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Letter

Patient perspectives on low level light therapy and laser therapies for rosacea-associated persistent facial redness

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Abstract

Introduction: There are no definitive treatments of facial redness for rosacea. All treatments aim to alleviate symptoms. Patients' perspectives of two emerging modalities, low level light therapy and laser treatments are not well characterized.

The purpose is to further understand rosacea patients' unmet needs about these modalities.

Methods: The publicly accessible, online rosacea forum was accessed during August 2013. Stratified random sampling method was done to identify a 10% sample of total 27,051 posts. The posts that were published in the "Laser and IPL therapy" and "Low level light therapy" forums were qualitatively analyzed.

Results: Patients discussed a variety of topics, but most commonly discussed effectiveness (34.2%), treatment education (19.3%), and adverse effects (18%). Relationship with the health care provider (9.9%), cost (8.1%), execution of treatments (8.1%), and convenience of treatments (2.5%) were less commonly discussed, but contributed to patients' decisions about utilizing laser and light therapies.

Conclusions: Online forums are utilized to fulfill patients' desire for educational, sympathetic, and collaborative relationships. Patients' adherence to laser and light therapies will likely increase if costs are reduced, reduction in redness is consistent with their expectations, and physicians provide adequate education on device choices and adverse effect management.

Keywords: facial erythema, online health communities, social media, peer health, patient physician relationship.

Introduction

Social media is changing the way patients obtain information, provide support, and make health care decisions. As many as one in three American adults have used online sources to diagnose a personal medical condition or that of a loved one. In 2013, 59% of adults sought health information online [1]. People living with one or more chronic diseases are more likely to go online to gather information about treatments and drugs; these patients also use these sources to read about others' health experiences [2]. With the population aging and technology increasingly available, online support groups for chronic diseases are flourishing.

Rosacea is a chronic skin condition that can be notoriously difficult to treat. Because rosacea generally affects central facial skin, it can cause significant psychosocial distress [3]. The treatment of rosacea is multimodal and rapidly changing. Several treatments focus on the redness associated with the disease, including topical brimonidine and forms of phototherapy [4]. Patients' perceptions of the new treatments are not well characterized.

Patients' responses to treatment varies, leading to productive online discussions between peers regarding experiences with topical, laser, over-the-counter, lifestyle alterations, and alternative and homeopathic treatments. In this study, we examine patients' discussions in an online rosacea support forum about their experience with intense pulsed light (IPL), low level light therapy (LLLT), and other light treatments in order to better understand and address unmet needs, which may not be readily identified in clinic.

Methods

A publicly accessible, English language, online rosacea forum was chosen owing to the large size of its community and high traffic volume. At the time of data collection in August 2013, the forum (<http://rosacea-support.org/community/>) had 14 threads, 3685 topics, 27,051 posts, and 3350 members. Membership is free, but required for posting privileges.

A stratified random sampling method was employed to identify a 10% sample of posts, 2390 in total. Posts included in the analysis were directly related to patient experiences in rosacea-related forums, including "General Stuff," "Just Diagnosed with Rosacea," "Advice by Rosacea Symptom," "Rosacea Research and News," "Systemic Rosacea Treatments," "Topical Rosacea Treatments," "Natural Rosacea Therapies," "Laser and IPL Therapy," "Low Level Light Therapy," "Experimental Rosacea Treatments," "Foods and Diet," "Psychological Aspects," and "The Lounge." Forum discussions not related to the patients' experience with rosacea were excluded.

Each post was coded by theme for in-depth analysis and understanding of the patient experience. Themes include: coping with rosacea, prescription medications, over-the-counter treatments, homeopathic therapies, laser and low-light therapy treatments, understanding rosacea, seeking advice, and stigma. Of the 2,390 posts collected, 1951 posts were relevant and included.

This study focused on 161 comments within 84 posts, comprising a representative 10% sample of posts from the "Laser and IPL therapy" and "Low level light therapy" forums. One researcher coded posts into domains of the "laser / phototherapy experience" and "barriers to successful treatment." Within these domains, posts were qualitatively analyzed for comments pertaining to "effectiveness," "execution," "adverse effects," "cost," "poor provider relationship," "convenience," and "education." We report several salient posts and summarize key findings in each section, illustrating major points with the patients' own words (Table 1).

IRB approval was obtained through Wake Forest University.

Results

From the laser and low light therapy topics, two thematic domains were identified that drove patient discussion: (1) descriptive experiences and (2) barriers to treatment. These were further broken down into sub-domains (Table 1).

