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Contents

Research Letters

Letter to the Editor

<u>Original Paper</u>

Experiences of Blogging About Visible and Long-term Skin Conditions: Interpretative Phenomenological Analysis

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Abstract

Background: Skin conditions can detract from people's quality of life, much like conditions such as cancer, chronic pain, and depression. Visible skin conditions can lead to risk of stigmatization. It is acknowledged that there is a lack of available psychosocial support for people living with chronic skin conditions. One way in which individuals with long-term conditions are self-managing and providing peer support is through blogging and exchanging information on the web. To date, no research has specifically investigated how individuals with skin conditions experience the use blogging for self-management.

Objective: This study sought to investigate the experiences of individuals with visible, long-term skin conditions when blogging about their conditions.

Methods: A systematic blog search and a short survey were used for recruitment. A total of 4 participants took part in email interviews, which were analyzed using interpretative phenomenological analysis (IPA). Skin conditions included alopecia, psoriasis, and hirsutism. The content of these individuals' blogs was also analyzed using a qualitative template method derived from the IPA analysis.

Results: The interviews and accounts revealed a clear sense of uncertainty about the course of the bloggers' skin conditions. This appeared to be associated with feelings of distress and isolation, searching for treatments, and ultimately a sense of defeat. The data revealed that blogging provided a space where this sense of defeat was managed and challenged. Posting on the web facilitated connection with others and enabled support networks to be established that assisted in challenging the feelings of isolation experienced. The data demonstrate the important role that blogging played for these participants in developing a sense of acceptance of their condition.

Conclusions: Blogging may provide a way for individuals to self-manage distress associated with visible skin conditions. It may provide similar benefits to those known to be derived from emotional disclosure that occurs during writing, with an added peer support dimension. Blogging has occurred naturalistically on web-based forums, and this study demonstrates how this form of interaction may warrant adaptation for use with web-based psychosocial interventions for people living with skin conditions. This study had a limited sample of 4 bloggers; therefore, further exploration would be needed to consider the utility of this approach.

KEYWORDS

Introduction

Skin conditions, such as atopic dermatitis, psoriasis, vitiligo, and urticaria, can be characterized by their long-standing, incurable, and dynamic nature [1]. Such conditions require continuing care [2] and can have an impact on quality of life similar to that of other long-term conditions (LTCs) such as heart disease, cancer, diabetes, and depression [3-6]. Skin conditions are known to be associated with levels of depression, anxiety, and suicidal ideation that are higher than those in the general population [7,8].

The visibility of skin conditions can be associated with additional distress [9,10]. Since individuals not only have to manage the symptoms but also the reaction of others [9,11], it is not surprising that these individuals can experience psychological distress. However, there is an acknowledged lack of available support for the ongoing emotional and psychosocial distress associated with having a skin condition [12,13].

The internet provides further opportunities for individuals to express themselves. For example, people have been found to write about personal experiences, ask questions, and receive direct feedback when discussing diabetes on moderated Facebook forums [14]. Different digital spaces offer different opportunities for emotional disclosure. For example, forums are typically moderated, and thus some forms of expression are restricted. Blogs are web-based journals where individuals can write their thoughts in a chronological format, to connect with others in a peer-led environment [15,16]. Blogs are not externally moderated, so bloggers can share their experiences in whatever form they wish; as such, they provide "cleaner" access to how people living with skin conditions may wish to use the web-based environment.

Through blogs, individuals with chronic conditions have been found to experience decreased isolation, be more able to make sense of their condition, gain support, and feel a sense of belonging [16-19]. However, little is understood about the personal benefits of blogging: why people turn to blogging, how it impacts their sense making, or how they self-manage through blogging [18-20]. Our study aims to explore the personal experiences of blogging about a long-term skin condition which affects one's appearance, and to consider this alongside analysis of the blog content.

Methods

Overview

In our study, we used two forms of data collection (direct email interviews and indirect blog content) and two forms of phenomenologically informed data analysis (interpretative phenomenological analysis [IPA] [21] and template analysis [TeA] [22]) to explore experiences of blogging about skin conditions.

Email interviews were chosen after consultation with two bloggers who blog about their visible skin conditions.

Sampling

A combination of different research terms was used to find the blogs using the web-based search engine Google. This search identified 37 suitable blogs.

Blogs were required to be written in the English language, have been active for at least 6 months, have at least 10 entries, and have been posted on the web within the last 3 months. Exclusion criteria included carers or parents writing about skin conditions and blogs primarily advertising or writing about other topics, including cancer.

The 37 potential participants were invited to complete a short web-based survey via email. The survey provided study information and a consent page for potential participants to complete prior to questions assessing their suitability.

Participants

Inclusion criteria for the study were having a skin-related LTC that was the primary motivation to start the blog and that was visible to others (ie, on the face, neck, or hands). Within this study, LTCs were identified in line with the World Health Organization's definition: health conditions that persist across time and require some degree of management.

A total of 11 individuals completed the survey, 8 of whom met the inclusion criteria. A total of 4 bloggers participated in the research (a sample size appropriate for IPA [21]): 2 women and 2 men, aged between 24 and 45 years. A total of 4 individuals did not respond to the interview invitation. Participants were based in three different countries (the United Kingdom, Canada, and Australia), but all identified as White British/other. Their conditions had been present for between 2 and 10 or more years and included alopecia, psoriasis, and hirsutism. The bloggers had been blogging for 2 to 10 years. The bloggers all engaged with their blogs through writing posts, reading comments, and responding to readers.

Procedure

Participants were invited to take part in a semistructured email interview with the first author. They received a £10 (US $13.50) Amazon voucher for their participation. The interviews involved an email exchange that was limited to 10 emails within a time frame of 6 weeks.

Ethical Considerations

Although blog content is freely available on the web, participants were asked to give consent for their blog data to be used within the study.

Steps were taken to ensure the anonymity of the interviews. For example, the quotes included do not detail the participant's condition or highlight distinguishable features of one individual, such as special events that may map onto a blog.

In addition, without verbal or facial cues, the ability to notice distress or need for support may be limited for email interviews. Participants were sent a list of support options (country-specific) that were available to them if needed. No participants reported any distress to the interviewer.

Our study was approved by the research ethics committee at the University of Birmingham (ERN_16-1472).

Data Collection

Email Interviews

Participants were provided with the interview schedule prior to the beginning of the study and then asked the initial question with prompts to begin the interview exchange. Questions focused on the participants' experiences prior to blogging, experiences of seeking help, and reasons for initiating the blog, as well as the role of blogging in living with their skin condition. The full interview schedule can be found in Multimedia Appendix 1, and it follows guidance for developing questions for an IPA study [21]. The interviewer would respond to the participant's response with questions to further explore, gain clarity on information provided, and elicit further information. The email interview was asynchronous and guided by the pace of the participant.

Blog Content

The first five and most recent five blog posts of the bloggers interviewed were used for the purposes of TeA.

Data Analysis

The first author conducted the IPA and TeA. Interview transcripts were read in turn and initial notes were made. A second read-through focused on line-by-line coding of objects of concern, tone or feeling, and language used [21]. A case summary was created for each participant to bring together notes, reflections, and codes. Codes across participants were then themed through their connections and associations by the first and last author.

The template for TeA was created using the preliminary IPA findings to align with the a priori defined themes approach of TeA. Subsequent revisions of the template were developed during the analysis of the blog transcripts. Codes across participants were linked and themed through their connections with one another and further refined.

The email interviews produced an average of 31 pages of double-spaced and wide-margined text for analysis (range 18-46 pages). The blog content analysis produced an average of 34 pages of text per blog (range 21-45 pages).

Research supervision with the second and last author helped to maintain the rigor of the research and coherence with IPA and TeA processes. The third author (external to the design and analysis) checked the quotes and themes for credibility. Participants were sent the preliminary themes and findings; one participant responded to the email to confirm that this fit with their understanding of their skin condition and blogging, as well as to ask for the final write-up. Other participants did not respond.

Results

Overview

The results presented here focus on the experience of blogging about skin conditions. We begin by briefly presenting the thematic structure from the TeA of the blog content. The template included the themes of symptoms, making sense of the condition, social experiences, treatment, and emotional impact. We then focus on the themes from the IPA of the interviews, and we discuss the similarities and differences between the two.

Blog Content Analysis

Six main themes were drawn out from the TeA of the blog content. Figure 1 depicts the thematic structure captured by the analysis. The blog accounts of living with a skin condition did not follow a linear pattern; instead, participants fluctuated between different positions dependent on the state of their skin, relating to the cyclical nature of their skin condition. Participants attempted to manage the threat in different ways, such as hiding away and seeking treatment. This was intertwined with their experience of others. Blogging appeared to assist participants in moving from being overwhelmed by their condition to a place where it was no longer a threat. This did not reflect an acceptance but rather a tolerance of the condition, and it reoccurred each time the condition worsened. The participants therefore moved between "levels" of the structure dependent on the state of their skin and their social experiences with others. There was a general sense of this threat being an isolating journey, in contrast to blogging, which allowed connection and expression.

Figure 1. A visual depiction of the Template Analysis Theming structure.

Blogging as an Experience

Five superordinate themes were developed from the IPA. Table 1 outlines these themes along with subthemes, contributions, and quotes. Alongside the themes developed from the IPA, we provided some quotes from the blog content which map onto the themes. To maintain anonymity of the interviews within this paper, aliases are used for the participants, and blogs are labelled as 1, 2, 3, and 4. Further quotes can be found in Multimedia Appendix 1.

Table 1. Themes identified for blogging through interpretative phenomenological analysis and comparison with template analysis.

Superordinate theme and subthemes	Quotes from interviews	Quotes from template analysis
Skin is an overwhelming threat to self		
Skin appraisal and attempts to manage	"I remember being self-conscious about my facial hair as an adolescent, when it was simply blond.... I vividly remember a boy commenting rudely on it in school, around the age of thirteen or fourteen, and that's the first time I recall feeling like I should do something about it, even though I had been concerned about it for a while" [Laura]	"...two tiny little dots which I thought were just that – wee dots where hair didn't grow. Until they started to spread. Obviously like any other person who cared about their looks I was worried – in fact I was majorly freaked out if truth be told. Bordering on daily obsession! As The 'wee dots' graduated into 'big dots' I tried to remain calm – while simultaneously obsessively checking the reaction of people I bumped into and whether they thought I had some human form of mange!" [Blog 1]
Defeat and discontent	"I felt that no one could help me and nothing could fix this" [Laura]	__a
	"I was losing hope with the condition as no-one seemed to give me any answers" [Debbie]	
Blogging for self—venting and building		
Having an outlet and processing	"I knew it was interfering with things and causing some low moods and blue days. I wasn't content … I couldn't keep living life the way I was." [Laura]	"I do feel that it has made me a stronger person and in many ways a very different person. I am by no means cured of my Alopecia but I am feeling more in control of it." [Blog 3]
	"I find that when I talk about it – it is usually weighing on my mind because I am sad." [Ian]	
Being built up	"It was much more rewarding then what I initially thought. I did not expect the reception and the feeling I had from helping others was very rewarding." [Debbie]	"But in all my wanderings, nothing has helped so much as hearing from other women struggling with the same things" [Blog 2]
	"My management strategies must have changed. This is a little blurry but suffice to say that before blogging I don't think I had any. [It] was clearly winning and I wasn't managing it at all." [Tom]	
	"The more I wrote about the condition, and the more questions I got from readers, the more I noticed holes in my knowledge and it prompted me to do research." [Laura]	
Blogging for others—sharing and informing		
Being there for others	"What was missing was the happy stories or the sad stories with a positive slant - or the fact that there could be people who coped fine with alopecia." [Ian]	"As you may have realised after reading my first few blog posts, I decided to write this to help and support others and to bring attention to this crippling condition" [Blog 3]
	"When I was writing to help others, I gained perspective and was distracted from my own problems, and they felt like much less of a burden" [Laura]	"I hope this gives the reader an understanding of what Psoriasis does to a person's soul" [Blog 4]
Complement but not a substitute for the real world	"They do have a better understanding of why sometimes I want peace and quiet, why I am tired and they don't have to ask how I am all the time. I guess my blogging saves them time and questions." [Tom]	—
	"I may have missed the opportunity to take the risk of relying on others" [Laura]	
Trying out a way to engage with others		
Safety in expression on the web	"It seemed less likely that I would be recognised amongst all that noise" [Laura]	—
	"I did not want to meet mass groups of other sufferers but I did still want help…. Blogging for me helps bring together communities of other sufferers without having to interact if you don't want to." [Debbie]	
	"For me it is easier to tell a stranger and I think the reason is that I am not worried too much about how they think of me after as I'm unlikely to see them again" [Tom]	

Superordinate theme and subthemes	Quotes from interviews	Quotes from template analysis
Social approval in blogging	"I am always wary not to be too negative as I don't think that is helpful. I am honest about the low times but don't want someone to be thoroughly depressed and leave my blog without some sort of hope." [Ian]	—
	"I think I was very aware of how I came across and never wanted to appear too self-indulgent or negative." [Laura]	
Blogging as a journey which ebbs and flows		
When is the time to blog	"I see blogging as something I'll continue to use as long as my condition persists." [Ian]	"It was something that I had expected and prayed wouldn't come" [Blog 1]
	"I no longer had those powerful emotions I needed to let out. And I felt increasingly drained by the emails I received. I just felt ready for a life where I wasn't forcing myself to think about [it] every day [...]. and blogging was the only thing keeping it 'big.'" [Laura]	
Making the condition more tolerable	"Before I started the blog I saw psoriasis as this big dark monster looming over my life and in a way that view hasn't really changed. Psoriasis has never been my friend and it never will be. Also unlike others who say they come to terms with it, I never have and refuse to do so. Mostly because I think if I do that then it has won. I perceive coming to terms with it as accepting it and I will never accept it, I want it gone." [Tom]	—

[a]—: no quote available.

Skin Is an Overwhelming Threat to Self

Defeat and Discontent

Participants experienced a sense of defeat and a loss of hope when they realized that no treatment was working. There was an expectation of a cure, and participants described feelings of defeat when this no longer seemed an option. This was difficult for participants to face, although this was not reflected much in the blog content itself.

Blogging for Self—Venting and Building

Having an Outlet and Processing

Participants described realizing that they needed to change the way they lived with their skin condition. Laura's account of the turning point is typical: "I knew it was interfering with things and causing some low moods and blue days. I wasn't content … I couldn't keep living life the way I was." Blogs were described as a place where the participants could unburden themselves of these strong emotions. All participants described the *heaviness* of their condition and reflected on how their blogs were an outlet for these difficult emotions.

As they faced the difficulties arising from long-term illness, blogging provided opportunities for the participants to gain perspective and normalize. Participants described how these combined benefits helped them to find the strength to cope. This was particularly important for those who had conditions which fluctuated. As the condition worsened, the blog provided a way to chart the emotional changes. Participants described a growing sense of tolerance (rather than acceptance), as their relationship to the condition changed over time. In this way, the blogs served as a vehicle for managing the psychological distress and uncertainty associated with the skin condition.

Being Built Up

Through helping others, the participants described how their sense of accomplishment and competency grew. Laura described moving from a place of fearing the unknown to being more determined to find a form of control. Similarly, there was a sense of accomplishment from receiving positive feedback.

Participants also described the development of coping strategies through advice offered by readers. Thus, blogging was represented as a *scaffold* that helped participants to build themselves up emotionally after struggling to cope with the perceived sense of their skin condition being overwhelming.

Blogging for Others—Sharing and Informing

Being There for Others

The participants expressed a desire to offer what was missing from their journeys to others. The participants attempted to normalize the condition for others. Being there for others meant that others did not experience the same frustrations they did. For Laura, blogging for others also provided a conscious escape from her own problems.

However, blogging was also seen as an exhausting process, because at times it meant supporting people who were often in a worse place. Laura described wondering whether her blog meant she never gained support herself. In this way, solely being there for others had the potential to prevent one from asking for or receiving help.

Complement but Not a Substitute for the Real World

It was clear that blogging did not replace a desire for interaction in the real world. Tom described blogging as an addition that helped his friends and family to better understand his experiences. Blogging supported Ian in connecting with others, whom he then met in person. It therefore helped him to grow

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his real-world network. In contrast, Laura described blogging as a barrier to connecting with people in the real world. Blogging did not appear to offer a viable *alternative*, but rather an *addition* to real-world contact.

Trying Out a Way to Engage With Others

Safety in Expression on the Web

Participants described their anxiety around people knowing about their condition and receiving judgmental responses. Consequently, participants socially withdrew as their condition worsened. The fear of negative reaction appeared to be less threatening when writing on the web. Talking on the web provided an emotional distance when talking about a distressing condition. It felt safe to participants that they could choose when and how to respond.

Participants described feeling that no one understood—friends were distant, professionals were matter of fact, and family members did not always offer empathy. Blogging provided a way for participants to voice their frustrations and be understood without fear of retribution from a "real" person. In this way, blogging supported safe expression and emotional distance.

Social Approval in Blogging

This subtheme was noticeably missing from the blog content; however, during the interviews, it appeared to be integral to writing on the web. Although blogging provided an avenue where appearance was not important, there was often pressure to "say the right thing."

Blogging was perceived to reduce appearance-related anxiety, and anxieties about saying the right thing were heightened. Sometimes, this caused more anxiety. Although blogging is not a face-to-face interaction, all participants described feeling the need to include a positive perspective; there was always a conscious awareness of those who might read the blog.

Blogging as an Experience That Ebbs and Flows

When Is the Time to Blog?

As the participants' skin conditions became more threatening, they used their blogs to manage the affect that came with it. Conversely, there appeared to be less need to blog when symptoms waned. Laura described how blogging eventually became a barrier. Interestingly, being there for others led her to maintain her web-based presence, although it no longer felt necessary for her personally.

Making the Condition More Tolerable

Blogging supported participants to feel less overwhelmed by the "looming" qualities of their conditions.

Participants described how blogging supported them in coping with overwhelming and unpredictable factors. However, it did not necessarily lead to feelings of acceptance. A hope for improvement remained; when the condition worsened, it was emotionally difficult. Participants used their blogs to make sense of the fluctuations but did not reach a place where worsening of their condition was easy to tolerate. However, participants also did not revert to their preblogging states: blogging appeared

to offer a means of "containing" the affect that was once overwhelming.

Discussion

Principal Findings

Similar to experiences in other LTCs, blogging served as a way for participants to make sense of their emotions, adjust to their condition, and share information [16,23-26]. This appeared to compensate for the feelings of loss and isolation brought on by the condition and provided participants with a way to regulate their emotions [25,27,28]. Similar to findings from Johnston et al [29], this study suggests that distress may arise from relying solely on problem-focused strategies when facing an LTC. Participants used the blog at times when they needed support to move back toward a place of health [16,30,31], suggesting that blogging is a functional, but optional, tool in adjusting to LTCs for the participants.

Changes in mood and perspective appeared to be more prominent in the participants' descriptions than changes in symptoms. Expressing emotional experiences through writing is associated with therapeutic benefits, such as positive health outcomes and reduced health appointments [32,33]. Thus, blogging about health conditions may be associated with similar benefits to emotional disclosure. This supports the idea of blogs as an emotion-focused strategy, as these strategies focus on changing the appraisal of a stressor that cannot itself be changed [28]. It is interesting to consider whether other web-based platforms (designed around image sharing or microexpressions) would be as well suited to supporting these reflective and connective strategies.

Negative impacts of blogging were also identified by the participants. The interviews identified a conscious awareness of audience and of readers' response to their writing. Participants described the need for some positivity in their writing and not wanting to leave readers feeling worse. At times, they also felt a sense of obligation to blog for others even when not wanting to do so for themselves. It is not clear whether this detracts from the personal benefits of blogging or maintains them. The participants also experienced some sense of regret that blogging commitments may have prevented them having more face-to-face relationships. The social dimension of blogging therefore had both positive and negative impacts.

The use of email interviews is still relatively new to IPA research. Within this study, it fit with the participants' sharing style (ie, writing on the web, anonymously), and we felt it was suitable for this population. However, this method can mean that verbal and nonverbal cues are missed, while it provides benefits such as fewer resources and more privacy [34]. Therefore, as with other methods, the advantages and disadvantages of this method need to be considered. One benefit of using interviews within this study was their ability to capture the personal benefits and challenges of blogging, which was not possible in previous studies focusing on content [16,35]. Within this study, the need for social approval in the context of writing on the web was highlighted in the interviews but not the blogs themselves. This suggests that what people post on

the web and what they think about what they post are not identical in nature, and therefore research focusing on content alone may limit our understanding of the experience of writing on the web. Within this population, there is also a possibility that the need for social approval may relate to the visible aspect of conditions and the particular social difficulties this creates. However, this was not found within the TeA to be a shared experience with readers but more of a private experience. Further research would support a better understanding of the motivations for blogging for this group and how this differs from traditional emotional disclosure methods such as journaling.

When thinking about care practices within the United Kingdom, the stepped model of care proposed for psychodermatology services does not explicitly report a need for both emotion- and problem-focused strategies [13]. Problem-focused treatment is dominant at the initial stages of managing skin conditions. This study and other previous findings indicate the utility of more emotion-focused strategies for patients in addition to solely managing symptoms of an incurable condition. It may be useful to further explore support avenues for individuals to find emotion-focused ways of coping. This may include signposting individuals to existing forums and blogging sites or through creating bespoke peer support forums or public web-based journals that patients can use to both express themselves and engage socially with peers if they choose to. This may reduce the development of psychological distress [7] when conditions are incurable through drawing on literature from psychosocial interventions in other LTCs. However, it is worth considering that this study looked at the experience of using self-initiated blogs. The experience may be different if it is professionally

led or organized. It would also be important to consider how people access such support and whether they would need to be receiving secondary dermatology services. The potential negative impact of writing on the web is also in need of consideration when thinking about its utility for individuals in their journey.

Limitations

The sample of active bloggers within this area was relatively small, and although all their skin conditions were visible, the conditions were different. It will be helpful to explore self-management through web-based platforms for one condition and also on other platforms such as Instagram, where communities of individuals living with skin conditions use other methods such as photojournaling. Although photojournaling is a different type of blogging, it allows individuals to chronologically post, express themselves, and connect with others. A larger, more diverse sample may help us to understand whether emotional expression within a web-based community is a functional tool for adjustment across platforms.

Conclusions

Blogging appears to share the benefits offered through emotional disclosure—with the added social dimension—and may support positive adjustment. Exploration of how blogging fits into current care and whether it would be a suitable self-help option to offer needs to be further considered. In particular, the social challenges of blogging may need further consideration, including the negative impacts of writing on the web. It still remains unclear how and under which conditions blogging can be successful in coping [36].

Conflicts of Interest

None declared.

Multimedia Appendix 1
Interview schedule.
[DOCX File , 7 KB - derma_v5i2e29980_app1.docx]

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Abbreviations

IPA: interpretative phenomenological analysis
LTC: long-term condition
TeA: template analysis

Original Paper

The Experience of 3D Total-Body Photography to Monitor Nevi: Results From an Australian General Population-Based Cohort Study

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Abstract

Background: Digital 3D total-body photography of the skin surface is an emerging imaging modality that can facilitate the identification of new and changing nevi.

Objective: We aimed to describe the experiences of study participants drawn from the general population who were provided 3D total-body photography and dermoscopy for the monitoring of nevi.

Methods: A population-based prospective study of adults aged 20-70 years from South East Queensland, Australia was conducted. Participants underwent 3D total-body photography and dermoscopy every 6 months over a 3-year period. Participants were asked to provide closed and open-ended feedback on their 3D total-body photography and dermoscopy experience (eg, comfort, trust, intended future use, and willingness to pay) at the halfway study time point (18 months) and final study time point (36 months). We assessed changes in participants' reported experience of 3D total-body photography, and patient characteristics associated with patient experience at the end of the study (36 months) were analyzed.

Results: A total of 149 participants completed the surveys at both the 18- and 36-month time points (median age 55, range 23-70 years; n=94, 63.1% were male). At the 18-month time point, most participants (n=103, 69.1%) stated they completely trusted 3D total-body imaging for the diagnosis and monitoring of their nevi, and this did not change at the 36-month (n=104, 69.8%) time point. The majority of participants reported that they were very comfortable or comfortable with the technology at both the 18- (n=138, 92.6%) and 36-month (n=140, 94%) time points, respectively; albeit, the number of participants reporting that they were very comfortable reduced significantly between the 18- and 36-month time points, from 71.1% (n=106) to 61.1%

(n=91; *P*=.01). Almost all participants (n=140, 94%) would consider using this technology if it were to become commercially available, and this did not change during the two study time points. Half of the participants (n=74) cited barriers to participating in 3D total-body photography, including trust in the ability of this technology to detect and monitor suspicious lesions, digital privacy, cost, and travel requirements.

Conclusions: The majority of participants expressed positive attitudes toward 3D total-body photography for the monitoring of their moles. Half of the participants identified potential barriers to uptake.

Introduction

The presence of many moles, or melanocytic nevi, is the strongest known risk factor for melanoma [1,2]. Melanocytic nevi vary in number, size, shape, and color depending on an individual's endogenous and exogenous factors. Studying the clinical features and changes to melanocytic nevi over time has the potential to provide greater insight into melanoma development. In 2020, almost 325,000 new cases of melanoma were detected, and melanoma resulted in nearly 60,000 deaths worldwide [3,4]. In Australia, melanoma was estimated to be the third most diagnosed cancer [5]. Survival outcomes worsen with increasing tumor thickness, and thicker melanomas require more invasive and intensive treatment; therefore, early detection is critical. For example, thin melanomas (<0.8 mm) have a 10-year survival rate of nearly 98% [6].

Total-body photography may help to confirm if nevi are stable or new and may reduce the number of nevus biopsies [7]. Recent technological advances have resulted in unprecedented changes to the landscape of dermatological photography, including the evolution from 2D photography to 3D total-body photography [8,9]. Two-dimensional images of the skin are taken and composed to form a body map, whereas 3D total-body photography allows for the collection of high-resolution macroscopic images that provide a record of almost the entire skin surface in an avatar format. Three-dimensional photography machines integrate software that presents the number, border irregularity, and color distribution of nevi and other skin lesions to the clinician, and tracking software facilitates comparison of nevi appearance over time [9,10]. Three-dimensional total-body photography allows people to view an avatar of their whole skin, including areas with sun damage, freckling, and nevus density. Furthermore, the process of 3D total-body photography takes a short time and only requires people to stand in one position, which is another advancement compared to 2D photography.

Currently 3D total-body photography is not widely available for commercial use. Few people have experienced 3D total-body photography to monitor their nevi, and no previous studies have described consumer-reported attitudes of using 3D photography in detail. The *Mind Your Moles* population-based cohort study aimed to improve the understanding of the epidemiology and biology of nevi in adults. The aim of this study was to explore the feedback provided within the *Mind Your Moles* study. This included evaluating the experience of 3D total-body photography

perceived by study participants, including evaluating their level of trust and comfort toward this new technology.

Methods

Study Design and Participant Inclusion Criteria

This study was part of a 3-year, population-based, prospective cohort study of adults aged 20-70 years from South East Queensland, Australia. The study protocol has previously been described [11]. Participants age 20-69 years were recruited from the Australian Electoral Roll register. Participants were eligible if they had at least one nevus (any size) and Fitzpatrick skin type I to IV, and were willing to attend the clinic for 3D total-body photography every 6 months to evaluate changes in nevi over 3 years. Participants attended study visits at the Princess Alexandra Hospital, Brisbane for a clinical skin examination by a junior clinician and received 3D total-body photography and dermoscopy (VECTRA WB360 Serial Number WB00009, Canfield Scientific, Parsippany, NJ). The diagnostic process was based on the junior clinicians' clinical examination, and if suspicious lesions were identified, a dermatologist (author HPS) reviewed the images for a second opinion. Artificial intelligence (AI) algorithms were used for providing total nevus counts over 2 mm and 5 mm.

Ethics Approval

This study was approved by the Metro South Health Human Research Ethics Committee (approval number HREC/16/QPAH/125).

Baseline Questionnaire

The sociodemographic characteristics of participants collected at baseline included age, sex, income, highest educational attainment, and employment status. The phenotypic and clinical characteristics collected at baseline included the innate skin color of the ventral upper arm, eye color, natural hair color at 21 years of age, BMI, and personal and familial skin cancer history.

Participant Experience Using 3D Total-Body Photography

At the 18-month (visit four) and 36-month (final visit) follow-up visits, participants were asked to provide feedback on 3D total-body photography (see Multimedia Appendix 1). Survey questions were based on a previously developed questionnaire

for consumer mobile teledermoscopy [12], adapted from the Technology Acceptance Model [13].

