

and history of recurrence. Indeed, we found in our pooled analysis that recurrence at 12 months was lower for patient-administered treatments, making these more relevant than provider-administered therapies as a global therapeutic response—although such recurrence is difficult to evaluate because of the methodologic limitations (eg, lost to follow-up, recontamination). Although provider-administered therapies presented the best clearance before 3 months, their reproducibility remains difficult to compare both among RCTs and among treatments (eg, lack of standardization of freezing or surgical procedures). Given the need for local anesthesia, the use of surgery, CO<sub>2</sub> laser, and electrosurgery seem justified when other treatments have failed. Last, knowledge of treatment side effects can assist physicians with adjusting anogenital wart management to the tolerance of the patient.

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## Pitfalls and proposed solutions for patient communication about erythropoietic protoporphyria: A survey of parents and adult patients

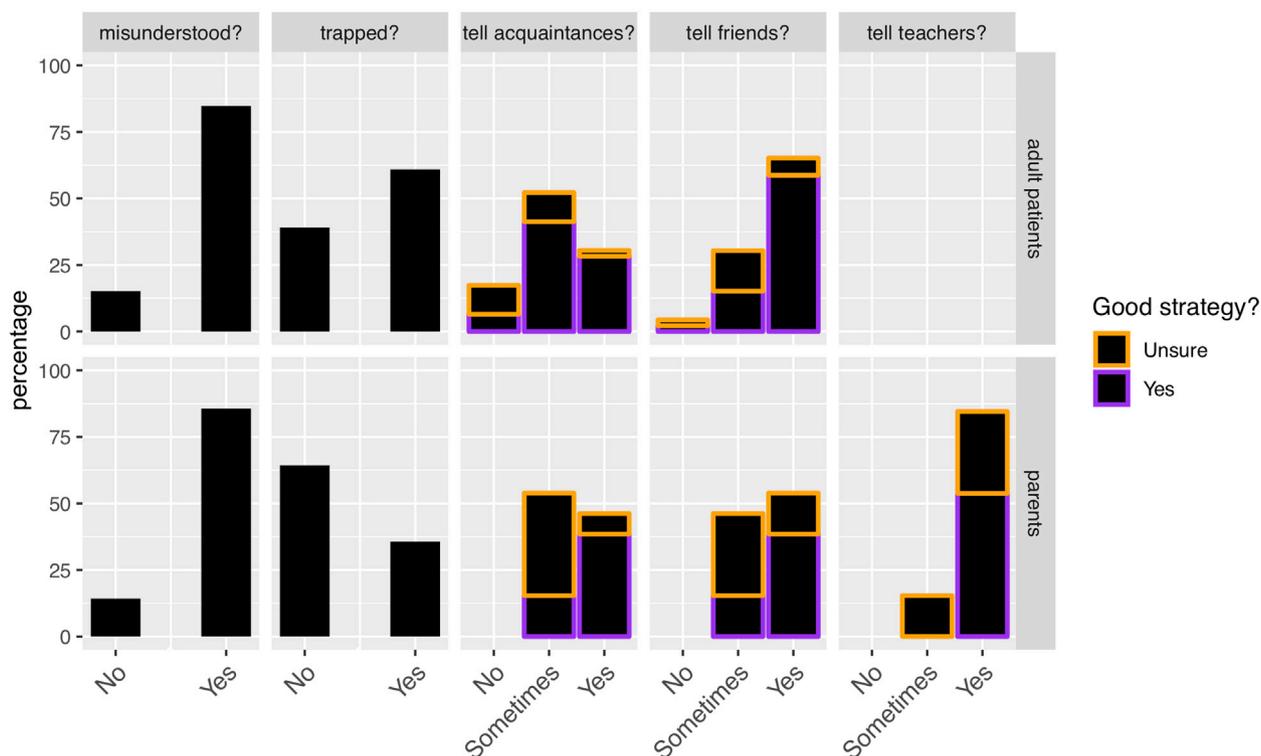


*To the Editor:* Erythropoietic protoporphyria (EPP) is a rare inherited defect of heme metabolism resulting in painful photosensitivity.<sup>1</sup> A 1987 survey of 17 EPP