Table 1. Breakdown of salient posts by category

Post Categories	(n) Coded posts (% of total)
Laser / phototherapy experience	
Effectiveness	55 (34.2%)

Execution	13 (8.1%)
Adverse effects	29 (18.0%)
Barriers to treatment	
Cost	13 (8.1%)
Poor provider relationship	16 (9.9%)
Convenience	4 (2.5%)
Education	31 (19.3%)

Laser / phototherapy experience

Patients were primarily interested in the time to improvement, quality of results, and methods of coping with adverse effects. Providers were judged based on how well they individualized treatments.

Effectiveness

Most patients were willing to endure pain and swelling associated with procedures as long as they reduced facial redness. Patients who noted decreased redness with fewer than 3 treatments were more likely to post positive reviews and pursue the recommended 5-8 treatment sessions mentioned in posts. Many patients voiced frustration with delayed results, particularly if no significant change was appreciated within the first 4-5 treatments. A few IPL patients report that their own research suggests that change should be evident by the third session if it is going to be effective.

“Surely if it was going to work for me then it would have by now?...this is the last resort and it doesn’t seem to be working,”

“It’s a LOT better, but it’s not “normal” by any means. Must say I’m disappointed”

“I’m still really happy with what IPL did for me and if I have to do touch ups, that’s just how it has to be.”

Execution

Procedural experience of the health care provider mattered more than job title. In other words, there was no preference for a technician versus a physician’s assistant or a nurse practitioner. In contrast, a few patients preferred a doctor; one even went to a neurologist for laser therapy. Technicians that frequently varied laser intensity, as opposed to using uniform intensity over the entire surface area, were positively perceived as “tailoring” treatments to each affected area. Most patients with “cautious” providers who used low-level laser settings for fear of causing burns described feeling like they did not receive the full “value” of treatments. Several patients who reported minor adverse effects, but subsequent reduction in redness were generally very satisfied.

“[S]he’s very thorough, and is always playing around with the settings to achieve the best result.”

“[The assistant] was so cautious that the treatment had no chance of either helping or hurting my skin.”

“I noticed a big difference after...the time I swelled. Bit of a trade-off.”

Adverse effects

Patients complained of burns, swelling, increased redness, and herpes simplex virus (HSV) outbreaks. Some patients’ post-laser swelling required time off from work and social engagements, which prompted a few to discontinue treatment. Most patients report being counseled by providers to expect transient increased redness, swelling, and possibly HSV outbreaks, but many seemed unprepared for the severity of symptoms, especially burned skin. Several of these patients report calling their physicians

for help managing these symptoms, but others drew from the community's suggestions for self-treatment at home. Patients with poorly managed expectations regarding the degree of erythema reduction and severity of adverse effects possible were more likely to post negative reviews and do fewer treatments.

"A week away from work and then another week to fully heal."

"[M]y face was red and swollen for days--well it frightened me so I won't do anymore."

Barriers to successful treatment

Cost

Cost was the most commonly cited reason for not pursuing laser treatments, and a major source of discontent among many home LLLT lamp users who buy expensive products without sufficient physician guidance.

"Most of us don't have the \$\$ to keep going back forever...why bother?"

"I am really, really working hard at building a relationship with my doctor so he either severely discounts or no charges the procedure...they can get creative with insurance company and call the session an 'office checkup.'"

Poor patient-physician relationship

Negative comments about physicians revealed fear that physicians value financial gain over patients' ability to afford treatments. Many patients also believed that physicians lack empathy by prescribing untenable lifestyle modifications, such as limiting physical exertion, avoiding hot beverages and spicy foods, and limiting exposure to ambient heat and humidity. One patient likened this advice to living "on the moon." No patients reported seeing their dermatologist between laser treatments. This may simply be an omission, but a few patients reported that technicians independently evaluated treatment response and decided how to tailor laser intensity. Poor follow-up, lack of education, and inadequate management of expectations left many patients frustrated, disappointed, and grappling with adverse effects on their own.

"...these Doctors are extremely flexible on laser pricing, no one is there to regulate it--its an ATM machine for them with the IRS not knowing [what's] deposited or withdrawn." "Considering the cost and lack of any clinical studies proving these devices work, I would suggest you save your money"

"I was upset because the results, side effects, or whatever you want to call it, were not what [were] described"

"[Y]ou need a new derm, one who has compassion."

Convenience

Non-compliance with home lamp use owing to availability and time constraints was more common than with laser treatments, which are spread several weeks apart.

"I just never have the time to do it."

"It's been a bit tiring using the lamp every day for 20 min."