In optional open-ended questions, participants were asked to list benefits or disadvantages (if any) of using 3D total-body photography both at 18 months and the final visit (36 months). Two independent researchers (MO and SS) read through the complete data set twice to familiarize themselves with the qualitative data [14]. A single researcher identified broad initial themes and significant patterns within the data, which were reviewed for consistency by a second researcher. The researchers met to identify, discuss, and agree upon core themes, with any disagreements settled by a third researcher. Participant responses were tallied into themes. Participant responses that were the same at both time points (ie, the participant mentioned the same advantage or same disadvantage at both the 18-month and final visit) were combined and counted as one response. Responses that were different between time points were counted separately.

Participant Satisfaction at the End of the Study

At the 36-month follow-up visit, participants were asked additional one-off questions with the entire photography process including if they thought it could improve the diagnosis and monitoring of skin lesions, it could be used for discovering new insights into skin well-being, they would recommend it to others, it was useful, it could help improve teaching people about their skin conditions, and it feels like an intrusion of their privacy. Participants were asked about the follow up of images including if they would like to see them at the end of the consultation, would like a copy, or would like to discuss the images with a doctor. Response options for each of these questions was *yes* or *no*. Participants were also asked their preference for the gender of the photographer (man, woman, no opinion).

Sample Size

Sample size calculations, including the number of nevi expected for observation, have been previously reported [11]. We aimed to recruit a minimum of 188 participants to account for a 20% dropout rate, leaving a final sample size of 150 participants at the end of the follow-up period.

Statistical Analysis

Descriptive statistics were used to present participant characteristics, experience, and satisfaction with 3D total-body photography.

The Wilcoxon matched pairs signed rank test was used to determine a change to participants' satisfaction with 3D total-body photography between the 18- and 36-month time points (including questions surrounding comfort, trust, intended future use, and willingness to pay). Chi-square tests (or Fisher exact tests when appropriate) for categorical factors and Mann-Whitney U tests for continuous factors were used to assess demographic and skin health–related factors with participants' trust and comfort with 3D total-body photography at the end of the study (36 months).

P values <.05 were considered statistically significant. All statistical analyses were performed in SPSS 28.0 (IBM Corp).

Results

Participant Characteristics

A total of 193 eligible participants participated at the baseline visit. Of these, 149 (77.2%) participants completed both the 18-month and 36-month time point patient experience questionnaire and were included in this analysis. Included participants had a median age of 55 (range 23-70) years, 63.1% (n=94) were male, and 6.7% (n=10) had previously been diagnosed with melanoma. Most participants had a fair skin type (n=116, 77.9%). Participants had a median of 49 (range 4-341) nevi >2 mm and a mean of 4 (range 0-72) nevi >5 mm (Table 1).

Attrition analysis showed that, compared to people included in the analysis, people who dropped out were mostly women (55/149, 36.9% vs 27/44, 61%; P=.007) and those who had fair skin (117/149, 78.5% vs 27/44, 61%; P=.04; data not shown).

Table 1. Participant characteristics (N=149).

	Participants
Sociodemographic characteristics	
Age (years)	
Mean (SD)	53.2 (11.5)
Median (range)	55 (23-70)
≤50 years, n (%)	54 (36.2)
≥51 years, n (%)	95 (63.8)
Sex, n (%)	
Female	55 (36.9)
Male	94 (63.1)
BMI (kg/m^2)	
Mean (SD)	27.00 (4.58)
Median (range)	25.97 (18.36-42.75)
18.5-24.9 (healthy), n (%)	58 (38.9)
25-29.9 (overweight), n (%)	54 (36.2)
30 or more (obese), n (%)	35 (23.5)
Not reported, n (%)	2 (1.3)
Combined household income (AU $)[a], n (%)	
≤$39,999	16 (10.7)
$40,000-$79,999	29 (19.5)
$80,000-$124,999	31 (20.8)
≥$125,000	53 (35.6)
Unsure	8 (5.4)
Prefer not to answer	12 (8.1)
Highest education level, n (%)	
University degree	66 (44.3)
No university degree	83 (55.7)
Employment status, n (%)	
Full-time	74 (49.7)
Part-time	19 (12.8)
Retired	36 (24.2)
Other[b]	20 (13.4)
Previous melanoma diagnosis, n (%)	
Yes	10 (6.7)
No	139 (93.3)
Familial history of melanoma, n (%)	
Yes	38 (25.5)
No	111 (74.5)
Phenotypic characteristics	
Skin color, n (%)	
Fair	116 (77.9)
Medium/olive	32 (21.4)

	Participants
Not reported	1 (0.7)
Natural hair color at 21 years old, n (%)	
Light brown	59 (39.6)
Fair or blonde	22 (14.8)
Red or auburn	6 (4.0)
Dark brown or black	62 (41.6)
Eye color, n (%)	
Blue or gray	72 (48.3)
Green or hazel	51 (34.2)
Brown	25 (16.8)
Not reported	1 (0.7)
Total nevus count >2 mm[c]	
Mean (SD)	68.01 (61.88)
Geometric mean	47.94
Median (range)	49 (4-341)
Total nevus count >5 mm[c]	
Mean (SD)	7.23 (9.72)
Geometric mean	4.34
Median (range)	4 (0-72)

[a]A currency exchange rate of AU $1=US $0.71 is applicable.

[b]Included home duties, self-employed, student, and unemployed.

[c]Total nevus counts calculated using artificial intelligence software.

Patient Experience With 3D Total-Body Photography

Table 2 provides a summary of changes to participants' experience of 3D total-body photography. At the 18-month time point, over two-thirds (n=103, 69.1%) of the 149 participants stated that they completely trusted 3D total-body imaging for the diagnosis and monitoring of their nevi, and this was similar at 36 months (n=104, 69.8%). Participants who reported a healthy BMI were more likely to report distrust or uncertainty toward the imaging process (10/58, 17%) compared to those with overweight or obese BMIs (5/89, 6%; P=.03). There was a statistically significant difference between groups of trust according to age (P=.04). Those who were trusting of the technology had a median age of 56 (range 23-70) years, and those who were not trusting or unsure had a median age of 48.5 (range 27-67) years.

A statistically significant difference was observed between the 18- and 36-month time points for comfort using this technology, with a reduction in the proportion of participants reporting the technology as *very comfortable* at the 36-month time point, from 71.1% (n=106/149) to 61.1% (n=91/149; P=.01; Table 2). Males were more likely (92/94, 98%) to report that they were more comfortable with the imaging process compared to females (48/54, 89%); however, this was only marginally significant (P=.05; Table 3). No other participant characteristics were associated with trust and comfort.

Almost all participants would pay a fee to use this service, and this did not change between the 18- and 36-month time points. At the end of the study, only 6.7% (n=10) of the 149 participants would not pay to use this service, 58.4% (n=87) would pay between AU $1 and AU $100, and 33.5% (n=50) would pay AU $101 or more (AU $1=US $0.71). The majority of participants (140/149, 94%) would consider using the technology in the future if it were commercially available with their regular medical practitioner, and this did not change between the 18- and 36-month time points.

A total of 149 participants provided a response to the open-ended question about advantages of 3D total-body photography (Table 4). Six key themes emerged, including (1) comprehensive skin check and early detection; (2) improved monitoring; (3) satisfaction, time efficiency, and improved health output; (4) noninvasive procedure; (5) accuracy and AI; and (6) contribution to research (altruism).

Many of the 149 participants (n=95, 63.8%) stated that the technology provided a "Comprehensive overview of all the body surface." Participants (n=88, 59.1%) were positive about 3D total-body photography providing an accurate baseline to record, compare, and follow changes in their skin over time. Over one-tenth (n=16, 10.7%) of participants described the process of 3D total-body photography as "painless," "non-intrusive," and "less invasive than [a] regular skin check procedure."

Half (n=74, 49.7%) of the 149 participants reported disadvantages of 3D total-body photography. Four key themes emerged, including (1) physical privacy, (2) travel, (3) concerns about new technology, and (4) cost. In terms of physical privacy, 20 (13.4%) participants stated they were "not comfortable in underwear" and disliked "feeling exposed." One-fifth (n=30, 20.1%) of participants expressed concerns regarding the new technology, including its ability to accurately detect suspicious lesions and body areas unable to be imaged, and 3 participants mentioned concerns about digital security.

Table 2. Patient experience of using 3D total-body photography at 18- and 36-month follow-up visits (N=149).

Question	Time point, n (%)		P value
	18-month	36-month	
How much do you trust this 3D total-body photography for the diagnosis and monitoring of your moles?			.68
Completely trust	103 (69.1)	104 (69.8)	
Slightly trust	26 (17.4)	29 (19.5)	
Unsure/slightly/completely do not trust	16 (10.7)	16 (10.7)	
Not reported	4 (2.7)	0 (0.0)	
How comfortable were you in participating in the 3D total-body photography?			.01
Very comfortable	106 (71.1)	91 (61.1)	
Comfortable	32 (21.5)	49 (32.9)	
Indifferent	2 (1.3)	3 (2.0)	
Slightly not comfortable	5 (3.4)	5 (3.4)	
Not at all comfortable	0 (0.0)	0 (0.0)	
Not reported	4 (2.7)	1 (0.7)	
Would you consider using 3D total-body photography if it becomes commercially available with your regular medical practitioner?			.71
Yes	140 (94.0)	141 (94.6)	
No	4 (2.7)	6 (4.0)	
Not reported	5 (3.4)	2 (1.3)	
How much would you be willing to spend on this service if it became available at your dermatologist's practice? (AU $)[a]			.68
$0	6 (4.0)	10 (6.7)	
$1 to $50	31 (20.8)	27 (18.1)	
$51 to $100	64 (43.0)	60 (40.3)	
$101 to $200	37 (24.8)	40 (26.8)	
$201 or more	6 (4.0)	10 (6.7)	
Not reported	5 (3.4)	2 (1.3)	

[a]A currency exchange rate of AU $1=US $0.71 is applicable.

Table 3. Patient characteristics associated with patient trust and comfort at the end (36 months) of the intervention.

Demographic characteristics	Trust[a] (N=149)			Comfort[b] (n=148)		
	Yes (n=133)	Unsure/no (n=16)	*P* value	Yes (n=140)	Unsure/no (n=8)	*P* value
Age (years)			.10			.14
≤50, n (%)	45 (83.3)	9 (16.7)		48 (90.6)	5 (9.4)	
≥51, n (%)	88 (92.6)	7 (7.4)		92 (96.8)	3 (3.2)	
Median (range)	56 (23-70)	48.5 (27-67)	*.04* [c]	55 (23-70)	47 (26-64)	.39
Sex, n (%)			.59			.05
Female	48 (87.3)	7 (12.7)		48 (88.9)	6 (11.4)	
Male	85 (90.4)	9 (9.6)		92 (97.9)	2 (2.1)	
Highest education level, n (%)			.18			.47
University degree	56 (84.8)	10 (15.2)		61 (92.4)	5 (7.6)	
No university degree[d]	77 (92.8)	6 (7.2)		79 (96.3)	3 (3.7)	
Personal history of melanoma, n (%)			.99			.99
Yes	9 (90.0)	1 (10.0)		10 (100.0)	0 (0.0	
No	124 (89.2)	15 (10.8)		130 (94.2)	8 (5.8)	
Family history of melanoma, n (%)			.12			.99
Yes	31 (81.6)	7 (18.4)		35 (94.6)	2 (5.4)	
No	102 (91.9)	9 (8.1)		105 (94.6)	6 (5.4)	
Skin color[e], n (%)			.99			.69
Fair	103 (88.8)	13 (11.2)		108 (93.9)	7 (6.1)	
Medium/olive	29 (90.6)	3 (9.4)		31 (96.9)	1 (3.1)	
BMI[e] (kg/m^2)			*.03*			.44
Healthy, n (%)	48 (82.8)	10 (17.2)		54 (93.1)	4 (6.9)	
Overweight/obese, n (%)	84 (94.4)	5 (5.6)		85 (96.6)	3 (3.4)	
Median (range)	26.2 (18.3-42.7)	23.4 (19.5-34.5)	.06	26.0 (18.3-42.7)	25.0 (21.1-34.9)	.78
Total nevus count >2 mm			.86			.34
0-19, n (%)	21 (95.5)	1 (4.5)		19 (90.5)	2 (9.5)	
20-49, n (%)	46 (85.2)	8 (14.8)		50 (92.6)	4 (7.4)	
≥50, n (%)	66 (90.4)	7 (9.6)		71 (97.3)	2 (2.7)	
Median (range)	49 (4-341)	43.5 (8-266)	.90	50 (4-332)	38.5 (17-341)	.60
Total naevus count >5 mm			.72			.63
0-4, n (%)	72 (91.1)	7 (8.9)		74 (93.7)	5 (6.3)	
5-10, n (%)	36 (87.8)	5 (12.2)		39 (97.5)	1 (2.5)	
≥20, n (%)	25 (86.2)	4 (13.8)		27 (93.1)	2 (6.9)	
Median (range)	4 (0-72)	6.5 (0-67)	.87	4 (0-36)	3.5 (2-72)	.59

[a]Completely trust and slightly trust were combined into a single category of trust, and unsure, slightly do not trust, or completely do not trust were combined into a single category of distrust.

[b]Very comfortable and comfortable were combined into a single category of comfort, and indifferent and slightly not comfortable were combined into a single category of discomfort.

[c]Italics indicate that the *P* value is significant at the .05 level.

[d]No university degree includes those who completed secondary school, certificate, diploma, trade, or apprenticeship.

[e]Data missing: 1 participant's skin type and BMI.

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Table 4. Qualitative feedback from participants on the advantages and disadvantages of total 3D total-body photography to monitor nevi.

	Participants (N=149), n (%)	Example
Advantages (themes)		
Comprehensive skin check and early detection	95 (63.8)	• "It covers every angle of the skin, comprehensive system, if anything is observed, it is sent to a specialist for review...can be followed up and acted on quickly." (male, 45 years old) • "Gives a clear picture of entire body." (male, 66 years old)
Improved monitoring (follow and record changes to skin over time; improved awareness and self-management)	88 (59.1)	• "Additional reassurance to have a thorough skin examination, kept on record, can be reviewed, can monitor changes over time." (male, 58 years old) • "Excellent way of tracking your moles, having a baseline for assessment." (male, 45 years old) • "Peace of mind, having a photographic record means you can track changes over time." (male, 61 years old)
Satisfaction, time efficiency, and improved health output	64 (43.0)	• "Fantastic, quicker to take photos, more detail from patient photos, overall great idea." (female, 56 years old) • "Time saving, maybe don't need a Doctor to check every single spot at time of appointment. Patient more likely to have skin checked if time efficient process, like VECTRA." (female, 37 years old)
Noninvasive procedure	16 (10.7)	• "Painless, not intrusive." (male, 53 years old) • "Simple process, non-invasive, comprehensive reference to look back on." (male, 58 years old)
Accuracy and artificial intelligence	33 (22.1)	• "Accuracy and precise - shows the whole body. Exciting new technology." (female, 64 years old) • "More preci[se], up to date technology, not just human only assessment of skin." (female, 52 years old)
Contribution to research (altruism)	23 (15.4)	• "To assist in research to benefit future generations." (female, 66 years old) • "Research towards future diagnosis of melanoma." (male, 52 years old)
No comments	5 (3.4)	• N/A[a]
Disadvantages (themes)		
Physical privacy (body image, self-conscious)	20 (13.4)	• "Undressing in front of strangers." (female, 38 years old) • "Looking at your body in 3D is confronting..." (female, 46 years old) • "Not everyone is comfortable taking [their] clothes off." (male, 32 years old)
Concerns about new technology (trust, ability to accurately detect suspicious lesions, digital security, and privacy)	30 (20.1)	• "[I] wouldn't trust 3D total-body photography without having a trained clinician present to look at [my] skin and/or review the images." (male, 45 years old) • "Do still need the naked eye. Doesn't take away the need for a human." (female, 34 years old) • "Should always be complimented by a doctor looking at the skin." (male, 65 years old) • "Human eye gives a more complete view of the whole body. Some areas are missed by VECTRA (scalp, soles of feet)." (male, 44 years old) • "Knowing there are all these identifiable photos of you stored." (female, 36 years old)
Travel (accessibility to machine)	14 (9.4)	• "Having to come into the hospital to do it. It is a big machine, so would not be able to have one in many locations." (female, 29 years old) • "One location at PA [Princess Alexandra Hospital], way to travel." (female, 48 years old) • "The time cost of travelling to the machine." (male, 66 years old)
Cost	10 (6.7)	• "If there was a cost associated with [3D body imaging], depending on the magnitude..." (male, 58 years old) • "Machine expensive." (male, 62 years old)

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	Participants (N=149), n (%)	Example
No disadvantages identified	75 (50.3)	• N/A

[a]N/A: not applicable.

Participant Satisfaction at the End of the Study

Table 5 reports participants' satisfaction with the 3D total-body photography processes, with 2 to 3 participants opting to not answer one or more of these questions. At the conclusion of the 36-month study, most participants (146/147, 99.3%) perceived 3D total-body photography to be a useful tool. The predominant belief was that this technology can improve the diagnosis and monitoring of skin lesions (147/148, 99.3%), with only 1 participant disagreeing. Only 2% (3/148) of participants would not recommend 3D total-body photograph to others. While most participants (130/148, 87.8%) had no preference for the gender of the photographer, no participant indicated preference for a male photographer. Following 3D total-body photography visits, most participants (115/146, 78.8%) wanted to discuss the images with a doctor, and 47.6% (70/147) wanted a copy of the images.

Table 5. Participant satisfaction with 3D total-body imaging at the 36-month time point (n=148).

Question	Participants, n (%)
It can improve diagnosis and monitoring of skin lesions	
Yes	147 (99.3)
No	1 (0.7)
It can be used for discovering new insights into skin well-being	
Yes	145 (98.0)
No	3 (2.0)
It feels like an intrusion on your privacy	
Yes	9 (6.1)
No	139 (93.9)
Would you rather be photographed by a...	
Man	0 (0.0)
Woman	18 (12.2)
No opinion	130 (87.8)
Would you recommend total 3D body photography to your friends and family?	
Yes	145 (98.0)
No	3 (2.0)
It is useful (n=147)	
Yes	146 (99.3)
No	1 (0.7)
It can improve teaching people about their skin conditions (n=147)	
Yes	143 (97.3)
No	4 (2.7)
Would you like to see the images at the end of the consultation (n=147)	
Yes	110 (74.8)
No	37 (25.2)
Would you like to have a copy of the images (n=147)	
Yes	70 (47.6)
No	77 (52.4)
Would you like to discuss the images with a doctor (n=146)	
Yes	115 (78.8)
No	31 (21.2)

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Discussion

Principal Findings

This study explored participants' experiences of 3D total-body photography. The majority of participants were comfortable and trusted the imaging process at both the 18- and 36-month time points. Results also showed almost all participants would pay a fee to use this service in the future and would recommend it to others. Furthermore, most participants thought it could improve diagnosis and monitoring of skin lesions. While high levels of satisfaction were reported, when asked to list barriers, half of the participants identified one or more including trust, privacy, cost, and travel requirements. The feedback collected in this study is important, as perceived usefulness and ease of use are essential constructs for the adoption of new technologies [13,15,16].

Developing and implementing a new medical device or technology requires insight into consumer preferences to ensure that the service is used. While 3D total-body photography is practiced in Australia, it is done so primarily in research settings and in an informal manner in practical settings. Total-body photography has been found to result in detection of a higher proportion of in situ melanomas and thin invasive melanomas compared to consults without total-body photography [17]. The exact localization of suspicious lesions is particularly useful in the clinical setting to enable accurate follow-up [17]. This study has the potential to assist with the translation and implementation of 3D total-body photography from the current informal provision into a formal service or screening program. Understanding the participant experience of 3D total-body photography allows researchers to identify which aspects are working (benefits) and which aspects are not working or suboptimal (barriers) in a research setting, and this information can help to identify areas for improvement in the clinical setting. Here, we found the benefits included a comprehensive record of the skin to allow improved monitoring, while the main barrier identified was trust, followed by privacy, cost, and travel requirements.

Issues surrounding trust are well known when researching new technological innovations in health care and have been previously reported in other studies assessing melanoma imaging [12,18,19]. Only 11% (n=16/149) of participants did not trust the imaging process at the end of the study. Two-thirds of these participants were those with a healthy BMI and younger than 50 years (Table 3). Previous research suggests that people may be less trusting and accepting of automation in health care settings compared to other aspects of life such as transport [20]. However, other research reported strong support for the use of automated diagnostic tools if clinicians continue to assess patients independently as well [20]. This emphasizes the value people assign to their doctor-patient relationships and suggests that clinicians will play a pivotal role in the acceptance of 3D total-body imaging as a part of routine practice. Clinicians have also cited barriers to using total-body photography including the belief that it may lead to more biopsies or greater patient anxiety, as well as logistical constraints such as lack of time,

availability, training, and associated costs [21]. We foresee that the introduction of AI into dermatology will present further challenges for trust of telemedicine services in both consumers and clinicians. In this study, the AI algorithms only provided the clinicians with a count of skin lesions and sorted them by size, color, and border irregularity. In the future, AI may assist clinicians in deciding what type of skin lesions are present, with some studies suggesting that AI can perform similarly to dermatologists, but further validation in practice is required [22-24]. Future studies are warranted to examine trust with health care technologies using AI.

We found that the majority of the participants were satisfied with this technology, and there were some differences in satisfaction based on gender, age, and BMI. The factors identified may help to create a profile of patients who would require attention to ensure adequate uptake of the technology. We found males were more likely to be comfortable with the imaging process than their female counterparts. Some females reported in the qualitative comments that undressing in front of strangers and looking at their body in the images could be confronting. In addition, after further analysis of the 18 participants who would prefer to be photographed by a woman, 16 were female (data not shown). Overall, we found participants in this study showed high engagement by wanting to discuss the images with their doctor, and this could be used as a potential learning opportunity in the future for clinicians to show their patients what changes to look for to further support monitoring and early detection efforts.

Strengths and Limitations

This prospective cohort study recruited participants from a population-based registry and achieved a good number of participants who completed both the 18- and 36-month time point questionnaires to provide feedback on 3D total-body photography (149/193, 77.2%), providing a rich data set of their attitudes and changes over time.

The limitations include that the data were self-reported and subject to potential biases (eg, recall bias and socially desirable responses). This study involved participants having regular skin checks, and therefore, the volunteer sample might be more motivated and accepting of this technology. Just under half the participants in the study had a high level of education.

Participants were first asked about their experiences of 3D total-body photography at the fourth photography session after using the technology several times. Asking participants about their views prior to use at baseline would have allowed greater insights into how participant views changed over time.

Conclusion

Participants from the general population supported the use of 3D total-body photography for the monitoring of their nevi; albeit, half had some concerns regarding the technology. Consultation with participants and understanding their experience using the new technology will be important for the future translation of 3D total-body photography into standard dermatological care.

Acknowledgments

Authors' Contributions

MJ, HPS, JFA, RAS, and TP contributed to the conception of the study and trial design. MJ, HPS, MO'H, and CH collected data. CH, MO'H, and SM drafted the manuscript. CH, DJ, and SS conducted the quantitative statistical analysis. SS and MO'H conducted the qualitative analysis. All authors reviewed, edited, and approved the final version.

Conflicts of Interest

HPS is a shareholder of MoleMap NZ Limited and e-derm consult GmbH, and undertakes regular teledermatological reporting for both companies. HPS is a medical consultant for Canfield Scientific Inc, MoleMap Australia Pty Ltd, Blaze Bioscience Inc, and Revenio Research Oy, and a medical advisor for First Derm.

Multimedia Appendix 1
The 3D total-body imaging questionnaire.
[PDF File (Adobe PDF File), 70 KB - derma_v5i2e37034_app1.pdf]

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Abbreviations

AI: artificial intelligence
NHMRC: National Health and Medical Research Council

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<u>Original Paper</u>

Using Implementation Science to Understand Teledermatology Implementation Early in the COVID-19 Pandemic: Cross-sectional Study

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Abstract

Background: Implementation science has been recognized for its potential to improve the integration of evidence-based practices into routine dermatologic care. The COVID-19 pandemic has resulted in rapid teledermatology implementation worldwide. Although several studies have highlighted patient and care provider satisfaction with teledermatology during the COVID-19 pandemic, less is known about the implementation process.

Objective: Our goal was to use validated tools from implementation science to develop a deeper understanding of the implementation of teledermatology during the COVID-19 pandemic. Our primary aims were to describe (1) the acceptability and feasibility of the implementation of teledermatology and (2) organizational readiness for the implementation of teledermatology during the COVID-19 pandemic. We also sought to offer an example of how implementation science can be used in dermatologic research.

Methods: An anonymous, web-based survey was distributed to Association of Professors of Dermatology members. It focused on (1) the acceptability, feasibility, and appropriateness of teledermatology and (2) organizational readiness for implementing teledermatology. It incorporated subscales from the Organizational Readiness to Change Assessment—a validated measure of organizational characteristics that predict implementation success.

Results: Of the 518 dermatologists emailed, 35 (7%) responded, and all implemented or scaled up teledermatology during the pandemic. Of the 11 care providers with the highest level of organizational readiness, 11 (100%) said that they plan to continue using teledermatology after the pandemic. Most respondents agreed or strongly agreed that they had sufficient training (24/35, 69%), financial resources (20/35, 57%), and facilities (20/35, 57%). However, of the 35 respondents, only 15 (43%) agreed or strongly agreed that they had adequate staffing support. Most respondents considered the most acceptable teledermatology modality to be synchronous audio and video visits with supplemental stored digital photos (23/35, 66%) and considered the least acceptable modality to be telephone visits without stored digital photos (6/35, 17%). Overall, most respondents thought that the implementation of synchronous audio and video with stored digital photos (31/35, 89%) and telephone visits with stored digital photos (31/35, 89%) were the most feasible. When asked about types of visits that were acceptable for synchronous video/audio visits (with stored digital photos), 18 of the 31 respondents (58%) said "new patients," 27 (87%) said "existing patients," 19 (61%) said "medication monitoring," 3 (10%) said "total body skin exams," and 22 (71%) said "lesions of concern."

Conclusions: This study serves as an introduction to how implementation science research methods can be used to understand the implementation of novel technologies in dermatology. Our work builds upon prior studies by further characterizing the

acceptability and feasibility of different teledermatology modalities. Our study may suggest initial insights on how dermatology practices and health care systems can support dermatologists in successfully incorporating teledermatology after the pandemic.

Introduction

When the COVID-19 pandemic began in the spring of 2020, restrictions were placed on in-person visits. This crisis led to the rapid increase in teledermatology implementation, which was made possible by policy changes that overcame prior barriers to implementation, such as the lack of insurance reimbursement, liability concerns, and licensing restrictions [1,2]. A recent review highlighted teledermatology's potential to reduce health care disparities in underserved and marginalized communities, calling for future efforts to study implementation, as teledermatology has expanded greatly during the pandemic [3]. Although much of the published work on teledermatology during the COVID-19 pandemic focused on satisfaction among patients and care providers, less is known about its actual implementation during the early months of the pandemic [4,5]. The field of implementation science has been recognized for its potential to improve the integration of evidence-based practices into routine dermatologic care [6].

In order for teledermatology to be successfully incorporated into routine dermatologic practice, there must be buy-in from dermatology patients, dermatologists, and health systems. Our study adds to the growing body of evidence for teledermatology by using validated implementation science tools to develop a deeper understanding of the implementation of teledermatology during the COVID-19 pandemic.

Implementation science uses specific terminology to describe key predictors of and outcomes for the implementation of evidence-based interventions. Implementation outcomes refer to "the effects of deliberate and purposive actions to implement new treatments, practices, and services," and they "[serve] as an indicator of implementation success" [7]. In this study, we focused on evaluating the *acceptability* and *feasibility* of teledermatology, which are defined, respectively, as follows: (1) "the perception among implementation stakeholders that a given treatment, service, practice, or innovation is agreeable, palatable, or satisfactory" and (2) "the extent to which a new treatment, or innovation, can be successfully used or carried out within a given agency or setting" [7]. We also evaluated *organizational readiness* for change, which is defined as "the extent to which organizational members are psychologically and behaviourally prepared to implement organizational change" [8].

We use the lens of implementation science to describe teledermatology implementation. The objective of our study was to understand the acceptability and feasibility of the implementation of teledermatology during the COVID-19 pandemic, as well as organizational readiness for the implementation of teledermatology. We also sought to offer an example of how implementation science can be used in dermatologic research.

Methods

Ethical Considerations

Our study was deemed exempt from ethics approval by the University of Washington Human Subjects Division and the University of Washington Institutional Review Board (IRB ID: STUDY00010266).

