

The CROWNing Event on Hair Loss in Women of Color: A Framework for Advocacy and Community Engagement (FACE) Survey Analysis

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PRACTICE POINTS

- Hair loss is associated with low self-esteem in women with skin of color; therefore, it is important to both acknowledge the social and psychological impacts of hair loss in this population and provide educational resources and community events that address patient concerns.
- There is a deficit of dermatology advocacy efforts that address conditions affecting patients with skin of color. Highlighting this disparity is the first step to catalyzing change.
- Dermatologists are responsible for advocating for women with skin of color and for addressing the social issues that impact their quality of life.
- The Framework for Advocacy and Community Efforts (FACE) model is a template for others to use when planning community engagement and advocacy efforts.

Hair loss is a primary reason for women with skin of color to seek dermatologic care. In addition to physical disfigurement, patients with hair loss are more likely to report feelings of depression, anxiety, and low self-esteem. There is a critical gap in dermatology advocacy efforts and educational information intended for women with skin of color. In July 2021, the Virginia Dermatology Society planned a virtual event on hair loss and practical political advocacy for women of color. Event attendees completed pre- and postevent Likert scale surveys that assessed participant attitudes, knowledge, and awareness surrounding hair loss. A resource toolkit for both patients and physicians also was created, which included articles about evaluating,

diagnosing, and treating different types of hair loss that would be beneficial for dermatologists, as well as informational articles, links, and videos that would be helpful to patients. Resource toolkits combined with outreach events can be used to engage communities, disseminate information, and close gaps that have led to health care disparities.

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Hair loss is a primary reason why women with skin of color seek dermatologic care.¹⁻³ In addition to physical disfigurement, patients with hair loss are more likely to report feelings of depression, anxiety, and low self-esteem compared to the general population.⁴ There is a critical gap in advocacy efforts and educational information intended for women with skin of color. The American Academy of Dermatology (AAD) has 6 main public health programs (<https://www.aad.org/public/public-health>) and 8 stated advocacy priorities (<https://www.aad.org/member/advocacy/priorities>) but none of them focus on outreach to minority communities.

Historically, hair in patients with skin of color also has been a systemic tangible target for race-based discrimination. The Create a Respectful and Open World for Natural Hair (CROWN) Act was passed to protect against discrimination based on race-based hairstyles in schools and workplaces.⁵ Health care providers play an important role in advocating for their patients, but studies have shown that barriers to effective advocacy include a lack of knowledge, resources, or time.⁶⁻⁸ Virtual advocacy events improve participants' understanding and interest in community engagement and

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advocacy.^{6,7} With the mission to engage, educate, and empower women with skin of color and the dermatologists who treat them, the Virginia Dermatology Society hosted the virtual CROWning Event on Hair Loss in Women of Color in July 2021. We believe that this event, as well as this column, can serve as a template to improve advocacy and educational efforts for additional topics and diseases that affect marginalized or underserved populations. Survey data were collected and analyzed to establish a baseline of awareness and understanding of hair loss in women with skin of color and to evaluate the impact of a virtual event on participants' empowerment and familiarity with resources for this population.

Methods

The Virginia Dermatology Society organized a virtual event focused on hair loss and practical political advocacy for women with skin of color. As members of the Virginia Dermatology Society and as part of the planning and execution of this event, the authors engaged relevant stakeholder organizations and collaborated with faculty at a local historically Black university to create a targeted, culturally sensitive communication strategy known as the Framework for Advocacy and Community Engagement (FACE) model (Figure). The agenda included presentations by 2 patients of color living with a hair loss disorder, a dermatologist with experience in advocacy, a Virginia state legislator, and a dermatologic hair loss expert, followed by a final question-and-answer session.

We created pre- and postevent Likert scale surveys assessing participant attitudes, knowledge, and awareness surrounding hair loss that were distributed electronically to all 399 registrants before and after the event, respectively. The responses were analyzed using a Mann-Whitney *U* test.

Results

All 399 registrants completed the pre-event survey; 115 (28.8%) and 189 (47.4%) identified as patients and health care professionals, respectively (Table 1). Overall, 137 (34.3%) respondents disagreed or strongly disagreed with the statement, "I am familiar with the various and specific resources for hair loss in women of color." Treatments and resources emerged as prevalent themes when respondents were asked about information or support they wished they had on hair loss. Respondents reported self-esteem/self-worth, treatment efficacy, and lack of knowledge/understanding as the most challenging aspects for women with skin of color experiencing hair loss.

Based on preliminary pre-event survey data, we created a resource toolkit (<https://bit.ly/vadermhairloss> toolkit) for distribution to both patients and physicians. The toolkit included articles about evaluating, diagnosing, and treating different types of hair loss that would be beneficial for dermatologists, as well as informational articles, online resources, and videos that would be helpful to patients.

Of the 399 registrants, 165 (41.4%) attended the live virtual event. The postevent survey was completed by 70 (42.4%) participants and showed that familiarity with resources and treatments ($z = -3.34$, $P = .0008$) and feelings of empowerment ($z = -3.55$, $P = .0004$) significantly increased from before the event (Table 2). Participants indicated that the event exceeded (84.3%) or met (15.7%) their expectations.