Education

Patients struggled with choice of LLLT lamp for home use. In addition, they were confused about how to use it correctly (distance from face, duration, intensity). Lamp options discussed include all-red, infrared, red and green combination lights, and multi-headed models. Patients relied on the internet, product reviews, and peer guidance. Patients were wary of ineffective products and "trolls" (salespeople posing as members) advertising specific clinics or products. One member challenged the authenticity of a new member's post endorsing a particular clinic, crowing: "Better luck elsewhere!"

“I sat with my face resting against the lamp, and when I finished I was red as a beet...just wanted to see what would happen...”

“As the FDA doesn’t regulate LED lamps, I don’t want to buy something that doesn’t work”

“LEDs are the little lights for xmas trees etc, red light therapy is an entirely different thing.”

Discussion

Laser and light therapies discussed in the forum include pulsed dye laser (PDL), IPL, and LLLT with infrared, all-red, or red and blue light lamps. Despite demonstrated effectiveness, cost remains a major limitation because most treatments are not covered by insurance [5]. Costs per treatment range from \$200-600 for pulsed dye lasers and \$300-700 for IPL [6]. Home LLLT lamps range from \$250 to \$7995 from one manufacturer commonly favored by patients [7]. Side effects include increased erythema, pain, swelling, burning, bruising, photosensitivity, skin crusting, and infection.

Given the expense and discomfort of treatments, patients want experienced providers and results consistent with or exceeding their expectations. They perceive more individualized treatment when technicians tailor laser intensity to different areas of the face and explain their thought process during the procedure. Because the most common subject of discussion is effectiveness (34%) vs. cost (8.1%), it suggests that patients are willing to pay for expensive treatments if they believe it is appropriate and effective. However, because laser treatments are not curative, the prospect of expensive maintenance therapies caused many patients to dismiss this treatment option. Better follow up and empathy from physicians may thus improve patient adherence to multimodal treatment compliance.

Patients are excited and willing to use LLLT but desire faster treatments and more guidance from physicians regarding which lamp to use at home and how to use it. Misinformation and trial-and-error techniques on the forum demonstrate a need for professional guidance. Many non-FDA approved lamps are available for purchase. In national surveys, 76% of more than 1200 rosacea sufferers endorsed lowered self-esteem, whereas 69% felt embarrassed by their condition [8]. Patients may feel vulnerable and be subject to prejudice in social and work environments. A strong patient-provider relationship and education may empower patients to treat the disease long-term at home, thus mitigating these anxieties.

A review of the literature supports a “minimal” rate of adverse events following IPL treatments, although procedural discomfort is nearly universal [9]. On this online forum, adverse effects were a major topic of discussion (18% of posts); this suggests selection bias on behalf of the relatively few patients who experience distressing adverse effects. However, swelling and erythema can be significant and should be stressed during informed consent. Preparing patients for treatment-associated swelling, purpura, HSV outbreaks, etc., may improve their experience and willingness to complete laser and LLLT therapies.

Collaboration and community experience are highly valued among other online message boards for chronic disease [10]. Patients may therefore benefit from professional health care worker interaction in the forum, which has improved patient self-care in other online communities [11]. Patients particularly benefit when they feel part of an egalitarian physician-patient relationship [12]. Beneficial physician forum interventions may thus include having an “ask the doctor” section for educational purposes and proofreading discussions to correct misinformation propagated by members. Additionally, patient perception of physician empathy has been shown to positively correlate with patient compliance with migraine treatment. A similar emphasis from dermatologists treating patients with rosacea may result in a strengthened relationship and improved treatment outcomes [13].

This study is limited by analysis of only one online message board. More posts from prolific or opinionated members may have biased the analysis. Additionally, the researchers can only utilize information patients volunteer in discussion with each other and cannot standardize patient contributions or characterize patient demographics. However, a unique advantage to this approach is that by analyzing patients’ uninhibited opinions, we captured thoughts that they may not have been willing to express to a physician in the clinic. Further, membership spans several continents (including North America, Europe and Australia), constituting a diverse subject group with a rich array of experiences that would be otherwise impossible to bring together.

This online rosacea community is a collaborative, supportive, and informative space for members contributing to discussions and for non-member viewers looking for instruction. Patients rely heavily on anecdotal experience for evaluating effectiveness of laser and light treatments, management of adverse effects, and treatment options. Although an excellent source for psychosocial support, the unregulated discussions leave patients vulnerable to misinformation, bad advice, and exploitation by sales representatives. Recurring themes indicate that patients desire physicians who are knowledgeable, supportive, empathetic, and willing to educate. They would like physicians to recommend effective home products and to potentially discount office treatment prices. Patient use and adherence to laser and light therapies will likely increase if costs are reduced, reduction in redness is consistent with their expectations, and if physicians educate them about device choices and the management of adverse effects.

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