Study Design

We conducted a cross-sectional study of dermatologists' perceptions of teledermatology implementation during the COVID-19 pandemic. We surveyed members of the Association of Professors of Dermatology (APD) between November 20 and December 9, 2020 (Multimedia Appendix 1). An initial email was sent on November 20, and it was resent on December 2 to try to increase the response rate. The survey focused on (1) the acceptability, feasibility, and appropriateness of teledermatology and (2) organizational readiness for implementing teledermatology. We used an abbreviated, single-item version of a validated scale [9] to assess the acceptability of different teledermatology modalities (eg, synchronous audio and video and stored digital photos). Using the same scale, we assessed the acceptability of teledermatology for different dermatologic conditions and purposes (eg, lesions of concern and medication monitoring). We also incorporated selected subscales from the validated Organizational Readiness to Change Assessment (ORCA) instrument (eg, culture and resources). There were 26 ORCA questions, which were scored on a 5-point Likert scale ranging from "Strongly Disagree" to "Strongly Agree." The possible ORCA scores ranged from 26 to 130, with higher scores indicating higher organizational readiness for change. The entire survey was tested for face validity and readability through pilots with dermatologists. It was iteratively refined based on their feedback. The survey was administered via email, and responses were collected anonymously. ORCA scores were reported as unweighed composite scores, and participants were stratified by ORCA score tertiles—"low," "medium," and "high" organizational readiness for change (Table 1). We did not perform statistical hypothesis testing, in accordance with best practices [10].

Table 1. Demographics and outcomes by Organizational Readiness to Change Assessment (ORCA) tertiles.

	ORCA score tertiles			Total (N=35)
	Low (n=11)	Medium (n=13)	High (n=11)	
Sex, n (%)				
Male	2 (18)	6 (47)	5 (46)	13 (37)
Female	9 (82)	7 (54)	6 (55)	22 (63)
Race, n (%)				
American Indian or Alaska Native	1 (9)	0 (0)	0 (0)	1 (3)
Asian	1 (9)	2 (15)	2 (18)	5 (14)
Black or African American	1 (9)	0 (0)	0 (0)	1 (3)
Hispanic, Latinx, or Spanish origin	1 (9)	2 (15)	1 (9)	4 (11)
White	7 (64)	9 (69)	8 (73)	24 (69)
Practice, n (%)				
Dermatology group practice	0 (0)	0 (0)	2 (18)	2 (6)
Multispecialty group practice	1 (9)	0 (0)	0 (0)	1 (3)
Academic practice	9 (82)	12 (92)	9 (82)	30 (86)
Veterans administration and academic practice	1 (9)	1 (8)	0 (0)	2 (6)
Number of years in practice				
Years, mean (SD)	3.91 (1.97)	3.69 (1.75)	3.82 (1.78)	3.80 (1.78)
Years, median (quartile 1, quartile 3)	4.00 (2.50, 6.00)	3.00 (2.00, 6.00)	4.00 (3.00, 5.00)	4.00 (2.00, 6.00)
Total ORCA score				
Score, mean (SD)	70.0 (9.58)	90.4 (5.36)	110.7 (8.75)	90.4 (18.1)
Score, median (quartile 1, quartile 3)	68.00 (66.0, 78.0)	91.0 (88.0, 96.0)	110.0 (104.0, 113.5)	91.0 (78.5, 102.5)
Stored digital photos alone are acceptable, n (%)				
Completely agree or agree	7 (64)	5 (39)	6 (55)	18 (51)
Completely disagree, disagree, or neither agree nor disagree	4 (36)	8 (62)	5 (46)	17 (49)
Telephone visits without photos are acceptable, n (%)				
Completely agree or agree	2 (18)	1 (8)	3 (27)	6 (17)
Completely disagree, disagree, or neither agree nor disagree	9 (82)	12 (92)	8 (73)	29 (83)
Telephone visits with photos are acceptable, n (%)				
Completely agree or agree	7 (64)	7 (54)	6 (55)	20 (57)
Completely disagree, disagree, or neither agree nor disagree	4 (36)	6 (46)	5 (46)	15 (43)
Synchronous audio and video visits without photos are acceptable, n (%)				
Completely agree or agree	3 (27)	4 (31)	5 (46)	12 (34)
Completely disagree, disagree, or neither agree nor disagree	8 (73)	9 (69)	6 (55)	23 (66)
Synchronous audio and video visits with photos are acceptable, n (%)				
Completely agree or agree	4 (36)	11 (85)	8 (73)	23 (66)
Completely disagree, disagree, or neither agree nor disagree	7 (64)	2 (15)	3 (27)	12 (34)
Plan to use telemedicine after the pandemic, n (%)				
Yes	10 (91)	12 (92)	11 (100)	33 (94)
No	1 (9)	1 (8)	0 (0)	2 (6)

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Results

Of the 518 dermatologists on the APD email listserv, 35 (7%) responded, and all implemented or scaled up teledermatology during the pandemic. Of the 35 respondents, 35 (100%) said that the peak use of teledermatology occurred between the months of April and September 2020. Thus, all respondents had completed the initial implementation by the time of survey distribution in December 2020. Further, 94% (33/35) plan to continue using teledermatology after the pandemic. The benefits of teledermatology included less travel time and expense for patients (n=35, 100%), continued patient care (n=33, 94%), the ability to avoid the risk of infection (n=35, 100%), and work flexibility (n=27, 77%). Respondents also experienced challenges with teledermatology, including technology issues (n=22, 63%) and challenges with caring for older adults (n=18, 51%). All 11 care providers with "high" ORCA scores said that they plan to continue using teledermatology after the pandemic (Table 1). With regard to organizational readiness for the implementation of teledermatology during the pandemic, 24 of the 35 care providers (69%) agreed or strongly agreed that they had sufficient training, 20 (57%) had sufficient financial resources, and 20 (57%) had sufficient facilities. Most respondents had care provider buy-in (25/35, 71%) and felt that teledermatology implementation took into consideration the needs and preferences of patients (27/35, 77%). On the other hand, fewer respondents had a dedicated team for implementing the intervention (14/34, 41%), had sufficient staffing support (15/35, 43%), or had successfully piloted telemedicine prior to the pandemic (13/35, 37%). Most of the 35 respondents reported using several implementation strategies, which included a dedicated clinical champion (n=26, 74%); feedback to clinicians (n=20, 59%); education (n=24, 69%); and, less commonly, staff incentives (n=4, 11%). Table S1 in Multimedia Appendix 2 shows these supplemental results. Of the 11 respondents with "low" ORCA scores, 6 (55%) agreed or strongly agreed with the ORCA components about having a clinical champion, 5 (45%) agreed or strongly agreed with giving feedback to clinicians, 2 (18%) agreed or strongly agreed with education, and 0 (0%) agreed or strongly agreed with staff incentives. Of the 11 participants with "high" ORCA scores, 11 (100%) agreed or strongly agreed with having a clinical champion, 9 (82%) agreed or strongly agreed with giving feedback to clinicians, 10 (91%) agreed or strongly agreed with education, and 4 (36%) agreed or strongly agreed with staff incentives (Table S2 in Multimedia Appendix 2).

The most acceptable teledermatology modality was synchronous audio and video visits with stored digital photos (23/35, 66%). The least acceptable modality was telephone visits without stored digital photos (6/35, 17%). When comparing participants with "low" ORCA scores to those with "medium" and "high" ORCA scores, synchronous audio and video visits with stored digital photos were less acceptable among those with "low" ORCA scores (4/11, 36%) relative to those with "medium" (11/13, 85%) and "high" (8/11, 73%) ORCA scores. However, the acceptability of consultations involving stored digital photos was higher among those with "low" ORCA scores (7/11, 64%) relative to those with "medium" (5/13, 39%) and "high" (6/11,

55%) ORCA scores. Along with acceptability (Table 1), feasibility was also addressed. Overall, among the 35 respondents, synchronous audio and video visits with stored digital photos (n=31, 89%) and telephone visits with stored digital photos (n=31, 89%) were deemed the most feasible teledermatology modalities. Other modalities were also deemed feasible, though less so, including consultations involving stored digital photos (n=26, 74%), synchronous audio and video visits without stored digital photos (n=23, 66%), and telephone visits without stored digital photos (n=21, 60%). When asked about types of visits that were acceptable for synchronous video/audio visits (with stored digital photos), 18 of the 31 respondents (58%) said "new patients," 27 (87%) said "existing patients," 19 (61%) said "medication monitoring," 3 (10%) said "total body skin exams," and 22 (71%) said "lesions of concern. The majority of surveyed dermatologists felt that synchronous video/audio (without stored digital photos was acceptable for "existing patients" (29/32, 91%) and "medication monitoring" (29/32, 91%). Fewer respondents felt that synchronous video/audio (without stored digital photos) was acceptable for "new patients" (12/32, 38%), and very few felt that teledermatology was acceptable for "lesions of concern" (5/32, 16%) and "total body skin exams" (2/32, 6%).. Additional detailed results are shown in Table 1.

Discussion

Principal Results

In our study, although most dermatologists (33/35, 94%) planned to continue using teledermatology after the pandemic, there was some indication that they lacked support in certain areas (eg, staffing and facilities) during implementation early in the COVID-19 pandemic. Additionally, not all teledermatology modalities were equally acceptable or feasible. Among respondents, telephone and synchronous audio and video visits were the least acceptable and feasible modalities, whereas modalities that combined stored digital photos with telephone visits or synchronous audio and video visits were the most acceptable and feasible modalities.

Teledermatology has been a part of dermatologic care for over 25 years [11]. Although consultations involving stored digital photos (store and forward) have historically been the dominant teledermatology modality in clinical practice [12], the COVID-19 pandemic has resulted in the rapid implementation of synchronous audio and video teledermatology [13].

Although the majority of dermatologists (33/35, 94%) in this study planned to continue using teledermatology after the pandemic, there is likely some variability in intentions to continue using teledermatology, depending on the population surveyed and timing. An earlier survey by the American Academy of Dermatology in May 2020, which included a larger proportion of private practice dermatologists, found that just over half (58%) of dermatologists planned to continue using teledermatology after the pandemic [13]. Despite the differences, both surveys highlight the importance of teledermatology in the future, with over 50% of dermatologists intending to practice teledermatology.

Overall, respondents supported the use of teledermatology after the pandemic; however, we found that both telephone visits and synchronous audio and video visits without stored digital photos were the two least acceptable and feasible modalities. This finding aligns with patients' experiences with teledermatology. Despite high levels of patient satisfaction and willingness to continue using teledermatology after the pandemic [4,5], satisfaction with dermatology telephone visits is lower, and fewer dermatology patients are willing to use telephone visits for future dermatologic care [14]. Taken as a whole, our findings build on a growing body of evidence that certain modalities, particularly telephone visits, are less acceptable to both patients and care providers. Dermatologists rely upon the clear and accurate visualization of the skin, which telephone and synchronous video/audio visits alone may not offer.

Incorporating stored digital photos may overcome some of the limitations of using synchronous audio and video visits and telephone visits in isolation. Acceptability was higher for including stored digital photos with synchronous audio and video visits or telephone visits when compared to that for visits without stored digital photos and consultations involving stored digital photos alone. Prior studies that were conducted during the COVID-19 pandemic showed that care providers were split between preferring synchronous (54%) and asynchronous (46%) modalities but did not assess the combination of asynchronous and synchronous approaches [15]. Dermatologists may be able to maximize the benefits of synchronous modalities (synchronous audio and video visits and telephone visits) and asynchronous modalities (stored digital photos) by combining them to create a more acceptable and preferable teledermatology experience.

We also found that there may be variability in the acceptability of teledermatology based on the type of dermatologic condition and visit. The majority of surveyed dermatologists felt that synchronous video/audio (without stored digital photos) was acceptable for "existing patients" (29/32, 91%) and "medication monitoring" (29/32, 91%). Fewer respondents felt that synchronous video/audio (without stored digital photos) was acceptable for "new patients" (12/32, 38%), and very few felt that teledermatology was acceptable for "lesions of concern" (5/32, 16%) and "total body skin exams" (2/32, 6%). The American Academy of Dermatology's survey found a similarly low number of dermatologists who were comfortable with performing total body skin exams via teledermatology, with 96% believing that this requires an in-person examination [13]. This work adds to our understanding of the types of patient concerns for which teledermatology is the most acceptable. We hope that teledermatology guidelines for best practices can evolve via this growing collection of work.

When implementing novel health care technologies (including teledermatology technologies), organizational factors, such as organizational readiness for change, are important determinants of implementation success [16]. We found that although support for teledermatology implementation was high in most areas (eg, training and care provider buy-in), dermatologists lacked organizational support in other areas, such as staffing support and facilities. In addition, we found that respondents with a "low" organizational readiness for change tended to find synchronous audio and video visits less acceptable when compared to respondents with "medium" and "high" ORCA scores. It is plausible that in dermatology practices with a lower organizational readiness for change, limited support for newly implementing synchronous audio and video teledermatology [13] resulted in negative experiences during the COVID-19 pandemic. This hints at the potential importance of organizational readiness in determining the success of teledermatology implementation. Although specific implementation process details were outside the scope of this work, lower scores for important implementation strategies, including having a clinical champion, giving feedback to clinicians, and providing education, contributed to respondents having "low" scores for organizational readiness for change, and this may provide clues as to the specific implementation strategies that are important for the successful implementation of synchronous audio and video teledermatology early in the COVID-19 pandemic. Future research will be needed to explore the roles of specific implementation strategies, implementation processes, and costs in determining the success of newly implemented teledermatology programs.

We acknowledge that this cross-sectional survey has significant limitations, given its modest sample size and response rate. Therefore, we cannot draw definitive conclusions on the associations between organizational readiness for change and teledermatology implementation outcomes. Still, our total of 35 respondents and response rate of 7% (35/518) are similar to those of other nonincentivized physician surveys [13]. For these reasons, the findings of this survey may not be generalizable. As the survey was distributed to the APD, the majority of respondents (32/35) practiced in academic dermatology settings. Thus, respondents with an interest in teledermatology may have been overrepresented. Additionally, respondents were mostly White (24/35, 69%); as such, the opinions of dermatologists from all backgrounds were not captured. Despite these limitations, this work provides valuable descriptive insights into the role of implementation science in understanding teledermatology implementation during the COVID-19 pandemic.

Conclusions

This study serves as an introduction to how implementation science research methods can be used to understand the implementation of novel technologies in dermatology. Our work builds on prior work by further characterizing the acceptability and feasibility of different teledermatology modalities. Our study also contributes initial insights on how dermatology practices and health care systems can support dermatologists in successfully incorporating teledermatology after the pandemic. Finally, this work highlights newer methods for identifying organizational factors that can be optimized to improve future teledermatology implementation efforts.

Acknowledgments

Conflicts of Interest

None declared.

Multimedia Appendix 1
Survey instrument and recruitment letter/email.
[DOCX File , 5610 KB - derma_v5i2e33833_app1.docx]

Multimedia Appendix 2
Supplemental results.
[DOCX File , 32 KB - derma_v5i2e33833_app2.docx]

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Abbreviations

APD: Association of Professors of Dermatology
ORCA: Organizational Readiness to Change Assessment

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Original Paper

Prevalence and Age-Related Patterns in Health Information–Seeking Behaviors and Technology Use Among Skin Cancer Survivors: Survey Study

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Abstract

Background: Information is an unmet need among cancer survivors. There is a paucity of population-based data examining the health information–seeking behaviors and attitudes of skin cancer survivors.

Objective: We aimed to identify the prevalence and patterns of health information–seeking behaviors and attitudes among skin cancer survivors across age groups.

Methods: We analyzed population-based data from the 2019 Health Information National Trends Survey 5 (Cycle 3).

Results: The 5438 respondents included 346 (6.4%) skin cancer survivors (mean age 65.8 years); of the 346 skin cancer survivors, the majority were White (96.4% [weighted percentages]), and 171 (47.8%) were men. Most reported having ever looked for health- (86.1%) or cancer-related (76.5%) information; 28.2% stated their last search took a lot of effort, and 21.6% were frustrated. The internet was most often cited as being the first source that was recently used for health or medical information (45.6%). Compared to skin cancer survivors younger than 65 years old, those 65 years of age or older were more likely to see a doctor first for important health information (≥65 years: 68.3%; <65 years: 36.2%; $P<.001$) and less likely to have health and wellness apps (≥65 years: 26.4%; <65 years: 54.0%, $P=.10$), to have watched a health-related YouTube video (≥65 years: 13.3%; <65 years: 27.4%; $P=.02$), and to have used electronic means to look for information (≥65 years: 61.4%; <65 years: 82.3%, $P<.001$)

Conclusions: Searches for health information are common among skin cancer survivors, but behaviors and attitudes are associated with age, which highlights the importance of access to doctors and personalized information sources.

Introduction

Information is an unmet need that is frequently reported by skin cancer survivors and patients [1-9]. An improved understanding of the etiology and risk factors of a disease and its prevention strategies could facilitate coping mechanisms and improve health care outcomes [10-12]. Most [13], but not all [14], individuals desire as much information as possible about their

disease and treatment [3]. A population-based survey [15] in 2003 found that approximately two-thirds of all cancer survivors sought cancer information and the predictors of information-seeking behaviors were younger age, female gender, higher income, and having a regular health care provider.

Few studies have examined information-seeking behaviors, attitudes, and preferences in skin cancer survivors. Survey studies of patients and survivors melanoma have found that

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many individuals desired more information about their diagnosis, prognosis, or treatment options [4-6,9], expressed high levels of dissatisfaction with the information they received [5,6], and used the internet as a supplementary information resource to their physician [3,6,16]. Internet use and smartphone ownership are strongly associated with age [17,18], however, and melanoma websites have been reported to have poor readability and variable quality [16,19-23]. Patients and survivors of keratinocyte carcinoma who reported dissatisfaction with the information provided have been found to exhibit lower levels of health-related quality of life, increased worry [7], and increased skin cancer–specific and general distress [24,25]. Despite the differences in prognosis between keratinocyte carcinoma and melanoma, the needs, concerns, and levels of distress about diagnosis and need for follow-up appear to be similar in these individuals [8]. There has been recent interest in the development of smartphone and other mobile apps to provide information and education about skin cancer etiology and risk factors, ultraviolet radiation exposure advice, and skin self-examination, as well as tools for analysis or monitoring and tracking of skin lesions [26]. However, the overwhelming majority (99%) of survivors of melanoma have reported never having used a skin cancer–related app [27].

The purpose of this study was to describe and identify age-related factors associated with (1) health information–seeking behaviors and attitudes and (2) use and ownership of technology among a nationally representative sample of skin cancer survivors in the United States. The resultant data would be expected to aid the design of interventions to improve health care outcomes in this patient population.

Methods

Ethics

The study was exempt from institutional review board review under US federal regulation [28] because the data were publicly available.

Study Population, Design, and Setting

Data for this study were obtained from the 2019 Health Information National Trends Survey (HINTS) 5, Cycle 3 [29], which is a nationally representative survey of civilian, noninstitutionalized US adults 18 years or older that was administered by the National Cancer Institute. A detailed description of survey methodology has been published [29]. The sample frame was a random sample of nonvacant residential addresses in the Marketing Systems Group database and was grouped into strata having high or low concentrations of minority populations using census tract–level characteristics from the 2013-2017 American Community Survey data file. An equal-probability sample of addresses was selected from each sampling stratum but oversampling of the high-minority stratum was performed. The total number of addresses selected was 23,430; of these, 6690 (28.6%) were from low minority areas and 16,740 (71.4%) were from high-minority areas. One adult per sampled household was selected to participate in the survey using the next birthday method; a US $2 prepaid

monetary incentive was used to encourage participation. The address sample was divided into 3 subsamples: traditional data collection sample using paper-mail survey (n=14,730), web option, offering respondents a choice between responding via paper (English or Spanish) or web (in English only) (n=4350), and web bonus, offering respondents a choice between responding via paper (English or Spanish) or web (in English only), with an additional US $10 incentive for those responding via web (n=4350). The overall response rate for the 23,430 samples was 30.3% (paper-mail 30.2%, web option 29.6%, web bonus 31.5%) [29].

Study Variables and Statistical Analysis

Descriptive statistics and graphical methods were used to assess the distributions of study variables. The analytic goal was to assess the prevalence and relationships between respondent age and survey responses related to health information–seeking behaviors, attitudes toward health information–seeking, and ownership and use of technology (Multimedia Appendix 1). Respondent age was dichotomized (<65 years or ≥65 years). This age cut-off corresponds to the median age at diagnosis of melanoma [30] and the age for Medicare eligibility [31] in the United States. In addition to these primary independent variables, we also assessed the associations between respondent age and demographic variables, which included sex (male or female), highest grade or level of schooling completed (less than high school, high school, some college, or college), health care coverage (yes or no), respondent race (White, Black, multiple races), total household income (<$50,000 or ≥$50,000), and ability to speak English (very well, well, and not well).

Since the HINTS study has a complex survey design, we utilized jackknife replication weights to adjust standard error estimates. Chi-square statistics along with the weighted relative proportions were used to assess bivariate associations between age and demographic and health information–seeking survey responses. Logistic regression was used to examine the association between respondent age and health information–seeking variables while controlling for respondent demographic characteristics. As there were several modes of survey administration, we evaluated the distribution of demographic characteristics and selected survey responses by mode. Differences in the distribution of these variables by survey mode were assessed by linear regression and chi-square analysis using jackknife estimates (Table S1 in Multimedia Appendix 1). Data management and analysis were completed using StataMP software (version 16.1; StataCorp LLC). Analyses were conducted from March 2020 through January 2021.

Results

The 5438 HINTS respondents included 346 (6.4%) with self-reported history of any skin cancer (melanoma: n=59; nonmelanoma skin cancer: n=258; both melanoma and nonmelanoma skin cancer: n=29), with a mean age of 65.8 years. Of the 346 respondents with a history of skin cancer, the majority were White (96.4% [weighted percentages]), and 171 were men (47.8%) (Table 1; Table S2 in Multimedia Appendix 1).

Table 1. Demographic characteristics of skin cancer respondents stratified by age (<65 years vs ≥65 years).

Variable	Respondents, n (weighted %)	Respondents by age		P value
		<65 years, n (weighted %)	≥65 years, n (weighted %)	
Sex				.14
Missing	23 (5.1)	7 (3.5)	16 (6.4)	
Male	171 (47.8)	43 (40.4)	128 (53.5)	
Female	152 (47.0)	63 (56.1)	89 (40.1)	
Education				.08
Missing	2 (0.1)	0 (0)	2 (0.2)	
Less than high school	9 (3.2)	1 (0.5)	8 (5.3)	
High school	51 (22.1)	11 (16.1)	40 (26.6)	
Some college	102 (39.8)	29 (41.0)	73 (38.9)	
College	182 (34.8)	72 (42.5)	110 (28.9)	
Health insurance				.21
Missing	4 (1.3)	0 (0)	4 (2.3)	
Yes	339 (97.7)	112 (99.7)	227 (96.1)	
No	3 (1.0)	1 (0.3)	2 (1.5)	
Race				.003
Missing	14 (3.1)	2 (0.7)	12 (5.0)	
White	326 (96.4)	107 (98.4)	219 (94.9)	
Black	1 (0)	1 (0.1)	0 (0)	
Multiple	5 (0.4)	3 (0.9)	2 (0.1)	
Income				.23
Missing	34 (10.9)	6 (7.6)	28 (13.4)	
<$50,000	141 (45.2)	41 (41.1)	100 (48.4)	
≥$50,000	171 (43.9)	66 (51.4)	105 (38.2)	
Speaks English				.02
Missing	2 (0.5)	1 (0.6)	1 (0.4)	
Very well	318 (92.7)	109 (96.9)	209 (89.5)	
Well	21 (5.7)	1 (1.1)	20 (9.3)	
Not well	5 (1.1)	2 (1.5)	3 (0.7)	

Health Information–Seeking Behaviors

Overall, 86.1% of skin cancer survivors reported having ever looked for information about health or medical topics from any source and 76.5% reported having ever looked for information about cancer from any source (Table 2; Table S3 in Multimedia Appendix 1). During the most recent search for health or medical information, 55.3% reported looking for information for themselves, 11.9% reported looking for information for someone else, and 17.7% reported looking for information for both themselves and someone else. Respondents reported that the internet was the most recent source of health information (45.6%), followed by a doctor or health care provider (20.9%) or other sources (9.5%); 21.6% of respondents felt frustrated in their search for information, and 28.2% of respondents felt it took a lot of effort to get the information they needed.

Compared to survivors aged 65 years and older, survivors <65 years old were more likely to use the internet as their first source of information during their most recent search for information about health or medical topics (<65 years: 59.2%; ≥65 years: 35.2%; P=.047) and to have ever looked for information about cancer (<65 years: 86.0%; ≥65 years: 69.2%; P=.02). In the model adjusted for sex, income, and English-speaking ability, having ever looked for information about cancer was not associated with being 65 years and older (odds ratio [OR] 1.14, 95% CI 0.81-1.61; P=.44) and using the internet as the first source of information about health or medical topics was not associated with being 65 years and older (OR 0.40, 95% CI 0.08-2.08; P=.27) (Table 3). No other relationships between general health information–seeking behavior and age were identified.

Table 2. Distribution of health seeking behaviors by skin cancer respondents stratified by age (<65 years vs ≥65 years).

Variable	Respondents (n=346)	Respondents by age		P value
	n (weighted %)	<65 years (n=113), n (weighted %)	≥65 years (n=233), n (weighted %)	
Health information–seeking behaviors				
Have you ever looked for information about health or medical topics from any source?				.10
Missing	7 (1.5)	2 (1.0)	5 (1.8)	
Yes	304 (86.1)	103 (91.9)	201 (81.7)	
No	35 (12.4)	8 (7.1)	27 (16.5)	
Have you ever looked for information about cancer from any source?				.02
Missing	6 (1.6)	2 (1.9)	4 (1.4)	
Yes	262 (76.5)	93 (86.0)	169 (69.2)	
No	78 (21.9)	18 (12.1)	60 (29.4)	
The most recent time you looked for information about health or medical topics, who was it for?				.84
Missing	45 (15.1)	12 (10.2)	33 (19.0)	
Myself	187 (55.3)	60 (60.1)	127 (51.5)	
Someone else	47 (11.9)	16 (12.5)	31 (11.5)	
Both myself and someone else	67 (17.7)	25 (17.3)	42 (18.0)	
The most recent time you looked for information about health or medical topics, where did you go first?				.047
Missing	77 (24.0)	23 (18.6)	54 (28.1)	
Doctor	71 (20.9)	13 (14.7)	58 (25.5)	
Internet	168 (45.6)	69 (59.2)	99 (35.2)	
Other	30 (9.5)	8 (7.5)	22 (11.1)	
You felt frustrated during your search for the information.				.88
Missing	62 (18.6)	13 (10.3)	49 (24.9)	
Strongly agree	25 (6.6)	9 (5.7)	16 (7.3)	
Somewhat agree	59 (15.0)	20 (16.5)	39 (13.9)	
Somewhat disagree	76 (20.7)	26 (22.6)	50 (19.3)	
Strongly disagree	124 (39.1)	45 (45.0)	79 (34.6)	
It took a lot of effort to get the information you needed.				.21
Missing	47 (15.6)	12 (10.2)	35 (19.7)	
Strongly agree	30 (7.7)	11 (6.7)	19 (8.6)	
Somewhat agree	82 (20.5)	19 (17.1)	63 (23.1)	
Somewhat disagree	87 (23.4)	29 (22.6)	58 (24.0)	
Strongly disagree	100 (32.8)	42 (43.5)	58 (24.7)	
Attitudes toward health information–seeking				
Imagine that you had a strong need to get information about health or medical topics. Where would you go first?				<.001
Missing	17 (5.1)	7 (6.0)	10 (4.4)	
Doctor or health care	179 (54.4)	39 (36.2)	140 (68.3)	
Internet	128 (36.9)	60 (55.3)	68 (22.9)	
Other	22 (3.7)	7 (2.6)	15 (4.5)	
Overall, how confident are you that you could get advice or information about health or medical topics if you needed it?				.80

Variable	Respondents (n=346)	Respondents by age		P value
	n (weighted %)	<65 years (n=113), n (weighted %)	≥65 years (n=233), n (weighted %)	
Missing	10 (2.3)	3 (1.1)	7 (3.2)	
Completely confident	90 (29.4)	32 (28.4)	58 (30.2)	
Very confident	133 (37.4)	41 (39.0)	92 (36.2)	
Somewhat confident	94 (26.6)	28 (25.5)	66 (27.4)	
A little confident	10 (3.0)	6 (4.61)	4 (1.7)	
Not confident at all	9 (1.4)	3 (1.4)	6 (1.3)	
In general, how much would you trust information about health or medical topics from each of the following?				
A doctor				.52
Missing	7 (1.4)	2 (1.0)	5 (1.8)	
A lot	261 (79.3)	84 (81.8)	177 (77.4)	
Some-Not at all	78 (19.2)	27 (17.3)	51 (20.8)	
Family or friends				.82
Missing	17 (5.1)	3 (2.3)	14 (7.3)	
A lot	20 (6.8)	9 (7.5)	11 (6.3)	
Some-Not at all	309 (88.0)	101 (90.1)	208 (86.4)	
Government health agencies				.60
Missing	21 (5.0)	2 (1.0)	19 (8.2)	
A lot	59 (16.9)	25 (16.0)	34 (17.6)	
Some-Not at all	266 (78.0)	86 (83.0)	180 (74.2)	
Charitable organizations				.30
Missing	21 (5.3)	2 (1.0)	19 (8.6)	
A lot	5 (1.0)	3 (1.5)	2 (0.5)	
Some-Not at all	320 (93.8)	108 (97.5)	212 (90.9)	
Religious organizations and leaders				.57
Missing	20 (4.3)	2 (1.0)	18 (6.9)	
A lot	4 (2.9)	2 (4.1)	2 (2.0)	
Some-Not at all	322 (92.8)	109 (94.9)	213(91.2)	
Ownership and technology use				
Please indicate if you have each of the following.				.045
Missing	5 (1.6)	1 (1.5)	4 (1.6)	
Tablet computer	19 (8.5)	5 (7.8)	14 (9.0)	
Smartphone	99 (31.0)	35 (33.7)	64 (29.0)	
Basic cell phone only	45 (13.2)	6 (5.7)	39 (18.9)	
None	22 (4.7)	2 (1.1)	20 (7.5)	
Multiple devices selected	156 (41.1)	64 (50.2)	92 (34.1)	
On your tablet or smartphone, do you have any apps related to health and wellness?				.10
Missing	75 (19.7)	10 (8.4)	65 (28.3)	
Yes	138 (38.3)	66 (54.0)	72 (26.4)	
No	113 (30.2)	33 (30.2)	80 (30.2)	
Don't know	20 (11.8)	4 (7.4)	16 (15.1)	
In the past 12 months, have you used the internet to look for information about cancer for yourself?				.86

Variable	Respondents (n=346)	Respondents by age		P value
	n (weighted %)	<65 years (n=113), n (weighted %)	≥65 years (n=233), n (weighted %)	
Missing	66 (23.8)	10 (11.5)	56 (33.2)	
Yes	93 (26.2)	38 (31.1)	55 (22.4)	
No	187 (50.0)	65 (57.4)	122 (44.4)	
In the last 12 months, have you used the internet to watch a health-related video on YouTube?				.02
Missing	6 (0.9)	0 (0)	6 (1.6)	
Yes	77 (19.4)	38 (27.4)	39 (13.3)	
No	263 (79.7)	75 (72.6)	188 (85.1)	
In the past 12 months, have you used a computer, smartphone, or other electronic device to look for health or medical information for yourself?				<.001
Missing	7 (2.0)	2 (1.8)	5 (2.2)	
Yes	236 (68.2)	93 (82.3)	143 (61.4)	
No	103 (29.8)	18 (15.9)	85 (36.5)	

Table 3. Associations between age (<65 years vs ≥65 years) and health information–seeking variables for skin cancer survivors.

