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Letter

Understanding the influence of social media in medicine: lesson learned from Facebook

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Abstract

Atopic dermatitis is a very common chronic skin disease. With increasing number of patients searching social media outlets such as Facebook for medical information, social media can be used by physicians as a powerful educational tool. We analyzed the unmoderated Q&A series on Facebook begun by members of National Eczema Association Scientific Advisory Committee. Four respondents accounted for more than 50% of all responses and the most common were negative posts about topical steroids (61%). Possible strategies to accomplish the safe dissemination of information in a public forum may include a moderator role for physicians.

Keywords: Atopic dermatitis, eczema, social media

Introduction

Atopic dermatitis, or eczema, is arguably the most common inflammatory skin condition with childhood prevalence rates as high as 20% in 2003 and steadily increasing [1]. Although most individuals outgrow their disease it may persist or demonstrate a protracted course, often requiring lifelong management and the expenditure of millions of healthcare dollars. Given the chronic nature of atopic dermatitis, patient education is paramount to ensuring adherence to treatment regimens and optimizing long-term outcomes. The Internet could be a useful tool for meeting these education needs.

By 2010, the percentage of Americans with access to the Internet reached 75%, a figure that represented a more than 50% increase since 1995 [2]. Americans are also increasingly turning to the Internet and social media in search of answers to health-related questions. Reportedly, 88% of Americans search for medical information online and 20% specifically search social media outlets such as Facebook, Twitter, BlogSpot, and YouTube [3]. Furthermore, a significant number of these patients report that the information found on these sites will “likely” or “very likely” influence their future health care decisions [4]. These statistics highlight the overwhelming need for physicians to establish a presence in social media forums.

The purpose of this paper is to describe a potential pitfall from the use of social media as an educational tool and to discuss strategies to avoid similar scenarios.

Methods

The National Eczema Association (NEA) is the leading patient education and advocacy group for patients with eczema and has recognized the potential value of using social media to educate patients. Responses to a post by a leading expert on atopic dermatitis on the NEA official Facebook page were de-identified, categorized, and analyzed.

A NEA Scientific Advisory Committee member recently composed a post on the NEA's official Facebook page suggesting that patient fear of the adverse effects associated with topical steroid use may interfere with adherence and thus effective management. The post concluded with a query to the public: "Do you have steroid phobia? Who or what scared you about using topical steroids?" The discussion that ensued provided insight into what can happen when misinformation is promoted by a few individuals in an unregulated manner. The Wake Forest University School of Medicine Institutional Review Board approved this study.

