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# JMIR Dermatology

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All topics related to diseases of the skin, hair, and nails, with special emphasis on technologies for information exchange, education, and clinical care

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## Contents

### Original Papers

Effects of Pain From Atopic Dermatitis: Interview and Focus Group Study With Patients and Their Families ( <a href="#">e29826</a> ) Ashley Snyder, Vanina Taliercio, Adelheid Brandenberger, Bianca Rich, Lisa Webber, Abram Beshay, Joshua Biber, Rachel Hess, Jamie Rhoads, Aaron Secrest. . . . .	4
Patients' Experiences of Using Skin Self-monitoring Apps With People at Higher Risk of Melanoma: Qualitative Study ( <a href="#">e22583</a> ) Emily Habgood, Christopher McCormack, Fiona Walter, Jon Emery. . . . .	18
Global Burden of Skin Disease Representation in the Literature: Bibliometric Analysis ( <a href="#">e29282</a> ) Kayd Pulsipher, Mindy Szeto, Chandler Rundle, Colby Presley, Melissa Laughter, Robert Dellavalle. . . . .	41
Publication Trends and Their Relationship With Academic Success Among Dermatology Residents: Cross-sectional Analysis ( <a href="#">e30015</a> ) J Anderson, David Wenger, Austin Johnson, Corbin Walters, Mopileola Adewumi, Lindy Esmond, Jourdan Waddell, Matt Vassar. . . . .	47
Skin of Color Representation on Wikipedia: Cross-sectional Analysis ( <a href="#">e27802</a> ) William Kim, Sophia Wolfe, Caterina Zagona-Prizio, Robert Dellavalle. . . . .	57
Identifying and Responding to Health Misinformation on Reddit Dermatology Forums With Artificially Intelligent Bots Using Natural Language Processing: Design and Evaluation Study ( <a href="#">e20975</a> ) Monique Sager, Aditya Kashyap, Mila Tamminga, Sadhana Ravoori, Christopher Callison-Burch, Jules Lipoff. . . . .	63
The Contact Dermatitis Quality of Life Index (CDQL): Survey Development and Content Validity Assessment ( <a href="#">e30620</a> ) Mary Hill, Melissa Laughter, Cecile Harmange, Robert Dellavalle, Chandler Rundle, Cory Dunnick. . . . .	71
Supporting Self-management Among Young People With Acne Vulgaris Through a Web-Based Behavioral Intervention: Development and Feasibility Randomized Controlled Trial ( <a href="#">e25918</a> ) Athena Ip, Ingrid Muller, Adam Geraghty, Kate Rumsby, Beth Stuart, Paul Little, Miriam Santer. . . . .	79
Comparing Risk Profiles in Critical Care Patients With Stage 2 and Deep Tissue Pressure Injuries: Exploratory Retrospective Cohort Study ( <a href="#">e29757</a> ) Jenny Alderden, Linda Amofo, Yue Zhang, Caroline Fife, David Yap, Tracey Yap. . . . .	115

Conflicts of Interest in “Throwaway” Dermatology Publications: Analysis of the Open Payments Database (e30126)  
 Jorge Roman, David Elpern. . . . . 130

Exploring Access to Surgical Interventions for Hidradenitis Suppurativa: Retrospective Population-Based Analysis (e31047)  
 Alexandra Finstad, Alex Lee, Ralph George, Raed Alhusayen. . . . . 167

**Research Letters**

Sunscreen Posts on Twitter in the United States and Canada, 2019: Content Analysis (e29723)  
 Sajjad Fazel, Emma Quinn, Chelsea Ford-Sahibzada, Steven Szarka, Cheryl Peters. . . . . 14

Surgical Surprise: Cutaneous Metastasis Presenting for Mohs Micrographic Surgery Without a Prior Diagnostic Biopsy (e33241)  
 Spencer Dunaway, Pushkar Aggarwal, Cristin Shaughnessy, Scott Neltner. . . . . 27

Global Melanoma Correlations With Obesity, Smoking, and Alcohol Consumption (e31275)  
 Nisha Batta, Sarah Shangraw, Andrew Nicklawsky, Takeshi Yamauchi, Zili Zhai, Dinoop Ravindran Menon, Dexiang Gao, Robert Dellavalle, Mayumi Fujita. . . . . 32

Teledermatology Consults in a County Hospital Setting: Retrospective Analysis (e30530)  
 Colton Funkhouser, Martha Funkhouser, Jay Wolverton, Toby Maurer. . . . . 37

The Role of Providers and Influencers in the Use of Social Media as Solace for Psoriasis: Qualitative and Quantitative Study (e29904)  
 Sarin Pakhdikian, Benjamin Woo. . . . . 99

Assessment and Evaluation of Social Engagement in Dermatology Residency Programs on Instagram: Cross-sectional Study (e32105)  
 Chapman Wei, Sophie Bernstein, Nagasai Adusumilli, Mark Marchitto, Frank Chen, Anand Rajpara. . . . . 107

From the Cochrane Library: Skin Care Interventions in Infants for Preventing Eczema and Food Allergy (e30197)  
 Jarett Anderson, Torunn Sivesind. . . . . 140

From the Cochrane Library: Systemic Treatments for Metastatic Cutaneous Melanoma (e30270)  
 Austin Hamp, Jarett Anderson, Torunn Sivesind, Mindy Szeto, Andreas Hadjinicolaou. . . . . 143

From the Cochrane Library: Topical Tacrolimus for Atopic Dermatitis (e31838)  
 Austin Hamp, Jarett Anderson, Torunn Sivesind, Mindy Szeto, Jade Cury-Martins. . . . . 147

From the Cochrane Library: Interventions for Impetigo (e33433)  
 Ani Oganessian, Torunn Sivesind, Robert Dellavalle. . . . . 150

From the Cochrane Library: Topical Treatments for Cutaneous Warts (e33900)  
 Ani Oganessian, Torunn Sivesind, Robert Dellavalle. . . . . 153

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## Corrigenda and Addenda

Correction: The Use of Person-Centered Language in Medical Research Journals Focusing on Psoriasis: Cross-sectional Analysis ([e31902](#))

Ryan Ottwell, Benjamin Heigle, Arjun Reddy, Nicholas Sajjadi, Alexis Wirtz, Courtney Cook, Hannah Howard, Micah Hartwell, Matt Vassar. . .  
4 6

## Short Paper

Performance of Artificial Intelligence Imaging Models in Detecting Dermatological Manifestations in Higher Fitzpatrick Skin Color Classifications ([e31697](#))

Pushkar Aggarwal. . . . . 111

## Reviews

Gamification and Game-Based Strategies for Dermatology Education: Narrative Review ([e30325](#))

Mindy Szeto, Daniel Strock, Jarett Anderson, Torunn Sivesind, Victoria Vorwald, Hope Rietcheck, Gil Weintraub, Robert Dellavalle. . . . . 122

Trends in Hidradenitis Suppurativa Disease Severity and Quality of Life Outcome Measures: Scoping Review ([e27869](#))

Jalal Maghfour, Torunn Sivesind, Robert Dellavalle, Cory Dunnick. . . . . 156

Original Paper

# Effects of Pain From Atopic Dermatitis: Interview and Focus Group Study With Patients and Their Families

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## Abstract

**Background:** Pain is an underappreciated symptom of atopic dermatitis that can affect the health-related quality of life (HRQL) of patients.

**Objective:** The aim of this study is to understand the effect of pain on patients with atopic dermatitis and their family members and to recognize how this symptom affects HRQL.

**Methods:** We conducted focus groups and interviews with patients with atopic dermatitis and their family members. Researchers independently coded the transcripts and reached a consensus on the major themes.

**Results:** A total of 33 adult participants, consisting of 21 patients with atopic dermatitis (median age 47 years, range 22-77) and 12 family members (median age 50, range 22-72), attended either focus groups (23/33, 70%) or interviews (10/33, 30%), where we assessed their experiences of pain. Four themes emerged in our study. Itchiness and pain can be intertwined: pain was often caused by or otherwise associated with itchiness and could result from open sores and excoriated skin. Characteristics of pain: pain was most often described as burning. Other descriptors included mild, persistent discomfort; stinging; and stabbing. Effects of pain: pain negatively affected various aspects of daily life, including choice of clothing, sleep, social activities, and relationships. The location of painful areas could also limit physical activity, including sex. Pain management: pain from atopic dermatitis could be managed to varying degrees with different over-the-counter and prescription treatments. Systemic agents that cleared the skin also resolved the pain associated with atopic dermatitis.

**Conclusions:** Pain can be a significant factor in the HRQL of patients with atopic dermatitis and should be considered by clinicians when caring for patients with atopic dermatitis.

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**KEYWORDS**

atopic dermatitis; eczema; pain; qualitative research; quality of life

## Introduction

### Background

Atopic dermatitis is a chronic inflammatory skin disease with a highly symptomatic clinical course [1]. The hallmark symptom of atopic dermatitis is itch, or pruritus [1]. However, pain has also been recognized as an important and highly prevalent symptom in patients with atopic dermatitis [2]. An international web-based survey of 1111 patients with atopic dermatitis from 34 countries showed that pain was the second most common symptom of atopic dermatitis after itchiness [3]. A prospective practice-based study found that over 40% of patients with atopic dermatitis experienced some level of pain [4], and a more recent cross-sectional study found that 61% of participants reported experiencing pain from atopic dermatitis [2].

Several studies have analyzed the effect of chronic pain on the lives of patients, highlighting the strong correlation between pain and the deterioration of health-related quality of life (HRQL) [5-8], and atopic dermatitis is no exception. Some patients with atopic dermatitis find that their pain is related to scratching, fissures on the skin, inflamed red skin, or burning from creams or ointments [2]. Pain from atopic dermatitis can have a negative impact on the ability of patients to shop, make clothing decisions, and maintain relationships, among other aspects of daily life [4]. Moreover, although pain is not universally experienced, one study found that the proportion of patients with moderate or severe atopic dermatitis who reported pain as the most burdensome symptom was more than six times the proportion of patients with mild atopic dermatitis who reported the same [9].

### Objective

Due to the time constraints of clinical practice, dermatologists are often unable to gain an in-depth understanding of all symptoms that the patient has and how they affect the HRQL of a patient. Dermatologists' assessment of the frequency of primary symptoms of a patient (often itchiness with atopic dermatitis) may not accurately reflect the perspectives of the patient. For diseases in which symptoms become debilitating, the primary goal of treatment is symptom control. Failure to understand how debilitating symptoms are for patients may leave them undertreated. We aimed to document the qualitative experience of atopic dermatitis from the perspectives of patients

and their families, specifically focusing on the understudied symptoms of pain with atopic dermatitis.

## Methods

### Study Design

We conducted a qualitative study using focus groups and interviews to understand the effect of pain on HRQL in patients with atopic dermatitis and their family members. Our study was approved by the University of Utah institutional review board (#98441).

### Participants and Setting

Participants were recruited either by recommendation from their dermatologist or by identifying patients with a diagnosis of atopic dermatitis in the electronic medical record with an upcoming appointment and having the study coordinator ask them about participating in the study at the time of the appointment. To be included, patients had to be aged  $\geq 18$  years, speak English, and have atopic dermatitis diagnosed by a University of Utah dermatologist. Family members had to be a partner or first-degree relative of a patient with atopic dermatitis, be aged  $\geq 18$  years, and speak English.

We attempted to recruit a sufficiently large sample to achieve thematic saturation. In total, 21 patients and 12 family members participated in the focus groups or interviews. Each participant provided demographic data via a written survey and written informed consent before the focus group or interview. One family member also had atopic dermatitis, so they contributed data from both family member and patient perspectives.

### Data Collection and Analysis

Semistructured interview guides with open-ended questions were developed regarding experiences with itchiness, pain, sleep quality, and personal relationships because of atopic dermatitis (Textbox 1). The principle of theory-driven qualitative research was used, including basing themes and interview questions on theoretical considerations, expert discussions, and an extensive literature review. Investigators used an integrative model of patient-centeredness to guide the development of guidelines [10,11]. Interviews lasted about 15-35 minutes, and focus groups lasted about 60-70 minutes. Meetings were audiorecorded and transcribed verbatim, though some utterances were left out if not considered important for meaning, for example, "mm-hmm."

**Textbox 1.** Interview guide questions about pain from atopic dermatitis (eczema).

#### Interview guide questions

Please tell me more about the pain associated with the eczema.

- What words would you use to describe the pain of the eczema?
  - Prompts: burning, stinging, pins and needles, aching, stabbing, tingling.
- What time of day is the eczema most painful?
- What are things that cause pain with eczema?
  - Prompts: scratching too much, putting creams/lotions on your eczema
- What helps when the pain is worst, what provides relief?
- How does eczema's pain affect your sleep? The sleep of your significant other?
  - How often is pain affecting sleep? How does it affect your bedroom relationship?
- How does eczema's pain affect your mood? The mood of your loved ones?
- How does pain from eczema affect relationships?
- What other areas of your life are affected by the pain of eczema?

A thematic analysis approach was used to assess transcripts [12,13]. Two investigators (AM Snyder and VLT) with previous training in qualitative methods assessed several transcripts for themes and ideas for an initial codebook, and themes evolved as they continued to code all the transcripts and analyzed the final set of codes. The two investigators reached a consensus on the major themes. Although no changes were made to the meaning of the quotes, it should be noted that minor aspects of some quotes (eg, punctuation and grammatical errors) were changed to account for errors during transcription. For the presentation of quotes, words inserted into quotes or replacing specific words to help convey meaning are shown in brackets; descriptions of actions during the interview or focus group are italicized and shown in brackets; and any text left out of a quote, whether to shorten the quote or replace the text where there was uncertainty about the transcription, was replaced by bracketed

ellipses. NVivo version 12 (QSR International) was used in assessing the codes. STATA version 16 (StataCorp) was used to calculate the demographic statistics.

## Results

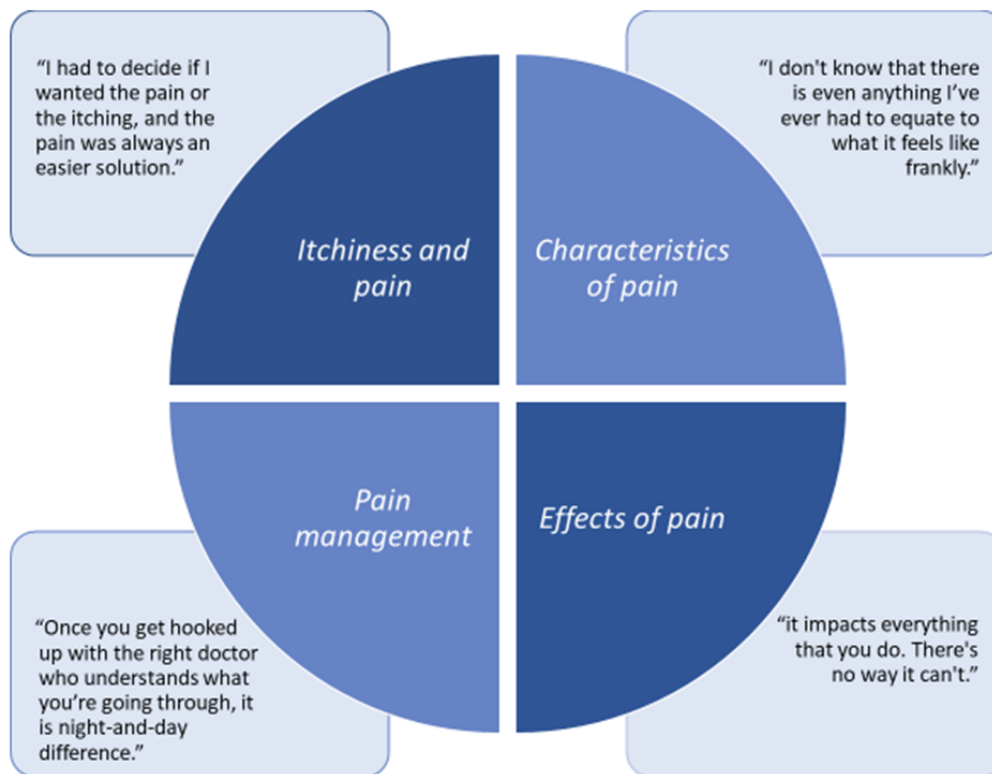
### Demographic Characteristics

Participants attended either focus groups (23/33, 70%) or interviews (10/33, 30%), where we assessed the experiences of 21 patients with atopic dermatitis and 12 family members. Most participants identified as female and non-Hispanic White (Table 1). Four themes emerged that indicated that pain had a significant effect on HRQL (Figure 1). Not all participants reported pain, but for those who did, pain created many different sensations and a variety of effects on daily life.

**Table 1.** Demographic characteristics of patients and family members (N=33).

Characteristics	Patients (n=21)	Family members (n=12)
Age (years), median (range)	47 (22-77)	50 (22-72)
<b>Gender, n (%)</b>		
Female	16 (76)	8 (67)
Male	5 (24)	4 (33)
<b>Race and ethnicity, n (%)</b>		
Non-Hispanic White	20 (95)	10 (83)
Other	1 (5)	2 (17)
<b>Education, n (%)</b>		
High school	3 (14)	2 (17)
College degree	7 (33)	6 (50)
Bachelor's degree	7 (33)	3 (25)
Master's degree or higher	3 (14)	1 (8)
Not reported	1 (5)	0 (0)
<b>Marital status, n (%)</b>		
Married or domestic partner	16 (76)	11 (92)
Single, widowed, or divorced	5 (24)	1 (8)
<b>Employment status, n (%)</b>		
Employed	11 (52)	10 (83)
Retired	4 (19)	2 (17)
Unable to work	1 (5)	0 (0)
Unemployed	4 (19)	0 (0)
Not reported	1 (5)	0 (0)

**Figure 1.** Four main themes regarding pain were elucidated from the transcripts of focus groups and interviews with patients with atopic dermatitis and their family members.



### Theme 1: Itchiness and Pain

Scratching was a necessity for some patients with atopic dermatitis, and pain was sometimes an unfortunate consequence of scratching to try to relieve itchiness. The urge to provide relief from itchiness could be more powerful than the desire to avoid further consequences. This behavior of *inducing pain* led to physical consequences for some, such as open sores and denuded skin:

*[That] is probably where the pain is coming from [...] he's scratched it raw and then it, especially on the inner crooks of his elbows and stuff like where he's bending them a lot, it just kind of opens those wounds back up.*

Conversely, scratching was not always viewed as a negative as scratching could provide relief from the pain:

*[Sometimes] you get the pain, but sometimes if you scratch it, now you have the sensation of scratching and now it's not hurting like it did in that moment before the scratch. You jarred it up a little bit so your body can get a break from the pain, some relief.*

Itchiness and pain were sometimes difficult to distinguish from each other. This *painful itch* phenomenon experienced by some patients appeared to be a significant component of the effects of the condition. One patient explained:

*[It] doesn't feel like it's just itching on top of the skin; it itches down in the skin [...] if you rub it and scratch*

*it, feels almost like a thrill going through your body but it's a hurting thrill or [...] it's like you're having sex or something and you get that climax. It is like that but the only thing is it's pain.*

This pain, described as *coming from deep within*, might not be stopped simply by scratching an itch. Patients in our study generally struggled with itchiness, but coexistent pain worsened daily struggles with atopic dermatitis.

### Theme 2: Characteristics of Pain

Itchiness was not always a part of the pain sensation for patients; instead, some patients felt a burning sensation that could be just as irritating. A *burning pain* was a somewhat common description of the pain experienced:

*[It's] amazing how there aren't any scars from it, because it's like a fire. I mean it's like you got burnt.*

One patient explained:

*There are times that my skin just feels like it's on fire and there is nothing [that] will put it out.*

Additional descriptors of pain included: *hot and burning, stabbing, dull, sharp, sunburn, sting, needle-like*, or even a persistent *discomfort* (Textbox 2). Some participants had difficulty describing their experience, and one patient expressed having trouble even talking about it:

*Pain [...] is hard to talk to people about, because people don't view [atopic dermatitis] in terms of pain.*



**Textbox 2.** Example descriptions of pain from atopic dermatitis.

#### Descriptions of pain

- Burning: “It is hot and burning. It’s true. And it’s like you just feel so helpless and nothing makes it feel better.”
- Discomfort: “I think...it’s not so much like the little bit of itchiness bothers me. It’s not so much that a little bit of pain that bothers me. It is more of the persistence of the two. You know what I mean? If I had it for a day and it went away, I’d be like, ‘Alright, that wasn’t so bad.’ Once it gets [to be], like, two to three weeks, then it’s like, ‘Alright, I’ve got to do something.’ They always ask me what’s the level of pain. I always felt that pain is not the right word for me. I feel like it’s more discomfort. I can sit and do my normal work and be bothered by it but not like in pain [...] just the persistence of the discomfort.”
- Dull: “there is just an overall dull pain that is never-ending.”
- Itching: “You will itch it even if it hurts to itch, because the itch feels way better than the pain does.”
- Needle-like: “because sometimes they would get infected, he would describe it as like, like needles, like poking.”
- Sharp: “I am glad you guys are focusing on the pain, because I feel like that is one aspect that is not even considered [...] I mean, it is just never stopping. It [is] like dull pain, sharp pain. Like you were saying, all the time.”
- Stabbing: “it is like a stabbing pain that radiates. If you think of like a reverse lightning bolt, there is one spot that hurts more than others, but it is also radiating to different areas—like a jab or a jolt. It feels like an itch, like a painful itch.”
- Stinging: “When mine breaks out, I say it burns, but it’s not heat burn. It’s more probably a sting. But I always say burn, but when I think about it, it’s probably more like a sting.”
- Sunburn: “it rubbed and I couldn’t hardly walk. I couldn’t hardly stand it, and [...] I was achy. [...] You know how you feel when you get sunburnt? Your skin just burns. [...] It doesn’t go away.”

### Theme 3: Effects of Pain

When present, pain could result in various consequences for daily life. Patients with atopic dermatitis and their family members expressed having to be careful about their clothing choices. For example, having clothes touch affected skin could lead to pain:

*[It] was mostly on his legs [...] the socks will really hurt.*

This could lead to avoidance of certain clothes to avoid pain from atopic dermatitis:

*When she gets these open sores [...] she could not wear bras or anything if it was in the sweat line.*

Conversely, as one patient expressed, clothes that cover more skin could be a necessity:

*[When] it’s so hot, I watch everyone else and they’ve got short-sleeved shirts. I’m all covered up, because the sun is so hard on my skin then. [...] I cannot wear sleeveless or short-sleeve clothes at all.*

The pain of an atopic dermatitis flare-up can also affect daily activities. Pain was not always limited to one time of day: “my pain goes all day long.” However, the time of day was reported to make a difference for some and could particularly affect sleep:

*It does hurt more when you lay down to go to sleep because I think you are starting to think about it more when you’re just lying there.*

Sleep was also affected for some family members. One family member expressed concern over the consequences of their loved one’s pain during the night:

*...when I know it’s flaring up, I might sleep a little bit lighter just because I don’t want him to wake up super, you know, bloody and in a ton a pain, and so*

*I have a tendency to wake up a couple times a night and be like, “Hey, let’s put some lotion [on it].” But that’s really only when it’s flaring up really bad.*

However, if the patient cannot control their reactions, family member comments are not helpful:

*He will say, “Do not itch it. It is going to hurt.” But I can’t control it; it’s really itchy.*

Daytime activities are also affected by atopic dermatitis–related pain. A hobby such as gardening became too painful to continue for a patient with atopic dermatitis:

*My mom used to like gardening, but she doesn’t anymore because her hands are so affected by it. But she tries to wear gloves, but it still just, like, kills her.*

However, as one patient expressed, other hobbies may then become favorable for their lack of resulting pain:

*I read, because that’s one thing I can do in spite of the pain.*

Showering can also be painful:

*If he just gets out of the shower, he’ll say it feels like it burns.*

The skin care regimen of a patient can be tedious and limited:

*I use surgical soap as a body soap at this point. I miss pretty smells, just smelling pretty, smelling like a girl.*

Warm environments can be problematic:

*In the summertime just, the sweat. [...] She spent a lot of time indoors with the air condition on, but if we have to go out, or we go to the store and she starts sweating, you know, I can tell that she will get uncomfortable.*

Furthermore, going out can be painful both physically and emotionally:

*[It's] depressing to go out. I'll put on makeup. [...] I haven't been able to wear eyeshadows or anything because my eyes are so sensitive [and they] swell up, and it's caused me to have a depression, just the itching and burning.*

Activities influenced specifically by pain were mentioned less often than those influenced by itchiness, but the range of effects was broad.

Similarly, social experiences can be affected by pain, and relationships can be strained by trying to care for pain in the affected patients. Physical relationships with a partner can be limited by pain from atopic dermatitis, and the location of the painful areas can limit sexual intimacy, as one patient explained:

*It affected [...] our sex life, because I have sores all over my chest [...] It is painful [...] I am so self-conscious of it. [...] now this has been going on for eight years, so there's been nothing in this area going on intimately, you know, with my husband.*

For family members, the pain of atopic dermatitis can be difficult simply because they see the burden of the disease:

*Every time she scratches, she's talking about it hurting and wishes she could get something to stop it from scratching.*

However, for family members, the effects of pain can be difficult to understand without knowing what the pain is like: "I can't feel the pain." However, the understanding of the family members of the effects may still be better than the understanding of others outside the family:

*You pick up on it a lot faster if you're living with them. We go over to friends' houses, and they don't understand it.*

This lack of understanding, both from family members and others, can be frustrating for the patient:

*The explaining to everyone what it is. You're at the grocery store and you have a big cut on your hand, and people are like, "Did you get in a fight?" and you are like, "No!" Yeah, it's just a crazy situation that is hard to explain. I wish they had groups for it because it is nice to talk to you [others in the focus group] because it is this connection that nobody else can understand, because even your partner doesn't understand the exact level to which it affects you on a daily basis.*

#### Theme 4: Pain Management

Another important component was the use of over-the-counter and prescription treatments to control the symptoms. Prescription treatments could be very helpful in improving the HRQL of the patient:

*I started the Dupixent and, oh my gosh, what a life-saver. [...] I can't believe the difference.*

One patient found cannabidiol helpful:

*[She] has been using CBD oil and [...] that really has helped the pain and helped her sleep.*

Steroids, such as triamcinolone, as well as over-the-counter treatments, such as acetaminophen and ibuprofen, were mentioned as ways to relieve pain. However, not all treatments work:

*[Betamethasone] really doesn't help. But I will put it on as soon as they pop out.*

Some medications, such as pregabalin, were mentioned as being ineffective for atopic dermatitis-associated pain:

*It kind of helps with these things [patient pointing to atopic dermatitis on hand]. But it wasn't necessarily nerve pain.*

One patient explained that it could also take time for a medication to start working:

*It takes some time; I mean like when I was taking cyclosporine and it didn't happen, like, overnight where it just stopped.*

In addition to pain directly associated with atopic dermatitis flares, open wounds can become infected, requiring special treatment:

*I think he scratches them to the point where they are open wounds and then they get a little infected, and so a lot of times we use a lot of Neosporin and stuff like that on his arms just, like, to keep the pain and everything at bay.*

One patient expressed difficulty in discerning between atopic dermatitis-related pain and treatment-related pain:

*I think certain ones are painful. [...] I'm trying to think if the creams cause the pain, and I don't think creams cause the pain.*

The pain for some patients was a direct result of medication use:

*[He's] been on steroids; it's made his skin super thin [...], so he gets cuts all the time [...] he can't even get stitches anymore 'cause his skin's so thin it just tears it. [...] it makes him not want to do stuff, which is hard for me 'cause I like to go out and do stuff and try new things and be active and he's a little more hesitant because he's just prone to getting hurt and sores and they take months to heal.*

Finding clinicians who could significantly help was difficult for some participants. Patients with atopic dermatitis and their family members had a variety of experiences with clinicians when figuring out treatments for symptoms of atopic dermatitis—some positive and some negative.

## Discussion

### Principal Findings

Atopic dermatitis is known for its itchiness; however, our study found that focusing only on itchiness does not capture the full range of experiences of patients with atopic dermatitis and their family members. This study found that pain could coincide with itchiness, be difficult to describe, and influence all aspects of daily life for patients (and their family members). In addition,

systemic agents could clear atopic dermatitis while also resolving the pain associated with this condition. The effects of pain from atopic dermatitis are relatively understudied but deserve further attention, both to identify the effects of pain on HRQL and to determine how to appropriately measure and potentially manage this symptom [14].

Increased frequency and intensity of pain from atopic dermatitis leads to worse HRQL, and for some, pain can affect relationships and numerous daily activities [2]. A study assessing the effects of pain from atopic dermatitis on patients and their caretakers found that 80% of participants had experienced effects on sleep, nearly as many (78%) experienced effects on leisure activities, and most (63%) experienced effects on other activities of daily living [15]. Although most comments in our study related to effects on HRQL were made about itchiness or atopic dermatitis more generally, we found that some patients experienced pain that affected the activities of daily living (eg, clothing choices, exercise, environmental exposures, and sexual relations) and could further affect overall HRQL. However, not all participants shared the same level of impact, likely due to differences in disease severity.

Some expressed having regained control over symptoms through medications. The use of systemic treatments, such as dupilumab, greatly improved both symptoms and HRQL outcomes for some participants, an observation supported by the literature [16]. However, not all systemic treatments share the same level of success [16], and prescribing systemic treatments must be carefully considered based on side effects, as was expressed by some participants in our study.

One of the most challenging aspects of pain is defining it. The root cause of pain from atopic dermatitis can be difficult to identify; one study found that about 17% of patients with atopic dermatitis thought pain was part of itchiness, whereas 72% thought it was part of both scratching and itchiness [4]. This is consistent with our results, as itchiness and pain overlapped for several patients. The two symptoms could be almost indistinguishable, and for some, scratching due to itchiness led to pain, although this trade-off was worth it when the pain felt better than an itch. The sensation of pain could be difficult to describe, underlining the problem that pain is a poorly understood and ill-defined symptom of atopic dermatitis.

Helping patients express concerns and how symptoms affect their daily lives is a necessity when addressing HRQL, and we believe that appropriate methods of identifying and defining pain are needed to further address this concern with patients.

One approach to measuring pain is through pain-specific patient-reported outcome (PRO) measures [17]. PROs capture information of interest from the patient perspective and have demonstrated utility in identifying concerns otherwise left unexpressed in a dermatology visit [18]. These measures track patient progress and problems over time when administered regularly at visits [19], and numerous PROs currently exist for a wide range of concerns, giving clinicians many options to choose from when deciding the best measures to use with their patients. However, further studies are needed to determine which methods work best for identifying pain specific to atopic dermatitis.

### Limitations of the Study

Our study is limited in generalizability because it took place at a single academic medical center in a high-altitude, low-humidity environment conducive to increased atopic dermatitis severity. Expanding to other institutions and other geographic locations outside Utah may produce different results. Furthermore, our study only included adults, and thus our results might not be generalizable to the experiences of children and adolescents with atopic dermatitis. Although investigators used open-ended questions to capture the participants' voices, it is possible that the way the questions were worded influenced participant responses. In using prompts to aid discussion, the interviewers may have directed a conversation toward those specifics, and some aspects were talked about more than others due to how questions were worded. This study is also limited in its interpretability because of its qualitative nature. Qualitative research provides an opportunity to learn about patient experiences and produce ideas for future research [20]. However, a small, nonrandom, single-institution cohort makes the findings from this study difficult to generalize if the data were quantified. The thematic analysis for this study does not involve quantification of themes or individual components of these themes but does provide information to help generate ideas for future studies that can appropriately quantify the phenomena presented here.

This study presents the experiences of patients and their family members in dealing with the effects of pain caused by atopic dermatitis. We found that many aspects of daily life can be affected by this symptom, and although pain can be very bothersome and significantly impact HRQL, it can be difficult for some patients to explain what they are experiencing. Clinicians must be aware that atopic dermatitis can cause pain and should ask patients about the presence and effects of pain when treating patients with atopic dermatitis.

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### Authors' Contributions

All authors were involved in the conceptualization of this paper, although AM Secrest led conceptualization and acquired funding.

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## Conflicts of Interest

RH serves on a data safety monitoring board of Astellas Pharmaceuticals unrelated to this work.

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## Abbreviations

**HRQL:** health-related quality of life

**PRO:** patient-reported outcome

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Research Letter

# Sunscreen Posts on Twitter in the United States and Canada, 2019: Content Analysis

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**KEYWORDS**

sunscreen; skin cancer; Twitter; misinformation; prevention; skin; social media; health promotion; melanoma

Skin cancer is a growing burden in Canada and the United States. One effective prevention method is the use of sunscreen; however, low sunscreen use [1] coupled with the spread of misinformation online can hinder health promotion activities.

Health-related social media posts (including sunscreen) may shape risk-related behaviors of users, so it is important to understand the accuracy of such posts [2].

Twitter's Application Program Interface was used to search for tweets in English containing the word "sunscreen" posted in Canada and the United States (May 1 to August 31, 2019). We used thematic content analysis to elicit the accuracy, sentiment, and theme of the tweets.

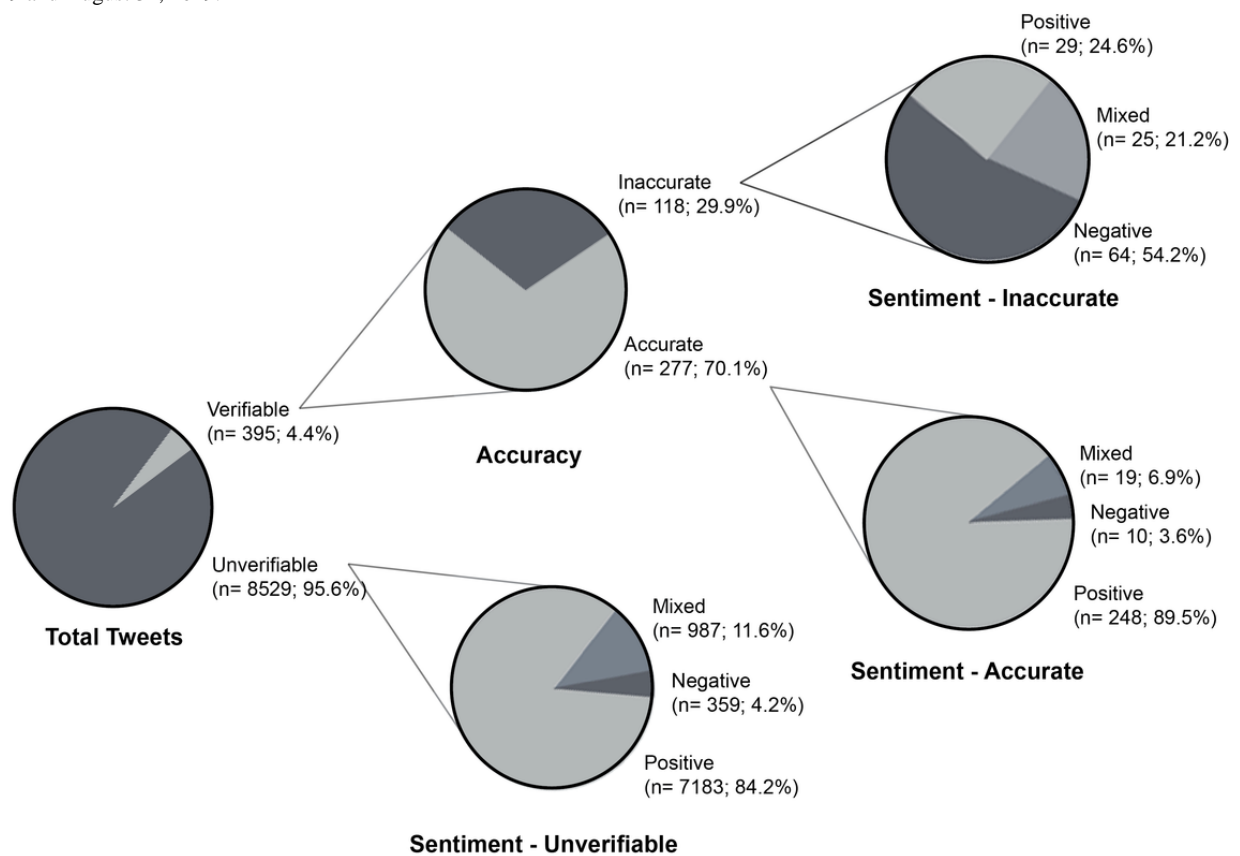
Tweets containing verifiable information (that could be assessed as factual or not) were analyzed for accuracy and coded as either "accurate" or "inaccurate" based on current evidence. All tweets were coded for sentiment (positive or negative).

Themes were analyzed using an a priori list of codes based on our previous study [3] and inductively modified based on emergent themes. Differences were tested using the chi-square statistic or the Fisher exact test.

In total, 9176 tweets were collected; 167 retweets and 85 irrelevant tweets were excluded. The remaining 8924 tweets were analyzed for accuracy (where applicable), sentiment, and theme. The observed percentage agreement between the coders for sentiment and accuracy was 76%. Only 395 tweets (4% of the total) contained verifiable information and were analyzed for accuracy. Among these, 277 (70%) were accurate and 118 (30%) were inaccurate (Figure 1).

The most common themes were personal story (n=5425, 61%), tips and recommendations (n=2591, 28%), and advertisements (n=457, 5%). The top theme for accurate and inaccurate tweets was tips and recommendations (n=171, 56%) and personal story (n=90, 62%), respectively.

**Figure 1.** Comparison of sentiments between accurate, inaccurate, and unverifiable sunscreen tweets originating from Canada and United States between May 1, 2019 and August 31, 2019.



The sentiment analysis found that 7460 (84%) of tweets had a positive sentiment, 1031 (11%) were mixed or neutral, and 433 (5%) were negative. Among the accurate tweets, the majority had a positive sentiment toward sunscreen (n=248, 89%), while over half (n=64, 54%) of the inaccurate tweets had a negative sentiment. Interestingly, inaccurate tweets were more likely to have any engagement than accurate tweets (Table 1).

We found that most tweets were personal stories and not verifiable for accuracy. This suggests that misinformation about sunscreen may not be an important contributor to low sunscreen use, as also noted by Silva et al [4]. The sentiment analysis found that over 80% of all sunscreen tweets had a positive

sentiment toward sunscreen use, which is similar to our previous study on sunscreen information in traditional media sources [3].

This study was limited to Twitter; further research on sunscreen misinformation using other social media platforms is recommended.

In conclusion, sunscreen misinformation was limited, but misinformation was more likely to have engagement from users. Organizations may have better success in promoting sunscreen use by producing tailored, engaging sunscreen and cancer prevention messages [5]. Furthermore, it may be beneficial for physicians and health organizations to share messages using lived experience, which may increase reach and engagement online.

**Table 1.** Comparison of Twitter data between verifiable and unverifiable tweets: Canada and United States, 2019.

Category and subcategory	Verifiable tweets		<i>P</i> value (accurate vs inaccurate tweets)	Unverifiable tweets, n (%)	<i>P</i> value (all verifiable vs unverifiable tweets)
	Accurate tweets, n (%)	Inaccurate tweets, n (%)			
<b>Sentiment</b>			<.001		<.001
Positive	248 (89)	29 (25)		7183 (84)	
Mixed	19 (7)	25 (21)		987 (12)	
Negative	10 (4)	64 (54)		359 (4)	
<b>Engagement<sup>a</sup></b>			.04		.68
0	96 (35)	29 (25)		2689 (32)	
1-5	126 (46)	66 (56)		4269 (50)	
6-10	18 (18)	13 (11)		711 (8)	
>10	37 (13)	10 (8)		860 (10)	
<b>Followers<sup>b</sup></b>			.049		.61
0-200	73 (26)	28 (24)		2011 (24)	
201-500	55 (20)	38 (32)		2222 (26)	
501-1000	58 (21)	24 (20)		1675 (20)	
>1000	91 (33)	28 (24)		2621 (31)	
<b>Attached URL</b>			<.001		<.001
Yes	205 (74)	60 (51)		4349 (51)	
No	72 (26)	50 (49)		4180 (49)	
<b>Type of URL</b>			.30		<.001
Social media	199 (88)	50 (83)		4214 (97)	
News	5 (2)	0 (0)		88 (2)	
Health organizations	4 (2)	1 (2)		18 (0.4)	
Peer-reviewed journal websites	1 (0.5)	1 (2)		2 (0.05)	
Other	17 (8)	8 (13)		268 (6)	
<b>Attached media</b>			.02		.86
Yes	57 (21)	13 (11)		1482 (17)	
No	220 (79)	105 (89)		7047 (83)	
<b>Type of media</b>			.87		.26
Photo	46 (81)	11 (85)		1095 (74)	
Video	1 (2)	0 (0)		82 (5)	
Animated GIF	10 (17)	2 (15)		305 (21)	

<sup>a</sup>Engagement was defined as the total number of “likes,” “retweets,” “quote tweets,” and “replies” for each tweet.

<sup>b</sup>Followers was defined as the number of individual Twitter accounts following the user.

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## Conflicts of Interest

None declared.

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Original Paper

# Patients' Experiences of Using Skin Self-monitoring Apps With People at Higher Risk of Melanoma: Qualitative Study

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## Abstract

**Background:** Melanoma is the fourth most commonly diagnosed cancer in Australia. Up to 75% of melanomas are first detected by patients or their family or friends. Many mobile apps for melanoma exist, including apps to encourage skin self-monitoring to improve the likelihood of early detection. Previous research in this area has focused on their development, diagnostic accuracy, or validation. Little is known about patients' views and experiences of using these apps.

**Objective:** This study aims to understand patients' views and experiences of using commercially available melanoma skin self-monitoring mobile apps for a period of 3 months.

**Methods:** This qualitative study was conducted in two populations: primary care (where the MelatoolsQ tool was used to identify patients who were at increased risk of melanoma) and secondary care (where patients had a previous diagnosis of melanoma, stages T0-T3a). Participants downloaded 2 of the 4 mobile apps for skin self-monitoring (SkinVision, UMSkinCheck, Mole Monitor, or MySkinPal) and were encouraged to use them for 3 months. After 3 months, a semistructured interview was conducted with participants to discuss their experiences of using the skin self-monitoring mobile apps.

**Results:** A total of 54 participants were recruited in the study, with 37% (20) of participants from primary care and 62% (34) from secondary care. Interviews were conducted with 34 participants when data saturation was reached. Most participants did not use the apps at all (n=12) or tried them once but did not continue (n=14). Only 8 participants used the apps to assist with skin self-monitoring for the entire duration of the study. Patients discussed the apps in the context of the importance of early detection and their current skin self-monitoring behaviors. A range of features of *perceived quality* of each app affected engagement to support skin self-monitoring. Participants described their skin self-monitoring routines and potential mismatches with the app reminders. They also described the technical and practical difficulties experienced when using the apps for skin self-monitoring. The app's positioning within existing relationships with health care providers was crucial to understand the use of the apps.

**Conclusions:** This study of patients at increased risk of melanoma highlights several barriers to engagement with apps to support skin self-monitoring. The results highlight the wide-ranging and dynamic influences on engagement with mobile apps, which extend beyond app design and relate to broader contextual factors about skin self-monitoring routines and relationships with health care providers.

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**KEYWORDS**

melanoma; skin cancer; early detection; mobile apps; qualitative; mHealth; mobile phone

## Introduction

Skin cancers account for 80% of all newly diagnosed cancers in Australia, with melanoma being the most harmful [1]. Early detection is key, as it provides a better chance of receiving timely treatment. More than 91% of Australians survive if their melanomas are detected early [1]. Up to 75% of melanomas are first detected by patients or their family or friends [2]. Encouraging people to self-monitor their skin for suspicious moles on their bodies could encourage early diagnosis [2]. Current guidelines already recommend Australians at increased risk of melanoma to monitor their own skin in between appointments [3,4]. However, there is currently little information on how patients are recommended to do this, and many patients are completing this insufficiently [5].

Mobile apps for melanomas are becoming increasingly popular. There is an abundance of commercially available mobile apps for melanoma across the different mobile app stores [6,7]. The purpose of these apps varies from prevention (UV exposure apps) to treatment management (drug and side effect management). Apps that encourage skin self-monitoring are designed to support the early detection of melanoma by identifying changes in moles. Most research into these mobile apps for skin self-monitoring for melanoma has focused on their development or diagnostic accuracy [8-11], but there have been limited studies on the actual use of these apps outside controlled *laboratory* settings. Qualitative research provides a deeper understanding of people's experiences, thoughts, and opinions to explore what determines the effective implementation of digital interventions [12,13]. Recent research has shed light on patients' perceptions of the use of mobile health apps for melanoma. Specifically, Koh et al [14] found that patients had positive views about apps for skin self-monitoring and thought they would benefit from using them, but this was based on the intended use of a hypothetical app. We suggest that allowing participants to experience using these types of apps over a period of time provides greater ecological validity. In this study, we aim to understand users' experiences and use of skin self-monitoring mobile apps for melanoma over a 3-month period, focusing on people who were at increased risk of melanoma, as this is consistent with the current Australian guidelines [3,4].

More specifically, we aim to understand participants' experiences of actually using these mobile apps and the reasons they chose whether to use and engage with the apps. We also wanted to determine if this was a potentially feasible way to recruit people at risk of melanoma in future studies of skin self-monitoring apps.

## Methods

### Study Design and Ethics Approval

This study used a qualitative design with a 3-month follow-up period using a baseline questionnaire and semistructured interviews. A 3-month period was considered to be sufficient to understand participants' interest and patterns of use of the mobile apps and understand their experiences. Participants downloaded the apps on their own phones, were provided with

a brief demonstration of both apps, and received automated reminders once per month via each app. Semistructured interviews were used to understand participants' thoughts and experiences after the 3-month period of ad libitum use of 2 of the 4 apps allocated to them on the basis of their phone's operating system (iOS or Android). This study was reviewed and approved by the University of Melbourne Health Sciences Human Ethics Committee (1749081) and the Peter MacCallum Cancer Centre Human Research Ethics Committee (HREC/17/PMCC/214).

### Recruitment

#### Study Setting

Participants were recruited from two different populations: Melbourne general practices, where participants were identified as at increased risk of melanoma on the basis of risk factors; and the Melanoma Outpatient Clinic at Peter MacCallum Cancer Centre (Melbourne, Australia), where participants had a previous diagnosis of melanoma. The study was conducted between October 2018 and February 2019.

#### Primary Care

In primary care, recruitment was undertaken across 3 busy Melbourne general practices. All patients in the waiting room of the practices were consecutively approached and invited to complete the MelatoolsQ tool [15] to determine if they were eligible. Patients were excluded if they were aged <18 years, unable to understand English, or acutely unwell.

The MelatoolsQ tool is a self-completed survey, which is delivered on an iPad. It contains a modified version of the Williams melanoma risk prediction model [16], which includes the following risk factors: sex, age, natural hair color at the age of 15 years, number of raised moles on both arms, the density of freckles on both arms before the age of 20 years, number of severe sunburns up to the age of 18 years, and previous nonmelanoma skin cancer (basal cell carcinoma and squamous cell carcinoma). A melanoma risk score was calculated from the patients' responses; if they scored 25 or more, they were categorized as increased risk of melanoma and invited to participate in the study [15,16].

#### Secondary Care

In secondary care, all patients attending an outpatient appointment for their current or previous early-stage melanoma (stages T0-T3a) and aged 18 years or older were approached and invited to participate in the study. Patients were ineligible if they had suspicion or evidence of metastatic disease or were receiving palliative treatment.

### Procedure

All participants who were eligible from either primary or secondary care were invited to participate. The aims of the study were discussed, and all participants were provided with a plain English statement explaining the details of participation. Participants recruited to the study had to own a compatible smartphone (Android or iOS operating system) and have sufficient data storage on their phone to download and store photographs (approximately 130 MB). Written consent was

obtained from all participants before completing a short baseline survey.

Consented participants were assisted in downloading 2 study apps onto their own phones, which were dependent on their phone's operating system. They were provided with a short booklet and demonstration of how to use each app. Participants were asked to use the apps at least once a month for the 3 months of the study, with a monthly SMS text reminder to check their moles through the app.

### Data Collection

A baseline questionnaire collected data on demographics and patterns of mobile phone use. All participants were invited to participate in a telephonic semistructured interview at the end of the 3-month time point, which was audio recorded. The interview guide was designed to explore participants' experiences and preferences for using the apps and their skin monitoring behaviors ([Multimedia Appendix 1](#)).

### App Selection

The melanoma skin self-monitoring mobile apps identified for the study were SkinVision, UMSkinCheck, Mole Monitor, and MySkinPal. The researchers have no association with the development or marketing of these apps. Inclusion criteria for app selection were apps that were designed for patient use, allowed users to take photographs of their skin within the app, compare photographs over time, and had built-in reminder notifications and information on skin self-monitoring.

The selected apps were identified through a previous review of available mobile apps designed for early detection of melanoma [7]. Kassianos et al [7] identified 39 apps available at that time on app stores for melanoma, and we selected 4 apps on the basis of their functionality. The apps varied by the operating system they were compatible with (either Android or iOS) and the level of assistance provided to determine changes between photos. The Mole Monitor and UMSkinCheck apps were only available on iOS at the time of the study. During the study period, there were no updates to 3 of the apps and minor bug fixes to SkinVision. The apps were allocated to participants depending on their phone's operating system. We wanted to understand participants' experiences of using a melanoma skin self-monitoring mobile app per se rather than the specific apps selected. Therefore, we decided to provide participants with 2 apps each (depending on their phone operating system) to allow comparison of app features and content but to minimize

participant burden. We believed that this more closely reflected the usual consumer approaches to trialing new apps while studying those that had similar functionality to support skin self-monitoring.

### Data Analysis

Quantitative baseline data were collected using REDCap (Research Electronic Data Capture) [17] and analyzed using descriptive statistics with Stata Statistical Software (version 17, StataCorp LLC) [18].

Qualitative data were audio recorded and transcribed verbatim. Transcripts from the semistructured interviews were analyzed using inductive and deductive thematic analyses, using the stepped approach described by Braun and Clarke [19]. All coding was undertaken by EH, a health services researcher, with a subsample coded by JDE, an academic general practitioner (GP); discrepancies were discussed and resolved as a team. The team also included a second academic GP and a dermatologist. All individuals in the team brought their perspectives to the analysis. Data saturation was reached when the team agreed that no new themes were arising from the transcripts. All analyses were performed using Dedoose (version 8.3.17) [20].

## Results

### Participant Demographics

A total of 54 participants (28/54, 52% female; mean age 57.3 years, SD 12.5 years) were recruited in the study between June and September 2018. A total of 20 participants were recruited from primary care and 34 from secondary care. Among the 54 participants who completed the baseline questionnaire, 34 (63%) were interviewed about their experiences (12 from primary care and 22 from secondary care). The demographic characteristics are presented in [Table 1](#). The median interview time was 21 (range 5-39) minutes. Nine participants were lost to follow-up, and 11 participants withdrew during the study period. The main reasons for withdrawal were competing health issues (n=3), difficulty using the apps (n=3), and being too busy to participate (n=2). These participants were mostly older and from rural areas.

[Table 2](#) presents data on patterns of use of apps by participants. Of the 34 participants interviewed, 88% (30) had downloaded an app in the last year and 73% (25) often use the apps on their phone more than once a day. More than half of the participants (20/34, 59%) had health-related apps on their phone.

**Table 1.** Demographic characteristics (N=54).

Variable	Total recruited, n (%)	Total interviewed (n=34), n (%)	Total not interviewed (n=20), n (%)
<b>Gender</b>			
Female	28 (52)	15 (44)	13 (65)
Male	26 (48)	19 (56)	7 (35)
<b>Age (years)</b>			
18-44	8 (15)	6 (18)	2 (10)
45-54	9 (16)	6 (18)	3 (15)
55-64	21 (39)	16 (47)	5 (25)
65-74+	16 (30)	6 (17)	10 (50)
<b>Education</b>			
Year 11 or below	15 (28)	8 (23)	7 (35)
Year 12 or equivalent	8 (15)	5 (15)	3 (15)
Trade or apprenticeship	10 (19)	7 (20)	3 (15)
Tertiary certificate or diploma	6 (11)	4 (12)	2 (10)
Undergraduate	4 (7)	2 (6)	2 (10)
Postgraduate	11 (20)	8 (24)	3 (15)
<b>ARIA<sup>a</sup> postcode classification</b>			
City	36 (67)	30 (88)	6 (30)
Rural	18 (33)	4 (12)	14 (70)
<b>Phone operating system</b>			
iOS	36 (67)	21 (62)	15 (75)
Android	18 (33)	13 (38)	5 (25)

<sup>a</sup>ARIA: Accessibility or Remoteness Index of Australia.

**Table 2.** Baseline survey responses (N=54).

Question	Total recruited, n (%)	Total interviewed (n=34), n (%)	Total not interviewed (n=20), n (%)
<b>Number of apps downloaded in the last year</b>			
0	7 (13)	4 (12)	3 (15)
1-4	16 (29)	9 (26)	7 (35)
5-10	21 (39)	14 (41)	7 (35)
11-20	8 (15)	6 (18)	2 (10)
≥20	2 (4)	1 (3)	1 (5)
<b>What types of apps do you use on your phone?<sup>a</sup></b>			
Games	21 (39)	10 (29)	11 (55)
Social networking	37 (69)	23 (68)	14 (70)
Video or movies	2 (4)	2 (6)	0 (0)
News	22 (41)	15 (44)	7 (35)
Maps or navigation	45 (83)	28 (82)	7 (35)
Weather	43 (80)	25 (73)	18 (90)
Banking or finance	38 (70)	24 (71)	14 (70)
Shopping or retail	19 (35)	11 (32)	8 (40)
Health-related	20 (37)	13 (38)	7 (35)
<b>How often do you typically use the apps on your smartphone?</b>			
More than 10 times a day	15 (28)	8 (23)	7 (35)
2-10 times per day	24 (44)	17 (50)	7 (35)
Once a day	8 (15)	4 (12)	4 (20)
Less than once a day	7 (13)	5 (15)	2 (10)
<b>How many health-related apps do you have on your phone?</b>			
0	24 (44)	14 (41)	10 (50)
≥1	30 (56)	20 (59)	10 (50)

<sup>a</sup>More than 1 option could be chosen; on average, 4.5 were selected, with a median of 5.

## Use of the Skin Self-monitoring Apps

Overall, although a minority of the participants who were interviewed thought the skin self-monitoring apps were helpful and used them for the entire duration of the study (n=8), most participants either did not use the apps at all (n=12) or tried them once and did not continue (n=14). Participants spoke about their preferences for the different apps, which mostly referred to their user experience of the apps. Of the 4 apps used in the study, no app was preferred over the other by a majority of users. There were no discernible differences in views about the skin self-monitoring apps between those with a previous melanoma and those recruited from primary care. We present the results of the qualitative data analysis in relation to the following core themes: perceived benefits of early detection and experiences of skin self-monitoring, the experience of using the apps to support skin self-monitoring, skin self-monitoring routines and the role of app reminders, and the apps and their positioning within existing relationships with health care providers (HCPs). Data saturation was reached by the last 3 interviews, where no new themes were arising for both primary

and secondary care participants. All relevant quotes are provided in [Multimedia Appendix 2](#).