Variable	Unadjusted odds ratio (95% CI)	P value	Adjusted[a] odds ratio (95% CI)	P value
Have you ever looked for information about health or medical topics from any source?				
Yes	2.59 (0.7-9.58)	.15	1.09 (0.76-1.57)	.62
No	1.0[b]	—[c]	1.0[b]	—
The most recent time you looked for information about health or medical topics, who was it for?				
Myself	0.93 (0.41-2.11)	.86	0.91 (0.37-2.23)	.83
Someone else	1.0[b]	—	1.0[b]	—
Both myself and someone else	1.13 (0.46-2.76)	.79	1.17 (0.42-3.25)	.75
The most recent time you looked for information about health or medical topics, where did you go first?				
Doctor	1.18 (0.26-5.30)	.83	1.16 (0.2-5.9)	.86
Internet	0.40 (0.09-1.83)	.23	0.40 (0.08-2.08)	.27
Other	1.0[b]	—	1.0[b]	—
Have you ever looked for information about cancer from any source?				
Yes	1.14 (0.95-1.36)	.16	1.14 (0.81-1.61)	.44
No	1.0[b]	—	1.0[b]	—
Please indicate if you have a tablet, smartphone, cell phone, basic cell phone, none, or multiple devices.				
Tablet computer	1.7 (0.21-13.94)	.61	1.55 (0.09-26.82)	.76
Smartphone	1.27 (0.65-2.47)	.48	1.44 (0.62-3.36)	.39
Basic cell phone	4.88 (1.24-19.24)	.03	3.64 (0.7-18.95)	.12
None	10.36 (0.82-130.35)	.07	8.13 (0.64-102.8)	.10
Multiple devices	1.0[b]	—	1.0[b]	—
On your tablet or smartphone, do you have any apps related to health and wellness?				
Yes	0.42 (0.25-0.70)	0.001	0.35 (0.13-0.93)	.04
No or don't know	1.0[b]	—	1.0[b]	—
In the last 12 months, have you used the internet to watch a health-related video on YouTube?				
Yes	0.42 (0.19-0.88)	0.02	0.38 (0.17-0.84)	.02
No	1.0[b]	—	1.0[b]	—
In the past 12 months, have you used a computer, smartphone, or other electronic device to get health-related information?				
Yes	0.23 (0.10-0.53)	.001	0.17 (0.05 -0.56)	.004
No	1.0[b]	—	1.0[b]	—
Imagine that you had a strong need to get information about health or medical topics. Where would you go first?				
Internet	1.0[b]	—	1.0[b]	—
Doctor	4.56 (2.01-10.37)	.001	3.88 (1.82-8.23)	.001
Elsewhere	4.19 (0.9-19.46)	.07	5.24 (0.99-27.84)	.05
Overall, how confident are you that you could get advice or information about health or medical topics if you needed it?				
Completely confident	1.0[b]		1.0[b]	—
Very confident	0.87 (0.36-2.14)	.76	0.90 (0.37-2.20)	.82
Somewhat or not confident	0.91 (0.38-2.14)	.82	0.80 (0.33-1.92)	.61
You felt frustrated during your search for the information				

Variable	Unadjusted odds ratio (95% CI)	P value	Adjusted[a] odds ratio (95% CI)	P value
Strongly agree or somewhat agree	1.0[b]	—	1.0[b]	—
Somewhat disagree	0.89 (0.33-2.41)	.82	1.08 (0.38-3.04)	.88
Strongly disagree	0.8 (0.38-1.71)	.57	0.99 (0.43-2.26)	.97
It took a lot of effort to get the information you needed				
Strongly agree	1.0[b]	—	1.0[b]	—
Somewhat agree	1.05 (0.25-4.32)	.95	1.62 (0.33-8.08)	.55
Somewhat disagree	0.82 (0.19-3.52)	.79	1.69 (0.28-10.35)	.56
Strongly disagree	0.44 (0.12-1.58)	.20	0.64 (0.15-2.68)	.53

[a]The model was adjusted for respondent sex, income, and English-speaking ability.

[b]Reference.

[c]No data or not applicable.

Attitudes Toward Health Information–Seeking

A majority of skin cancer survivors (54.4%) reported that they would first go to their doctor if they had a strong need to get information about health or medical topics, followed by the internet (36.9%) or other sources (3.7%). Most respondents reported high levels of confidence in their ability to get advice or information about health or medical topics if needed, with 66.8% completely or very confident, 26.6% somewhat confident, and 4.4% a little confident or not at all confident. A plurality of skin cancer survivors reported a lot of trust in health information from a doctor (79.3%) but not in health information from government health agencies (16.9%), charitable organizations (1.0%), or religious organizations and leaders (2.9%) (P<.001 for all comparisons).

Compared to survivors aged 65 years and older, survivors <65 years old were less likely to first go to their doctor for health information (<65 years: 36.2%; ≥65 years: 68.3%; P<.001) and more likely to go to the internet (<65 years: 55.3%; ≥65 years: 22.9%; P<.001). In the model adjusted for sex, income, and English-speaking ability, going to their doctor first was strongly associated with being 65 years and older (OR 3.88, 95% CI 1.82-8.23; P=.001) compared to going to the internet first. No other relationships between general health information–seeking behavior and age were identified.

Ownership and Use of Technology

Although 81.0% of skin cancer survivors reported owning a smartphone or tablet device, 13.2% owned a basic mobile phone only. In the past 12 months, 68.2% of survivors had used a smartphone, computer, or other electronic means to look for health or medical information pertinent to their health, and 26.2% had used the internet to look for information about cancer. A minority of survivors reported having watched a health-related video on YouTube in the past 12 months (19.4%) or having apps related to health and wellness on a tablet or smartphone (38.3%).

Age was strongly associated with the ownership and use of technology (Table 2). Compared to survivors aged 65 years and older, survivors younger than 65 years old were more likely to have apps related to health and wellness (<65 years: 54.0%;

≥65 years: 26.4%; P=.10), more likely to have watched a health-related YouTube video (<65 years: 27.4%; ≥65 years: 13.3%; P=.02), and more likely to have used an electronic means to look for health and medical information (<65 years: 82.3%; ≥65 years: 61.4%; P<.001). After adjusting for sex, income, and English-speaking ability, having health and wellness apps (OR 0.35, 95% CI 0.13-0.93; P=.04), watching a health-related YouTube video (OR 0.38, 95% CI 0.17-0.84; P=.02), and using electronic means to look for health information (OR 0.17, 95% CI 0.05-0.56; P=.004) were associated with being <65 years old (Table 3).

Discussion

General

We found that health- and cancer-related information-seeking behaviors are common among skin cancer survivors but that 21.6% of respondents felt frustrated, and 28.2% felt that their most recent search for health information took significant effort. Age was strongly associated with survivor preferences and use of technology. Younger survivors were more likely to use and prefer technology-based means, such as the internet, health and wellness apps, or YouTube, to access information. These findings are relevant to clinical practice as well as to research efforts aimed at improving patient education and primary and secondary prevention behaviors, particularly as the population older than 65 years is rapidly expanding in the United States [32] and technology ownership and use varies by age [17,18,33].

Previous studies [3,34] have tended to survey survivors in tertiary-care specialty clinics, limiting generalizability. Brutting et al [3] found that the internet was strongly preferred as a media information resource by younger (<55 years) more than older patients with or who had a history of melanoma in Germany and that the information source most frequently used by patients with or who had a history of melanoma was their physician, followed by family or friends, other health care professionals, the internet, and booklets. Self-help groups, cancer counseling centers, and health insurance companies were infrequently used as an information resource [3]. Damude et al [34] conducted a prospective study in which, prior to an outpatient visit, a printed melanoma brochure and links to 2 educational YouTube videos

about skin self-examination were sent to Dutch stage I-II melanoma survivors, who subsequently reported that they preferred their treating physician over YouTube videos or printed brochures as the primary information source. Their findings [34] and ours highlight that skin cancer survivors strongly value their doctor as an information resource. In addition, the majority of melanoma survivors felt that YouTube videos gave complementary information, had additional value and increased their confidence; most would recommend them to other patients [34]. Interestingly, in our study, we found very low use of health-related videos from YouTube, which suggests that although there may possibly be interest in this medium among skin cancer survivors, they may not be aware of, or know how to, identify or access, reputable resources. This challenge was highlighted by Petukhova et al [35], who found that 87% of posts involving medical advice shared in Facebook support groups for keratinocyte carcinoma survivors included unsupported claims.

Web-based and print-based materials for melanoma education have been recently complemented by device (such as smartphone) apps, with which people interact with daily. With the rise in smartphone ownership, apps are a promising resource to help encourage patients and survivors to increase preventive health behaviors, including ultraviolet radiation protective behaviors and skin self-examinations [36-52]. However, because smartphone ownership varies by demographics [18], alternative strategies must be developed in parallel to prevent health care disparities.

Interestingly, few respondents reported high levels of trust in information about health or medical topics from government health agencies. This is consistent with the findings of a 2021 survey [53] of 1305 US adults that showed that the American public has significantly higher trust in health care professionals than in public health institutions and agencies. Addressing concerns of a lack of trust in US public health institutions and agencies, therefore, appears to be an opportunity for improvement. This is particularly relevant for skin cancer as it is the most commonly diagnosed cancer in the United States, most cases are preventable, and it was the topic of the US surgeon general's 2014 call to action [54].

Limitations

Data were limited by the survey response rate and the potential for recall and selection biases. Additionally, these data were in relation to general health information and not specific to skin cancer–related information. Given the low number of non-White skin cancer survivors in the data set, our findings may not be generalizable to other races and ethnicities. Selection bias was limited by the use of data from a rigorously conducted, population-based, nationally representative sample, that provided modest monetary compensation. Finally, we did not analyze data from prior HINTS surveys to determine temporal changes in measures, and we did not assess similarities or differences in information-seeking behaviors and use of technology between skin cancer survivors and other individuals.

Conclusion

Searches for health information are common among skin cancer survivors. Although behaviors and attitudes are associated with age, individuals of all ages have varied preferences, highlighting the importance of access to doctors and personalized information sources.

Authors' Contributions

All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by MAM, LS-G, SWD, JKN, and JLH. The first draft of the manuscript was written by MAM, and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplement.
[DOCX File , 51 KB - derma_v5i2e36256_app1.docx]

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Abbreviations

HINTS: Health Information National Trends Survey
OR: odds ratio

Original Paper

Crowdsourcing Medical Costs in Dermatology: Cross-sectional Study Analyzing Dermatologic GoFundMe Campaigns

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Abstract

Background: Crowdfunding for medical costs is becoming increasingly popular. Few previous studies have described the fundraising characteristics and qualities associated with success.

Objective: This study aimed to characterize and investigate the qualities associated with successful dermatological fundraisers.

Methods: This cross-sectional study of dermatological GoFundMe campaigns collected data, including demographic variables, thematic variables using an inductive qualitative method, and quantitative information. Linear regression examined the qualities associated with success, which are defined based on funds raised when controlling for campaign goals. Logistic regression was used to examine qualities associated with extremely successful campaigns, defined as those raising >1.5 times the IQR. Statistical significance was set at $P<.05$.

Results: A total of 2008 publicly available campaigns at the time of data collection were evaluated. Nonmodifiable factors associated with greater success included male gender, age 20-40 years, and White race. Modifiable factors associated with success included more updates posted to the campaign page, non–self-identity of the campaign creator, mention of a chronic condition, and smiling in campaign profile photographs.

Conclusions: Understanding the modifiable factors of medical crowdfunding may inform future campaigns, and nonmodifiable factors may have policy implications for improving health care equity and financing. Crowdfunding for medical disease treatment may have potential implications for medical privacy and exacerbation of existing health care disparities. This study was limited to publicly available GoFundMe campaigns. Potential limitations for this study include intercoder variability, misclassification bias because of the data abstraction process, and prioritization of campaigns based on the proprietary GoFundMe algorithm.

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KEYWORDS

crowdfunding; crowdsourcing; fundraising; GoFundMe; social media; medical expenses; financial burden; health equity

Introduction

Background

Crowdsourcing medical expenses is an increasingly popular method of financing health care costs [1]. In particular, GoFundMe is the most popular crowdfunding website worldwide in terms of funds raised. As of 2021, one-third of the funds raised by GoFundMe (approximately US $650 million) are for medical campaigns [2]. In the United States, a staggering 62% of bankruptcies are related to medical costs [3]. The high financial burden of medical expenditures has contributed to the rise of popular crowdfunding sites such as GoFundMe [4]. Fundraising campaigns on GoFundMe are broadly advertised

via social media outlets such as Facebook or Twitter, and potential donors are encouraged to share campaigns to increase visibility. By January 2020, 22% of American adults reported contributing to a GoFundMe campaign at least once, and 3% had created their own campaigns [5]. However, only approximately 10% of campaigns are successful in meeting their target goals [4]. With increased competition, campaigners are tasked with creating engaging and compelling appeals [4].

Limited research has considered the factors that influence the success of crowdfunding campaigns. Previous studies have suggested that demographic characteristics such as age and race, medical history, and proposed fund use are associated with fundraising outcomes, raising concerns about health care inequity and privacy [4-8]. Crowdfunding may be partly conceptualized as a marketing endeavor that requires creation of a campaign that will be seen as deserving to attract donations, especially if a medical condition is associated with any stigma. For instance, patients with lung cancer had more successful fundraising if they mentioned that they had never smoked, and patients with hepatitis C had more successful fundraising if they specified a source of infection that was ostensibly not intravenous drug use (blood transfusion, organ donation, and occupational exposures) [5,7]. Descriptive campaigns appear to raise more money, especially when patients provide a breakdown of specific medical and nonmedical expenditures; however, this may come at the expense of patient privacy [4-8]. We sought to analyze the specific themes most commonly associated with fundraising success when mentioned in campaign narratives. Previous studies have also suggested that racial minorities and older individuals are at a fundraising disadvantage [6,8]. Thus, in evaluating GoFundMe campaigns, we wished to evaluate any possible biases against marginalized groups, namely any gender-associated or race-associated biases.

Objectives

Dermatological conditions may generally be viewed by the public with a low level of urgency [9]. However, 1 in 3 Americans may experience skin disease, and the direct costs associated with skin disease in 2013 were US $75 billion, with indirect costs (eg, loss of labor force) totaling US $11 billion [10,11]. We aim to characterize the fundraising campaigns on GoFundMe for dermatological conditions. Further, we sought to identify the qualitative themes and demographic variables associated with campaign success.

Methods

Ethics Considerations

This study was deemed exempt by the institutional review board of the University of Virginia.

Data Collection

This study was deemed exempt by the institutional review board of the University of Virginia. We analyzed publicly available GoFundMe campaigns sorted by the platform algorithm from

March 20, 2021, to May 31, 2021, until the completion of available qualifying campaigns using dermatology-specific search terms (dermatology, skin, cutaneous, dermatologist, rash, skin disease, skin infection, skin biopsy, finger and toenail infection, Mohs, scalp, alopecia, epidermal, dermal, birthmark, and skin cancer) chosen by author consensus. Exclusion criteria included campaigns outside the United States, recently activated GoFundMe campaigns (active <1 day), or if the primary reason for fundraising was not considered dermatologic. Demographic data pertaining to the beneficiary were either objectively mentioned or subjectively coded from the campaign text and images. Campaigns were classified under diagnostic categories based on the condition described and the intention for seeking treatment (eg, repair for cosmetic reasons vs functionality). Qualitative themes were coded using an inductive qualitative method until thematic saturation was reached, meaning that themes were continuously added as they appeared in the data until no novel themes emerged [12]. Each campaign was read completely by 2 independent coders and was associated with a maximum of 3 different themes.

Statistical Analysis

The cleaned data were exported to RStudio (version 4.0.2). The frequencies of themes were calculated based on the percentage of times a theme was mentioned. Mann-Whitney U tests were performed for univariate analysis. Regression analyses were performed by comparing the number of shares and updates with the amount raised, controlling for race, age, gender, and campaign goal. A total of 2 separate models were used because of concerns regarding collinearity. Multivariable linear regression was performed to investigate the amount raised against the demographic and thematic variables. The Interquartile Method of Outlier Detection was applied to the amount raised and goal of the campaign. On the basis of this outlier detection method, campaigns raising >US $17,345 were excluded from the regression analysis. A binary logistic regression was run to compare demographic variables and themes in fundraisers that raised >US $17,345 with those that raised below this amount to investigate qualities associated with extreme success in fundraising. Extreme success was defined as an amount >1.5 times the IQR (>US $17,345). The significance threshold was set at $P<.05$.

Results

Demographic Variables and Campaign Summary

A total of 2008 fundraisers were analyzed. Most campaign recipients were White (1570/2008, 78.19%). There were more women (1109/2008, 55.23%) than men (896/2008, 44.62%). The campaigns raised a total of US $15,886,807 (mean US $7911.76, SD US $18,330.94, median US $3182) and had a total goal of US $45,860,361 (mean US $23,045.41, SD US $55,814.35, median US $10,000). A few campaigns met their goals at the time of the analysis (316/2008, 15.74%; Table 1).

Table 1. Demographic variables and campaign summary (N=2008).

Demographic variables	Values
Gender, n (%)	
Female	1109 (55.23)
Male	896 (44.62)
Age (years), n (%)	
<10	343 (17.08)
11-20	163 (8.12)
21-40	911 (45.37)
41-60	466 (23.21)
≥61	120 (5.98)
Relationship status, n (%)	
Single	1273 (63.4)
In a relationship	735 (36.6)
Race, n (%)	
White	1570 (78.19)
African American	216 (10.76)
Asian	56 (2.79)
Hispanic	157 (7.82)
Other	9 (0.45)
Insurance status, n (%)	
Insured	813 (40.49)
Uninsured	220 (10.96)
Unclear	974 (48.51)
Top 5 most common themes for fundraising, n (%)	
Inadequacy of current insurance	1050 (52.29)
Medical condition limiting earning potential	601 (29.93)
Need to travel for care	448 (22.31)
Basic living expenses (utilities and food)	326 (16.23)
No insurance	213 (10.61)
Top 10 most common diagnoses, n (%)	
Melanoma	302 (15.04)
Nonmelanoma skin cancer	232 (11.55)
Alopecia	207 (10.31)
Road rash	117 (5.83)
Laceration	90 (4.48)
Burn	71 (3.54)
Systemic lupus erythematosus	64 (3.19)
Systemic scleroderma	61 (3.04)
Cellulitis	59 (2.94)
Lyme disease	56 (2.79)
Category of diagnosis, n (%)	
Malignant	615 (30.63)
Autoimmune	347 (17.28)

Demographic variables	Values
Traumatic	291 (14.49)
Infectious	206 (10.26)
Cosmetic	172 (8.57)
Inflammatory	168 (8.37)
Congenital	155 (7.72)
Outreach	54 (2.69)
Relationship to creator of campaign, n (%)	
Self	493 (24.55)
Partner	116 (5.78)
Family member	877 (43.68)
Friend	486 (24.2)
Other	36 (1.79)
Mention of religion, n (%)	
Yes	479 (23.9)
No	689 (34.31)
Amount raised (US $)	
Mean (SD)	7911.76 (18,330.94)
Median	3182.00
Goal of campaign (US $)	
Mean (SD)	23,045.41 (55,814.35)
Median	10,000.00
Number of updates	
Mean (SD)	4.24 (10.14)
Median	1
Number of donors	
Mean (SD)	89.96 (280.09)
Median	39
Number of shares	
Mean (SD)	529.34 (1035.47)
Median	232

Regression Analysis

The mean number of shares on social media was nearly 6 times the mean number of donations. Men had higher median shares (279, IQR 60.75-694.25) than women (201, IQR 18-492; W=424,586; P<.001) and more median donors (45, IQR 18-112) than women (35, IQR 12-69; W=414,304; P<.001). After adjusting for age, race, gender, and goal of the campaign, every additional share was associated with an additional US $6 raised for the recipient (P<.001) and each additional campaign profile update was associated with an additional US $262 raised ($P$<.001; Table 2).

With respect to demographic characteristics, Black recipients earned a mean of US $1146 less than White recipients (P<.001). Those in the age group of 41 to 60 years earned a mean of US $762 less than those in the 21 to 40 age group (P=.02). Men

earned a mean of US $389 more than women did (P=.02). Those who mentioned the following themes received more donation money: medical conditions limiting earning potential (US $878; P<.001), need to travel for care (US $857; P<.001), complications from treatment (US $527; P=.04), funeral expenses (US $2013; P<.001), and having a chronic condition (US $622; P=.049). Smiling in profile photographs was associated with an earning mean of US $604 more than those without smiling (P=.01). Fundraisers created by friends earned a mean of US $1126 more ($P$<.001), and those created by someone other than a family member, friend, or partner earned a mean of US $1655 more than if created by the beneficiary themselves (P=.02; Table 3).

Age was a significant predictor of the likelihood of extreme success (defined as positive outlier campaigns raising >US $17,345) for those in the 21 to 40 age group, who raised more

funds than those in the 61 to 80 age group (odds ratio [OR] 0.94, 95% CI 0.89-0.99). Men were more likely to experience extreme success than women (OR 1.04, 95% CI 1.01-1.06). Themes that were more frequently mentioned in the group with extreme success included the expressed loss of control (OR 1.150, 95% CI 1.012-1.306), chronic medical conditions (OR 1.060, 95% CI 1.012-1.110), need for medical equipment (OR 1.124, 95% CI 1.042-1.213), and rare medical conditions (OR 1.100, 95% 1.027-1.178). Themes that were less frequently mentioned in the group with extreme success included complicated comorbid conditions (OR 0.915, 95% CI 0.876-0.955). If the recipient was smiling in the profile photograph, the campaign was associated with an increased likelihood of extreme success (OR 1.032, 95% CI 1.002-1.061). If the relationship with the campaign creator was more peripheral or ill-defined, the campaign had a higher likelihood of extreme success (OR 1.170, 95% CI 1.061-1.292). An increase in the number of updates was seen in the group with extreme success (OR 1.006, 95% CI 1.005-1.007; Table 4).

Commentary associated with each theme is seen in Table 5.

Table 2. Linear regression of the amount raised association with number of shares and updates controlled for other variables[a].

Dependent variable: amount raised	Shares			Updates		
	β (SE)	95% CI	P value	β (SE)	95% CI	P value
Number of shares or updates, respectively	5.729 (.2974)[b]	5.15 to 6.31	<.001	262.3 (31.71)[b]	200.08 to 324.45	<.001
Goal	.1743 (.0055)[b]	0.16 to 0.18	<.001	.1869 (.0058)[b]	0.18 to 0.20	<.001
Age group (years; reference: 21-40 years)						
<10	−367.5 (854.4)	−2043.16 to 1308.21	.67	−185.3 (913.8)	−1977.38 to 1606.72	.84
11-20	466.9 (1139)	−1757.57 to 2701.42	.68	−82.41 (122)	−2475.38 to 2310.55	.95
41-60	−159.1 (767.1)	−1663.58 to 1345.31	.84	−1210 (819.9)	−2818.16 to 397.85	.14
61-80	−1487 (1309)	−4053.90 to 1078.98	.26	−3501 (1394)[c]	−6235.36 to −766.78	.01
>81	−946.5 (5963)	−12,640 to 10,747.78	.87	−3635 (6371)	−16,129.83 to 8859.52	.57
Race (reference: White)						
African American	−3561 (988.4)[b]	−5499.47 to −1622.75	<.001	−3550 (1057)[b]	−5622.48 to −1477.06	<.001
Asian	2547 (1808)	−998.40 to 6091.47	.16	2568 (1949)	−1253.48 to 6389.43	.19
Hispanic	−1310 (1125)	−3516.84 to 896.70	.24	−461.5 (1203)	−2821.50 to 1898.57	.70
Other	1274 (4442)	−7437.70 to 9985.73	.77	−13.21 (4747)	−9322.41 to 9295.99	.99
Gender (reference: female)						
Male	927.3 (608.2)	−265.50 to 2120.19	.13	1841 (648.9)[d]	568.74 to 3113.79	.005

[a]Adjusted R^2 for shares=0.4687 and R^2 for updates=0.3865.

[b]$P<.001$.

[c]$P<.05$.

[d]$P<.01$.

Table 3. Multivariable linear regression of the amount raised by thematic and demographic variables of most campaigns[a,b].

Dependent variable: amount raised	β (SE)	95% CI	*P* value
Goal	.210 (.016)[c]	0.19 to 0.23	<.001
Age group (years; reference: 21-40)			
<10	393.5 (268.2)	−132.49 to 919.53	.14
11-20	228.9 (322.0)	−401.66 to 860.43	.48
41-60	−716.7 (216.2)[c]	−1185.74 to −337.69	<.001
61-80	−417.5 (360.1)	−1123.84 to 288.80	.25
>80	−2207 (1451)	−5053.80 to 640.06	.13
Race (reference: White)			
African American	−1146 (270.0)[c]	−1675.96 to −616.76	<.001
Asian	−690.6 (507.5)	−1686.09 to 304.93	.17
Hispanic	−36.48 (305.7)	−636.07 to 563.11	.91
Other	−872.2 (1323)	−3467.55 to 1723.15	.51
Gender (reference: female)			
Male	389.2 (170.3)[d]	55.23 to 723.16	.02
Fundraiser themes			
Loss of employment	567.6 (391.9)	−201.09 to 1336.37	.15
Medical condition limiting earning potential	878.0 (186.1)[c]	512.93 to 1243.01	<.001
Need to travel for care	857.3 (202.5)[c]	460.07 to 1254.61	<.001
Complications from treatment	527.3 (255.1)[d]	26.94 to 1027.62	.04
Funeral expenses	201.3 (519.1)[c]	995.08 to 3031.55	<.001
Medical condition limiting activities	513.5 (281.4)	−38.40 to 1065.35	.07
Chronic condition needing long-term treatment	621.5 (314.9)[d]	3.83 to 1239.23	.05
Delayed medical attention	908.4 (491.7)	−56.14 to 1872.93	.06
Money for childcare or family during treatment	−2316 (1318)	−4900.54 to 268.64	.08
Fundraiser creator (reference: self)			
Family member	300.5 (230.6)	−151.91 to 752.90	.003
Friend	1126 (240.1)[c]	655.51 to 1597.23	<.001
Partner	−232.0 (407.8)	−1031.93 to 567.85	.57
Other	1655 (682.2)[d]	316.64 to 2992.95	.02
Miscellaneous			
Patient smiling	603.6 (182.6)[c]	245.46 to 961.74	<.001
Patient single (reference: in relationship)	300.5 (230.6)[e]	−1017.49 to −211.27	.19
Number of updates	87.99 (11.0)[c]	66.37 to 109.61	<.001

[a]Amounts raised >US $17,345 were excluded from analysis.