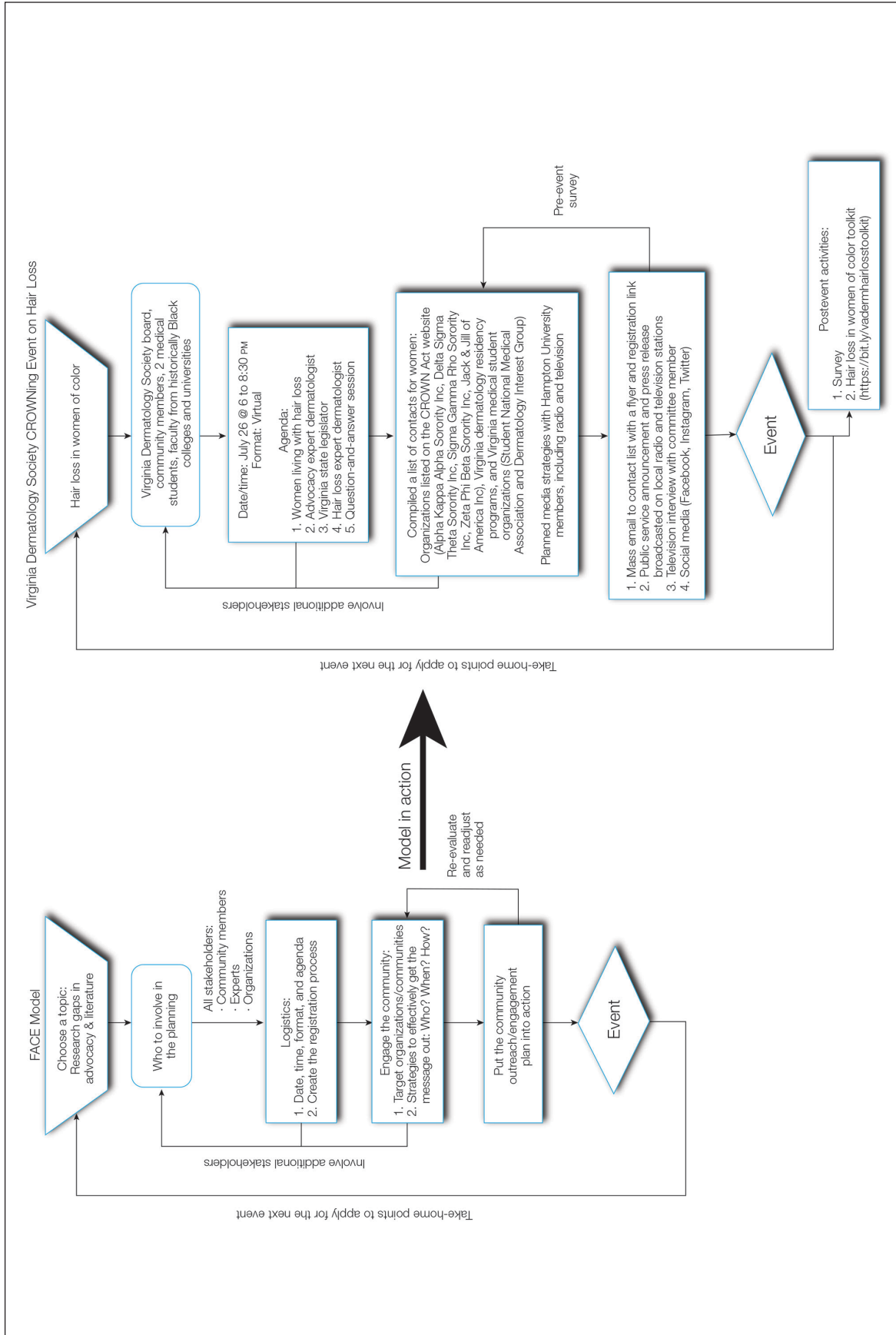
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Hair Loss Is Prevalent in Skin of Color Patients—Alopecia is the fourth most common reason women with skin of color seek care from a dermatologist, accounting for 8.3% of all visits in a study of 1412 patient visits; however, it was not among the leading 10 diagnoses made during visits for White patients.³ Traction alopecia, discoid lupus erythematosus, and central centrifugal cicatricial alopecia occur more commonly in Black women,⁹ many of whom do not feel their dermatologists understand hair in this population.^{10,11} Lack of skin of color education in medical school and dermatology residency programs has been reported and must be improved to eliminate the knowledge gaps, acquire cultural competence, and improve all aspects of care for patients with skin of color.¹¹⁻¹⁴ Our survey results similarly demonstrated that only 66% of board-certified dermatologists reported being familiar with the various and specific resources and treatments for hair loss in women of color. Improved understanding of hair in patients of color is a first step in diagnosing and treating hair loss.¹⁵ Expertise of dermatologists in skin of color improves the dermatology experience of patients of color.¹¹