## Benefits of Early Detection

Many participants, regardless of their use, discussed the importance of early detection of melanoma and how these apps could support patients in identifying melanomas at an early stage. As a result, all participants who used the app throughout the study thought that using the app provided peace of mind and reduced some of the uncertainty about checking their skin for signs of melanoma. Despite recognizing the potential benefits of using apps for the early detection of melanoma, there were variable degrees of engagement with them. Some participants felt that they were more relevant to their needs, and this was driven, in part, by their perceived increased risk of melanoma.

## Experience of Skin Self-monitoring

In the context of the perceived benefits of early detection of melanoma, all participants discussed skin self-monitoring and recognized the importance of checking their own skin regularly. Some participants discussed the importance of routine to engage in regular skin self-monitoring, for example, performing it while

they were dressing for the day. However, some participants felt that skin self-monitoring was not appropriate for them, describing the challenges of skin self-monitoring on having large numbers of moles and the challenges of deciding which ones to monitor, especially when they had many to choose from.

### **Experience of Using Apps to Support Skin Self-monitoring**

Although individual opinions on skin self-monitoring varied, most participants perceived skin self-monitoring positively and continued to perform it regardless of their engagement with the apps. Participants described several factors that influenced their perceptions of the quality of the apps, which affected their engagement with them. People were more likely to engage with an app that they felt was of high quality, although what exactly determined this perception differed among users. Primarily, users described the importance of intuitive design and the simplicity of use to foster engagement. This was key as the app was only recommended to be used once a month and not on a more frequent basis, as in most other apps.

When discussing their experience of the different apps, participants described the importance of simple navigation through the app and the ability to move through the app easily as they checked individual moles. Not surprisingly, key functions in the apps were considered better in some apps compared to others—a critical function related to the ability to capture good quality images of the mole to enable comparison over time.

### **Technical Challenges of Using the Apps**

In addition to such key aspects of image capture, the participants discussed other important technical challenges they experienced. A particular one, relevant to skin self-monitoring more broadly, is viewing moles in less accessible parts of the body, including the back. For many, this required seeking assistance from a partner or carer but was a greater challenge for those who lived alone.

Although all participants were regular users of smartphones, there were varying levels of reported proficiency in their use. Some were, therefore, not confident enough to use the app in the way it was intended. There were concerns related to this issue about the amount of time needed to learn how to use the individual apps and maintain the photos.

Participants also experienced specific technical issues with the apps; some participants complained about the apparent impact on battery life, whereas others had difficulties reinstalling the app when purchasing a new phone.

### **App Reminders and Skin Self-monitoring Routines**

All the apps had a reminder function to prompt users to examine their skin. There was mixed feedback on these reminders. Most participants thought they were helpful and used them to help keep on track with monitoring their skin. However, there were problems with the reminders not coinciding with individuals' skin self-monitoring routines. For younger participants who were less regular with conducting skin self-monitoring, the app reminders were insufficient to prompt them to check their skin.

### **The Apps and Their Positioning Within Existing Relationships With HCPs**

Participants discussed the importance of the HCPs involved in managing their skin, and this often involved seeing multiple doctors, even for those participants recruited in primary care who had not been previously diagnosed with melanoma. Many participants spoke to their GPs regarding concerns about a specific mole, and some participants also attended primary care skin clinics; those with a previous melanoma also consulted their specialists for signs of recurrence and a whole-body examination. Participants also discussed how the app fit into these relationships with their HCP and how they could share and discuss the photographs they had been taking.

They felt that the ability to compare photographs over time within the app and have all their photographs stored in a single accessible place could help communicate with their doctors.

However, some participants felt that there was no place for the app because they were already being monitored closely by their doctors.

Related to this was the issue of greater trust in continuing to see their doctor than relying on an app. This model of care provided them with greater peace of mind and was more effective for the early detection of melanoma.

Others thought the apps were potentially more relevant to a rural audience, who did not have such good access to health care.

There was some support for the potential use of the apps to enable a telehealth model and change the way they interacted with their health professionals about their skin. They supported the idea of sending images directly to a specialist through an app for review, whereas others were more skeptical about this model of care. By assuming that even if they did send a photograph in for review, they would be asked to consult a doctor every time.

## **Discussion**

### **Principal Findings**

To our knowledge, this is one of the first studies to assess the experiences of people at higher risk of melanoma using mobile apps for skin self-monitoring. This qualitative study found that participants were receptive to the potential benefits of using mobile apps for skin self-monitoring. Not all participants engaged on a monthly basis with the use of apps, despite acknowledging their potential benefits. This is related to technical and practical barriers, including infrequent use limiting learning about app use. Additional barriers to adoption were the relationship of the apps to existing skin self-monitoring routines and skin checks provided by HCPs.

We found that perceptions of the quality of the apps were integral to its use and how it was experienced. Technology literacy was highly variable; although almost all participants used their smartphones regularly, they did not necessarily perceive the apps to be easy to use. Although some of these technical barriers could potentially be overcome by better app

design, we must recognize the practical challenges related to the specific task; obtaining a high-quality image of a skin lesion, especially in certain parts of the body, is difficult, more so without assistance.

To our knowledge, this is the first qualitative study reporting the lack of actual use of skin self-monitoring apps in people at increased risk of melanoma. Only a quarter of the participants regularly used the app for the entire duration of the study. This was in an at-risk population who already had an increased personal incentive to use these melanoma skin self-monitoring apps. It is possible that even fewer people would actively engage with mobile app use among people at population-level risk. A recent randomized controlled trial of skin self-monitoring app use among a UK primary care population who were at increased risk of melanoma found no evidence of increased consulting about skin lesions over a 12-month period [21]. This study was unable to collect data on the actual use of the mobile app; however, according to our findings, the lack of effect in that trial may well have been due to limited engagement with the app.

Previous qualitative research has focused on patients' intentions and attitudes toward using skin self-monitoring apps [14,22]. Dieng et al [22] interviewed patients who had a previous diagnosis of melanoma and asked about the possible use of digital technology to assess changes in skin lesions over time. Similar to our findings, participants had positive attitudes toward this type of technology and thought it would prompt them to visit their HCP if a concern was found ahead of their regular appointments. Our study suggests a large gap between intentions and actual engagement with the currently available skin self-monitoring apps.

Our study has highlighted the many technical and practical factors at play when patients experience skin self-monitoring apps. It emphasizes the importance of participants' personal circumstances and their context as to whether they engage with these apps. It is important to understand patients' existing relationships with HCPs and their access to regular clinical skin examinations, their current skin self-monitoring routines, and the role of partners or carers for assistance using the app. Only a minority of people in our study were regular users of these apps after 3 months. We do not know if they continued to use them for longer-term skin self-monitoring, but we suggest that both personal and contextual issues as well as the app-related technical issues are likely to determine this. This is echoed in many studies on health apps more broadly, where uptake is low and dropout is high. This has been observed in mental health apps [23], asthma apps [24], and diabetes apps [25]. Using

depression health apps as an example, the completion of apps within the real-world setting was as low as 1%-28% [23].

### Strengths and Limitations

We conducted qualitative interviews in a relatively large sample, providing a rich, in-depth understanding of the factors influencing app use.

We recruited participants from two different populations: those at increased risk of melanoma in the general practice setting and those who have had a previous diagnosis of melanoma in the hospital setting. Both populations represent potential target users of these apps. We had initially expected app engagement to be higher in those with a previous melanoma but found that this may not hold true.

There were some limitations to this study. Although we recruited a large sample for a qualitative study, we experienced moderate attrition. A third of the participants withdrew or were lost to follow-up before completion, likely representing people who were even less inclined to engage with the apps. Nonetheless, it is clear that the sample we interviewed did not represent a self-selected group that was highly motivated to use these apps.

Considering the use of commercially available apps, we were unable to record the exact amount of time or the frequency of actual interactions with the apps used during the study and relied on self-reporting. We had no control over changes to app functions or updates. Therefore, we deliberately monitored use for a relatively short period of follow-up, which limits our understanding of or additional barriers to long-term adoption.

Finally, the participants themselves did not choose the apps but were only given 2 apps to try on the basis of their phone's operating system. We do not know how the public currently selects skin self-monitoring apps from app stores or how payment for an app might influence whether users persevere with them for longer.

### Conclusions

This qualitative study provides important new findings about engagement with skin self-monitoring apps in people at increased risk of melanoma. The findings can make useful contributions to designing future apps or interventions for promoting skin self-monitoring. If such apps are to play a role in the early detection of melanoma, we must move beyond a focus on app design and diagnostic accuracy. This will require acknowledgment of the complex contextual factors affecting app use and incorporating app-based skin self-monitoring into existing models of care and skin assessments.

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of the authors and not necessarily those of the National Health Service, the National Institute for Health Research, or the Department of Health.

## Conflicts of Interest

None declared.

### Multimedia Appendix 1

Interview guide.

[[DOCX File , 18 KB - derma\\_v4i2e22583\\_app1.docx](#) ]

### Multimedia Appendix 2

Participant quotes table.

[[DOCX File , 16 KB - derma\\_v4i2e22583\\_app2.docx](#) ]

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## Abbreviations

**GP:** general practitioner

**HCP:** health care provider

**REDCap:** Research Electronic Data Capture

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Research Letter

# Surgical Surprise: Cutaneous Metastasis Presenting for Mohs Micrographic Surgery Without a Prior Diagnostic Biopsy

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**KEYWORDS**

cutaneous metastasis; Mohs surgery; biopsy; micrographic surgery; dermatology; dermatologist; skin cancer; melanoma

## Case Report

A 60-year-old Caucasian woman presented for Mohs micrographic surgery (MMS) after being referred for a clinically presumed basal cell carcinoma of the scalp. Three months prior, while living abroad, the patient developed a nodule on the vertex of her scalp. The patient's primary care physician initially

treated the lesion as a cyst with antibiotics. However, after no improvement, she received a second opinion and was told it was a basal cell carcinoma. The patient returned to the United States for treatment and was seen by a plastic surgeon, who subsequently referred her to a Mohs micrographic surgeon.

Upon presentation, the patient had a 1.7-cm violaceous, slightly scaly nodule on the vertex of the scalp ([Figure 1](#)).

**Figure 1.** A 1.7-cm violaceous, slightly scaly nodule at the vertex of the patient's scalp, revealed through preoperative evaluation.

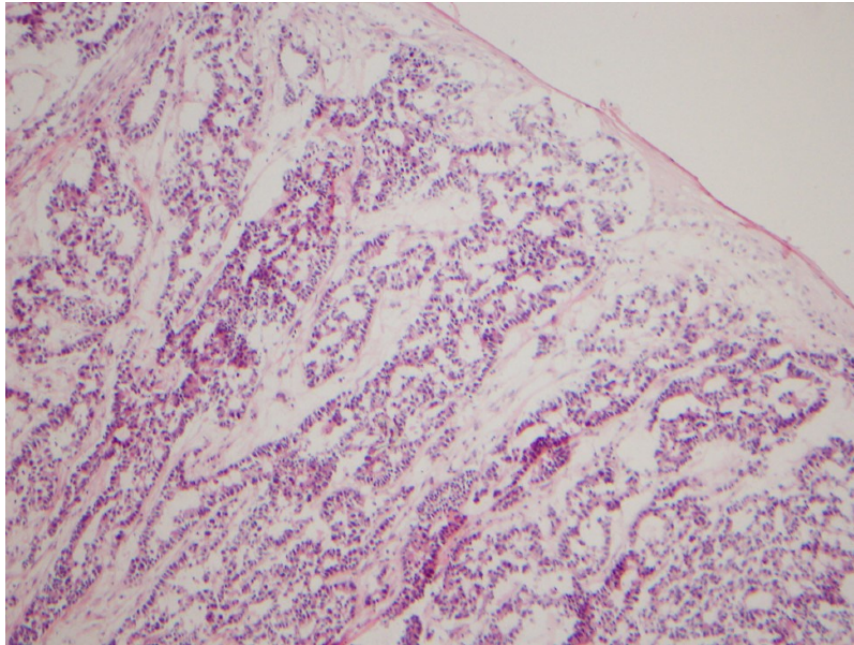


The patient also complained of a tender subcutaneous nodule on her right flank that was noted after a bicycle accident, also approximately 3 months prior. Pertinent history included 10 pack-years of smoking in her 20s. Prior to initiating Mohs surgery, a shave biopsy was performed, revealing a basaloid proliferation with adenomatous differentiation diffusely involving the dermis and subcutis. Given the diagnostic

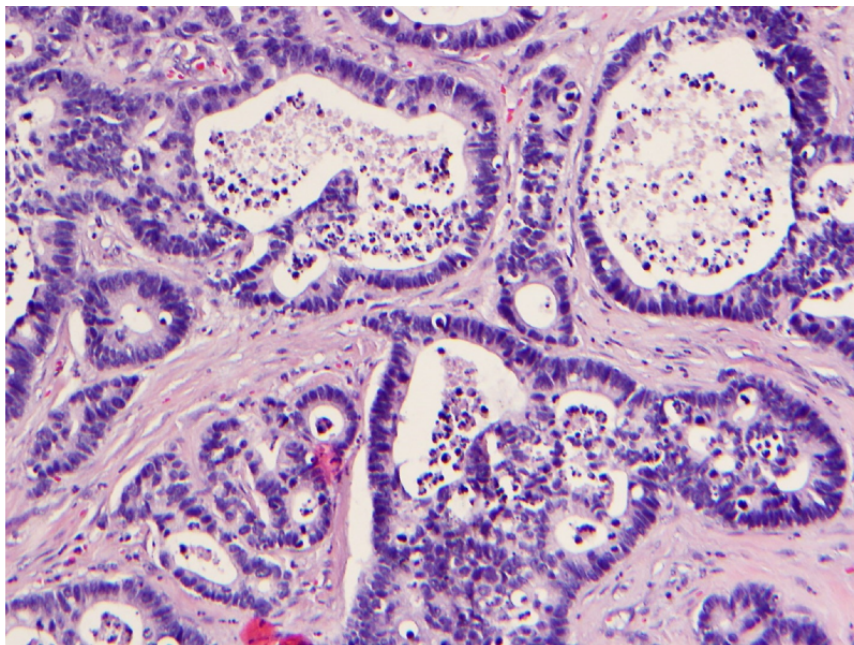
ambiguity regarding this lesion, it was sent for permanent section processing.

Evaluation of the permanent section was consistent with metastatic adenocarcinoma. Immunohistochemical studies were performed and revealed the neoplastic cells to be positive for CK7 (cytokeratin 7) and TTF-1 (thyroid transcription factor-1) consistent with lung origin (Figures 2-5).

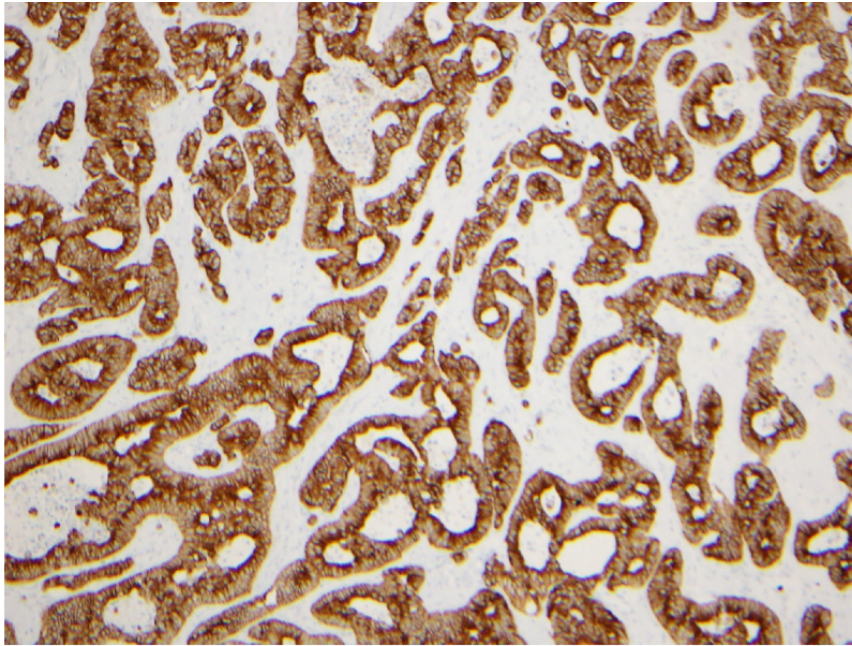
**Figure 2.** Frozen section with basaloid proliferation with adenomatous differentiation.



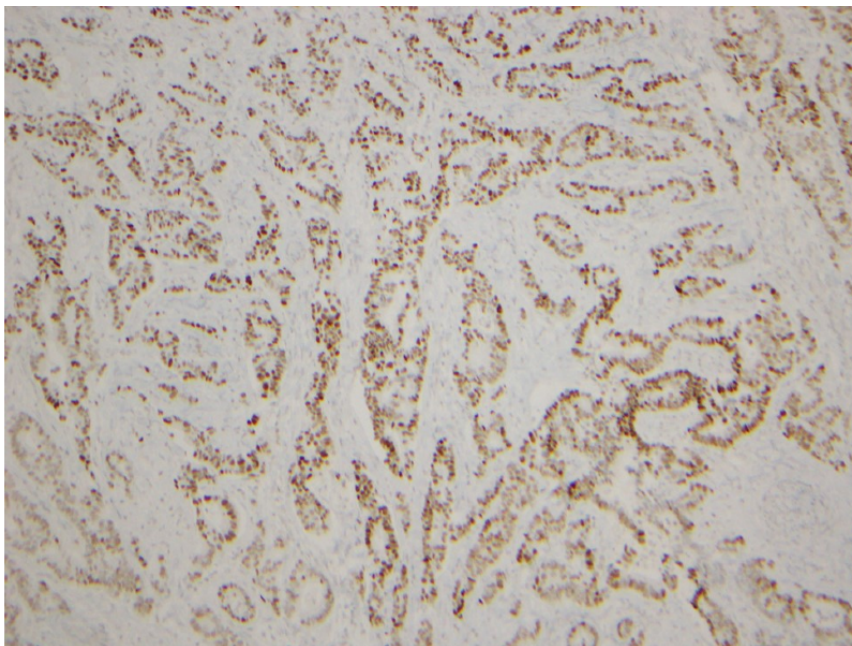
**Figure 3.** Permanent section with proliferation of variably shaped and sized islands with a central lumen lined by crowded, hyperchromatic, and large columnar cells with many atypical mitotic figures.



**Figure 4.** CK7 (cytokeratin 7) positive.



**Figure 5.** TTF-1 (thyroid transcription factor-1) positive.



The patient was referred to oncology and was found to have stage IV adenocarcinoma of the lung with extensive bony metastasis and involvement of the adrenals, pelvis, and parietal lobe. Excision of the abdominal mass by plastic surgery revealed similar histology.

## Discussion

Cutaneous metastases develop in 0.7% to 9% of patients with cancer. In men, the most frequent sources of metastases are the lung (24%), colon (19%), melanoma (13%), and oral cavity (12%). In women, the most frequent sources of metastases are the breast (69%), colon (9%), melanoma (5%), ovaries (4%), and lung (4%) [1]. Cutaneous metastasis is rather uncommon and has been reported to occur in approximately 5% of all cancer

patients [2]. In lung cancer, it is usually a sign of late disease, and concomitant poor prognosis, with a median survival of 3.9 months [3]. In a recent retrospective study of 2130 patients with nonsmall cell carcinoma, only 2.8% had cutaneous metastasis at the time of diagnosis [3]. Our case describes an even rarer occurrence in which cutaneous metastasis manifested as the presenting sign of an underlying malignancy.

Despite the rarity, dermatologists should always consider cutaneous metastasis in their differential for solitary nodules. Our case demonstrates the characteristic lesion of a cutaneous metastasis, which has been described as a flesh-colored or violaceous, nonpainful nodule [2]. The lesion also was located in a high-risk area, the scalp, which makes up 6.9% of cases of cutaneous metastasis [4]. A study of 398 Taiwanese patients

with scalp malignancies reported that other than squamous cell carcinoma and basal cell carcinoma, metastatic cutaneous tumors were most common, making up 12.8% of cases. Lung cancer was the leading primary lesion, causing almost a quarter of the cases [5].

This case also demonstrates the critical importance of performing a biopsy and establishing a firm diagnosis prior to initiating MMS. One recent study reported that in 450 patients presenting for MMS with a clinical diagnosis only, 13 of the diagnoses changed following examination of the Mohs debulk specimen. In these patients, a skin biopsy would have changed the management of 9 patients (1%). In 6 of these cases, MMS would not have been performed due to precancerous or benign histology, and in 3 cases, MMS would have been expedited due

to the histological presentation of squamous cell carcinoma rather than basal cell carcinoma [6].

In summary, it is rare for an underlying malignancy to present as a cutaneous metastasis. Despite this, it is essential for dermatologists to recognize the classic features and have a high index of suspicion. A timely biopsy can significantly expedite definitive diagnosis, which was delayed in our case by 3 months, potentially impacting the long-term prognosis. Confirmation of a clinical diagnosis with a biopsy prior to MMS can avoid unnecessary procedures and may reveal a more serious pathology. In situations of histologic ambiguity on frozen sections, diagnostic certainty is paramount prior to initiating MMS.

## Conflicts of Interest

None declared.

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## Abbreviations

**CK7:** cytokeratin 7

**MMS:** Mohs micrographic surgery

**TIF-1:** thyroid transcription factor-1

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Research Letter

# Global Melanoma Correlations With Obesity, Smoking, and Alcohol Consumption

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melanoma incidence; melanoma mortality; non-UV risk factors; obesity; alcohol consumption; smoking; wine; World Health Organization; WHO; Global Cancer Observatory; GCO; Global Health Observatory; GHO; aldehyde dehydrogenase 2; ALDH2; polymorphism

The incidence of melanoma has continued to rise over the last few decades [1]. Although many explanations have been posited, such as increased screening, detection, and UV exposure [2], it is essential to examine non-UV-related risk factors contributing to its continued rise.

We reviewed published data on obesity, smoking, and alcohol consumption trends worldwide to understand human behaviors and their relationship to melanoma. We collected data for the three risk factors from the Global Health Observatory (GHO), World Health Organization (WHO), published in 2010, as these were the most comprehensive available data with minimal changes in trends noted in the following years. We also collected data for melanoma incidence and mortality from the Global Cancer Observatory (GCO), WHO, published in 2018, as they were the most currently available data. Compiled data were displayed using choropleth maps with color gradients to visualize variations across geographic areas (Figure 1A). Subsequently, each country's data were plotted, and Spearman rank correlation coefficient (R) was calculated for melanoma incidence and mortality with each risk factor. The choropleth map of each risk factor showed similar patterns to melanoma incidence and melanoma mortality. The statistical analysis

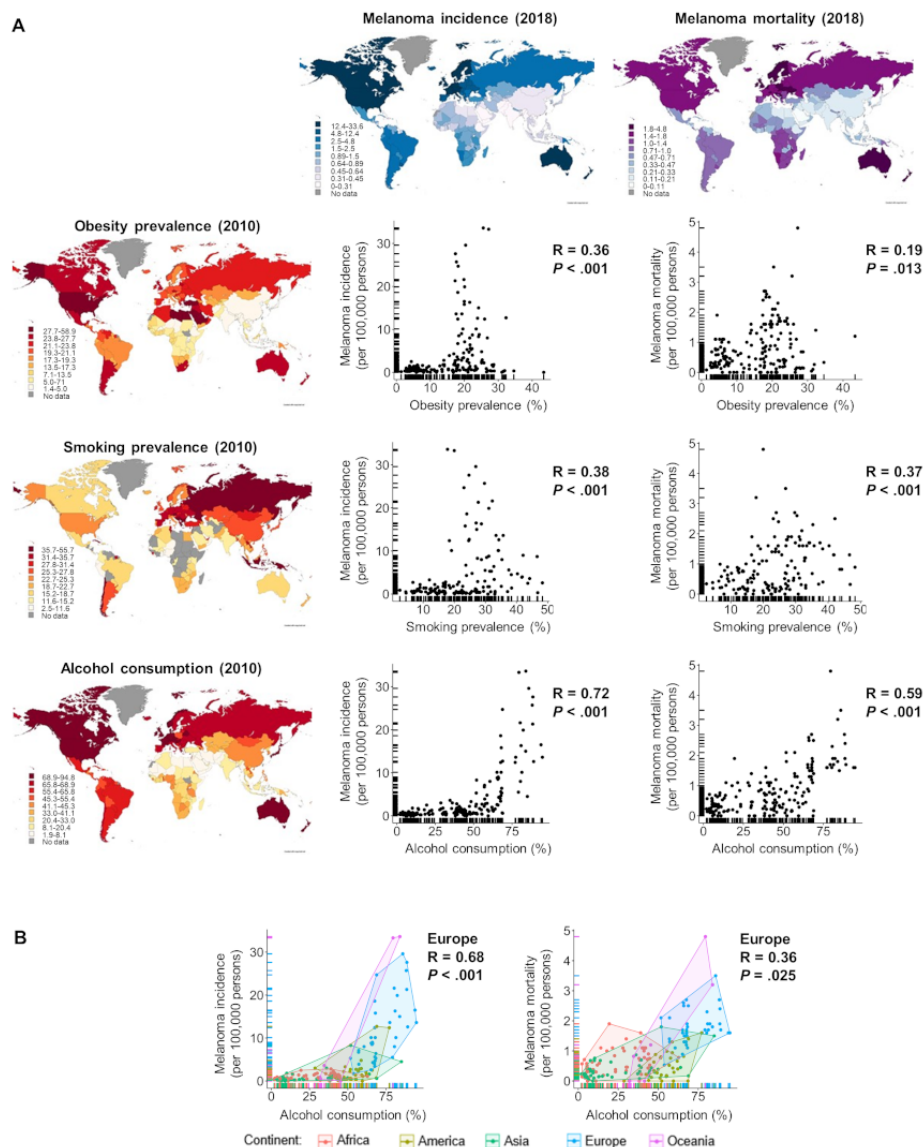
depicted a positive correlation (with a positive R) between melanoma incidence/mortality and all risk factors (obesity, smoking, and alcohol consumption). Among them, alcohol consumption showed the strongest positive correlation with both melanoma incidence ( $R=0.72$ ;  $P<.001$ ) and mortality ( $R=0.59$ ;  $P<.001$ ). Because individuals with lighter skin color (eg, Caucasians) have a higher melanoma incidence, this correlation data might implicate that alcohol consumption is high in countries with lighter skin color, such as European ancestry. To address whether the correlation between alcohol consumption and melanoma incidence is skin color dependent or independent, we reanalyzed the data by continent (Figure 1B). A positive correlation still existed between alcohol consumption and melanoma incidence in Europe, Asia, and Africa (Multimedia Appendix 1, Supplementary Table S1). In particular, the strongest correlation ( $R=0.68$ ;  $P<.001$ ) was observed in European countries with exclusively lighter skin color (1-12 or 12-14 of skin color numbers, per a human skin color distribution map in the second figure by Barsh [3]), suggesting that the correlation between alcohol consumption and melanoma incidence is likely to be skin color independent. A positive correlation was also observed between alcohol consumption and melanoma mortality in all continents.



To understand how genetic risk factors have a role in the observed correlation between alcohol consumption and melanoma incidence/mortality, we examined the correlation of aldehyde dehydrogenase 2 (ALDH2) rs671 polymorphism with both alcohol consumption and melanoma outcomes. ALDH2 is an alcohol-metabolizing enzyme, and its allelic variation affects alcohol detoxification [4]. The correlation analysis showed that it was the wild-type ALDH2 allele that was strongly positively correlated with melanoma incidence ( $R=0.70$ ;  $P<.001$ ) and mortality ( $R=0.74$ ;  $P<.001$ ; Table 1). On the other hand, the allelic variants had a modest to strong negative correlation with melanoma incidence ( $R=-0.70$  to  $-0.51$ ;  $P<.001$ ) and mortality ( $R=-0.73$  to  $-0.57$ ;  $P<.001$ ). Possible explanations for the opposing effect of ALDH2 polymorphism include that individuals with risk alleles consume less alcohol than wild-type individuals, which is consistent with our data showing a positive and a negative correlation to alcohol consumption in wild-type individuals and allelic variants, respectively.

Overall, our findings highlight an association between alcohol and melanoma outcomes globally. The association was observed not only with melanoma incidence but also with its mortality. We also found a potential involvement of the alcohol-related gene ALDH2. Limitations of our analyses include unavailability of the population statistics for some risk factors by some countries, binary questionnaire of alcohol use without reflecting the quantity of alcohol consumption, and country-based analysis rather than individualized data. To determine whether our cross-country data support individual-level conclusions at individual levels, individual-level studies, such as a recent one [5], need to be conducted. Furthermore, our findings do not necessarily indicate causation from alcohol, and other factors might be involved, including skin/hair color, ethnicity, geography, economy, and lifestyle. Further investigation is warranted to verify these associations at individual levels and elucidate alcohol's effects on melanoma outcomes by eliminating potential confounding factors such as skin/hair color genotypes.

**Figure 1.** Global maps and scatter plots of melanoma burden and potential lifestyle factors. A: Correlation of melanoma outcomes and 3 lifestyle factors. Melanoma incidence (2018) is the number of new melanoma cases in 2018, including both sexes and all ages, and expressed as a rate per 100,000 persons per year. Melanoma mortality (2018) is the number of deaths due to melanoma in 2018, including both sexes and all ages, and expressed as a rate per 100,000 persons per year. Obesity prevalence (2010) refers to the percentage of obesity among adults (20+ years, both sexes) with a BMI of 30 kg/m<sup>2</sup> or higher in 2010. Smoking prevalence (2010) refers to the percentage of men and women ages 15 and older who smoked any tobacco product daily or nondaily in 2010. Smokeless tobacco use is excluded and not available from the original data source. Alcohol consumption (2010) refers to the proportion of adults (15+ years, both sexes) who consumed any alcohol in 2010. Sources: Global Cancer Observatory (melanoma incidence and mortality) and Global Health Observatory (obesity prevalence, smoking prevalence, and alcohol consumption) from World Health Organization. The choropleth maps were created with MapChart. Scatter plots of each country's metrics were created to visualize the distributions of lifestyle factors and outcomes. The left panel of scatter plots: correlation of melanoma incidence with obesity prevalence (n=174), smoking prevalence (n=140), and alcohol consumption (n=175). The right panel of scatter plots: correlation of melanoma mortality with obesity prevalence (n=174), smoking prevalence (n=140), and alcohol consumption (n=175). The original data set included the following number of countries: melanoma incidence and mortality (n=185), obesity prevalence (n=174), smoking prevalence (n=140), and alcohol consumption (n=190). B: Correlation of alcohol consumption and melanoma outcome by continent. Figure 1A data were reanalyzed by grouping countries into continents: Africa (n=55), Americas (n=39), Asia (n=48), Europe (n=40), and Oceania (n=17; [Multimedia Appendix 1](#), Supplementary Table S1). Each symbol represents an individual country. Hashes on each axis are included to assist in visualizing the distribution of each variable. Spearman rank coefficient was used to assess correlation due to skewed data and the influence of outliers. P values were reported based on a null hypothesis of no monotonic association against a two-sided alternative at the .05 level. The statistical analysis was conducted using R version 4.0.2.



**Table 1.** Correlations between melanoma outcomes and ALDH2 alleles in 23 countries.<sup>a</sup>

Variable	Correlation with					
	Melanoma incidence	<i>P</i> value	Melanoma mortality	<i>P</i> value	Alcohol consumption	<i>P</i> value
<b>Genetic alleles</b>						
ALDH2 <sup>b</sup> *1/*1	0.70	<.001	0.74	<.001	0.39	.07
ALDH2 *1/*2	-0.70	<.001	-0.73	<.001	-0.38	.07
ALDH2 *2/*2	-0.51	.01	-0.57	.005	-0.25	.26
Alcohol consumption	0.79	<.001	0.71	<.001	N/A <sup>c</sup>	N/A

<sup>a</sup>The source of melanoma incidence (2018), melanoma mortality (2018), and alcohol consumption (2010) is explained in the [Figure 1](#) legend. ALDH2 allele frequency was obtained by searching research papers ([Multimedia Appendix 1](#), Supplementary Table S2). The original data set included the following number of countries: melanoma incidence (n=185), melanoma mortality (n=185), alcohol consumption (n=175), and ALDH2 alleles (n=23). Only 23 countries had all 4 factors available for the correlation analysis. Spearman rank coefficient was used to assess correlation due to skewed data and the influence of outliers. The data represent correlation coefficients (R) with *P* values. Alcohol consumption was reassessed to determine the correlation coefficient with an associated *P* value for the subset of countries that were considered. The statistical analysis was conducted using R version 4.0.2 (R Foundation for Statistical Computing).

<sup>b</sup>ALDH2: aldehyde dehydrogenase 2.

<sup>c</sup>N/A: not applicable.

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## Conflicts of Interest

RPD serves as an Institute for Health Metrics and Evaluation (IHME) Global Burden of Disease collaborator, editor-in-chief of JMIR Dermatology, joint coordinating editor of Cochrane Skin, and a dermatology section editor of UpToDate. Other authors have no conflicts of interest.

Multimedia Appendix 1

Supplemental tables.

[[PPTX File](#), 48 KB - [derma\\_v4i2e31275\\_app1.pptx](#) ]

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## Abbreviations

**ALDH2:** aldehyde dehydrogenase 2

**WHO:** World Health Organization

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Research Letter

# Teledermatology Consults in a County Hospital Setting: Retrospective Analysis

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dermatology; teledermatology; telemedicine; referrals; primary care; keratosis; digital health; skin cancer; dermatitis

Teledermatology is increasingly used by primary care providers (PCPs) for diagnosis and triage of skin conditions [1,2]. Many dermatology practices have increased telemedicine services in light of the COVID-19 pandemic [2]. Current teledermatology guidelines provide standards for effective teledermatology practice but do not detail recommendations for management of specific conditions [2]. By understanding the distribution of cases sent to teledermatology, and which are seen in-person, guidelines can be properly structured to optimize teledermatology use.

Prior studies have found that 20% to 50% of teledermatology cases required an in-person visit after teledermatology evaluation [3-5]. However, there is limited information on the distribution of cases sent for teledermatology consultation. In our study, teledermatology consults from PCPs at a county hospital were analyzed to identify common diagnoses that prompted the use of the teledermatology system and which diagnoses required an in-person visit. PCPs were encouraged to send any dermatologic cases to teledermatology, even if they felt comfortable managing it independently.

We conducted a retrospective analysis of 450 store-and-forward consults from PCPs to teledermatologists via Medweb from 2017 to 2019 at San Mateo County Medical Center in California. Diagnoses were made by the teledermatologist based on the teledermatology consult. Our analysis captured 471 diagnoses encompassing a wide range of dermatologic conditions (Table 1). The most frequent diagnoses were seborrheic keratosis, eczema, and acne. Overall, 39.9% of diagnoses seen via teledermatology were referred for an in-person visit, the most common of which were nonmelanoma skin cancer, actinic keratosis, and alopecia areata. Others such as atopic dermatitis and lentigo were never referred for an in-person visit. When grouped into categories based on similar types of dermatologic diseases (Figure 1), the most frequent group was banal and precancerous neoplasms. The groups with the highest proportion of referrals for in-person visits were malignant neoplasms and hair disorders. The papulosquamous disorders and acneiform disorders groups were referred for an in-person visit less frequently. We found that 6.2% of consults could not be diagnosed via teledermatology due to insufficient photo quality or patient history.

**Table 1.** Top 25 diagnoses sent to teledermatology listed in order of frequency and the proportion requiring referral to an in-person visit.

Diagnosis	Cases, n	Referred, n (%)	Not referred, n
Seborrheic keratosis	48	4 (8)	44
Eczema NOS <sup>a</sup>	30	1 (3)	29
Acne	27	6 (22)	21
Rule out NMSC <sup>b,c</sup>	28	28 (100)	0
Seborrheic dermatitis	20	2 (10)	18
Actinic keratosis	17	17 (100)	0
Poor photo quality	12	8 (67)	4
Vitiligo	12	4 (33)	8
Banal neoplasm NOS	12	9 (75)	3
Insufficient data	11	7 (64)	4
Wart	11	10 (91)	1
Nevus	10	6 (60)	4
Contact dermatitis	9	3 (33)	6
Alopecia areata	8	8 (100)	0
Rosacea	8	2 (25)	6
Papulosquamous disorder NOS	8	2 (25)	6
Cyst	8	3 (38)	5
Keloid	6	5 (83)	1
Dermatologist unable to make diagnosis	6	4 (67)	2
Onychodystrophy NOS	6	2 (33)	4
Atopic dermatitis	6	0 (0)	6
Lentigo	6	0 (0)	6
Idiopathic guttate hypomelanosis	5	2 (40)	3
Urticaria	5	1 (20)	4
Angioma	5	3 (60)	2

<sup>a</sup>NOS: not otherwise specified.

<sup>b</sup>NMSC: nonmelanoma skin cancer.

<sup>c</sup>NMSC includes basal cell carcinoma, squamous cell carcinoma, and dermatofibroma sarcoma protuberans.

**Figure 1.** Diagnoses referred to teledermatology grouped into categories based on similarity. TBSE was due to: patient high risk, patient history of melanoma/NMSC, and patient request. NMSC: nonmelanoma skin cancer; NOS: not otherwise specified; NR: not referred; R: referral; TBSE: total body skin exam.

Banal/Precancerous Neoplasms				Inflammatory Dermatoses				Papulosquamous Disorders				Infections				Other			
Diagnosis	n	R	NR	Diagnosis	n	R	NR	Diagnosis	n	R	NR	Diagnosis	n	R	NR	Diagnosis	n	R	NR
Seborrheic keratosis	48	4	44	Urticaria	5	1	4	Eczema NOS	29	1	28	Wart	11	10	1	Poor photo quality	12	8	4
Actinic keratosis	17	17	0	Granuloma annulare	2	1	1	Seborrheic dermatitis	20	2	18	Herpetic infection	6	0	6	Insufficient data	11	7	4
Banal neoplasm	12	9	3	Hypersensitivity reaction	2	1	1	Contact dermatitis	9	3	6	Folliculitis	4	0	4	Keloid	6	5	1
Nevus	10	6	4	Morphea	2	2	0	Papulosquamous disorder NOS	8	2	6	Candida	4	0	4	Dermatologist unable to make diagnosis	6	4	2
Cyst	8	3	5	Viral exanthem	2	0	2	Atopic dermatitis	6	0	6	Scabies	4	0	4	Keratosis pilaris	3	0	3
Lentigo	6	0	6	Bites	2	0	2	Lichen amyloidosis	3	0	3	Intertrigo	3	0	3	TBSE	3	3	0
Angioma	5	3	2	Bullous pemphigoid	2	1	1	Lichen simplex chronicus	3	0	3	Molluscum	3	2	1	Actinic purpura	2	0	2
Dermatofibroma	4	1	3	Erythema annulare centrifugum	1	1	0	Lichen Planus	2	2	0	Infection NOS	2	2	0	Keratoderma	2	1	1
Lichen planus-like keratosis	2	1	1	Hidradenitis suppurativa	1	0	1	Pityriasis rosea	2	0	2	Erythrasma	2	0	2	Acanthosis nigricans	1	0	1
Benign nevus	1	0	1	Inflammatory disorder NOS	1	1	0	Dyshidrotic eczema	2	1	1	Cellulitis	1	0	1	Atrophic blanche	1	1	0
Cherry angioma	1	0	1	Leukocytoclastic vasculitis	1	0	1	Hand eczema	2	0	2	Erysipelas	1	0	1	Burn	1	0	1
Congenital nevus	1	1	0	Lipodermatosclerosis	1	1	0	Dermatitis NOS	2	1	1	Erosio interdigitalis blastomycetica	1	0	1	Callus	1	0	1
Digital mucous cyst	1	0	1	Scleroderma	1	0	1	Macular amyloidosis	1	0	1	Tinea	1	0	1	Chilblains	1	1	0
Dysplastic nevus	1	0	1	Vasculitis	1	1	0	Prurigo nodularis	1	0	1	Total	43	14	29	Ecchymosis	1	1	0
Fibroma	1	1	0	Discoid lupus erythematosus	1	1	0	Nummular eczema	1	0	1	<b>Nail Disorders</b>				Hypertrichosis	1	0	1
Halo nevus	1	0	1	Dissecting cellulitis of scalp	1	1	0	Pityriasis lichenoides chronica	1	1	0	Diagnosis	n	R	NR	Pachyonychia congenita	1	0	1
Neurofibroma	1	0	1	Drug rash	1	1	0	Total	92	13	79	Onychodystrophy NOS	6	2	4	Photodermatitis	1	0	1
Nevus comedonicus	1	0	1	Dermatitis herpetiformis	1	1	0	<b>Malignant Neoplasms</b>				Onychomycosis	2	0	2	Pigmented purpura	1	0	1
Nevus sebaceous	1	1	0	Pemphigus vulgaris	1	1	0	Diagnosis	n	R	NR	Ingrown nail	1	1	0	Redness of hands	1	0	1
Pyogenic granuloma	1	1	0	Zoon's balanitis	1	1	0	Rule out NMSC	28	28	0	Nail psoriasis	1	1	0	Striae distensae	1	0	1
Sebaceous hyperplasia	1	0	1	Total	30	16	14	Rule out melanoma	4	4	0	Paronychia	1	0	1	Terra firma	1	1	0
Venous lake	1	1	0	<b>Pigmentary Disorders</b>				NMSC	1	1	0	Total	11	4	7	Ulcer	1	1	0
Total	125	49	76	Diagnosis	n	R	NR	Atypical nevus	1	1	0	<b>Hair Disorders</b>				Xanthelasma	1	1	0
<b>Acneiform Disorders</b>				Vitiligo	12	4	8	Total	34	34	0	Diagnosis	n	R	NR	Total	60	33	27
Diagnosis	n	R	NR	Idiopathic guttate hypomelanosis	5	2	3					Alopecia areata	8	8	0				
Acne	27	6	21	Melasma	4	0	4					Alopecia NOS	3	2	1				
Rosacea	8	2	6	Postinflammatory hyperpigmentation	1	0	1					Frontal fibrosing alopecia	1	1	0				
Perioral dermatitis	2	0	2	Total	22	6	16					Telogen effluvium	1	0	1				
Acne excoriee	1	0	1									Total	13	11	2				
Total	38	8	30																

Our study demonstrates that teledermatology is frequently used to manage benign skin conditions while serving as a triage tool for more concerning lesions that should be evaluated in person. The diagnoses most commonly referred for an in-person visit were ones with concern for precancer or malignancy, or that required procedural management, such as alopecia areata, verruca, and keloids. Furthermore, hair disorders and scalp lesions can be difficult to capture via photo and frequently necessitated an in-person visit. Benign conditions without concern for malignancy were able to be managed completely via teledermatology.

The results of this study can provide support for guidelines delineating which dermatologic conditions are appropriate to be managed via teledermatology and which require in-person management. There are several limitations of this study: it did not specifically quantify the severity of disease, it did not follow long-term outcomes of cases managed via teledermatology, and it focused on patients only in a county hospital setting. Future work should focus on addressing these limitations with studies in other patient populations to provide more robust support for teledermatology guidelines.

**Conflicts of Interest**

TM is a technical advisor teledermatology platform Medweb. All other authors have no conflicts to declare.

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## Abbreviations

**PCP:** primary care provider

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Original Paper

# Global Burden of Skin Disease Representation in the Literature: Bibliometric Analysis

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## Abstract

**Background:** The global burden of skin disease may be reduced through research efforts focused on skin diseases with the highest reported disability-adjusted life years.

**Objective:** This study evaluates the representation of dermatologic conditions comprising the highest disability-adjusted life years in dermatology literature to identify areas that could benefit from greater research focus.

**Methods:** The top 10 skin disorders according to their respective disability-adjusted life years as per the 2013 Global Burden of Disease were identified using previous studies. The top 5 dermatology journals ranked by the 2019 h-index were also identified. A PubMed search of each journal was performed using individual skin disease terms. From 2015 to 2020, all indexed publications pertaining to each disease were recorded and compared to the total number of publications for each journal surveyed.

**Results:** A total of 19,727 papers were published in the 5 journals over the span of 2015-2020. Although melanoma ranked as the eighth highest in disability-adjusted life years, it had the highest representation in the literature (1995/19,727, 10.11%). Melanoma was followed in representation by psoriasis (1936/19,727, 9.81%) and dermatitis (1927/19,727, 9.77%). These 3 conditions comprised a total of 29.69% (5858/19,727) of the total publications, while the remaining 7 skin conditions were represented by a combined 6.79% (1341/19,727) of the total publications.

**Conclusions:** This research identifies gaps in the literature related to the top skin diseases contributing to the global burden of disease. Our study provides insight into future opportunities of focused research on less-studied skin diseases to potentially aid in reducing the global burden of skin disease.

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**KEYWORDS**

global burden of disease; global health; global dermatology; disability-adjusted life years; GBD; DALYs; journalology; dermatology; skin disorders

## Introduction

The 2013 Global Burden of Disease (GBD) Morbidity and Mortality report identified skin diseases as the fourth leading cause of global disability-adjusted life years (DALYs) [1]. One DALY is the sum of years of life lost to a disease plus years lived with disability, with 1 DALY equating to 1 year of healthy life lost [1]. Research pertaining to skin disorders with higher reported DALYs has potential to reduce the global burden of skin disease through improvements in management guidelines, public health initiatives, policy changes, and increased awareness within the scientific and greater community [2]. This study evaluates the representation of dermatologic conditions comprising the highest DALYs in dermatology literature to identify areas that could benefit from increased research focus.

## Methods

A comprehensive search was performed using PubMed to identify peer-reviewed papers. A previous GBD study has identified and ranked individual skin disorders according to their respective DALYs [1]. This GBD study was used to select our specific search terms such as dermatitis, acne vulgaris, psoriasis, urticaria, viral skin diseases, fungal skin diseases, scabies, melanoma, pyoderma, and cellulitis. The h-index is a noted metric used to measure individual author and journal research influence and impact [3]. The top 5 dermatology

journals ranked by the 2019 h-index were identified using the Scimago Journal and Country Rank [4]. PubMed searching was performed by pairing individual skin disease terms with each journal title (eg, “dermatitis” AND “Journal of the American Academy of Dermatology”). From 2015 to 2020, all indexed publications pertaining to each disease were recorded and compared to the total number of publications for each journal surveyed. All article types were included to obtain a complete picture of relevant skin disease research. Duplicate papers were excluded.

## Results

Over the span of 2015-2020, 19,727 publications were recorded from the previously mentioned journals. Melanoma (eighth in DALYs) had the highest representation in the literature at 10.11% (1995/19,727) of the total publications, followed by psoriasis (1936/19,727, 9.81%) and dermatitis (1927/19,727, 9.77%) (Table 1). Melanoma, psoriasis, and dermatitis comprised a total of 29.69% (5858/19,727) of all the publications from 2015 to 2020. The remaining 7 skin diseases comprised only 6.79% (1341/19,727) of the total publications. Acne vulgaris, the second highest contributor to skin GBD, followed dermatitis with a much lower representation in the literature (477/19,727, 2.42%). Scabies accumulated the lowest percentage of the total publications (54/19,727, 0.27%). The proportions of publications by year for each disease are shown in Figure 1.

**Table 1.** Top 10 skin conditions contributing to the global burden of disease [1] and their representation in the dermatology literature.<sup>a</sup>

Skin disease search term	Global burden of skin disease rank	Rank by percentage of total publications	Percentage of global burden of disease (measured in disability-adjusted life years) <sup>b</sup>	Proportion of global burden of skin disease measured in disability-adjusted life years, fraction (%) <sup>c</sup>	Publications in 2015-2020 (N=19,727), n (%)	Percentage of total publications/Percentage of global burden of skin disease
Dermatitis	1	3	0.38	0.38/1.70 (22.35)	1927 (9.77)	0.44
Acne	2	4	0.29	0.29/1.70 (17.06)	477 (2.42)	0.14
Psoriasis	3	2	0.19	0.19/1.70 (11.18)	1936 (9.81)	0.88
Urticaria <sup>d</sup>	3	7	0.19	0.19/1.70 (11.18)	139 (0.70)	0.06
Viral skin disease	5	5	0.16	0.16/1.70 (9.41)	283 (1.38)	0.15
Fungal skin disease	6	6	0.15	0.15/1.70 (8.82)	193 (0.98)	0.11
Scabies	7	10	0.07	0.07/1.70 (4.12)	54 (0.27)	0.07
Melanoma	8	1	0.06	0.06/1.70 (3.53)	1995 (10.11)	2.86
Pyoderma	9	8	0.05	0.05/1.70 (2.94)	124 (0.63)	0.21
Cellulitis	10	9	0.04	0.04/1.70 (2.35)	81 (0.41)	0.17
All other skin and subcutaneous diseases	N/A <sup>e</sup>	N/A	0.12	0.12/1.70 (7.00)	N/A	N/A

<sup>a</sup>The following journals ranked by the 2019 h-index were searched: rank 1, Journal of the American Academy of Dermatology; rank 2, Journal of Investigative Dermatology; rank 3, British Journal of Dermatology; rank 4, Journal of the American Medical Association Dermatology; and rank 5, Dermatologic Surgery.

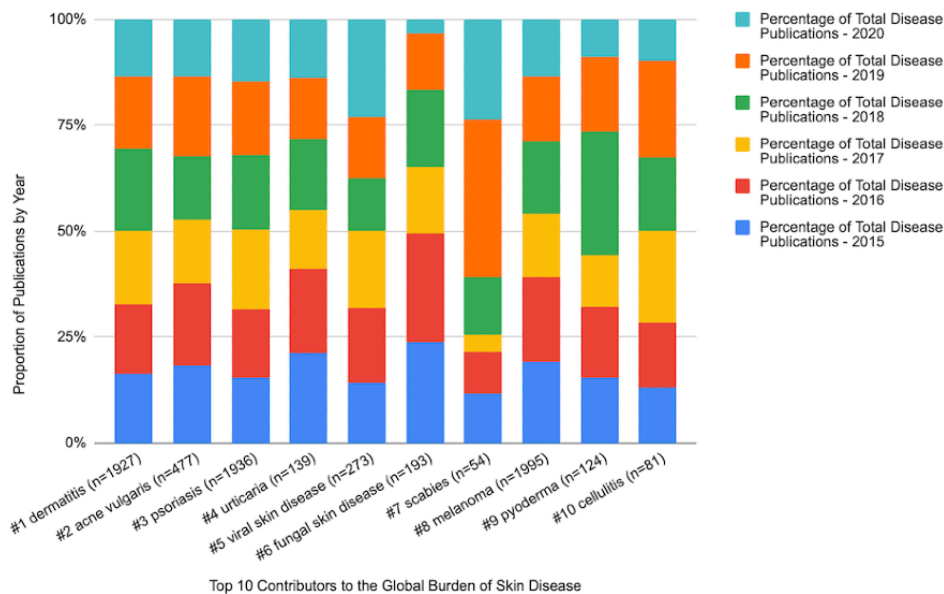
<sup>b</sup>The percentage values in this column have been directly taken from the global burden of disease paper [1]. Total skin-related percentage of global burden of disease=1.70%.

<sup>c</sup>This column shows the fractions of the total skin-related global burden of disease over the total percentage of global burden of disease (1.70%) calculated for the 10 skin diseases.

<sup>d</sup>Urticaria has the same ranking as psoriasis in the calculation of the global burden of skin disease rankings [1].

<sup>e</sup>N/A: not applicable.

**Figure 1.** Proportion of publications by year for each global burden of skin disease condition.



## Discussion

The disproportionate representation of melanoma in the literature compared to overall GBD is likely explained by the increased mortality risk of melanoma relative to other skin diseases [5,6]. Additionally, a large portion of the examined publications originated from North American- and European-based journals, which are regions with high melanoma incidence reported globally [5]. Notably, these regions have minimal incidence of scabies [1], which had the lowest representation in the literature. However, literature representation is likely multifactorial, with epidemiologic factors and research funding contributing to literature representation [7].

Although this study utilizes 2013 GBD data to guide our literature search, it does not implicate the literature gaps identified in this study. Our study was limited by the use of 1 specific search term pertaining to the individual skin diseases. We recognize that performing our search across 5 journals with a single term per skin disease could have led to possible omissions. Although a variety of terms could be searched for some skin diseases within our study, such as fungal skin diseases, we elected to use a single term for consistency across all the skin diseases studied and recognize that certain publications discussing multiple skin diseases may have been listed under more than one search term. Lastly, we acknowledge

that many of the mentioned skin diseases may be represented outside of dermatology-specific journals, which our study did not examine. Nonetheless, we offer a valuable initial survey of these skin diseases in highly read and influential dermatology literature and hope that our study will prompt future necessary work to identify potential avenues for refinement of current research efforts.

Indeed, a primary purpose of the GBD collaboration is to aid clinical researchers in determining priority of research at local, national, and global levels [1]. Herein, our study provides insight into possible future investigative pathways for dermatologic research. For example, urticaria accounts for 11.18% (0.19/1.70) of skin-related DALYs (equal to psoriasis), yet these rank sixth and second in the percentage of the total publications, respectively [8]. Thus, researchers have opportunities to further elucidate causal mechanisms and the clinical impact of less-studied dermatologic conditions as a means to guide clinical decision-making, public health initiatives, policy changes, and education for dermatologists.

Dermatologic disease is a significant source of global DALYs. Although there has been significant research focus on dermatologic malignancies, dermatitis, and psoriasis in the last 5 years, this study highlights significant gaps and opportunities that remain in skin disease literature.

## Authors' Contributions

KJP contributed to the project conceptualization, methodology, data collection, writing of manuscript, review, and editing. MDS contributed to the methodology, statistical analysis, review, and editing. CWR contributed to the writing of manuscript, review, and editing. CLP contributed to project conceptualization, writing of manuscript, review, and editing. MRL contributed to the methodology, statistical analysis, review, and editing. RPD contributed to the review and editing, project supervision, and project administration.

## Conflicts of Interest

RPD is the Editor-in-Chief of JMIR Dermatology, a Joint Coordinating Editor for Cochrane Skin, a Dermatology Section Editor for UpToDate, a Social Media Editor for the Journal of the American Academy of Dermatology, and a Podcast Editor for the Journal of Investigative Dermatology. He is a coordinating editor representative on Cochrane Council.

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## Abbreviations

**DALY:** disability-adjusted life year

**GBD:** Global Burden of Disease

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Corrigenda and Addenda

# Correction: The Use of Person-Centered Language in Medical Research Journals Focusing on Psoriasis: Cross-sectional Analysis

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(*JMIR Dermatol* 2021;4(2):e31902) doi:[10.2196/31902](https://doi.org/10.2196/31902)

In “The Use of Person-Centered Language in Medical Research Journals Focusing on Psoriasis: Cross-sectional Analysis” (*JMIR Dermatol* 2021;4(1):e28415) two errors were noted.

In the originally published manuscript, incorrect ORCID numbers were listed for authors Benjamin Heigle and Matt Vassar. The ORCID numbers have been corrected as follows:

Benjamin Heigle: 0000-0003-3724-0756

Matt Vassar: 0000-0003-2859-6152

The correction will appear in the online version of the paper on the JMIR Publications website on July 16, 2021, together with the publication of this correction notice. Because this was made after submission to PubMed, PubMed Central, and other full-text repositories, the corrected article has also been resubmitted to those repositories.