[b]Adjusted R^2=0.316.

[c]$P<.001$.

[d]$P<.05$.

[e]$P<.01$.

Table 4. Binary logistic regression comparing campaigns with extreme success (>US \$17,345 raised) with most campaigns by demographic and thematic variables[a].

Dependent variable: amount raised >US \$17,345 compared with below	β (SE)	Odds ratio (95% CI)	P value
Goal	.008 (.025)[b]	1.008 (0.961-1.058)	<.001
Age group (reference: 21-40 years)			
<10	−.030 (.021)	0.970 (0.932-1.011)	.15
11-20	−.039 (.026)	0.962 (0.915-1.012)	.05
41-60	−.032 (.016)	0.968 (0.938-1.000)	.13
61-80	−.061 (.028)[c]	0.941 (0.891-0.993)	.03
>80	−.050 (.126)	0.951 (0.744-1.216)	.69
Race (reference: White)			
African American	.008 (.021)	1.008 (0.967-1.051)	.71
Asian	.075 (.038)[c]	1.078 (1.000-1.163)	.05
Hispanic	.010 (.024)	1.010 (0.964-1.058)	.68
Other	.126 (.094)	1.135 (0.945-1.363)	.18
Gender (reference: female)			
Male	.036 (.013)[d]	1.037 (1.010-1.064)	.006
Fundraiser themes			
Inadequate insurance or financial capacity	.022 (.013)	1.022 (0.996-1.049)	.09
Diagnostic difficulty	.045 (.024)	1.046 (0.999-1.095)	.06
Donation to charity or research	−.072 (.035)[c]	0.930 (0.868-0.997)	.04
Loss of family time	.049 (.033)	1.051 (0.985-1.120)	.13
Medical condition limiting activities	−.054 (.022)[c]	0.947 (0.908-0.989)	.01
Express loss of control	.140 (.065)[c]	1.150 (1.012-1.306)	.03
Chronic condition needing LT[e] treatment	.059 (.024)[c]	1.060 (1.012-1.110)	.01
Need for medical equipment	.117 (.039)[d]	1.124 (1.042-1.213)	.003
Rare medical condition	.095 (.035)[d]	1.100 (1.027-1.178)	.007
At-home care expenses	−.059 (.032)	0.943 (0.886-1.003)	.06
Complicating comorbidities	−.089 (.022)[b]	0.915 (0.876-0.955)	<.001
Lacking self-confidence because of illness	−.043 (.027)	0.958 (0.909-1.010)	.11
Fundraiser creator (reference: self)			
Family member	.035 (.018)	1.035 (0.999-1.072)	.05
Friend	.031 (.019)	1.032 (0.994-1.071)	.1
Partner	.038 (.031)	1.039 (0.977-1.104)	.22
Other	.158 (.050)[d]	1.171 (1.062-1.292)	.002
Miscellaneous			
Patient smiling	.031 (.014)[c]	1.032 (1.002-1.061)	.03
Patient Single (reference: in relationship)	−.033 (.016)[c]	0.968 (0.938-0.999)	.04
Number of updates	.006 (.001)[b]	1.006 (1.005-1.007)	<.001

[a]Nagelkerke R^2=0.502.

[b]$P<.001$.

[c]$P<.05$.

[d]$P<.01$.

[e]LT: long-term.

Table 5. Representative quotes per thematic variable.

Variable	Participants[a], n (%)	Quotes[b]
Inadequate insurance	1050 (22.9)	• "The copay for each ER visit with my insurance is $450, not to mention the copays for all the follow-up visits. I have a $3000 deductible to meet before my insurance starts covering anything."
Limited ability to work	601 (13.1)	• "I also have had a difficult eczema-like rash for 2 weeks, which has prevented me from working my usual schedule." (eczema) • "Although he has insurance, his copays and travel expenses to visit specialists are quite significant. Because he works from home, this has limited his income." (melanoma)
Travel	448 (9.8)	• "The cost of specialists, labs, procedures, etc. really begin to add up. Not to mention the cost of transportation without a car." • "I can't imagine what the medical bills will be, but the reality is that even now my mom is struggling to afford the daily parking fee to go see him."
Money for basics (food, rent, and utilities)	326 (7.1)	• "My primary concern is keeping the power and water on and food on the table." (cellulitis) • "They know that if the cancer does not devastate him, the inability to provide for his family might."
No insurance	213 (4.6)	• "I used to rely on Medicaid but now I don't qualify since our income is too high. I am accumulating more debt on top of my old debt, so much so that I'm willing to tend to my own foot dressings and sutures."
Complications from treatment	210 (4.6)	• "They injected me with steroids, and I gained 100 lbs in less than one month. I developed huge stretch marks all over my stomach and legs. I can't even bear to look at myself in the mirror."
Limited activities	187 (4.1)	• "I lost nearly all my friends since I was too sick to leave the house and they didn't know how to deal with my chronic illness."
Complicating comorbidities[c]	184 (4)	• "As a diabetic patient, life has had its challenges. She deals with so much already. This is not what she needs right now."
Chronic condition with need for long-term care	157 (3.4)	• "Half of his life he has only known hospitals, needles and doctors and there is no end in sight, he needs help from people who want to help him." (unspecified rash) • The doctors say she could come home any day now but because she is going to require a lot of medical attention." (systemic scleroderma)
Diagnostic difficulty	156 (3.4)	• "Because typical mastocytosis is rare, not to mention the systemic form, doctors were skeptical, and thought she had an eating disorder. A lot of precious time was wasted."
Self-esteem	133 (2.9)	• "By reducing my scarring, I hope to bolster my self-esteem and move forward in both society and my career."
Wig or hair prosthetic	100 (2.2)	• "My wife is the most wonderful woman I've ever met, but I see the light in her eyes diminishing because of her hair loss. Wigs are very expensive."
COVID-19	88 (1.9)	• "Due to my condition, my fiancé had to take time off of work to care for our newborn. With this pandemic and a newborn baby, it is not easy to get child care at the moment. And because I am immunosuppressed, it adds new challenges for working outside of the home."
At-home care expenses	87 (1.9)	• "These funds will help pay for skilled home care as she adjusts to not being able to walk and learns how to regain her independence." (systemic scleroderma)
Loss of employment	86 (1.9)	• "Her employment has been terminated since she cannot provide them with a "reasonable" return date. Consequently, she will lose her medical coverage unless she pays more."
Burden of previous debt	83 (1.8)	• "I cannot afford to be afflicted with anything right now. I'm already behind on rent and bills."

Variable	Participants[a], n (%)	Quotes[b]
Loss of family time	77 (1.7)	• "Not being together as a normal family has been tough on everybody to say the very least."
Outreach	71 (1.6)	• "Doctors are increasingly relying on private donations to continue their research and make progress in the field, and any dollar amount helps. The more people that see this, the closer we will be to finding answers!"
Rare medical conditions	69 (1.5)	• "Since medical companies don't make a profit off of rare diseases, they invest less in finding cures for these conditions. Insurance rarely covers cutting-edge treatments, and her doctors keep sending her for costly second opinions."
Medical devices	59 (1.2)	• "We want to provide him the independence he needs so he can live a normal life. Please help us get him a wheelchair he can operate himself (one-handed)." (epidermolysis bullosa)
Funeral expenses	55 (1.2)	• "There still is a funeral to plan. Now we are asking for help for the funeral cost so we can put him to rest the way he would have wanted." (epidermolysis bullosa)
Delay in medical attention	54 (1.2)	• "She has struggled to get timely access to medications she needs to treat her disease. These delays—caused by a fundamentally broken health care and insurance system—have resulted in relapses of her disease and rejection by her body of the medications." (psoriatic arthritis)
Trying to connect with people with similar diseases	22 (0.5)	• "We are raising money so that she can attend an out-of-state conference about her rare condition in which many specialists will be presenting." (epidermolysis bullosa)
Loss of control	19 (0.4)	• "I am having trouble sleeping because I'm worried I'll lose everything if my bills are not paid. My life revolves around cancer and worries like am I eating right, should I be exercising, how much sleep did I get, and what strange symptom do I have today? What does it mean? What is it from?"
End of life costs	15 (0.3)	• "This fund has been created to support my father's end of life costs. My siblings and I want to provide great hospice care and give him a proper send off."
Preventative and alternative health	15 (0.3)	• "To have a safe home they need an air filtration system, new windows. etc. to help decrease the number of allergens and bacteria within their home."
Familial conflict because of disease	7 (0.2)	• "I have been diagnosed with hypothyroidism and mast cell activation syndrome. Additionally, my spouse deserted me due to my chronic conditions knowing that as a stay-at-home mother I didn't have an income of my own."

[a]As campaigns endorsed multiple themes, and n reflects the total times a theme was endorsed, the total n does not equal the number of campaigns.

[b]Quotes have been paraphrased for anonymity and brevity.

[c]Complicating comorbidities refer to any expense incurred because of concurrent medical problems not associated with the primary disease stated in the fundraiser.

Discussion

Principal Findings

Our study identified factors associated with successful fundraising for dermatologic conditions on GoFundMe and specifically showed that thematic and demographic factors, including race and gender, have associations. Importantly, increasing the use of web-based crowdfunding introduces a new variable in the relationship between social media and medicine. The results of our study support the hypothesis that greater web-based social capital may be associated with successful fundraising. However, mobilizing these resources almost necessarily compromises patient privacy. Modifiable factors associated with success included a larger number of updates, non–self-identity of the campaign creator, mention of a chronic condition, and smiling in campaign profile photographs. Nonmodifiable factors associated with greater success included male gender, early to middle adulthood (age 21-40 years), and White race. Improved understanding of modifiable factors may guide future campaigns, and these identified nonmodifiable factors may have policy implications for improving health care equity and financing. Further, any reliance on crowdfunding to supplement insurance coverage highlights the potential shortcomings of the health care system and introduces questions regarding the balance between the risks and benefits for patients using social media to support their health care expenses. In particular, the identified nonmodifiable differences in crowdfunding may perpetuate the existing disparities in disadvantaged populations.

Social media literacy and robust web-based networks may increase the success of campaign fundraising. For every additional campaign profile update, fundraisers earned US $262 more per post, and for every additional share on social media, fundraisers earned US $6 more per post when controlling for race, age, gender, and goal of campaign. On an average, it took 6 shares to garner a single donation. Therefore, those with larger following on the web or followers with greater access to disposable capital may be at an advantage. Notably, higher income and educational levels have been associated with a larger number of donors and donation size in fundraisers for COVID-19 [6]. Together, these findings suggest that crowdfunded donations may be distributed inequitably, favoring the privileged [4,13]. Income and educational level were not available for analysis in our study and could provide further evidence to support this hypothesis. Access to technology, literacy, social capital, robust web-based networks, and self-marketing skills are factors that may contribute to a widening digital divide by enhancing opportunities to increase crowd appeal.

The need to mobilize these social networks and create an effective emotional appeal may undercut the right to medical privacy and patient autonomy. Campaigners noted detail information not only about their medical conditions but also personal expenses (Table 5). This information was provided voluntarily; however, pressure to increase appeal and legitimacy because of impending financial needs may undermine the right to medical privacy. The process of consent is also a concern when a campaigner is fundraising on behalf of a recipient and sharing second-hand personal information [14]. Interestingly, our study found that when the campaign creator was not the fundraising recipient, there was an association with increased success. Relationships that were more peripheral (friends) or ill-defined (others) had the greatest success. Potential donors may view fundraising by surrogates as credible evidence of increased disease severity, strong social ties that merit more donations, or an otherwise greater need for donation. Along the same line, other studies regarding GoFundMe success in patients with hepatitis C and lung cancer have shown that successful campaigns featured motifs emphasizing self-sufficiency, use of this platform as a last resort, framing the request for help as atypical, and highlighting that the individual was not at fault for their illness [4,7]. Campaigns that provided more information about etiology of disease and a breakdown of treatment costs were likely to receive higher donations [4]. GoFundMe encourages the release of this information through their "Top Tips" page, which includes recommendations for frequent updates, inclusion of ≥5 images, and divulsion of details regarding the recipient's personal life and medical treatment [2]. Other studies have similarly noted the trend of including extensive personal information, with some advocating for GoFundMe to change their recommendations; institute a consent process for fundraising on behalf of others; and obtain a release for personal information or restrict information posted without consent [6,14].

Medical fundraising campaigns may affect the relationship between physicians and patients on social media. For instance, campaigns may mention physician names and private medical details to increase campaign legitimacy. Jia et al [15] found that if the physician's name was mentioned in melanoma campaigns, the amount raised was doubled. Other studies have noted concerns over the use of GoFundMe without physician supervision as it may promote unfounded medical treatments [16-18]. Currently, it is not common practice for patients to consult physicians about information shared via social media. If physicians see their obligation to their patients as maximizing patient benefits and minimizing harm, this implies that physicians may choose to expand their roles as patient consultants in web-based and social media venues. However, it is worth noting that this raises further questions regarding physician privacy and traditional professional boundaries.

Disclosure of a chronic medical condition was another modifiable variable associated with increased success in both regressions. Previous reports have recognized that individuals with chronic conditions often have unmet needs within the American health care system [19]. Furthermore, chronic rather than acute conditions are hypothesized to more strongly invoke the sick role and increase donor sympathy [19]. Some believe that this phenomenon occurs because of reinforcement of the concept that the resolution of chronic disease is unexpected and thus may be costlier [20]. Consistent with other studies on GoFundMe donations, the success of campaigns citing this theme may be related to creating an image of deservingness and emphasizing the lack of culpability in their disease processes or financial situations [4,7]. This knowledge could potentially be applied to educate patients seeking to maximize their returns from GoFundMe fundraising. Similar to many profit-based endeavors, improving social media skills and expertise could assist patients in increasing fundraising success through comprehension of which qualities to emphasize and which to avoid.

Along these lines, smiling in campaign profile photographs was also associated with increased success, suggesting the benefits of strategized visual campaign curation. Other studies have theorized that this effect may be because of observers mimicking the emotions depicted in images, thus motivating donations to maintain these sentiments [21,22]. Smiling may also influence the perceived attractiveness of a recipient. Previous research suggests that the perceived attractiveness of female recipients may lead to larger donations [23]. These observations, in conjunction with the fact that this study found men to be more likely to achieve campaign success, may have ethical implications regarding distributive justice and evoke concerns about unconscious biases in crowdfunding. Canadian researchers have suggested that, paradoxically, although campaigns are typically created in response to known gaps in the social system, the resulting campaign outcomes reinforce rather than rectify established socioeconomic disparities [6,8]. If health care financing shifts from an institutionalized to an individual system, resources may be distributed not based on need but rather based on social worthiness or appeal.

In both regressions, the goals of campaigns were related to increases in the amounts raised. There are limitations to interpreting this relationship, given several confounding factors. Those with higher goals are less likely to meet their fundraising ceilings. In theory, having a high unmet goal could potentially

encourage additional donations until an inflection point is reached, and these exceptionally high goals may seem futile and unobtainable for donors. In addition, higher goals may reflect disease states of greater severity and need. Conditions that are more severe may inherently have a greater crowd appeal and contribute to the higher amount raised.

Regarding nonmodifiable variables, our study suggests that demographic differences, including race, age, and gender, affect fundraising. Black, female, and older patients were all less successful in their fundraising campaigns. Kenworthy et al [4] also found that, although women were less likely to be as successful as men in fundraising, women created most fundraisers. In this study, men also had more shares and donations than women. Notably, trends in fundraising success within the limited landscape of GoFundMe may not mimic trends in earning potential and health care burden seen in society at large. Previous studies have found that compared with their White counterparts, people of color are more likely to be both underinsured and experience adverse health outcomes [24]. In addition, according to the Pew Research Center, the salary of American women in 2020 was 84% of the salary earned by men [25]. Older individuals have more limited income opportunities and are also more likely to experience medical conditions, particularly skin cancers [26]. These differences may be exacerbated by the increased burden that traditionally marginalized groups (ie, older patients, racial minorities, and individuals of lower socioeconomic status) have accessing web-based resources, thereby leading to smaller web-based social networks and influence. In interpreting these findings, it is imperative to question the role that donor bias may play in fundraising success. Unconscious bias regarding darker skin tones has been associated with lower fundraising amounts, even when controlling for donor education, race, gender, political ideology, and past giving behavior [27]. Although gender and age biases against women and older individuals in nonmedical fundraising have been documented, controlled experiments to evaluate unconscious biases in health care crowdfunding are needed [4]. Given that these specific populations, on average, earned less money fundraising, these observed trends suggest that patients with the greatest need for financial assistance may be particularly disadvantaged.

Although increased reliance on crowdfunding for medical expenses could be criticized as a natural consequence of an imperfect health care system failing to meet the needs of a large segment of the population, crowdfunding may currently serve a purpose as a social safety net for those facing financial hardship. However, to ensure parity and that any social safety net provides coverage for those who need it the most, future work should continue to explore the amount of invested labor and derived benefits for all demographic groups.

Limitations

This study was conducted using data from GoFundMe. Future studies are needed to examine whether these findings can be generalized to other crowdfunding platforms. There is a possibility of misclassification bias as the authenticity of each campaign could not be verified. In addition, age could only be evaluated as a categorical variable as many patients referenced their decade of life but not specific ages. There is also the possibility of misclassification because of the data abstraction process; however, each post was reviewed by 2, reviewers and entries were discussed as a team to minimize the potential introduction of bias. Furthermore, GoFundMe does not release the proprietary algorithm that guides search tools; as only the first 960 campaigns per search term are displayed, it is possible that some campaigns could not be assessed depending on how GoFundMe's search algorithm prioritizes different content. Finally, it is worth noting that our study coincided with the COVID-19 pandemic. Although mentions of COVID-19 were not significantly associated with campaign success, future studies should seek to explore the crowdfunding frequency and success of campaigns coinciding with the pandemic.

Conclusions

The results of this cross-sectional study suggest that dermatologic crowdfunding success is associated with modifiable and nonmodifiable variables such as race, gender, and age. Improved understanding of modifiable factors may guide future campaigns, and identified nonmodifiable factors may have policy implications for improving health care equity and financing. GoFundMe may have the potential to exacerbate and introduce health care inequalities skewed along the lines of these factors and web-based social capital. However, identifying the factors associated with successful fundraising and social media education may assist patients in self-advocacy. Future research should further investigate the impact of GoFundMe campaigns in the medical field.

Conflicts of Interest

None declared.

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Abbreviations

OR: odds ratio

<u>Short Paper</u>

Investigating Turf Burn–Related Videos on TikTok: Cross-sectional Study

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Abstract

Background: Due to the increased use of artificial turf, turf burn has become a common sports injury. Turf burn is caused by exposed skin sliding on artificial turf. Health complications, such as methicillin-resistant *Staphylococcus aureus* outbreaks, sepsis, and pneumonia, have been linked to untreated turf burns, and many athletes have been turning to social media for advice and companionship regarding their sports injuries.

Objective: The goal of this study is to categorize and quantitatively assess the percentage of turf burn–related posts on TikTok based on creator type, content, athletes' experiences, and treatment and prevention methods. With these data, we not only investigate if there is room for health care professionals to assist in the distribution of evidence-based health education to athletes to counteract misinformation but also investigate if there is a potential audience of athletes on TikTok who have the potential to develop problematic responses to injuries.

Methods: By using the *Discover* page on TikTok, we searched for the term *turf burn* on October 17, 2021. In total, 100 videos were analyzed. Videos were categorized and analyzed based on creator type, content, experiences of the athletes, and treatment and prevention methods. The number of likes and comments was recorded.

Results: Most videos (98/100, 98%) were created by athletes. A small number of videos (2/100, 2%) were created by health care professionals. In terms of content, most videos (67/100, 67%) displayed turf burns. A small amount of videos (15/100, 15%) showed the incidents when turf burns were acquired, while around one-quarter of the videos (23/100, 23%) demonstrated the treatment and prevention of turf burns. Of the 23 treatment and prevention videos, a minority (4/23, 17%) showed the preferred treatment of turf burns, while most videos (19/23, 83%) showed nonpreferred treatments. The smallest amount of videos (2/100, 2%) were about turf burn education. Most of the videos created by athletes (56/98, 57%) depicted the negative experiences that patients had with turf burns. Some videos (37/98, 38%) depicted neutral experiences, while the smallest amount of videos (5/98, 5%) depicted positive experiences.

Conclusions: Our study suggests that there is a potential audience of athletes on TikTok who could develop problematic responses to sports injuries, such as turf burns, as most of the people who post videos are athletes, and many of the posts demonstrate negative experiences associated with turf burns. TikTok is a growing social media platform that should be studied to determine if it can be used to create a social support group for injured athletes to prevent the progression of negative emotional responses into problematic responses. Physicians should also have a role in establishing their social media presence on TikTok and offering evidence-based advice to athletes while disproving misinformation on TikTok.

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Introduction

Due to increased artificial turf use, turf burn has become a common sports injury. Turf burn is caused by exposed skin sliding on artificial turf. Untreated turf burns are associated with methicillin-resistant *Staphylococcus aureus* (MRSA) outbreaks, sepsis, and pneumonia [1]. Many athletes turn to social media for advice regarding their injuries, since they experience emotions of sadness, irritation, anger, and frustration; isolation; a lack of motivation; sleep disturbances; and disengagement. These emotions and experiences can persist or worsen, leading to problematic responses for which athletes should seek help [2]. TikTok is a growing social media platform that is used to share personal experiences and education [3]. Our study aims to categorize and quantitatively assess the percentage of turf burn–related posts on TikTok based on creator type, content, athletes' experiences, and treatment and prevention methods. We investigate if there is room for health care professionals to distribute evidence-based health education to athletes to counteract misinformation and if there is a potential audience of athletes on TikTok who may develop problematic responses due to their injuries.

Methods

By using the *Discover* page on TikTok—a page designed for searching and exploring TikTok content by using keywords—we searched for the term *turf burn* and used the tab labeled *top* on October 17, 2021. This showed trending videos at that time. We used the first top 100 videos; each video was from a different user, and all videos were posted within March 2021 to October 2021. Videos were categorized and analyzed based on creator type, content, athletes' experiences, and treatment and prevention methods. In addition, information in treatment and prevention videos was compared to clinical information by using UpToDate (UpToDate, Inc)—an evidence-based medical resource—and turf burn guidelines from the article "Athletic Skin Injuries" published by the peer-reviewed medical journal The Physician and Sportsmedicine [4,5]. One reviewer (BJUH) determined if the treatment and prevention video content was a preferred or nonpreferred form of treatment and prevention, while another reviewer (BKPW) independently reviewed the videos. The categorizations were all agreed upon by both evaluators, with no disagreements. Videos depicting a positive experience included videos showing injury improvement and treatment and prevention benefits. Videos depicting a negative experience included videos showing emotions that could develop into problematic responses [2]. Neutral videos consisted of videos in which athletes showed no overt opinions about their turf burns. The number of likes and comments was recorded.

Results

Contentwise, most videos (67/100, 67%) displayed turf burns. A small amount of videos (15/100, 15%) showed the incidents when turf burns were acquired, while nearly one-quarter of the videos (23/100, 23%) demonstrated the treatment and prevention of turf burns. The smallest amount of videos (2/100, 2%) were about turf burn education (Table 1). Athletes created most of the videos (98/100, 98%), while health care professionals created a small fraction of the videos (2/100, 2%). Most athlete-created videos (56/98, 57%) depicted athletes' negative experiences with turf burn. Some videos (37/98, 38%) depicted neutral experiences, while the smallest amount of videos (5/98, 5%) depicted positive experiences. Of the 23 treatment and prevention videos, a minority (4/23, 17%) showed the preferred treatment methods for turf burns, while most (19/23, 83%) showed nonpreferred treatments (Table 2). There was no mention of wound cleaning frequency in any video.

Table 1. Analysis of content in turf burn–related TikTok videos.

Video subject material	Videos (N=100), n	Comments (N=38,207), n (%)	Likes (N=2,428,435), n (%)
Displays turf burn	67	34,248 (89.6)	2,234,054 (92)
Incident of turf burn	15	724 (1.9)	85,550 (3.5)
Treatment and prevention	23	33,587 (87.9)	2,036,033 (83.8)
Education	2	129 (0.3)	14,452 (0.6)

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Table 2. Analysis of turf burn–related videos on TikTok based on creator type, content, athletes' experiences, treatment and prevention type, and methods for treatment and prevention.

Characteristic	Videos, n (%)	Comments, n (%)	Likes, n (%)
Creator type	100 (100)	38,207 (100)	2,428,435 (100)
Athlete	98 (98)	38,078 (99.7)	2,413,983 (99.4)
Health care professional	2 (2)	129 (0.3)	14,452 (0.6)
Athletes' experiences	98 (100)	37,166 (100)	2,391,925 (100)
Positive experience	5 (5.1)	102 (0.3)	8298 (0.4)
Negative experience	56 (57.1)	35,901 (96.6)	2,287,253 (95.6)
Neutral experience	37 (37.8)	1163 (3.1)	96,374 (4.0)
Treatment and prevention type	23 (100)	33,587 (100)	2,036,033 (100)
Preferred treatment and prevention	4 (17.4)	148 (0.4)	20,816 (1)
Nonpreferred treatment and prevention	19 (82.6)	33,439 (99.6)	2,015,217 (99)
Cleaning method	17 (100)	N/A[a]	N/A
Washing with soap and water[b]	3 (17.6)	N/A	N/A
Washing with water alone[b]	0 (0)	N/A	N/A
Washing with normal saline[c]	0 (0)	N/A	N/A
Washing with full-strength hydrogen peroxide[b]	14 (82.3)	N/A	N/A
Washing with a diluted 50% hydrogen peroxide and 50% water solution[b]	0 (0)	N/A	N/A
Washing with other cleaning solution	0 (0)	N/A	N/A
Bandage method	3 (100)	N/A	N/A
Saline dressing[c]	1 (33.3)	N/A	N/A
Petrolatum[c]	0 (0)	N/A	N/A
Single antibiotic ointment[b]	0 (0)	N/A	N/A
A combination of antibiotic ointments[c]	1 (33.3)	N/A	N/A
Cotton pads[b]	1 (33.3)	N/A	N/A
Prevention method	2 (100)	N/A	N/A
Protective clothing[c]	2 (100)	N/A	N/A

[a]N/A: not applicable.

[b]Nonpreferred treatment.

[c]Preferred treatment.

Discussion

Our study found a disproportionate amount of nonpreferred methods for turf burn treatment and prevention. The majority of the treatment videos (19/23, 83%) demonstrated nonpreferred ways of treating and preventing turf burn, and these videos had the most comments (33,439/33,587, 99.6%) and likes (2,015,217/2,036,033, 99%). Most of these videos (14/23, 61%) showed the use of hydrogen peroxide to treat turf burns. Hydrogen peroxide is cytotoxic and can delay wound healing and increase the risk of complications [4]. MRSA-related turf burn injuries have been shown to be linked to hospitalized cases of cellulitis, septic arthritis, and abscesses, and proper wound care has been shown to decrease the risk of turf burn injury complications [1]. Consequently, physicians should establish a

social media presence on TikTok and offer evidence-based treatment advice to athletes with turf burns, such as using a saline solution and dressings that provide a moist environment [4,5]. Furthermore, they should disprove misinformation to create awareness of common wound care mistakes. Future studies should examine the methods that health care professionals on TikTok use to interact with athletes and the methods used to refute misinformation. In addition, our study found that most people who post turf burn–related TikTok videos are athletes (98/100, 98%), and many posts (56/98, 57%) demonstrated negative emotional experiences associated with turf burns. The majority of videos (50/98, 51%) depicted an athlete feeling angry and frustrated due to pain from a turf burn. Pain can prevent athletes from participating in their sports and competing at their highest level, and negative emotions increase

the likelihood of developing a problematic response to sports-related injuries, such as depression and substance abuse [2]. Because many of the videos depicted a negative experience resulting from a turf burn (56/98, 57%) and athletes created most of the videos (98/100, 98%), there is a potential group of athletes on TikTok who could develop problematic responses to their injuries, including turf burns, and could benefit from obtaining guidance from a physician. One limitation we encountered in this study was that we could not obtain information regarding the countries from which the TikTok videos were posted, as TikTok users do not have access to this information. As a result, more research is needed to investigate if there are any cultural differences in how athletes react to turf burn injuries and other sports injuries. There should also be future studies that investigate if physicians on TikTok and injured athlete support groups on TikTok can play a role in preventing the development of problematic responses to sports injuries.

