectives and obtain an overall picture of the treatment. The interviews consistently revealed severe pain in patients undergoing PDT on sensitive areas such as the face and scalp. We chose to interview patients with experience of treatment both with and without NB in order to acquire knowledge of the same person’s different experiences of PDT.

It should be emphasized that we selected a group of patients who were expected to feel severe pain during treatment. Pain during treatment is not prevalent for all patients, but it is most common in the treatment of field cancerization. When field cancerization on the face and scalp is treated with PDT, all patients are offered NB in advance at our clinic. This is due to previous studies at our clinic that have shown that NB are able to provide adequate pain relief (12, 13). It was of special interest for us to acquire more knowledge of the patients’ different experiences in order to obtain new information on the problems of pain and an opportunity to further develop the use of NB as pain relief. The patients still remembered how painful the PDT without NB was, despite the fact that a long time had passed (a mean of 42 months) since they had the treatment.

Some patients expressed disappointment that they might have to undergo more PDT sessions in the future even though they had followed the recommendations relating to sun protection. Information that the regular use of sun-screens can reduce the formation of AK and squamous cell carcinomas is very important (24, 25). In spite of this, it is a difficult pedagogical task to communicate this fact and the information has to be repeated. Many patients said that the final result of the treatment was successful; unfortunately, one patient, although satisfied with the end result, described the treatment without pain relief as an assault. This strongly underlines the fact that analgesic action is needed.

The opportunity to perform NB during the PDT session was highly appreciated. The majority of patients felt that pain from the injections was short-lived and that the NB resulted in a major reduction in pain during PDT. Nonetheless we wish to stress the importance of information given prior to administering the NB. Although all patients were given oral and written information about the procedure, the study shows the need for individualized information based on patients’ specific needs. Receiving injections in the area around the eye was described by several patients as especially unpleasant.

One option for reducing the pain is to treat small areas separately; however, this is rarely done, as it is inconvenient for patients to have to make several visits instead of one. The patients also preferred to have larger areas treated simultaneously, as treating all the areas at once results in a single healing period.

In the interviews, the patients said that they had experienced redness, crusts and scaling after treatment. Fortunately, only 2 patients had been concerned after treatment when looking at their skin. This underlines the necessity for providing information about the temporary negative effects of treatment.

Several studies have been conducted to examine the various topical pain relief methods during PDT, without convincing results (26–30). In a recent study by Tyrell et al. (31), the use of air cooling as pain relief resulted in less protoporphyrin IX photobleaching and consequently in reduced efficacy. A different approach regarding the use of cool air is reported by Stangeland & Kroon (32). In this study, the skin temperature during PDT was not as low as in the study by Tyrell et al. (31) and pain relief and an improved treatment outcome were therefore achieved.

In our study population, the patients reported that NB produced satisfactory pain relief. However, nerve blocks are not appropriate for all individuals, nor is it possible to use them on all body sites. More studies are needed to investigate options for reducing the pain experienced during PDT, based on the individual patient’s needs.

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