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Original Paper

# Publication Trends and Their Relationship With Academic Success Among Dermatology Residents: Cross-sectional Analysis

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## Abstract

**Background:** Involvement in scholarly activities is considered to be one of the foundational pillars of medical education.

**Objective:** This study aims to investigate publication rates before, during, and after residency to determine whether research productivity throughout medical training correlates with future academic success and research involvement.

**Methods:** We successfully identified a list of 296 graduates from 25 US dermatology residency programs from the years 2013-2015. The publication history for each graduate was compiled using Scopus, PubMed, and Google Scholar. The Pearson correlation test and linear regression were used to assess the relationship between research productivity and continued academic success after residency graduation.

**Results:** Before residency, graduates published a mean of 1.9 (SD 3.5) total publications and a mean of 0.88 (SD 1.5) first-author publications. During residency, graduates published a mean of 2.7 (SD 3.6) total publications and a mean of 1.39 (SD 2.0) first-author publications. Graduates who pursued a fellowship had more total publications ( $t_{294}=-4.0$ ;  $P<.001$ ), more first-author publications ( $t_{294}=-3.9$ ;  $P<.001$ ), and a higher h-index ( $t_{294}=-3.8$ ;  $P=.002$ ). Graduates who chose to pursue careers in academic medicine had more mean total publications ( $t_{294}=-7.5$ ;  $P<.001$ ), more first-author publications ( $t_{294}=-5.9$ ;  $P<.001$ ), and a higher mean h-index ( $t_{294}=-6.9$ ;  $P<.001$ ). Graduates with one or more first-author publications before residency were 1.3 times more likely to pursue a career in academic medicine (adjusted odds ratio 1.3, 95% CI 1.1-1.5). Graduates who pursued a fellowship were also 1.9 times more likely to pursue a career in academic medicine (adjusted odds ratio 1.9, 95% CI 1.2-3.2).

**Conclusions:** Our results suggest that research productivity before and during residency training are potential markers for continued academic success and research involvement after completing dermatology residency training.

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**KEYWORDS**

publication trends; dermatology residency; academic medicine

## Introduction

**Background**

Successful matching into selective residency programs, such as dermatology, is multifactorial in nature and requires thoughtful planning by medical students to ensure that they have a competitive, well-rounded application. Previous studies suggest that higher medical licensing exam scores (eg, United States Medical Licensing Exam [USMLE] step 1 and step 2

clinical knowledge scores), honor society memberships, and medical school rankings are associated with an increased likelihood of successfully matching into a residency program [1,2]. Beyond these objective measures, an applicant's research experiences—in the form of abstracts, presentations, and peer-reviewed publications—are an important component in the residency application process [3]. A 2011 survey of medical school graduates who successfully matched into a dermatology residency program found that >85% of graduates listed publications on their Electronic Residency Application Service

application. In this cohort of graduates, the average number of publications before matching was >5 total publications per graduate. As the importance placed on early research exposure has increased, more medical students may elect to participate in research during medical school to enhance their residency application, given that research is a core requirement placed on residency programs and program coordinators to maintain the program's accreditation status [4].

Since its conception in 1994, the Accreditation Council for Graduate Medical Education (ACGME) [5] has required research participation by residency programs and their residents during training. These requirements mandate that residency programs educate residents on the “basic principles of scientific inquiry, including how research is designed, conducted, evaluated, explained to patients, and applied to patient care” [6] and that residents must then engage in scholarly activities as part of their training. Despite mandating these scholarly requirements for accreditation, previous studies have shown that residency programs often fall short of meeting such requirements [7]. Although efforts have been made to determine the level of research participation by residents in other medical specialties [8-10], little is known regarding the extent to which dermatology residents participate in scholarly activities.

Here, we sought to identify whether a correlation exists between research productivity of dermatology residency graduates with continued academic successes and research involvement (eg, careers in academic medicine vs private practice) or whether those with higher research output elected to pursue a fellowship upon completion of residency training. Thus, we explore current research practices and publication trends of dermatology residency graduates to determine whether research efforts made during medical training are associated with future academic achievements (in the form of peer-reviewed publications). Furthermore, we assess whether higher research output during residency correlated with the pursuit of fellowship training or a career in academic medicine.

## Objectives

Our primary objectives are to (1) quantify the number of peer-reviewed publications per resident during the periods before, during, and after residency training and (2) determine whether increased research productivity and academic success (eg, number of peer-reviewed publications and individual h-index scores) are associated with future academic production (eg, careers in academic medicine vs private practice).

## Methods

### Residency Program Selection

We used the Doximity Residency Navigator to generate our sample of dermatology residency programs. The Doximity residency ranking is based on subjective reviews of programs that combine objective data, such as alumni research output and board examination pass rate, with subjective data, including current and graduate resident satisfaction scores and *reputation data*, which is collected from past and present residents on an annual basis [11].

To identify top US dermatology residency programs and graduates, we used a search strategy similar to that performed by Yang et al [8]. This process entailed one of the authors (JMA) searching the 2019-2020 Doximity Residency Navigator using the *Dermatology* specialty search tool. Next, the programs were sorted as A-Z and exported to a Microsoft Excel document. Finally, we assigned a random number to each residency program using Microsoft Excel's random number generator.

After randomization, we selected the first 50 residency programs to be included in our sample. Next, we searched for the names of residency graduates (graduating in the years 2013, 2014, and 2015) on each program's institutional website. If this search was unsuccessful, we searched for the name and email address of each residency coordinator using the advanced program search on the ACGME website [12]. We attempted to retrieve a list of residency graduates from each program coordinator. This email correspondence, which has been used in previous studies [13,14], was included to increase the cogency of our methodology. Furthermore, we used the same standardized email process, which entailed repeating the attempted email correspondence one time per week for 3 consecutive weeks, as used in a systematic review by Song et al [15]. Finally, we allotted program coordinators 8 weeks from the date of the initial email to respond before deeming that program *noncontactable*. If no response was received or if the email was returned as *inactive*, the program was excluded, and a subsequent program was randomly selected from the original list of residency programs, and the above process was repeated until a 50% inclusion rate was met.

### Training

To ensure consistency among investigators, 3 of the authors (DW, LE, and JW) completed in-person training before data extraction. During this training session, the following items were addressed and discussed at length: (1) description of study design and objectives, (2) a thorough review of the study protocol, (3) step-by-step instructions on how to use the standardized Google form for extraction, and (4) discussion of specific data points to be extracted. The Google form was pilot-tested by each investigator during training with the help of 3 residency graduates and their publication history as examples. After pilot testing, data were extracted for the next 10 graduates in our sample. Responses were subsequently discussed, and any discrepancies among investigators were resolved before proceeding to the remaining list of graduates.

### Screening and Data Extraction

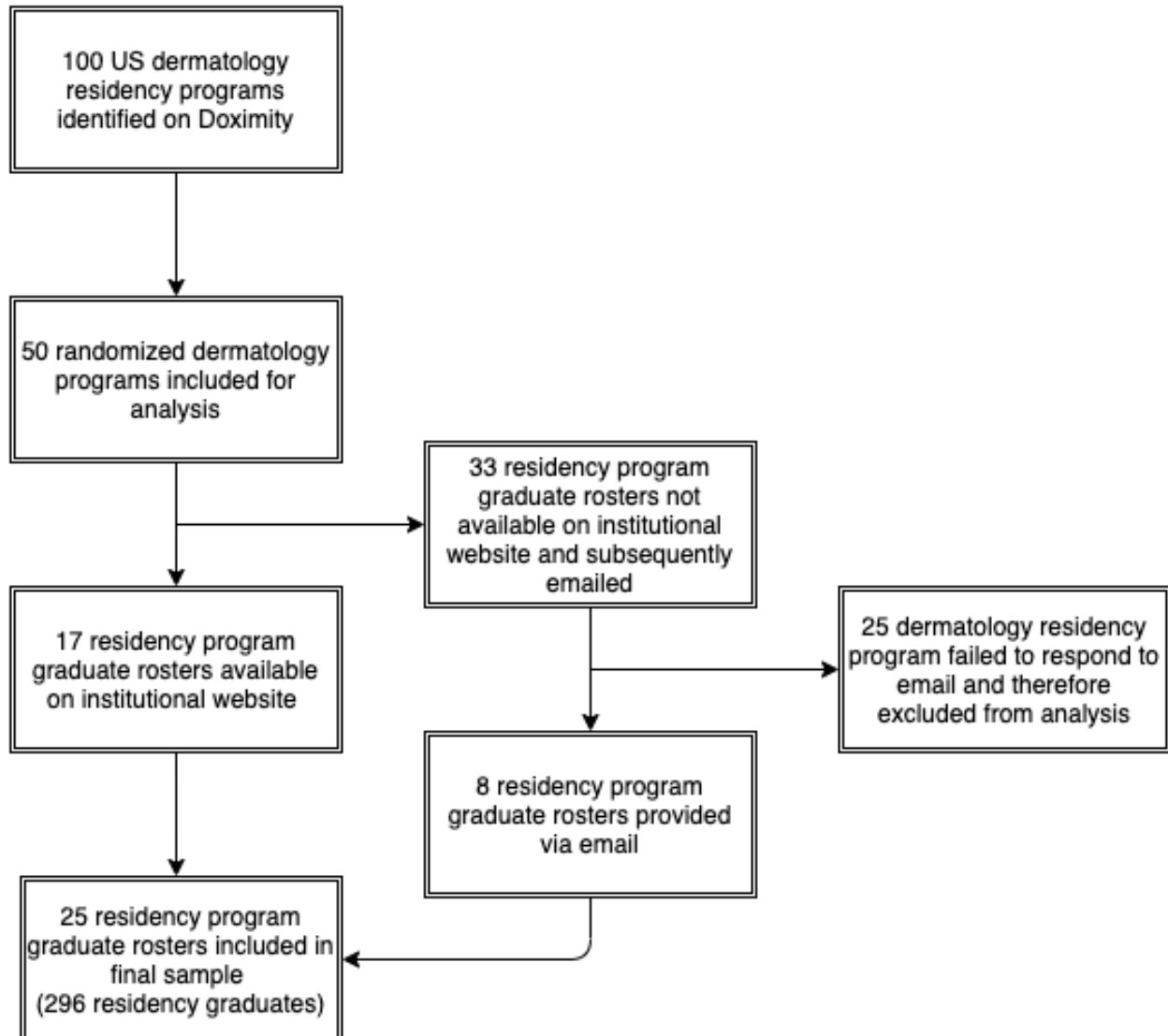
After training, 3 of the authors (DW, LE, and JW) extracted data in triplicate, independent, and blinded fashion. Extraction began on October 5, 2019, and concluded on September 10, 2020. To obtain a comprehensive publication history, we searched for each graduate on Scopus using the following demographic information: (1) full name, (2) institution, (3) residency program, (4) fellowship program, and (5) area of interest (dermatology). The list of publications returned for each graduate using this information was subsequently compared with the list of publications generated by searching for authors (using the same demographic information as above) on PubMed and Google Scholar searches. Results from the three individual



searches were compared to ensure an accurate record of total publications per resident. More specifically, a publication was included only if it was included in the search return for all three databases. After we compiled a list of publications for each

graduate, we extracted the following information from each publication: (1) type of publication, (2) year of publication, and (3) graduate affiliation at the time of publication. In addition, the author h-index was recorded (Figure 1).

**Figure 1.** Stepwise approach used to identify peer-reviewed publications for dermatology residency graduates.



## Data Analysis

Data were separated into the following three cohorts of time: before residency (including undergraduate and medical school education), during residency (4 years in duration in the United States), and after residency (including fellowship training, if applicable). The decision was made to include a 6-month overlap period to capture publications that were likely initiated and completed during the previous period. For example, publications that were published in the first 6 months of residency were classified as *before residency* as these studies were likely started during the *before residency* time frame, given the length of time required to conduct a research project, complete the peer review process, and see a research question through to publication. The results were presented as frequencies and percentages. We used a Pearson product coefficient to examine the relationships among each publication time frame (before, during, and after

residency). An independent sample two-tailed *t* test was used to compare the mean number of publications for graduates who elected to enter academic medicine with those who entered private practice after completing their residency training. We also used an independent sample two-tailed *t* test to compare the mean number of publications between those who pursued fellowship training with those who did not. Binary logistic regression was used to analyze the relationship between career type (academic or private practice) and total author publications and fellowships, controlling for gender. Analyses were performed using STATA 15.1 (StataCorp, LLC).

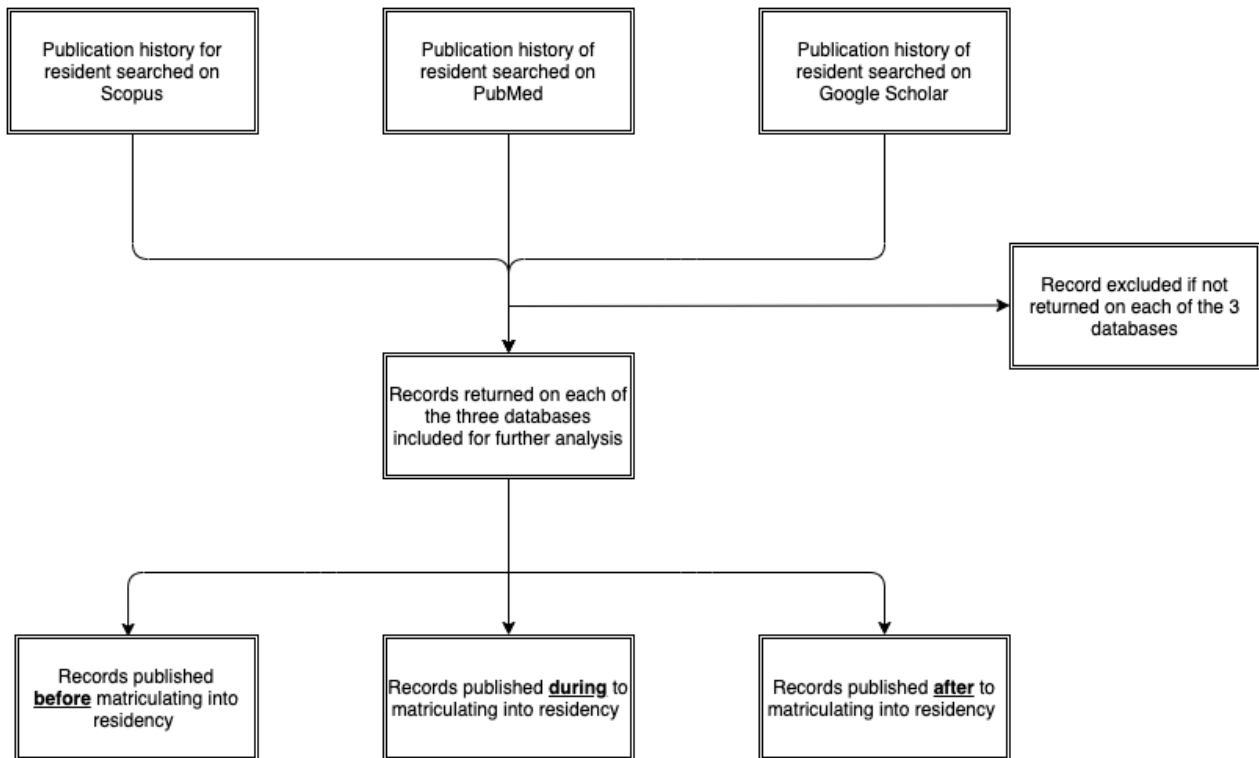
## Results

### Overview

A total of 100 US dermatology programs were found on the Doximity website. Of the 50 randomly sampled programs, we were able to locate a list of graduates for 17 (34%) programs using institutional websites. For the remaining 66% (33/50)

programs, we attempted to obtain this list via email from each program coordinator. An additional 24% (8/33) programs provided a complete list of residency graduates via email correspondence. The remaining 76% (25/33) programs did not respond by the end of the 8-week time frame. Of the 50 sampled programs, 25 (50%) dermatology residency programs were included in total (Figure 2).

**Figure 2.** Program and resident inclusion flowchart.



### Subject and Publication Characteristics

A total of 296 graduates were included in our final sample. Most graduates were female (222/296, 75%). Approximately 35.5% (105/296) graduates pursued a fellowship, with the most common being Mohs surgery (27/105, 25.7%), pediatric dermatology (20/105, 19%), dermatopathology (16/105, 15.2%),

and procedural dermatology (15/105, 14.3%). Approximately 25% (74/296) of graduates entered academic medicine. Of the 105 graduates who pursued fellowship training, 45 (42.9%) also went on to pursue a career in academic medicine. The average h-index among all residency graduates was 3.6 (range 0-24; Table 1).

**Table 1.** Resident graduate sample characteristics (N=296).

Characteristics	Value, n (% , 95% CI)
<b>Sex</b>	
Female	222 (75, 70.1 to 79.9)
Male	74 (25, 20.1 to 29.9)
<b>Medical degree obtained</b>	
MD <sup>a</sup>	295 (99.7, 99 to 100.3)
DO <sup>b</sup>	1 (0.3, -0.3 to 0.9)
<b>Current setting of practice</b>	
Private	222 (75, 70.1 to 79.9)
Academic	74 (25, 20.1 to 29.9)
<b>Pursued fellowship</b>	
No	191 (64.5, 59.1 to 70)
Yes	105 (35.5, 30 to 40.9)
<b>Fellowships (n=105)</b>	
Mohs surgery	27 (25.7, 17.4 to 34.1)
Pediatric dermatology	20 (19, 11.5 to 26.6)
Dermatopathology	16 (15.2, 8.4 to 22.1)
Procedural dermatology	15 (14.3, 7.6 to 21)
Clinical research	9 (8.6, 3.2 to 13.9)
Cutaneous oncology or melanoma	7 (6.7, 1.9 to 11.4)
Laser and aesthetic surgery	4 (3.8, 0.1 to 7.5)
Cosmetic dermatology	3 (2.9, -0.3 to 6)
Rheumatology	3 (2.9, -0.3 to 6)
Biotechnology	1 (0.9, -0.9 to 2.8)
<b>h-index</b>	
0	50 (16.9, 12.6 to 21.2)
1-5	183 (61.8, 56.3 to 67.4)
6-10	44 (14.9, 10.8 to 18.9)
11-15	13 (4.4, 2.1 to 6.7)
>15	6 (2, 0.4 to 3.6)
<b>Number of publications per resident</b>	
0	39 (13.2, 9.3 to 17)
1-5	129 (43.6, 37.9 to 49.2)
6-10	53 (17.9, 13.5 to 22.3)
11-15	27 (9.1, 5.8 to 12.4)
16-20	15 (5.1, 2.6 to 7.6)
21-25	12 (4.1, 1.8 to 6.3)
26-30	8 (2.7, 0.8 to 4.6)
>30	13 (4.4, 2.1 to 6.7)

<sup>a</sup>MD: doctor of medicine.

<sup>b</sup>DO: doctor of osteopathic medicine.

## Publications

Before residency, graduates had a mean of 1.9 (SD 3.5) total publications and a mean of 0.88 (SD 1.5) first-author publications. During residency, graduates had a mean of 2.7 (SD 3.6) total publications and a mean of 1.39 (SD 2.0) first-author publications (Table 2). Residents who graduated in 2013 produced a total of 889 (9.6 publications per person) publications, 2014 graduates produced 803 (7.44 per person) publications, and 2015 graduates produced 753 (7.93 per person) publications. A moderate positive correlation existed between the number of publications obtained before and during residency ( $r=0.35$ ) and the number of publications obtained during

residency and after residency training ( $r=0.37$ ). A weak correlation was present between publications before residency and total publications after residency ( $r=0.19$ ).

Graduates who pursued a fellowship had more total publications ( $t_{294}=-4.0$ ;  $P<.001$ ), first-author publications ( $t_{294}=-3.9$ ;  $P<.001$ ), and higher h-index ( $t_{294}=-3.8$ ;  $P=.002$ ) than graduates who did not pursue fellowship training. In a similar manner, we found that graduates who chose to go into academic medicine had a higher number of mean total publications ( $t_{294}=-7.5$ ;  $P<.001$ ), first-author publications ( $t_{294}=-5.9$ ;  $P<.001$ ), and mean h-index ( $t_{294}=-6.9$ ;  $P<.001$ ) than those going into private practice (Table 3).

**Table 2.** Mean and median publications per resident before, during, and after completion of residency training.

Author position	Value, mean (SD)	Value, median (IQR)	Total publications among all residents, n (%)
<b>Any author position</b>	8.3 (1.6)	5 (1-11)	2445 (100)
Before	1.9 (0.40)	1 (0-2)	577 (23.59)
During	2.7 (0.54)	2 (0-4)	800 (32.72)
After	3.6 (1.02)	1 (0-4)	1068 (43.68)
<b>First-author position</b>	3.14 (0.52)	0 (0-5)	965 (100)
Before	0.9 (0.18)	0.9 (0-1)	261 (27.05)
During	1.4 (0.29)	1 (0-2)	411 (42.59)
After	1 (0.25)	0 (0-1)	293 (30.36)

**Table 3.** Association between research productivity and pursuit of fellowship training, career in academic medicine, and gender (N=296).

	Total publications			Total first-author publications			h-index		
	Value, mean (SD)	t test (df)	P value	Value, mean (SD)	t test (df)	P value	Value, mean (SD)	t test (df)	P value
<b>All residency graduates</b>									
Overall	8.3 (1.2)	N/A <sup>a</sup>	N/A	1.2 (0.23)	N/A	N/A	3.7 (0.45)	N/A	N/A
<b>Fellowship</b>									
Yes	11.5 (2.3)	-4.0 (104)	<.001 <sup>b</sup>	4.4 (0.35)	-3.9 (104)	<.001 <sup>b</sup>	4.8 (0.79)	-3.8 (104)	.002 <sup>b</sup>
No	6.5 (1.3)	-4.0 (190)	<.001 <sup>b</sup>	2.6 (0.29)	-3.9 (190)	<.001 <sup>b</sup>	3 (0.53)	-3.8 (190)	.002 <sup>b</sup>
<b>Career path</b>									
Academic medicine	14.2 (1.7)	-7.5 (197)	<.001 <sup>b</sup>	5 (0.48)	-5.9 (197)	<.001 <sup>b</sup>	5.8 (0.99)	-6.9 (197)	<.001 <sup>b</sup>
Private practice	5.3 (0.9)	-7.5 (97)	<.001 <sup>b</sup>	2.4 (0.24)	-5.9 (97)	<.001 <sup>b</sup>	2.6 (0.40)	-6.9 (97)	<.001 <sup>b</sup>
<b>Gender</b>									
Male	10 (2.7)	-1.7 (73)	.09	3.9 (0.61)	-1.7 (73)	.09	3.9 (0.98)	-0.78 (73)	.44
Female	7.7 (1.3)	-1.7 (221)	.09	3 (0.23)	-1.7 (221)	.09	3.5 (0.51)	-0.78 (221)	.44

<sup>a</sup>N/A: not applicable.

<sup>b</sup>Statistical significance was set at  $P<.005$ .

Our logistic regression model examined the relationship between first-author publications before residency and pursuit of fellowship training, as well as whether the graduate went into academic medicine. Graduates with one or more first-author publications were 1.3 times more likely to pursue a career in academic medicine than those with no first-author publications

before residency (adjusted odds ratio 1.3, 95% CI 1.1-1.5). Graduates who pursued a fellowship were also 1.9 times more likely to enter into a career in academic medicine than those who did not pursue a fellowship (adjusted odds ratio 1.9, 95% CI 1.2-3.2).

## Discussion

### Principal Findings

Our results indicate that the total number of publications, first-author publications, and author h-index scores are highly associated with the pursuit of fellowship training, as well as entering into academic medicine following completion of dermatology residency training. Of the graduates included in our sample, over one-third elected to pursue a career in academic medicine, and one-third pursued fellowship training upon graduation. Residency graduates with at least one first-author publication before starting residency were more likely to pursue a career in academic medicine and continue their postgraduate education through fellowship subspecialty training. This emphasis on research appears to carry over into residency training, as we observed that the highest mean research output among the included dermatology graduates occurred during their years of residency training. Here, we discuss the implications that our findings may have on the dermatology match process for prospective applicants, as well as discuss how research throughout medical training may help open doors to future career opportunities and specialized fellowship training.

Our results demonstrate that dermatology residents published, on average, 2.7 (SD 0.54) articles during residency, with an average of 1.3 (SD 0.29) first-author publications. The research productivity among residents included in our sample is similar to that of residents in other fields [8,9,16]. These results are likely attributable to a recent push by the ACGME and individual residency locations to increase resident exposure to research activities [17,18]. Research involvement during residency promotes a well-rounded educational experience during residency—with a particular focus on evidence-based medicine—thereby strengthening resident confidence in research design and methodology, and it has been shown to be associated with higher clinical competency scores [19]. Stevenson et al [20] concluded that residency programs offering protected research time, established research curricula, and providing a specialized research track had increased residency scholarly activity, including the total number of publications. Perhaps integrating research into a program's curriculum will not only ensure that the program is compliant with ACGME standards but also provide an opportunity for residents to establish a track record of scholarly successes. This increased research output during residency makes graduates more competitive for fellowship training positions, increases the likelihood of practicing in academia, and supports mentorship and networking opportunities [21].

Research productivity in the form of total publications, first-author publications, and higher author h-index scores was associated with the pursuit of fellowship training and academic medicine positions after completion of residency training. A recent study in the field of surgical oncology indicates that, along with research, factors such as attending a university-based residency, attending a residency associated with fellowship programs, and attending an allopathic medical school have an effect on matching into a fellowship [22]. Our results suggest that research during residency is associated with an increased

likelihood of pursuing fellowship training in dermatology after completion of residency training. Although a higher total number of publications was observed among residents who pursued fellowship positions, previous research showing more career publications among residents who pursued additional training is conflicting. For example, Yang et al [8] found a strong association between the number of publications of urology residents during and after residency training. In contrast, Prasad et al [23] found that the number of total publications is a poor predictor of future publication among internal medicine residency graduates who pursue fellowship training. These contrasting findings may be the result of varying expectations of scholarly involvement among medical specialties. Despite the disconnect between early scholarly activity and continued research production among specialties, program directors (PDs) may still place emphasis on scholarly involvement when evaluating residency applicants.

Although PDs have many responsibilities, some of the key responsibilities include developing, overseeing, and improving their residency program's education [24], as well as making crucial decisions in selecting residents who are most likely to be successful in their respective fields. In fields such as dermatology, where applicants outnumber available residency positions [25], PDs have historically relied on several metrics to stratify applicants. A major metric heavily considered by dermatology PDs for interview selection is the USMLE step 1 score [26]. Recently, the USMLE step 1 scoring reporting system changed from a 3-digit official score to a pass or fail system [27]. This modification of the step 1 scoring indicates that PDs will rely on other objective measures to stratify qualified applicants for interviews in the future. A potential stratification measure is research productivity in medical schools. For example, a recent survey of PDs suggests an increasing emphasis on research production as a potential stratification model for applicant selection [28]. Although previous studies have shown that other measures, including letters of recommendation, performance on audition clerkship rotations, and scholarships in medical school, are associated with success in residency training [29], the skills involved in research production are an underpinning of traits associated with good clinical practice. For example, participation in research has been shown to increase ethical awareness [30], teamwork and communication skills [31], and the ability to critically evaluate and synthesize new evidence [32], all of which are essential to becoming a competent physician.

In the 2018 match, dermatology yielded one of the lowest match percentages, with only 81.6% of applicants successfully matching, second only to interventional radiology [25]. Osteopathic and international medical graduates have historically low rates of matching competitive specialties, such as dermatology [33,34]. A common strategy taken by medical students, especially osteopathic and international medical graduates medical students who have lower match rates in dermatology programs compared with their allopathic counterparts, is to complete an extra research year between graduating medical school and applying for residency positions to increase their competitiveness. As higher research productivity during preclinical training years has been shown

to increase the chances of successfully matching into a dermatology program [35], research remains one of the modifiable factors for prospective residency applicants. Of note, it is important for PDs to take into account potential limitations to research resources available to each applicant depending on their background or school attended. As an alternative to considering peer-reviewed publications as the sole measure of research success, we contend that PDs should also place emphasis on applicants' enthusiasm and desire to participate in research. For instance, applicants may seek out opportunities that may have not resulted in a peer-reviewed publication but still provided the opportunity to develop a research question, conceptualize and implement a study protocol, and demonstrate the ability to think critically while attempting to answer critical research questions.

Our study has both strengths and limitations. In regard to the limitations, a metric used for comparing research production was the author h-index. Although the h-index is considered a robust metric, it does not account for authorship order, which may limit our ability to determine the extent of an author's involvement in the associated research projects [36]. In addition, the cross-sectional nature of our study prevents the generalization of our results to other periods or fields of

medicine. Finally, although extensive efforts were made to ensure the inclusion of all authors and their associated publications, we cannot ensure that some authors were missed and therefore, not included in our final statistical analysis. Similarly, our sample included one-quarter of dermatology residency programs listed on the Doximity website. The selection of a different time frame or medical specialty may yield varying results. In regard to strengths, data extraction was conducted in a duplicate and masked fashion, which is considered the gold standard by the Cochrane collaboration [37]. The second strength is the transparent and reproducible nature of our study. For ensuring transparency, our protocol was published in the Open Science Framework before commencing the study.

### Conclusions

Our results highlight research productivity before and during residency training as a potential marker for continued academic success in the field of dermatology. In addition, early scholarly involvement may be associated with successful matching into competitive subspecialty fellowships within the field of dermatology, as well as the pursuit of careers in academic medicine.

### Authors' Contributions

Conception or design of the work, data analysis and interpretation, drafting of the manuscript, critical revision of the manuscript, and final approval of the manuscript were carried out by JMA. Data collection, data analysis and interpretation, drafting of the manuscript, critical revision of the manuscript, and final approval of the manuscript were carried out by DW. Drafting of the manuscript, critical revision of the manuscript, and final approval of the manuscript were carried out by CW. Conception or design of the work, data analysis and interpretation, critical revision of the manuscript, and final approval of the manuscript were carried out by ALJ. Drafting of the manuscript, critical revision of the manuscript, and final approval of the manuscript were carried out by MTA. Data collection, critical revision of the manuscript, and final approval of the manuscript were carried out by JW and LE. Conception or design of the work, critical revision of the manuscript, and final approval of the manuscript were carried out by MV.

### Conflicts of Interest

MV reports grant funding from the National Institutes of Health, the US Office of Research Integrity, and the Oklahoma Center for the Advancement of Science and Technology, all outside the present work. All other authors have nothing to report.

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## Abbreviations

**ACGME:** Accreditation Council for Graduate Medical Education

**PD:** program director

**USMLE:** United States Medical Licensing Exam

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Original Paper

# Skin of Color Representation on Wikipedia: Cross-sectional Analysis

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## Abstract

**Background:** Wikipedia is one of the most popular websites and may be a go-to source of health and dermatology education for the general population. Prior research indicates poor skin of color (SOC) photo representation in printed dermatology textbooks and online medical websites, but there has been no such assessment performed to determine whether this discrepancy also exists for Wikipedia.

**Objective:** The aim of this study was to investigate the number and quality of SOC photos included in Wikipedia's skin disease pages and to explore the possible ramifications of these findings.

**Methods:** Photos of skin diseases from Wikipedia's "List of Skin Conditions" were assigned by three independent raters as SOC or non-SOC according to the Fitzpatrick system, and were given a quality rating (1-3) based on sharpness, size/resolution, and lighting/exposure.

**Results:** We identified 421 skin disease Wikipedia pages and 949 images that met our inclusion criteria. Within these pages, 20.7% of images of skin diseases (196 of 949 images) were SOC and 79.3% (753 of 949 images) were non-SOC ( $P < .001$ ). There was no difference in the average quality for SOC (2.05) and non-SOC (2.03) images ( $P = .81$ ). However, the photo quality criteria utilized (sharpness, size/resolution, and lighting/exposure) did not capture all aspects of photo quality. Another limitation of this analysis is that the Fitzpatrick skin typing system is prone to subjectivity and was not originally intended to be utilized as a non-self SOC metric.

**Conclusions:** There is SOC underrepresentation in the gross number of SOC images for dermatologic conditions on Wikipedia. Wikipedia pages should be updated to include more SOC photos to mend this divide to ameliorate access to accurate dermatology information for the general public and improve health equity within dermatology.

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**KEYWORDS**

skin of color; Wikipedia; dermatology; skin photographs; skin color; dermatology; eHealth; representation; SOC; skin conditions; photos; images; medical images

## Introduction

Wikipedia provides a broad range of information for the general public as the 8th most visited website in the United States and the 13th most visited website in the world [1]. Wikipedia may also be a go-to source of health education for the general

population, including for information about dermatologic conditions. For example, the Wikipedia pages for psoriasis and leprosy have over 1 million views each, and one project to improve dermatologic Wikipedia pages found that 40 of these pages had over 10 million views combined [2]. Most of the pages dedicated to skin diseases have accompanying pictures

to highlight these common skin pathologies, and the Cochrane Skin Wikipedia Initiative, supported by a board-certified dermatologist, has recently updated 80 dermatologic Wikipedia pages with information and photographs from Cochrane reviews [3]. However, many of the skin disease Wikipedia pages often do not offer adequate photo representation of skin of color (SOC) individuals. As more research on dermatologic conditions for SOC individuals emerges, it is clear that certain conditions such as melanoma, plaque-type psoriasis, and acne can present visually differently in people with darker skin compared to people with lighter skin [4]. These variable presentations can also alter treatment; for example, acne treatment may be based on expected hyperpigmentation levels [4].

Given these visual variations in skin disease presentations based on an individual's skin color, adequate SOC photo representation on Wikipedia is important for the information to be applicable to and usable by people of all skin colors. Ensuring accurate skin disease photo representation contributes to health equity by allowing individuals of all skin colors to access relevant information. Therefore, the aim of this study was to investigate the number and quality of SOC photos included in Wikipedia's skin disease pages and explore the possible ramifications of these findings.

## Methods

Skin diseases from Wikipedia's "List of Skin Conditions" page (that either specified dermatology as a specialty in the article or were discussed in a separate dermatology textbook) were included in this study [5]. We followed the categorization system from Wikipedia's "List of Skin Conditions" for the major categories listed in Table 1 and Table 2 [6]. Each category of skin condition contained multiple individual skin pages. For

example, under the category acneiform eruptions, there were pages on neonatal acne and acne vulgaris, among others. Each page had varying amounts of information on the skin pathology, with some more extensive pages including signs and symptoms, causes, pathophysiology, diagnoses, management, prognosis, and epidemiology, in addition to photographs displaying the associated skin findings. In our review, we categorized these photographs into Fitzpatrick skin types, with Fitzpatrick scores of 1-3 deemed as non-SOC and Fitzpatrick skin types 4-6 deemed as SOC [7,8].

Three raters independently counted the images on each skin page, assigned the Fitzpatrick type, and scored the photo quality [7,8]. The raters were third-year medical students at the University of Colorado School of Medicine who were interested in dermatology, with all raters having a bachelor's degree and one having a master's degree. The photos were rated on a scale of 1-3, with 1 being poor quality, 2 being average quality, and 3 being excellent quality. Each photo was assessed for sharpness, size/resolution, and lighting/exposure. A photo received a score of 1 if it failed all three of these criteria, 2 if it had 2/3 criteria, and 3 if it met all three criteria. Any discrepancies in photo quality among the raters were discussed until a consensus was reached.

Our photo quality criteria were chosen as dermatology is an exceedingly visual specialty that requires clear images to accurately identify and interpret skin pathology. Black and white images, paintings and drawings, or images with ambiguous Fitzpatrick type were excluded, as were images unrelated to the skin disease. Some images appeared in more than one article, and these were counted more than once, as they were important in the context of each individual article. The quality and quantity of images were then compared between the SOC and non-SOC groups using the Student *t* test.

**Table 1.** Percentage of skin of color (SOC) to non-SOC photos on the Wikipedia list of skin conditions.

Skin condition	Non-SOC photos, n (%)	SOC photos, n (%)	Total number of photos
Acneiform eruptions	13 (81)	3 (19)	16
Autoinflammatory syndromes	3 (60)	2 (40)	5
Chronic blistering	11 (92)	1 (8)	12
Conditions of the mucous membranes	30 (91)	3 (9)	33
Conditions of the skin appendages	43 (78)	12 (22)	55
Conditions of the subcutaneous fat	8 (89)	1 (11)	9
Congenital anomalies	9 (82)	2 (9)	11
Connective tissue diseases	48 (92)	4 (8)	52
Dermal and subdermal growths	45 (66)	23 (34)	68
Dermatitis	32 (84)	6 (16)	38
Disturbances of pigmentation	12 (71)	5 (29)	17
Drug eruptions	11 (79)	3 (21)	14
Endocrine-related	7 (50)	7 (50)	14
Eosinophilic	2 (100)	0 (0)	2
Epidermal nevi, neoplasms, and cysts	45 (88)	6 (12)	51
Erythemas	11 (92)	1 (8)	12
Genodermatoses	31 (74)	11 (26)	42
Infection-related	146 (67)	71 (33)	217
Lichenoid eruptions	2 (40)	3 (60)	5
Lymphoid-related	11 (92)	1 (8)	12
Melanocytic nevi and neoplasms	36 (92)	3 (8)	39
Monocyte- and macrophage-related	3 (75)	1 (25)	4
Mucinoses	3 (75)	1 (25)	4
Neurocutaneous	11 (79)	3 (21)	14
Noninfectious immunodeficiency-related	2 (100)	0 (0)	2
Nutrition-related	0 (0)	4 (100)	4
Papulosquamous hyperkeratotic	12 (100)	0 (0)	12
Pregnancy-related	6 (86)	1 (14)	7
Pruritic	8 (67)	4 (33)	12
Psoriasis	15 (100)	0 (0)	15
Reactive neutrophilic	8 (100)	0 (0)	8
Recalcitrant palmoplantar eruptions	2 (100)	0 (0)	2
Resulting from errors in metabolism	10 (100)	0 (0)	10
Resulting from physical factors	65 (88)	9 (12)	74
Urticaria and angioedema	7 (100)	0 (0)	7
Vascular-related	45 (90)	5 (10)	50

**Table 2.** Average quality rating of skin of color (SOC) and non-SOC photos.

Categories	Average quality of non-SOC photos	Average quality of SOC photos
Acneiform eruptions	1.69	2.33
Autoinflammatory syndromes	1.67	2.5
Chronic blistering	2.27	2.0
Conditions of the mucous membranes	2.07	1.67
Conditions of the skin appendages	1.74	1.75
Conditions of the subcutaneous fat	2.0	2.0
Congenital anomalies	2.33	2.0
Connective tissue diseases	1.92	1.75
Dermal and subdermal growths	2.24	2.65
Dermatitis	1.78	1.5
Disturbances of pigmentation	1.5	2.6
Drug eruptions	2.36	2.67
Endocrine-related	2.43	2.67
Eosinophilic	1.5	N/A <sup>a</sup>
Epidermal nevi, neoplasms, and cysts	2.31	2.17
Erythemas	2.36	2.0
Genodermatoses	1.77	2.09
Infection-related	2.08	1.89
Lichenoid eruptions	1.5	1.33
Lymphoid-related	1.55	3.0
Melanocytic nevi and neoplasms	1.64	2.0
Monocyte- and macrophage-related	2.0	2.0
Mucinoses	1.67	2.0
Neurocutaneous	1.64	2.0
Noninfectious immunodeficiency-related	1.5	N/A
Nutrition-related	N/A	1.75
Papulosquamous hyperkeratotic	1.75	N/A
Pregnancy-related	2.0	1.0
Pruritic	1.38	3.0
Psoriasis	2.27	N/A
Reactive neutrophilic	2.25	N/A
Recalcitrant palmoplantar eruptions	2.0	N/A
Resulting from errors in metabolism	2.5	N/A
Resulting from physical factors	2.29	2.0
Urticaria and angioedema	2.43	N/A
Vascular-related	2.18	2.0

<sup>a</sup>N/A: not applicable.

## Results

We identified 421 skin disease Wikipedia pages and 949 images that met our inclusion criteria. Within these pages, 20.7% of images of skin diseases (196 of 949 images;  $s=1.52$  cm) were

SOC (Table 1) and 79.3% (753 of 949 images;  $s=2.02$  cm) were non-SOC, representing a significant difference ( $P<.001$ ); the  $s$  values are the standard deviations of the  $t$  tests. Lichenoid eruptions had the highest percentage of SOC photos (60%) with 3 out of 5 images being SOC images. Categories with no SOC representation included eosinophilic, noninfectious

immunodeficiency-related, papulosquamous hyperkeratotic, psoriasis, reactive neutrophilic, recalcitrant palmoplantar eruptions, resulting from errors of metabolism, and urticaria and angioedema. The average quality for SOC images was 2.05 ( $s=0.79$  cm) compared to 2.03 ( $s=0.75$  cm) in non-SOC images ( $P=.81$ ) (Table 2).

## Discussion

### Principal Findings

This study found significantly fewer SOC images compared to non-SOC images in the dermatology-related Wikipedia skin pages. There was no significant difference in photo quality between SOC and non-SOC photos.

### Limitations

This study highlights the discrepancies in the total number of SOC photos represented on Wikipedia's list of skin conditions. However, our findings did not show a significant difference in the quality of SOC vs non-SOC photos. This may have been influenced by the small range of the rating scale (1-3) or the photo quality criteria utilized (sharpness, size/resolution, and lighting/exposure). If the rating scale was more granular, it may have allowed for more nuanced differences in photo quality to emerge between the SOC and non-SOC mean photo qualities. Additionally, other aspects of photo quality, including noise amount, noise pattern, and compression quality, may have led to differences in photo quality between SOC and non-SOC photographs. The study was also limited by the nature of the Fitzpatrick skin typing system, which was not originally intended to be utilized as a non-self SOC metric [9]. Therefore, some SOC individuals fell into our grouping of non-SOC (Fitzpatrick skin types 1-3), which may have influenced our results.

### Recommendations

Regardless of the quality of the photographs, there is underrepresentation in the total number of images for SOC dermatologic conditions on Wikipedia. Previous research has shown SOC photo underrepresentation in a wide range of resources, including printed dermatology textbooks [7], online websites such as VisualDx and Dermnet [7], and USMLE preparatory materials [8]. Alvarado et al [7] assessed the percentages of dark-skin (Fitzpatrick types 5 and 6) images across a variety of dermatologic resources [7]. DermNet NZ had 2.8% dark skin images, whereas VisualDx had 28.5% dark skin images [7]. In comparison, our study found 20.7% SOC images on Wikipedia (Fitzpatrick types 4-6).

Compared to websites such as VisualDx (ranked in position 113,182) and Dermnet (ranked in position 26,412), Wikipedia (ranked in position 8) has substantially more US internet traffic and engagement as evidenced by the listed rankings on the Alexa website [1]. Although VisualDx and Dermnet are well-known sources of dermatology information for the medical community, they may not be as well utilized by the general public. Wikipedia is arguably one of the main sources of dermatology information for the general public, and the discrepancies in SOC representation have a larger influence on the public's perception of dermatologic disease and care compared to other dermatology resources previously reported in the literature. Possible ramifications of this discrepancy include decreased access to accurate information for SOC patients, skewed societal perceptions of how dermatologic conditions manifest in SOC individuals, inadequate treatment, and potentially poorer outcomes.

Specific dermatology-related Wikipedia pages that need updating with more SOC photographs to reflect the higher rates in individuals with SOC include hyperpigmentation, acral lentiginous melanoma, melasma, pityriasis alba, acne, and atopic dermatitis [4,10,11]. Wikipedia's "melasma" skin page has only one photograph highlighting skin pathology, and it is of an ambiguous Fitzpatrick skin type. Similarly, Wikipedia's atopic dermatitis page has only one picture, and it is of a non-SOC individual. Potentially lethal skin diseases should also have their pages updated. For example, acral lentiginous melanoma is a dangerous skin pathology that disproportionately affects SOC individuals but has no SOC skin photographs on Wikipedia [4].

One skin page that did have a significant number of SOC photographs was "keloid" (under the dermal and subcutaneous growth category) with 20 of 26 photographs being SOC photos, which is more aligned with the higher rates seen in black patients [12]. The other Wikipedia skin pages should be updated similarly to more closely match population statistics in order to improve access to accurate information and potentially improve safety.

### Conclusion

Wikipedia pages should be updated to include more SOC photos. Given that Wikipedia is open to editing, more teams dedicated to updating the material information on SOC dermatology findings and presentations, particularly those supported by board-certified dermatologists, can help bolster the information available. Doing so will help mend the divide between SOC and non-SOC photos on Wikipedia's dermatology pages and improve access to accurate dermatology information for the general public, thereby improving health equity within dermatology.

### Conflicts of Interest

RD is the Editor in Chief for JMIR Dermatology, a Joint Coordinating Editor for Cochrane Skin, a dermatology section editor for UpToDate, a Social Media Editor for Journal of the American Academy of Dermatology (JAAD), and a Podcast Editor for Journal of Investigative Dermatology (JID). He is a coordinating editor representative on Cochrane Council. RD receives editorial stipends (JAAD, JID, JMIR Dermatology), royalties (UpToDate), and expense reimbursement from Cochrane Skin.

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## Abbreviations

**SOC:** skin of color

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Original Paper

# Identifying and Responding to Health Misinformation on Reddit Dermatology Forums With Artificially Intelligent Bots Using Natural Language Processing: Design and Evaluation Study

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## Abstract

**Background:** Reddit, the fifth most popular website in the United States, boasts a large and engaged user base on its dermatology forums where users crowdsource free medical opinions. Unfortunately, much of the advice provided is unvalidated and could lead to the provision of inappropriate care. Initial testing has revealed that artificially intelligent bots can detect misinformation regarding tanning and essential oils on Reddit dermatology forums and may be able to produce responses to posts containing misinformation.

**Objective:** To analyze the ability of bots to find and respond to tanning and essential oil-related health misinformation on Reddit's dermatology forums in a controlled test environment.

**Methods:** Using natural language processing techniques, we trained bots to target misinformation, using relevant keywords and to post prefabricated responses. By evaluating different model architectures across a held-out test set, we compared performances.

**Results:** Our models yielded data test accuracies ranging 95%-100%, with a Bidirectional Encoder Representations from Transformers (BERT) fine-tuned model resulting in the highest level of test accuracy. Bots were then able to post corrective prefabricated responses to misinformation in a test environment.

**Conclusions:** Using a limited data set, bots accurately detected examples of health misinformation within Reddit dermatology forums. Given that these bots can then post prefabricated responses, this technique may allow for interception of misinformation. Providing correct information does not mean that users will be receptive or find such interventions persuasive. Further studies should investigate this strategy's effectiveness to inform future deployment of bots as a technique in combating health misinformation.

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**KEYWORDS**

bots; natural language processing; artificial intelligence; Reddit, medical misinformation; health misinformation; detecting misinformation; dermatology; misinformation

## Introduction

### Background

Health misinformation—defined as information that is incorrect, and possibly intended to deceive [1]—is rampant on the internet. Well-intentioned social media users often advise each other regarding health care treatments and home remedies. Prior studies have assessed health misinformation on Facebook and Twitter, yet one of the most active communities in health care discussions remains less investigated: the social media forums of Reddit [2]. As a social media and commentary platform with 330 million users, Reddit is the fifth most popular site in the United States [3]. The forums, known as subreddits, also cover nearly every medical specialty; for example, dermatology (known as “r/Dermatology”), cardiology, and others.

One of the most active medical forums on Reddit is r/Dermatology, with users seeking to crowdsource for free medical opinions. Indeed, posts often begin with variations of “I cannot afford a dermatologist.” The advice ranges from homeopathic remedies suggested by uncredentialed users to evidence-based medical treatments offered by dermatologists volunteering their time on the forum. A significant portion of medical advice from nonphysicians promotes non-evidence-based homeopathic treatments over scientifically validated medical treatments. For example, a user posting a photograph of a suspicious mole may be falsely reassured by other posters that in-person evaluation is unnecessary or that it can be resolved with the application of essential oils. Given that Reddit posts are anonymous, people may be empowered to reveal their medical concerns more candidly. In contrast, the public nature of a forum such as Facebook may discourage candid sharing [4]. Thus, the design of Reddit makes it a uniquely promising target for studying this crowdsourcing and potential health misinformation.

The audience for Reddit dermatology forums is large and highly engaged; over 55,000 users follow r/Dermatology, over 1.3 million users follow r/SkincareAddiction, and over 19,000 follow r/essentialoils [5]. These users (known as Redditors), log in globally, though a majority are from the United States (58%) [6]. While the majority of Redditors are young men, the skin care forums are largely female-dominated. Subreddit r/SkincareAddiction is one of the largest dermatology-related forums with 87% of female users, of whom 70% are between 19 and 29 years old [7].

### Prior Work

Our previous work has used the artificial intelligence subfield of natural language processing techniques to analyze Reddit

dermatology forums’ content [8]. Our data suggest that these forums are a rich source of patient engagement, presenting an untapped opportunity for expert involvement. Our study aimed to investigate the feasibility of engaging in these forums using bots, with the goal of intercepting health misinformation.

Preliminary analysis of Reddit dermatology forums identified a potential target: rampant confusion and misinformation regarding sun exposure. For instance, many users had questions about the dangers of sun exposure, questioning if these supposed dangers are a scam perpetuated by sunscreen companies. Further, tanning beds were often touted as a cure for acne and other skin conditions. Sun exposure-related misinformation was identified as a good target for intervention because of the clear consensus on guidance from the medical establishment. Indoor tanning devices are classified as the highest class of carcinogens by the World Health Organization, and it is well established that tanning bed use is a risk factor for developing melanoma, with multiple tanning bed sessions increasing the risk of melanoma [9-11]. Melanoma leads to an estimated 7000 deaths per year in the United States [12].

Essential oil (EO) use and safety was selected as a second target of misinformation. Users discussed EOs as a remedy for many health conditions, though no such efficacy has been established in the medical literature, and EO use is not without risk. For instance, 1 user solicited information on using EOs to treat Sjogren syndrome and was told to seek out a local herbalist.

In this context, we aimed to develop artificially intelligent bots for Reddit forums as a means to intercept and correct health misinformation.

## Methods

### Methods Overview

To develop bots to intercept health misinformation, we developed 2 sets of machine learning models: 1 targeting posts that discussed sun exposure or tanning, and the second for posts that discussed EOs. We used Google’s BigQuery application programming interface (API) to query publicly available Reddit data [13], pulling from the forums r/Dermatology, r/essentialoils, and r/tanning from January 2018 to August 2019. Google BigQuery API analyses 100% of full-text posts. We used the API to extract Reddit posts and comments that belonged to the subreddits we targeted and then locally ran our scripts over the entirety of the text posts. Using the data from BigQuery, we filtered by subreddit and searched for keywords (Textbox 1) [14].



**Textbox 1.** Keywords used.

<b>Essential oil–related keywords</b>
<ul style="list-style-type: none"><li>• essential oils</li><li>• Bay</li><li>• cinnamon bark</li><li>• clove</li><li>• frankincense</li><li>• citronella</li><li>• cumin</li><li>• lemongrass</li><li>• lemon verbena</li><li>• oregano</li><li>• thyme</li><li>• lavender</li><li>• nutmeg</li><li>• peppermint</li><li>• tea tree</li><li>• cinnamon leaf</li><li>• camphor oil</li><li>• oil of wintergreen</li><li>• jasmine</li><li>• ylang-ylang</li><li>• sandalwood oil</li></ul>
<b>Tanning-related keywords</b>
<ul style="list-style-type: none"><li>• sun exposure</li><li>• tanning</li><li>• tanning bed</li><li>• base tan</li></ul>

For the sun exposure/tanning data set, we included all posts from the r/tanning subreddit as positive training instances in addition to posts from r/Dermatology, which contained tanning-related keywords. The remaining posts from r/Dermatology were taken as negative training instances. Similarly, for the essential oils data set, all posts from the r/essentialoils subreddit were considered positive training instances in addition to posts from r/Dermatology that contained EO-related keywords. Positive training instances meant that the targeted content was identified, while negative training instances indicated that no such content was identified within the post. Next, we removed the search keywords from the positive comments to ensure that the classification task was nontrivial.

Two medical student annotators read through over 350 posts on the aforementioned forums and annotated posts as containing misinformation or not. This analysis was performed to determine that a sufficient number of posts contained misinformation in r/essentialoils and r/tanning to establish those forums as misinformation in our data set. To annotate the posts, the

annotators used UpToDate and PubMed. UpToDate is the most frequently utilized clinical decision database for physicians, and all information included is evidence-based and peer reviewed [15]. PubMed (the database of science journals for the National Library of Medicine of the National Institutes of Health) supplemented with additional journal articles when needed.

As mentioned, during bot development, we trained the bot to treat all comments related to “tanning” or “essential oils” as positive for misinformation. As a result, we did not exclude posts with phrases such as “avoid tanning,” despite the risk of causing the bot to respond to posts containing accurate information. This workflow was chosen because we felt that false positives were acceptable, but false negatives (where misinformation is present and we failed to reply to it) could be harmful. After the bot had been trained to identify “misinformation” versus “valid posts,” our human annotators reviewed posts to ascertain the number of false positives vs false negatives, using the aforementioned annotation. In our

training data set, the percentage of false positives for EOs and tanning was 2% and 5% respectively.

Once the quality of these data sets was verified, we were then able to posit an “accuracy” score for each model to determine how much true misinformation they could assimilate. These scores were calculated by evaluating the trained models on a held-out test set.

**Table 1.** Number of instances in the data set.

	Essential oils	Tanning
Training instances, n	1971	586
Test instances, n	221	66

In this study, we aimed to examine the theoretical ability of bots to detect and respond to misinformation. In developing our methods, we found that by using natural language processing techniques, bots can learn differentiating terms such as “tanning,” “essential oils,” or “sun exposure.” These bots have the ability to post prefabricated responses to comments related to a variety of skin conditions. These responses were developed and condensed from the American Academy of Dermatology (AAD) into user-friendly lengths and include a link for viewers to directly access the AAD website.

When these terms are identified, bots can reflexively provide condensed AAD recommendations in a comment. For example, with a mention of sun exposure, the bot can post a brief response detailing risk factors such as blistering sunburns, rates of skin cancer in the United States, and recommendations on sunscreen use. For EOs, the bot can return guidance on safe usage and potential adverse reactions. To be clear, these responses have not been posted in any live forums on Reddit, but the design was aimed at a live endpoint in the future.

### Model Creation

We compared the test accuracy for 3 different models. The first model included a baseline logistic regression model, which used a simple bag-of-words representation considering unigram, bigram, and trigram features. A vocabulary consisting of the 20,000 most frequent ngrams was chosen after converting the text to lowercase.

The second model involved fine-tuning a pretrained Bidirectional Encoder Representations from Transformers

(BERT) model [16] with a fully connected feed forward classification layer on top. The posts in the training data were first tokenized using a word piece tokenizer, following which [CLS] and [SEP] tokens were appended to the beginning and end of the sequences, respectively. Adam optimizer with a learning rate of  $2e-5$  and Binary Cross Entropy Loss was used to finetune this model over 4 epochs.

For the third model, we developed a fine-tuned XLNet model [17] with a single feed forward layer on top for classification. The optimizer, loss, and model hyperparameters were similar to those selected for the BERT model. The held-out test data set was used to evaluate each model’s performance and estimate the prediction error.