Conflicts of Interest

None declared.

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Abbreviations

MRSA: methicillin-resistant *Staphylococcus aureus*

Review

A Glance at the Practice of Pediatric Teledermatology Pre- and Post–COVID-19: Narrative Review

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Abstract

Background: The COVID-19 pandemic has accelerated the use of pediatric teledermatology, with centers showing increased uptake of teledermatology. Pediatric patients possess unique characteristics that pose different challenges with teledermatology compared to adults, in turn affecting the feasibility and uptake of pediatric teledermatology in the community.

Objective: This narrative review summarizes the evolution of pediatric teledermatology from pre–COVID-19 pandemic times to the post–COVID-19 period.

Methods: A search of MEDLINE, PubMed, and Embase was performed for original articles written in English and published from December 1, 2019, to April 1, 2022.

Results: A total of 22 publications were included.

Conclusions: Teledermatology will continue to play an increasing role in the management of skin diseases. A mindset shift in the types of conditions deemed suitable for pediatric teledermatology is needed.

Introduction

The COVID-19 pandemic has accelerated the use of pediatric teledermatology, with centers showing increased uptake of teledermatology. Pediatric patients possess unique characteristics that pose different challenges with teledermatology compared to adults, in turn affecting the feasibility and uptake of pediatric teledermatology in the community. As compared to more self-directed adult patient care, caregivers tend to be more deeply involved in the care of the pediatric patient, with Naka et al [1] having suggested that adopting a family-oriented approach to care and communication is essential. Physicians are obliged to conduct a safe, child-friendly, family-centric consult across a virtual platform when teledermatology for children is used. The limitations and difficulties intrinsic to pediatric teleconsultation may be compounded by obstacles in obtaining details of the full pediatric medical history (including details on prenatal, birth, and developmental history), which can be time-consuming [1]. Heavy reliance on caregivers as sources of information in relation to the child may inadvertently lead to inaccuracy and bias. Pediatric patients, compared to their adult counterparts, are also protected by additional laws governing health care delivery—hence, ethical and legislative-related concerns may escalate when dealing with a pediatric patient [1].

The COVID-19 pandemic has given new impetus for pediatric teledermatology to be embraced as infection control, physical distancing measures, and reduction in hospital attendances post–COVID-19 necessitate more remote yet viable options for pediatric care. This narrative review summarizes the evolution of pediatric teledermatology from pre–COVID-19 pandemic times to the post–COVID-19 period.

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Methods

A search in MEDLINE, PubMed, and Embase was performed for original articles written in English and published from December 1, 2019, to April 1, 2022. Articles were evaluated by reviewing their titles and abstracts for relevance. Articles that lacked relevance to pediatric teledermatology either pre- or post–COVID-19 were excluded. Articles that reported on the practice, outcomes, and experiences with pediatric teledermatology both pre- and post–COVID-19 were used in this narrative review. The search terms used were "paediatric teledermatology," "telemedicine," "telehealth," "virtual," "videoconferencing," and "teleconferencing."

Results

A total of 22 publications were included.

Discussion

Modes of Pediatric Teledermatology Pre- and Post–COVID-19

Pediatric teledermatology can be delivered via synchronous, asynchronous, and hybrid means [2]. Synchronous teledermatology involves real-time/live video teleconferencing, while asynchronous teledermatology, including direct-to-consumer applications, involves store-and-forward platforms transmitting submitted images from the patient, caregiver, or other nondermatological physicians. Hybrid platforms were a mix of the aforementioned modes [2].

A 2015 survey of US dermatologists reported up to 89% of pediatric dermatologists having experience with teledermatology, using store-and-forward platforms, synchronous live consults, and hybrid platforms [2]. Direct-to-consumer pediatric virtual urgent care can be beneficial for viewing the child in the setting of their own home, enabling more reliable observation and assessment of the child's behaviors and condition. A post–COVID-19 study in a large academic medical center reported that pediatric emergency virtual urgent care could be conducted via telephone calls, allowing practitioners to manage pediatric concerns that were COVID-19–related (36%), dermatologic (15%), and trauma-related (10%) [3]. The authors cited a 4-fold increase in pediatric emergency virtual urgent care volume post–COVID-19 compared to the same period pre–COVID-19, underscoring the need for pediatric telehealth during the pandemic.

There is scope for creativity and optimization of teledermatology delivery modes post–COVID-19 to improve patient access and uptake. Virtual reality (VR) technology, where a headset can be worn by the teleprovider in various settings and even on-the-go, removes logistical barriers for teleproviders. Adoption of VR technology for parents/families may, on the other hand, be challenging. It may be costly to ensure adequate access with provision of VR technology to families. Parents may also face physical difficulties with using VR for the roving active child. We propose that VR consultation would be better suited for the older pediatric patient who may be able to sit still for the duration of the consultation. Families/parents offered VR consultation should ideally be financially stable or adequately supported.

The challenges physicians face with teledermatology consults pre- and post–COVID-19 are likely to remain similar, with the potential inability of physicians to make the correct dermatological diagnosis as a result of information inadequacy (insufficient history obtained over virtual consult, limited ability to examine the patient thoroughly, poor quality clinical images, limited ability to use bedside equipment such as dermoscopy to examine lesions).

We suggest that when there are difficulties, physicians can consider using hybrid platforms to improve the accuracy of teledermatology. For example, a caregiver could photograph a young child's skin lesions while the child was asleep to enable better quality photographs without the child's movement. A synchronous teledermatology consultation could then improve evaluation of the skin lesions. This use of hybrid platforms is similarly useful if there are challenges in the child being present for the entire length of the consult.

Privacy concerns can be ameliorated using photographs curated by the caregiver in lieu of real-time/live visual examination of sensitive body sites [4]. For older children who may have private information to divulge directly to health care practitioners, their parents/caregivers could be invited to leave the teledermatology consult room. This practice would mirror traditional face-to-face consultation.

The importance of high-quality photographs of skin disorders cannot be understated, with various studies highlighting the use of clinical photography in teledermatology [1,2,5,6]. With advancements in digital photography and storage/transmission technology, obtaining photographs assists not merely clinical care via teledermatology but also education, research, and patient documentation. With store-and-forward platforms, good photography forms the basis of the consult—where clinical photos inform on the evolution of a skin disease and assist in more objective assessments of a patient when different doctors are involved in patient care such as in larger public hospitals [5]. A scoping review by Kim and Sivesind [7] had also demonstrated that patients adopt positive attitudes toward medical photography. Most patients had expressed that medical care could be improved in the clinical setting with photography [7].

In the transmission of clinical images, data protection is paramount. The personal data of patients could be protected by pseudo anonymization (limiting access to authorized personnel), entity authentication, and data encryption [8].

Conditions Managed by Teledermatology Pre- and Post–COVID-19

Pre–COVID-19, diagnoses during pediatric teledermatology consults were similar to in-person visits, including inflammatory dermatoses such as atopic dermatitis; pityriasis alba; acne; xerosis; infective issues such as molluscum contagiosum; verruca vulgaris; benign and malignant tumors including melanocytic nevi, infantile hemangiomas (IH), and other skin tumors; wound care; pigmentary conditions (including tinea

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versicolor, vitiligo, postinflammatory hyperpigmentation, and hypopigmentation); and alopecia [2,9,10]. Prior to the COVID-19 pandemic, a cross-sectional Brazilian study [11] had commented that 63% of lesions in the primary care settings could be managed via store-and-forward teledermatology without the need for an in-person visit, as only 1% of cases required biopsy.

Post–COVID-19, reported pediatric teledermatology consult diagnoses included atopic dermatitis, Gianotti Crosti Syndrome, intertrigo, photodermatitis, acne, adnexal disorders, alopecia, IH, skin infections/infestations, molluscum contagiosum, verruca vulgaris, melanocytic nevi, pigmentary disorders, and psoriasis [2,11].

Apart from the consensus statement released by the Society of Pediatric Dermatology on the management of IH, suggesting that follow-up visits for IH could be safely performed via synchronous or asynchronous means, there is relative paucity of teledermatology practice guidelines for the other pediatric conditions. Prior to the COVID-19 pandemic, strides in teledermatology had lagged at least in part from a lack of confidence in telediagnoses and fears of missing or delaying critical diagnoses [12]. With the ongoing pandemic, and in line with the American Academy of Pediatrics, clinical practice guidelines could give practitioners a collective personal experience on teledermatology management. This may aid in assuaging diagnostic apprehension.

Havele et al [13] retrospectively reviewed 1110 patient-provider live video consults and 89 store-and-forward, provider-to-provider pediatric teledermatology consults during the COVID-19 pandemic and described that dermatologists faced different issues in terms of connectivity, video quality, and photograph quality when managing myriad conditions. In this study, the management of alopecia was associated with issues with video and photograph quality. Pre–COVID-19, a 2017 randomized controlled trial of 40 patient-parent dyads at a US pediatric dermatology clinic found high concordance between photograph-based and in-person diagnosis but had also highlighted that alopecia and neoplasms tended to have lower concordance rates between photographs and in-person diagnoses [14]. We suggest that providers could consider using hybrid platforms integrating both synchronous and asynchronous communication. Close-up photos with applied dermoscopy may assist.

As the pandemic lingers on, pediatric teledermatology should evolve to cater to a wider range of conditions. Contact dermatitis and mask-induced acne arising from pandemic-related health precautions could be effectively managed via teledermatology [15]. Pediatric teledermatology should be expanded to slowly include the review of genodermatoses, which had already in pre–COVID-19 times seen a scarcity of expert pediatric dermatologists, with multidisciplinary clinics being typically restricted to large cities [2].

Reimbursement and Medicolegal Implications With Teledermatology Pre- and Post–COVID-19

One of the most substantial barriers to widespread adoption of teledermatology is likely related to the lack of reliable systems for reimbursement. A large survey carried by the American Academy of Dermatology (AAD) in 2021 of 5000 participants revealed that reimbursement concerns formed the majority (69.8%) of all reported barriers [16]. Teledermatology services globally operate via a variety of business models (which need to be sustainable) including per-case service contracts, direct-to-consumer, and standard fee-for-service reimbursement [17].

Prior to the COVID-19 pandemic in the United States, private insurers offered reimbursement for teledermatology as an alternative to self-pay and federal health insurance programs such as Medicare and Medicaid. However, such policies varied between states and payer status. This was similarly poorly delineated in the realm of teledermatology in many centers worldwide, thus disincentivizing uptake. Since the COVID-19 pandemic, the AAD has advised that Medicare could allow reimbursement of telehealth services rendered via telephone with payment for telephone-only encounters being reimbursed at the same rate as in-person (new/established) office visits. Rates are based on the national Medicare Physician Fee Schedule [18].

Although the pandemic has likely improved flexibility of reimbursement for telephonic consults, reimbursement policies for store-and-forward services would similarly likely benefit from review. The comparatively low reimbursement rates for store-and-forward teledermatology consults may undervalue the time and expertise of the practicing dermatologists. Practitioners may instead choose to use store-and-forward platforms for image control and quality while completing consults using videoconferencing. Ensuring reasonable reimbursement for multimodal/combination methods of teledermatology consults can improve both uptake among dermatologist and patient-centric outcomes.

Medicolegal implications associated with teledermatology may pose significant challenges to uptake, with the AAD survey highlighting 27% of participants having concerns with malpractice/liability [16]. To date, the extent of legal responsibility in cases of incorrect/delayed diagnosis remains ambiguous, and malpractice risk is not generally well characterized. Although a 2019 study [19] cited no reported cases of medical malpractice against direct-to-patient telemedicine, the fact that patients' privacy could be compromised at various checkpoints of image capture, transmission, and storage remains concerning. In the United States, the Health Insurance Portability and Accountability Act (HIPAA) governs the compliance of clinical images to follow appropriate security precautions, with providers who fail to do so being subjected to legal penalties. Although temporarily waived as part of the initial response to the COVID-19–imposed public health emergency [20], the unlikely continuation of this waiver in postpandemic times reminds dermatologists that good clinical practice entails documented patient consent for all clinical images, providing explanations on the use of images, and ensuring HIPAA-compliant security in storage and transmission.

Cultural and Socioeconomic Considerations for the Implementation of Pediatric Teledermatology Post–COVID-19

A US study comparing pediatric teledermatology visits scheduled post–COVID-19 with in-person appointments in the same period pre–COVID-19 reported that certain demographic groups such as Spanish-speaking patients were less likely to have teledermatology visits [21]. Another single center US study [22] demonstrated via multivariate analyses that independent factors associated with lower rates of telemedicine use were patients identifying as Black/African American and having a non-English preferred language. In this study, patients on public insurance were also found to have significantly lower odds of telemedicine use despite widely expanded telehealth coverage by US health insurance plans. Low-income households may experience gaps in access to technology and internet connectivity that are requisites for teledermatology visits. Differential digital literacy and connectedness among cultural and socioeconomic groups can create inequity in pediatric teledermatology uptake and care delivery. Physicians need to be sensitive and remain current about patient communication preferences. For instance, for patients who may be less likely to engage in patient portal communications, other modes of communication via SMS text messaging or video calls could be alternative modes of telehealth delivery for underserved populations.

There are also disparities in trust toward dermatologists providing teledermatology among patients of different racial groups. Kim and Sivesind [7], in a scoping review, revealed that patients of Latin and African American descent had expressed less trust in the utility of medical photography to improve patient care, compared to patients who were Asian and White. Ethnic disparities in patient perceptions may need to be taken into consideration by practitioners to improve the teledermatology experience for socially marginalized patients. This could be done by using nonphysician photographers and clinic-owned cameras, and by improving patient education surrounding the safety of electronic medical record phone apps [7].

Conclusion

Teledermatology will continue to play an increasing role in the management of skin diseases. A mindset shift in the types of conditions deemed suitable for pediatric teledermatology is needed. Practitioners should also be aware of the various modes of teledermatologic delivery to select the most appropriate mode that is sensible for both practitioner and patient, taking into account potential socioeconomic challenges and cultural preferences. Given that previous studies have shown that both store-and-forward and live interactive teledermatology could be diagnostically comparable, hybrid models may further help ameliorate physician-patient diagnostic and logistical difficulties. Further study into the comparable diagnostic accuracy of teledermatology in skin conditions in pediatric versus adult patients will help highlight advantages and shortfalls of teledermatology in different age groups. A similar comparison between acute emergent versus chronic dermatoses in the pediatric age group will be useful. A concerted effort to characterize the practice of teledermatology in the post–COVID-19 era will allow practitioners to fine-tune and get comfortable with this modality.

Conflicts of Interest

None declared.

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Abbreviations

AAD: American Academy of Dermatology
HIPAA: Health Insurance Portability and Accountability Act
IH: infantile hemangiomas
VR: virtual reality

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Review

Current Landscape of Generative Adversarial Networks for Facial Deidentification in Dermatology: Systematic Review and Evaluation

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Abstract

Background: Deidentifying facial images is critical for protecting patient anonymity in the era of increasing tools for automatic image analysis in dermatology.

Objective: The aim of this paper was to review the current literature in the field of automatic facial deidentification algorithms.

Methods: We conducted a systematic search using a combination of headings and keywords to encompass the concepts of facial deidentification and privacy preservation. The MEDLINE (via PubMed), Embase (via Elsevier), and Web of Science (via Clarivate) databases were queried from inception to May 1, 2021. Studies of incorrect design and outcomes were excluded during the screening and review process.

Results: A total of 18 studies reporting on various methodologies of facial deidentification algorithms were included in the final review. The study methods were rated individually regarding their utility for use cases in dermatology pertaining to skin color and pigmentation preservation, texture preservation, data utility, and human detection. Most studies that were notable in the literature addressed feature preservation while sacrificing skin color and texture.

Conclusions: Facial deidentification algorithms are sparse and inadequate for preserving both facial features and skin pigmentation and texture quality in facial photographs. A novel approach is needed to ensure greater patient anonymity, while increasing data access for automated image analysis in dermatology for improved patient care.

KEYWORDS

facial recognition; deidentification; facial photographs; HIPAA; dermatology; guidelines

Introduction

Facial Deidentification in Dermatology

Over the last several years, there has been an explosion of artificial intelligence (AI) and deep learning for dermatological image analysis. These tools have demonstrated efficacy in the diagnosis and quantification of skin conditions at par with or surpassing human performance [1,2]. Additionally, there have been use cases in dermatology where the human eye is unable to precisely quantify the burden of disease, while AI can be used to support the clinical decision-making process with better consistency [3,4].

Facial image data are needed for developing models that evaluate attributes such as redness (ie, acne and rosacea models), texture (ie, wrinkles and aging models), pigmentation (ie, melasma, seborrheic keratoses, aging, and postinflammatory hyperpigmentation models), and skin lesions. To advance AI in dermatology, image data are needed at scale. For patient data to be used for research, consent may be obtained; however, for data at scale where this is not possible, adequate deidentification must be applied to images. Traditionally, journals have required facial feature concealment that typically covers the eyes, but these guidelines are largely insufficient to meet the ethical and legal guidelines from the Health Insurance Portability and

Accountability Act for patient privacy and identity protection [5,6]. Facial features, tattoos, jewelry, birthmarks, and other identity-informative background features are additional features that are considered identifying; facial feature deidentification is considered the most challenging task, given a lack of expert consensus and a lack of testing infrastructure and quantitative metrics for adequacy of automatic and manual facial image deidentification algorithms.

Identity protection challenges extend to other industries involved with facial images as well as video privacy. Hence, there have been increasing efforts to propose facial deidentification algorithms in the literature with corresponding use cases. Ideally, the methods should both hide the original identity of participants and preserve data reusability. We hypothesize that automated facial deidentification algorithms currently proposed in the literature may be useful for dermatological research use. To this end, we conducted a systematic review to search for studies reporting facial deidentification and summarized their proposed methodology and application to image analysis in dermatology.

Comparison of Different Facial Deidentification Algorithms

Conventional methods of ad hoc facial deidentification use blur [7], pixelation [8], masking, random swapping, perturbation, and face region replacement [7,9-18] to obfuscate parts or entire images to protect visual privacy. This set of obfuscating techniques prevent the rendering of the original image, but they do not necessarily guarantee preservation of privacy (ie, masks and blur can be removed) and often compromise data utility (ie, preservation of dermatological characteristics with diagnostic value) [19,20]. To test if these techniques protect privacy, studies have explored whether these methods can fool computer and human detection. Many studies have successfully avoided detection by use of computer algorithms but have found that human eyes can easily notice the alteration [21-24]. Furthermore, simply applying distorting filters to images risks identity revelation after reconstruction [13].

The k-anonymity–based algorithms were proposed as one of the original feasible approaches in solving this issue of data utility after deidentification [25]. Briefly, the k-anonymity–based methods and their variations deidentify an image by replacing the face with the average of k images from a given collection of images, and they achieve privacy protection with a rate lower than $1/k$. The most commonly used k-algorithm is from the k-Same family [8,13,17]. However, one of the key issues with the variations of the k-Same algorithm is the introduction of ghosting artifacts caused by the misalignment of images. The ghosting artifacts compromise privacy protection by making the images appear unnatural. The ghosting effect can be overcome by employing a large k in the algorithms, but this requires a large image collection, otherwise it results in a lack of distinction among the deidentified faces; this is because the number of discriminative faces in the deidentified face set is limited by the total number of images divided by k. This is problematic for applications in skin image analysis in dermatology because adequate privacy protection is achieved with averaging a greater number of images, which, in turn, will dilute redness, pigmentation, and other image attributes that are

critical to dermatologic data utility. In other words, there is an intrinsic trade-off when choosing k between identifiability and preservation of dermatological features.

The k-Same-M algorithm was developed to eliminate the ghosting effects in order to enhance privacy protection with minimal loss of data utility [26]. This algorithm uses an active appearance model (AAM), which is an algorithm that can reconstruct an image representation based on its shape and texture [26]. In this way, an AAM coupled with the k-based algorithms can help reduce the ghosting effect in the deidentified images by ensuring a better alignment of the synthesized identity onto the original images. However, the reconstructed images from an AAM are still averaged images from the respective data set and, hence, some important aspect of data utility, such as facial expression, could be compromised.

Another technique for achieving facial deidentification is through the use of machine learning methods involving deep neural networks [27-31]. Convolutional neural networks (CNNs) are effective in extracting features from raw faces and, hence, facilitate image transformation into target outcomes. Limitations associated with methods involving CNNs and convolutional autoencoders are that they are time costly because they require a large sample size to be trained and optimized. Specifically for CNNs, these are supervised algorithms that also need labels for ground-truth classifications. Furthermore, the output images are still not natural enough to effectively preserve privacy.

Generative neural networks (GNNs) constitute a novel method to generate realistic face surrogates that can be used for deidentification. This quality can be exploited to retain skin attribute quality from a source image of interest. These also allow for retaining certain aspects of the original data, such as age, gender, and facial expressions, while replacing sensitive personal attributes with artificial objects, such as facial features. GNNs are originally based on generative adversarial networks (GAN), which combine a generative model that produces a synthetic image and a discriminator (ie, critic) network that classifies the synthetic image as either real or artificial. This method works by training the discriminator network as a standard classifier to distinguish between the two image sources as real or artificial and training the generative network as an image-generating model that can fool the discriminator network, with the goal of generating the most realistic-appearing synthetic images [32]. The model is improved in an adversarial manner via back-propagation with both generative and discriminator networks to identify the generator's parameters that should be optimized to make the generated images increasingly challenging for the discriminator. After completion of training, the output images from the generator network should be indistinguishable from the real images for the discriminator as well as look visually convincing for humans [13,25,33-35].

The use of GANs in facial deidentification is intriguing due to their potential for disentanglement of facial features and skin attributes. Theoretically, facial images can be deidentified by a GAN that recognizes facial features, such as eyes, nose, and lips, and then replaces them with features from another facial image, while continuing to preserve the realistic-appearing facial image as well as features of interest, such as redness,

pigmentation, texture, and skin lesions. Hence, based on their high data utility, GANs hold the promise of privacy protection by completely changing image identification by human and automated detection. This study focused on reviewing the GAN-based models published to date for facial deidentification for dermatologic use cases. We also evaluated the performance of top-performing GANs in deidentifying dermatological images while preserving the important facial and skin quality features in these images.

Methods

Search Strategy

We conducted a systematic search using a combination of headings and keywords to encompass the concepts of facial deidentification and privacy preservation. The MEDLINE (via PubMed), Embase (via Elsevier), and Web of Science (via Clarivate) databases were queried from inception to May 1, 2021. We also performed referential backtracking on the most recent studies to ensure inclusion of all relevant articles. Studies of incorrect design and outcomes were excluded during the screening and review process. The search strategies are outlined in Multimedia Appendix 1.

Definitions and Inclusion and Exclusion Criteria

Facial features were defined as identifying features associated with an individual, including the eyebrows, eyes, nose, mouth, and ears. For deidentification in dermatologic use cases, these features are important to remove and replace. The skin was then defined as the remaining facial area bounded by the hairline.

Preservation of skin quality by algorithms was evaluated as to how well the algorithms preserved the quality of the skin tone and texture from the input images. We included studies that focused on variations of the GAN algorithm for the purpose of facial deidentification in images, video, or both. Studies were excluded if they focused on any other facial deidentification algorithms due to low preservation of pixel-level skin quality based on the methodology.

Ethics Approval

This study was approved by the Institutional Review Board (Retrospective cutaneous dermato-oncological conditions treated by dermatology service) for protocol No. Pro00100765. Patient consent was not required due to the nature of this study.

Results

Overview

A total of 18 studies using GAN methodology were included in the final review (Figure 1). Table 1 [36-53] summarizes the different types of GAN algorithms and the goals of all the studies as well as an evaluation of their ability to preserve skin quality (ie, color and texture), capacity for data utility, and demonstration of adequate facial deidentification with human eyes based on the results illustrated in the studies. We then applied two of the best GAN-based algorithms that were publicly available to the SD-260 (260 classes of skin diseases) data set [54], a public data set of images of dermatological conditions, to assess whether the output images appropriately preserved skin quality.

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) diagram.

Table 1. Overview of included GAN-based studies.

Author, year	Method of facial deidentification	Novelty in proposed method of facial deidentification	Skin attribute preservation		Data utility	Facial deidentification (human)
			Color	Texture		
Pan et al, 2019 [36]	k-Same-Siamese-GAN[a]	Maintenance of high resolution of images to preserve their utility	Partial	No	Low	Yes
Song et al, 2019 [37]	Evolutionary GAN	Structural similarity index and the distance between the original face and the deidentified face	Partial	Partial	Low	No
Agarwal et al, 2021 [38]	StyleGAN and GAN	Preservation of emotion and nonbiometric facial attributes of a target face	N/A[b]	No	Low	Yes
Nitzan et al, 2020 [39]	Disentanglement coupled with GAN	Disentanglement of identity from other facial attributes with minimal training	Yes	No	High	No
Lin et al, 2021 [40]	Facial privacy GAN for social robots	Strengthened feature-extraction ability to improve the discriminatory accuracy	Partial	No	Low	Partial
Maximov et al, 2020 [41]	Conditional identity anonymization GAN	Development of a model for image and video anonymization with removal of identifying characteristics of faces and bodies	Yes	No	High	Yes
Brkic et al, 2017 [42]	Conditional GAN	Production of realistic deidentified human images that avoid human- and machine-based recognition	N/A	N/A	Low	N/A
Meden et al, 2017 [43]	Generative neural network	Synthesis of artificial surrogate faces with preservation of nonidentity-related aspects of the data for data use	No	No	Low	Yes
Mirjalili et al, 2017 [44]	Convolutional autoencoder using semiadversarial network	Autoencoder-based transformation of an input face image	N/A	No	Low	No
Radford et al, 2016 [45]	DCGAN[c]	Unsupervised GAN	No	No	Low	No
Wu et al, 2019 [46]	Privacy-protective GAN	Privacy protection, utility preservation, and structure similarity	N/A	Partial	Low	Yes
Hukkelås et al, 2019 [47]	Conditional GAN	Novel generator architecture for face anonymization via synthesis of realistic faces	No	No	Low	Yes
Ren et al, 2018 [48]	Multitask extension of GAN	Deidentification in video with preservation of action	No	No	High	Yes
Sun et al, 2018 [49]	DCGAN	Novel head inpainting obfuscation technique	Partial	No	Low	Yes
Sun et al, 2018 [50]	GAN	New hybrid approach for identity obfuscation in photos via head replacement	Partial	No	Low	Yes
Bao et al, 2018 [51]	GAN	Disentanglement of identity and attributes from faces for recombination into different identities and attributes for identity-preserving face synthesis in open domains	No	No	High	No
Li et al, 2019 [52]	Adaptive embedding integration network	High-fidelity face swapping	Yes	No	High	Yes
Nirkin et al, 2019 [53]	Face-swapping GAN	Face re-enactment with adjustment for pose and expression variations	No	No	High	Yes

[a]GAN: generative adversarial network.

[b]N/A: not applicable; this information was not reported in this study.

[c]DCGAN: deep convolutional generative adversarial network.

Disentanglement-Coupled GAN

One of the algorithms we chose was the disentanglement-coupled GAN presented by Nitzan et al [39]. The goal of this model is to generate an image by combining the identity of a given identity image with the attributes extracted from an attribute image. The author generates 70,000 images using StyleGAN [55], which are then used as the training data set. Identity is preserved by penalizing the identity difference between the identity image and attribute image. Attribute preservation is achieved by penalizing the difference in pixel-level and facial landmarks between identity image and attribute image. The network architecture is illustrated in Figure 2.

The performance of this method was compared against previously published methods, such as latent optimization for representation disentanglement [56], FaceShifter [52], and face-swapping GAN [53], for qualitative assessment; the performance was also compared against the adversarial latent autoencoder (ALAE) method [57] and the pixel2style2pixel (pSp) method [58] for quantitative assessment. Qualitatively, the authors demonstrated that their method showed better preservation for facial expression (ie, attribute image), head shape, and hair (ie, identity image) compared to the other models noted above. Quantitatively, the reconstruction performance was assessed by measuring pixel-wise reconstruction and preservation of semantic features, followed by comparison of the outcome to that of ALAE and pSp methods. This evaluation indicated that the pSp method showed better performance, but the author emphasized that their method was mainly for disentanglement and was not necessarily designed to reconstruct pixel-level information for reconstruction. This indicates that the model was able to replace and preserve realistic facial features, head shape, hair, and expressions due to superior performance of the disentanglement component while compromising pixel-level detail.

