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# Utilization of Facebook for support and education by patients with skin cancer

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## Abstract

The expanding role of social media in medical care has resulted in dermatology patients seeking support online regarding personal experience with diagnosis and treatment of skin cancer. Owing to increased privacy settings in closed Facebook groups, the current study analyzed themes of keratinocyte carcinoma patients' posts within a relatively private social media network. Although the majority of messages included sharing personal experience and provided psychosocial support (50%), there were a significant number of posts offering medical advice (35%), with the majority of such replies being unsupported by evidence-based medicine (87%). The level of medical misinformation and potential harm to patients seeking advice online is important for medical practitioners treating skin cancer and provides impetus for possible further research into online support and education groups that are moderated for misinformation.

*Keywords: internet, Facebook, social media, education, support, skin cancer, keratinocyte, carcinoma*

## Introduction

With rising rates of social media use in dermatology, patients are increasingly seeking direct information for prevention, treatment, and emotional support regarding skin cancer on the Internet [1-6]. The available online resources from societal organizations such as the Skin Cancer Foundation or the American Academy of Dermatology offer online

educational materials and some melanoma support groups. However, support groups specific to the population of patients undergoing Mohs Micrographic Surgery for keratinocyte carcinoma (basal cell carcinoma and squamous cell carcinoma) who do not have metastatic or invasive disease, are not readily available live or on the Internet [7]. Highlighting the need for such resources, patients have taken it upon themselves to create their own online grassroots support groups in closed Facebook groups such as "Skin Cancer is For Real," "Mohs Surgery Support," and "Skin Cancer and Other Treatments" that have collectively garnered greater than 15,000 members worldwide. The goal of this study was to systematically review and categorize available patient-driven support and education resources focused on keratinocyte carcinoma on Facebook.

## Methods

Facebook was searched with key terms, including: skin cancer, skin carcinoma, basal cell, squamous cell, BCC, SCC, skin cancer treatment, skin cancer therapy, skin cancer support, and Mohs. Selection criteria were limited to groups that were in English, were patient-driven, and had at least 50 members; we excluded groups focused on broad cutaneous disorders or metastatic disease. Of the 14 groups meeting criteria, requests to join were granted by 7. In a retrospective review from 01/01/2018 to 06/30/2018, up to 500 consecutive posts in each group were analyzed by a single reviewer. The posts

were subjectively categorized into qualitative themes according to content as initial forum posts (e.g. sharing experiences, posting photos, seeking support, asking medical advice) and comments responding to posts (e.g. providing psychosocial support, offering treatment or diagnostic advice, advertising products). An independent reviewer re-analyzed the data for verification of inter-reviewer reliability with concordance rates averaging 0.99 per group [8].

### Results

A total of 3,130 posts were catalogued with 444 posts initiating a conversation thread and an average of 6 reply comments (**Table 1**). Of these posts, 40% had an attached photo, frequently of skin lesions or wounds from recent treatment. In addition, 50% of

initiating posts were of patient experiences seeking support and 42% were seeking medical advice. Of the responses, 28% were sharing personal experiences, 37% expressing motivation and prayers, and 35% offering medical advice. Of the peer-to-peer medical advice provided, 87% were unsupported claims, including medical misinformation and non-evidence based alternative therapies. This included the promotion of nonspecific escharotic black salve and the recommendation of sunscreen avoidance. In addition, unqualified diagnosis of skin disease from posted photos was offered.

The study was limited by selection bias of closed Facebook groups limiting access of medical professionals; requests to join remained pending for months despite attempts to contact administrators for membership. There was also limited information

**Table 1.** Classification of Facebook keratinocyte carcinoma support and education group messages.

Initiating Posts	N	Image
Sharing personal experience (i.e. expressing fear, anxiety, awaiting results)	222	126
Expressing distrust in medical community (i.e. cancer scam, profiting)	13	0
Seeking Medical Advice (i.e. posting photo of lesion for diagnosis, seeking "before and after photos", skincare products, alternative therapy)	187	45
Seeking Financial Advice (i.e. charges for specific procedures)	3	0
Lifestyle questions (i.e. advice on sun protection and behavior)	19	5
<b>Comments in Response</b>		
Sharing personal experience (i.e. stories of post-procedure course, "before and after" photos)	740	94
Words of motivation prayer	996	6
<b>Giving medical Advice</b>		
Supported (i.e. from a medical professional, citing research literature, citing Skin Cancer Foundation)	122	6
Unsupported (i.e. biopsy spreads cancer, toxic sunscreen causes cancer, anti-vaccine, diagnosing lesions from photos)	372	9
Alternative Product Recommendations (i.e. black salve, gumby gumby, blood root, cannabis, coconut oil, apple cider vinegar, colloidal silver, diet)	431	37
Alternative Product Advertising (i.e. where to buy specific products)	25	0
<b>Total</b>	<b>3130</b>	<b>328</b>

regarding the individuals joining and participating in these groups and whether they can be generalized to the skin cancer population.

## Discussion

There is limited data currently available on the impact of social media regarding skin cancer awareness, prevention, and treatment [1-6]. This study focused on keratinocyte carcinoma related posts in closed Facebook groups to qualitatively assess the type of information patients were seeking, as well as disseminating, on the Internet. Facebook has a higher privacy setting than Twitter, Instagram, and Pinterest, thus making it more difficult to collect inclusive data regarding a particularly topic [5]. An advantage, as well as a limitation, of this study is the inclusion of closed groups for analysis. Although not all Facebook groups meeting criteria could be analyzed owing to the inability to obtain permission for entry from the administrators, the groups that were analyzed provide insight in the level of information sharing among participants on a relatively secure platform.

Previous studies analyzing social media in the use of skin cancer awareness found fear-invoking messages and posts containing images to have a higher probability of propagation [2, 4, 6]. Although images are an essential part of other social platforms, only 10% of the total posts in this Facebook cohort were accompanied by a photo. In fact, 63% of posts focused on sharing personal experiences and providing words of encouragement or offering prayers, similar to a social support group, in which the level of intimacy may be difficult to obtain in the more public setting of other social media platforms. Similarly, a previous thematic analysis of Twitter and Instagram posts after Mohs Micrographic Surgery found that by sharing personal experiences, social media may be a cathartic platform for patients to spread awareness and education regarding skin cancer as real-time reflections of the patient experience, and regret of past behavior [5].

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Although many posts in the analyzed Facebook groups offer messages of solidarity, understanding, and positive support for anxious patients, there is also a significant level of medical misinformation and a lack of security of personal health information. Of the 35% of posts offering medical advice, only 13% included supported information from primary literature or medical personnel. Patients relying on such medical advice may be exposed to negative consequences, especially as a result of posts that contain misdiagnosis of lesions from photos or promotion of treatment products that are not evidence-based methodologies. Medical providers' awareness of the information disseminated in these Facebook groups is valuable in understanding the type of support and education patients may need beyond the clinical setting.

## Conclusion

An advantage of Internet-based support groups is the ability to reach a large, geographically diverse, group of people who may have limited access to care. Previous online dermatology-specific support groups have reported consistent improvement in perceived emotional and informational support among participants [9]. However, given the significant level of medical misinformation identified in the current study of closed Facebook groups regarding keratinocyte carcinoma, further research is warranted to determine whether skin cancer patients would benefit from an Internet-based group that is secure, anonymous, and moderated for misinformation to provide emotional support, to improve patients' sense of community, and to offer education beyond the limited time allotted in clinical visits.

## Potential conflicts of interest

The authors declare no conflicts of interests.

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