## Results

Test accuracies by model are shown in Table 2. We compared the results against a random baseline (where there is an equal probability for each label to be picked for a test instance). Our preliminary results show that all 3 models had high test accuracies for both EOs and tanning. The baseline logistic regression model performed well with an accuracy of over 95%. The top positive features of the logistic regression model included words such as “diffuser” and “blends” for essential oils, “bronzer” and “St. Tropez” for tanning, and top negative features included words such as “rash” and “acne.” The XLNet fine-tuned model was also effective, with a test accuracy over 98%, while the BERT fine-tuned model had the highest test accuracy of 100%.

**Table 2.** Validation accuracy of the models.

Model	Test accuracy for “essential oils,” %	Test accuracy for “tanning,” %
Random predictor	50.00	50.00
Logistic regression model	97.29	95.65
BERT <sup>a</sup> fine-tuned	99.56	100
XLNet fine-tuned	98.70	98.61

<sup>a</sup>BERT: Bidirectional Encoder Representations from Transformers.

## Discussion

### Principal Findings

Our study demonstrates, in a test environment, the ability for artificially intelligent bots to identify health misinformation related to tanning and EOs on Reddit forums, which have the ability to subsequently post corrective prefabricated responses. These results raise the question of whether benevolent bots should play a role in identifying and intercepting health misinformation on live forums. To date, social media bots have largely failed to promote credible sources. An analysis of 14 million Twitter messages by Shao et al [18] in 2017 revealed that social media bots overwhelmingly spread information from low-credibility sources. They reported that bots can “tailor misinformation” to “target those who are most likely to believe it.” The public’s vulnerability to misinformation is further enhanced by inundation of such untruths from multiple sources. For instance, similar tweets, news stories, and Facebook articles popping up on social media feeds, even if all incorrect, may appear to falsely validate each other [19]. By automatically targeting inaccuracies with accurate medical information, we can potentially interrupt this inundation of untruths.

Beyond the issue of noncredible bots, media coverage related to bots has focused on their potential negative impact on society. These concerns mainly revolve around the use of malicious bots to alter outcomes of elections, seed political and social turmoil, or even endanger lives via public health propaganda. One recent study showed, for example, that bots and Russian trolls on Twitter post more content about vaccination than the average user [20]. However, we would argue that the potential upside makes benevolent bots, at the very least, worthy of further study, with any potential impacts carefully studied before transitioning from proof of concept to real-world application.

Specifically, while bots have been used to spread misinformation, they can also be harnessed proactively to disseminate information from high-credibility sources, such as the National Institutes of Health and various academies of medicine. Indeed, some nonmedical projects have already attempted to harness the power of benevolent bots. For example, the United States Geological Service uses @earthquakeBot, a bot that detects earthquakes of 5.0 magnitude and automatically alerts the public. In 2017, the World Economic Forum experimented with an official Twitter bot, @forumfactbot, to combat misinformation about its funding sources, targeting World Economic Forum–related misinformation in tweets and automatically linking to accurate stories [21]. These examples show how transparent, fact-based bots have previously been harnessed to combat misinformation on social media. The creators of any benevolent bot must preemptively consider all ethical and practical issues prior to and during implementation.

Though concerns about bots are justified, our study builds on a growing body of work arguing that bots can—and should—be studied as forces for public health benefits. Many believe that a critical part of combating misinformation is the strong assertion of the truth, with many effective (though nonbot) examples such as Politifact, Factcheck.org, and Snopes [19]. Others have suggested that the public health community should

“go on the offense with our messages,” and perhaps benevolent bots could be 1 avenue to deliver such messages [22]. This reveals the possibility that those with malicious intent could use bots to further their own interests or stymie healthy discussions of differing viewpoints.

### Strengths and Limitations

Our approach has several limitations. Methodologically, we chose to have the bot treat all posts on the r/essentialoils and r/tanning subreddit forums as misinformation. The basis for this assumption came from having annotators read through over 350 posts on r/tanning and r/essentialoils and determine that a sufficient number of posts contained misinformation, which we would be able to consider it misinformation in our data set. Of note, an additional limitation is that while the annotators used evidence-based sources and support from a senior physician to annotate the posts for misinformation, there was no formal training prior to the annotation process. Thus, no standards were developed from which a formal training process could be created.

Many posts simply promoted the practice of tanning, which is undoubtedly misinformation given consensus among experts regarding the risk of melanoma with tanning. Similarly, many posts promoted EO use instead of evidence-based medical treatments. For r/Dermatology, more information was deemed accurate and thus required a different strategy. We considered only posts containing those keywords included in this study on r/Dermatology as misinformation.

Given that bots consider entire forums as misinformation, they are highly sensitive but fairly nonspecific. We run the risk of automatically posting replies to posts containing phrases such as “avoid tanning.” This reflexivity could prompt users to consider the bots as unreliable and thus begin to ignore the responses. In future iterations, we intend to refine this approach to increase the specificity of posts captured.

The bots currently only search for a limited set of keywords, as shown in [Multimedia Appendix 1](#) [23-26]. Given that these keywords do not encompass all the words that users describe when discussing tanning or essential oils, we are inevitably missing posts containing misinformation. We hope to increase the effectiveness of the bots by including a wider set of keywords in future searches, such as commonly used words for tanning in countries outside of the United States.

Furthermore, to be an effective public health intervention, we must assume that users will read both the post containing the misinformation and any corrective responses. However, the massive amount of content on these forums makes it impossible for a casual browser to read everything. Many posts on Reddit are either unread or only have 1 or 2 comments in response to them. The forums are constantly refreshed as new content is generated, meaning that our responses to a post could be buried under a new post within a few hours. One safeguard against this is the “search” function that exists within the forums; if a user is searching for advice on a topic such as “tanning,” Reddit returns results spanning back to the creation of the forum, which could be years prior. The user can then see all posts about the topic, including those that have our responses attached to them.

Another factor complicating Reddit visibility of posts is the order in which posts are displayed. Responses to Reddit posts are displayed in order of how often they are “upvoted,” which is essentially the same function as a “like” on Facebook. Thus, a highly upvoted but inaccurate opinion could become the top comment users see, lending it more visibility than our post. Future research could benefit from addressing how to boost the visibility of validated information, such as running advertisements or “featured spots” on social media sites.

A final limitation is that even if users see factual evidence opposing misinformation, they may disregard corrective responses. Politics and sociology have repeatedly demonstrated that when facts are incongruent with a person’s opinion, a person may in fact disregard the facts presented to them and cling to the misinformation, a phenomenon called “cognitive consistency” [27,28]. Ideological beliefs, or simply rumors heard enough to have reached a “social consensus,” can impair one’s ability to assess the validity of a statement and lead readers to process incongruent information less fluently [27,28]. Further, users may not be receptive to corrective information provided by nonhuman users; indeed, the presence of bots could potentially interrupt a tacit community standard and violate users’ trust, even if bots were completely transparent in their roles to correct health misinformation.

## Conclusions

In our study, our bot models all had high test accuracies, which suggests that artificially intelligent bots may accurately target Reddit posts containing commonly misunderstood health content. The ability to consistently detect comments at risk of misinformation is merely the first step toward using benevolent bots to disseminate high-quality scientific information to the public. Our ultimate goal is to test a novel method of addressing dermatology misinformation on Reddit by posting active replies with bots to posts deemed misinformation. Our results suggest that using artificial intelligence is a potentially beneficial and valid method of targeting misinformation on the internet. Having now established feasibility of both detecting misinformation and reflexively responding to it in test environments, subsequent steps include testing the bots on Reddit and other social media forums, with user satisfaction surveys and links to track user engagement with bot-delivered posts. While this initial work has focused on a subset of dermatology misinformation, it demonstrates proof of concept of the potential for using bots to promote fact-based discussions on any medical topic or public health conversation. Thus, we anticipate continued and necessary work to explore and validate the potential for benevolent bots in the health misinformation space.

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## Conflicts of Interest

None declared.

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## Multimedia Appendix 1

Bot responses to misinformation.

[[DOCX File , 13 KB - derma\\_v4i2e20975\\_app1.docx](#) ]

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## Abbreviations

- AAD:** American Academy of Dermatology  
**API:** application programming interface  
**BERT:** Bidirectional Encoder Representations from Transformers  
**EO:** essential oil

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Original Paper

# The Contact Dermatitis Quality of Life Index (CDQL): Survey Development and Content Validity Assessment

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## Abstract

**Background:** There is limited measurement and reporting of quality of life (QoL) outcomes for patients with contact dermatitis (CD).

**Objective:** The purpose of this study is to develop a standardized Contact Dermatitis Quality of Life index (CDQL) for adult patients.

**Methods:** A list of 81 topics was compiled from a review of QoL measures used previously in CD research. A total of 2 rounds of web-based Delphi surveys were sent to physicians who registered to attend the 2018 American Contact Dermatitis Society meeting, asking that they rank the relevance of topics for measuring QoL in CD using a 4-point scale. Items met consensus for inclusion if at least 78% of respondents ranked them as relevant or very relevant, and their median score was  $\geq 3.25$ .

**Results:** Of the 210 physicians contacted, 34 physicians completed the initial survey and 17 completed the follow-up survey. A total of 22 topics met consensus for inclusion in the CDQL, addressing symptoms, emotions, functions of daily living, social and physical functions, work/school functions, and treatment.

**Conclusions:** This study was limited by the following factors: few open-ended questions in the initial survey, a lack of direct patient feedback, and long survey length, which likely contributed to lower survey participation. The CDQL is a comprehensive, CD-specific QoL measure developed on the basis of expert consensus via a modified Delphi process to be used by physicians and other health care professionals who care for adult patients with contact dermatitis.

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## KEYWORDS

contact dermatitis; allergic contact dermatitis; irritant contact dermatitis; quality of life; outcomes instruments; health outcomes

## Introduction

Measures of quality of life (QoL) have become a fundamental component in evaluating the benefits of dermatologic interventions, especially for chronic, incurable diseases. Supplementary to the objective clinical indices used to assess disease severity, QoL instruments incorporate patients'

impressions of their functioning and well-being, allowing for a more complete picture of their health status. Unlike generic questionnaires, disease-specific instruments are more responsive to changes over time in QoL [1,2].

The negative impact of contact dermatitis (CD) on QoL has been established in existing literature [3-13]. Worse QoL is

associated with the presence of several features, including pruritus, discomfort, and trouble working with one's hands or carrying out everyday activities [14]. Chronically, the impact of dermatologic diseases on QoL can result in considerable emotional and functional impairment [15]. The extent of CD's effect on QoL is not always adequately reflected by disease severity, possibly due to the psychological stress and embarrassment caused by visual manifestations of the disease [14]. It is therefore essential to use a standardized tool for quantitatively assessing QoL in patients with CD. However, as revealed by a systematic review of outcomes instruments used for CD in randomized controlled trials (RCTs) published between 2005 and 2015 [16], only a small minority of RCTs (6%) assessed QoL, and among those studies, there was a lack of consensus on what tool to use for this purpose.

A standardized measure of QoL for adult patients with CD would be beneficial in guiding individual treatment strategies and to potentially help prevent the risks associated with chronically depressed QoL. Additionally, such a universal tool would allow for greater comparability among articles in the CD literature. The purpose of this study, therefore, was to develop the Contact Dermatitis Quality of Life index (CDQL), a QoL measure specific to CD that quantifies the impact of the disease on functioning and well-being from a patient perspective. This tool was created for use by physicians and other health care professionals caring for patients with contact dermatitis.

## Methods

The process of developing the CDQL consisted of initial topic generation via a literature review, followed by a 2-step modified Delphi method to establish the content validity of the instrument.

Preliminary topics compiled for the questionnaire were based on a review of QoL outcome measures used in previous studies of CD. A systematic review [16] of CD outcome measures in RCTs published from 2005 to 2015 found that QoL was evaluated using the Dermatology Life Quality Index (DLQI) [17] and various general assessments of pruritus. According to a 2003 literature review [12], other QoL tools used for patients with CD include the Dermatology-Specific Quality of Life (DSQL) instrument [15], the Skindex-29 [18,19], and the 36-item Short Form Health Survey [20]. Additionally, the Skindex-16 [21] was previously modified for use in allergic CD, with the addition of 5 questions specific to the effect on one's occupation [22]. A subsequent QoL measure for CD incorporated modifications of both the Skindex-16 and the DLQI, as well as 6 additional items addressing feelings and functioning [14].

A total of 81 topics were generated from a review of the aforementioned QoL instruments. Similar to the Skindex-16 [21], each topic was worded to ask patients how often the event in the topic bothered them. Expert consensus was sought regarding questionnaire topics in accordance with a modified Delphi technique, with 2 rounds of surveys conducted to maximize consensus [23]. Following institutional review board approval, the initial voluntary, anonymous web-based surveys were sent to the 210 registrants of the 2018 annual meeting of the American Contact Dermatitis Society (ACDS), asking that

dermatology physicians rank the relevance of each questionnaire topic using the following 4-point Likert scale: (1) not relevant, (2) somewhat relevant, (3) relevant, or (4) very relevant (Multimedia Appendix 1). Topics derived from the Skindex-16 were italicized. Survey respondents were also asked to provide their opinion regarding the time frame which the CDQL should be designed to address, keeping in mind both the potentially intermittent nature of CD [15] and the goal of maximizing patient recollection [17].

Definitions of consensus vary throughout the literature. A prior systematic review investigating consensus in Delphi studies found that consensus is most often defined by the percentage of agreement, followed by the proportion of subjects' ratings falling within a specified range [24]. Thresholds set for consensus definitions based on percentages or proportions range from 50% to 97%, with a median of 75%. Green et al [25,26] suggested that consensus is achieved when at least 70% of Delphi respondents rank the item as 3 or 4 on a 4-point Likert scale, and the median is at least 3.25. Lynn et al [27,28] suggested that with at least 6 professionals ranking the relevance of a topic for a new instrument, the content validity index (CVI) of the topic (the proportion of professionals ranking it as a 3 or 4 on a 4-point scale) should be  $\geq 0.78$  in order to reduce the possibility of agreement due to chance. A combination of these criteria was used for this study, with items meeting consensus for inclusion in the CDQL if at least 78% of respondents ranked them as relevant or very relevant (a score of 3 or 4), and the median score was at least 3.25. Also in line with precedent [29-34], items rated as relevant or very relevant by less than 50% of respondents were excluded.

In response to expert comments from the initial survey recommending less repetition and a shorter questionnaire length to improve practicality for clinical use, similar questionnaire topics were combined and/or excluded. The remaining topics with CVIs of 50% to 77% were compiled in a second survey, which listed the initial CVI for each item and asked respondents of the first survey to rank topic relevance on a 4-point scale again (Multimedia Appendix 2). A total of 7 new topics were included in the second survey based on preliminary results from a study aimed at developing a QoL index for allergic CD [35]. Additionally, based on comments from the initial survey, 4 other new topics were included under a treatment domain. Survey respondents were asked to provide a brief explanation for their ranking of relevance if the initial CVI for a topic was  $< 60\%$  or if they ranked an item with a CVI of  $> 60\%$  as somewhat relevant or not relevant. Again, individual items from the second survey were included as items in the final CDQL if the CVI among respondents was  $\geq 0.78$  and the median score was  $\geq 3.25$ .

In order to further establish the CDQL's content validity, the CVI for the total scale was calculated. Different ways of quantifying this value exist, although it is recommended (especially when larger numbers of experts are involved, as in this study) that it be calculated by taking the average of the CVIs for the individual questionnaire topics [28]. A total scale CVI of  $\geq 0.90$  has been previously deemed acceptable [28,36].

Survey data were collected and managed using REDCap (Research Electronic Data Capture; Vanderbilt University)



electronic data capture tools hosted at the University of Colorado Denver [37]. REDCap is a secure, web-based application designed to support data capture for research studies, providing the following: (1) an intuitive interface for validated data entry, (2) audit trails for tracking data manipulation and export procedures, (3) automated export procedures for seamless data downloads to common statistical packages, and (4) procedures for importing data from external sources. Statistical analysis was performed using Excel (Microsoft Corporation).

This study was reviewed and approved by The Colorado Multiple Institutional Review Board.

## Results

Of the 210 individuals contacted, 43 (20.5%) completed the initial Delphi survey. A total of 8 surveys were completed by nonphysicians and were therefore excluded. Additionally, 13 partially completed surveys were excluded. A total of 34 physicians completed the initial survey, of whom 33 were attending dermatologists and 1 was a fellow. Of the 34 physicians who completed the survey, 27 (79%) patch tested >41 patients per year; only 1 physician did not do any patch testing. All but 2 of the physicians were members of the ACDS, American Academy of Dermatology, and/or American Academy of Allergy, Asthma, and Immunology.

A total of 12 topics from the first Delphi survey with a CVI of <50% were excluded. Of the remaining topics, 22 were deemed repetitive and also excluded. Initially, 23 topics from the first Delphi survey met consensus for inclusion in the CDQL; however, based on expert feedback, several redundant topics were either removed or combined, ultimately resulting in 19 topics meeting consensus for inclusion (Table 1). The CVIs and median relevance scores for these topics ranged from 0.79 to 1.0 and 3.5 to 4.0, respectively.

The follow-up Delphi survey consisted of 35 questionnaire topics not yet meeting consensus for inclusion or exclusion

(including 11 new topics). Of the 43 individuals contacted (those who had responded to the initial survey), 23 (53%) completed the second Delphi survey. The final analysis included a total of 17 surveys fully completed by physicians who had also completed the initial survey. Following completion of the second survey, an additional 4 topics met consensus for inclusion, with CVIs ranging from 0.82 to 1.0, and a median relevance score of 4.0 for all 4 questions (Table 2).

Based on the first survey, 20 (59%) of the 34 respondents felt the questionnaire should ask about QoL over the past 6 months, 8 (24%) felt it should address the past month, 4 (12%) felt it should address the past year, and 2 (6%) felt it should address the past week. Agreement improved in the follow-up survey, with 16 (70%) of the 23 respondents suggesting that the CDQL inquire about the past 6 months.

The resulting CDQL consists of 23 items, asking patients how often they have been bothered by each item over the past 6 months (Multimedia Appendix 3). Responses are structured on a 4-point Likert scale: (1) never bothered, (2) sometimes bothered, (3) often bothered, or (4) always bothered. For ease of use, this was simplified from the Skindex-16 [21], which uses a continuous bipolar scale with 7 answer choices.

The CDQL can be broken down into 6 different domains: symptoms (1 item), emotions (9 items), functions of daily living (3 items), social and physical functions (2 items), work/school functions (4 items), and treatment-related items (4 items). The CVI for the total scale was 0.85. A total of 10 topics were at least in part derived from the Skindex-16 [21], 9 topics were derived from the Skindex-29 [18,19], 7 topics were derived from the DSQL [15], 5 topics were derived from the DLQI [17], 6 topics were derived from the CD-specific quality of life measure by Ayala et al [14], 2 topics were derived from the 36-item Short Form Health Survey [20], 2 topics were derived from the modified Skindex-16 by Kadyk et al [22], and 3 topics were based on expert recommendations from the first survey.

**Table 1.** Topics meeting consensus for inclusion after the initial Delphi survey.

Topics <sup>a</sup>	Content validity index <sup>b</sup>	Median (SD) <sup>c</sup>
<b>Symptoms</b>		
Itching of your skin <sup>d,e,f,g</sup>	1.0	4.0 (0.24)
<b>Emotions</b>		
Your skin condition persisting or reoccurring <sup>d</sup>	0.94	4.0 (0.58)
Your skin condition's appearance <sup>d</sup>	0.91	4.0 (0.65)
Frustration because of your skin condition <sup>d,e,f</sup>	0.91	4.0 (0.66)
Feeling embarrassed <sup>d,e,f,g</sup> or ashamed <sup>e</sup> because of your skin condition <sup>h</sup>	0.82-0.91	3.5-4.0 (0.66-0.84)
Feeling uncomfortable because of your skin condition <sup>i</sup>	0.91	4.0 (0.75)
Feeling annoyed or irritated because of your skin condition <sup>d,e,i</sup>	0.85	3.5 (0.87)
Feeling depressed because of your skin condition <sup>d,e</sup>	0.85	4.0 (0.82)
Lack of self-confidence because of your skin condition <sup>f</sup>	0.82	4.0 (0.85)
Concern about what others think about you because of your skin condition <sup>f</sup>	0.82	4.0 (0.86)
<b>Functions of daily living</b>		
Effects of your skin condition on your daily activities <sup>d</sup>	0.97	4.0 (0.38)
Your skin condition interfering with your sleep <sup>e,i</sup>	0.97	4.0 (0.53)
<b>Social and physical functions</b>		
Effects of your skin condition on your social or leisure activities <sup>e,f,g,k</sup>	0.88	4.0 (0.70)
Effects of your skin condition on your interactions with others (for example, your partner, friends, or relatives) <sup>d,e</sup>	0.85	4.0 (0.81)
<b>Work/school functions</b>		
Difficulties using your hands at work because of your skin condition <sup>i,j</sup>	0.91	4.0 (0.75)
Difficulties working or studying because of your skin condition <sup>d,e,g,k</sup>	0.85	4.0 (0.75)
Concerns that you may lose your job (either because you need to quit or are fired) due to your skin condition <sup>i,j,l</sup>	0.85	4.0 (0.82-0.83)
Effects of your skin condition on your finances <sup>i</sup>	0.79	4.0 (0.94)
<b>Treatment</b>		
Problems from the treatment of your skin condition (for example, taking up time or being messy) <sup>g,m</sup>	0.88	3.5 (0.77)

<sup>a</sup>Topics are intended to ask patients how often they have been bothered by them.

<sup>b</sup>The proportion of physicians ranking a topic's relevance as 3 or 4 on a 4-point Likert scale: (1) not relevant, (2) somewhat relevant, (3) relevant, or (4) very relevant. All values are based on a total of 34 physicians completing the survey.

<sup>c</sup>Values are based on relevance scoring using a 4-point scale, as noted previously.

<sup>d</sup>Topics derived from the Skindex-16 [21].

<sup>e</sup>Topics derived from the Skindex-29 [18,19].

<sup>f</sup>Topics derived from the Dermatology-Specific Quality of Life (DSQL) instrument [15].

<sup>g</sup>Topics derived from the Dermatology Life Quality Index (DLQI) [17].

<sup>h</sup>The following topics were combined: "embarrassment because of your skin condition" and "feeling ashamed of your skin condition." Listed values display the range of values for the combined topics.

<sup>i</sup>Topics derived from a contact dermatitis (CD)-specific quality of life measure from Ayala et al [14].

<sup>j</sup>Topics derived from the 36-item Short Form Health Survey [20].

<sup>k</sup>Topics derived from a modified Skindex-16 from Kadyk et al for use in allergic CD [22].

<sup>l</sup>The following topics were combined: "concerns that you may need to quit your job because of your skin condition" and "concerns about being fired from your job because of your skin condition." The range of standard deviations is listed; other values for the two combined topics were the same.

<sup>m</sup>Prior to the development of a treatment domain in the second round of surveying, this topic was initially categorized under functions of daily living.

**Table 2.** Topics meeting consensus for inclusion after the second Delphi survey.

Topics <sup>a</sup>	Content validity index <sup>b</sup>	Median (SD) <sup>c</sup>
<b>Functions of daily living</b>		
Limitations in shaving or wearing makeup because of your skin condition <sup>d</sup>	0.88	4.0 (0.86)
<b>Treatment</b>		
Lack of treatment success using recommended remedies for your skin condition <sup>e</sup>	1	4.0 (0.51)
Difficulty finding products that are safe for your skin <sup>e</sup>	0.94	4.0 (0.62)
The cost of products that are safe for your skin <sup>e</sup>	0.82	4.0 (0.93)

<sup>a</sup>Topics are intended to ask patients how often they have been bothered by them.

<sup>b</sup>The proportion of physicians ranking a topic's relevance as 3 or 4 on a 4-point Likert scale: (1) not relevant, (2) somewhat relevant, (3) relevant, or (4) very relevant. All values are based on a total of 34 physicians completing the survey.

<sup>c</sup>Values are based on relevance scoring using a 4-point scale, as noted previously.

<sup>d</sup>Topics derived from the Dermatology-Specific Quality of Life (DSQL) instrument [15].

<sup>e</sup>Topics added to the second survey round based on expert recommendations from the first survey.

## Discussion

There are multiple tools to assess QoL in dermatology; however, few of these tools have been validated for use in CD. The 36-item Short Form Health Survey is frequently used in dermatology as a broad questionnaire to assess a wide variety of skin concerns. The DLQI, DSQL instrument for CD, Skindex-16 and its modified versions, and Skindex-29 are more commonly used tools for measuring QoL specifically in CD [38]. However, there are many aspects important for assessing QoL that are not completely incorporated into these questionnaires [39]. Some areas lacking in these questionnaires include psychosocial impact, impact on occupation, and treatment concerns. For these reasons, we developed a new QoL tool specific to CD that can adequately assess all important aspects of QoL in one complete questionnaire. This tool aims to increase detection of QoL changes related to CD in order to better assess disease-related QoL, disease progression, and response to therapies.

Previously validated tools such as the Skindex-16 and the Skindex-29 were used to aid the creation of our new tool. Topics such as those exploring stinging or burning of the skin, irritation of the skin, and worry caused by the skin condition are all validated questions present in the Skindex-16 and also included in the CDQL; these overlapping topics are indicated in Table 1. In terms of more recently published QoL measures, the disease-specific questionnaire for allergic contact dermatitis proposed by Botto et al [35] explores a variety of topics that are also included in the CDQL, such as “concern for infecting others because of your skin condition” and “I am bothered by cracking of my skin.” While the CDQL includes similar types of questions under the categories of function, emotions, and symptoms, it also further addresses topics of “functions of daily living” and “work and school function,” allowing for a more complete understanding of the impact this skin condition has on patients' daily lives. For example, we include impacts on types of clothes worn, the ability to participate in certain sports,

and the duration of time needed to find treatment or care for their condition. Additionally, our tool examines contact dermatitis more broadly, rather than focusing on the specific subset of allergic contact dermatitis, allowing for a more universal application of the tool.

The Delphi technique, a series of successive questionnaires aimed at determining opinion consensus among a group of experts [40], was used to formulate the CDQL. The strength of this technique comes from its ability to efficiently achieve consensus on topics of uncertainty [41]. Furthermore, the controlled feedback following each round of the questionnaire can broaden thinking and stimulate new ideas among experts [42]. However, the weakness of the Delphi technique typically stems from a lack of agreement on how consensus is defined [43]. Varying interpretations and methodology to define consensus and validity can diminish the credibility of this technique.

The precedent is to deem the content validity of an instrument excellent if the following criteria are met: (1) The CVIs for individual topics are  $\geq 0.78$  when at least 6 experts are assessing the relevance of the topics, and (2) the CVI of the total scale (when calculated in the same manner as for this study) is  $\geq 0.90$  [27,28,36]. The final individual topics included in this tool had CVIs ranging from 0.79 to 1.0. However, the CVI of the total scale was 0.85, falling slightly below the previously determined 0.90 standard to be considered excellent. Of note, some studies recommend a minimum total scale CVI of 0.80 [44]. While this may be a more realistic benchmark for the total CVI, some researchers have argued that a total scale CVI of 0.90 would better protect against exceedingly low individual CVIs (eg,  $< 0.4$ ) [36]. As the CDQL had final individual topic CVIs ranging from 0.79 to 1.0, a total scale CVI  $\geq 0.80$  may be a suitable indication of content validity.

One limitation of this study was the long length of the surveys, which likely played a role in the lower survey completion rate. Additionally, while a typical Delphi method would have

consisted of an initial survey with a series of open-ended questions intended to generate a list of QoL issues [45], this was replaced by a literature search in this study. Nevertheless, experts were still given the opportunity in the first survey to note additional topics that they felt were relevant. Additionally, while this study did not directly incorporate patient feedback during development of the scale, the second round of surveying incorporated unique topics from another recent study [35] aimed at developing a QoL index for allergic CD based on patient interviews. This index is intended for use in conjunction with another more comprehensive QoL scale, whereas the CDQL is designed to be sufficient by itself for assessing QoL in CD. Furthermore, 1 respondent to the initial survey felt that the questionnaire was limited by its lack of items incorporating

intensity and localization of CD. However, these factors are specific to disease severity and the CDQL is meant to be used in combination with, not in lieu of, a validated disease severity tool. As previously noted, the degree of impact of CD on QoL may not always correlate with disease severity [14].

Future studies are planned to further establish the CDQL's validity, reliability, and responsiveness to changes in QoL. It is hoped that the resulting validated outcomes instrument will be suitable for use in both clinical practice and research to quantitatively determine the effect of health care interventions on QoL among patients with CD.

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None.

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### Authors' Contributions

MKH performed data collection, data analysis, and manuscript writing. MRL performed data analysis and manuscript writing. RPD performed manuscript editing and direction for the study. CWR performed manuscript writing and editing. CIH performed manuscript editing. CAD conceived of the study and performed manuscript editing and direction for the study.

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### Conflicts of Interest

RPD is the Editor-in-Chief of *JMIR Dermatology*, but had no role in the evaluation of this work for publication.

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#### Multimedia Appendix 1

Initial questionnaire sent to registrants of the 2018 American Contact Dermatitis Society meeting.

[DOCX File, 32 KB - [derma\\_v4i2e30620\\_app1.docx](#)]

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#### Multimedia Appendix 2

Second round of the questionnaire sent out to respondents.

[DOCX File, 34 KB - [derma\\_v4i2e30620\\_app2.docx](#)]

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#### Multimedia Appendix 3

Contact Dermatitis Quality of Life Index.

[DOCX File, 19 KB - [derma\\_v4i2e30620\\_app3.docx](#)]

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## Abbreviations

**ACDS:** American Contact Dermatitis Society

**CD:** contact dermatitis

**CDQL:** Contact Dermatitis Quality of Life index

**CVI:** content validity index

**DLQI:** Dermatology Life Quality Index

**DSQL:** Dermatology-Specific Quality of Life instrument

**NIH/NCRR CSTI:** National Institutes of Health/National Center for Research Resources Colorado Clinical and Translational Science Institute

**QoL:** quality of life

**RCT:** randomized controlled trial

**REDCap:** Research Electronic Data Capture

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Original Paper

# Supporting Self-management Among Young People With Acne Vulgaris Through a Web-Based Behavioral Intervention: Development and Feasibility Randomized Controlled Trial

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## Abstract

**Background:** Acne is a common skin condition that is most prevalent in young people. It can have a substantial impact on the quality of life, which can be minimized with the appropriate use of topical treatments. Nonadherence to topical treatments for acne is common and often leads to treatment failure.

**Objective:** The aim of this study is to develop a web-based behavioral intervention to support the self-management of acne and to assess the feasibility of recruitment, retention, and engagement of users with the intervention.

**Methods:** The intervention was developed iteratively using the LifeGuide software and following the person-based approach for intervention development. The target behavior was *appropriate use of topical treatments*. Barriers and facilitators identified from the qualitative research and evidence from the wider literature were used to identify techniques to improve and promote their use. Young people with acne aged 14-25 years who had received treatment for acne in the past 6 months were invited to participate through mail-out from primary care practices in the South of England in a parallel, unblinded randomized trial. Participants were automatically randomized using a computer-generated algorithm to usual care or to usual care plus access to the web-based intervention. Usage data was collected, and a series of questionnaires, including the primary outcome measure for skin-specific quality of life (Skindex-16), were collected at baseline and at the 4- and 6-week follow-ups.

**Results:** A total of 1193 participants were invited, and 53 young people with acne were randomized to usual care (27/53, 51%) or usual care plus intervention (26/53, 49%). The response rate for the primary outcome measure (Skindex-16) was 87% at 4 weeks, 6 weeks, and at both time points. The estimate of mean scores between groups (with 95% CI) using linear regression showed a trend in the direction of benefit for the web-based intervention group in the primary outcome measure (Skindex-16) and secondary measures (Patient Health Questionnaire-4 and the Problematic Experiences of Therapy Scale). Intervention usage data showed high uptake of the core module in the usual care plus web-based intervention group, with 88% (23/26) of participants completing the module. Uptake of the optional modules was low, with less than half visiting each (myth-busting quiz: 27%; living with spots or acne: 42%; oral antibiotics: 19%; what are spots or acne: 27%; other treatments: 27%; talking to your general practitioner: 12%).

**Conclusions:** This study demonstrated the feasibility of delivering a trial of a web-based intervention to support self-management in young people with acne. Additional work is needed before a full definitive trial, including enhancing engagement with the intervention, recruitment, and follow-up rates.

**Trial Registration:** ISRCTN 78626638; <https://tinyurl.com/n4wackrw>

**KEYWORDS**

feasibility study; acne vulgaris; intervention study; self-management; primary care; acne; dermatology

## *Introduction*

Acne is a common condition that is most prevalent among adolescents, affecting >85% of adolescents at some point [1-3]. It can have a substantial physical and psychological impact; however, its main effects are on quality of life (QoL) [4]. First-line treatments for acne are topical treatments that work well at improving acne [5] and have been shown to improve QoL when used appropriately [6,7]. However, studies have highlighted how adherence to topical treatments is poor [8], and discontinuing treatment is associated with a rapid increase in microcomedones, resulting in more acne lesions and subsequent treatment failure [9].

A limited number of interventions have been developed to improve adherence to acne treatments [10-15], many of which have significant shortcomings. A systematic review of the effect of mobile and electronic health technology on adherence [16] (SMS text message reminders [12], telephone call reminders [13], an internet-based education tool [11], and an internet-based survey [14]) found that a weekly internet-based survey was more effective than telephone-based reminders. However, the sample size was small and not powered to determine significance [14]. Other studies included in the review also had small sample sizes ranging between 40 and 61 participants and no power calculations, which may have limited their ability to detect statistically significant differences. To our knowledge, none of these interventions have been informed by theory or developed using robust methods. Interventions developed using theory have proven to be more effective than those without a theoretical base [17].

There is also little information on recruiting through primary care in acne trials. One randomized controlled trial (RCT) investigating the use of supplementary patient educational materials on adherence recruited patients from primary care clinics in the United Kingdom; however, there was no calculation for sample size [10]. As there is very little information regarding uptake and retention rates for this group, further feasibility trials are needed to establish this.

Feasibility trials are an essential part of complex intervention development [18]. However, few interventions for acne have been subjected to feasibility or pilot testing [11,13,19] and, as a result, these trials may have a number of issues around

acceptability, delivery, recruitment, and retention and are often small in sample size [20].

In this study, we describe the development of a web-based behavioral intervention to support self-management of acne. We also present the results of a feasibility randomized trial delivering this intervention to young people with acne recruited through primary care.

## *Methods*

### **Development of Web-Based Intervention**

The Template for Intervention Description and Replication (TIDieR) guideline [21] was used to facilitate the appropriate reporting of intervention development.

### **Person-Based Approach**

The intervention was developed using the Person-Based Approach (PBA) for planning, developing, and evaluating the feasibility of the intervention [22]. The aim of this method is to ground the intervention in the views and experiences of the people who will use it to ensure that it is persuasive, accessible, and engaging for the target population [22]. The PBA involves in-depth qualitative research to identify key objectives and barriers and facilitators to target behaviors [22]. We carried out a systematic review and synthesis of qualitative research to explore the qualitative literature on acne among patients, carers, and health care professionals [23]. The review protocol was registered on PROSPERO (International Prospective Register of Systematic Reviews; registration number CRD42016050525). A secondary analysis of qualitative interviews with people with acne was also carried out to understand young people's views and experiences with acne and its treatments [24].

### **Creating Guiding Principles**

Alongside intervention planning, guiding principles were drafted and iteratively developed throughout, identifying distinctive intervention features to address these. This method involved highlighting key objectives from qualitative research (1). to support young people in gaining autonomy and competence around acne management, (2) to support and promote autonomy in making treatment choices, and (3) to provide support and acknowledge the psychological impact of acne (see [Table 1](#) for guiding principles developed for this intervention).



**Table 1.** Guiding principles.

Key intervention objectives	Patient characteristics	Evidence for key behavioral issues	Guiding principles	
			Design objectives	Key (distinctive) intervention features
<ul style="list-style-type: none"> <li>To improve the lives of young people with acne</li> <li>To promote self-management of acne</li> <li>To promote the appropriate use of topical treatments</li> </ul>	Young people who have mild to moderate acne vulgaris	<ul style="list-style-type: none"> <li>Little knowledge about acne and its treatments (QR)<sup>a</sup></li> <li>Young people can be confused with the myths and misconceptions around acne and are unaware or unwilling to acknowledge that acne requires ongoing treatment.</li> <li>Low motivation to engage with long-term treatment (QR)</li> <li>Certain beliefs about the causation of acne may affect people's perceived necessity of treatment.</li> <li>Difficulty judging efficacy of topical treatments (QR)</li> <li>Belief that topical treatments do little and are only keeping their acne at bay may result in early abandonment of treatment.</li> <li>Difficulty overcoming barriers (QR)</li> <li>Young people can be uncertain about how to manage side effects of treatment, financial constraints, lengthy routines, and uncertainties around how to use medication.</li> <li>Confusion between cosmetic and medical treatments for acne (QR)</li> <li>Young people perceive they have tried all the topical treatments available</li> <li>Need for control over treatment choice and disease (SR)<sup>b</sup></li> <li>Young people want control over their treatment choice as well as their condition and this has been shown to improve adherence and psychological impact</li> </ul>	<p>To support young people in gaining autonomy and competence around acne management</p> <p>To support and promote autonomy for making treatment choices</p>	<ul style="list-style-type: none"> <li>Offer users choice wherever possible</li> <li>Minimize disruption to lifestyle</li> <li>Dispel myths and misconceptions about the causes of acne</li> <li>Autonomy-supportive language</li> <li>Ensure they have a complete understanding of acne and the rationale behind their treatment</li> <li>To build their self-efficacy for the target behaviors (eg, 4-week challenge to support patients to formulate a personal goal or action plan, advice on how to minimize side effects including skin irritation, and a video with step-by-step instructions on how and when to apply topical treatments)</li> <li>Educational information or rationale supported by scientific evidence (topical treatments are equally as effective as antibiotics)</li> <li>Stories and testimonials to model successful management using topical therapies</li> <li>Addressing common concerns</li> <li>Provide a list of topical treatments and explain how they work</li> </ul> <ul style="list-style-type: none"> <li>Provide advice on how people can effectively communicate with their GP<sup>c</sup></li> <li>Invite, acknowledge, and value views or preferences (eg, CAM<sup>d</sup> therapies)</li> <li>Provide a list of topical treatments and explain how they work</li> <li>Offering user choice wherever possible</li> <li>Autonomy-supportive language throughout</li> </ul>

Key intervention objectives	Patient characteristics	Evidence for key behavioral issues	Guiding principles	
			Design objectives	Key (distinctive) intervention features
		<ul style="list-style-type: none"> <li>• Difficulty dealing with psychological issues (SR and QR)</li> <li>• Young people can be unsure about how to cope with the psychological impact of acne, including depressive symptoms, stress, anxiety, and embarrassment</li> <li>• Difficulty presenting psychological issues to HCP<sup>e</sup> (SR)</li> <li>• Young people may be unwilling to present psychological problems to their HCP</li> </ul>	<p>To provide support and acknowledge the psychological impact of acne</p>	<ul style="list-style-type: none"> <li>• Acknowledge the psychological impact of acne (eg. (1) emphasize that everyone with a skin disease can be at risk of psychological symptoms and (2) provide patient stories about how they dealt with the impact of acne)</li> <li>• Provide advice on how people can effectively communicate with their GP</li> <li>• Provide advice on different coping strategies</li> </ul>

<sup>a</sup>QR: qualitative research (barriers identified from the secondary analysis of qualitative interview data [24]).

<sup>b</sup>SR: systematic review (barriers emerged from systematic review and synthesis of qualitative papers on acne) [23].

<sup>c</sup>GP: general practitioner.

<sup>d</sup>CAM: complementary and alternative medicine.

<sup>e</sup>HCP: health care practitioner.

### Target Behavior

The hypothesized outcome of the intervention was to improve QoL for young people with acne through the target behavior *appropriate use of topical treatments*. This target behavior was chosen as it has been shown that effective use of topical treatments can improve acne [5] and benefit QoL [6,7]. For addressing this target behavior, barriers and facilitators identified from the qualitative research were described along with the proposed intervention element.

Evidence from the literature and qualitative research (including the systematic review and synthesis of qualitative data [23] and the secondary analysis of interview data with young people [24]) highlighted several barriers to the appropriate use of topical treatments that needed to be addressed in the intervention. These included concerns about side effects, confusion about the different types of topical treatments, beliefs around the ineffectiveness of topical treatments, belief that acne is a short-term condition that will resolve on its own, confusion about how to use treatment, the time-consuming nature of topical treatments, and the belief that oral treatments were more effective than topical treatments.

### Behavioral Analysis

Alongside the PBA, a behavioral analysis was carried out to map the intervention components to the behavior change taxonomy, which is a list of consensually agreed techniques for specifying interventions [25]. The behavioral analysis showed that the intervention targeted nine behavior change techniques from the 93 behavior change taxonomies [25]. A central behavior change technique was *instructions on how to perform the behavior* in terms of advice about choosing the right topical treatment and instructions and demonstrations on how to use topical treatments appropriately. The intervention components were also mapped onto the COM-B model, part of the behavior change wheel [26], to map the target constructs and functions for the intervention [26]. This included six target constructs (physical capability, psychological capability, physical opportunity, social opportunity, automatic motivation, and reflective motivation) and five intervention functions (persuasion, education, training, enablement, and modeling).

Qualitative research showed the Extended Common Sense Model of Illness [27] to be a useful model for understanding how people with acne conceptualize illness and treatment and was therefore used in the behavioral analysis to check that all important components of the model were covered in the intervention (Table 2).

**Table 2.** Behavioral analysis of Spotless intervention.

Barrier or facilitator for target behavior <sup>a</sup> and intervention component	Spotless module	Target construct (BCW) <sup>b</sup>	Intervention function (BCW)	Behavior change technique (using 93 BCTTv1) <sup>c</sup>	Target construct (ECSM) <sup>d</sup>
<b>Concerns about side effects from topical treatments (eg, dry skin and bleaching; QR<sup>e</sup> and SR<sup>f</sup>). Fabbrocini et al [28]: having no side effects was reported as one of the most important attributes of topical treatments (EBL<sup>g</sup>)</b>					
Provide persuasive and credible information about the side effects of topicals and their safety via scientific evidence and personal stories	Core treatments	Psychological capability, reflective motivation, and social opportunity	Education, persuasion, and modeling	<ul style="list-style-type: none"> <li>5.1. Information about health consequences</li> <li>6.2. Social comparison</li> <li>6.3. Information about others' approval</li> <li>9.1. Credible source</li> </ul>	Beliefs about necessity and concerns over its use
Provide advice on how to choose the right topical	Core treatments	Psychological capability	Training and education	4.1. Instructions on how to perform the behavior	Beliefs about necessity and concerns over its use
<b>Confusion about the different types of topical treatments resulting in difficulty with making own treatment choices (QR and SR)</b>					
Provide advice on how to choose the right topical	Core treatments	Psychological capability	Training and education	4.1. Instructions on how to perform the behavior	Curability or controllability
Provide information about different topicals (eg, most common or least common topicals and how they work)	Core treatments	Psychological capability	Education	5.1. Information about health consequences	Curability or controllability
<b>Belief that topical treatments do little to help as they are only keeping their acne at bay (QR)</b>					
<ul style="list-style-type: none"> <li>Provide persuasive and credible information about the effectiveness of topicals via scientific evidence and personal stories</li> <li>Provide rationale for how topicals control acne</li> <li>Explain via personal stories or video that it can take time for topical treatments to work</li> </ul>	Core treatments	Psychological capability, reflective motivation, and social opportunity	Education, persuasion, and modeling	<ul style="list-style-type: none"> <li>5.1. Information about health consequences</li> <li>6.2. Social comparison</li> <li>6.3. Information about others' approval</li> <li>9.1. Credible source</li> </ul>	Beliefs about necessity
Provide a chart for them to monitor how their skin is after applying topical treatments each day as part of the 4-week challenge	Core treatments	Reflective motivation	Education and persuasion	<ul style="list-style-type: none"> <li>5.1. Information about health consequences</li> <li>2.3. Self-monitoring of outcomes of behavior</li> </ul>	Beliefs about necessity
<b>Belief that acne is a short-term condition caused by puberty and therefore it will go away on its own (QR); McNiven [29]: belief that acne is a cosmetic problem rather than a medical condition (EBL)</b>					

Barrier or facilitator for target behavior <sup>a</sup> and intervention component	Spotless module	Target construct (BCW) <sup>b</sup>	Intervention function (BCW)	Behavior change technique (using 93 BCTTv1) <sup>c</sup>	Target construct (ECSM) <sup>d</sup>
<ul style="list-style-type: none"> <li>Provide information on the causes of acne and dispel misconceptions using a myth-busting quiz</li> <li>Provide persuasive and credible information about how acne can be effectively managed using treatment, including scientific evidence and personal stories</li> <li>Provide information about what acne is, the importance of treating it early, and information about referrals</li> <li>Provide advice on when to see an HCP<sup>h</sup> about acne</li> <li>Provide advice on speaking with an HCP about acne</li> </ul>	Myth-busting quiz; What are spots or acne; Talking to your GP <sup>i</sup>	Psychological capability, reflective motivation, social opportunity, and physical opportunity	Education, modeling, persuasion, and training	<ul style="list-style-type: none"> <li>4.1. Instructions on how to perform the behavior</li> <li>5.1. Information about health consequences</li> <li>6.2. Social comparison</li> <li>6.3. Information about others' approval</li> <li>9.1. Credible source</li> </ul>	Cause, timeline, and identity

**Lack of skills regarding how to apply topicals and for how long (QR); Myhill et al [10]: supplementary patient education materials and video about application of topical treatment led to improved adherence (EBL); Sandoval et al [19]: education via physical demonstration led to 15% overall higher adherence rates (EBL)**

<ul style="list-style-type: none"> <li>Provide written instructions and an instructional video on how to use topical treatments correctly</li> </ul>	Core treatments	Physical capability, social opportunity, and reflective motivation	Training, modeling, and persuasion	<ul style="list-style-type: none"> <li>4.1. Instructions on how to perform the behavior</li> <li>6.1. Demonstration of the behavior</li> <li>6.2. Social comparison</li> <li>6.3. Information about others' approval</li> <li>9.1. Credible source</li> </ul>	Concerns over its use
4-week challenge: provide a chart to help people record their skin condition when they have used their topical treatment each day	Core treatments	Reflective motivation	Education and persuasion	<ul style="list-style-type: none"> <li>5.1. Information about health consequences</li> <li>2.3. Self-monitoring of outcomes of behavior</li> </ul>	Concerns over its use

**Belief that topicals are time-consuming to apply (QR); Rueda [15]: simplifying regimen and considering patient preference increases adherence (EBL)**

<ul style="list-style-type: none"> <li>Provide information on how to incorporate topicals in everyday life</li> <li>Reassure people that applying topicals should not be time-consuming</li> <li>Advise people to plan when to apply their topical</li> <li>Suggest applying their topical at the same time in the same context each day</li> </ul>	Core treatments	Psychological capability and automatic motivation	Education and enablement	<ul style="list-style-type: none"> <li>1.4. Action planning</li> <li>4.1. Instructions on how to perform the behavior</li> <li>5.3. Information about social and environmental consequences</li> </ul>	Concerns over its use
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**Belief that tablets are easier, stronger, and quicker to take effect than topicals (QR); Santer et al [30] found that some participants preferred oral treatments as they perceived these to be *stronger* than topicals (EBL)**

Barrier or facilitator for target behavior <sup>a</sup> and intervention component	Spotless module	Target construct (BCW) <sup>b</sup>	Intervention function (BCW)	Behavior change technique (using 93 BCTTv1) <sup>c</sup>	Target construct (ECSM) <sup>d</sup>
<ul style="list-style-type: none"> <li>Provide persuasive and credible information about the effectiveness of topicals and antibiotics via scientific evidence and personal stories</li> <li>Provide information about the consequences of long-term oral antibiotic use</li> </ul>	Core treatments and antibiotics	Psychological capability, social opportunity, and reflective motivation	Education, modeling, and persuasion	<ul style="list-style-type: none"> <li>5.1. Information about health consequences</li> <li>6.2. Social comparison</li> <li>6.3. Information about others' approval</li> <li>9.1. Credible source</li> </ul>	Concerns over its use

<sup>a</sup>Target behavior: appropriate use of topical treatments.

<sup>b</sup>BCW: behavior change wheel.

<sup>c</sup>BCTTv1: behavior change technique using the Behavior Change Technique Taxonomy (v1).

<sup>d</sup>ECSM: Extended Common-Sense Model of Illness.

<sup>e</sup>QR: qualitative research (barriers identified from the secondary analysis of published interview data; evidence-based literature).

<sup>f</sup>SR: systematic review (barriers emerged from systematic review and synthesis of qualitative papers on acne); qualitative research.

<sup>G</sup>EBL: barriers and facilitators emerged from a review of literature on acne (including studies testing the effectiveness of interventions to improve adherence to acne treatments).

<sup>h</sup>HCP: health care practitioner.

<sup>i</sup>GP: general practitioner.

### Web-Based Intervention

The web-based intervention, Spotless, was developed using the LifeGuide software [31]. The intervention was delivered on the web via the internet and included a compulsory core module on topical treatment. This included information about the different types of topical treatments available, how they work, how to use them appropriately, common side effects, and how to manage them. Information was adapted from accurate web-based sources, including National Health Service [32],

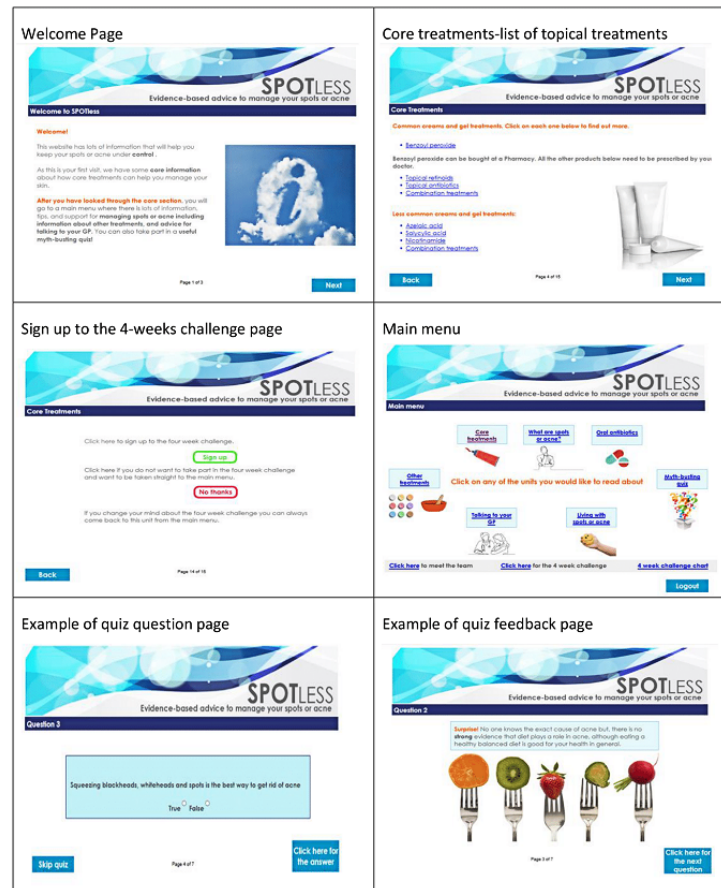
National Institute for Health and Care Excellence [33], and the British National Formulary [34]. This was initially carried out by artificial intelligence, and the team (MS, AG, PL, and IM) provided suggestions throughout. The purpose of adapting the information was to ensure that it was easily understood by young persons. An example of this was using information about types of treatments, including how they are used and the side effects, but rewriting this in lay language. Six optional modules were highlighted as important for the self-management of acne in earlier qualitative studies (Textbox 1).

#### Textbox 1. Overview of intervention.

##### Overview

- When participants first visit the website, they are taken to a *core module* on topical treatments. In the module, they have the option to take part in a 4-week challenge using their choice of topical along with the advice from the website. After completing this module, participants are taken to a main menu page with six optional modules, which they can visit as many times as they want throughout the course of the study. These include *What are spots or acne*, *Myth-busting quiz*, *Oral antibiotics*, *Living with spots or acne*, *Talking to your general practitioner*, and *Other treatments* (see Figure 1 for screenshots of the website).
- After the initial visit, participants are taken directly to the main menu page, where they can choose which modules to explore with the option of looking at the *core module* again.
- The intervention includes a *Meet the team* page where participants are able to see who developed the website (general practitioners, psychologists, and academic researchers); quotes adapted from qualitative research and relevant statistics are presented throughout the intervention, and a downloadable chart is available to help participants self-monitor their progress during the 4-week challenge. The intervention also includes audio, visual, and interactive features including a *myth-busting quiz* where participants can answer questions about popular myths and misconceptions around acne.

Figure 1. Screenshots of the Spotless website.



### Intervention Optimization Using Think-Aloud Interviews

As part of the development stage, think-aloud interviews [35] were carried out with 19 participants with acne using the draft intervention to gather feedback and further modify the intervention. Participants were recruited through mail-out from primary care practices, opportunistic sampling using posters, and advertising via social media. The inclusion criteria for the study were young people aged 14-25 years with acne or those who had consulted about their acne or obtained a prescription for their acne in the past year. Potential participants were excluded if they were outside the age range or did not have acne. General practitioners (GPs) were also asked to screen lists to ensure that the invitation pack was not sent to patients where they felt this would be inappropriate. Face-to-face think-aloud interviews were conducted by following a semistructured interview guide to ensure that all topics were covered while also allowing participants to discuss any concerns they had about the intervention. This process involved asking participants to use the intervention while speaking out their thoughts aloud. Interviews were transcribed and analyzed using a deductive approach to code the data using the objectives of the study (engagement, persuasiveness, and usability) and identify positive and negative comments to aid intervention development.

Overall, participants found the intervention engaging, persuasive, and usable, with some suggestions for changes. Main changes made as a result of the interviews were adding pseudonyms and ages to quotes (these quotes were adapted from the qualitative interview study [24] and included to provide

other peoples' experiences in managing acne); changing the context of certain quotes to make them more relatable to the intended user; providing further clarification on how people can manage sun sensitivity as a potential side effect of topical treatments; further clarification on steps for applying topical treatments (time of day and quantity) and what *sensitive areas of the face* referred to; changing the 6-week challenge to 4 weeks as some participants felt that 6 weeks would be too long to commit and based on evidence that topical treatments could take effect sooner [10]; changing the core module name from *universal core treatments* to *core treatments* so that participants would not misinterpret the website as advertising something; and changing the layout of the intervention including the banner, images, and color scheme.

### Patient and Public Involvement

Two public contributors aged 24 and 26 years with experience of acne provided input throughout to enhance the usability and accessibility of the intervention. This included providing feedback to further enhance the intervention before the feasibility trial, commenting on participant facing documents, and advising on the choice of the primary outcome measure for the trial. Comments about the intervention were both positive and negative regarding the layout, content, and appropriateness of the website for the target population. One contributor commented on their preference of the primary outcome measure for the feasibility trial and opted for Skindex-16 [36] over various other skin-specific QoL measures for reasons including the appropriateness of the questions. Input on the participant

facing documents led to changes in wording, making it more appropriate for a layperson and for the target population.