When applying the disentanglement-coupled GAN to the SD-260 data set, there were two sources for the input data: one for *identity* and another for *attribute*. For this model, we experimented with whether the attributes, such as redness and pigmentation, of the faces from the dermatological images could be encoded in a new identity. Figure 3A shows the qualitative results derived from the model: in the data set where the images of interest, with redness and pigmentation, are the *attribute* images, there is no transfer of skin features of interest, only transfer of facial positions and expressions. Figure 3B shows that when the images of interest are the *identity* images, features are transferred without pixel-level accuracy to preserve high data utility for dermatology use. Overall, we can see that while the model generates realistic faces, it is unable to preserve pixel-level details of the faces.

Figure 2. Disentanglement scheme. Solid lines indicate data flow and dashed lines indicate data loss. The identity and attribute codes are first extracted from two input images using encoders E_{id} and E_{attr}, respectively. Through the mapping network M, the concatenated codes are mapped to W, the latent space of the pretrained generator G, which, in turn, generates the resulting image. An adversarial loss L_{adv} ensures proper mapping to the W space. Identity preservation is encouraged using L_{id}, which penalizes differences in identity between I_{id} and I_{out}. Attribute preservation is encouraged using L_{rec} and L_{lnd}, which penalize pixel-level and facial landmark differences, respectively, between I_{attr} and I_{out} (reproduced from Nitzan et al [39], with permission from Yotam Nitzan). D_w: discriminator; Elnd: landmark encoder; z: latent code.

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Figure 3. Output using the disentanglement-coupled GAN on dermatological images derived from the SD-260 data set. (A) Identity images assuming the facial pose and alteration of facial features from the attribute images. The attribute images fail to transfer the features of interest (ie, redness and pigmentation). (B) When switching the identity images to the images with features of interest, the model fails to preserve the dermatological features. GAN: generative adversarial network; SD-260: 260 classes of skin diseases.

Conditional Identity Anonymization GAN

The goal of this paper was to develop a model that can deidentify images and videos while preserving features for other computer vision tasks, such as detection, tracking, or recognition [41]. The overview of the methodology is as follows. The method first extracted the landmarks of a given image that contained a sparse representation of the face with limited information on the identity. This allowed the generator to adjust to the face shape, which enabled better preservation of the input pose. The authors used only the face silhouette, the mouth, and the bridge of the nose instead of using all 68 landmarks in order to allow the network to freely choose the facial features. The method also extracted masked background images to allow the model to learn to generate faces and not the background. Once the landmark and the background were extracted, the method used a conditional GAN (CGAN) [59] to generate realistic images by encoding the landmark and masked image and combining them with the identity images to feed into the decoder. The generated output image was then fed into the identity discriminator network to prevent the network from generating faces similar to the training data set and to ensure facial anonymization. The model architecture is shown in Figure 4.

The model was trained and evaluated on three public data sets: CelebA (CelebFaces Attributes), MOTS (Multi-Object Tracking and Segmentation), and Labeled Faces in the Wild. The performance of the model was assessed by using face detection and reidentification metrics with other existing methods, such as blurring and pixelization. When compared with a state-of-the-art facial deidentification method by Gafni et al [60], conditional identity anonymization GAN (CIAGAN) showed better deidentification rates by computer detection on two different data sets. The authors concluded that their method can both deidentify the source images better and generate much more diverse images compared to Gafni et al's method.

When we applied the CIAGAN to the SD-260 data set, we first processed the landmarks of the dermatological images. Then, we allowed the model to deidentify each individual's face from the processed landmark and background images. The model was pretrained using 1200 identities from the CelebA data set. Figure 5 shows the result from this model. The qualitative results show a reduction in pixel-level resolution as well as poor preservation of the dermatological attributes of interest in the mid to lower part of the face, while preserving the skin features of interest (ie, redness and pigmentation) in the forehead area. While this is a good method for facial swapping, CGAN at this level fails to preserve significant areas of interest with high-utility pixel-level detail.

Figure 4. CIAGAN model scheme. The model takes the image and its landmarks, the masked face, and the desired identity as input. The generator is an encoder-decoder model where the encoder embeds the image information into a low-dimensional space. The identity given as a one-hot label is encoded via a transposed convolutional neural network and is fed into the bottleneck of the generator. Then, the decoder decodes the combined information of source images and the identities into a generated image. The generator plays an adversarial game with a discriminator in a standard GAN setting. Finally, the identity discriminator network is introduced, whose goal is to provide a guiding signal to the generator about the desired identity of the generated face (reproduced from Maximov et al [41], with permission from Laura Leal-Taixe). CIAGAN: conditional identity anonymization generative adversarial network; GAN: generative adversarial network.

Figure 5. Output using CIAGAN on dermatological images derived from the SD-260 data set. Images on the left serve as source images, and a facial swap is done on the mid and lower part of the face for the images on the right. Generated images are of poor quality and only partially preserve facial attributes. CIAGAN: conditional identity anonymization generative adversarial network; SD-260: 260 classes of skin diseases.

Discussion

Principal Findings

Apart from the conventional facial deidentification methods, many of the advanced algorithms aim to preserve key facial features and expressions while maintaining privacy protection for the input images. Specifically, for GANs, there exist three major general limitations with these algorithms. Firstly, the outputs from these models that use face synthesis exhibit significant similarities between the synthetic and original images [61], which can be detected via human evaluation. Many of the currently existing algorithms are effective at modifying the images to avoid identification by face recognition software [17] but are not good enough to pass deidentification by humans. Thus, additional effort needs to be focused on addressing human detection, such as facial feature swap. Secondly, it is difficult to integrate the synthesized faces smoothly into the original image and make the images look unnatural, which compromises

privacy protection [17,62]. Finally, synthetic faces can decrease data usability due to changes in skin attributes, such tone and texture, and due to changes in patient identity, such as age, gender, and race [13,49,63-65]. Particularly for medical applications, even with the recently developed, well-intentioned algorithms, such as disentanglement and CIAGAN, the existing facial deidentification models fail to precisely and accurately preserve the color and texture of the facial skin for applications in their attempt to protect the identity of individuals with dermatological conditions, such as rosacea, melasma, among others, included in the data sets. Hence, the challenge involved with sharing large data sets that include facial images of patients with dermatological conditions, while adequately protecting their identity, remains unresolved.

The current standards for deidentifying patient images involve blurring, pixelating, and masking out important identifying facial features, such as the eyes and eyebrows [6]. Kuang et al [66] showed that pixelation and blurring demonstrate high

deidentification performance on computer detection compared to other advanced methods, such as privacy-protective GAN [67], natural and effective obfuscation [49], and AnonymousNet [63], which is one of the reasons that they remain as popular methods of facial deidentification. However, these conventional methods are at risk of identity restoration via decoding and reconstruction.

We propose that an ideal facial deidentification algorithm for dermatological application needs to (1) preserve facial architectural (ie, shape and gender) and skin features (ie, color and texture) to maintain data utility, while achieving adequate deidentification, and (2) avoid detection by computer and human analysis. To optimally protect the privacy of individuals in the images, the algorithm must be able to modify the image in a way that will be perceived as unaltered. In other words, the replacement identity will need to fuse well with the original content of the image. However, while altering the original content of the image, the skin attributes have to be preserved well enough so that the data utility of the data set involving the dermatological condition is not lost.

Herein, we demonstrate the utility of GAN-based facial deidentification methods to serve as use cases for AI development in dermatology, such as models quantifying redness (acne, rosacea, dermatitis, etc), pigmentation (melasma, postinflammatory hyperpigmentation, lentigines, etc), and texture (aging-related changes, volumetric assessment for neurotoxins or fillers, etc). While GAN development efforts for facial deidentification are not currently focused on skin-based use cases, focusing future efforts to achieve these goals can lead to an optimal facial deidentification model for dermatology.

Conclusions

Although facial deidentification is a rapidly evolving field with several advanced algorithms for achieving facial deidentification by computer-level recognition, their application to dermatology use cases is currently suboptimal. However, GAN-based models have the potential to preserve skin attributes while replacing facial features that risk detection, holding promise to solve the dilemma of data sharing while preserving patient privacy and identity. Future work should focus on developing a model that can achieve both skin attribute preservation as well as detection avoidance by both computers and humans.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Search strategy.
[PDF File (Adobe PDF File), 40 KB - derma_v5i2e35497_app1.pdf]

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Abbreviations

AAM: active appearance model
AI: artificial intelligence
ALAE: adversarial latent autoencoder
CelebA: CelebFaces Attributes
CGAN: conditional generative adversarial network
CIAGAN: conditional identity anonymization generative adversarial network
CNN: convolutional neural network
GAN: generative adversarial network
GNN: generative neural network
LORD: latent optimization for representation disentanglement
MOTS: Multi-Object Tracking and Segmentation
pSp: pixel2style2pixel
SD-260: 260 classes of skin diseases

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Research Letter

From the Cochrane Library: Hydrosurgical Debridement Versus Conventional Surgical Debridement for Acute Partial-Thickness Burns

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Partial-thickness burns often require surgical excision with dressings or reconstruction. Standard of care includes early debridement (tangential excision of nonviable tissue) followed by split-thickness skin grafting. The goal of debridement is to reach a plane of viable tissue, while sparing healthy, uninjured tissue, expediting healing and minimizing scarring. Conventional debridement (scalpel or knife) is potentially limited by inaccurate differentiation between viable and nonviable tissues, with resultant delayed healing and greater scarring. Hydrosurgery is an alternative tool for surgical debridement that uses pressurized saline and a vacuum system to create a Venturi effect, ideally improving debridement accuracy and tissue-sparing. The Cochrane systematic review "Hydrosurgical debridement versus conventional surgical debridement for acute partial-thickness burns" analyzed existing randomized controlled trials (RCTs) enrolling participants with acute partial-thickness burn injuries requiring debridement and grafting; this yielded one eligible study randomizing 61 pediatric patients to either conventional debridement (n=31) or hydrosurgery (n=30) [1].

In this RCT, no clear differences were observed in the mean time to complete healing (mean difference [MD] 0 days, 95% CI –6.25 to 6.25), postoperative infection risk (risk ratio 1.33, 95% CI 0.57-3.11), operative time (MD 0.2 minutes, 95% CI –12.2 to 12.6), or 6-month scar outcome (MD not computed). Study conclusions were very low certainty on the GRADE

(Grading of Recommendations Assessment, Development and Evaluation) assessment, showed a high risk of reporting bias, and were limited by the small sample size (not powered to detect differences in primary outcomes). Generalizability was limited, as the study focused on a pediatric population and smaller burn injuries (3%-4% of total body surface area). No information was reported on clinical resource use, health-related quality of life, or adverse events. The authors concluded that it remains unknown if hydrosurgery is superior to conventional surgery for treatment of middepth burns.

Following the publication of the Cochrane review, no further RCTs have been published that compare the efficacy of hydrosurgical debridement to conventional blade debridement for burns. However, one study is still "awaiting classification," and one multicenter RCT (n=137) is underway to examine long-term (12 months) scar quality for hydrosurgical versus conventional debridement of dermal burns [2].

In addition to its application for burns, there is evidence for hydrosurgery treating other dermatological pathologies. For example, in a study of axillary osmidrosis (n=93), hydrosurgery showed improved patient satisfaction and fewer postoperative complications compared to traditional surgery [3]. Case reports of severe phymatous rosacea, which currently lacks standard surgical guidelines, document successful treatment with

hydrosurgery [4]. Additionally, hydrosurgery can safely and rapidly debride various ulcer types in outpatient settings [5]. As the COVID-19 pandemic continues to decrease the availability of inpatient rooms and services, the possibility of providing outpatient hydrosurgical debridement for wounds may be important for continuing patient care. Dermatologists manage numerous wounds in daily practice; therefore, providers should be informed of the current recommendations for wound debridement. Future research should include additional high-quality RCTs comparing the efficacy of hydrosurgery versus standard debridement for burns. Outcome measures could focus on patient-reported scarring and adverse events. This would increase the certainty and generalizability of the results, and provide evidence for procedural recommendations.

Conflicts of Interest

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Abbreviations

GRADE: Grading of Recommendations Assessment, Development and Evaluation
JID: Journal of Investigative Dermatology
MD: mean difference
NIHR: National Institute of Health Research
RCT: randomized controlled trial

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Research Letter

Geospatial Heterogeneity of Hidradenitis Suppurativa Searches in the United States: Infodemiology Study of Google Search Data

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KEYWORDS

Although hidradenitis suppurativa (HS) is a debilitating skin disease, clear epidemiology of HS is incomplete due to difficulties in data collection [1]. Infodemiology, the utilization of web-based data such as Google Trends for public health purposes, offers a potential solution [2]. With the use of online searches for health information, Google Trends offers a rich data source to address the challenges of population-level HS research [3]. Given that HS is a disorder of disparities [4], we hypothesize that there would be nonuniform HS search interest across the United States.

Relative search volume (RSV) data for Google searches using the keyword "hidradenitis suppurativa" were obtained with the following parameters: *United States*, *January 1, 2016 - December 31, 2021*, *all categories*, and *web search*. RSV data are scaled from 0 to 100, where 100 corresponds to the highest RSV. State-level RSV was normalized by search interest for "hidradenitis suppurativa" relative to all searches in that particular state during the time span of interest. The US geographic distribution of HS searches was visualized with a choropleth map. The heterogeneity of state-level RSV for "hidradenitis suppurativa" was compared with that of "skin" and "acne," which are expected to have a more uniform distribution of searches. The Levene test was used to assess variance heterogeneity. R software (version 3.6.3; The R Foundation) was used for data analysis.

The heterogeneity of "hidradenitis suppurativa" searches is shown in Figure 1. The corresponding SD for the state-level "hidradenitis suppurativa" RSV was 13.8. In contrast, the SD for the state-level "skin" and "acne" RSV were 6.1 and 7.3, respectively. There was significant heterogeneity in the variance of "hidradenitis suppurativa" searches compared with that of both "skin" ($P<.001$) and "acne" ($P<.001$) searches.

We conclude that there are large geographic variations in HS searches that are not observed for skin or acne. Although a lack of population-level data on HS prevalence limits the ability to confirm whether "hidradenitis suppurativa" search heterogeneity is reflective of differences in the state-level prevalence of HS, prior work has demonstrated the correlation of Google search volume with cancer incidence [5]. Given the difficulty of data collection for population-level HS research, further exploring publicly available, real-time data from Google can offer a convenient way to examine the disparities associated with HS. A limitation is that different portions of the population utilize Google to varying extents and may not provide representative estimates for HS interest.

Our study presents insights into HS distribution and the potential for precision public health efforts to address areas with increased "hidradenitis suppurativa" searches that may be correlated with higher HS burden. This research provides the groundwork for using publicly available data as surveillance tools that can provide insights specific to populations of interest and offers a

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general methodological framework applicable to the investigation of dermatological diseases with challenging data collection. Overall, this big data digital dermatoepidemiological approach serves as an important foundation for further public health efforts and epidemiological studies on HS and health care disparities.

Figure 1. Choropleth map displaying the geographic distribution of search interest for the search term "hidradenitis suppurativa" through state-level relative search volume (RSV) data from January 1, 2016, to December 31, 2021, where dark red corresponds to the highest RSV and light red corresponds to the lowest RSV.

Acknowledgments

Conflicts of Interest

GAO is a consultant for Unilever; is on the advisory board for Pfizer, Janssen, Novartis, UCB, and Lilly; and receives grants from Pfizer and Janssen.

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Abbreviations

HS: hidradenitis suppurativa
NIH: National Institutes of Health
RSV: relative search volume

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<u>Research Letter</u>

Novel Kappa-Opioid Receptor Agonist for the Treatment of Cholestatic Pruritus: Systematic Review

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Chronic pruritus is a common and debilitating symptom associated with many dermatologic conditions and substantially impairs patients' quality of life (QOL). In fact, the impact of chronic pruritis is thought to be comparable to that of chronic pain. Unfortunately, effective management for chronic pruritus remains limited and primarily consists of nonspecific measures, such as antihistamines and moisturizers.

There has been emerging evidence from various clinical trials demonstrating the efficacy and tolerability of a highly selective kappa-agonist, nalfurafine hydrochloride (TRK-820), for the treatment of pruritus in patients with chronic liver disease. Therefore, we conducted a systematic review to assess the efficacy of this agent in liver disease–associated pruritus.

PubMed and Embase were searched from inception to February 9, 2022, using the keywords "nalfurafine hydrochloride," "itch," and "pruritus" without restrictions. Two independent reviewers (authors AB and HOYL) screened and extracted data from all articles, with the supervising author (MK) providing consensus. All full-text single-arm, case-control, cohort, and randomized controlled trials with >10 patients describing the use of nalfurafine hydrochloride for the treatment of liver disease–associated pruritus were included. Editorials, commentaries, guidelines, and reviews were excluded. Outcomes included itch scores, QOL scores, and adverse events. The Cochrane Risk of Bias Tool 2.0 and the National Institutes of Health Pre-Post Study Quality Assessment Tool were applied to assess study quality (Multimedia Appendix 1).

Of 233 unique records, 5 studies were included (Figure 1). Study characteristics are summarized in Table 1. All studies were of low risk of bias or good quality.

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Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram of the study selection process.

Table 1. Characteristics of included studies.

Study name	Country	Study type (data range)	Type of liver disease	Total participants, N (% female)	Age (years), mean	Treatment	Outcomes[a]	Study quality
Yagi et al, 2018 [1]	Japan	Single arm (2015-2016)	• PBC[b] with refractory pruritus	44 (89)	66.8 (SD 12.3)	2.5 mcg nalfurafine once daily for 12 weeks	• VAS[c]: 42.9 at baseline to 29.3 at the end point (P=.001) • PBC-40: 8.56 at baseline to 7.63 at the end point (P=.04)[d] • SF-36[e]: 42.9 at baseline to 29.3 at the end point (P=.001)[d]	Good
Akuta et al, 2018 [2]	Japan	Single arm (2015-2017)	• Positive for HBsAg[f] (n=19) • Positive for HCV[g] antibody (n=70) • HCC[h] (n=44) • Others (n=5)	138 (53)	66 (range 24-91)	2.5 mcg nalfurafine once daily for a median of 6.4 (range 1-38) weeks	• 93 of 138 (67.4%) patients experienced a clinically relevant decrease in itch severity at the end point compared to baseline, predefined as a >50 mm decrease in their VAS score. • This did not vary according to the etiology of liver disease (HBsAg+, HCV+, or HCC; P=.16).	Good
Yoshikawa et al, 2021 [3]	Japan	Single arm (2017-2018)	• HCV (n=12) • AFLD[i] (n=5) • NAFLD[j] (n=1) • PBC (n=5) • Other (n=1) with refractory pruritus	24 (50)	68 (range 18-87)	2.5 mcg nalfurafine once daily for 12 weeks	• 17 of 24 (71%) patients experienced a clinically relevant decrease in itch severity at the end point compared to baseline, predefined as a >30 mm decrease in their VAS score. • VAS: 50 at baseline to 25 at the end point (P=.001)	Good
Kumada et al, 2017 [4]	Japan	Randomized double-blind trial (2010-2012)	• Chronic hepatitis (n=78) • Cirrhosis (n=142) • PBC (n=87) • Others (n=28) with refractory pruritus	317 (57)	66.5 (SD 10.6)	2.5 mcg or 5 mcg nalfurafine once daily for 4 weeks	• Decrease in VAS: 28.56 and 27.46 mm in the 2.5 µg and 5 µg groups at the end point from baseline, respectively, compared to 19.25 mm in the placebo group (P=.002 and P=.006, respectively)	Low risk of bias
Kamimura et al, 2018 [5]	Japan	Single arm (2015-2017)	• PBC (n=11) • AFLD (n=2) • HCV (n=2) • Vanishing bile duct syndrome (n=2) • AIH[k] (n=1)	11 (78)	69 (range 45-82)	2.5 mcg nalfurafine once daily for >20 weeks	• The reduction in pruritus scores was correlated with the time of administration (Pearson correlation coefficient r^2=0.636; P=.001).	Good

[a]Unless otherwise indicated comparisons between baseline and the end point across studies were determined using a paired Student t test for continuous and normally distributed variables and the Mann Whitney U test for variables without normal distribution.

[b]PBC: primary biliary cholangitis.

[c]VAS: visual analog scale.

[d]Both the SF-36 and PBC-40 are validated tools that assess the symptoms and health-related quality of life in patients with PBC.

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[e]SF-36: 36-Item Short Form Health Survey.

[f]HBsAg: hepatitis B surface antigen.

[g]HCV: hepatitis C virus.

[h]HCC: hepatocellular carcinoma.

[i]AFLD: alcoholic fatty liver disease.

[j]NAFLD: nonalcoholic fatty liver disease.

[k]AIH: autoimmune hepatitis.

In a double-blind randomized controlled trial [4], patients with chronic liver disease and refractory pruritus experienced significant reductions in itch severity compared to a placebo capsule at 12 weeks, with a decrease in the visual analog scale of 41.6 and 39.3 mm in the 2.5 µg and 5 µg groups, respectively, compared to 32 mm in the placebo group (P=.007 and P=.03, respectively). The incidence of adverse drug reactions was higher in the experimental groups than in the placebo group. Patients reported these reactions were mild and did not impact patients' daily activities. Major adverse drug reactions included polyuria, somnolence, insomnia, and constipation, all of which had a prevalence of 8% or lower at both doses and had a similar incidence in the placebo group.

Accounting for a combined 217 patients, 4 single-arm studies found that nalfurafine hydrochloride provided a clinically relevant decrease in itch severity in 67% to 71% of patients [2,3] and significantly improved patient QOL compared to baseline (PBC-40 decreased from 8.56 to 7.63, P=.04, and the 36-Item Short Form Health Survey decreased from 42.9 to 29.3, P=.001) [1], with no signs of dependence or abuse. The reduction in pruritus scores was also correlated with time of administration (r^2=0.636; P=.001) [5].

In conclusion, nalfurafine hydrochloride has demonstrated efficacy in the treatment of liver disease–associated pruritis, significantly reducing itch scores compared to the placebo and improving patient QOL. Its advantage over nonspecific measures is its efficacy in refractory pruritus and favorable side effect profile. Considering this agent's efficacy and tolerability, and the detrimental effect of refractory pruritus on patient well-being, dermatologists and other physicians should strongly consider this agent for future investigation and eventual use in chronic liver disease–associated pruritus.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplementary material.
[PDF File (Adobe PDF File), 315 KB - derma_v5i2e30737_app1.pdf]

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Abbreviations

QOL: quality of life

Letter to the Editor

Lack of Skin of Color Representation in Dermatology-Related Instagram Posts: Content Analysis

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Introduction

There is growing recognition that disparities in health care utilization affect patient outcomes. Notably, Black and Hispanic patients are more than 45% less likely compared to White patients to utilize dermatology care for a skin condition [1]. One factor contributing to health care underutilization by racial and ethnic minority groups may be the lack of health information [2]. Previous work has studied the credentials of social media influencers in dermatology and the lack of skin type diversity in dermatology textbooks [3,4]. Given the increasing use of social media as a health information resource, we aimed to evaluate and characterize skin type representation in popular dermatology-related posts on Instagram [5].

Methods

Some of the most used Instagram hashtags encompassing common dermatologic diagnoses (#acne, #eczema, #psoriasis), procedures (#botox, #chemicalpeel, #mohs), and #dermatology [6] were selected for review. With every hashtag, Instagram's "Top Posts" feature was used to account for user-specific feed differences and was evaluated every other day for 15 consecutive days in February 2021. For each post, we recorded account type, number of account followers, engagement rate (ER), and skin type of the featured individual. The social media ER, determined using SocialBlade (a social media analytics website [7]), is a quantitative measure of the amount of interaction that content receives relative to a user's audience size. Two independent observers (FA and PO) estimated the Fitzpatrick skin type (I-VI). With any ambiguity regarding skin types or when multiple individuals were displayed, photographs were labeled with the highest evident Fitzpatrick score. In cases of interrater disagreement, a third observer (JL) independently evaluated the photograph to reach a consensus. This study was considered exempt by the Institutional Review Board.

Results

Of the posts reviewed (N=441), 46 (10.4%) displayed skin of color (SOC), characterized as Fitzpatrick types IV to VI (Table 1). Cohen κ, measuring interrater reliability for Fitzpatrick skin type, was almost perfect at 0.87. The mean follower count and ER for lighter skin type (Fitzpatrick types I-III) posts were 167,660 and 3.75%, respectively. The mean follower count and ER for SOC posts were 87,440 and 4.68%, respectively. Of the posts made by provider accounts, 9.8% (17/173) displayed SOC individuals. Counts of Fitzpatrick skin types by hashtag are reported in Table 2.

Table 1. Fitzpatrick skin types by account type.

Fitzpatrick skin type	Business accounts (n=128), n	Provider accounts (n=173), n	Personal accounts (n=140), n	Total (N=441), n (%)
I	7	7	4	18 (4.1)
II	78	121	102	301 (68.3)
III	25	28	23	76 (17.2)
IV	10	14	9	33 (7.5)
V	7	3	2	12 (2.7)
VI	1	0	0	1 (0.2)

Table 2. Fitzpatrick skin types by hashtag.

Hashtag	Fitzpatrick skin type I-III (n=395), n	Fitzpatrick skin type IV-VI (n=46), n
#acne	57	6
#eczema	56	7
#psoriasis	57	6
#botox[a]	62	1
#chemicalpeel	47	16
#mohs[a]	62	1

[a]The hashtags #botox and #mohs each had the fewest posts (n=1) with darker skin color, possibly due to skin cancer incidence and Botox use being different among the 2 groups.

Discussion

Our findings suggest that SOC individuals may be underrepresented on dermatology-related Instagram posts and have a smaller reach as demonstrated by lower follower counts. However, SOC posts had a higher ER, suggesting that users were more likely to interact and engage with SOC content. Limitations include Fitzpatrick skin type estimation being based on photographs alone; however, by recording intermediate skin types as darker during data collection, this would have biased against the hypothesis of underrepresentation of SOC. Additionally, the user demographics of Instagram are not publicly available to assess relative underrepresentation. Lastly, this classification system is not a direct proxy of race, and racial and ethnic minority groups may not only have Fitzpatrick skin types IV to VI.

Given the increasing importance of social media in sharing health information, it is imperative that we understand and proactively address the issue of underrepresentation. For example, at one institution, educational physician-created social media videos helped increase health care appointment demand and patient health education [5]. Increasing the number of SOC influencers may also help, similar to how patient-provider racial concordance is correlated with increased trust [2]. Thus, increasing representation in dermatologic content on social media may help achieve an opportunity for improved community outreach for racial and ethnic minority groups. Providers, professional organizations, and commercial organizations can play an active role in improving this representation.

Conflicts of Interest

None declared.

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Abbreviations

ER: engagement rate
SOC: skin of color

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<u>Research Letter</u>

Top Skin-of-Color Publications in Dermatology

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Introduction

Tools such as the Altmetric Attention Score (AAS) and Web of Science (WoS) allow researchers to qualify their work's impact. WoS uses publication citation counts and is often utilized in academia, while the AAS analyzes online media attention to determine the impact of research [1].

Methods

Using Altmetric Explorer to obtain an article's AAS and WoS to measure an article's citation count, the top 50 papers from each search engine were collected using the keywords "skin of color" and "dermatology." An article's mention in news outlets and on blogs and Twitter were recorded from Altmetric Explorer as well as whether these mentions came from members of the public or practitioners; this we defined as metrics indicative of online media "attention." The mean (SD), 95% CI, and *P* values

were determined by comparing the metrics provided by the top 50 papers from Altmetric and WoS.

Results

Table 1 presents a comparison of the top 10 cited articles on WoS and the top 10 articles with the highest AAS.

The mean AAS for the top 50 papers from Altmetric and WoS were 39.1 and 24.2, respectively (*P*=.02). The *P* values were statistically significant in several of the categories compared, including the AAS (*P*=.02), news outlet mentions (*P*=.008), and Twitter mentions (*P*=.02) (Table 2). Recurring themes in the top AAS skin-of-color (SoC) papers included skin cancer; cosmetic dermatology, notably pigmentation disorders; and inadequate knowledge among health care practitioners in identifying dermatologic conditions in SoC patients. By contrast, the top-cited SoC papers from WoS involved basic science research of dermatologic conditions and recommendations for assessment tools for clinicians and patients.

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Table 1. Top 10 cited dermatology papers on Web of Science compared to the top 10 high-scoring Altmetric papers.