Results

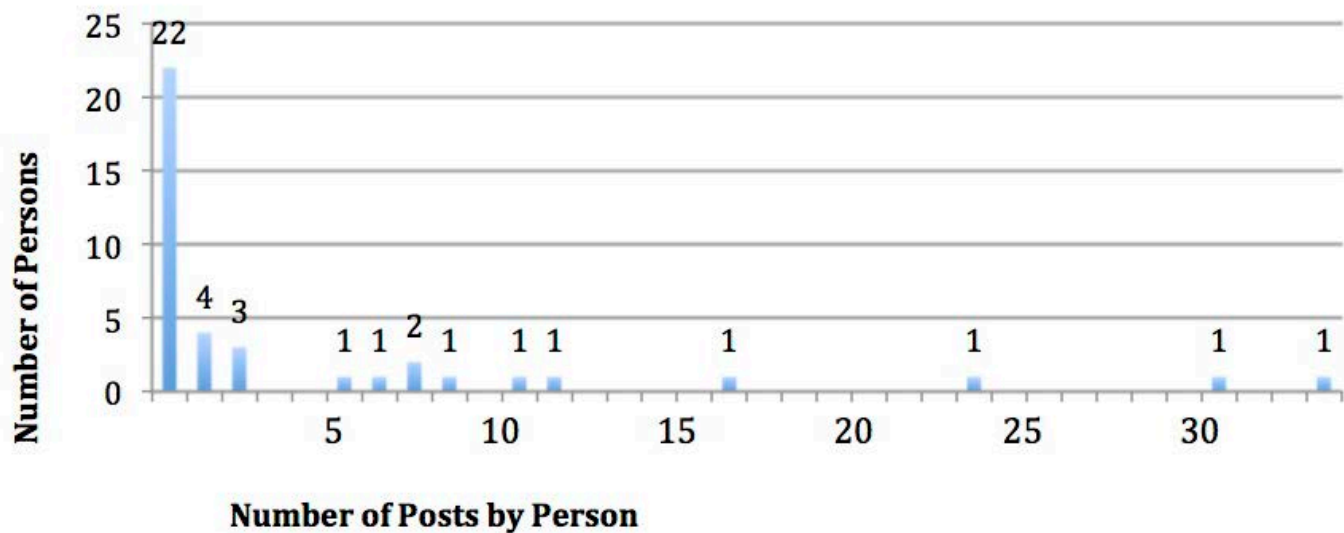


Figure 1. Number of people with definite post numbers - Four respondents accounted for more than 50% of all responses.

There were 206 responses by 40 respondents (Figure 1). Four respondents accounted for more than 50% of all responses. The most common topics of the responses were negative posts about topical steroids (61%), posts mentioning personal experiences (37%), and posts including side effects (26%) (Table 1).

-Table 1- Frequency Distribution between different comment categories

Type of Comment	Number of posts (% of all posts)
Negative about steroids	125 (61%)
Personal experience	76- (37%)
Side effects	54- (26%)
Neutral about steroids	42- (20%)
Positive about steroids	39- (19%)
Alternative treatments	39- (19%)
Citing medical literature	20- (10%)
"Steroid addiction" or "Steroid withdrawal"	15- (7%)

Albeit the minority opinion, the direction and tone of the discussion was largely dictated by one or two dissenting opinions who spread a radical message of fear and distrust of health professionals. Several claims that topical steroid use had worsened or actually caused their eczema were made along with reports that the years of “topical steroid addiction” and “topical steroid withdrawal” symptoms were far worse than eczema itself. One individual claimed that after being prescribed topical steroids they had gained fifty pounds and developed cirrhosis of the liver. Perhaps more alarming than the exhausting list of alleged side effects was the mal-intent that several posters assigned to the physicians prescribing the medications. Multiple claims were made that topical steroids are overprescribed because physicians are lazy or incompetent and do not actually understand the natural course of eczema. Moreover, a general attitude of anger towards medical professionals for “down-playing” the side effects and purposely withholding information in an effort to manipulate patient decisions permeated the message board.

Conclusions

There is growing recognition of the importance of patient education in atopic dermatitis. To provide this education in an efficient manner, “atopic dermatitis schools” have been developed and tested. A further step in the modernization is the use of social media to provide education. The potential pitfall of this approach is illustrated by the non-moderated Facebook discussion on topical steroid phobia.

A study by Coviello et al has confirmed that individual expression of emotions depends on what others in an individual's social network are expressing. The estimated ratio of the indirect to the direct effect in this study was 1.5:1. These results imply that emotions themselves might ripple through social networks to generate large-scale synchrony that gives rise to clusters of happy and unhappy individuals [5].

Unexpected consequences may result when medical information is espoused by non-medical professionals in an open forum. Among these, the fear and distrust of medical professionals with the attendant dismissal of any and all physician recommendations. The downstream effects of this may result in unnecessary and avoidable office visits for “refractory” disease and/or “treatment-related adverse effects” owing to a lack of or improper use of medications. Additionally, the amount of time required to dispel any misconceptions a patient may have acquired online takes up valuable time during an office visit.

The way the initial question was worded in this study, “Do you have steroid phobia? Who or what scared you about using topical steroids?” is likely to have influenced the outcome. This wording may have predisposed respondents to express their fears. Although a more neutral question may have been less likely to induce the observed responses, this study illustrates what can happen when a controversial medical issue such as this is discussed in an open forum.

Although expert’s beginning questions require careful neutral construction, possible strategies to accomplish the safe and responsible dissemination of information may include a role for a moderator. Given that a public forum is open to a variety of opinions, some based on reasonable information and others less so, the moderator’s primary responsibility would be to correct any postings characterized by misinformation and to provide evidence-based resources to which patients can reliably turn.

As medicine ventures into the world of social media, the burden may fall on physicians to ensure that these forums remain a valuable tool, rather than a barrier to care that must be overcome.

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