## Feasibility Study

### Trial Design

This was a randomized, unblinded feasibility trial comparing two parallel groups: usual care and usual care plus web-based intervention.

### Study Population and Eligibility Criteria

The intervention was aimed at young people with acne managed through primary care in the United Kingdom. Participants were recruited through mail-outs from 20 GP practices in the South of England to people aged 14-25 years whose electronic record included a diagnosis of acne and who had received one or more prescriptions for acne in the past 6 months.

People who had previously taken part in the think-aloud study were excluded, as were people who said their acne had cleared and those taking oral isotretinoin, as it is not recommended to use topical acne treatments at the same time as isotretinoin because of the side effects of dry skin.

### Procedure

Patients aged  $\geq 16$  years, who met the criteria, were sent an *adult study pack* from their GP, and patients  $< 16$  years received a *child study pack* (addressed to the parent or carer). Initially, the pack included an information sheet, a freepost envelope, and a covering letter. Those interested returned a reply slip, and a member of the study team contacted the participant, providing them with a unique participant identification number and the link to the web-based intervention. Amendments were made to the process, and these were approved by both the university and National Health Service ethics committees. Changes included an additional A5 flyer about the study to appeal to the target population and a sign-up sheet providing participants with their unique identification number and a link to the intervention. These changes were essential for assessing the feasibility of the study with a challenging population to recruit. Implied parental consent was approved for participants aged  $< 16$  years as invitation letters were sent to the parents; therefore, passing log-in details to their child implied consent. This is because young people from 14 years usually self-manage their acne and are responsible for using topical treatments themselves. The link directed all participants to further information and a web-based consent procedure. After consenting, participants were asked to complete a set of baseline questionnaires before being randomized into 1 of 2 groups. Follow-up questionnaires for the trial were conducted at 4 and 6 weeks as a recent study suggested that topical treatments could take effect within 1 to 4 weeks and that continuation after the 4 weeks would lead to further improvements [10]. Participants received an automated email followed by a reminder email a week after (5 and 7 weeks) if they had not completed these. Further text and subsequent phone follow-ups were conducted for nonresponders to complete the outcome measures, particularly the primary outcome Skindex-16.

## Intervention and Comparator

The usual care group received treatment as usual from their GP, including appointments, prescriptions, and referrals to the dermatologist, if necessary. Participants in this group were given access to the intervention after they had completed the 6-week follow-up questionnaires.

Participants in the usual care plus web-based intervention group received care as usual with immediate access to the website as described to help them self-manage their acne.

## Outcome Measures

We sought to assess a range of feasibility outcomes including the following:

- The rate of recruitment and the number of practices required
- Completion rates of questionnaire outcome measures
- The acceptability of measuring skin-specific QoL using Skindex-16
- The feasibility of a range of quantitative measures
- Intervention usage in terms of number of log-ins and modules accessed

Outcome measures included the following: Skindex-16 [36] was included as a skin-specific QoL measure. Skindex-16 is a validated measure that includes 16 items on a 6-point Likert scale ranging from 0 (never bothered) to 6 (always bothered), which are transformed into a 100-point scale, with higher scores indicating a lower level of QoL [36].

EQ-5D-5L [37] was included as a health-related QoL measure collected at all intervals. It comprised five domains (mobility, self-care, usual activities, pain or discomfort, and anxiety or depression) with five response levels (no problems, slight problems, moderate problems, severe problems, and extreme problems) that describe the current health state. The visual analog scale was also included alongside this [37].

The Problematic Experiences Therapy Scale (PETS) [38] was included and data collected at each interval to explore barriers to treatment adherence. This measure includes 12 items with four subscales: *problems due to symptoms*, *problems due to uncertainty about therapy*, *problems due to doubts about treatment efficacy*, and *practical problems*. Participant responses were scored on a scale ranging from 1 (disagree strongly) to 5 (agree strongly), with higher scores indicating fewer barriers to adherence [38].

Participants also completed the Credibility/Expectancy Questionnaire at baseline as a process predictor. It measures how a person thinks and feels about their therapy and its likely success [39]. These are measured using two types of rating scales, one from 1 (not at all) to 9 (very much) and another from 0% (not at all) to 100% (very much), and it provides an overall score ranging from 3-27 for each factor [40].

The Patient Health Questionnaire-4 (PHQ-4) was used to measure anxiety and depression [41] collected at all intervals. This brief screening tool has been shown to be a reliable and valid measure in young people [42] and includes 4 items measured on a 4-point Likert scale ranging from 0 (not at all) to 4 (nearly every day) [41].

Treatment monitoring questions were included in order to collect data on what topical treatments participants were using, whether they experienced side effects, how they dealt with these, how often they were using treatment, and any other treatments they were using for their acne.

Sociodemographic questions included age, gender, education, age of onset of acne, and whether living with parents or independently.

### Sample Size

The target sample size was 65 participants, with 40 in the intervention group and 25 in the usual care group. This was deemed appropriate as guidance on sample sizes in feasibility trials ranged from 12 to >30 participants in each arm [43,44].

### Randomization

We intended randomizing all participants into 2 groups in a 2:1 ratio using a computer-generated algorithm. However, because of an error in the randomization software, the block randomization was changed to a 1:1 ratio. The sequence was concealed as this was all done via a computer.

### Data Collection and Analysis

Data were automatically collected via the LifeGuide software [31], including information about recruitment, number of log-ins, and which modules or pages participants had accessed. Descriptive statistics were used to describe the data, and outcome measures were analyzed using SPSS version 25 [45]. Linear regression, adjusting for baseline scores, age, gender,

education, and age of onset of acne, was performed to provide estimates of mean scores between groups (with 95% CIs). Intention-to-treat analysis was used, including all participants who were randomized, without imputing missing data. There was no significance testing, as this was a feasibility trial and was not sufficiently powered to seek differences between groups.

### Ethics Approval

The feasibility trial was approved by the National Research Ethics Service Committee east of England (ref: 18/EE/0105) and registered on the ISRCTN registry (78626638).

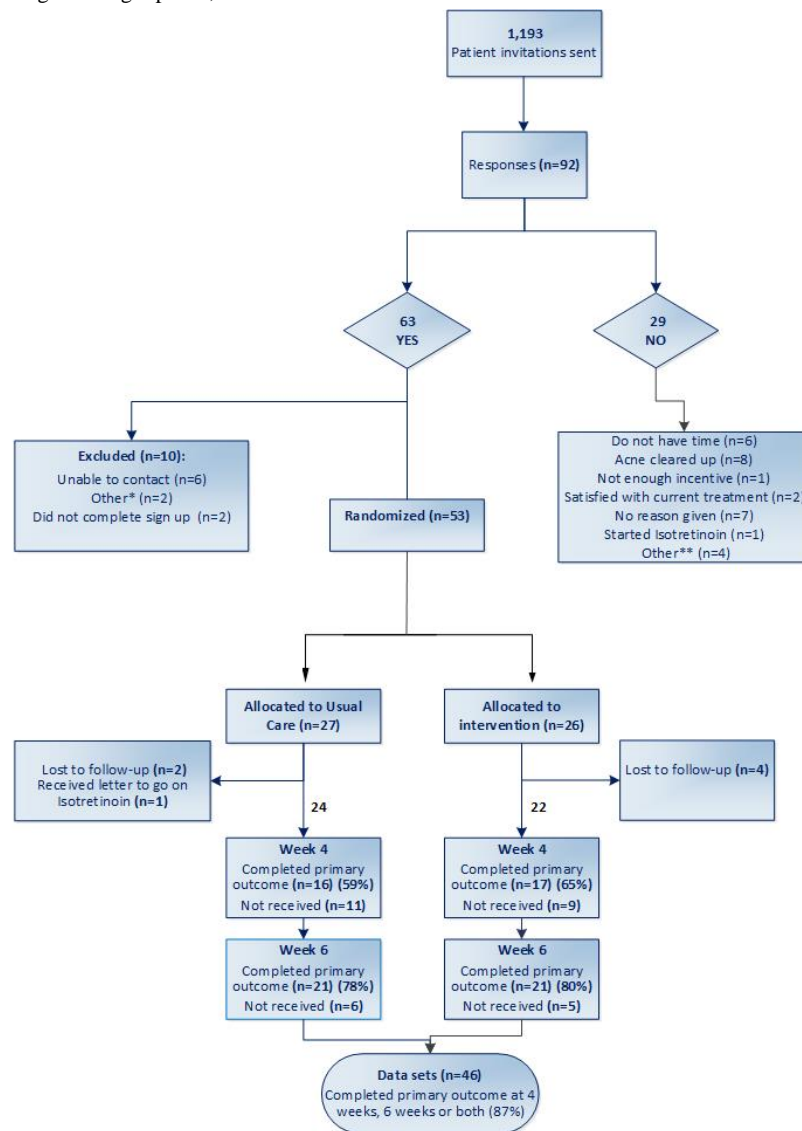
## Results

### Recruitment

Recruitment took place from September 2018 to April 2019, and the follow-up ended in June 2019. In total, 1193 invitation letters were sent from 20 primary care practices in the South of England. Of the 1193 invitations sent, we received 92 (7.71%) responses, with 63 (5.28%) agreeing to take part and 29 (2.43%) giving reasons why they could not. Of the 63 participants, 53 (84%) registered on the web and were randomized (usual care: 27/53, 51%; usual care plus web-based intervention: 26/53, 49%). Of the 53 registered participants, 46 (87%) participants completed follow-up at 4 weeks, 6 weeks, or both time points (Figure 2). Five practices carried mail-out using the amended documents, which led to a small increase in participants signing up for the study—from 4.5% to 4.8%.



**Figure 2.** Flow diagram of recruitment process. \*Problem with LifeGuide randomization procedure incurred delay and participants did not log back in; \*\*Felt like homework; not planning on using topicals; not interested.



**Participant Characteristics**

The sample comprised 72% (38/53) female and 28% (15/53) male participants with a mean age of 19 (SD 2.6) years. The

mean age at the onset of acne was reported as 14 (SD 2.1) years. Of the 53 participants, 39 (74%) reported living at home, and 44 (83%) were in full-time education (Table 3).

**Table 3.** Participant characteristics at baseline (N=53).

Participant characteristics	Intervention (n=26)	Usual care (n=27)	Total (n=53)
<b>Gender, n (%)</b>			
Female	21 (81)	17 (63)	38 (72)
Male	5 (19)	10 (37)	15 (28)
Age (years), mean (SD)	18.3 (2.6)	18.8 (3.4)	18.6 (3)
Age at onset of acne (years), mean (SD)	13.54 (2.1)	13.8 (2.5)	13.7 (2.3)
<b>Living at home, n (%)</b>			
Yes	21 (81)	18 (67)	39 (74)
No	5 (19)	9 (33)	14 (26)
<b>Currently in full-time education, n (%)</b>			
Yes	22 (85)	22 (82)	44 (83)
No	4 (15)	5 (19)	9 (17)

### Questionnaire Completion

Baseline completion rates were high for all questionnaires (Table 4). Not all participants experienced side effects; therefore, the question about their management had a lower completion rate at each interval. Completion rates were higher at 6 weeks than at 4 weeks as there was a longer period to contact participants

by phone to complete the questionnaires if they had not done so after receiving the reminder emails. At 4 weeks, 6% (1/17) of participants in the intervention group and 6% (1/16) of participants in the usual care group completed the primary outcome measure from the questionnaire over the phone. At 6 weeks, this was 24% (5/21) of participants in the intervention group and 14% (3/21) in the usual care group.

**Table 4.** Questionnaire completion rates (N=53).

Outcome measure	Baseline, n (%)	4 weeks, n (%)	6 weeks, n (%)
Overall Skindex-16	53 (100)	33 (62)	42 (79)
EQ-5D-5L	53 (100)	32 (60)	39 (74)
EQ VAS <sup>a</sup>	53 (100)	31 (59)	34 (64)
PHQ-4 <sup>b</sup>	53 (100)	31 (59)	36 (68)
Credibility	53 (100)	N/A <sup>c</sup>	N/A
Expectancy	53 (100)	N/A	N/A
PETS <sup>d</sup> symptoms (n=26)	26 (100)	17 (65)	17 (65)
PETS uncertainty (n=26)	25 (96)	17 (65)	17 (65)
PETS doubts (n=26)	25 (92)	17 (65)	17 (65)
PETS practical problems (n=26)	25 (96)	17 (65)	17 (65)
What topical using	53 (100)	31 (59)	36 (68)
How often using treatment	53 (100)	31 (59)	34 (64)
Side effects	51 (96)	31 (59)	32 (60)
Management of side effects (people who reported side effects)	31 (59)	19 (36)	25 (47)
Other treatment	53 (100)	30 (57)	37 (70)

<sup>a</sup>EQ VAS: EuroQol Visual Analogue Scale.

<sup>b</sup>PHQ-4: Patient Health Questionnaire-4.

<sup>c</sup>N/A: not applicable.

<sup>d</sup>PETS: Problematic Experiences Therapy Scale.

## Outcome Measures

### Skindex-16

The Skindex-16 overall mean score at baseline was 55.4 (SD 21.8) across both groups. There was a substantial improvement in both groups, and the mean differences between groups, when

controlling for baseline scores and covariates (gender, age, age onset, and education), suggested a trend toward benefit at both 4 and 6 weeks: at 4 weeks, the intervention group had a score 5.2 points lower (95% CI -14.58 to 4.09) than the usual care group and at 6 weeks 2.9 points lower (95% CI -13.27 to 7.47; Table 5).

**Table 5.** Scores at baseline and follow-up and estimate of mean differences controlling for baseline and covariates (n=53).

Score description	Baseline		4-week follow-up		4-week follow-up, controlling for baseline and other covariates, mean difference (95% CI)	6-week follow-up		6-week follow-up, controlling for baseline and other covariates, mean difference (95% CI)
	n value	Value, mean (SD)	n value	Value, mean (SD)		n value	Value, mean (SD)	
<b>Overall Skindex-16 scores</b>								
Usual care	27	55.4 (24)	16	54.2 (18.7)	N/A <sup>a</sup>	21	48 (23.8)	N/A
Web-based intervention	26	55.3 (19.8)	17	45.8 (19.9)	-5.2 (-14.58 to 4.09)	21	43.4 (22.2)	-2.9 (-13.27 to 7.47)
<b>Skindex-16 symptom</b>								
Usual care	N/A	41.3 (25.5)	N/A	35.5 (21.5)	N/A	N/A	37.3 (24.3)	N/A
Web-based intervention	N/A	31.9 (19.8)	N/A	30.6 (24.1)	5.4 (-8.41 to 19.22)	N/A	27 (21.5)	-0.9 (-11.76 to 10.03)
<b>Skindex-16 emotional</b>								
Usual care	N/A	72.7 (27.5)	N/A	74.2 (23.4)	N/A	N/A	63.6 (28.1)	N/A
Web-based intervention	N/A	76.6 (21.1)	N/A	63.7 (22.3)	-12.4 (-24.23 to -0.67)	N/A	62 (24.3)	-3.9 (-16.65 to 8.75)
<b>Skindex-16 functioning</b>								
Usual care	N/A	42.6 (28.3)	N/A	41.2 (22.7)	N/A	N/A	34.8 (27.8)	N/A
Web-based intervention	N/A	44.1 (27.9)	N/A	31.9 (26.8)	-6.4 (-20.52 to 7.79)	N/A	30.5 (28.9)	-3.4 (-16.75 to 9.9)
<b>PHQ-4<sup>b</sup> total</b>								
Usual care	27	4 (3.5)	16	3.9 (3.3)	N/A	18	3.7 (3.3)	N/A
Web-based intervention	26	4.6 (3.7)	15	2.3 (2.9)	-1.7 (-3.66 to 0.18)	18	3.2 (3.3)	-0.8 (-2.6 to 0.97)
<b>PETS<sup>c</sup> symptoms</b>								
Usual care	26	3.9 (1)	14	4 (1.1)	N/A	17	4.1 (0.9)	N/A
Web-based intervention	26	3.9 (0.9)	17	4.2 (1.2)	0.2 (-0.65 to 1.15)	17	4.2 (0.9)	0.2 (-0.47 to 0.82)
<b>PETS uncertainty</b>								
Usual care	26	4.5 (0.9)	15	4.5 (1.2)	N/A	18	4.2 (1.1)	N/A
Web-based intervention	25	4.4 (1)	17	4.7 (0.6)	0.1 (-0.51 to 0.67)	17	4.9 (0.2)	0.6 (0.19 to 1.08)
<b>PETS doubt</b>								
Usual care	27	3.8 (1)	19	3.7 (1.1)	N/A	18	3.7 (1.1)	N/A
Web-based intervention	24	3.4 (1.3)	17	4.2 (0.8)	0.5 (-0.23 to 1.25)	17	4.2 (1)	0.5 (-0.18 to 1.24)
<b>PETS practical problems</b>								
Usual care	27	3.4 (1.3)	15	3.6 (1.3)	N/A	18	3. (1.3)	N/A
Web-based intervention	25	3.8 (1)	17	4 (1.1)	0.1 (-0.44 to 0.73)	17	4.1 (1.1)	0.7 (0.02 to 1.3)

<sup>a</sup>N/A: not applicable.

<sup>b</sup>PHQ-4: Patient Health Questionnaire-4.

<sup>c</sup>PETS: Problematic Experiences Therapy Scale.

### Individual Subscales for Skindex-16

There was no evidence of a trend toward benefit in the symptoms subscale (intervention group 5.4 points higher at 4 weeks: 95% CI -8.41 to 19.22; 0.9 points lower at 6 weeks: 95% CI -11.76 to -10.03); however, some evidence of a trend toward benefit in the emotional subscale (intervention 12.4 points lower at 4 weeks: 95% CI -24.23 to -0.67; 3.9 points lower at 6 weeks: 95% CI -16.65 to 8.75) and functioning subscale (intervention group 6.4 points lower at 4 weeks: 95% CI -20.52 to 7.79; 3.4 points lower at 6 weeks: 95% CI -16.75 to 9.9; Table 5).

### Other Outcome Measures

The baseline mean score for anxiety and depression (PHQ-4) suggests that the overall scores between groups were in the mild

range for anxiety and depression with a score of 4.3 (SD 3.6) and a trend toward improvement in the intervention group at 4 weeks compared with the usual care group. For all PETS subscales (symptoms, uncertainty, doubt, and practical problems), there were also suggestions of a trend toward benefit (Table 5).

### Treatment Monitoring

#### Topical Treatment Used

More people in the usual care group reported using topicals at baseline compared with those in the intervention group. In the intervention group, the percentage of people using topicals increased from baseline to 4 weeks by 13.5% and decreased by 0.8% in the usual care group (Table 6).

**Table 6.** Reported topical treatment use between groups at each interval.

Topical used	Intervention		Usual care	
	n (%)	N	n (%)	N
<b>Topical treatments</b>				
Baseline	16 (62)	26	20 (74)	27
4 weeks	12 (75)	16	11 (73)	15
6 weeks	15 (88)	17	15 (79)	19
<b>None</b>				
Baseline	3 (12)	26	6 (22)	27
4 weeks	3 (19)	16	4 (27)	15
6 weeks	2 (12)	17	4 (21)	19
<b>Other<sup>a</sup></b>				
Baseline	7 (27)	26	1 (4)	27
4 weeks	1 (6)	16	0 (0)	15
6 weeks	0 (0)	17	0 (0)	19

<sup>a</sup>Other topical treatments including branded products.

### Topical Treatment Side Effects and Management

At 4 and 6 weeks, the usual care groups reported similar rates of side effects compared with the intervention group (Table 7). There was an increase of 13.5% from baseline to 4 weeks in the number of people reporting continuing treatment (including altering application as advised by the website) when

experiencing minor side effects compared with the usual, which decreased by 2.4% at 4 weeks (Table 8). In both groups, the most common frequency of application at all intervals was *once or more than once a day or most days*. The intervention group and the usual care decreased similarly in the number of people reporting application of *once or more than once a day or most days* at 4 weeks (Table 9).

**Table 7.** Reported side effects from topical treatments.

Side effects	Intervention		Usual care	
	n (%)	N	n (%)	N
<b>Topical treatments</b>				
Baseline	15 (60)	25	16 (62)	26
4 weeks	9 (53)	17	8 (57)	14
6 weeks	10 (67)	15	12 (71)	17
<b>None</b>				
Baseline	10 (40)	25	10 (39)	26
4 weeks	8 (47)	17	6 (43)	14
6 weeks	5 (33)	15	5 (29)	17

**Table 8.** Reported management of side effects from topicals.

Management of side effects	Intervention		Usual care	
	n (%)	N	n (%)	N
<b>Continued treatment</b>				
Baseline	9 (64)	14	14 (82)	17
4 weeks	7 (78)	9	8 (80)	10
6 weeks	7 (64)	11	10 (71)	14
<b>Stopped treatment</b>				
Baseline	5 (36)	14	2 (12)	17
4 weeks	2 (22)	9	0 (0)	10
6 weeks	2 (18)	11	1 (7)	14
<b>Other<sup>a</sup></b>				
Baseline	2 (14)	14	1 (6)	17
4 weeks	1 (11)	9	2 (20)	10
6 weeks	1 (9)	11	3 (21)	14

<sup>a</sup>Other management included using moisturizer, hydrating masks, or face washes.

**Table 9.** Reported frequency of application of topicals.

Frequency of application	Intervention		Usual care	
	n (%)	N	n (%)	N
<b>Once or more than once a day or most days</b>				
Baseline	19 (73)	26	19 (70)	27
4 weeks	11 (65)	17	9 (64)	14
6 weeks	13 (81)	16	12 (67)	18
<b>Not at all or once or twice a week</b>				
Baseline	7 (27)	26	8 (30)	27
4 weeks	6 (35)	17	5 (36)	14
6 weeks	3 (19)	16	6 (33)	18

### Intervention Use

Approximately 88% (23/26) of participants in the intervention group completed the core module *core treatments*. Completion was decided based on whether participants clicked through to

the end of the core module pages without logging off the web-based intervention. Approximately 69% (18/26) of participants visited the website three times or more, including baseline visits. There was a low uptake of the 4-week challenge

(38%), although this was based on whether participants entered a start date; however, it is possible that some participants engaged without entering a start date. Visits to some of the optional modules were low: 42% of participants accessed the

module on *living with spots or acne*, and more than a quarter viewed the *myth-busting quiz*; fewer were interested in *talking to your GP* (Table 10).

**Table 10.** Intervention use (N=26).

Measures of intervention use	Web-based intervention, n (%)
Core module completed	23 (88)
<b>Total number of visits to intervention</b>	
1	3 (12)
2	5 (19)
3	7 (27)
4	7 (27)
5	2 (8)
6	2 (8)
Signed up to 4-week challenge	10 (38)
<b>Visits to other modules</b>	
Living with spots or acne	11 (42)
Myth-busting quiz	7 (27)
What are spots or acne	7 (27)
Other treatments	7 (27)
Oral antibiotics	5 (19)
Talking to your GP <sup>a</sup>	3 (12)

<sup>a</sup>GP: general practitioner.

## Discussion

### Principal Findings

To our knowledge, this is the first web-based behavioral intervention developed for young people with acne, using the PBA along with theory and evidence [22]. The recruitment rate of 8% was lower than expected; however, retention rates for people completing the primary outcome measure at either 4 or 6 weeks were high (87%). There was a suggestive trend toward benefit in the primary (Skindex-16) and secondary outcome measures (PHQ-4 and PETS) when looking at the mean differences. More people in the intervention group reported using topical treatments, and they were also more likely to manage side effects from topical treatments by continuing treatment as opposed to stopping treatment compared with the usual care group. Completion of the core module was high (88%), although it was low for the optional modules. Although promising, these findings should be viewed with caution, as this study was not powered to determine effectiveness.

### Limitations

There were several limitations and changes that should be considered based on the findings of this feasibility trial. First, the mail-out through primary care practices received a low response rate, suggesting that people who took part in the trial may be more motivated and possibly have higher literacy than those who did not respond. Therefore, the sample may not be fully representative of young people who consult primary care

for their acne. A key reason for not participating was time commitment, which suggests that the level of involvement in the study may need to be made clearer. Another reason for not participating was that some participants' skin had cleared up. This could be a reflection on the search strategy or the unpredictable nature of their skin condition. The changes to the recruitment process led to a slight increase in response rate which suggests that if implemented earlier this could have potentially improved the numbers recruited. People who took part in the study also seemed to be using topical treatments already, which suggests that recruitment in a future trial should seek participants who are not already using them to benefit from the intervention. We may also need to consider other ways of reaching the target population, including other platforms such as social media, pharmacies, and schools.

Second, there was a low uptake of the optional modules, which suggests that the intervention may need to be refined further. However, the reason for including these modules as optional was that they might not be applicable to everyone at that time but were seen as important in earlier qualitative research. Uptake of the *4-week challenge* was low; however, this was only determined by people entering a date to start the challenge. In the future, this should be monitored more closely, and perhaps there should be a question in the survey to identify those who did and did not take part. It is also unclear whether people in the usual care group attended their GP practices and were prescribed treatment as usual, making it difficult to fully

understand why people in the usual care increased on a number of outcome measures.

Although the target sample size was not reached, this was a feasibility study and provided useful information about the changes that need to be considered for a future trial. Owing to the randomization error, participants were randomized in a 1:1 ratio instead of 2:1 for intervention to usual care group. This resulted in less usage data for the intervention group, which could have provided further information on intervention use. Although there was a trend toward benefit in both the primary and secondary outcome measures, a larger sample is needed to draw conclusions about the effect of the intervention.

### Comparison with Prior Work

The findings from this feasibility trial reflect the results of previous trials testing the effectiveness of interventions for acne [11,13-15,19]. For example, a pilot RCT of an interactive health education tool also found that those in the intervention group had improved QoL scores compared with the control group, although these findings were not statistically significant [11]. However, this study did not specify which treatments were being used by participants in the intervention (topical or oral treatments); therefore, comparisons should be made with caution. In this study, we used PETS scores to determine adherence to topical treatments, which suggested a trend in the direction of benefit. A previous RCT investigating the effectiveness of supplementary educational materials on a

combination topical treatment also found improved adherence, although using an objective measure (medication event monitoring system) [10]. There is currently no standardized or fully validated method of measurement for adherence to acne treatments [46], and further work would benefit in addressing this so that heterogeneity and adherence can be compared across trials.

The rate of follow-up in this study was high at 6 weeks (79%) in terms of those completing the primary outcome measure (Skindex-16). This is in line with a previous trial that found a follow-up rate of 84.5% when recruiting through primary care [10]. Similarly, a study investigating adherence rates using an internet-based survey for young people with acne had a follow-up rate of 75%, although it is unclear where participants were recruited from, and the sample size was small with 20 participants [14].

### Conclusions

This feasibility trial demonstrates that a web-based behavioral intervention for young people with acne can be delivered with high retention, high engagement with the core module, and trends in the direction of benefit for the primary outcome measure. However, recruitment to this study was challenging, and alternative methods of seeking participants should be considered for a full-scale trial of a similar intervention, particularly when seeking a population less likely to be using effective topical treatments for acne.

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### Conflicts of Interest

None declared.

### Multimedia Appendix 1

CONSORT-EHEALTH checklist (V 1.6.1).

[PDF File (Adobe PDF File), 1133 KB - [derma\\_v4i2e25918\\_app1.pdf](#) ]

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## Abbreviations

**GP:** general practitioner

**PBA:** Person-based approach

**PETS:** Problematic Experiences Therapy Scale

**PHQ-4:** Patient Health Questionnaire-4

**PROSPERO:** International Prospective Register of Systematic Reviews

**QoL:** quality of life

**RCT:** randomized controlled trial

**TIDieR:** Template for Intervention Description and Replication

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Research Letter

# The Role of Providers and Influencers in the Use of Social Media as Solace for Psoriasis: Qualitative and Quantitative Study

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## Abstract

**Background:** Psoriasis is a multisystem chronic inflammatory skin disease and is a relatively common disorder in children and adults. The burden of psoriasis impacts both the physiological and psychological areas of one's life. Given the robust use of the internet and social media, patients have turned to Instagram for educational and social support to discuss psoriasis.

**Objective:** This study aimed to characterize how patients interact with Instagram to cope with the biopsychosocial aspects of psoriasis. We analyzed journals and organizations, and compared them with the public profiles of individuals diagnosed with psoriasis who provided information and refuge. Our goal was to identify how followers engaged and what type of content they were most receptive to in terms of psoriasis.

**Methods:** All journals and organizations representing psoriasis were selected for review. The top 10 public profiles of individuals diagnosed with psoriasis were also selected for comparison. The numbers of followers, followings, and posts were noted to evaluate popularity. The numbers of likes and comments were also recorded to understand engagement.

**Results:** On comparing journals and organizations to public profiles, we found that the former had a greater number of followers but engaged less with the audience on Instagram based on the number of profiles they followed. Profiles of individuals with psoriasis produced content that was more personal and relatable, including experiences with flares, motivational text, and emotional support. The content produced by journals and organizations was geared toward education and providing peer-reviewed resources and commentary from licensed health care professionals. Followers were more engaged via "likes" than "comments" on the Instagram profiles of journals and organizations, as well as the public profiles of individuals diagnosed with psoriasis.

**Conclusions:** There was evident online presence of journals and organizations, and public profiles of individuals providing content regarding psoriasis on Instagram. However, there were distinguishing features for the type of content being produced. Journals and organizations took the traditional approach in providing evidence-based information, whereas the public profiles of individuals provided content related to the psychosocial needs of the psoriasis community. The 10 profiles of individuals provided posts involving creativity and real experiences, which were evidently well-received based on "likes" and "comments." This research helps us appreciate what the audience on Instagram is looking for to further address how we can merge these needs to provide a holistic platform on Instagram for both providers and patients. Social media creates a space for collaboration, which can be advantageous for journals and organizations to work with patient volunteers from diverse backgrounds who can help build a therapeutic alliance and public presence on Instagram with their viewers in order to deliver medical peer-reviewed information.

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## KEYWORDS

psoriasis; psychodermatology; social media; Instagram; coping skills; stigma; depression; anxiety; psychosocial; influencers; internet

## Introduction

Psoriasis is a multisystem chronic inflammatory skin disease and is a relatively common disorder in children and adults. There are many risk factors associated with the disease, including genetic, environmental, and behavioral factors. The primary pathophysiology of psoriasis is mediated by the immune system, where T lymphocytes, dendritic cells, and cytokines play important roles [1]. Patients typically present with scaling, induration, and erythema of the skin, which leads to hyperproliferation and abnormal differentiation of the epidermis, vascular dilatation, and inflammatory cell infiltrates [2].

The burden of psoriasis impacts both the physiological and psychological areas of one's life. The prevalence of depression and anxiety in patients with psoriasis is significantly higher than that in the general population [3]. On comparing quality of life between those with psoriasis and those with different dermatological conditions, discrepancies have been observed. Patients diagnosed with psoriasis have been compared to those with urticaria, acne, nonatopic eczema, and alopecia [4]. The findings showed that those with psoriasis most often reported stress as the predominant factor in disease exacerbation, which impacted their activities of daily living more frequently than other conditions. Evidence based on systematic reviews of the literature on the psychopathology in psoriasis has indicated that stress is the driving factor of onset, exacerbation, and relapse [5]. The economic impact of psoriasis has been studied by examining the costs of various therapeutic options. The average monthly expense for treatment ranges from US \$100 to \$200, and this is prior to the consideration of the severity of the disease [6]. The financial burden of this disease is associated with lower quality of life as severity increases, which can further exacerbate the psychosocial stressors. Psychodermatology addresses the interaction between the mind and the skin. While psychiatry is focused on the internal nonvisible disease, dermatology explores the external visible aspects. A neuroimmunocutaneous system has been described as the interplay between these two specialties, where the courses of inflammatory skin diseases and psychiatric conditions disrupt this inherent system [7]. Visibility of lesions significantly affects body image in this patient population, often leading to stigmatization, and it has negative effects on psychological health.

Our interest lies in how patients cope with the psychological impacts of the illness using social media, specifically Instagram, as a resource. The increase in internet users in the past few decades has been exceptional, with 8% activity in 2005 rising to 74% in 2012 [8]. Various social media platforms are readily available for discussion on everyday trials and tribulations, including dermatology. Given the visual component of scrolling through a media feed, platforms like Instagram can be a cornerstone in providing education and resources for patients with psoriasis. Previous research has explored Facebook, Twitter, YouTube, and LinkedIn as means of communication [8-11], but limitations consistently point toward the lack of

medical resources presented in a way to garner enough attention of users and the targeted audience [9].

Given the robust use of the internet and social media, we explored how journals and organizations, as well as public accounts on psoriasis, discuss education or personal experience in the context of their posts on Instagram. We studied how this information is received and which profiles had the most popularity (or engagement) based on their social media presence. We further investigated the possible implications of the utility of these applications for communication between health care professionals and patients.

## Methods

### Data Collection

We began collecting data by searching Instagram for notable journals and organizations that study and educate the public about psoriasis. The first 50 public posts of each account were studied for performance based on the number of followers, the number of accounts followed, and audience interaction through likes and comments.

Four Instagram accounts with respect to journals and organizations specific to psoriasis included the *Journal of American Academy of Dermatology*, *Journal of the American Medical Association (JAMA) Dermatology*, American Academy of Dermatology Association, and National Psoriasis Foundation. Psoriasis Speaks and the *Journal of Psoriasis and Psoriatic Arthritis* did not have an Instagram presence.

It is important to clarify that although *JAMADermatology* had a direct link to their Instagram account on their webpage, the Instagram account itself encompassed the entire JAMA Network, reflecting all medical specialties. It was included in our research for completeness. We surveyed the posts for all material related to dermatology and then filtered specifically for psoriasis.

Next, public Instagram accounts of individuals who are advocates for psoriasis were reviewed. There were more than a dozen accounts that represented people living with psoriasis; however, we limited our search to profiles that explicitly included "psoriasis" or "skin" (or other terms related or implying psoriasis, such as spot, spotty, and spotted) in their Instagram handle. The first 10 accounts with a prominent social media presence were reviewed. These were @getyourskinout, @psoriasis\_thoughts, @beautifullyspotted, @overcoming\_psoriasis, @fixmypsoriasis, @klmpsoriasis, @spottiettoohottie, @cyapsoriasis, @thegirlwithpsoriasis, and @pspotted.

### Data Analysis

This is both a qualitative and quantitative study. Quantitatively, we gathered statistics based on the numbers of followers, followings, and posts by each account in order to understand the popularity of these profiles. Next, we studied the data on

the numbers of likes and comments to interpret receptivity from the Instagram community. Qualitatively, we observed the context of the posts on each account, limited to the first 50 as previously mentioned, to explore which ideas and experiences are well received based on the numbers of likes and comments on each post.

By summarizing the numbers of followers, followings, and posts, we were also able to assess the visibility of the content. More likes and comments increase online presence, and therefore given the algorithms of social networks, they increase the visibility of the profiles themselves.

In our qualitative analysis, the themes we were interested in exploring were who, what, and how people responded to the content on Instagram. To identify the “who,” we observed if the content was produced by physicians or people with psoriasis. To answer the “what,” we explored the type of content being produced, for example, educational versus personal experiences with flares, treatment, and psychosocial aspects of psoriasis. To investigate the “how,” we inquired if the audience engaged more so by liking the post or commenting on it.

We excluded video posts on Instagram from our data analysis as this feature was not utilized on the platforms of journals and organizations during the timeframe of our search. We will comment on the use of videos briefly in the Discussion section.

**Table 1.** Instagram profile data of medical journals and national organizations.

Name	Followers, n	Followings, n	Posts, n
JAMA Network	84,900	82	423
<i>Journal of the American Academy of Dermatology</i>	44,700	291	634
American Academy of Dermatology	63,100	452	802
National Psoriasis Foundation	18,000	327	852

The results showed that journals and national organizations had a larger group of followers but had a relatively low number of accounts they interacted with, indicated by their “followings.” The mean number of posts by journals and national organizations collectively was 667.8 (SD 193.7). Within the context of these posts, summarized in Table 2, the American Academy of Dermatology failed to produce any content on psoriasis. The JAMA Network had a total of 432 medically related posts, and there were only 20 posts that focused on dermatology and only one that discussed psoriasis. The post illustrated the inflammatory process in psoriasis. The text provided a link to a JAMA article for more information on the topic. The *Journal of the American Academy of Dermatology* produced two posts related to medical complications secondary to psoriasis, as well as alternative medicine as a therapeutic option. The National Psoriasis Foundation produced 43 posts related to psoriasis, and its impact on other organ systems, as well as one’s personal and professional life. There were various

The described work presents minimal risk research. We used public user data from Instagram, adhering to the terms and conditions, terms of use, and privacy policies of Instagram. Any identifying and personal health information was redacted from the profiles.

## Results

The data presented in the tables below were reflective statistics as on April 8, 2021.

From the six major journals and organizations that represent psoriasis and speak about psoriasis, only four had a presence on Instagram. The opposite was true when searching for public profiles of individuals representing or advocating for psoriasis. Therefore, we had to limit our consideration of public profiles to the top 10 accounts that personified psoriasis through their content. We did not review profiles that had personal names in their account screen names.

Table 1 presents the journals and national organizations on Instagram organized by the number of followers, number of people they followed, and number of posts. The JAMA Network profile, as discussed above, was included for completeness after filtering for dermatology and then psoriasis in particular.

infographics of patient testimonies that provided feedback and support to the online psoriasis community. Treatment options were also discussed in their content. It was observed that for the mentioned accounts, the audience participated to a greater extent via “likes” than “comments.” On average, there were collectively 805.5 (SD 361.5) likes compared to 16.0 (SD 7.3) comments. The people who provided the information were cited as physicians or postdoctoral scholars. Each post included a peer-reviewed source that the audience could read if they needed more information that was not provided. The illustrations were consistent throughout multiple posts, using the same color scheme and inclusion of relevant logos or trademarks. There was no content created by patients or other individuals dealing or working with psoriasis. In addition, there were no pharmaceutical advertisements targeted at the treatment of psoriasis. Therapeutic options were explained by physicians. In summary, the popularity of these posts was driven by “likes.”

**Table 2.** Categorization of identified posts and audience engagement based on journals and national organizations.

Name	Number of related posts <sup>a</sup>	Summary of content (“What”)	Information provider (“Who”)	Number of likes (“How”), mean or mean (SD)	Number of comments (“How”), mean or mean (SD)
JAMA Network	1	Pathophysiology of psoriasis	Physician	839	9
<i>Journal of the American Academy of Dermatology</i>	2	Psoriasis-related medical issues and alternative medicine as a treatment	Physicians and researchers	1149 (553)	15.5 (11.5)
National Psoriasis Foundation	43	Psoriasis and the impact in other organ systems, personal and professional life, patient testimonies, and treatment options	Physicians, researchers, patients, and unspecified content creators	438.4 (619.3)	23.6 (32.7)
American Academy of Dermatology	0	N/A <sup>b</sup>	N/A	N/A	N/A

<sup>a</sup>The number of related posts is based on the first 50 recent posts on the social media page.

<sup>b</sup>N/A: not applicable.

**Table 3** outlines the top 10 public profiles reviewed that were related to psoriasis. The profile data were noted similarly to the journals and national organizations. Although, on average, they had a lower number of followers, these profiles engaged more with the Instagram network as shown by the increase in people

the accounts themselves followed. The relationship between followers and followings appeared to be more evenly distributed. Collectively, the 10 public profiles had a mean of 264.7 posts (SD 217), which was less compared with that of journals and national organizations.

**Table 3.** Instagram profile data on public profiles advocating for psoriasis.

Name	Followers, n	Followings, n	Posts, n
@psoriasis_thoughts	15,100	1309	361
@cyapsoriasis	11,600	3548	182
@getyourskinout	10,200	1711	652
@fixmyspsoriasis	3940	813	141
@beautifullyspotted	3719	1320	162
@overcoming_psoriasis	3547	7141	594
@thegirlwithpsoriasis	2628	302	28
@pspotted	2067	791	150
@klmpsoriasis	1549	664	335
@spottiettoohottie	1465	1422	42

With regard to these public profiles on Instagram advocating for psoriasis, each one presented a quantifiable number of posts about the topic. The content of these profiles included personal experiences and struggles of psoriasis, most commonly speaking about flares and how they influenced their mood, behaviors, and self-esteem, as summarized in **Table 4**. Popularity was not based on how many posts these accounts had, but resonated more so with the type of content that was posted. @getyourskinout produced content that spoke about psoriasis 100% of the time, but had less popularity when compared to other accounts based on “likes” and “comments.” The Instagram account that had the highest average number of likes was @psoriasis\_thoughts, which created content to promote psoriasis

webinars, poetry to reflect personal experiences with psoriasis, and photo updates of flares. This account also had the largest number of followers. The account with the least number of likes was @overcoming\_psoriasis, which created content that solely focused on treatment. This account was selling its own brand of products targeted for psoriasis treatment. @pspotted used the Instagram platform to talk about clinical trials available for psoriasis interventions. The posts were not advertisements, but rather a journey of the progress through treatment. From the 10 accounts reviewed, it was the only one that educated the audience on variable options for care. The account, however, was not run or managed by a licensed health care professional.

**Table 4.** Categorization of identified posts and audience engagement based on public profiles advocating for psoriasis.

Name	Number of related posts <sup>a</sup>	Summary of content (“What”)	Information provider (“Who”)	Number of likes (“How”), mean (SD)	Number of comments (“How”), mean (SD)
@psoriasis_thoughts	31	Psoriasis webinars, poetry, and personal experiences about flares	Individual with psoriasis	1127.3 (511.2)	121.3 (81.4)
@cyapsoriasis	21	Sponsored treatment and personal experiences about flares	Individual with psoriasis	285.1 (248.3)	17.5 (15.8)
@getyourskinout	50	Personal experience and reflection living with psoriasis and its contributions to all aspects of one’s life	Individual with psoriasis	491.4 (256.3)	20.1 (15.7)
@fixmypsoriasis	40	Treatment options, and personal experiences during pregnancy and flares	Individual with psoriasis	147.1 (49.7)	20.9 (16.4)
@beautifullyspotted	14	Motivational text and personal experiences about flares	Individual with psoriasis	163.0 (85.1)	19.7 (12.1)
@overcoming_psoriasis	35	Selling products, personal testimonies, and experiences	Individual with psoriasis	53.0 (32.9)	5.5 (7.3)
@thegirlwithpsoriasis	24 <sup>b</sup>	Selfies with motivational text regarding psoriasis and flare updates	Individual with psoriasis	303.2 (195.2)	37.3 (30.1)
@pspotted	20	Clinical trial journey, motivation, and self-care	Individual with psoriasis	229.7 (150.6)	16.9 (16.6)
@klmpsoriasis	11	Makeup and fashion tips to boost confidence in people dealing with psoriasis	Individual with psoriasis	119.3 (46.9)	151.0 (12.4)
@spottiettoohottie	4 <sup>c</sup>	Raised awareness about psoriasis	Individual with psoriasis	557.8 (248.1)	61.5 (43.6)

<sup>a</sup>The number of related posts is based on the first 50 recent posts on the social media page.

<sup>b</sup>This account only had 28 posts in total; videos were excluded from the count.

<sup>c</sup>This account only had 42 posts in total; videos were excluded from the count.

On average, followers engaged more so via “likes” (mean 347.7, SD 317.2) than “comments” (mean 47.2, SD 49.8), as observed similarly in the journal and national organization profiles. The exception was @klmpsoriasis, with followers, on average, engaging more via comments. The content was based on makeup and fashion tips to boost confidence in people dealing with psoriasis and its impact on their self-esteem. It was the only account that strayed away from educational or reflective content and was geared heavily on the psychosocial factors of psoriasis. @beautifullyspotted provided various motivational images and text to influence followers toward a mindful approach of dealing with psoriasis as a chronic condition. @cyapsoriasis had a lot of sponsored content on the Instagram page to treat psoriasis. The products that were being showcased were also used to describe personal experiences about flares and their resolution secondary to the use of these treatments.

@fixmypsoriasis depicted psoriasis in conjunction with pregnancy. Each flare throughout the course of a 9-month pregnancy was discussed and reflected upon. The content creator briefly touched on heritable concerns of psoriasis, as well as fatigue secondary to flares, and childbirth and childcare itself. @thegirlwithpsoriasis was the most “traditional” Instagram account, as it was filled with “selfies” accompanied by motivational texts, which were geared toward self-care.

@spottiettoohottie had the least number of psoriasis-related posts, but was the second highest account in terms of user popularity based on the average number of likes. The content on psoriasis was geared toward raising awareness about the condition.

## Discussion

### Principal Findings

Psoriasis is a prevalent skin condition that impacts many people’s lives across the world [12]. The internet is a staple that connects over a billion people with one another. Its use in educating, connecting, and advocating for those with psoriasis is instrumental. As many more health care professionals begin to appreciate its role in medicine, a sense of community can be built with it. Technology has created a platform to address the learners’ needs (in our discussion, the patients’ needs). The concept of “digital natives” explores the usability and convenience in receiving educational information online [13]. There is evidence of an increase in the number of patients who seek medical advice from the internet [14,15]; therefore, all medical specialties should become more comfortable navigating various social media platforms to become a part of the conversation online.

There are six prominent national journals and organizations that pertain to psoriasis. Based on their social media presence only four are engaged on Instagram (*Journal of the American Academy of Dermatology*, *JAMADermatology*, American Academy of Dermatology Association, and National Psoriasis Foundation). *JAMA Dermatology* was collectively a part of the JAMA Network Instagram account. Psoriasis Speaks and the *Journal of Psoriasis and Psoriatic Arthritis* did not have an Instagram presence.

Based on the above results, the majority of the content these organizational Instagram profiles provided spoke about the pathophysiology and therapeutic options for psoriasis. The content was cited by peer-reviewed sources and detailed the names of the health care professionals who were providing the information. Consumers of online health information are generally skeptical about misinformation [16,17]. Therefore, the approach of providing resources and citations is the transparency that many patients expect from their providers, which is a reputable way to build partnership with the online community [17,18]. What makes social media, and Instagram in our discussion, unique is the range of formality this network can take. One can take time to design and publish information in a thoughtful way or engage with a natural spontaneous post, more in line with the “real-time” connection social media promotes [19]. The use of such networks has been shown to improve the patient-provider relationship, where patients felt empowered to assert their decision-making skills based on information provided on platforms that were accessed on a daily basis [20]. Only one profile, the National Psoriasis Foundation, incorporated real patients with real experiences. It is important to understand the way content is consumed by people on social media, who are evidently the drivers of its popularity. Instagram is perhaps the most visual platform, which allows posts, videos, and real-time interactions [15,21]. Its relative ease of use allows many people to engage and connect. Given that the National Psoriasis Foundation focuses solely on psoriasis, it would likely be a more frequently accessed page by followers looking for organizations related to psoriasis on Instagram.

The receptiveness and popularity of the content created by the top 10 public profiles were the “real experiences,” which captivated a larger audience based on the data from “likes” and “comments.” Their content tended to be more personal and relatable to the average viewer, but it failed to include educational material at the level of peer-reviewed sources or health care professional citations. It is important to recognize the value of evidence-based medicine, which promotes preventative and therapeutic care. Influencers on social media may blur the lines on what is in fact evidence-based versus content that is driven by sponsorship from pharmaceutical companies or other products related to psoriasis. Although some of these profiles shared brand name products used during psoriasis flares, it was unclear whether they were sponsored by these companies, presenting the risk of conflicts of interest. It would be recommended that moving forward, influencers strive for greater transparency in the driving factors of their content, with appropriate reconciliation from medical professionals. What the public profiles of individuals with psoriasis do

appreciate, however, is the psychosocial implications psoriasis has on one’s mental health, self-efficacy, and self-esteem.

It is important to point out that the journals and organizations had a higher number of “likes” and “comments,” which may help us differentiate why each account is popular to begin with. The journals and organizations serve the audiences’ need for reputable resources, while the individual profiles allow followers to relate to the whole person impacted by psoriasis. This research helps us appreciate what the audience on Instagram is looking for, but the question lies in how we merge these needs to provide a more holistic platform on Instagram for both providers and patients, while avoiding the dangers of misinformation that is readily found online.

The posts curated by the individuals with psoriasis aim to reduce stigma and bias by forming an online community of “psoriasis warriors.” What the journals and national organizations fail to portray on their Instagram accounts is made up for by the individuals who share vulnerable experiences of flares, treatments, and psychologic effects of psoriasis on their personal public accounts. Given the growth surrounding psychodermatology, it is important to consider how engaging individuals with specific dermatologic diseases and their related internal nonvisible diseases via platforms, such as Instagram, should be used more readily to provide a source of information and support. Social media provides the opportunity to build and establish a reputable online presence. Conversations online are not necessarily private; thus, it is important to recognize both the positive and negative feedback that comes along with it [22], such as the boundary of professional versus personal advice. The use of social media is also beneficial to those having limited access to medical care, who can turn to these networks for evidence-based medical advice [23]. Therefore, it is important for medical professionals to gain an online presence to provide information that is free from bias to navigate patients to accurate medical information for both physiological and psychological purposes. In addition, it creates a platform for collaboration, which can be advantageous for journals and organizations to work with patient volunteers from diverse backgrounds who can help medical professionals gain a therapeutic alliance and public presence on Instagram with their followers in order to deliver evidence-based medical information.

### Limitations and Future Directions

We acknowledge that our study was limited to exploring only Instagram under the context of psychodermatology. To further strengthen the validity of our study, future research can incorporate and cross-analyze the way in which people may respond differently on Facebook, Twitter, and Instagram, as well as other related social networks. In general, likes are more amenable to gauge receptiveness to content, while comments allow for a greater understanding of how and what people may take away from the post. Future studies can dissect the comments under these posts to discuss the types of conversations prompted by content on social media.

Another limitation of our study was that not all public profiles of individuals advocating for psoriasis on Instagram were reviewed, as compared to all the journals and organizations that we included. Our methods involving screening for the top 10



profiles were limited to direct text that involved “psoriasis” or its related descriptors “spotted” and “spottie.” To allow for a more complete review, all public profiles should be taken into consideration. In between large organizations and individual content creators, there are dermatologists with large Instagram followings. It is important to consider how they engage and provide content on psoriasis to their audience.

The video function is a relatively new feature on Instagram. We did not include videos in our analysis in order to keep our discussion focused on imagery that was photo based. This limits our ability to assess if videos would be a noteworthy function

to create a more personal experience between health care providers and followers online.

Further recommendations include surveying the validity of the content produced online by nonmedical professionals. It is important to observe how readily the information provided is backed by evidence-based research or consulted with medical professionals. Therefore, once medical professionals develop a more consistent presence on their respective media platforms, we can revisit the effectiveness in the delivery of information, as well as the reception by followers online.

## Conflicts of Interest

None declared.

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## Abbreviations

**JAMA:** Journal of the American Medical Association

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Research Letter

# Assessment and Evaluation of Social Engagement in Dermatology Residency Programs on Instagram: Cross-sectional Study

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**KEYWORDS**

Instagram; social media; dermatology residency; Instagram engagement score; residency recruitment; medical education

The majority of dermatology residency applicants could not complete away rotations or in-person interviews during the 2021 match cycle due to the COVID-19 pandemic [1]. Without these traditional in-person experiences, applicants needed new ways to get to know one another and learn about programs. Thus, many programs created or enhanced their social media accounts, specifically Instagram, providing an avenue for students to learn about their specific program [2]. By utilizing Instagram, students can be updated on departmental information and the program's overall culture. In a survey study by Steel et al [3], 73% of respondents followed a plastics surgery residency social media account, with 86% using Instagram.

The Instagram engagement score (IES) is a tool that quantifies an Instagram account's engagement [4]. It is the rate of the total number of likes and comments per the number of followers [4]. This study assessed the factors that influence the total follower count and IES of dermatology residency programs' Instagram accounts.

Dermatology residency programs accredited by the Accreditation Council of Graduate Medical Education (ACGME) were identified using the ACGME Directory. Dermatology residency programs with Instagram accounts were identified and evaluated on March 6-7, 2021. Table 1 displays the evaluated variables. Posts were categorized as educational, departmental, academic and professional, social, or other.

Univariate and multivariate analyses were performed (Table 2). Three authors independently collected data and resolved any discrepancies unanimously.

Of 145 programs, 78 (53.8%) had Instagram accounts, with 69 (88%) accounts that were active or posted content after November 2020. Other than posts, Instagram Stories Highlights was used most frequently (n=40, 51.3%). Most accounts (n=60) were created in 2020. The average total followers, total accounts following, and IES were 567.4 (SD 289.8), 186.5 (SD 251.1), and 9.06 (SD 3.4), respectively. The University of Miami had the most followers (n=2260) and the University of Kansas had the highest IES (IES=23.76). Program location and affiliation did not affect total followers or IES. Being top 10 on Doximity in terms of reputation (mean 870.9, SD 45.1 vs mean 537.5, SD 286.5;  $P=.003$ ) and utilizing Instagram TV (mean 701.5, SD 429.0 vs mean 524.2, SD 215.9;  $P=.02$ ) significantly increased total followers, but not IES.

Multivariate regression analyses showed that total accounts following ( $P<.001$ ), account age ( $P<.001$ ), and top 10 status on Doximity ( $P=.01$ ) strongly correlated with a greater number of total followers ( $R^2=0.75$ ) (Table 2). Similarly, total followers ( $P<.001$ ) and account age ( $P=.04$ ) were moderately correlated with a greater IES ( $R^2=0.42$ ).

Instagram is a valuable platform for dermatology residency programs' self-promotion and recruitment activities following COVID-19. Relative to Twitter and Facebook, Instagram is the ideal social media platform for recruitment because it offers the

least amount of negative emotional content while providing positive entertainment, social interaction, and quick information [5]. Thus, dermatology residency programs can easily interact with potential applicants through their posts.

**Table 1.** Characteristics of dermatology residency programs' Instagram accounts (N=78).

Characteristics	Value
<b>Categorical variables, n (%)</b>	
Active (posts more recent than November 2020)	69 (88.5)
Instagram Stories Highlights (photos or videos up to 15 seconds in length that are featured on the profile permanently)	40 (51.3)
Instagram Reels (15-30-second videos that can incorporate music or special effects)	3 (3.8)
Instagram TV (long-form videos up to 60 minutes in length)	19 (24.4)
<b>Location, n (%)</b>	
East North Central (IL, IN, MI, OH, WI)	17 (21.8)
East South Central (AL, KY, MS, TN)	4 (5.1)
Mid-Atlantic (NJ, NY, PA)	9 (11.5)
Mountain (AZ, CO, ID, MT, NM, NV, UT, WY)	2 (2.6)
New England (CT, MA, ME, NH, RI, VT)	6 (7.7)
Pacific (AK, CA, HI, OR, WA)	8 (10.3)
South Atlantic (DC, DE, FL, GA, MD, NC, SC, VA, WV)	17 (21.8)
West North Central (IA, KS, MN, MO, ND, NE, SD)	8 (10.3)
West South Central (AR, LA, OK, TX)	7 (9.0)
Territory (PR)	0 (0)
<b>Program affiliation, n (%)</b>	
Community	3 (3.8)
Community with university affiliation	10 (12.8)
University	65 (83.3)
Military	0 (0)
<b>Continuous variables, mean (SD); range</b>	
Account age (days) (as of March 07, 2021)	346.8 (396.7); 6-2471
Total followers <sup>a</sup>	567.4 (289.8); 81-2260
Total accounts following	186.5 (251.1); 3-2045
Total posts	51.7 (57.0); 2-263
Number of education posts	3.1 (5.5); 0-25
Number of departmental posts	29.8 (37.1); 2-191
Number of academic and professional posts	7.8 (10.8); 0-50
Number of social posts	7.7 (8.6); 0-37
Number of other posts	3.2 (5.5); 0-26
Instagram engagement score	9.06 (3.4); 2.8-23.8

<sup>a</sup>Outcome of interest.