**Table I.** Demographics and clinical characteristics of EPP patients

Characteristic	Children with EPP, n = 13	Adults with EPP, n = 46
Mean age, y	14.3	49.7
Sex, n (%)		
Male	8 (61.5)	22 (47.8)
Female	5 (38.5)	24 (52.2)
Age at diagnosis, y, mean (range)	6.5 (3-10)	17 (2-57)
Sensitive to indoor lights, n (%)	3 (23.1)	18 (39.1)
Sunlight exposure limit, n		
0-10 min	4	18
10-30 min	4	17
30 min-1 hr	2	8
1-2 hr	2	2
2-3 hr	0	1
≥3 hr	1	0
Words used to describe EPP, %		
Allergy	46	52
Burn	46	50
Internal sunburn	31	28
Photosensitive	54	35
Phototoxic reaction	23	20
Sensitive to the sun	77	83
Other	31	26

Demographics and clinical characteristics were acquired via survey. For EPP patients who were children (<18 years of age), questions were answered by their parents. EPP diagnosis was patient reported or parent reported (for children) and accompanied by the survey participant's description of the method of diagnosis. EPP, Erythropoietic protoporphyria.



**Fig 1.** Patient communication about erythropoietic protoporphyria (EPP). Adult patients or parents of children with EPP were invited to choose yes or no in answer to whether or not they have felt misunderstood when explaining EPP and whether or not they (or their children) had been trapped in the sun because of another’s inability to understand EPP. They were also asked to select yes, no, or sometimes to answer a series of questions inquiring if they tell acquaintances, friends, or teachers about EPP. Immediately following these questions, they were also asked, “Do you think that this has been a good strategy regarding telling people or not telling people?” The responses to these questions are displayed in different figure panels by survey respondent type (parent or patient). *EPP*, Erythropoietic protoporphyria.

patients revealed that, in addition to physical and psychologic distress, patients also experience social isolation and frequently feel misunderstood.<sup>2</sup> The current study describes the complicated nature of patients’ communication attempts about their condition, which is a difficult aspect of their experience that has received little attention in the medical literature.

EPP patients have difficulty explaining their disease to others because, when they are exposed to sunlight, their skin often appears normal, even though they have extreme pain.<sup>1,3</sup> Physical signs might not be evident for hours to days or might not develop at all.<sup>4</sup> Because bystanders might erroneously equate photosensitivity with rapid sun burning, EPP patients might be regarded as melodramatic, despite drastically minimizing their symptoms.<sup>1</sup> Clinically, cutaneous symptoms in other diseases are typically assessed by what is visibly apparent. In EPP, this practice might be of little-to-no value, given the frequent lack of physical examination findings.<sup>4</sup>

This study describes EPP patients’ choices related to communication about their disease and the self-perceived benefits; this study was not intended to measure health-related quality of life. An important factor guiding design of the survey questions is the perspective of the author, as the author has EPP. The survey was sent through the American Porphyria Foundation e-mail listserv. Data were collected and managed using REDCap.<sup>5</sup> The Partners HealthCare Institutional Review Board approved this study.

The survey was completed by 46 adult patients and 13 parents of children with EPP (Table 1). The survey revealed that patients frequently feel misunderstood when describing EPP, and this lack of understanding can lead to them becoming trapped outside in the sunlight (Fig 1). These experiences were not correlated with patients’ degree of sunlight tolerance. Being trapped in sunlight during an EPP reaction can be traumatic and heighten an EPP patient’s fear of the sun.<sup>2</sup>

**Table II.** Representative patient responses to survey questions

## How patients tell others about EPP:

- "I have a rare genetic disorder that causes my blood to have a phototoxic chemical reaction when my skin is exposed to light, any light. It causes extreme pain like standing in a campfire."
- "I tell them it is a rare blood disease that causes a photoreactive chemical called protoporphyrin to accumulate...[It] is like hot wax being sprayed on my skin."
- "I used to say I was allergic to the sun, but then everyone would say they or a relative were also."

## Feeling misunderstood:

- "I've felt misunderstood more times than I can remember or count."
- "People do not understand that if your skin isn't burnt, then why are you unable to go in the sun."
- "The type and level of pain from a photoreaction, and the inability to ease that pain, can be difficult to communicate...Nothing is worth that level of pain."
- "Only doctors that already know about EPP understand and take it seriously."

## Being trapped in the sun:

- "This is the PTSD question! Stuck on a beach at a lake [with] nowhere to hide, and I didn't have a way to protect myself. That was the worst. [I] spent all night with feet and hands in water and covered with washcloths suffering."