Article title	Authors	Altmetric Attention Score	Total citations (on Web of Science), n	Publication year	Journal	Country
Top 10 Altmetric articles						
Postinflammatory hyperpigmentation: A review of the epidemiology, clinical features, and treatment options in skin of color	Davis et al [2]	211	359	2010	JCAD[a]	United States
Acne vulgaris in skin of color: Understanding nuances and optimizing treatment outcomes	Alexis [3]	179	12	2014	JDD[b]	United States
Background and room illumination in color identification of skin lesions	Maymone et al [4]	128	6	2017	*JAMA* [c] *Dermatology*	United States
Skin cancer and photoprotection in people of color: A review and recommendations for physicians and the public	Agbai et al [5]	122	120	2014	JAAD[d]	United States
UV Exposure and the risk of cutaneous melanoma in skin of color: A systematic review	Lopes et al [6]	102	7	2021	*JAMA Dermatology*	United States
Skin color in dermatology textbooks: An updated evaluation and analysis	Adelekun et al [7]	98	17	2021	JAAD	United States
Skin cancer in skin of color	Bradford [8]	80	196	2009	*Dermatology Nursing*	United States
The use of noncultured regenerative epithelial suspension for improving skin color and scars: A report of 8 cases and review of the literature	Ren et al [9]	72	2	2019	*Journal of Cosmetic Dermatology*	China
Gaps in the understanding and treatment of skin cancer in people of color	Kailas et al [10]	54	4	2016	JAAD	United States
How dermatology is failing melanoma patients with skin of color: Unanswered questions on risk and eye-opening disparities in outcomes are weighing heavily on melanoma patients with darker skin	Nelson [11]	53	3	2020	*Cancer Cytopathology*	United States
Top 10 Web of Science articles						
Skin cancer in skin of color	Gloster Jr et al [12]	26	301	2006	JAAD	United States
Skin of color: Biology, structure, function, and implications for dermatologic disease	Taylor [13]	34	220	2002	JAAD	United States
A mouse model of vitiligo with focused epidermal depigmentation requires IFN-gamma for autoreactive CD8(+) T-cell accumulation in the skin	Harris et al [14]	24	159	2012	JID[e]	United States
Skin cancer and photoprotection in people of color: A review and recommendations for physicians and the public	Agbai et al [5]	122	120	2014	JAAD	United States
Acne vulgaris in skin of color	Taylor et al [15]	2	102	2002	JAAD	United States
The Asian dermatologic patient review of common pigmentary disorders and cutaneous diseases	Ho et al [16]	1	84	2009	*American Journal of Clinical Dermatology*	China

Article title	Authors	Altmetric Attention Score	Total citations (on Web of Science), n	Publication year	Journal	Country
Melasma: an up-to-date comprehensive review	Ogbechie-Godec et al [17]	10	61	2017	*Dermatology and Therapy*	United States
Development and validation of a vitiligo-specific quality-of-life instrument (VitiQoL)	Lilly et al [18]	2	61	2013	JAAD	United States
Accuracy of self-report in assessing Fitzpatrick skin phototypes I through VI	Eilers et al [19]	18	53	2013	*JAMA Dermatology*	United States
Defining pseudofolliculitis barbae in 2001: A review of the literature and current trends	Perry et al [20]	3	52	2002	JAAD	United States

Table 2. The top 50 Altmetric papers versus the top 50 cited papers in Web of Science.

	Altmetric Attention Score	Citations	News outlet mentions	Blog mentions	Twitter mentions	Count of mentions by members of the public	Count of mentions by practitioners
Top 50 skin-of-color Altmetric publications, mean (95% CI)	39.1 (27.1-51.1)	41.9 (20.2-63.6)	4.7 (3.0-6.4)	0.2 (0.1-0.4)	9.9 (6.2-13.6)	5.6 (3.5-7.8)	1.0 (0.5-1.5)
Top 50 skin-of-color Web of Science publications, mean (95% CI)	24.2 (14.6-33.8)	46.1 (31.2-61.0)	2.1 (1.1-3.2)	0.2 (0.1-0.4)	5.9 (2.9-8.8)	4.1 (2.0-6.2)	0.7 (0.2-1.2)
P value[a]	.02	.34	.008	.42	.02	.17	.11

[a]JCAD: *Journal of Clinical & Aesthetic Dermatology*.

[b]JDD: *Journal of Drugs in Dermatology*.

[c]JAMA: *Journal of the American Medical Association*.

[d]JAAD: *Journal of the American Academy of Dermatology*.

[e]JID: *Journal of Investigative Dermatology*.

[a]*t* test.

Discussion

Principal Findings

While highly cited publications often guide clinical recommendations and carry substantial influence on practitioners, they may fail to highlight the discussions taking place outside of the scientific community [21]. For SoC patients, their interests and concerns regarding dermatologic conditions must be understood by health care providers as disease processes often manifest differently in this population compared to the general public [13]. With over 70% of the US population using social media, these platforms will allow increased sharing of research topics, supporting the utility of Altmetric scoring compared to citation count alone [22]. Within our study, the difference in recurrent themes between top AAS versus top-cited publications indicated that the clinical mindset and patient-centered topics may not align.

Limitations and Future Work

Limitations to our study include a small sample size, narrow inclusion criteria, and a lack of time constraints. Future studies comparing AAS and WoS should be confined to a short time period to mitigate temporal confounding factors due to the differing accrual rates of citation count and AAS [23]. Medical societies and health care providers can use insights from this study to shape the practice of dermatology to better understand the interests and expectations of SoC patients.

Conclusion

AAS and WoS provide different metrics on the influence of academic research. Factors that may generate greater social media attention include papers with more pictures and an author's social media presence. Elements that may produce greater citation counts include a journal's impact factor and an author's academic reputation and home institution. Altmetric uniquely represents the attention of the general public, which can facilitate patient-centered decision-making.

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Conflicts of Interest

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Abbreviations

AAS: Altmetric Attention Score
SoC: skin of color
WoS: Web of Science

Research Letter

From the Cochrane Library: Interventions for the Prevention of Herpes Simplex Labialis (Cold Sores on the Lips)

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In 2016, the World Health Organization estimated that 67% of the global population is infected with herpes simplex virus type 1 (HSV-1), which causes herpes simplex labialis (HSL) [1].The lifetime prevalence of recurrent HSL is 20% to 52.5% [2].It is highly contagious and mainly transmitted through oral-to-oral contact [1]. HSL is a lifelong, often asymptomatic infection that lays dormant in the trigeminal nerve. Common symptoms include prodromal tingling or burning sensation around the mouth and eruption of painful, self-limiting vesicles ("cold sores") progressing to unsightly crusts [1,2]. HSV-1 recurrence can be triggered by ultraviolet light, stress, premenstrual changes, and surgical procedures; its highly visible nature can lead to embarrassment and psychological distress [2]. Antiviral medications are the standard treatment but have adverse effects such as rash, headache, and gastrointestinal upset [1].

A 2015 Cochrane review [2] assessed the effects of preventative interventions for HSL in immunocompetent people of all ages, analyzing evidence from 32 randomized controlled trials on 19 preventative measures. Primary outcomes and key findings are summarized in Table 1.

Table 1. Treatment comparison from the Cochrane review [2] for herpes simplex labialis (HSL) with respective results, risk ratio (RR) with CI, comparative risk (CR) with or without *P* value, or mean difference (MD) with CI.

Comparison	Measurement (primary outcome)	Result	Statistical results	Quality of evidence
Oral acyclovir vs placebo (short term ≤1 month): (1) 800 mg 2×/day; (2) 400 mg 2×/day; (3) 200 mg 5×/day	Incidence of HSL during use of the preventive intervention	Unclear. No preventative effect; not currently recommended	• (1) RR 1.08 (0.62 to 1.87) • (2) RR 0.26 (0.13 to 0.51) • (3) RR 0.46 (0.20 to 1.07)	• (1) Moderate • (2) Low • (3) Low
Oral acyclovir vs placebo (long term >1 month): 400 mg 2×/day	Incidence of HSL during use of the preventive intervention (clinical recurrences)	Acyclovir was slightly superior. Recommended (small effect)	• CR 0.85 vs 1.80 episodes per participant per 4-month period • MD –3.6 (–7.2 to 0)	• Low
Oral valaciclovir vs placebo (short term ≤1 month): 2 g 2×/day for the first day, 1 g 2×/day for the second day	Incidence of HSL during use of the preventive intervention	No significant difference. No preventative effect; not currently recommended	• RR 0.55 (0.23 to 1.28)	• Moderate
Oral valacyclovir vs placebo (long term >1 month): 500 mg 1×/day	Incidence of HSL during use of the preventive intervention	Valacyclovir was slightly superior. Recommended (small effect)	• CR 0.12 vs 0.21 episodes per participant per month • MD 0.009	• Moderate
Oral famciclovir vs placebo (short term ≤1 month): (1) 125 mg 3×/day; (2) 250 mg 3×/day; (3) 500 mg 3×/day	Incidence of HSL during use of the preventive intervention	No significant difference. No preventative effect; not currently recommended	• (1) RR 0.74 (0.5 to 1.11) • (2) RR 0.69 (0.45 to 1.04) • (3) RR 0.82 (0.56 to 1.21)	• (1) Moderate • (2) Moderate • (3) Moderate
Oral levamisole vs placebo (long term >1 month): 2.5 mg/kg 2×/week	Incidence of HSL during use of the preventive intervention	No consistent data. No preventative effect; not currently recommended	• MD –2 (–2.24 to –1.76)	• Very low
Oral lysine vs placebo (long term >1 month): 1000 mg 1×/day	Incidence of HSL during use of the preventive intervention	No significant difference. No preventative effect; not currently recommended	• MD –0.04 (–0.37 to 0.29)	• Very low
Topical acyclovir 5% cream vs placebo (short term ≤1 month): 5×/day	Incidence of HSL during use of the preventive intervention	No significant difference. No preventative effect; not currently recommended	• RR 0.91 (0.48 to 1.72)	• Moderate
Topical acyclovir 5% and 348U87 3% cream vs placebo (short term ≤1 month): 1×/2 hours during awake hours	Incidence of HSL during use of the preventive intervention (by culture)	No significant difference. No preventative effect; not currently recommended	• RR 0.78 (0.19 to 3.14)	• Very low
Topical foscarnet 3% vs placebo (short term ≤1 month): 8×/day	Incidence of HSL during use of the preventive intervention	No significant difference. No preventative effect; not currently recommended	• RR 1.08 (0.82 to 1.4)	• Moderate
Topical 1,5 pentanediol vs placebo (long term >1 month): 2×/day	Incidence of HSL during use of the preventive intervention	No significant difference. No preventative effect; not currently recommended	• CR 120 episodes out of 53 (topical) vs 109 episodes out of 50 (placebo); *P*>.05	• Moderate
Sunscreen vs placebo (short term ≤1 month); 1× prior to immediate exposure to (1) solar radiation and (2) experimental ultraviolet light	Incidence of HSL during use of the preventive intervention	Unclear. Not currently recommended; further research warranted	• (1) Under sunlight: RR 1.13 (0.25 to 5.06) • (2) Under experimental ultraviolet light: RR 0.07 (0.01 to 0.33)	• (1) Low • (2) Very low

Comparison	Measurement (primary outcome)	Result	Statistical results	Quality of evidence
Interferon injection (70,000 U/kg) vs placebo (short term ≤1 month): (1) presurgical 2×/day; (2) postsurgical 2×/day; (3) pre- and postsurgical 2×/day	Incidence of HSL during use of the preventive intervention	Unclear. No preventative effect; not currently recommended	• (1) RR 1.59 (1.05 to 2.41) • (2) RR 0.99 (0.59 to 1.66) • (3) RR 0.57 (0.34 to 0.95)	• (1) Low • (2) Low • (3) Low
Gamma globin injection vs histamine (control, dilute 1:5000) (short term ≤1 month): 0.2 ml 1× dose	Duration of HSL outbreak	No significant difference. No preventative effect; not currently recommended	• MD 0.7 (–0.55, 1.95)	• Low
Thymopentin injection vs placebo (long term >1 month): 50 mg 3×/week	Incidence of HSL during use of the preventive intervention	Thymopentin was superior. Not currently recommended; further research warranted	• CR median 0.2 for thymopentin vs 0.9 for placebo; P=.0027	• Moderate
Herpes simplex virus type I vaccine injection vs placebo (short term ≤1 month): 1× dose	Incidence of HSL during use of the preventive intervention	No significant difference. No preventative effect; not currently recommended	• CR 1.6 vs 1.3 recurrences in 4 months (P=.1)	• Moderate
Laser (low intensity, 690 nm, 80 mW/cm^2, 48 J/cm^2) vs no intervention (short term ≤1 month): 1×/day	Time to first occurrence	Low-intensity diode laser was superior but low-energy gallium-aluminum-arsenide laser was not. Not currently recommended; further research warranted	• Low-energy gallium-aluminum-arsenide laser: CR 0.076 vs 0.116 recurrences per month (P=.076) • Low-intensity diode laser, median recurrence-free interval: MD 30 (21.42 to 38.58)	• Very low
Hypnotherapy vs control (long term >1 month): 1×/week	Change in the frequency of recurrence	Hypnotherapy was superior. Not currently recommended; further research warranted	• MD –6.5 (–8.76 to –4.24)	• Very low

Compared to the placebo, long-term oral acyclovir and valaciclovir reduced recurrences, although clinical benefit is limited. Limited data suggest thymopentin, low-level laser therapy (LLLT), and hypnotherapy may be effective, but further research is required. There was no evidence supporting the efficacy of lysine, LongoVital supplementation, gamma globulin, the HSV vaccine, the yellow fever vaccine, levamisole, or interferon. Compared to the placebo, there was no significant increase in adverse effects for any of the interventions assessed.

Further research is needed to establish the safety and efficacy of other preventive methods, such as HSV-1 subunit and dendritic cell–based vaccines, LLLT, and topical corticosteroids [1]. A dendritic cell vaccine pilot study (n=14) reported a 3-fold reduction in recurrence during the posttreatment period [3]. Laser therapy relies on analgesic, anti-inflammatory, anti-infective, and biostimulating effects, promoting tissue regeneration and immune response. Although LLLT is promising, caution is warranted due to heterogenicity in study methods and laser parameters [4].

This Cochrane review [2] confirms the preventative efficacy of long-term oral antivirals, highlights the need for further research on sunscreen and natural sunlight, and emphasizes the importance of defining core outcome sets for future studies to adopt. Establishing additional preventative options for HSL remains of paramount importance, considering its significant disease burden and growing antiviral resistance.

Conflicts of Interest

Editorial Notice

The views expressed in this paper are those of the author(s) and in no way represent the Cochrane Library or Wiley. This article is based on a Cochrane Review previously published in the Cochrane Database of Systematic Reviews 2015, Issue 8, DOI: 10.1002/14651858.CD010095.pub2 (see www.cochranelibrary.com for information). Cochrane Reviews are regularly updated as new evidence emerges and in response to feedback, and Cochrane Database of Systematic Reviews should be consulted for the most recent version of the review.

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Abbreviations

HSL: herpes simplex labialis
HSV-1: herpes simplex virus type 1
LLLT: low-level laser therapy

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<u>Research Letter</u>

Pharmaceutical Payments to Authors of Dermatology Guidelines After Publication

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KEYWORDS

Clinical practice guidelines (CPGs) play increasingly vital and influential roles in clinical decision-making, optimization of patient care, and establishment and assessment care quality standards, and can affect insurance coverage. Oftentimes, CPG author expertise is sought by insurance and pharmaceutical companies, creating industry-physician relationships that may influence physicians' professional decisions. This is known as a conflict of interest (COI). Previous studies [1,2] provide strategies for reducing COI impact on guideline development (eg, restricting voting on final recommendations by committee members with COIs [1], requiring conflict-free periods prior to participation in guideline development [2]). In a June 2020 statement, the American Academy of Dermatology (AAD) announced revisions to its guideline development process, specifying that at least 51% of those authoring guidelines be nonconflicted (ie, no relevant financial COIs) and requiring nonconflicted authors to remain so for the entire guideline development process (ie, no new relevant industry relationships initiated during development) [3]. CPG development ends when the draft guideline is approved by the AAD's Board of Directors and submitted for publication [4]. The AAD requires disclosure of financial interests occurring within the 2-year period prior to CPG authorship [5]. Although a prior study[6] demonstrated that former Food and Drug Administration committee members

frequently received payments from the industry after the approval of dermatologic drugs, to our knowledge, there exists no similar exploration of industry payments to authors of recently published AAD guidelines.

Post hoc general industry payments to AAD guideline authors in the period shortly following guideline publication (defined as publication year and 1 subsequent year) were analyzed. We reviewed all current AAD CPGs, including acne vulgaris, atopic dermatitis, keratinocyte carcinoma (basal cell carcinoma and squamous cell carcinoma, same guideline authors), melanoma, psoriasis, and surgery, with publication dates spanning from 2013 to 2018. General payments made by companies to each CPG author were extracted and aggregated from publicly available data in the Centers for Medicare and Medicaid Services Open Payments database [7]. The psoriasis guideline was excluded from further analysis because, unlike the other guidelines, it was published after the recent changes to the AAD's COI policy for guideline authors, and Open Payments data was only available through 2020. The Food and Drug Administration Orange [8] and Purple [9] Book databases were searched to identify companies (and subsidiaries, according to US Securities and Exchange Commission filings) that were manufacturers of CPG drugs.

Of the 6 dermatology CPGs (Table 1), total payments to CPG authors by pharmaceutical companies manufacturing CPG-recommended drugs ranged from $46,554 (melanoma) to $1,374,780 (acne).

Of 99 unique CPG authors, 56 (57%) received at least one payment from a company responsible for a CPG-recommended drug (range 39%-74% across guidelines) (Table 2). A total of 22 (22%) received ≥$10,000 and 10 (10%) received ≥$50,000.

Overall, AAD CPG authors received substantial industry payments from companies with financial interests in the guideline recommendations, corroborating previous studies [10]. Industry payments occurring in the early postpublication period were received by more than 51% of the authors of CPGs on atopic dermatitis, acne, and surgery. Efforts to improve the transparency of author disclosures and minimize commercial bias are encouraged, and future studies should assess the impact of the recently implemented changes to the AAD's guideline development.

Table 1. Pharmaceutical payments[a] to American Academy of Dermatology (AAD) clinical practice guideline (CPG) authors.

Rank	Atopic dermatitis guideline drug company	Payments to authors ($)	Acne vulgaris guideline drug company	Payments to authors ($)	Local anesthesia for dermatologic surgery guideline drug company	Payments to authors ($)	BCC[b] and SCC[c] guideline drug company	Payments to authors ($)	Melanoma guideline drug company	Payments to authors ($)
1	Medimetriks Pharmaceuticals	223,630.70	Galderma (and subsidiaries)	453,849.76	Teva (and subsidiaries)	53,630.20	Lilly (and subsidiaries)	123,696.59	Merck	21,546.61
2	Pfizer (and subsidiaries)	170,815.50	Abbvie (and subsidiaries)	429,684.33	Purdue Pharma	12,837.50	Novartis (and subsidiaries)	73,842.97	Bristol Myers Squibb (and subsidiaries)	14,548.21
3	Novartis (and subsidiaries)	147,242.97	Valeant Pharmaceuticals	209,588.28	Sun Pharma (and subsidiaries)	9178.76	Pfizer (and subsidiaries)	16,490.66	Novartis	7271.78
4	Celgene Corporation	76,003.29	Bayer	110,725.18	Genentech	8394.02	Pierre Fabre Pharmaceuticals	6842.92	Bausch (and subsidiaries)	2238.43
5	Valeant Pharmaceuticals	47,953.71	Pfizer (and subsidiaries)	85,442.24	Novartis (and subsidiaries)	5495.04	Bausch (and subsidiaries)	4496.13	Roche (and subsidiaries)	949.61
6	Galderma (and subsidiaries)	35,197.51	Sanofi (and subsidiaries)	27,533.66	Pfizer (and subsidiaries)	2561.25	Biofrontera	540.67	__[d]	—
7	Lilly (and subsidiaries)	29,300.02	Dr Reddy's Laboratories (and subsidiaries)	19,922.14	Bristol Myers Squibb (and subsidiaries)	1185.94	Smith & Nephew (and subsidiaries)	325.56	—	—
8	Abbvie (and subsidiaries)	27,875.65	Novartis (and subsidiaries)	19,880.38	Abbott Laboratories	325.00	Sun Pharma (and subsidiaries)	231.67	—	—
9	Sanofi-Aventis	24,989.05	Almirall (and subsidiaries)	5565.86	Bayer	117.13	Taro Pharmaceuticals	108.78	—	—
10	Merck (and subsidiaries)	22,693.38	Sun Pharma (and subsidiaries)	4235.73	Valeant Pharmaceuticals	73.87	Genentech	61.92	—	—
11	Astellas Pharma	18,777.96	Janssen (and subsidiaries)	2783.54	Merck	45.71	Almirall	33.51	—	—
12	Roche (and subsidiaries)	17,618.10	Taro	2472.86	Lilly	35.58	Amgen	14.33	—	—
13	Ranbaxy	16,385.19	Exeltis	1750.00	Promius Pharma	19.14	—	—	—	—
14	GlaxoSmithKline	16,102.24	Lilly	650.40	—	—	—	—	—	—
15	Aqua Pharmaceuticals	13,812.70	Merz (and subsidiaries)	565.31	—	—	—	—	—	—
16	Taro Pharmaceuticals	10,010.42	Lupin Pharmaceuticals	49.66	—	—	—	—	—	—
17	Bayer	9000.00	Biofrontera	30.99	—	—	—	—	—	—

Rank	Atopic dermatitis guideline drug company	Payments to authors ($)	Acne vulgaris guideline drug company	Payments to authors ($)	Local anesthesia for dermatologic surgery guideline drug company	Payments to authors ($)	BCC[b] and SCC[c] guideline drug company	Payments to authors ($)	Melanoma guideline drug company	Payments to authors ($)
18	Dr Reddy's Laboratories (and subsidiaries)	6680.09	Shire	22.15	—	—	—	—	—	—
19	Leo Pharma (and subsidiaries)	5618.60	Teva	14.86	—	—	—	—	—	—
20	Medimmune	1844.42	Arbor	12.77	—	—	—	—	—	—
21	Teva (and subsidiaries)	1394.09	—	—	—	—	—	—	—	—
22	UCB SA	358.00	—	—	—	—	—	—	—	—
Total payments to authors		923,303.59	—	1,374,780.10	—	93,899.14	—	226,685.71	—	46,554.64

[a]General payment data from Open Payments was totaled for each AAD CPG author in the year of CPG publication and the subsequent year. General payments include payments or other transfers of value that were not made in connection with a research agreement or research protocol. Company subsidiaries were determined according to recent US Securities and Exchange Commission filings.

[b]BCC: basal cell carcinoma.

[c]SCC: squamous cell carcinoma.

[d]N/A: not applicable.

Table 2. American Academy of Dermatology (AAD) clinical practice guideline (CPG) authors receiving payments[a] from pharmaceutical companies manufacturing CPG-recommended drugs.

	Atopic dermatitis	Acne vulgaris	Local anesthesia for dermatologic surgery	BCC[b] and SCC[c]	Melanoma	Total unique guideline authors
Total payments to guideline authors ($)	923,303.59	1,374,780.10	93,899.14	226,685.71	46,554.64	2,665,223.18
Total guideline authors, n	23	22	14	31	16	99
Authors receiving payments, n (%)	17 (74)	14 (64)	8 (57)	12 (39)	7 (44)	56 (57)
Mean payment to authors receiving payments ($)	54,311.98	98,198.58	11,737.39	18,890.48	6650.66	47,593.27
Median payment to authors receiving payments ($)	9319.02	23,475.75	1940.41	256.34	2194.87	4939.40
Authors receiving payments ≥$10,000, n (%)	7 (30)	11 (50)	1 (7)	3 (10)	1 (6)	22 (22)
Authors receiving payments ≥$50,000, n (%)	3 (13)	5 (23)	1 (7)	1 (3)	0 (0)	10 (10)

[a]General payment data from Open Payments was totaled for each AAD CPG author in the year of CPG publication and the subsequent year. General payments include payments or other transfers of value that were not made in connection with a research agreement or research protocol.

[b]BCC: basal cell carcinoma.

[c]SCC: squamous cell carcinoma.

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. TES is an editorial board member at large for *JMIR Dermatology*.

RD receives editorial stipends (JAAD, JID), royalties (UpToDate), and expense reimbursement from Cochrane Skin. TES receives fellowship funding from Pfizer Inc.

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Abbreviations

AAD: American Academy of Dermatology
COI: conflict of interest
CPG: clinical practice guideline
JAAD: *Journal of the American Academy of Dermatology*
JID: *Journal of Investigative Dermatology*

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Research Letter

Correlation Between Interest in COVID-19 Hair Loss and COVID-19 Surges: Analysis of Google Trends

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Introduction

There is an increasing body of evidence documenting an appreciable incidence of hair loss in patients with a past history of COVID-19 [1]. In general, COVID-19 has been accompanied by reports of increased mental health stress; this has serious implications for the psychosocial well-being of the overall population given the most recent emergence and surge of the omicron variant, characterized by unprecedented infectivity and spread [2,3]. Since both stress and infection are potential factors leading to telogen effluvium (hair shedding), it is important to understand how the surges of the initial COVID-19 strain and subsequent variant strains have influenced public interest in telogen effluvium and hair loss [1].

Methods

To assess the public perception between hair loss and COVID-19, we analyzed search volume data on the Google search engine for the terms "COVID hair loss" and "Telogen Effluvium," using the Google Trends data set spanning from January 1, 2020, to January 16, 2022. New case counts for COVID-19 were obtained from a publicly available COVID-19 repository [4]. We associated average daily new cases with the number of Google Trends search results for "COVID hair loss" for each week using a linear regression model and also

performed a Spearman rank correlation test. The Mann-Kendall test was used to determine the significance of the upward trend of search term data for "COVID hair loss" over time.

Results

The relative search volume (RSV) for "COVID hair loss" significantly increased over time ($P<.001$) (Figure 1). The RSV for "COVID hair loss" first peaked during the initial surge in August 2020, and had local maxima during the subsequent delta and omicron variant surges, with an all-time peak during January 2022. The RSV was on an upward trend since late 2021, coinciding with the discovery of the omicron variant. Interest in "COVID hair loss" during the second week of January 2022 was 14% higher than that during the mid-2020 peak of the initial COVID-19 surge, and 82% higher than that during the mid-2021 peak of the delta variant surge. While frequently cyclical, interest in "Telogen Effluvium" reached a new peak level of interest in December 2021, surpassing the mid-2020 peak by 19% and the mid-2021 peak by 33%. For each week between February 1, 2020, and January 16, 2022, the average weekly RSV for "COVID hair loss" was significantly associated with the number of new COVID-19 cases ($r=0.59$, Spearman rank correlation $P<.001$) (Figure 2). Regionally, search interest, derived as search term popularity as a proportion of total searches within an area, was generally greater for both "COVID

hair loss" and "Telogen Effluvium" in higher-income countries including the United States and the United Kingdom, which demonstrated up to 10 times more interest than lower-income countries including South Africa and India. However, an

outsized search interest was observed for "Telogen Effluvium" in the Philippines and Pakistan with an average of 12% higher search interest compared to the United States and the United Kingdom.

Figure 1. Trend over time of relative search volume results for "COVID hair loss" in the United States. The CI is shown in gray. The *P* value was determined using the Mann-Kendall test.

Figure 2. Spearman correlation between the relative search volume for "COVID hair loss" and the average number of daily new cases of COVID-19 in the United States per 1 million people. The *P* value was calculated using a linear regression model.

Conclusions

People are paying more attention than ever before to COVID-19–related hair loss and telogen effluvium, which may suggest a growing incidence of such cutaneous ailments in the COVID-19 pandemic environment. More directly, it is clear that the population believes in a linkage between hair loss symptoms and COVID-19. While increased interest was largely exhibited by higher-income countries, certain lower-income countries demonstrated similar interest levels, suggesting that this potential association is of a global nature and has

widespread relevance. These findings align with those of other reports of diverse clinical scope, which suggest that associations between certain events, such as seasonal changes, and variation in Google search data for specific skin conditions may be indicative of health interests among the general public [5]. Though it is uncertain whether the heightened search interest in COVID-19 hair loss and its positive correlation with daily new COVID-19 cases stems from current or prior illness, breakthrough infectivity of the omicron variant, or greater media attention, the public is avidly searching for explanations. Dermatologists and other physicians will continue to be called upon to discuss this association in clinical practice, especially

around periods of surging COVID-19 cases when internet search   interest peaks.

Conflicts of Interest

None declared.

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Abbreviations

RSV: relative search volume

XSL•FO
RenderX

XSL•FO
RenderX