**Table 2.** Univariate and multivariate linear regression results: total followers or Instagram engagement score gained relative to study variables ( $P < .05$  was considered statistically significant).

Variable	Univariate		Multivariate	
	<i>P</i> value	<i>R</i> <sup>2</sup>	<i>P</i> value	<i>R</i> <sup>2</sup>
<b>Total followers</b>				0.749
Account age	<.001	0.208	.01	
Total accounts following	.002	0.120	<.001	
Total posts	<.001	0.366	.87	
Educational posts	.06	0.044	.86	
Departmental posts	<.001	0.430	.90	
Academic posts	<.001	0.239	.86	
Social posts	.03	0.060	.86	
Other posts	.01	0.084	.77	
Active (posts more recent than November 2020)	.08	N/A	.68	
Instagram Stories Highlights	.14	N/A	.66	
Instagram Reels	.64	N/A	.79	
Instagram TV	.02	N/A	.35	
Doximity (top 10 reputation-wise)	.003	N/A	.01	
Program location	.54	N/A	.30	
Program affiliation	.58	N/A	.48	
<b>Instagram engagement score</b>				0.418
Account age	.44	0.008	.04	
Total followers	<.001	0.258	<.001	
Total accounts following	.16	0.026	.49	
Total posts	.02	0.071	.61	
Educational posts	.85	0.000	.60	
Departmental posts	.008	0.089	.60	
Academic posts	.07	0.043	.61	
Social posts	.27	0.016	.62	
Other posts	.28	0.016	.65	
Active (posts more recent than November 2020)	.30	N/A	.50	
Instagram Stories Highlights	.09	N/A	.28	
Instagram Reels	.90	N/A	.55	
Instagram TV	.51	N/A	.12	
Doximity (top 10 reputation-wise)	.32	N/A	.16	
Program location	.94	N/A	.69	
Program affiliation	.35	N/A	.83	

We found several modifiable factors that may increase a program's IES. Programs can indirectly increase their IES by following more accounts to increase the chances of likes and comments. In addition, programs should start utilizing tools like Instagram Stories Highlights, Instagram TV, and Instagram Reels.

This study has several limitations. The data were collected from only one social media platform because Instagram content was associated with more positive emotions compared to Twitter and Facebook, which is essential for marketing and recruitment [5]. This study is cross-sectional in design, which means the information presented may change over time.

## Conflicts of Interest

None declared.

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## Abbreviations

**IES:** Instagram engagement score

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## Short Paper

# Performance of Artificial Intelligence Imaging Models in Detecting Dermatological Manifestations in Higher Fitzpatrick Skin Color Classifications

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## Abstract

**Background:** The performance of deep-learning image recognition models is below par when applied to images with Fitzpatrick classification skin types 4 and 5.

**Objective:** The objective of this research was to assess whether image recognition models perform differently when differentiating between dermatological diseases in individuals with darker skin color (Fitzpatrick skin types 4 and 5) than when differentiating between the same dermatological diseases in Caucasians (Fitzpatrick skin types 1, 2, and 3) when both models are trained on the same number of images.

**Methods:** Two image recognition models were trained, validated, and tested. The goal of each model was to differentiate between melanoma and basal cell carcinoma. Open-source images of melanoma and basal cell carcinoma were acquired from the Hellenic Dermatological Atlas, the Dermatology Atlas, the Interactive Dermatology Atlas, and DermNet NZ.

**Results:** The image recognition models trained and validated on images with light skin color had higher sensitivity, specificity, positive predictive value, negative predictive value, and F1 score than the image recognition models trained and validated on images of skin of color for differentiation between melanoma and basal cell carcinoma.

**Conclusions:** A higher number of images of dermatological diseases in individuals with darker skin color than images of dermatological diseases in individuals with light skin color would need to be gathered for artificial intelligence models to perform equally well.

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## KEYWORDS

deep learning; melanoma; basal cell carcinoma; skin of color; image recognition; dermatology; disease; convolutional neural network; specificity; prediction; artificial intelligence; skin color; skin tone

## Introduction

### Background

In dermatology, artificial intelligence (AI) is poised to improve the efficiency and accuracy of traditional diagnostic approaches, including visual examination, skin biopsy, and histopathologic examination [1]. Deep-learning image recognition models have had success in differentiating between dermatological diseases using images of light-skinned individuals. However, when these

models are tested on images of people with skin of color, the performance drops [2]. It is thought that the primary reason for this difference is the lack of available images of dermatological diseases in individuals with darker skin color (Fitzpatrick classification of skin types 4 and 5) [3]. However, is it also possible that even when the same number of images are available, image recognition models will have a harder time differentiating between dermatological diseases in individuals with Fitzpatrick skin types 4 and 5 compared to skin types 1, 2, and 3?

## Objective

The objective of this research was to assess whether image recognition models perform differently when differentiating between dermatological diseases in individuals of color (Fitzpatrick skin types 4 and 5) than when differentiating between the same dermatological diseases in Caucasians (Fitzpatrick skin types 1, 2, and 3) when both models are trained on an equal number of images.

## Methods

Open-source images of melanoma and basal cell carcinoma (BCC) were acquired from the Hellenic Dermatological Atlas [4], the Dermatology Atlas [5], the Interactive Dermatology Atlas [6], and DermNet NZ [7]. Two image recognition models were trained, validated, and tested using methodology as described previously [8]. TensorFlow [9], an open-source software library by Google, was used as a deep-learning framework and was used to retrain Inception, version 3 (v3). Inception v3 is a deep convolutional neural network. This neural network consists of a hierarchy of multiple computational layers that each have an input and output. All layers except the final layer of this neural network are pretrained with more than 1.2 million images. The final layer of the neural network was retrained with the gathered dermatological images. During the retraining process, the neural network underwent both a training and validation step. In the training step, the inputted images were used to train the neural network. In the validation step, inputted naïve images were used to iteratively assess training accuracy [10].

After the model had been retrained (trained and validated), a user-inputted testing/assessment step was performed in which test images were inputted and the results were statistically analyzed. The program assessment output is expressed in terms of percentages of the probability of each of the dermatological manifestations for each testing image inputted. R software (R Foundation for Statistical Computing) [11] was used to perform the statistical analysis. Sensitivity, specificity, positive predictive value (PPV), negative predictive value (NPV), and F1 score were calculated for each dermatological manifestation. The F1 score is the harmonic average of the sensitivity and PPV (mean of the recall and precision).

The goal of each model was to differentiate between melanoma and BCC.

The first model was:

- Trained on 150 images of individuals with light skin color (Fitzpatrick skin types 1, 2, and 3), 75 melanoma and 75 BCC images;

- Validated on 38 images of individuals with light skin color (Fitzpatrick skin types 1, 2, and 3), 19 melanoma and 19 BCC images;
- Tested on 30 images of individuals with light skin color (Fitzpatrick skin types 1, 2, and 3), 15 melanoma and 15 BCC images.

The second model was:

- Trained on 150 images of individuals with skin of color (Fitzpatrick skin types 4 and 5), 75 melanoma and 75 BCC images;
- Validated on 38 images of individuals with skin of color (Fitzpatrick skin types 4 and 5), 19 melanoma and 19 BCC images;
- Tested on 30 images of individuals with skin of color (Fitzpatrick skin types 4 and 5), 15 melanoma and 15 BCC images.

Area under the receiver operating characteristic (AUC) curves for melanoma and BCC were calculated to determine the performance of the two models.

## Results

When asked to differentiate between melanoma and BCC, the image recognition model trained and validated on images of light skin color had higher sensitivity, specificity, PPV, NPV, and F1 score than the image recognition model trained and validated on images of skin of color (Table 1).

In predicting melanoma, the image recognition model trained and validated on images of light skin color had a sensitivity of 0.60, specificity of 0.53, PPV of 0.56, NPV of 0.57, and F1 score of 0.58. On the other hand, in predicting melanoma, the same image recognition model trained and validated on images of skin of color had a sensitivity of 0.53, specificity of 0.47, PPV of 0.50, NPV of 0.50, and F1 score of 0.52.

In predicting BCC, the image recognition model trained and validated on images of light skin color had a sensitivity of 0.53, specificity of 0.60, PPV of 0.57, NPV of 0.56, and F1 score of 0.55. On the other hand, for prediction of BCC, the same image recognition model trained and validated on images of skin of color had a sensitivity of 0.47, specificity of 0.53, PPV of 0.50, NPV of 0.50, and F1 score of 0.48.

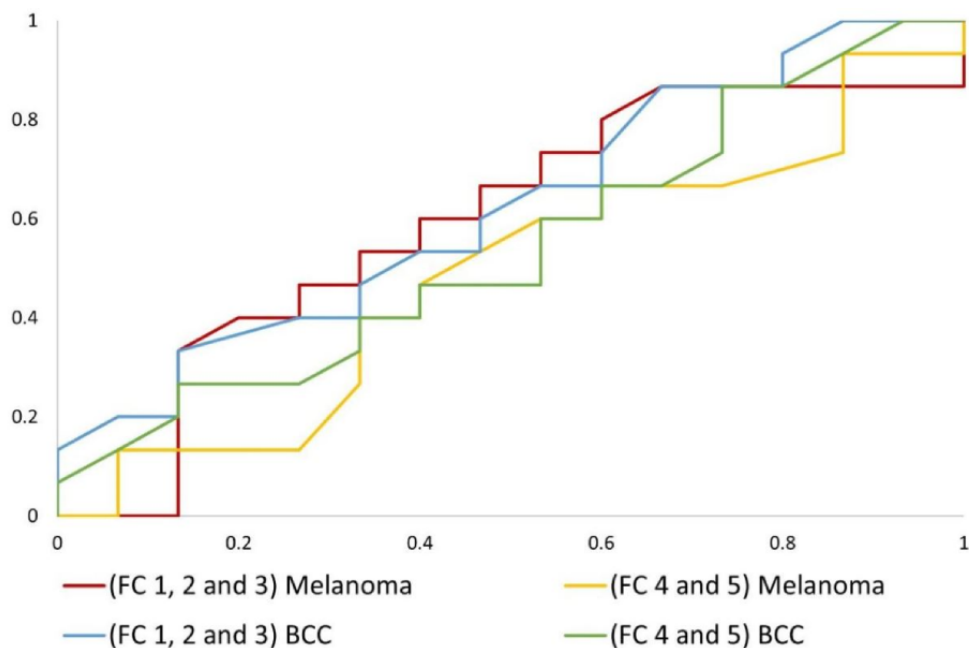
The average AUC for the two light skin color image recognition models was 0.598, compared to 0.500 (values point out the difference) for the skin of color image recognition models (Table 1 and Figure 1).



**Table 1.** Statistical measures of the deep-learning model trained, validated, and tested on different Fitzpatrick skin type classifications (types 1, 2, and 3 vs types 4 and 5) for evaluating melanoma and basal cell carcinoma.

Measure	Melanoma model		Basal cell carcinoma model	
	Skin types 1, 2, and 3	Skin types 4 and 5	Skin types 1, 2, and 3	Skin types 4 and 5
Sensitivity	0.60	0.53	0.53	0.47
Specificity	0.53	0.47	0.60	0.53
Positive predictive value	0.56	0.50	0.57	0.50
Negative predictive value	0.57	0.50	0.56	0.50
F1 score	0.58	0.52	0.55	0.48
Area under the receiver operating characteristic curve	0.59	0.57	0.60	0.53

**Figure 1.** Receiver operating characteristic curves for melanoma and basal cell carcinoma (BCC) in each of the two models for different skin types. FC: Fitzpatrick classification.



## Discussion

### Limitations

The number of images available was limited for Fitzpatrick skin types 4 and 5; as such, both the light skin color and skin of color models were investigated with this constraint for the number of images used during training. A larger sample size would have been better to test if the results recur consistently.

### Conclusion

When the same number of images is used for training, validation, and testing, the AI model that was provided images

of melanoma and BCC belonging to Fitzpatrick classification skin types 1, 2, and 3 performed better than the AI model that was provided with images of melanoma and BCC in skin types 4 and 5. This may be because dermatological diseases can have more variability in presentation in individuals with darker skin; additionally, cutaneous manifestations may not be as easily distinguished from the surrounding skin in darker-skinned individuals. As such, a higher number of images of skin of color with dermatological diseases than images of light skin color with dermatological diseases would need to be gathered for the AI models to perform equally well.

### Conflicts of Interest

None declared.

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## Abbreviations

**AI:** artificial intelligence

**AUC:** area under the receiver operating characteristic

**BCC:** basal cell carcinoma

**NPV:** negative predictive value

**PPV:** positive predictive value

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Original Paper

# Comparing Risk Profiles in Critical Care Patients With Stage 2 and Deep Tissue Pressure Injuries: Exploratory Retrospective Cohort Study

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## Abstract

**Background:** Understanding hospital-acquired pressure injury (HAPrI) etiology is essential for developing effective preventive interventions. Pressure injuries are classified based on the degree of visible tissue damage; the two most commonly identified HAPrI stages in critical care patients are stage 2 and deep tissue injury (DTI). Some experts speculate that stage 2 and DTI have different etiologies, with stage 2 injuries formed from the “outside in” as a result of tissue deformation, decreased perfusion, and subsequent ischemia caused by external pressure and/or shear forces, whereas DTI emerges from the “inside out” due to inadequate perfusion to the deeper tissues causing tissue ischemia.

**Objective:** The purpose of this study was to compare risk profiles of intensive care unit (ICU) patients who developed stage 2 injuries versus DTIs.

**Methods:** This was a retrospective cohort study to compare the risk profiles of patients in the ICU with stage 2 injuries and DTIs using electronic health record data. Eligible patients were admitted to the surgical or cardiovascular ICU at an academic medical center in the United States between 2014 and 2018. Anatomic locations were examined, and differences in anatomic patterns were compared using the  $\chi^2$  test. Risk profile variables included demographic characteristics, Braden Scale scores, vasopressor infusions, hypotension, surgical factors, length of stay, BMI, laboratory values, diabetes, Charlson Comorbidity Index, and the levels of sedation or agitation. The distributions of potential risk variables between patients with stage 2 injuries and DTIs were summarized and compared. A logistic regression model with the least absolute shrinkage and selection operator method was developed to identify the critical risk factors for distinguishing stage 2 and DTI patients.

**Results:** A total of 244 patients developed a stage 2 injury or DTI during the study period. Of those, 38 patients with medical device-related pressure injury were excluded. The final study sample consisted of 206 patients (n=146 stage 2 and n=60 DTI). Compared with DTIs, stage 2 HAPrIs were more likely to be located on a bony prominence (n=206,  $\chi^2_1=8.43$ ,  $P=.03$ ). The multivariate model showed that patients who developed stage 2 HAPrIs had a longer length of stay in the ICU than those with DTIs (odds ratio [OR] 1.001, 95% CI 1-1.002,  $P=.03$ ) but were less likely than patients with DTIs to experience a diastolic blood pressure <50 mmHg (OR 0.179, 95% CI 0.072-0.416,  $P<.001$ ) or receive an epinephrine infusion (OR 0.316, 95% CI 0.079-0.525,  $P=.008$ ).

**Conclusions:** Stage 2 injuries and DTIs have different risk factors and different anatomic patterns. Patients who developed DTIs were more likely to experience low diastolic blood pressure and receive epinephrine, a potent vasopressor. Stage 2 injuries were more likely to occur on the bony prominences, whereas DTIs commonly occurred on the fleshy parts of the body such as the buttock.

**KEYWORDS**

pressure ulcer; pressure injury; critical care; intensive care; hospital-acquired pressure injury; tissue damage; electronic health records; EHRs

## Introduction

The United States has an estimated cost burden exceeding US \$26 billion for hospital-acquired pressure injury (HAPrI) treatment [1], although these injuries are considered to be mainly preventable. The prevailing belief about the development of HAPrIs is that a localized injury occurs to an area of the skin and underlying tissue—usually over a bony prominence—as a result of external pressure and sometimes shear forces, along with additional factors that have yet to be elucidated [2]. Patients admitted to the intensive care unit (ICU) are more likely than other hospitalized patients to experience hemodynamic instability and hypotension; in fact, their risk tends to double [3] given a constellation of other factors such as longer length of stay [4,5], surgical factors [6], vasopressor infusions [7,8] older age [9], increased severity of illness [10], and decreased mobility [8,9].

Understanding the etiology of HAPrI is foundational for developing effective preventive interventions. The National Pressure Injury Advisory Panel and the European Pressure Ulcer Advisory Panel provide a pressure injury (PrI) classification staging system (stages 1-4, deep tissue injury [DTI], and unstageable) along with common descriptions of the extent of the visible skin and tissue damage for the purpose of clinical practice, audits, and research [2]. Stage 2 and DTI, the two most commonly occurring injuries within the classification system, appear to be markedly different: stage 2 injuries are generally shallow ulcers, whereas DTIs present as discolored intact skin as a result of damage to the underlying tissue. Some experts speculate that stage 2 injuries and those considered to be DTIs have different etiologies, with stage 2 injuries forming from the “outside in” as a result of tissue deformation, decreased perfusion, and subsequent ischemia caused by external pressure and/or shear forces, whereas DTIs emerge from the “inside out” due to inadequate perfusion to the deeper tissues causing tissue ischemia [11]. If a stage 2 injury occurs from the “outside in” and a DTI forms from the “inside out,” it is likely that ICU patients with a DTI would experience more perfusion-related risk factors. Therefore, the purpose of this study was to compare the risk profiles of ICU patients who developed stage 2 injuries and DTIs.

## Methods

### Design

This was a retrospective cohort study of electronic health record (EHR) data to establish risk factor profiles of ICU patients comparing stage 2 injuries and DTIs. The institutional review board of the University of Utah approved the study (IRB\_00111380).

### Sample and Setting

Eligible patients were those who were admitted to the surgical or cardiovascular ICU at an academic medical center in the United States between 2014 and 2018. Inclusion criteria were age >18 years and development of a nonmedical device-related stage 2 injury or DTI during the ICU stay. Exclusion criteria were pediatric patients (<18 years old) and the absence of an ICU-acquired stage 2 injury or DTI. Patients with a medical device-related PrI were included in the study only if they also developed a nonmedical device-related PrI of stage 2 or a DTI [12]. Patients with PrI present on admission to the ICU were only included in the study if they also subsequently developed an ICU-acquired PrI.

Critical care nurses at this institution conduct a head-to-toe skin assessment each shift and document results in the EHR, noting the location and stage of any HAPrI, which is then confirmed by a certified wound care nurse. Patients unable to reposition independently are repositioned every 2 hours, and skincare protocols are employed to encourage nurses to keep the skin as clean and dry as possible. All of the ICU beds are pressure redistribution/low air loss beds; bariatric pressure redistribution/low air loss beds are used for patients with obesity.

### Data Collection

Data were obtained using a combination of a query of the institution’s critical-care datamart cross-referenced with data maintained by the institution’s quality department, along with a manual review of the EPIC EHR system when necessary. Data extracted were limited to the first ICU stay for patients with multiple ICU stays. To capture HAPrI risk factors, only data from the timeframe between ICU admission and HAPrI detection were included.

### Measures

Stage 2 injury and DTI were defined according to the National Pressure Injury Advisory Panel definitions [13]; a PrI was considered to be hospital-acquired if it was detected  $\geq 48$  hours after admission. The anatomic location was recorded from structured fields in the EHR and also verified with photographic evidence when available. Risk profile variables included demographic characteristics [14], Braden Scale scores [15], vasopressor infusions [7], hypotension [16], surgical factors [6,16,17], length of stay [5,18], BMI [19], laboratory values [16], diabetes [4], Charlson Comorbidity Index (categorizing comorbidities of the patients’ disease burden and their 1-year mortality risk) [20], and the Riker score (levels of sedation or agitation) [21].

### Analysis

All statistical analyses were performed in R version 3.6.1. (R Foundation for Statistical Computing). First, the distributions of potential risk variables between patients with stage 2 injuries and DTIs were summarized and compared using *t* tests (or

Wilcoxon rank-sum tests) for continuous variables and with the  $\chi^2$  test (or Fisher exact test) for categorical variables. Variance inflation factors (VIFs) were calculated to detect if multicollinearity was present among the list of potential predictors. If none of the potential predictors had a VIF exceeding 5, we treated all predictors as independent predictors. We employed a logistic regression model with the least absolute shrinkage and selection operator (LASSO) method [22] to identify the critical risk factors for distinguishing stage 2 injury and DTI patients.

Unlike other variable selection approaches—such as the stepwise approach—the LASSO approach does not select important risk factors based on  $P$  values. Instead, by imposing a penalty in the regression model fitting, the LASSO approach shrinks the coefficients of unimportant predictors to zero while retaining the important coefficients [22]. The optimal penalty term was determined using 10-fold cross-validation criteria; the predictor was selected if, and only if, its coefficient was nonzero. The final model included all important predictors with parsimonious representation, enhanced interpretability, and improved precision. From the soft-thresholding property of LASSO in generalized linear regression models, the estimated regression coefficients from the penalized logistic regression were biased

toward zero. To mitigate these bias problems, we report a more unbiased estimation of the regression coefficients from unpenalized logistic regression using the selected factors from the LASSO.

## Results

A total of 244 patients developed a stage 2 injury or DTI during the study period. Of those, 38 patients with a medical device-related PrI were excluded. The final study sample consisted of 206 patients ( $n=146$  stage 2 and  $n=60$  DTI). Univariate relationships between study variables and HAPrI stage are presented in Table 1. The multivariate model for the effects of risk profiles on stage 2 versus DTI development is presented in Table 2.

Compared with DTIs, stage 2 HAPrIs were more likely to be located on a bony prominence ( $n=206$ ,  $\chi^2_1=8.43$ ,  $P=.03$ ). Among the 146 stage 2 HAPrIs, 93 (63.7%) were located on the sacrum or the coccyx and 11 (7.5%) were located on other bony prominences (ischium, heel, or spine). Among the 60 DTIs, 30 (50%) were found on a bony prominence (sacrum, coccyx, ischium, heel, or spine), whereas the other 30 (50%) occurred on fleshy parts of the body, particularly the buttock ( $n=23$ , 38%).

**Table 1.** Risk factor profiles in stage 2 and deep tissue hospital-acquired pressure injury.

Variable	Stage 2 injury (n=146)	Deep tissue injury (n=60)	P value
<b>Demographic factors</b>			
Age (years), mean (SD)	57.5 (16.4)	57.5 (14.0)	.99 <sup>a</sup>
Sex (male), n (%)	86 (58.9)	43 (71.7)	.09 <sup>b</sup>
Race (White), n (%)	117 (80.1)	48 (80.0)	.98 <sup>b</sup>
Ethnicity (Non-Hispanic), n (%)	123 (84.2)	50 (83.3)	.87 <sup>b</sup>
Hospital length of stay (days), mean (SD)	31 (23)	28 (19)	.52 <sup>c</sup>
ICU <sup>d</sup> length of stay (days), mean (SD)	20 (18)	18 (18)	.35 <sup>c</sup>
<b>Surgical factors, mean (SD)</b>			
Longest surgery (hours)	3 (3)	5 (4)	<.001 <sup>c</sup>
Total surgical time (hours)	6 (4)	4 (5)	.001 <sup>c</sup>
<b>Laboratory values, mean (SD)</b>			
Minimum albumin (g/dl)	2.7 (0.7)	2.6 (0.5)	.23 <sup>a</sup>
Minimum hemoglobin (g/dl)	7.5 (2.1)	7.4 (2.2)	.76 <sup>a</sup>
Maximum lactate (mmol/l)	7.3 (6.0)	5.1 (4.1)	.008 <sup>c</sup>
Maximum creatinine mg/dL	2.9 (2.1)	2.9 (2.2)	.78 <sup>c</sup>
<b>Blood pressure, n (%)</b>			
Systolic <90 mmHg	120 (82.2)	54 (90.0)	.16 <sup>b</sup>
MAP <sup>e</sup> <60 mmHg	99 (67.8)	43 (71.7)	.59 <sup>b</sup>
Diastolic <50 mmHg	60 (41.1)	44 (73.3)	<.001 <sup>b</sup>
Epinephrine	49 (33.6)	40 (66.7)	<.001 <sup>b</sup>
Norepinephrine	71 (48.6)	33 (55.0)	.41 <sup>b</sup>
Dopamine	12 (8.2)	2 (3.3)	.36 <sup>f</sup>
Vasopressin	63 (43.2)	41 (68.3)	.001 <sup>b</sup>
Phenylephrine	8 (5.5)	3 (5.0)	.99 <sup>b</sup>
<b>Diagnosis and comorbidities</b>			
Charlson Comorbidity Index, mean (SD)	4.3 (2.9)	4.5 (2.7)	.53 <sup>c</sup>
Diabetes, n (%)	28 (19.2)	14 (23.3)	.50 <sup>b</sup>
Minimum Braden scale score, mean (SD)	11.1 (3.0)	11.5 (2.8)	.32 <sup>c</sup>
Minimum Riker score, mean (SD)	2.2 (1.2)	1.8 (1.0)	.08 <sup>c</sup>

<sup>a</sup>Based on the *t* test.<sup>b</sup>Based on the  $\chi^2$  test.<sup>c</sup>Based on the Wilcoxon rank-sum test.<sup>d</sup>ICU: intensive care unit.<sup>e</sup>MAP: mean arterial pressure.<sup>f</sup>Based on the Fisher exact test.

**Table 2.** Logistic regression model for stage 2 vs deep tissue injury after least absolute shrinkage and selection operator variable selection.

Variable	Odds ratio	95% CI	P value
Sex (reference: male)	0.335	0.14-0.755	.11
Hospital length of stay (days)	1.001	1-1.002	.03
Longest surgery (hours)	0.998	0.996-1	.06
Minimum albumin (g/dl)	0.696	0.353-1.351	.29
Diastolic blood pressure <50 mmHg	0.179	0.072-0.416	<.001
Epinephrine	0.316	0.079-0.525	.008
Dopamine	4.277	0.836-33.803	.11

## Discussion

### Principal Findings

This exploratory study investigated differences in risk factors and anatomic patterns between surgical and cardiovascular ICU patients who developed stage 2 injuries vs DTIs. Understanding HAPrI risk factors and the associated etiology is essential for developing effective prevention approaches. It is possible that etiological differences exist between different PrI stages, with stage 2 PrI resulting primarily from external pressure and/or shearing forces affecting perfusion to the superficial tissues and DTI resulting from inadequate blood flow (perfusion) to the deeper tissues [23]. ICU patients are an ideal population for studying perfusion in relation to HAPrIs because they are more likely to experience hypotension and hemodynamic instability.

In this exploratory study, low diastolic blood pressure had the strongest correlation with the development of a DTI. This finding is consistent with a prior study aimed at identifying risk factors for DTI in ICU patients [16], which found that for every 1 mmHg decrease in diastolic blood pressure, the odds of a DTI increased by about 8%. Considering that the heart is in diastole about 2/3 of the time (and in systole 1/3 of the time), it is logical that inadequate diastolic blood pressure is a significant factor contributing to tissue perfusion.

The finding that epinephrine, a potent vasopressor, was associated with DTI is further evidence for the importance of tissue perfusion in DTI etiology. Vasopressor drugs are administered to improve organ perfusion in patients with hypotension; however, the alpha-adrenergic properties of certain vasopressors, including epinephrine, cause arterial vasoconstriction and therefore decrease blood flow to the vessels in the muscles and peripheral tissues. Although it is well established that vasopressor drugs are risk factors for HAPrI, likely as a result of their indication (severe illness and hypotension) and the mechanism of action (arterial vasoconstriction) [8,9,24], this is the first study to examine vasopressors in relation to HAPrI stage.

This study showed that stage 2 HAPrIs were more likely than DTIs to be located on a bony prominence, whereas DTIs were mostly located on the fleshy parts of the body (primarily the buttock). This finding has important clinical implications for routine nursing care because routine skin assessment usually involves checking the bony prominences and not the fleshy areas [2]. Therefore, the fleshy areas, particularly the buttock, should be included in routine nursing skin assessments.

The differences in anatomic patterns, with stage 2 injuries mostly occurring on the bony prominences and DTIs mainly occurring on the fleshy areas, suggest a potential etiological difference between stage 2 injuries and DTIs. Stage 2 HAPrIs are likely primarily caused by pressure (tissue compression) between a surface (eg, a bed) and a bony prominence, or pressure combined with shear force [2]. However, fleshy areas are typically not exposed to significant external pressure, and therefore an “inside-out” etiology driven by perfusion should be considered [11,16,24].

### Limitations

The study is limited by its small sample size, and therefore the results are considered exploratory. We were limited to the data contained in the EHR, and consequently unable to accurately obtain variables difficult to capture retrospectively, such as repositioning frequency. Moreover, these data are based on a single study site and therefore may not be generalizable to other institutions.

### Conclusion

Results from this exploratory study performed in surgical and cardiovascular ICU patients showed that deep tissue and stage 2 HAPrIs have different risk factors and different anatomic patterns. Patients who developed DTIs were more likely than patients with stage 2 HAPrIs to experience low diastolic blood pressure and to have received epinephrine, a potent vasopressor. Stage 2 HAPrIs were more likely to occur on the bony prominences, whereas DTIs commonly occurred on the fleshy parts of the body such as the buttock. Future research is needed to elucidate the detailed etiologic differences between stages, which will lead to identifying effective preventive interventions.

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## Conflicts of Interest

None declared.

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## Abbreviations

**DTI:** deep tissue injury  
**EHR:** electronic health record  
**HAPrI:** hospital-acquired pressure injury  
**ICU:** intensive care unit  
**LASSO:** least absolute shrinkage and selection operator  
**PrI:** pressure injury  
**VIF:** variance inflation factor

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Review

# Gamification and Game-Based Strategies for Dermatology Education: Narrative Review

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## Abstract

**Background:** Game-based approaches, or gamification, are popular learning strategies in medical education for health care providers and patients alike. Gamification has taken the form of serious educational games and simulations to enable learners to rehearse skills and knowledge in a safe environment. Dermatology learners in particular may benefit from gamification methods, given the visual and procedural nature of the field.

**Objective:** This narrative review surveys current applications of gamification within general medical training, in the education of dermatology students, and in dermatology patient outreach.

**Methods:** A literature search was performed using PubMed, Google Scholar, and ResearchGate to access and review relevant medical education- and dermatology-related gamification studies published in peer-reviewed journals. Two independent researchers with education and experience in dermatology screened publications to select studies featuring a diversity of gamification approaches and study subjects for in-depth examination.

**Results:** A total of 6 general medical education-related and 7 dermatology-specific gamification studies were selected. Gamification generally increased motivation and engagement, improved reinforcement of learning objectives, and contributed to more enjoyable and positive educational experiences compared to traditional modes of instruction. Enhancing examination scores, building confidence, and developing stronger team dynamics were additional benefits for medical trainees. Despite the abundance of gamification studies in general medical education, comparatively few instances were specific to dermatology learning, although large organizations such as the American Academy of Dermatology have begun to implement these strategies nationally. Gamification may also provide promising alternative means of diversifying patient education and outreach methods, especially for self-identification of malignant melanoma.

**Conclusions:** Serious games and simulations in general medical education have successfully increased learner motivation, enjoyment, and performance. In limited preliminary studies, gamified approaches to dermatology-specific medical education enhanced diagnostic accuracy and interest in the field. Game-based interventions in patient-focused educational pilot studies surrounding melanoma detection demonstrated similar efficacy and knowledge benefits. However, small study participant numbers and large variability in outcome measures may indicate decreased generalizability of findings regarding the current impact of gamification approaches, and further investigation in this area is warranted. Additionally, some relevant studies may have been omitted by the simplified literature search strategy of this narrative review. This could be expanded upon in a secondary systematic review of gamified educational platforms.

**KEYWORDS**

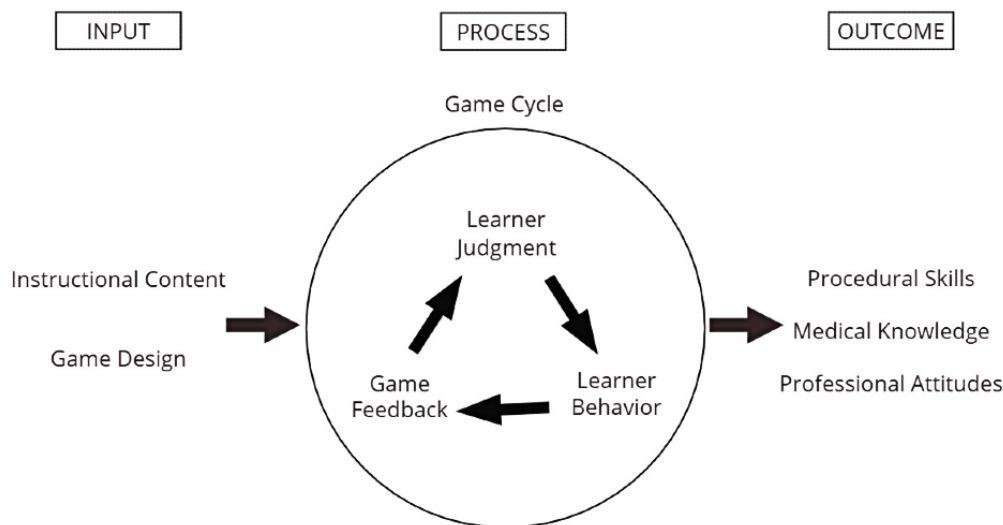
games; game-playing; gamification; serious games; simulations; education; medical education; dermatology education; patient education; review

**Introduction**

Game-based approaches, or gamification, are becoming increasingly popular in health care education. These novel and innovative strategies use game design elements such as the concept of a player or players, rules, conflicts, and predetermined goals in an artificial setting [1,2]. Previous literature has formally defined gamification as the application of game characteristics and benefits to real-world processes or problems [3]. The concept of gamification has been separated from that of *serious games*, which are complete games for specifically educational, nonentertainment purposes [3,4]. Related to but outside the strict definition of serious games are *simulations*, defined as virtual or “concentrated” realities offering opportunities for learners to rehearse skills and knowledge [1]. Because these delineations have been the subject of some debate [3], for the purposes of this review, we will broadly use gamification to refer to both serious games along with other applications leveraging game and simulation elements for a utilitarian purpose.

Generally, gamification provides a structured, safe, and low-risk environment for learners to build skills and confidence without real-world consequences [5,6]. It can help students to engage in a particular activity, think critically about both their plan and outcome, and then apply important insights gained from their analyses to improve and learn. Emerging digital technologies have transformed how gamification strategies can be used in education. With the dramatic rise of digital gaming as a widespread pastime, incoming students and the general public are more accustomed to gaming in their daily lives than ever before [3,7,8], which presents an ideal opportunity. Studies have shown that students prefer gamification over traditional educational curricula [9,10], especially if they enjoy diverse and alternative learning styles such as primarily visual, auditory, or kinesthetic methods [11]. A general model [12] of how game-based learning achieves desired outcomes in medical education, in which the game cycle is an iterative process of learner judgment, behavior, and feedback, is demonstrated in Figure 1.

**Figure 1.** Input-process-outcome model of game-based learning [12] adapted for medical education.



Many gamification formats in medical education have been presented including simulations, virtual/alternative reality environments, and social and cooperative gaming [1]. Moreover, the practice-focused nature of health care allows gamification to provide a cost-effective method of optimizing procedural skills such as thoracentesis [13]. Patients also stand to benefit greatly from gamification [14]. Compelling aspects of games such as rewards, competition, self-expression, and social interaction have been extracted to encourage healthy habits and track fitness goals in many popular programs and mobile apps. Game-based challenges can also benefit patients by driving frequent patient engagement, increasing education through quizzes and daily tips, and by motivating difficult long-term behaviors such as medication adherence [15].

Dermatology, as a highly visual and procedural field, is well positioned to take advantage of the learning methods employed in many game-based approaches. This narrative review therefore aims to survey gamification in medical training as well as to explore how the current knowledge base of gamification applications can be expanded in dermatology education for both providers and patients alike through further evidence-based examination of game-based learning.

**Methods**

A survey of peer-reviewed scientific literature was performed throughout January and February of 2021, with the purpose of identifying studies for a narrative review of gamification in

health care education and dermatology. Key search terms included *gamification*, *games*, *game-playing*, *serious games*, and *simulation games*, in combination with terms such as *healthcare*, *healthcare education*, *medical education*, *dermatology*, and *dermatology education*. PubMed electronic database searches were supplemented by Google Scholar and ResearchGate to retrieve the full English-language text of each article and remove duplicate search results. The articles included studies from multiple academic institutions worldwide, and they included randomized controlled trials, cohort studies, and case studies. The participants in the studies encompassed medical students, medical residents, and members of the general public. To provide a broad overview of gamification and game-based

interventions, both serious games and simulations were surveyed. Two independent researchers with education and experience in dermatology performed separate screenings of the article titles and abstracts, ultimately selecting 6 general medical education–related studies and 7 dermatology-related studies featuring a diversity of gamification approaches and study subjects for in-depth discussion in this narrative review. Additional consultation with board-certified dermatologists involved in medical education led to the inclusion of two recent *Jeopardy* game show–like events tailored toward dermatology residents at national conferences. [Table 1](#) provides a summary of the studies and various gamification approaches examined.

**Table 1.** Summary of the gamification approaches and studies surveyed.

Game	Classification	Target audience	Participants studied, n	Topic
Kaizen [16]	Serious game	Medical residents	94	Clinical knowledge
SIU <sup>a</sup> uRCADE [17]	Serious game	Clinicians and medical students	Unknown	Bladder cancer and renal cell carcinoma
Stanford 360 VR <sup>b</sup> [18]	Simulation	Clinicians and medical students	207	Mass pediatric casualty incident
Recreational escape room [19]	Blended	Emergency medicine residents	10	Teamwork
Team-based competition [20]	Serious game	General surgery residents	Approximately 50	Medical knowledge, patient care, professionalism, interpersonal and communication skills, scholarship
Video games and <i>Jeopardy</i> -style contest [21]	Blended	Cardiothoracic surgery residents	43	Procedural skills and surgical knowledge
Kahoot! [22]	Serious game	Medical students	51	Medical knowledge, histopathology, tumor identification
Skinquization [23]	Serious game	Medical students	384	Skin diseases and applied dermatology knowledge
American Academy of Dermatology Annual Meeting Resident Jeopardy [24]	Serious game	Dermatology residents	Unknown	Dermatological conditions
DermPath Bowl [25]	Serious game	Dermatology residents	48 residency programs	Dermatopathology
i-DERMIFY [26]	Serious game	Medical students	28	Dermatological conditions
Stud2yBuddy [27]	Serious game	Medical students	65	Dermatological conditions
“Zombie apocalypse” escape room [28]	Blended	Medical students	16	Clinical knowledge, attitudes toward the field of dermatology
Mountain View High School Survey [29]	Serious game	Patients (adolescents)	271	Malignant melanoma identification
Tapamole [30]	Serious game	Patients	60	Malignant melanoma identification

<sup>a</sup>SIU: Société Internationale d’Urologie.

<sup>b</sup>VR: virtual reality.

## Results

### Gamification in General Medical Education

Gamification has been employed by medical schools and training programs to engage learners outside the traditional text-based or didactic setting. The effectiveness of gamification in general medical education has been the subject of several

studies, many of which examine the impact of game-based learning on objectives such as knowledge, skills, professional attitudes, or satisfaction. Although we retrieved several hundred articles in our initial literature search, the vast majority discussed gamification approaches in general medical education and were not specific to dermatology learning. We discuss a selection of applications of gamification in general medical education below.

One example of a serious game in general medical education is Kaizen, which tested clinical knowledge of medical residents in several university departments using a web-based multiple-choice quiz [16]. Achievement badges were earned for answering questions daily or answering multiple questions correctly in a row. To align with evolving technological experiences of incoming learners, future Kaizen developments may include Android/iPhone mobile apps and “boss battle” features or leaderboards for team challenges [31]. Indeed, many organizations have introduced serious educational gaming applications to engage medical learners. The Société Internationale d’Urologie (SIU, the International Society for Urology) recently launched web-based applications focusing on bladder cancer and renal cell carcinoma through their official education gaming arcade (SIU uRCADE), and they experienced overwhelming demand [17]. Participants could even earn approved Continuing Medical Education (CME) credits by completing uRCADE games, highlighting their effectiveness and utility.

Virtual reality and simulation games have proved to be very popular among medical learners of all levels. Stanford University recently used the existing 360 Virtual Reality platform, which is already used in entertainment, military training, and pilot training, to create a training module for mass casualty incident training [18]. Actors created realistic scenes of a care point involving 150 potential pediatric casualties, with the immersive virtual reality story allowing users to select triage categories and decide on interventions. The user would then see the intervention as it took place and would learn of the child’s outcome, earning points and achievement levels based on their responses. Attending physicians, residents, and students all reported the virtual reality simulation to be enjoyable and engaging, more so than traditional mannequin-based simulations. They also reported feeling more prepared to respond to a pediatric mass casualty incident after completing the exercise.

Blended gamified approaches and applications of gamification to traditional education have likewise been favorably received. For instance, an “escape room” game in which groups solved puzzles and completed tasks within a time limit boosted team-building and multitasking skills for emergency medicine residents. These games may be effective approaches to fulfill difficult-to-teach core Accreditation Council for Graduate Medical Education competencies, such as teamwork [19]. Incorporating game-based elements into existing curricula has also been fruitful. Team-based competitions converting surgical resident performance into game points with leaderboards and *Jeopardy*-style game shows were found to increase resident satisfaction, training scores, and board examination pass rates. The competitive nature of the trainees may be a contributing factor to the success of the gamification interventions [20,21]. Corroborating this, leaderboards have been suggested to be the most important motivator of game participation among medical residents, while nondaily play worsened attrition [32]. Integration of competitive gaming features with public platforms such as Twitter was found to increase professional social media presence and trainee engagement with their specialty [33]. Video games were also seen to effectively supplement surgical skills education in laparoscopy and robotic surgery [34]. Clearly,

synergistic combinations of serious games, simulations, and supplementing traditional education with games and game-based elements may be enjoyable and effective for participants.

### Gamification in the Education of Dermatology Students

While gamification has been shown to have a positive impact on general medical education, we also sought to examine whether this held true in dermatology-specific game-based learning. The visual and procedural nature of dermatology would be expected to align well with the gamified educational methods discussed previously. As with gamification in general medical education, every dermatology-focused study reported beneficial effects of gamification on learning outcomes or student satisfaction, although it appears that only 7 dermatology-specific games are reported in the literature overall. Thus, further research and game development is needed in this area to fully elucidate the impact and future dermatology-specific utility of gamification.

One instance of adapting games previously used in general medical education for dermatology students was seen in Kahoot!, a widely used and free real-time platform for formative educational assessment. Participants can compete for top scores in game-based quizzes, surveys, puzzles, and discussion forums. Kahoot! was previously found to motivate medical students to study, prioritize topics, and self-reflect on their learning [35]. The platform was then applied as a simple, low-cost method to teach histopathology and proper identification of benign and malignant tumors, including cutaneous neoplasms. Subsequently, quiz questions and answers were presented in random order, and the 36 students participating were given 30 seconds to answer each question. Ultimately, percentages of correct quiz answers increased after use of Kahoot! compared to classroom teaching, and there was a notable decrease in the time needed to correctly answer questions. Students evaluated their Kahoot! educational experience positively [22].

Skinquization is another serious game using educational quizzes for formative assessment [23]. The game was developed especially for dermatology, as it allowed questions about diverse skin diseases, incorporated images, and could assess a large amount of applied knowledge in a short period of time. Assigned medical student laboratory groups were pitted against each other in a countdown-timed competition to correctly answer dermatology questions with an audience response system, popularly known as “clickers.” To incentivize active participation throughout the competition and even the odds between teams, teams were periodically offered the option to wager some or all of their points on the next question before seeing it, similar to a “Final Jeopardy” round. The gaming elements of a countdown timer, a wagering system, and prizes for winning teams made Skinquization a thrilling learning experience for students. Afterwards, average class dermatology examination scores improved, along with student motivation and engagement.

Similar elements from *Jeopardy* have been leveraged to exciting effect at the American Academy of Dermatology annual meetings, where resident teams can compete in competitions related to dermatology and dermatopathology knowledge, trivia, and correct diagnoses of cases and images. Multiple fast-paced

competition rounds and single elimination of contestants in front of a national conference audience have made the game show events perennial favorites among trainees. Prizes have included educational grants [25], gift cards [24], and “bragging rights.”

i-DERMIFY is an additional serious game learning tool developed to specifically harness dermatology’s visual and descriptive nature [26]. Teams of medical students drew action cards to either illustrate or describe skin conditions to each other, with hints provided when a difficult diagnosis was drawn. Each skin condition in the game was part of the British Association of Dermatologists’ required medical undergraduate curriculum. The game was iteratively developed with action research, where reflections from 28 student participants guided improvements to later games over time. Average assessment scores showed statistically significant positive increases (compared to knowledge gained from standard teaching,  $P < .005$ ) after playing. Student confidence in describing, drawing, and recognizing skin diseases also grew. As with other studies of serious games, students responded positively and appreciated the learning techniques of visual representation and group work promoted by the game. In addition to building confidence and recognition during the limited time available for dermatology learning, i-DERMIFY also had the advantage of building the transferable clinical skills of accurately documenting skin conditions in medical records, and it allowed students to practice the concise verbal descriptions of skin lesions that are essential to communicating as future physicians. Thereafter, the game was incorporated into the regular medical school curriculum and made freely available for educational use.

Because serious educational games have been found to build confidence and reduce student stress and anxiety, the card-based board game Stud2yBuddy was specially designed to help medical students study dermatology for final examinations [27]. Learning objectives were mapped from a traditional British medical curriculum, and developers deliberately incorporated different learning styles into the game. Student attitude surveys reported increased confidence among students in the diagnosis, investigation, management, description, and recognition of dermatological conditions. However, no objective measures outside of Likert responses from these surveys of student confidence were assessed, though the 65 students participating did describe increased motivation and decreased stress after playing the game, as was originally expected.

Blending a serious game with a simulation in an “escape room” format also worked well for dermatology trainees, similar to the results of aforementioned studies in general medical education. Surveys of British medical students previously established that trainees have misconceptions about the field of dermatology, along with feelings of being inadequately prepared to manage skin conditions. It was speculated that these were possible barriers to engagement with dermatology as a specialty. After participating in a “zombie apocalypse”-themed escape room featuring a deadly skin disease outbreak, which consolidated previous lecture-based and clinical teaching, the majority of students reported a desire to experience more dermatology, and all enjoyed the session [28]. However, only 16 students were ultimately able to participate due to logistical

and practical challenges with securing the physical venue for the escape room. Although further analysis with large-scale standardized studies is needed, our examination of available dermatology literature provides promising evidence for disrupting the paradigm of traditional classroom-based dermatology learning with both serious games and blended simulations.

### Gamification in Patient Dermatology Education

Successfully implemented gamification strategies in medical and dermatology education have also been applied to patient education, especially in regard to recognizing melanoma. Because most malignant melanomas are initially identified by the patients themselves or their partners, impactful melanoma education for the general public is essential [36]. Past efforts have focused on distributing pamphlets in physicians’ offices, a nonoptimal education format given that patients are increasingly web-centered and now receive most health care information from internet-based sources. Noninteractive websites may also be too passive for comprehensive patient understanding. An important consideration in the development of education materials is that patient education varies, and it often differs greatly from the training received by medical professionals. Although there are time constraints in patient counseling and necessity for individualization, given different personal needs, priorities, and resources, gamification approaches have still been effective for patients.

One example of a game-based intervention for nonmedical learners successfully taught features of malignant melanoma and alarming lesions. In a study of 271 adolescents, participants who were randomly selected to learn from a gamified six-round image matching program with built-in feedback such as “this lesion image shows irregular borders and uneven coloration, notice the irregular black spots on the left edge of this melanoma” performed significantly better than those receiving traditional “ABCDE” melanoma identification instruction [29]. Another study, developed by the Mayo Clinic, used a web-based pattern recognition game called Tapamole, which showed ABCDE melanoma examples (25 images of malignant melanoma and 60 of benign nevi). Volunteers were able to complete the game in <5 minutes, and they later demonstrated significantly greater sensitivity in recognizing malignant melanoma compared to their preintervention assessment performance. A follow-up Tapamole trial comparing the game, a traditional informational pamphlet, and no intervention showed similar melanoma detection sensitivity results between the game and pamphlet, but participants in the Tapamole game group reported the highest level of enjoyment [30]. Although many outcome measures reported by these studies were subjective (eg, motivation and enjoyment by the participants), these findings are vital to the development of future game-based learning programs, as patient willingness to participate in these programs will be key in moderating the long-term effects of patient education and driving persistence of engagement.

## Discussion

### Principal Findings

It is apparent that relatively few gamification studies specifically focused on dermatology currently exist in the literature, and of those studies, many are limited by small sample sizes or poor study design; for example, a control group where the gamification intervention was not administered was often lacking. Small numbers of participants and effect sizes as well as flaws in study design were detrimental to the quality of reported evidence. Our results corroborate recent systematic reviews of gamification interventions in general health care education, which have recognized that the extent of any positive impact is highly variable and nonuniformly measured [37] and largely of limited generalizable quality [3]. Additionally, the skills necessary to develop engaging games in dermatology (and health care education in general) may not directly overlap with the strengths of traditional medical educators; this would require more extensive collaboration with organizations outside of higher education and commitment of significant resources. The implementation of serious games and simulations can be both expensive and time-consuming. To that extent, some experts have suggested that gamification be considered part of an iterative process for directing learner engagement, rather than an end-product in itself [38]. Future investigations focusing on more robust, theory-driven methods should be encouraged. This evidence is complemented by generally positive attitudes regarding gamification by learners and educators; in one recent survey, 92% of residency program directors supported the use of games as an educational strategy [39], matching overwhelmingly positive responses from students [22].

### Limitations of This Narrative Review

Our narrative review is limited by its highly simplified search strategy, in which only a small subset of English-language peer-reviewed publications indexed in PubMed, Google Scholar,

and ResearchGate were examined in detail. A secondary systematic review could be beneficial in extending the preliminary survey we have presented. Gamification is a relatively new approach to education, made possible by the increasing ubiquity of the internet and digital applications in daily life. Given the extreme pace of technology development, it follows that in-depth scientific studies of many gamified platforms may not yet be published; for example, a new iPhone and Android mobile game called “Top Derm: A Game for Dermatologists” is being increasingly advertised on Facebook and Doximity as of July 2021 [40]. Created by board-certified dermatologists, “Top Derm” allows users with an interest in dermatology to attempt challenges testing dermatology knowledge, gain experience points through answering diagnosis quizzes, and unlock achievements. The information presented in the game is based on verified medical knowledge resources, and the game may be eligible for CME credits in the near future. While the game may hold great potential for effective gamified dermatology learning, subsequent investigation of this and other applications is required before evidence-based recommendations can be established.

### Conclusion

Overall, previous studies indicate that gamification approaches—both serious games and simulations—provide a promising means of future dermatology-related education for students, professionals, and patients. The numerous advantages and reviews of gamification in medical education, however, are in stark contrast to the dearth of available gamification resources for dermatology-specific learning. Moreover, the moderate observed benefits for learner engagement and knowledge require further examination beyond pilot studies. Although there may be widespread support for gamification, our review of current literature provides a case for further investment in large-scale studies of gamified educational platforms, especially in dermatology, and more robust assessment of the true long-term impact of this learning enhancement on standardized outcomes.

### Conflicts of Interest

RPD is a Joint Coordinating Editor for *Cochrane Skin*, a dermatology Section Editor for *UpToDate*, a Social Media Editor for the *Journal of the American Academy of Dermatology* (JAAD), Editor in Chief of *JMIR Dermatology*, and a Podcast Editor for the *Journal of Investigative Dermatology* (JID). He is a coordinating editor representative on the *Cochrane Council*. TES is a Section Editor for *JMIR Dermatology*. RPD receives editorial stipends (JAAD, JID, *JMIR Dermatology*), royalties (*UpToDate*), and expense reimbursement from *Cochrane Skin*. TES receives fellowship funding from the Pfizer Global Medical Grant (58858477) Dermatology Fellowship 2020 (Principal Investigator: RPD) and fees for serving as a Medical Advisor and Investigator for Antedotum Inc.

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## Abbreviations

**CME:** Continuing Medical Education

**JAAD:** Journal of the American Academy of Dermatology

**JID:** Journal of Investigative Dermatology

**SIU:** Société Internationale d'Urologie

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Original Paper

# Conflicts of Interest in “Throwaway” Dermatology Publications: Analysis of the Open Payments Database

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## Abstract

**Background:** Dermatology journals, periodicals, editorials, and news magazines are influential resources that are not uniformly regulated and subject to influence from the pharmaceutical industry. This study evaluates industry payments to physician editorial board members of common dermatology publications, including “throwaway” publications.

**Objective:** The aim of this study was to characterize the extent and nature of industry payments to editorial board members of different dermatologic publications in order to ascertain differences in payments between different types of publications.

**Methods:** A list of editorial board members was compiled from a collection of clinical dermatology publications received over a 3-month period. Data from the Open Payments database from 2013 to 2019 were collected, and analysis of payments data was performed.

**Results:** Ten publications were evaluated, and payments data for 466 physicians were analyzed. The total compensation across all years was US \$75,622,369.64. Consulting, services other than consulting, and travel or lodging payments constituted most of the payments. A fraction of dermatologists received the majority of payments. The top payers were manufacturers of biologic medications. Payment amounts were higher for throwaway publications compared to peer-reviewed journals.

**Conclusions:** Editorial board members of dermatology publications received substantial payments from the pharmaceutical industry. A minority of physicians receive the lion’s share of payments from industry. “Throwaway” publications have more financial conflict of interest than do peer-reviewed journals. The impact of these conflicts of interest on patient care, physicians’ practice patterns, and patient perception of physicians is noteworthy.

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## KEYWORDS

pharmaceutical industry; continuing medical education; dermatology; influence; payments; Open Payments database; publications; medical education; compensation; consulting; dermatologists

## Introduction

Health care professionals across all specialties use a myriad of resources for staying up to date on the medical literature. Peer-reviewed journals are touted as the gold standard, while little attention has been given to the role of “throwaway” journals in keeping clinicians abreast of advances in the literature. Throwaway journals are characterized as publications

that contain no original investigations, are provided free of charge, have a high advertisement to text ratio, are nonsociety publications, and are seldom peer reviewed [1]. Previous studies have shown that throwaway journals are more widely read than some peer-reviewed journals [1,2]. Throwaway journals are attractive to practicing clinicians given their ease of readability. The use of color, larger font size, graphics, and short summaries

improve the appeal of throwaway journals to their readership [3].