## Strategies to avoid being trapped in the sun:

- "Just finally being open and honest about EPP helps."
- "We have role-played how to talk to adults about his EPP. If someone asks him to do something that he cannot do, he not only says that he can't, but he also says why and offers a solution."
- "I never get myself in a situation that I don't have a way out."

## Benefits of telling others about EPP:

- "I find I am way more comfortable wearing my sun gear now instead of not wearing it around others and being in pain. Plus, I would always make up stories about why I couldn't attend outdoor events."
- "I have decided to tell people because it is part of me that I cannot change...for the most part it explains a lot of my choices."
- "Others are supportive, even if they still don't fully understand my restrictions."
- "Less isolation."

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EPP, Erythropoietic protoporphyria; PTSD, posttraumatic stress disorder.

In addition, respondents were asked questions concerning whom they tell about EPP and whether they consider this a good strategy. On the basis of their responses, participants were grouped into those more or less open to telling others about EPP. Patients who were more open in communication were most confident their strategy was beneficial ( $P = .0003$ , Fisher's exact, [Fig 1](#)).

In the open-ended question responses, many commented on the usefulness of describing EPP as a rare genetic disorder that causes a light-sensitive substance to build up in the blood resulting in severe internal pain that lasts for days ([Table II](#)). Although patients commonly use the term allergy (for ease of communication), this term contributes to misunderstandings. A couple of parents of children with EPP described the importance of role-playing to teach children to advocate for themselves when they might otherwise be trapped in sunlight.

A single communication strategy might not be ideal for every patient and situation. Nevertheless, because communication strategies have the potential

to influence both control over sunlight exposure and patients' social isolation, physicians should work with EPP patients to thoughtfully develop effective communication approaches.

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### **Patient satisfaction with patient–provider interactions at time of diagnosis among early stage melanoma survivors: A cross-sectional survey**



*To the Editor:* Melanoma is the fifth most common cancer in the United States.<sup>1</sup> A melanoma diagnosis can cause stress and anxiety as patients learn about treatment options and prognosis. We assessed if patient characteristics and physician specialty were associated with satisfaction with care and information needs among individuals with early stage melanoma.

Participants from the Skin Health Study (1167 individuals aged 25-59 years with melanoma diagnoses during 2004-2007), a population-based case–control study,<sup>2</sup> completed a survey in 2015 regarding their quality of life, health behaviors, and health care experience.<sup>3</sup> The study was approved by the University of Minnesota Institutional Review Board. Of 724 (62%) melanoma survivors who completed the survey, we analyzed 572 with stage I disease to reduce confounding by stage.

The following 6 outcomes, adapted from the National Survey of Households Affected by Cancer,<sup>4</sup> were analyzed: patient satisfaction with provider knowledge/expertise; level of compassion; attention to outside factors, including support network for dealing with cancer; receipt of conflicting information; failure to get important questions answered; and experience of stress and anxiety waiting for test results.

Multivariable logistic regression models yielded adjusted odds ratios and 95% confidence intervals for the associations between outcomes and patient characteristics or physician specialty.

Very few rated their provider's knowledge/expertise as fair or poor (Table I). Participants whose cancer registry–recorded physician was in family medicine, rather than dermatology, were more likely to report fair/poor satisfaction. About 6% rated their providers as having fair/poor levels of compassion; this was higher among those whose physician was not a dermatologist. Approximately 27% noted dissatisfaction with their provider's attention to outside factors and support; women were more likely than men to give this rating.

Few reported receiving conflicting information at diagnosis; the youngest participants reported this significantly more often than the older participants (Table II). Overall, and by age, results were similar for leaving appointments without getting important questions answered. Those whose physicians were nondermatologists were less likely to get questions answered. Most participants reported stress waiting for results, with younger age, being female, and having a dermatologist physician being associated with more stress.

Early stage melanoma patients reported high satisfaction with their providers' knowledge and compassion level. Patients were most dissatisfied with their providers' attention to outside factors and support. Although receipt of conflicting information or difficulty getting questions answered was uncommon, many experienced stress and anxiety waiting for test results.

Patients with nonmetastatic melanoma have previously indicated they want more physician involvement when discussing therapy options, clearer information regarding melanoma, and sincerity from medical staff.<sup>5</sup> Patients seen by nondermatologists reported their health care team had poorer knowledge of melanoma and less compassion. We speculate that having cared for larger numbers of melanoma patients, dermatologists are more accurately able to anticipate and address patient concerns.