Industry-physician interaction is common in all medical specialties, and dermatology is no exception [4]. Previous studies have examined conflicts of interests among authors of dermatology textbooks, dermatology patient advocacy organizations, dermatology clinical practice guideline authors, and clinical trials in dermatology [5-9]. Under the Physician Payment Sunshine Act, a part of the Affordable Care Act, payments and other transfers of value by manufacturers and group-purchasing organizations to physicians are reported to the Centers for Medicare and Medicaid Services. These payments are reported in categories including consulting, speaking fees, food, travel, and research [10].

Given the important role that journals play in the education and clinical practice of dermatologists, we sought to characterize the extent and nature of industry payments to editorial board members of different dermatologic publications, including the throwaway journals. Specifically, we examined the number, amount, and type of payments received, the companies that are contributing the payments, and physician-specific characteristics (sex, practice setting, fellowship training).

## Methods

To replicate a real-world scenario, publications related to clinical dermatology received by author JR (a dermatology resident) over a 3-month period were collected. All publication types, including peer-reviewed journals, non-peer-reviewed journals, and periodicals, such as news magazines and tabloids, were included for analysis. A list of editors was compiled by individually reviewing each publication. Editorial board

members whose primary affiliation was outside of the United States and nonphysicians (ie, physician assistants and PhDs) were excluded from the study. Editor names were entered into the Open Payments database, and all payment data from 2013 to 2019 were collected. Physician-specific information on sex, practice setting, and training was collected via examination of professional information and biographies on individual practice websites. This study did not require approval by an institutional review board, as it did not contain human participants and used publicly available data. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guidelines were used for this study [11]. Data analysis was completed using Excel version 16.41 (Microsoft Corporation). Descriptive statistics, including mean, median, IQR, and percentages were calculated. Median and IQR were used when appropriate as descriptors when there was a skewed distribution. The statistical significance of intergroup differences was tested by using an independent samples *t* test. A 2-tailed *P* value less than .05 was considered statistically significant.

## Results

Ultimately, 10 publications were evaluated, and 466 individual physicians were identified. The publications included 5 periodicals and 5 journals. The group consisted of mostly men (267/466, 57.3%). The proportions of physicians in academic and private practice settings were almost equal, with 51.9% (242/466) in private practice and 48.1% (224/466) in academic settings. However, of those in private practice, 67.8% (164/242) also held academic appointments. Furthermore, 21.0% (98/466) served on more than 1 editorial board. Further physician characteristics are shown in [Table 1](#).

**Table 1.** Physician characteristics.

Physician characteristics and payment data	Value, n
Number of physicians	466
Physicians without payment data	52
Males	267
Osteopathic medicine	24
Mohs micrographic surgery	93
Dermatopathology	73
Pediatric dermatology	24
Private practice	242
Academic only	224
Serving on more than 1 editorial board	98

## Overall Payments

The total compensation across all years was US \$75,622,369.64, and the total number of payments was 124,651. Of all physicians, 11.2% (52/466) had 0 payments reported. The median total industry payment was US \$5334.69 (IQR US \$331.23-89,837.74). This was higher than the median payment amount averaged from 2013 to 2019 for all US dermatologists (US \$376.37) as well as the median payment for physicians

across all specialties (US \$1083.94) [12]. The median number of payments was 55 (IQR 4.3-295). This was also higher compared to the median number of payments for all dermatologists and US physicians across all specialties, with medians of 12 and 4, respectively. Apart from the period spanning 2017 to 2018, the total payment and number of payments increased yearly ([Table 2](#)).

Of the total payments (total amount), services other than consulting (US \$31,392,593.02), consulting (US \$22,201,879.20), and travel or lodging (US \$8,071,910.76) payments constituted 81.54% (US \$61,666,383/US \$75,622,369.64) of payments ([Multimedia Appendix 1](#)). Associated research funding and research payments across all years totaled US \$171,251,038.77 and US \$17,618,505.85, respectively. The percentage of the cohort that received any

kind of payments for associated research funding or research was small, at just 33.3% (155/466) and 25.5% (119/466), respectively. Of those who received payments, the median payment amount for associated research funding was US \$204,284.45 (IQR US \$39,659.32-960,049.20) and that for research payments was US \$24,484.15 (IQR US \$5017.50-144,941.78).

**Table 2.** Overall payment data<sup>a</sup>.

Payment data	Value
<b>All years</b>	
General payments (number of payments)	75,622,369.64 (124,651)
Research payments (number of payments)	17,618,505.85 (3325)
Associated research funding (number of payments)	171,251,038.77 (22,076)
Ownership and investment (number of payments)	26,144.08 (15)
Median payment amount (IQR)	5334.69 (331.23-89,837.74)
Median number of payments (IQR)	55 (4.3-295)
<b>2013-2019</b>	
2013 total payments (number of payments)	30,64,126.60 (6462)
2014 total payments (number of payments)	8,422,480.15 (17,094)
2015 total payments (number of payments)	11,270,847.59 (19,093)
2016 total payments (number of payments)	11,398,940.55 (20,021)
2017 total payments (number of payments)	13,784,709.09 (21,225)
2018 total payments (number of payments)	13,211,193.36 (20,232)
2019 total payments (number of payments)	14,470,072.30 (20,815)

<sup>a</sup>Payment amounts are in US \$.

### Academic Versus Private

Further analysis was performed after splitting the cohort by practice setting (academic vs private). Compared to those in academic settings, physicians in private practice had higher payments across all categories. The difference in payments was

statistically significant for total general payments but not for research payments or associated research funding. Payment differences in the categories of services other than consulting, food and beverage, education, honoraria, and gifts were also found to be statistically significant ([Table 3](#)).

**Table 3.** Comparison of payments between physicians in academic versus private practice settings<sup>a</sup>.

Payment	Academic	Private	P value
Total general payments (number of payments)	26,210,268.14 (31,001)	49,412,101.50 (93,650)	.03 <sup>b</sup>
Total research payments (number of payments)	5,505,040.83 (1234)	12,113,465.02 (2091)	.09
Associated research funding (number of payments)	67,213,288.37 (7946)	104,037,750.40 (14,130)	.32
Median total general payments (IQR)	1,048.69 (94.46-19,575.68)	19,743.92 (1750.20-18,5248.15)	N/A <sup>c</sup>
Median number of total payments (IQR)	11 (1-63)	173 (41-463)	N/A
<b>Categories of payments</b>			
Consulting (number of payments)	9,601,983.18 (2,981)	12,599,896.02 (3,838)	.44
Services other than consulting (number of payments)	9,986,340.41 (3,545)	21,406,252.61 (7,810)	.02
Travel and lodging (number of payments)	3,338,185.31 (8,634)	4,733,725.45 (13,608)	.31
Food and beverage (number of payments)	807,956.04 (14,601)	2,505,852.32 (63,696)	<.001
Education (number of payments)	66,933.34 (529)	192,825.57 (2,969)	.01
Current or prospective ownership or investment interest (number of payments)	84,830.47 (4)	256,278.64 (2)	.52
Honoraria (number of payments)	1,036,814.31 (288)	3,172,273.45 (829)	.02
Faculty/speaker at an unaccredited/noncertified CME <sup>d</sup> (number of payments)	777,345.36 (268)	1,463,257.45 (576)	.18
Gift (number of payments)	2161.24 (126)	73,895.71 (401)	.02
Grant (number of payments)	482,568.48 (18)	2,306,195.79 (58)	.12
Faculty/speaker at an accredited CME (number of payments)	14,150 (6)	6310.50 (6)	.41
Entertainment (number of payments)	0 (0)	101.85 (2)	.16
Royalty or license (number of payments)	11,000 (1)	690,334.87 (4)	.32

<sup>a</sup>Payment amounts are in US \$.

<sup>b</sup>Numbers in italics indicate statistical significance ( $P < .05$ ).

<sup>c</sup>N/A: not applicable.

<sup>d</sup>CME: continuing medical education.

### Top Earners

The top 10% of physicians receiving payments collectively received US \$56,060,893.28 which represented 74.13% (US \$56,060,893.28/US \$75,622,369.64) of the total payment amount for the entire study group. Moreover, 80.4% (37/46) of this subgroup received payments for research and associated research funding. In total, this cohort received US \$102,076,943.74 in associated research funding and US

\$9,348,517.09 in research payments across all years, accounting for 59.61% (US \$102,076,943.74/US \$171,251,038.77) and 53.06% (US \$9,348,517.09/US \$17,618,505.85) of all payments in those categories, respectively. This group comprised mostly men (36/46, 78%), and the majority (33/46, 72%) worked in private practice. Of those in private practice, 79% (26/33) also held academic appointments, and 25 physicians served on more than 1 editorial board (mean 2.96; Table 4).

**Table 4.** Characteristics of the top 10% of physicians receiving payments<sup>a</sup>.

Characteristic	Value
Number of physicians	46
Total general payments (number of payments)	56,060,893.28 (65,644)
Total research payments (number of payments)	9,348,517.09 (1,832)
Total associated research funding (number of payments)	102,076,943.74 (12,715)
Males, n	36
Osteopathic medicine, n	2
Mohs micrographic surgery, n	5
Dermatopathology, n	3
Pediatric dermatology, n	3
Private practice, n	33
Academic only, n	13
Serving on more than 1 editorial board, n	25

<sup>a</sup>Payment amounts are in US \$.

### Top Payers

The top 20 companies making payments were pharmaceutical manufacturers and combined paid US \$64,774,389.91,

representing 85.65% (US \$64,774,389.91/US \$75,622,369.64) of total disbursement. The majority of the companies were manufacturers of biologic medications ([Table 5](#)).

**Table 5.** Highest paying companies.

Company	Total general payments (US \$)	Manufactured products
Abbvie	7,365,101.61	Adalimumab (Humira), risankizumab (Skyrizi), upadacitinib (Rinvoq)
Galderma	7,302,686.12	Hyaluronic acid gel filler (Restylane), abobotulinumtoxina (Dysport), poly-L-lactic acid filler (Sculptra), ivermectin cream (Soolantra), brimonidine topical gel (Mirvaso), adapalene and benzoyl peroxide (Epiduo)
Allergan (subsidiary of Abbvie)	5,993,810.99	Cross-linked hyaluronic acid filler (Juvederm), deoxycholic acid (Kybella), onabotulinumtoxina (Botox), cryolipolysis (Coolsculpting)
Bausch (Ortho dermatologics)	5,342,108.74	Brodalumab (Siliq), laser devices (via Solta)
Celgene	4,938,532.20	Apremilast (Otezla; sold in 2019)
Lilly	4,295,681.28	Ixekizumab (Taltz)
Regeneron	3,835,317.28	Dupilimab (Dupixent)
Novartis	3,599,007.79	Secukinumab (Cosentyx), ruxolitinib (Jakafi), omalizumab (Xolair)
Pfizer	3,435,221.32	Etanercept (Enbrel), tofacitinib (Xeljanz)
Genzyme	2,670,075.41	Dupilimab (Dupixent)
Janssen	2,500,056.99	Golimimumab (Simponi), infliximab (Remicade), ustekinumab (Stelara), guselkumab (Tremfya)
Merz pharmaceuticals	2,232,056.79	Incobotulinumtoxina (Xeomin), calcium hydroxylapatite gel filler (Radiesse), hyaluronic acid filler (Belotero), intense focused ultrasound (Ultherapy), polidocanol (Asclera)
Leo pharma	1,967,161.84	Azelaic acid gel (Finacea), tacrolimus ointment (Protopic), topical vitamin D analogues
Almirall	1,938,517.92	Sarecycline (Seysara), dapsone gel (Aczone)
Bayer	1,521,718.32	Clotrimazole
Genentech	1,489,473.68	Vismodegib (Erivedge), rituximab (Rituxan), omalizumab (Xolair)
Amgen	1,276,055.07	Etanercept (Enbrel), apremilast (Otezla)
Sensus	1,071,990.39	Laser devices
Promius (subsidiary of Dr. Reddy's Laboratories)	1,012,017.41	Topical corticosteroids
Sun Pharma	987,798.76	Tildrakizumab-asmn (Ilumya)

## Individual Journal Analysis

Payment data for each individual publication was also performed. For simplicity, the publications were categorized into 2 groups, periodicals (including news magazines, tabloids, and editorials) and peer-reviewed journals. The average number of editorial board members for periodicals (mean 26.2) was lower than the average for peer-reviewed publications (mean 97.4). The averaged median payment amount (median US \$113,877.02) to physicians on the editorial board members of the periodical publications was 3.5 times higher than to those on editorial boards of peer-reviewed publications (US \$32,670.59). Associations with professional societies, patient advocacy organizations, access requirements, and other journal data are shown in [Multimedia Appendix 2](#).

## Discussion

In this study we characterized payments from industry to editorial board members of clinical dermatology publications used as important resources in dermatology education and clinical practice. Our study shows that members of editorial boards of various types of publications have ties to industry.

Exploration of this group demonstrates a facet of the medical industrial complex that pervades medicine. The data from this study showed that the remuneration received by editorial board members was on average 14 times higher compared to that received by dermatologists at large. Compensation for speaker fees, consulting, travel, and lodging made up most of the total payments. The 20 highest-paying manufacturers and most of the companies making payments to dermatologists belonged to the pharmaceutical industry. Dermatology as a specialty is a valued target for the pharmaceutical industry, being a relatively small field that treats several common and chronic conditions. Dermatologists are one of a few specialties that prescribe high-price biological medications. Of note, 11 of the top-20 paying companies in our study were manufacturers of biologic medications. Biologics for the treatment of psoriasis is a multibillion-dollar industry, representing some of the top-grossing medications in the world. Adalimumab (Humira) has been the top-selling drug for several years with over 19 billion dollars in global sales in 2019 alone [13]. Since gaining Food and Drug Administration approval for the treatment of adults with moderate to severe atopic dermatitis, dupilimab (Dupixent) sales have skyrocketed into the billions. The predominance of pharmaceutical payments in dermatology

differs from other specialties such as orthopedic surgery, otolaryngology, and ophthalmology, in which device and diagnostic companies provide a greater amount of support [14-16].

Over the last several decades, the number of media by which clinicians acquire information to stay abreast of changes in their respective fields has increased. Historically, peer-reviewed journals were the mainstay source of information. With advancing technology, the market for resources that clinicians use for continuing medical education (CME) has expanded dramatically to embrace new formats, such as podcasts, webinars, virtual conferences, and social media applications (Instagram, Facebook, Twitter). Although most academic organizations have guidelines and policies to minimize or prevent conflicts of interests in publishing or the dissemination of information, the same cannot be said for other avenues that are independently sponsored or promoted. Today, most physicians, when faced with a surplus of journals, do not have the time to critically appraise each individual article. Instead of trying to grasp increasingly complex science or statistical methods, the more practical solution is to read summaries or condensations of educational material. This has paved the way for the “throwaway” journals. Throwaway journals usually do not contain any original investigations, have a high advertisement to text ratio, and are often provided free of charge, as they are funded by pharmaceutical companies. These journals are seldom peer-reviewed but are quite popular given their high readability [10]. The articles are frequently written by employees of the publication’s sponsoring companies and are seldom fact-checked by independent reviewers. They often include capsule summaries of conferences, journal article synopses, or therapeutic guides—all sandwiched between pharmaceutical ads. The information within throwaway journals is rarely antagonistic towards the pharmaceutical companies funding the journal [17]. Despite the popularity of throwaway journals and their direct role in clinician education, there is a dearth of research or discussion of throwaways in the literature. A PubMed search for throwaway journals returns just 8 results, with the last article being published in 2005 [18].

Distinguishing between a classic throwaway and a prototypical peer-reviewed journal has become increasingly difficult. For example, one of the periodicals (*DermWorld*) that was examined in this study was affiliated with a peer-reviewed journal (*Journal of the American Academy of Dermatology* [JAAD]). The median payment amounts (US \$693.68 and US \$1885.65, respectively) for both of these publications were the lowest (*DermWorld*) and second lowest (*JAAD*) in each of their respective groups. In contrast, the median payment amount for one of the peer-reviewed journals (US \$146,159.48, *Journal of Clinical and Aesthetic Dermatology* [JCAD]) was 11 times greater than the next highest median payment for peer-reviewed journals (US \$12,526.52, *Journal of Drugs in Dermatology*). *JCAD* is a peer-reviewed, PubMed-indexed publication platform wherein every article published is available as full text and free via PubMed but with costs covered by advertising and subscriptions. With the commercialization of medical literature and a move toward open-access type publishing, these hybrid types of journals are increasingly common. The bias is clear, and the

conflicts of interest run deep. Affiliations with other entities, including patient advocacy organizations, specialty societies, and other groups that also receive financial support from the pharmaceutical industry, add another layer of complexity to the relationship.

It stands to reason that industry companies would select for well-known authorities and leaders in the field to provide their knowledge and expertise when evaluating their products. Historically, key opinion leaders (KOLs) have earned their positions by performing original research, discovering new therapies, and advancing the field. KOLs are well known in their respective fields, recognized as the authors of innovative journal articles, senior editors of major textbooks, specialty committee or leadership members, clinical practice guidelines authors, expert speakers at societal meetings, and institutional faculty leaders. Traditionally, the road to becoming a KOL involved years of research, teaching, and dissertation. However, currently some have asserted that becoming a KOL is more of a commercial enterprise carried out by the pharmaceutical industry and private KOL consulting firms [19,20]. A usual and effective method for industry to disseminate information is through peer advocacy [21]. This practice makes sense from a business standpoint, as KOLs are valuable figures that can lend expertise and credibility to new pharmaceuticals. Depending on the need, whether a company is looking to introduce a new product, rebrand a previous or newly reformulated product, or develop CME programs, KOLs can function as medical brand ambassadors to target specific audiences. The marketing value of KOLs is analogous to celebrity sponsorship deals in commercial ventures. The line between a trusted colleague sharing their knowledge and a salesperson selling a product is consequently blurred. In an unadulterated world, delivery of information by KOLs would be moral if the material were impartial and rooted in evidence-based medicine. However complete objectivity seems questionable when one party benefits so greatly. Industry offers many advantages to KOLs, including paid consultancy, participation in clinical trials, prestige in the eyes of peers, and opportunities for article authorship. The medical literature represents a useful avenue for industry to take advantage of the credibility and standing of KOLs [22]. The web of interaction is broad as evidenced by the activities of the top-paid dermatologists in our study. Many of the top earners serve on multiple editorial boards, hold dual private and academic appointments, and run a conglomerate of CME activities backed by industry for the purpose of influencing dermatologists at large. As examples, the highest earner received payments from 53 different companies, and one physician in the top 10% served on 6 editorial boards, including several of the peer-reviewed journals. A further 88.8% (414/466) of physicians in this study received payments from industry. This was higher than the percentage reported for dermatology textbook authors [6] (54.0%) and the 73.3% and 86% reported in the studies by Feng et al [4] and Checketts et al [23], respectively.

Historically, collaboration between physicians and the pharmaceutical industry has resulted in innovations and advancements in medicine. When conducted properly, the relationship between physicians and industry serves to advance



the field of medicine as a whole with the ultimate goal of improving the lives of patients. However, the interests and commitments of physicians should deviate from those of industry. Where caring for patients is the primary responsibility of physicians, those in industry are chiefly concerned with their responsibility to their shareholders. As with any other business, the objectives of industry are geared towards profit. Industry engagement occurs so often that the practice has become a normalized component of physician education. This element of medical education has evolved over several decades and is so ubiquitous that many trainees and clinicians have become anesthetized to the practice. The fraternity of medicine is one in which new inductees observe their teachers and mentors giving industry-sponsored lectures, serving on industry advisory boards, and receiving industry funding for research [24]. These practices are so ingrained in our profession that participation is actually desirable for advancing academic careers or enhancing prestige. The “supportive” role of industry in medical education is ethically problematic.

Patients expect physicians to deliver effective, safe, and compassionate care based on evidence and best practices. As medicine is always changing, physicians must stay abreast of new therapeutics, devices, skills, and treatments. Establishing and upholding standards of competence is a responsibility of physicians to society. When these standards are perverted by industry, patients become unknowing victims of commerce.

Over recent years, industry has played an increasingly direct role in physician education. The pharmaceutical industry's exploitation of medicine is alive and well, flourishing through academic literature, commercial marketing, and compliant colleagues. Industry has become so intertwined with medicine that it shapes medical knowledge and opinion to suit its commercial needs. It has injected its presence into clinics, conferences, research, journals, and medical education. This relationship is not completely clandestine. Funding from industry supports research grants, clinical trials, and educational programs. As physicians we need to be aware of how industry influences the information required to care for our patients. To suit the needs of industry, promotion and marketing sway the independence of information presented to clinicians. The quality and integrity of clinician education is paramount in maintaining the public's trust in our profession. In order to maintain the standards of postgraduate professional education, the relationship between industry and accredited education must be made transparent.

Editorial board members of dermatology publications received substantial payments from the pharmaceutical industry. A minority of physicians receive the lion's share of payments from industry. Throwaway publications have more financial conflicts of interest than do peer-reviewed journals. The impact of these conflicts of interest on patient care, physicians' practice patterns, and patient perception of physicians is noteworthy.

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## Conflicts of Interest

None declared.

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### Multimedia Appendix 1

Categories of payments.

[PDF File (Adobe PDF File), 31 KB - [derma\\_v4i2e30126\\_app1.pdf](#) ]

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### Multimedia Appendix 2

Individual journal characteristics and payments data.

[PDF File (Adobe PDF File), 36 KB - [derma\\_v4i2e30126\\_app2.pdf](#) ]

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## Abbreviations

**CME:** continuing medical education

**JAAD:** *Journal of the American Academy of Dermatology*

**JCAD:** *Journal of Clinical and Aesthetic Dermatology*

**KOL:** key opinion leaders

**STROBE:** Strengthening the Reporting of Observational Studies in Epidemiology

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## Research Letter

# From the Cochrane Library: Skin Care Interventions in Infants for Preventing Eczema and Food Allergy

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## KEYWORDS

eczema; atopic dermatitis; skin care; emollients; pediatrics; food allergy; allergy; dermatology

Eczema is a common and taxing condition, with an estimated prevalence of 10.7% among pediatric patients in the United States and a cost of US \$5 billion annually [1]. Eczema has a known association with food allergies, with both conditions commonly developing during the first year of life. The cost of care and daily attention required to treat both eczema and food allergy represent significant burdens to individuals and families. Without a global standard for neonatal or infant skin care, and with few emollient studies performed in term infants, Kelleher

et al's Cochrane review [2] provides a much-needed assessment of the evidence for emollients and other interventions to prevent eczema, as well as their effects on the development of food allergy.

This systematic review assessed 33 randomized controlled trials (n=25,827), all of which studied term (>37 weeks) infants (<12 months) without a pre-existing diagnosis of eczema, food allergy, or other skin condition. Clinically relevant findings are summarized in Table 1.

**Table 1.** Clinically relevant findings.

Outcomes	Comparison	Relative risk (RR) or hazard ratio (HR) (CI)	Number of studies and participants in the pooled analysis	Quality of evidence
Development of eczema by 1-2 years	Skin care interventions vs standard care <sup>a</sup>	RR=1.03 (CI 0.81-1.31)	7 trials, 3075 participants	Moderate
Time needed to develop eczema	Skin care interventions vs standard care	HR=0.86 (CI 0.65-1.14)	9 trials, 3349 participants	Moderate
Development of skin infections	Skin care interventions vs standard care	RR=1.34 (CI 1.02-1.77)	6 trials <sup>b</sup> , 2728 participants	Moderate
IgE <sup>c</sup> -mediated food allergies at 1-2 years	Skin care interventions vs standard care	RR=2.53 (CI 0.99-6.47)	1 trial, 996 participants	Very low
Sensitization to food allergens at 1-2 years	Skin care interventions vs standard care	RR=0.86 (CI 0.28-2.69)	2 trials, 1055 participants	Very low

<sup>a</sup>Standard care is defined as no skin care or care as usual.

<sup>b</sup>While 2 out of the 6 studies in the pooled analysis slightly favored skin care interventions (not statistically significant), the pooled data suggested an increased risk of skin infection with emollients. The studies contributing to the pooled data varied in a number of study-related and patient-specific characteristics.

<sup>c</sup>IgE: immunoglobulin E.

There was limited evidence concerning the impact of skin care interventions on IgE (immunoglobulin E)-mediated food

allergies; the few trials that investigated these outcomes produced broad CIs that failed to achieve statistical significance.

An important strength of this review was its inclusion of 7 studies in a meta-analysis evaluating study-specific factors (eg, type of emollient, duration) and participant covariates (eg, age, FLG [filaggrin] genotype, family history of atopy), which revealed no interplay between these factors and the intervention on eczema risk. Other potential confounders (such as bath water composition, detergent type, diet, climate and geographical factors, and dust and home allergens) were not assessed.

Further, the intervention and control groups varied widely between the included studies such that single and combination emollients of differing contents were considered together. The control (standard care) was likewise variable, depending upon national standards and cultural norms. These limitations highlight the need for additional research to improve the generalizability of the results to diverse populations.

Efforts to identify the effects of different skin care interventions on the prevention of eczema and their effects on food allergy are also warranted. There are currently a number of ongoing

clinical trials assessing skin care interventions for the prevention of atopic dermatitis and food allergy; one trial recently concluded there is no evidence that the use of daily emollients reduces the risk of eczema by the age of 2 years in high-risk patients (patients with first-degree relatives with a history of eczema, asthma, or allergic rhinitis) [3].

The incidence of eczema has increased, especially since the onset of the COVID-19 pandemic. With an enhanced emphasis on frequent hand washing, hand hygiene has become an increasingly popular topic among individuals and families [4]. In recent years prior to the pandemic, an increase in the incidence of eczema in the pediatric population was reported, most prominently among infants [5]. With this in mind, it is important for clinicians to familiarize themselves with evidence-based treatment regimens, supported by data from sources like the Cochrane Library. Utilizing information from numerous studies simultaneously, as in the review summarized here, supports best practice and enables physicians to effectively counsel patients.

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## Conflicts of Interest

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## Abbreviations

**FLG:** filaggrin

**IgE:** immunoglobulin E

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Research Letter

# From the Cochrane Library: Systemic Treatments for Metastatic Cutaneous Melanoma

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**KEYWORDS**

melanoma; metastatic melanoma; skin neoplasms; angiogenesis inhibitors; monoclonal antibodies; antineoplastic agents; Cochrane reviews; systematic reviews; clinical trials; randomized controlled trials; dermatology

Melanoma is the most lethal type of skin cancer, with a 5-year survival rate of only 22.5% for stage IV (metastatic) disease [1]. Furthermore, with its steadily increasing incidence rate of 5% to 7% per year predicted through 2031, melanoma represents a significant health burden in the United States [1]. Treatment options for metastatic melanoma have changed dramatically with novel therapeutic strategies. However, a consensus on treatment and quality of evidence has yet to be established. “Systemic treatments for metastatic cutaneous melanoma,” a 2018 Cochrane review, assessed the beneficial and harmful effects of these new classes of drugs in treating unresectable metastatic melanoma, defined as stage IIIc or stage IV [2].

This review found high-quality evidence that many newer agents, such as immune checkpoint inhibitors and targeted therapies in the form of small-molecule inhibitors, were more effective than conventional chemotherapies (ie, dacarbazine and temozolomide) in treating unresectable metastatic

melanoma. [Table 1](#) summarizes significant findings of the Cochrane review on drug comparisons.

As noted in [Table 1](#), BRAF inhibitors and BRAF inhibitors + mitogen-activated protein kinase (MAPK; MEK) inhibitors (both are MAPK pathway inhibitors) provide improved survival for patients with metastatic melanoma with BRAF gene mutations. These treatment options are of particular importance, as 40% to 60% of metastatic melanomas harbor the BRAF mutation [3]. A 2021 meta-analysis supported the findings of this Cochrane review, concluding improved overall survival (hazard ratio [HR] 0.59, 95% CI 0.47-0.74) and progression-free survival (HR 0.24, 95% CI 0.19-0.3) when comparing BRAF + MEK inhibitors against conventional chemotherapy for unresectable metastatic melanoma (TNM [tumor, node, metastasis] stage IIIc) [3]. While these data are encouraging, additional randomized controlled studies are warranted to further elucidate outcome differences between these combination treatment strategies.

**Table 1.** A Cochrane review of metastatic melanoma therapies for overall survival, progression-free survival, and toxicity rate.

Drug therapy comparison	Overall survival	Progression-free survival <sup>a</sup>	Toxicity rate <sup>b</sup>
<b>Antiprogrammed cell death protein 1 (anti-PD1) vs conventional chemotherapy<sup>c</sup></b>			
Outcome	Improved	Improved	Decreased
Corresponding risk <sup>d</sup> vs assumed risk <sup>e</sup>	320 (95% CI 290-360) deaths per 1000 vs 600 deaths per 1000, respectively	610 (95% CI 520-690) per 1000 vs 850 per 1000, respectively	165 (95% CI 93-291) toxicities per 1000 vs 300 per 1000, respectively
Relative effect	HR <sup>f</sup> 0.42, 95% CI 0.37-0.48, 1 study, N=418	HR 0.49, 95% CI 0.39-0.61, 2 studies, N=957	RR <sup>g</sup> 0.55, 95% CI 0.31-0.97, 3 studies, N=1360
Evidence quality <sup>h</sup>	High	Moderate	Low
<b>Anti-PD1 vs anticytotoxic T-lymphocyte-associated protein 4 (anti-CTLA4)</b>			
Outcome	Improved	Improved	Decreased
Corresponding risk vs assumed risk <sup>e</sup>	428 (95% CI 423-454) deaths per 1000 vs 600 deaths per 1000, respectively	641 (95% CI 612-679) per 1000 vs 850 per 1000, respectively	278 (95% CI 215-362) toxicities per 1000 vs 398 per 1000, respectively
Relative effect	HR 0.63, 95% CI 0.60-0.66, 1 study, N=764	HR 0.54, 95% CI 0.50-0.60, 2 studies, N=1465	RR 0.70, 95% CI 0.54-0.91, 2 studies, N=1465
Evidence quality	High	High	Low
<b>Anti-PD1 and anti-CTLA4 vs anti-CTLA4 alone</b>			
Outcome	— <sup>i</sup>	Improved	No significant difference
Corresponding risk vs assumed risk <sup>j</sup>	—	425 (95% CI 375-478) per 1000 vs 750 per 1000, respectively	278 (95% CI 215-362) toxicities per 1000 vs 398 per 1000, respectively
Relative effect	—	HR 0.40, 95% CI 0.35-0.46, 2 studies, N=738	RR 1.57, 95% CI 0.85-2.92, 2 studies, N=764
Evidence quality	—	High	Low
<b>BRAF inhibitors vs conventional chemotherapy<sup>c</sup></b>			
Outcome	Improved	Improved	No significant difference
Corresponding risk vs assumed risk <sup>e</sup>	307 (95% CI 226-407) deaths per 1000 vs 600 deaths per 1000, respectively	401 (95% CI 328-475) per 1000 vs 600 per 1000, respectively	433 (95% CI 163-1135) toxicities per 1000 vs 341 toxicities per 1000, respectively
Relative effect	HR 0.40, 95% CI 0.28-0.57, 2 studies, N=925	HR 0.27, 95% CI 0.21-0.31, 2 studies, N=925	RR 1.27, 95% CI 0.48-3.33, 2 studies, N=408
Evidence quality	High	High	Low
<b>Mitogen-activated protein kinase (MEK) inhibitors vs conventional chemotherapy<sup>c</sup></b>			
Outcome	No significant difference	Improved	Increased
Corresponding risk vs assumed risk <sup>e</sup>	541 (95% CI 412-682) deaths per 1000 vs 600 deaths per 1000, respectively	667 (95% CI 549-781) per 1000 vs 850 per 1000, respectively	665 (95% CI 446-995) toxicities per 1000 vs 413 toxicities per 1000, respectively
Relative effect	HR 0.85, 95% CI 0.58-1.25, 3 studies, N=496	HR 0.58, 95% CI 0.42-0.80, 3 studies, N=496	RR 1.61, 95% CI 1.08-2.41, 1 study, N=91
Evidence quality	Low	Moderate	Moderate
<b>BRAF inhibitors + MEK inhibitors vs BRAF inhibitors alone</b>			
Outcome	Improved	Improved	Increased
Corresponding risk vs assumed risk <sup>k</sup>	260 (95% CI 204-321) deaths per 1000 vs 350 deaths per 1000, respectively	490 (95% CI 411-574) per 1000 vs 700 per 1000, respectively	500 (95% CI 421-594) toxicities per 1000 vs 495 toxicities per 1000, respectively



Drug therapy comparison	Overall survival	Progression-free survival <sup>a</sup>	Toxicity rate <sup>b</sup>
Relative effect	HR 0.70, 95% CI 0.59-0.82, 4 studies, N=1784	HR 0.56, 95% CI 0.44-0.71, 4 studies, N=1784	RR 1.01, 95% CI 0.85-1.20, 4 studies, N=1774
Evidence quality	High	Moderate	Moderate
<b>Chemotherapy + antiangiogenic drugs<sup>l</sup> vs conventional chemotherapy<sup>c</sup></b>			
Outcome	Improved	Improved	No significant difference
Corresponding risk vs assumed risk <sup>e</sup>	423 (95% CI 338-524) deaths per 1000 vs 600 deaths per 1000, respectively	730 (95% CI 627-825) per 1000 vs 850 per 1000, respectively	185 (95% CI 25-1447) toxicities per 1000 vs 272 toxicities per 1000, respectively
Relative effect	HR 0.60, 95% CI 0.45-0.81, 2 studies, N=324	HR 0.69, 95% CI 0.52-0.92, 2 studies, N=324	RR 0.68, 95% CI 0.09-5.32, 2 studies, N=324
Evidence quality	Moderate	Moderate	Low
<b>Polychemotherapy<sup>m</sup> vs conventional chemotherapy<sup>c</sup></b>			
Outcome	None	None	Increased
Corresponding risk vs assumed risk <sup>e</sup>	No significant difference	No significant difference	372 (95% CI 272-512) toxicities per 1000 vs 189 toxicities per 1000, respectively
Relative effect	HR 0.99, 95% CI 0.85-1.16, 6 studies, N=594	HR 1.07, 95% CI 0.91-1.25, 5 studies, N=398	RR 1.97, 95% CI 1.44- 2.71, 3 studies, N=390
Evidence quality	High	High	Moderate

<sup>a</sup>Progression-free survival is defined as the time from randomization until diagnosis of disease recurrence (local or distant/metastatic). The numbers listed refer to event rates (death rates and progression rates) [2].

<sup>b</sup>Toxicity is defined as the occurrence of grade 3 or higher adverse events according to the World Health Organization scale.

<sup>c</sup>Dacarbazine and its orally available derivative, temozolomide, both of which cross-link DNA, inhibiting transcription and replication [2].

<sup>d</sup>Corresponding risk is based on the assumed risk in the comparison group and the relative effect of the intervention.

<sup>e</sup>Assumed risk (which is defined as the median control group risk across all studies): 1-year overall survival rate (40%); assumed risk in the control population: 1-year progression-free survival rate (15%); assumed risk in the control population: toxicity rate across the control arms of the included trials.

<sup>f</sup>HR: hazard ratio.

<sup>g</sup>RR: risk ratio.

<sup>h</sup>High-quality evidence: further research is very unlikely to change the confidence in the estimate of effect; moderate-quality evidence: further research is likely to have an important impact on the confidence in the estimate of effect and may change the estimate; low-quality evidence: further research is very likely to have an important impact on the confidence in the estimate of effect and is likely to change the estimate; very low-quality evidence: very uncertain about the estimate.

<sup>i</sup>No data available.

<sup>j</sup>Assumed risk in the control population: 1-year progression-free survival rate (15%); assumed risk in the control population: toxicity rate across the control arms of the included trials.

<sup>k</sup>Assumed risk in the control population: 1-year overall survival rate (65%); assumed risk in the control population: 1-year progression-free survival rate (30%); assumed risk in the control population: toxicity rate across the control arms of the included trials.

<sup>l</sup>Bevacizumab and endostar.

<sup>m</sup>Dacarbazine in combination with other chemotherapeutics.

Despite the efficacy of BRAF + MEK inhibitors in treating BRAF-mutated melanoma, about 20% of BRAF-mutated melanomas demonstrate resistance to this therapy [4]. Therefore, the pursuit of alternative treatments is necessary. New therapies, such as T-cell therapies, which include tumor-infiltrating lymphocytes (TILs), T-cell receptor therapy, and chimeric antigen receptor T-cell therapy, have shown promising results in treating metastatic melanoma. A recent study reported an objective response rate of 36% (95% CI 25%-49%) and a median duration of response that was not reached after an 18.7-month median follow-up (range 0.2-34.1 months) in

patients with metastatic melanoma (stage IIIc or IV) treated with TILs [5]. These therapies present an exciting new avenue to treating metastatic melanoma in patients who have not responded to approved therapy, as there remain very few treatments to improve outcomes in these patients. Additional studies are underway to determine the efficacy of these T-cell therapies on metastatic melanoma and assess the duration of response.

In conclusion, this Cochrane review provides convincing evidence supporting the use of new therapeutics compared to

chemotherapy alone. Given recent evidence of resistance to older drugs, there is an ongoing and urgent need for alternative treatment options and approaches [4]. We encourage additional study and evaluation of evidence regarding novel therapies to

accurately and comprehensively identify the most effective treatments for metastatic melanoma, especially the individualized treatment of specific melanoma subsets.

### Conflicts of Interest

TS serves as a section editor for *JMIR Dermatology*. In addition, TS receives fellowship funding from the Pfizer Global Medical Grant (58858477) Dermatology Fellowship 2020 and fees for serving on the Medical Advisory Board of Antedotum Inc. JA and A Hamp serve as social media editors for Cochrane Skin. MS is a member of the Cochrane Collaboration.

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### Abbreviations

**HR:** hazard ratio

**MAPK:** mitogen-activated protein kinase

**TIL:** tumor-infiltrating lymphocyte

**TNM:** tumor, node, metastasis

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Research Letter

# From the Cochrane Library: Topical Tacrolimus for Atopic Dermatitis

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**KEYWORDS**

atopic dermatitis; eczema; calcineurin inhibitor; tacrolimus; lymphoma; dermatology; dermatitis

Among chronic skin disorders, atopic dermatitis demonstrates the greatest negative impact on quality of life for both affected patients and their families, and is associated with anxiety, guilt, and depression [1]. Emotional stress from uncontrolled eczema can be displaced on coworkers, students, and teachers, affecting the entire community. Thus, effective eczema management potentially has far-reaching benefits.

Eczema is commonly treated with topical corticosteroids (TCS), the long-term use of which may cause dermal atrophy, striae, and hypertrichosis, among other adverse effects [2]. Additionally, patients may experience treatment-resistant eczema. Therefore, cost-effective alternative treatments with fewer side effects may be prudent. A 2015 Cochrane review, titled “Topical tacrolimus for atopic dermatitis,” assessed the efficacy and safety of the topical calcineurin inhibitors (TCIs) tacrolimus and pimecrolimus in comparison to conventional treatments (20 randomized controlled trials, n=5885) [2]. Significant drug comparison findings are summarized in [Table 1](#). This review found convincing evidence that tacrolimus 0.1% was significantly more effective than low-potency TCS, pimecrolimus 1%, and tacrolimus 0.03% at improving physician- and patient-assessed appearance of eczema-affected skin in many settings. While results were mainly obtained using the subjective measures mentioned previously, several trials included in the review indicated that tacrolimus significantly improved objective measures such as the Eczema Area and Severity Index, quality of life, and Scoring Atopic Dermatitis (SCORAD) when compared to certain TCS in various settings. However, lack of data on these secondary outcomes limited the

completeness of evidence. Unfortunately, since the publication of this Cochrane review, only 1 randomized controlled trial analyzing the efficacy of TCIs has been published [3]. Despite this study validating the findings of this Cochrane review, further research is warranted to investigate the true relationship between TCS and TCIs utilizing objective standardized criteria.

One notable side effect found in this review was burning and pruritus experienced in the first days of TCI treatment, which was most pronounced when comparing topical tacrolimus with TCS (risk ratio 2.48, 95% CI 1.96-3.14, 5 studies, n=1883, high-quality evidence). These symptoms were mild and transient, and generally did not lead to discontinuation of treatment. There were no reported TCI-related cases of skin atrophy nor evidence of increased risk of malignancies.

Despite the minimal side-effects profile, a black box warning for topical tacrolimus remains due to concern for malignancies associated with systemic absorption, which is low when administered topically [4]. Nevertheless, patients with rare skin diseases such as Netherton syndrome and lamellar ichthyosis should be cautioned, as systemic absorption of TCIs was noted in these patients [2]. Reassuringly, a recent 10-year prospective longitudinal study following 7954 children with atopic dermatitis who used topical tacrolimus for ≥6 weeks reported no cases of lymphoma [5].

The efficacy of tacrolimus was further substantiated with a recent 2020 study reporting that tacrolimus 0.1% was more likely to achieve clear or almost clear skin at 28 to 42 days versus vehicle (hazard ratio 1.74, 95% CI 1.13-3.05) based on

the Investigator's Static Global Assessment [6]. Eczema results in psychological stress to the patient, as well as to the patient's family and community. Options with a favorable side-effects profile for treatment-resistant eczema or for patients who are

intolerant to TCS are desirable [1]. Tacrolimus is a suitable and effective alternative under these conditions. Thus, tacrolimus appears to be an effective treatment for eczema.

**Table 1.** Eczema drug efficacy comparisons with respective measurements, results, risk ratios (RRs), and quality of evidence.

Comparison	Measurement <sup>a</sup>	Result	RR	Quality of evidence <sup>b</sup>
Tacrolimus 0.1% vs low-potency TCS <sup>c</sup> (follow-up: mean 3 weeks)	Physician's assessment	Tacrolimus 0.1% superior	RR 3.09, 95% CI 2.14-4.45, 1 RCT <sup>d</sup> , n=371	Moderate
Tacrolimus 0.1% vs moderate-potency TCS (follow-up: 6 months)	Physician's assessment	Tacrolimus 0.1% marginally better	RR 1.32, 95% CI 1.17-1.49, 2 RCTs, n=506	Moderate
Tacrolimus 0.1% vs pimecrolimus 1% (follow-up: mean 6 weeks)	Physician's assessment	Tacrolimus 0.1% superior	RR 1.80, 95% CI 1.34-2.42, 2 RCTs, n=506	Moderate
Tacrolimus 0.03% vs tacrolimus 0.1% (follow-up: 3-12 weeks)	Physician's assessment	Tacrolimus 0.1% superior	RR 0.82, 95% CI 0.72-0.92, 6 RCTs, n=1640	High
Tacrolimus 0.1% vs moderate to high potency TCS (follow-up: mean 3 weeks)	Physician's assessment	No difference	RR 0.95, 95% CI 0.78-1.16, 1 RCT, n=377	Low
Tacrolimus 0.1% vs moderate to high potency TCS (follow-up: mean 6 months)	Participant's self-assessment	Marginal benefit favoring tacrolimus 0.1%	RR 1.21, 95% CI 1.13-1.29, 1 RCT, n=974	Low
Tacrolimus 0.03% vs mild-potency TCS (follow-up: mean 3 weeks)	Physician's assessment	Tacrolimus 0.03% superior	RR 2.58, 95% CI 1.96-3.38, 2 RCTs, n=790	Moderate

<sup>a</sup>Physicians and participants rate skin improvement in a subjective manner. Though subjective, these tools are commonly used to assess treatment efficacy. For example, skin improvement is evaluated as excellent improvement (>90% improvement), marked improvement (75%-89%), or moderate improvement (50%-74%) from the participant's or physician's viewpoint [4].

<sup>b</sup>High quality: further research is very unlikely to change the confidence in the estimate of effect; moderate quality: further research is likely to have an important impact on the confidence in the estimate of effect and may change the estimate; low quality: further research is very likely to have an important impact on the confidence in the estimate of effect and is likely to change the estimate; very low quality: very uncertain about the estimate.

<sup>c</sup>TCS: topical corticosteroids.

<sup>d</sup>RCT: randomized controlled trial.

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## Editorial Notice

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## Conflicts of Interest

TS serves as a section editor for *JMIR Dermatology*. TS also received fees for serving as a medical advisor for Antedotum Inc. JA and AH serve as social media editors for Cochrane Skin. MS is a member of the Cochrane Collaboration.

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## Abbreviations

**SCORAD:** Scoring Atopic Dermatitis

**TCI:** topical calcineurin inhibitor

**TCS:** topical corticosteroids

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Research Letter

# From the Cochrane Library: Interventions for Impetigo

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**KEYWORDS**

impetigo; pustular lesions; *Staphylococcus aureus*; *Streptococcus pyogenes*; dermatology; skin infection

Impetigo is a contagious, superficial skin infection, most commonly affecting children, caused by *Staphylococcus aureus*, group A beta-hemolytic streptococcus (*Streptococcus pyogenes*), or both pathogens in combination [1]. Bacteria infect the epidermis, leading to itchy or painful, yellow-crusts, erythematous plaques. If blisters are present, the infection is referred to as bullous impetigo [2]. While untreated impetigo is often self-limited, treatment is important for symptom control, limiting the spread of infection and minimizing the risk of developing life-threatening complications. Due to the prevalence and risks associated with impetigo, evidence-based research to inform treatment guidelines is critical to decreasing its disease burden [1].

Current treatment options for impetigo, summarized in [Table 1](#), include topical and systemic antibiotics, as well as topical disinfectants [2]. A 2012 Cochrane review, “Interventions for Impetigo” [2], assessed 68 randomized controlled trials (26 oral treatments and 24 topical treatments for the management of primary impetigo). Specifically, various management strategies were evaluated: watchful waiting, topical disinfectants (saline, hexachlorophene, povidone-iodine, chlorhexidine), topical antibiotics (neomycin, bacitracin, polymyxin B, gentamycin, fusidic acid, mupirocin, retapamulin, topical steroid/antibiotic combination), and systemic antibiotics (penicillin, [flu]cloxacillin, amoxicillin/clavulanic acid, erythromycin, cephalexin). Primary outcome measures included an assessment of clearance of crusts, blisters, and redness, as well as resolution of associated symptoms.

**Table 1.** Current guidelines for the management of impetigo.

Treatment	Dosing and usage	Evidence grade <sup>a</sup>
<b>Topical antibiotics</b>		
Mupirocin 2% ointment	3 times daily for 5-7 days	Strong recommendation
Retapamulin 1% ointment	2 times daily for 5 days	Strong recommendation
Fusidic acid 2% cream	3 times daily until healed or up to 14 days	Not available in the United States
<b>Oral antibiotics</b>		
Dicloxacillin, 250 mg; cephalexin, 250 mg	4 times daily for 7 days for empiric therapy in adults	Strong recommendation
Cephalexin, 250 mg	4 times daily for 7 days for empiric therapy in adults	Strong recommendation
Cephalexin, 25-50 mg/kg/day	3-4 divided doses for empiric therapy in children	Strong recommendation
Penicillin	If culture yields streptococci alone	Strong recommendation
Doxycycline, clindamycin, or trimethoprim-sulfamethoxazole	If methicillin-resistant <i>Staphylococcus aureus</i> (MRSA) is suspected or confirmed	Strong recommendation

<sup>a</sup>Recommendation according to the Infectious Diseases Society of America, using the GRADE (Grading of Recommendations, Assessment, Development, and Evaluation) system's strength of recommendation: *strong recommendation* (desirable effects clearly outweigh undesirable effects or vice versa) and *weak recommendation* (desirable effects closely balanced with undesirable effects, or [with low- or very low-quality evidence] uncertainty in the estimates of desirable effects, harms, and burden so they may be closely balanced).

Topical antibiotics (mupirocin, retapamulin, fusidic acid) were found to be more effective than the placebo and preferable to oral antibiotics for limited impetigo. Topical antibiotics were also superior to disinfection methods. No significant differences were found in studies evaluating oral antibiotics, with the exception that penicillin was less effective than most other antibiotics. Due to insufficient evidence, the efficacy of these treatments for patients with more extensive disease could not be established. However, newer data suggest systemic antibiotics are more efficacious for patients with 5 or more lesions, or with oral or deep tissue involvement [3]. Significant findings pertaining to the treatment comparisons in this review are summarized in Table 2.

Of note, the authors of the Cochrane review pointed to a lack of evidence regarding impetigo treatment in developing countries and endemic populations—a significant data gap given that impetigo disproportionately affects children in resource-poor communities and has the highest prevalence among Australian Aboriginal children (up to 49%). A recent systematic review [4] provided much-needed insight, calling for research into topical antimicrobials for impetigo as alternatives to current first-line therapy (oral co-trimoxazole and intramuscular benzathine penicillin G) in rural Australia. Currently, there are no trials of topical antibiotics for impetigo in high-burden settings, highlighting the need for further studies.

**Table 2.** Treatment comparison with respective results, risk ratio (RR), 95% CI, and number of studies and participants.

Comparison	Measurement	Result	Statistics
Topical antibiotic vs placebo	Investigator assessment	Topical antibiotic was superior	RR 2.24, 95% CI 1.61-3.13; 6 studies, n=575
Topical mupirocin vs topical fusidic acid	Investigator assessment	No difference	RR 1.03, 95% CI 0.95-1.11; 4 studies, n=440
Topical mupirocin vs oral erythromycin	Investigator assessment	Topical mupirocin was superior	RR 1.07, 95% CI 1.01-1.13; 10 studies, n=581
Penicillin vs erythromycin	Investigator assessment	Erythromycin was superior	RR 1.29, 95% CI 1.07-1.56; 2 studies, n=79
Penicillin vs cloxacillin	Investigator assessment	Cloxacillin was superior	RR 1.59, 95% CI 1.21-2.08; 2 studies, n=166
Topical antibiotics vs disinfecting treatments	Investigator assessment	Topical antibiotic was superior	RR 1.15, 95% CI 1.01-1.32; 2 studies, n=292

In industrialized settings, data continue to support the use of topical mupirocin and retapamulin as first-line treatments for primary impetigo. Current guidelines (Table 1) recommend topical antibiotics as the initial therapy for most patients. In patients with numerous lesions, ulceration into the dermis, or

in outbreaks affecting several people, oral antibiotics are preferred [5].

The commonality of impetigo and its rapidly changing antibiotic resistance patterns make it a moving target. Its contagious nature and associated morbidity further emphasize the need for updated guidelines.

### Editorial Notice

The views expressed in this paper are those of the authors and in no way represent the Cochrane Library or Wiley.

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### Conflicts of Interest

RD is editor in chief of *JMIR Dermatology*, a joint coordinating editor for *Cochrane Skin*, a dermatology section editor for *UpToDate*, a social media editor for the *Journal of the American Academy of Dermatology* (JAAD), and a podcast editor for the *Journal of Investigative Dermatology* (JID). He is a coordinating editor representative on Cochrane Council and Cochrane Council cochair. TS is a section editor for *JMIR Dermatology*.

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Research Letter

# From the Cochrane Library: Topical Treatments for Cutaneous Warts

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cutaneous wart; plantar wart; topical treatment; papillomavirus infections; evidence-based medicine; wart; treatment; disease management; dermatology

## Research Letter

Below is the body of our research letter. There is no associated abstract due to the nature of our submission.

Cutaneous warts (CWs) are common infections caused by human papillomavirus (HPV) that affect children and young adults. The treatment of CWs aims to relieve associated pain, functional impairment, and psychological discomfort. Lack of data supporting any single curative treatment for the diverse cutaneous manifestations of HPV has created a challenge for healthcare providers in recommending the “most effective” first-line therapy. A 2012 Cochrane Review, “Topical Treatments for Cutaneous Warts,” evaluated treatment outcomes for extra-genital warts in healthy, immunocompetent adults and children, and provides valuable guidance in treatment selection [1].

This analysis [1] compared therapeutic outcomes – namely, cure and decreased incidence of recurrence -- from 85 RCTs (8,815 participants) and reported that salicylic acid (SA) significantly increased the clearance of warts compared to placebo. Data from a meta - analysis of cryotherapy favored neither intervention nor placebo. Aggressive cryotherapy was more effective than gentle cryotherapy, but with adverse effects such as pain, blistering, and scarring. Metanalysis did not demonstrate a significant difference in effectiveness between cryotherapy and SA, but suggested that combined SA and cryotherapy was more effective than SA alone. Dinitrochlorobenzene was twice as effective as placebo. One study demonstrated local hyperthermia was more effective than

placebo in the treatment of plantar warts, but further investigation is necessary to validate these results. Trials of clear duct tape demonstrated no advantage over placebo. Evidence regarding bleomycin was inconsistent. 5-fluorouracil (5-FU) was found to be effective in the treatment of cutaneous warts; however, due to its high side effect profile, its utility is limited to that of refractory cases and elimination of neoplastic lesions. The results of the treatment comparisons are summarized in [Table 1](#).

Notable limitations of this review were that it did not identify RCTs evaluating surgery, formaldehyde, podophyllotoxin, cantharidin, or topical immunotherapy. Furthermore, there was insufficient data to evaluate the use of 80% phenol, 5% imiquimod cream, intralesional antigen, and topical alpha - lactalbumin - oleic acid and cantharidin, when not coupled with SA. While there are limited RCTs evaluating the efficacy of intralesional candida antigen, existing studies suggest it's a viable option in clinical settings and may be particularly helpful in cases nonresponsive to traditional treatment modalities. To provide guidance for the use of these potentially harmful second-line treatments and better characterize efficacy of first-line agents, additional studies with standard end points are necessary.

Recent data supports the successful treatment of small, new-onset warts with SA and cryotherapy, largely due to their safety and simplicity. Regarding recurrent and extensive warts, immunotherapy was shown to be a promising approach to clearing injected warts and those at sites distant to the initial intralesional injection [2-4]. A study [5] comparing

immunotherapy to cryotherapy found the former yielded a better therapeutic response with fewer sessions. However, given the novelty of intralesional immunotherapy, further RCTs are needed to compare intralesional immunotherapy options and the associated adverse effects. Lastly, quality of life outcomes

associated with each treatment have yet to be determined. Management of warts continues to be a challenge; however, evidence remains strongest for SA and cryotherapy as the safest, most effective initial therapies [1].

**Table 1.** Treatment comparison with respective results, risk ratio, and CI.

Comparison	Result	Risk ratio (95% CI)
SA <sup>a</sup> vs placebo for all sites	SA was superior	1.56 (1.20-2.03)
SA vs placebo for hand sites	SA was superior	2.67 (1.43-5.01)
SA vs placebo for plantar sites	SA was superior	1.29 (1.07-1.55)
Cryotherapy vs placebo for warts at all sites	Neither intervention nor control was favored	1.45 (0.65-3.23)
Cryotherapy vs placebo for hand sites	Neither intervention nor control was favored	2.63 (0.43-15.94)
Cryotherapy vs placebo for plantar sites	Neither intervention nor control was favored	0.90 (0.26-3.07)
Aggressive cryotherapy vs gentle cryotherapy	Aggressive cryotherapy was superior	1.90 (1.15-3.15)
SA and cryotherapy combined vs SA alone	SA and cryotherapy combined was superior	1.24 (1.07-1.43)
Intralesional bleomycin vs saline injections	No significant difference	1.28 (0.92-1.78)
Dinitrochlorobenzene vs placebo	Dinitrochlorobenzene was superior	2.12 (1.38-3.26)
Clear duct tape vs placebo	Neither intervention nor control was favored	1.43 (0.51-4.05)

<sup>a</sup>SA: salicylic acid.

The notable limitations of this review were that it did not identify RCTs evaluating surgery, formaldehyde, podophyllotoxin, cantharidin, or topical immunotherapy. Furthermore, there was insufficient data to evaluate the use of 80% phenol, 5% imiquimod cream, intralesional antigen, and topical alpha - lactalbumin - oleic acid and cantharidin, when not coupled with SA. Although there are limited RCTs evaluating the efficacy of intralesional candida antigen, existing studies suggest it is a viable option in clinical settings and may be particularly helpful in cases nonresponsive to traditional treatment modalities. To provide guidance for the use of these potentially harmful second-line treatments and better characterize the efficacy of first-line agents, additional studies with standard end points are necessary.

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## Acknowledgments

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Review

# Trends in Hidradenitis Suppurativa Disease Severity and Quality of Life Outcome Measures: Scoping Review

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## Abstract

**Background:** Although there has been an increase in the number of randomized controlled trials evaluating treatment efficacy for hidradenitis suppurativa (HS), instrument measurements of disease severity and quality of life (QoL) are varied, making the compilation of data and comparisons between studies a challenge for clinicians.

**Objective:** We aimed to perform a systematic literature search to examine the recent trends in the use of disease severity and QoL outcome instruments in randomized controlled trials that have been conducted on patients with HS.

**Methods:** A scoping review was conducted in February 2021. The PubMed, Embase, Web of Science, and Cochrane databases were used to identify all articles published from January 1964 to February 2021. In total, 41 articles were included in this systematic review.

**Results:** The HS Clinical Response (HiSCR) score (18/41, 44%) was the most commonly used instrument for disease severity, followed by the Sartorius and Modified Sartorius scales (combined: 16/41, 39%). The Dermatology Life Quality Index (18/41, 44%) and visual analogue pain scales (12/41, 29%) were the most commonly used QoL outcome instruments in HS research.

**Conclusions:** Randomized controlled trials conducted from 2013 onward commonly used the validated HiSCR score, while older studies were more heterogeneous and less likely to use a validated scale. A few (6/18, 33%) QoL measures were validated instruments but were not specific to HS; therefore, they may not be representative of all factors that impact patients with HS.

**Trial Registration:** National Institute of Health Research PROSPERO CRD42020209582; [https://www.crd.york.ac.uk/prospero/display\\_record.php?ID=CRD42020209582](https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020209582)

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## KEYWORDS

hidradenitis suppurativa; severity of illness index; patient-reported outcome measures; quality of life; treatment outcome; illness index; patient outcomes; disease severity; Sartorius; dermatology; treatment interventions

## Introduction

Hidradenitis suppurativa (HS) is a debilitating chronic inflammatory condition that most commonly involves the axilla, inframammary, inguinal, and anogenital regions [1]. HS is characterized by inflamed nodules that generally progress to

painful abscesses, sinus tracts, fibrosis, and scarring [2]. HS has been shown to be associated with the increased incidence of metabolic, autoimmune, and psychosocial comorbidities [2]. Although it has been historically difficult to ascertain the exact prevalence of the disease due to underdiagnosis and variations in the estimates among epidemiologic studies, a recent

meta-analysis [3] estimated a worldwide prevalence of 0.3% (range 0.2%-0.6%).

Despite the burden of the disease, the treatment of HS is heterogeneous, and effective management has proven difficult; however, new therapies are under investigation. Randomized controlled trials (RCTs) that are investigating these new therapies have used various instruments to quantify HS disease severity and its impact on patients' quality of life (QoL).

It is well established that HS results in significant emotional, social, and psychological burdens on patients [4]. Recent studies have reported on the increased prevalence of anxiety, depression, and suicidality among patients with HS [5]. These psychological conditions are indicative of a poor QoL [6] and highlight the importance of incorporating patient-focused outcome measures in HS research. Both the US Federal Drug Administration and European Medicines Agency have recommended the evidence-based use of patient-reported outcome measures (PROMs) in clinical trials and have emphasized their importance [7]. PROMs are particularly important in chronic debilitating skin diseases, such as HS. In HS research, RCTs have reported objective and subjective outcomes via a diverse assortment of scales and questionnaires, making the compilation of data and comparisons between studies quite difficult. A previously published study identified 30 different outcome instruments in HS research [8] and found that nearly 90% of these instruments had not been validated. Given the role of clinical research in providing evidence to inform clinical decision-making, the standardization of outcome measures is crucial to enabling data comparisons between studies.

The purpose of this study was to investigate trends in disease severity scales and QoL instruments that were used in HS-related RCTs conducted between January 1964 and February 2021 via a systematic search of the literature.

## Methods

A scoping review of the literature was conducted in February 2021 by using the following four databases: PubMed, Embase,

Web of Science, and Cochrane. To ensure transparency and reproducibility, the literature search was conducted according to the framework established by the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) reporting guidelines [9] and was prospectively registered with PROSPERO. The key search terms were *Hidradenitis Suppurativa*, *acne inversa*, *randomized controlled trial*, *RCT*, *quality of life*, *QoL*, *QOL*, *patient reported outcome measures*, *PROM*, *HS severity*, *severity of HS*, *Sartorius scale*, *Hurley stage*, and *severity of illness index*. Detailed search results are included in [Multimedia Appendix 1](#).

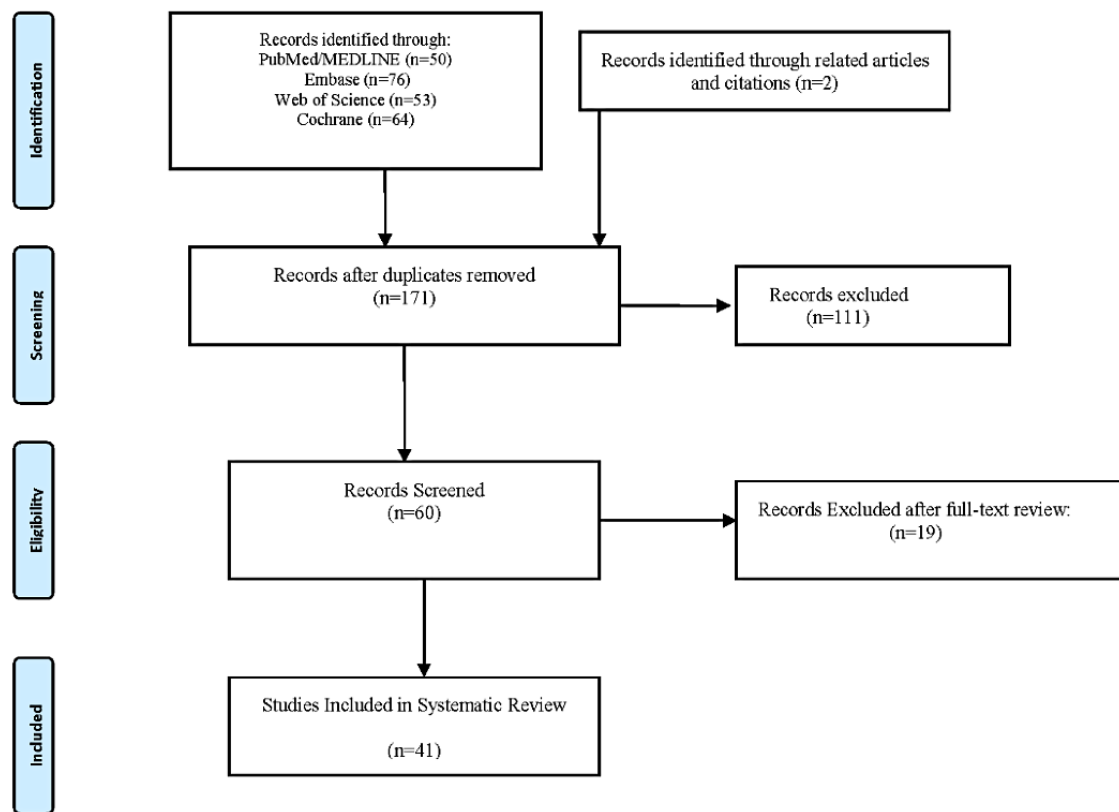
This scoping review included published RCTs that reported disease severity, QoL, or both. Secondary articles (eg, reviews and meta-analyses), case reports and case series, cohort studies, letters to editors, commentaries, and in vivo and in vitro experimental studies were excluded. Two reviewers (JM and TS) independently screened articles to include those that met the defined inclusion criteria, were written in English, and were available as full texts. In total, 111 articles were excluded during title and abstract screening for the following reasons: (1) a non-RCT study design (eg, cohort studies, observational studies, reviews, letters), (2) insufficient data, (3) articles written in languages other than English, and (4) articles that were unavailable in a full-text format. An additional 19 studies were excluded after careful review due to the lack of reporting on disease severity and QoL outcome measures.

## Results

### Summary of Articles

A total of 171 nonduplicated reports were identified; 60 articles underwent a full-text review, and a total of 41 studies [10-50] were included in this review ([Figure 1](#)). For each included RCT, the level of evidence was rated according to the evidence levels established by the Oxford Centre for Evidence-Based Medicine [51].

**Figure 1.** The search process is depicted by using a flow diagram that was adapted from the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines.



## Data Extraction

The following data were extracted: (1) the proportion of RCTs that used disease severity indices or QoL outcome instruments, (2) the total number of and the frequency of use of disease severity scales, and (3) the total number of and the frequency of use of QoL outcome measures.

## Study Characteristics

A total of 41 RCTs that were published between 1986 and 2021 were identified; these accounted for a total of 3235 participants. The appraisal of studies via the methods outlined by the Oxford Centre for Evidence-Based Medicine evidence ratings scheme was performed; 17 RCTs qualified as level 1b studies, while the remaining 24 studies were level 2b studies. Summary information for the characteristics of the included studies, including evidence levels, is available in [Multimedia Appendix 2](#). Of the 41 included RCTs, 38 (93%) used disease severity outcome measures, and of these 38 RCTs, 30 (79%) used more than 1 scale to assess disease severity. Additionally, 30 of the 41 studies (73%) included QoL measures; of these 30 studies, 20 studies (67%) assessed more than 1 QoL measure.

## Disease Severity Outcome Measures

A total of 25 disease severity outcome measures were identified in this review. The HS Clinical Response (HiSCR) score (19/41,

46%) was the most common instrument used in HS clinical research. HiSCR score use increased from the year 2012 onward. Of the 27 RCTs published since 2012, 18 (67%) used the HiSCR score as an outcome measure ([Table 1](#)).

The Sartorius Scale and its modified version—the Modified Sartorius Scale (MSS), which was denoted by some authors as the *Hidradenitis Suppurativa Lesion, Area, Severity Index* (HS-LASI; Sartorius Scale: 7/41, 17%; MSS: 9/41, 22%)—were the second most frequently used instruments for disease severity assessment. The Physician Global Assessment (PGA; 8/41, 20%) was the third most commonly used instrument for disease severity. Only 5 of the 41 RCTs (12%) used the PGA scale that was specific to HS (also known as the HS-PGA). The Hurley stage was primarily used to stratify patients' disease severity prior to enrollment; only 3 studies incorporated the Hurley stage as an outcome measure. A recently developed and validated HS outcome measure—the International HS Severity Scoring System (IHS4)—was identified in a single RCT that was published in 2021 [50].

There were several studies that used inflammatory markers, including C-reactive protein levels, erythrocyte sedimentation rates, and cytokine profiles (7/41, 17%). Further, 1 RCT used noninvasive sonographic imaging to evaluate lesion depth and vascularity ([Table 2](#)).

**Table 1.** The frequency and proportion of disease severity outcome measures.

Disease severity outcome instrument	Studies, n (%)
Hidradenitis Suppurativa Clinical Response <sup>a</sup>	18 (44)
Modified Sartorius Scale <sup>a</sup> ; Hidradenitis Suppurativa Lesion, Area, Severity Index; and Modified Hidradenitis Suppurativa Lesion, Area, Severity Index	9 (22)
Physician Global Assessment and evaluation	8 (20)
Sartorius Scale	7 (17)
Hidradenitis Suppurativa Physician Global Assessment <sup>a</sup>	5 (12)
Adverse events	5 (12)
Hurley stage	5 (12)
Abscess and nodule count	5 (12)
Mean improvement in abscesses, fistulae, and nodules	3 (7)
Recurrence	2 (5)
Hidradenitis Suppurativa Severity Index	2 (5)
Time to hidradenitis suppurativa exacerbation	2 (5)
Histological changes	2 (5)
International Hidradenitis Suppurativa Severity Scoring System <sup>a</sup>	1 (2)
Disease Activity Score (visual analogue scale)	1 (2)
Wound healing	1 (2)
Incidence of hidradenitis suppurativa flare	1 (2)
Manchester postinflammatory scar scoring	1 (2)
Hair follicle count	1 (2)
Average number of days to lesion resolution	1 (2)
Investigator and physician assessment	1 (2)

<sup>a</sup>A validated hidradenitis suppurativa scale.

**Table 2.** Laboratory and noninvasive imaging as outcome measures of disease severity.

Diagnostic and inflammatory markers as outcome measures	Studies, n (%)
C-reactive protein	5 (12)
Erythrocyte sedimentation rate	1 (2)
Cytokine profile	1 (2)
Ultrasound findings (eg, vascularity and the depth of lesions)	1 (2)

## QoL Outcome Measures

A total of 18 QoL outcome instruments were identified. These are summarized in [Table 3](#).

The Dermatology Life Quality Index (DLQI) was the most common patient-centered outcome reported in this review (18/41, 44%). A total of 17 studies assessed participants' pain. Pain was primarily measured by using a visual analogue scale (11/41, 27%) or a numerical ranking (6/41, 15%), although 1 study used the HS-related skin pain scale. In total, 5 of the 41 studies (12%) used the Patient/Participant Global

Self-Assessment, which measures various parameters, including pain, pruritus, and disease burden. Patients' satisfaction with treatment was assessed in 4 of the 41 studies (10%), and 3 RCTs used the Workers Productivity and Impairment Activity Index-Specific Health Problem (WPAI-SHP). Psychological distress was assessed by 2 of the 41 studies (5%), which incorporated the 9-question Patient Health Questionnaire-9 (PHQ-9) depressive symptom scale as a PROM, and by 1 study that used the Hospital Anxiety and Depression Scale (HADS). The European QoL-5 Dimension (EQ-5D), which includes a domain for the assessment of anxiety and depression, was used in 1 RCT.

**Table 3.** Frequency and proportion of quality of life outcome measures.

QoL instrument	Frequency of use in studies, n (%)
Dermatology Life Quality Index <sup>a</sup>	18 (60)
Pain using a visual analogue scale	12 (37)
Pain using a numeric rating scale	6 (20)
Patient/Participant Global Assessment and evaluation	6 (20)
Patient satisfaction	4 (10)
Workers Productivity and Impairment Activity Index-Specific Health Problem <sup>a</sup>	3 (10)
Self-reported pruritus	2 (7)
Patient Health Questionnaire-9 <sup>a</sup>	2 (7)
European Quality of Life-5 Dimension <sup>a</sup>	1 (3)
Hidradenitis suppurativa-related skin pain	1 (3)
Patient's overall disease severity and impression (visual analogue scale)	1 (3)
Treatment Satisfaction Questionnaire for Medication <sup>a</sup>	1 (3)
Number of self-reported hidradenitis suppurativa flares	1 (3)
Soreness (visual analogue scale)	1 (3)
Self-assessment of disease burden	1 (3)
Hidradenitis suppurativa-related impairment of general health using a visual analogue scale	1 (3)
Change in the number of daily dressings per week	1 (3)
Hospital Anxiety and Depression Scale <sup>a</sup>	1 (3)

<sup>a</sup>A validated quality of life outcome instrument.

## Discussion

### Principal Findings

HS continues to represent a disease management challenge and result in a substantial disease burden for patients [2]. Our review of 41 RCTs (published in English) identified 25 disease severity measurements (Tables 1 and 2) and 18 QoL instrument scales (Table 3). Overall, we identified a diverse assortment of outcome measures, which may indicate a barrier to their synthesis and translation into clinical practice.

With regard to the validity of the outcome measures identified in our review, both the HS-PGA and HiSCR score have been shown to be valid assessments, with HiSCR being the most extensively validated outcome measure in published RCTs. The two most commonly reported disease severity scales in our study—the HiSCR score and the Sartorius Scale and MSS—differ substantially in their approaches and frames of reference; the HiSCR assesses clinical responses from baseline (namely, a reduction in inflammatory lesion count), and the Sartorius Scale and MSS assess the extent of HS inflammation by counting anatomic regions and the types and numbers of lesions.

The HiSCR score was the only validated scoring system that appeared in the studies reviewed (all reviewed articles: 18/41, 44%; articles reporting disease severity as an outcome: 18/38, 47%), making it the most commonly used validated scale in HS research. The HiSCR score is a validated scoring system that

is used to evaluate treatment response, and it has been shown to be reliable in both clinical research and daily practice [24]. Although the minimal clinically important difference for HiSCR scores has not been established, a 50% reduction in the total abscess and nodule count appears to be meaningful to both patients and physicians [33].

Although only 5 RCTs used the HS-PGA, it is important to highlight that it is considered to be a relatively easy scoring system that assesses treatment efficacy in clinical research. Similar to the HiSCR score, it is a dynamic outcome instrument that can be used to monitor disease progression [52]. However, compared to the HiSCR score, the HS-PGA has a lower sensitivity for rapidly identifying changes in HS-specific lesions. For instance, some patients with severe HS-specific lesions can experience clinically important improvements without achieving meaningful reductions in their HS-PGA scores [52].

The Sartorius Scale, which is widely used to assess clinical responses to treatment based on the involved anatomical regions and the number and type of lesions involved (nodules, fistulae, and abscesses), the distance between lesions, and whether normal skin exists between lesions, poses a challenge to results interpretation [53]. In addition to being only partially validated, the Sartorius Scale may be quite time consuming to administer and difficult to replicate in a busy outpatient clinic.

The MSS (or HS-LASI) represents a more streamlined version of the original Sartorius Scale; the MSS includes a reduced number of specific types of lesions and a reduced number of



points for each parameter [54]. Although it is simpler than the traditional Sartorius Scale, the MSS (or HS-LASI) remains time-consuming and difficult to interpret in the context of assessing coalescing and large lesions. In this review, we identified 2 RCTs that used the HS-LASI scale [22,27], whereas 11 RCTs used a combination of both the MSS and the traditional Sartorius Scale. The overlap in the naming and content of the Sartorius Scale and its variants, such as the MSS and HS-LASI, can hinder meaningful comparisons between studies and thus create challenges in interpreting data and making informed clinical decisions.

In 2016, Ingram et al [8] found that 90% of outcome measures that are used in HS research are not validated; however, the research landscape appears to be changing. We found that RCTs published from 2014 onward were more likely to use the validated HiSCR scale, while older studies used more diverse outcome measures, of which many had low interobserver reliability [55], and were less likely to have used a validated scale. In 2018, the HS ALLIANCE working group highlighted the need to incorporate validated outcome measures and PROMs in HS research [56]. In 2017, the members of the European HS Foundation demonstrated the validity of a novel instrument—the IHS4 [57]. The IHS4 has been shown to be a dynamic instrument for assessing HS severity and is applicable to both clinical research and daily clinical practice [57]. We found a single, recent RCT (published in 2021) that used the IHS4 as an outcome measure [50].

As with instruments of disease severity assessment, patient-reported QoL measures demonstrate significant heterogeneity and are generally nonspecific [57]. Although the majority of articles (30/41, 73%) discussed the impact of HS on patients' lives, the instruments that were used remain inadequate for capturing the overall impact of disease burden on patients. Of all of the QoL instruments identified in this review, the DLQI appeared in 44% (18/41) of RCTs, making it the most commonly used patient-centered instrument in HS research. The DLQI is a validated instrument that is widely used for an array of dermatologic conditions, such as psoriasis and atopic dermatitis, but is not specific to HS.

In addition to QoL instruments, specific outcomes pertaining to pain assessment are needed. Although the visual analogue pain scale has been validated in clinical research, it is not specific to HS. Despite various treatment options, a recent survey study revealed that inadequate pain management is perceived as an unmet need by both patients and health care providers [58]. Given that pain is associated with psychosocial comorbidities [34], it is essential to develop specific core outcome scales that assess pain management and treatment responses.

In contrast to disease severity outcome measures, we identified 6 validated QoL instruments. These include the DLQI, PHQ-9, HADS, EQ-5D, WPAI-SHP, and Treatment Satisfaction Questionnaire for Medication [59]. However, these are not HS-specific QoL instruments. The emotional, social, and psychological impacts of HS on patients cannot be overstated; while QoL can be measured in various ways, the current QoL

instruments that are used in HS research may not adequately capture changes that specifically pertain to the HS population.

In 2018, the first HISTORIC (HS Core Outcomes Set International Collaboration) Delphi study [60] reached a consensus on the following five core domains that are relevant to all types of clinical research: pain, physical signs, HS-specific QoL, global assessment, and the progression of the disease course. HISTORIC Delphi also developed the HS QoL (HiSQOL) scale—an HS-specific QoL instrument [61].

Over the past several years, there has been an increased effort to develop validated, HS-specific QoL outcome instruments, including the aforementioned HiSQOL scale, the HIDRADisk, and the 44-item HS-QoL questionnaire [61-64]. Promising HS-specific QoL instruments such as these may soon be incorporated in future clinical trial outcome measurements.

Kimball et al [65] introduced the following two specific questionnaires in 2018: the HS Symptom Assessment (HSSA) and the HS Impact Assessment (HSIA). Both the HSSA and HSIA are validated instruments and are considered to be reliable tools for assessing symptoms and the efficacy of HS treatment. We identified no RCTs that used these two instruments for the evaluation of therapeutic interventions for HS.

Ongoing research may soon allow for new technologies to supplement the clinical assessment of HS lesion severity, which relies, in part, on manual palpation—noninvasive imaging techniques such as medial infrared thermography, and may soon aid in the evaluation of disease state and treatment response [66]. The broader adoption of standardized, validated QoL and disease severity measurement tools may allow for the better assessment of the overall impact of disease burden on patients, including the effect of HS on mental health [65], which, in our review, was not well characterized by the limited patient outcome measures reported.

## Limitations

The limitations of this review include that it was restricted to published RCTs and that it excluded other types of publications, such as cohort studies, case control studies and case series, and ongoing or current clinical trials, that may provide further insight. We chose to include RCTs exclusively, as it was a priority to assess evidence of the highest level. It is unclear if other studies with less rigorous methods have similar trends in reporting disease severity and QoL outcome measures—an area that remains open for further follow-up studies. None of the included studies in this review involved pediatric participants; therefore, the trends in outcome measures that we identified may not be applicable to this population group. In addition, this review did not explore the utility of HS interventions and therefore cannot add to the body of knowledge regarding treatment efficacy in HS.

## Conclusion

This review highlights the heterogeneity of outcome measures that are used in RCTs to assess disease severity and QoL for patients with HS. Among the 41 English RCTs published from 1964 to 2021, the HiSCR score remained the predominant outcome instrument that was used to assess HS disease severity.

The IHS4, which is representative of an expanding number of validated disease severity outcome measures, was used in only 1 RCT among those published from 1964 to 2021. Patient QoL measures remain central to evaluating disease impact and the degree of improvement for patients in clinical studies. PROMs are gaining importance in clinical research and are strongly supported by guidance from both the US Federal Drug

Administration and European Medicines Agency. Recently developed instruments with proven validity, such as the HSSA, HSIA, and HiSQOL scale, represent advancements in measuring the QoL outcomes of HS. Our findings underscore the need for standardized outcome measures that are essential for comparability among studies and the improved quality of research evidence.

## Conflicts of Interest

RPD is a joint coordinating editor for *Cochrane Skin*, the editor in chief of *JMIR Dermatology*, a dermatology section editor for *UpToDate*, a social media editor for the *Journal of the American Academy of Dermatology*, and a podcast editor for the *Journal of Investigative Dermatology*. He is a coordinating editor representative on the *Cochrane Council*. TES serves on the editorial board of *JMIR Dermatology*. RPD receives editorial stipends (*Journal of the American Academy of Dermatology* and *Journal of Investigative Dermatology*), royalties (*UpToDate*), and expense reimbursements from *Cochrane Skin*. TES receives fellowship funding from the Pfizer Global Medical Grant (grant 58858477) Dermatology Fellowship 2020 (principal investigator: RPD) and serves as a medical advisor and principal investigator for Antedotum Inc. CD serves as a reviewer for *JMIR*, but had no role in the review of this article. He has participated in clinical trials for Pfizer, Arcutis, Target Pharmaceuticals, ArgenX, Amgen, AbbVie, and Kyowa, but none of these trials are related to the topic of this paper, hidradenitis suppurativa. All study related reimbursement were paid directly to the University of Colorado.

### Multimedia Appendix 1

Search strategies.

[[XLSX File \(Microsoft Excel File\), 21 KB - derma\\_v4i2e27869\\_app1.xlsx](#)]

### Multimedia Appendix 2

Study characteristics and evidence levels.

[[XLSX File \(Microsoft Excel File\), 14 KB - derma\\_v4i2e27869\\_app2.xlsx](#)]

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## Abbreviations

**DLQI:** Dermatology Life Quality Index

**EQ-5D:** European Quality of Life-5 Dimension

**HADS:** Hospital Anxiety and Depression Scale

**HiSCR:** Hidradenitis Suppurativa Clinical Response

**HiSQOL:** Hidradenitis Suppurativa Quality Of Life

**HISTORIC:** Hidradenitis Suppurativa Core Outcomes Set International Collaboration

**HS:** hidradenitis suppurativa

**HSIA:** Hidradenitis Suppurativa Impact Assessment

**HS-LASI:** Hidradenitis Suppurativa Lesion, Area, Severity Index

**HSSA:** Hidradenitis Suppurativa Symptom Assessment

**IHS4:** International Hidradenitis Suppurativa Severity Scoring System  
**MSS:** Modified Sartorius Scale  
**PGA:** Physician Global Assessment  
**PHQ-9:** Patient Health Questionnaire-9  
**PRISMA:** Preferred Reporting Items for Systematic Reviews and Meta-Analyses  
**PROM:** patient-reported outcome measure  
**QoL:** quality of life  
**RCT:** randomized controlled trial  
**WPAI-SHP:** Workers Productivity and Impairment Activity Index-Specific Health Problem

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Original Paper

# Exploring Access to Surgical Interventions for Hidradenitis Suppurativa: Retrospective Population-Based Analysis

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## Abstract

**Background:** Hidradenitis suppurativa (HS) is a painful inflammatory disorder that confers significant distress to patients, with surgery as an integral treatment modality.

**Objective:** To inform improvements in care, patterns in HS surgery were assessed.

**Methods:** A retrospective population-based analysis was performed on Ontario billing claims for HS surgery across a period of 10 years from January 1, 2008 to December 31, 2017. HS surgery was defined as the excision of inguinal, perineal, or axillary skin and sweat glands for hidradenitis. The top 5 billing specialties, including general and plastic surgery, were analyzed. The total number of procedures performed as well as the number performed per physician were investigated. Patient and physician locations were compared.

**Results:** A total of 7195 claims for the excision of inguinal, perineal, or axillary skin and sweat glands for HS were submitted across the study period. Annual HS surgery claims showed an increasing trend across 10 years, ranging between 4.9 and 5.8 per 100,000 population. However, overall, for every additional year, the number of claims per 100,000 population only increased slightly, by 0.03 claims. The number of providers steadily decreased, ranging between 1.7 and 1.9 per 100,000, with approximately twice as many general than plastic surgeons. However, again overall, for every additional year, the number of providers per 100,000 population decreased slightly, by 0.002 physicians. The mean annual number of procedures per physician rose from 2.8 to 3.1. In rural areas, analyzed per claim, general surgeons performed the majority of surgeries (1318/2003, 65.8%), while in urban areas, surgeries were more equally performed by general (2616/5192, 50.4%) and plastic (2495/5192, 48.1%) surgeons. Of HS surgery claims, 25.7%-35.9% were provided by a physician residing in a different area than the patient receiving care.

**Conclusions:** No significant improvements in access to HS surgery were seen across the study period, with access potentially worsening with annual HS claims rising overall and number of providers decreasing, with patients travelling further to access surgery. System barriers across the continuum of HS diagnosis and management must be evaluated to improve access to surgical care.

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**KEYWORDS**

hidradenitis suppurativa; surgery; dermatology; access; epidemiology; universal health care

## Introduction

Hidradenitis suppurativa (HS) is a painful, inflammatory disorder involving a dysfunction of the pilosebaceous unit, which confers significant distress to patients due to its relapsing and remitting nature [1-3]. HS management is complex, with both medical and surgical treatment options and the first North American clinical management guidelines only recently published in 2019 [4,5]. A variety of options for medical treatment is available depending on the severity of disease, including topical and intralesional therapies, systemic antibiotics, hormonal therapies, retinoids, immunosuppressants, and biologics [4,5]. However, surgery remains an integral treatment modality regardless of disease severity [4-6]. Approximately 80% of patients were shown to be satisfied with surgical treatment of HS and considered it as the best treatment option [6].

Unfortunately, the diagnosis of HS is relatively rare, and it is often mistaken for a simple infection, limiting access to proper treatment [7]. HS is commonly diagnosed after a significant delay, with one multinational study reporting a mean delay of 10.2 years [8] and Canadian data reporting a median delay of 7 years with an average of 3 misdiagnoses [9]. Treatment has also been found to be fragmented over multiple specialties, including dermatology, primary care, general surgery, and plastic surgery [10,11], with patients trying an average of 15 different methods to manage their HS symptoms [9]. The absence of a designated specialty for HS management has been suggested to further delay diagnosis and treatment [12,13].

The prevalence of HS has been reported to range from 0.03% to 4.10% [14]. Although guidelines have been published for the surgical management of HS, they commonly rely on low-quality, uncontrolled, retrospective reports, and whether there is adequate access to HS surgery is unknown [5]. Moreover, although early surgical interventions are believed to potentially prevent progression of disease, data are sparse, and the extent of adoption of surgical management for HS is unclear [15].

To inform improvements in HS care, patterns in current and past HS surgery must be assessed. The objectives of this study were to evaluate patient access to surgical procedures for HS and investigate trends in HS surgery across different specialties and geographical regions.

## Methods

### Data Source

Ontario was chosen as the study setting as it is the most populous province in Canada with approximately 14.7 million inhabitants [16] and provides its citizens with universal health care through the Ontario Health Insurance Plan (OHIP). Data on OHIP medical claims were obtained from the Medical Services and Population data source within IntelliHealth, a

province-wide data repository operated by the Ontario Ministry of Health and Long-Term Care containing information on physician billing. IntelliHealth has been utilized in prior population-based studies on physician billing and practices [17-22]. Research ethics board approval was not required for this study as information obtained through IntelliHealth is anonymized and publicly available.

### Study Population

A retrospective, population-based analysis was performed on Ontario physicians who surgically treated HS. Data were collected across 10 years from January 1, 2008 to December 31, 2017. Physicians who surgically treated HS or hyperhidrosis were identified by procedure codes R059 (unilateral excision of inguinal, perineal, or axillary skin and sweat glands for hyperhidrosis and/or hidradenitis) and R060 (excision of inguinal, perineal, or axillary skin and sweat glands for hyperhidrosis and/or hidradenitis with skin graft(s) or rotation flap(s)) [23]. From these, claims billed under diagnostic code 799 for “excessive sweating” (hyperhidrosis) were excluded to further isolate those for HS, as no OHIP diagnostic code currently exists for HS [24]. The top 5 billing specialties were analyzed, excluding family physicians and anaesthesiologists, to further ensure that the procedure was being performed for the purposes of HS.

### Data Analysis

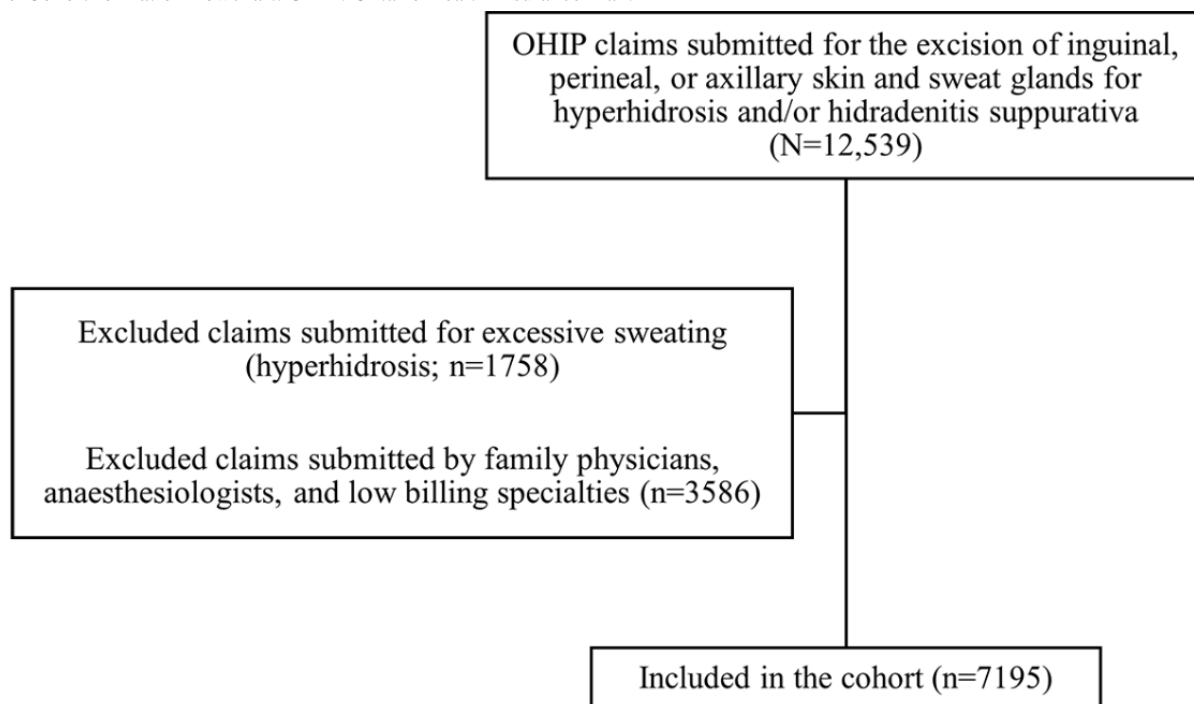
Data were exported from IntelliHealth’s online system and analyzed using Microsoft Excel version 16.36. Physician specialty was defined as the specialty billed for the procedure. The number, location, and specialty of physicians who performed the excision of inguinal, perineal, or axillary skin and sweat glands for HS were analyzed. The total number of procedures performed as well as the number performed per physician were investigated. Patient and physician locations were compared. Location was determined based on the assigned Local Health Integration Network (LHIN). Each LHIN was further classified as rural or urban following previously applied methodology in which a LHIN is deemed rural if its population is less than 1,000,000 and urban if greater [17,20,21].

## Results

### Demographics

Across the study period, a total of 12,539 claims were submitted for the excision of inguinal, perineal, or axillary skin and sweat glands for hyperhidrosis and/or HS. Of these cases, 1758 were excluded because they were submitted for hyperhidrosis (excessive sweating). A further 3586 claims were excluded based on specialty billed. A final total of 7195 claims was included in the study (Figure 1). Patient demographics are shown in Table 1 for patients with a valid health card number. Approximately 10% of patients had multiple surgeries over the study period.



**Figure 1.** Cohort formation flowchart. OHIP: Ontario Health Insurance Plan.**Table 1.** Ontario hidradenitis suppurativa surgery patient demographics.

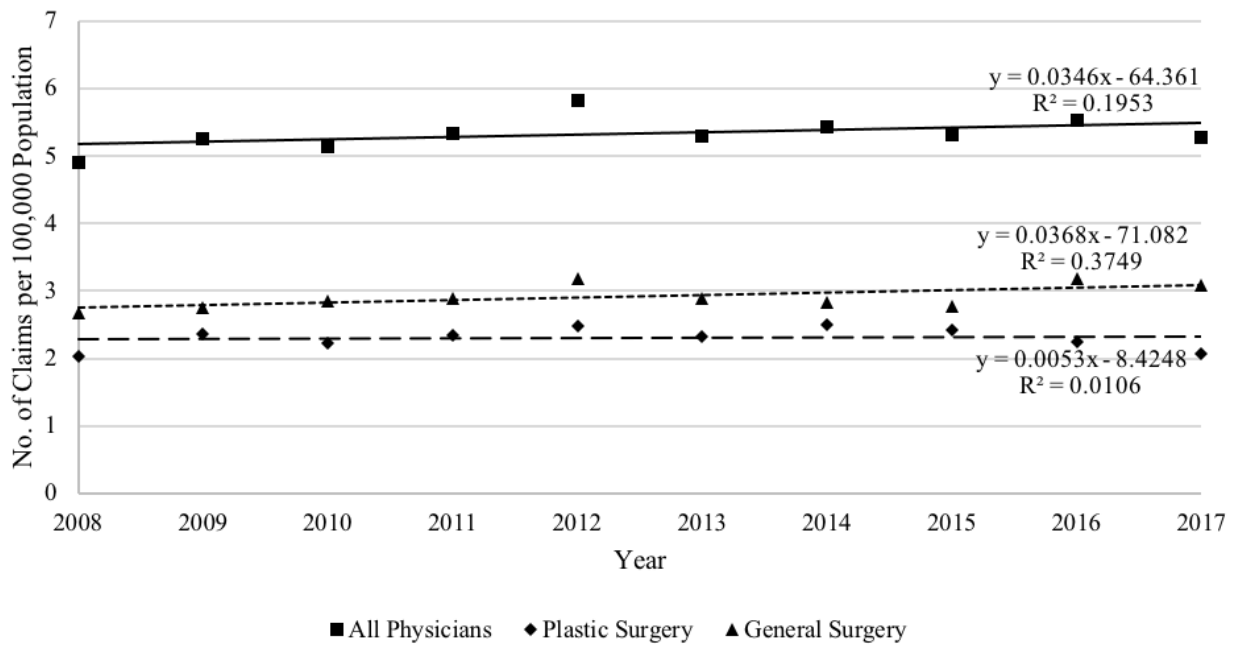
Characteristics	2008 (n=569)	2009 (n=628)	2010 (n=624)	2011 (n=631)	2012 (n=704)	2013 (n=667)	2014 (n=669)	2015 (n=640)	2016 (n=668)	2017 (n=670)
<b>Sex, n (%)</b>										
Female	366 (64.3)	427 (68.0)	441 (70.7)	433 (68.6)	458 (65.1)	453 (67.9)	454 (67.9)	415 (64.8)	426 (63.8)	419 (62.5)
Male	203 (35.7)	201 (32.0)	183 (29.3)	198 (31.4)	246 (34.9)	214 (32.1)	215 (32.1)	225 (35.2)	242 (36.2)	251 (37.5)
Age (years), mean	40.4	40.8	41.0	40.7	40.2	40.3	39.9	41.8	41.6	42.8
<b>Age (years), n (%)</b>										
0-19	41 (7.2)	26 (4.1)	31 (5.0)	36 (5.7)	55 (7.8)	36 (5.4)	32 (4.8)	30 (4.7)	30 (4.5)	31 (4.6)
20-44	306 (53.8)	350 (55.7)	349 (55.9)	351 (55.6)	386 (54.8)	372 (55.8)	396 (59.2)	347 (54.2)	381 (57.0)	340 (50.7)
45-64	181 (31.8)	215 (34.2)	203 (32.5)	194 (30.7)	216 (30.7)	217 (32.5)	192 (28.7)	219 (34.2)	197 (29.5)	234 (34.9)
65-74	23 (4.0)	24 (3.8)	25 (4.0)	36 (5.7)	29 (4.1)	29 (4.3)	36 (5.4)	28 (4.4)	35 (5.2)	46 (6.9)
≥75	18 (3.2)	13 (2.1)	16 (2.6)	14 (2.2)	18 (2.6)	13 (1.9)	13 (1.9)	16 (2.5)	25 (3.7)	19 (2.8)

### Providers of HS Surgery

The top 5 billing specialties for HS surgery were general surgery, plastic surgery, obstetrics and gynecology, urology, and dermatology (Multimedia Appendix 1, Supplemental Table 1). Over the course of the entire study period, general and plastic surgeons submitted the vast majority of claims for surgical treatment of HS, at 3934 and 3107 claims, respectively. General surgeons performed the majority of unilateral excision

procedures (R059), while plastic surgeons performed the majority of procedures that involved a skin graft or rotation flap (R060). The annual number of claims submitted for HS surgery experienced an overall slight increase across the study period when standardized by population, ranging between 4.9 (2008) and 5.8 (2012) claims per 100,000 population (Figure 2). However, overall, for every additional year, the number of claims per 100,000 population only slightly increased, by 0.03 claims.

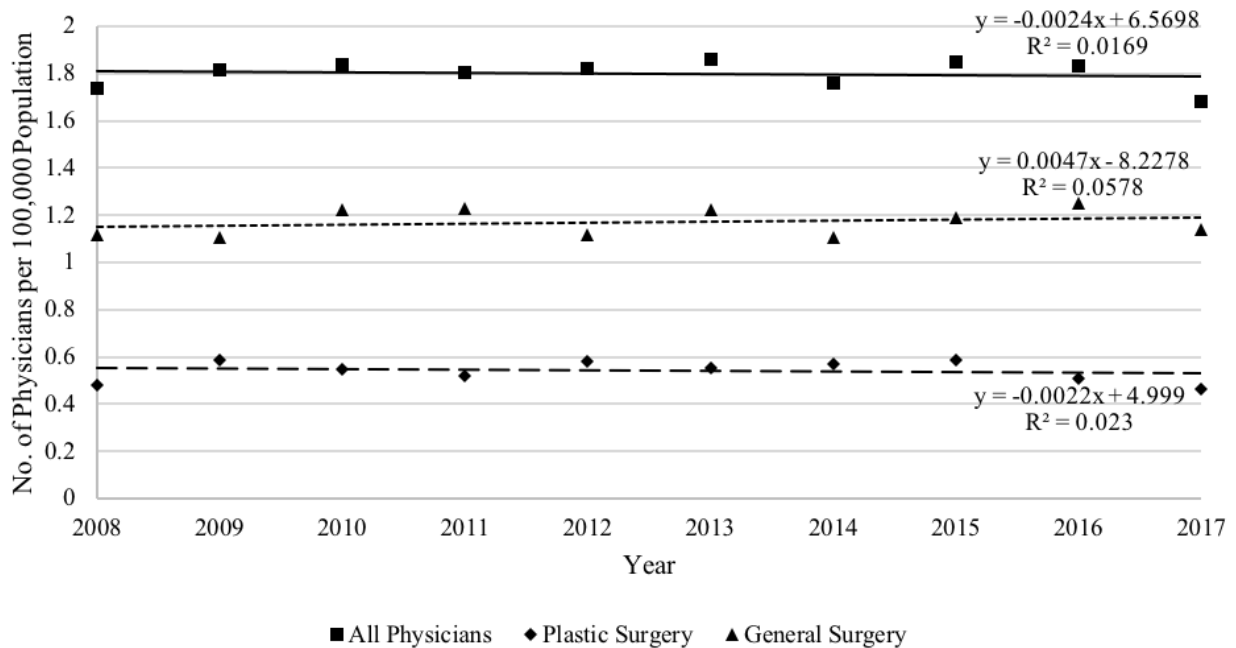
**Figure 2.** Submission of claims for hidradenitis suppurativa surgery over time per 100,000 population.



By specialty, annual claims submitted by general surgeons increased slightly more than those by plastic surgeons. The number of HS surgery providers per 100,000 population ranged from 1.7 to 1.9, with general surgeons ranging from 1.1 to 1.3

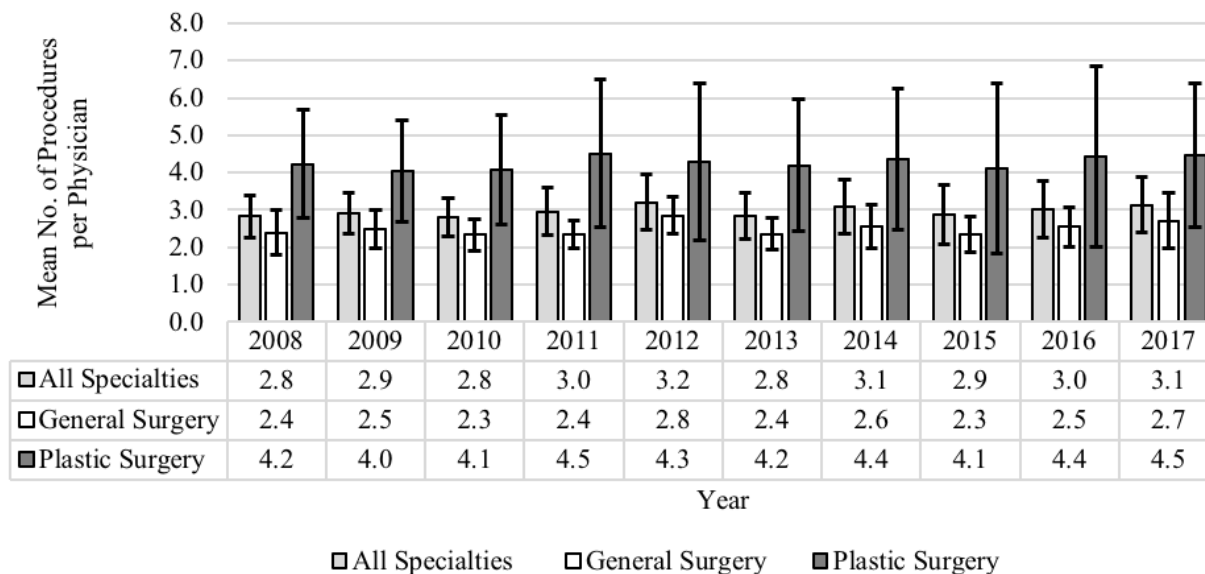
and plastic surgeons ranging from 0.5 to 0.6 (Figure 3). However, overall, for every additional year, the number of providers per 100,000 population decreased slightly, by 0.002 physicians.

**Figure 3.** Providers of hidradenitis suppurativa surgery over time per 100,000 population.



The mean number of procedures performed annually per physician rose from 2.8 to 3.1 across 10 years (Figure 4). Plastic surgeons performed more procedures per physician than did general surgeons, ranging from 4.0 to 4.5 compared with 2.3 to 2.8. However, the change in procedures per physician over time for all providers, as well as plastic surgeons and general

surgeons, was not statistically significant. It is also important to note that, averaged across the 10 years, 85.2% (2069/2427) of physicians submitted <5 claims per year, while only 14.8% (358/2427) submitted ≥5 claims per year. Furthermore, many only performed 1 HS surgery per year, therefore not necessarily qualifying as a specialized provider of HS care.

**Figure 4.** Annual hidradenitis suppurativa surgeries performed per physician.

### Geographic Distribution of Claims

In total, analyzed per claim, more patients (2281/7195, 31.7%) than physicians (2003/7195, 27.8%) resided in a rural area, while more physicians (5192/7195, 72.2%) than patients (4914/7195, 68.3%) resided in an urban area (see [Multimedia Appendix 2](#), Supplemental [Figure 1a](#)). Furthermore, over time, HS surgeries were increasingly being performed by physicians residing in a different geographic region than the patient receiving care (low of 176/684, 25.7% in 2009 to a high of 269/749, 35.9% in 2017; [Multimedia Appendix 3](#), Supplemental [Figure 2](#)). When comparing surgeries performed in rural areas to those in urban areas, in rural areas, surgery was most often performed by a general surgeon (1318/2003, 65.8%), while in urban areas, surgeries were more equally performed by general surgeons (2616/5192, 50.4%) and plastic surgeons (2495/5192, 48.1%; [Multimedia Appendix 2](#), Supplemental [Figure 1b](#)).

## Discussion

### Principal Findings

In this population-based analysis of HS surgical care in Canada, there was a slight trend towards increasing number of claims for HS surgery per 100,000 population over the 10-year study period, while the number of providers per 100,000 population decreased, particularly in general surgery. However, procedures performed per physician increased overall, although the increase was not statistically significant. Geographically, patients were also travelling further to access surgery. These findings suggest that overall access to HS surgery has not significantly improved over the study period and in fact may be decreasing as more and more patients seek care away from home as the number of clinicians providing surgery decreases.

The female:male ratio of patients included in this study was similar to that of a previous report on surgical interventions for HS patients in Ontario [25]. In comparison, the general female:male ratio among all HS patients is 3:1 [26-28],

suggesting that men diagnosed with HS are more likely to undergo surgery than women. This is possibly due to men generally experiencing more severe disease [28,29], underestimation and dismissal of pain in female patients [30], or a lack of surgical expertise for female care due to common lesion localization to the inguinofemoral area [28], as well as low numbers of gynecologists providing HS surgery. This emphasizes the need for improved access to care for female patients through improved surgical expertise and increased awareness surrounding perception of pain in women.

The mean age of disease onset has been reported as 20.5 (SD 9.3) years, with a mean age at diagnosis of 30.7 (SD 10.9) years, representing a mean delay from onset of symptoms to diagnosis of 10.2 (SD 8.9) years [8]. In our study, the mean age at the time of surgery was in the early 40s and increased by 2 years during the study period, representing a duration of potentially 10 more years from diagnosis to surgical treatment. One reason for the general rise in the mean age of patients undergoing HS surgery and the decrease in claims among patients 20-44 years old may be that medical therapy for control of early disease is increasingly being utilized over surgery, which remains a necessary adjunct intervention for refractory HS cases [6,10,31,32]. The mean age of surgery may also be increasing as patients may be receiving multiple surgeries, found to be approximately 10% in this study, with surgical intervention potentially starting at a later age due to surgical options only being explored once the disease has progressed to a more severe state. Furthermore, in Canada, 3.8% of the population, or approximately 3800 per 100,000 persons, are estimated to be living with HS [33]. Exact estimates of HS severity still vary widely, with reports of 3.9% to 23.7% of HS patients diagnosed with Hurley Stage III [28,29,34]. However, in this study, only 4.9 to 5.8 claims per 100,000 persons were submitted annually for the surgical excision of HS. Despite the considerable number of severe cases reported in the literature, surgical management of HS may therefore be underutilized.

Other recent advances in HS care have focused on new systemic drugs that target different immune mediators in the pathogenesis of HS [35]. Research on various monoclonal antibodies and small molecules are currently underway, while the use of anti-tumor necrosis factor biologic therapy has already demonstrated reductions in HS severity in clinical trials [35]. However, patients have reported high satisfaction with surgical management and experience relatively low recurrence of HS [5,6,36,37]. This suggests the need to consider surgery earlier as part of HS management to limit the long-term morbidity and prolonged progression of the disease. Combined management with biologic therapy has also been advocated in the setting of moderate-to-severe disease [38].

HS surgery was found to be primarily performed by general and plastic surgeons, consistent with previous literature [13]. Although general surgeons were the primary providers of HS surgical care, plastic surgeons submitted more claims per physician. Plastic surgeons also performed the majority of procedures that involved a skin graft or rotation flap, with a previous study showing that flap reconstructions by plastic surgeons had significantly shorter operation times and lower transfusion rates than those by general surgeons, reflecting the specialized training plastic surgeons receive in reconstructive procedures [13]. Investigation into the education of relevant surgical programs on specialized HS surgical care may highlight areas of training requiring further improvement.

Furthermore, it is likely that more surgeons are choosing narrower scopes of practice, especially in general surgery where broader scopes of surgical services are diminishing with highly specialized postresidency fellowships [39]. This is reflected in the study, with more HS surgery claims being accompanied by more claims per provider but fewer providers overall. Increased specialization and narrowing scopes of practice may also lead to patients having to travel further to receive care from an available provider. Accordingly, approximately one-third of patients received care away from their home, with this number also increasing over time. This has important implications for postsurgical follow-up care, with HS being a chronic relapsing disease requiring months to even years of follow-up post-surgical excision [6,31]. This highlights the need for recruitment of more surgeons to perform HS surgery as well as the training of rural surgeons on the surgical treatment of HS.

### Strengths and Limitations

This study benefited from the use of a comprehensive, large, longitudinal database, allowing for future comparison studies. However, a limitation to this study was the lack of a specific

diagnostic code for HS. Therefore, we were unable to evaluate and compare changes in HS surgery over time to changes in HS claims. Future studies should explore this association, to further help characterize patient access to HS surgical care. Second, the two billing codes used in this study, R059 and R060, do not reflect the entirety of procedures that can be offered for HS, such as abscess drainage, laser treatments, or electrosurgical peeling procedures [5,40]. However, these treatment modalities are relatively novel and are rarely performed as standard of care. Procedures such as abscess drainage also have high recurrence rates of up to 100% and are not performed as a curative option [5,41]. Furthermore, we were unable to assess demographic factors of patients and physicians such as gender, race, and ethnicity, limiting our analysis. However, evidence suggests unequal access leading to racial disparities in surgical care [42]. Further investigation into HS patient and physician demographic factors would be impactful to analyze in future studies.

### Comparison With Prior Work

Barriers to seeking HS care have previously been reported to include a lack of knowledge about HS among providers, difficulty accessing specialists, poor patient-physician communication, distrust in the medical community, and patients' experiences with HS [43]. This can be amplified by the significant delay to diagnosis that adds to patient frustration and disease severity and affects the likelihood of receiving well-planned, individual management [35]. Despite ongoing research on new treatment modalities, there is also a need to evaluate the circumstances of these barriers including access to operating room time, extent of provider education on HS, role of subspecialization among surgical providers, and public awareness around HS. This also translates to potential areas for public health authorities and hospital administrations to improve HS care, specifically in regard to increasing operating room time for HS surgeries.

### Conclusions

Unfortunately, no significant improvements in patient access to surgery were seen across the study period, with annual HS claims rising overall, number of providers decreasing, and patients travelling further to access surgery. A lack of access to operating room time and narrowing scopes of practice may be contributing factors potentially worsening access over time. Further research on HS surgery, including evaluation into system barriers across the continuum of HS diagnosis and management, are required in order to improve access to surgical care for HS patients.

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### Authors' Contributions

RA conceived the study. All authors contributed to the study design. AF acquired the data through IntelliHealth. AF and AL contributed to analysis and interpretation of data and drafting of the article. RA and RG critically revised the article. All authors approved the final version to be published.

## Conflicts of Interest

None declared.

### Multimedia Appendix 1

Supplemental Table 1. Claims submitted for hidradenitis suppurativa (HS) surgery by specialty.

[DOCX File, 29 KB - [derma\\_v4i2e31047\\_app1.docx](#)]

### Multimedia Appendix 2

Supplemental Figure 1. (a) Percentage of claims submitted by physician and patient location. (b) Percentage of claims billed by specialty using physician location.

[PNG File, 75 KB - [derma\\_v4i2e31047\\_app2.png](#)]

### Multimedia Appendix 3

Supplemental Figure 2. Percentage of claims submitted by physician and patient location (defined as their Local Health Integration Network [LHIN]) over time. Shown by claims submitted by physicians who resided in the same location as the patient at the time of surgery, and by those who did not.

[PNG File, 69 KB - [derma\\_v4i2e31047\\_app3.png](#)]

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## Abbreviations

**HS:** hidradenitis suppurativa

**LHIN:** Local Health Integration Network

**OHIP:** Ontario Health Insurance Plan

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