Hair loss is more than a cosmetic issue, and it is essential that it is regarded as such. Patients with hair loss have an increased prevalence of depression and anxiety compared to the general population and report lower self-esteem, heightened self-consciousness, and loss of confidence.^{4,9} Historically, the lives of patients of color have been drastically affected by society's perceptions of their skin color and hairstyle.¹⁶

Hair-Based Discrimination in the Workplace—To compound the problem, hair also is a common target of race-based discrimination behind the illusion of "professionalism." Hair-based discrimination keeps people of color out of professional workplaces; for instance, women of color are more likely to be sent home due to hair appearance than White women.⁵ The CROWN Act, created in 2019, extends statutory protection to hair texture and protective hairstyles such as braids, locs, twists, and knots in the workplace and public schools to protect against discrimination due to race-based hairstyles. The CROWN Act provides an opportunity for dermatologists to support legislation that protects patients of color and the fundamental human right to nondiscrimination. As societal pressure for damaging hair practices such as hot combing or chemical relaxants decreases, patient outcomes will improve.⁵

How to Support the CROWN Act—There are various meaningful ways for dermatologists to support the



FACE (Framework for Advocacy and Community Engagement) model and diagram of the planning process for the CROWning Event on Hair Loss in Women of Color in July 2021. CROWN indicates Create a Respectful and Open World for Natural Hair.

TABLE 1. Participant Information and Survey Results

Survey responses	Pre-event survey results, n (%)	Postevent survey results, n (%)
Total responses	399/399 (100)	Total responses: 70/165 (42.4)
Participant demographics	HCP: 189 (47.4); non-HCP: 210 (52.6); dermatologist: 104 (26.1); patient: 115 (28.8)	Anonymous
“The issue that I feel is most challenging for women experiencing hair loss is” (n=188)	Self-esteem/worth, embarrassment: 49 (26.1); treatment efficacy: 16 (8.5); lack of knowledge/understanding: 29 (15.4)	NA
“Please share the 3 things you plan to do differently as a result of this event” (n=69)	NA	Find/go to a dermatologist: 17 (24.6); learn more about different hairstyles: 12 (17.4); learn about Black-owned products: 10 (14.5)
“What specific information and/or support do you wish you had regarding the issues surrounding hair loss?” (n=163)	Treatments/resources: 37 (22.7); hair loss prevention: 20 (12.3); how to grow and regrow hair: 8 (4.9)	NA
“Please rate this event” (n=70)	NA	Below expectations: 0 (0); meets expectations: 11 (15.7); exceeds expectations: 59 (84.3)
“The one thing I hope to learn that will make this event successful for me is” (n=176)	Hair loss prevention: 13 (7.4); resources/treatments for hair loss: 53 (30.1); caring for natural/ethnic hair: 5 (2.8)	NA

Abbreviations: HCP, health care professional; NA, not applicable.

CROWN act, including but not limited to signing petitions, sending letters of support to elected representatives, joining the CROWN Coalition, raising awareness and educating the public through social media, vocalizing against hair discrimination in our own workplaces and communities, and asking patients about their experiences with hair discrimination.⁵ In addition to advocacy, other antiracist actions suggested to improve health equity include creating curricula on racial inequity and increasing diversity in dermatology.¹⁶

There are many advocacy and public health campaigns promoted on the AAD website; however, despite the AAD’s formation of the Access to Dermatologic Care Task Force (ATDCTF) with the goal to raise awareness among dermatologists of health disparities affecting marginalized and underserved populations and to develop policies that increase access to care for these groups, there are still critical gaps in advocacy and information.¹³ This gap in both advocacy and understanding of hair loss conditions in women of color is one reason the CROWNing Event in July 2021 was held, and we believe this event along with this column can serve as a template for addressing additional topics and diseases that affect marginalized or underserved populations.

Dermatologists can play a vital role in advocating for skin and hair needs in all patient populations from the personal or clinical encounter level to population-level policy legislation.^{5,8} As experts in skin and hair,

dermatologists are best prepared to assume leadership in addressing racial health inequities, educating the public, and improving awareness.^{5,16} Dermatologists must be able to diagnose and manage skin conditions in people of color.¹² However, health advocacy should extend beyond changes to health behavior or health interventions and instead address the root causes of systemic issues that drive disparate health outcomes.⁶ Every dermatologist has a contribution to make; it is time for us to acknowledge that patients’ ailments neither begin nor end at the clinic door.^{8,16} As dermatologists, we must speak out against the racial inequities and discriminatory policies affecting the lives of patients of color.¹⁶

Although the CROWNing event should be considered successful, reflection in hindsight has allowed us to find ways to improve the impact of future events, including incorporating more lay members of the respective community in the planning process, allocating more time during the event programming for questions, and streamlining the distribution of pre-event and postevent surveys to better gauge knowledge retention among participants and gain crucial feedback for future event planning.

How to Use the FACE Model—We believe that the FACE model (Figure) can help providers engage lay members of the community with additional topics and diseases that affect marginalized and underserved populations. We recommend that future organizers engage stakeholders early during the design, planning, and

TABLE 2. Likert Scale Questions Average Results

Statement	Pre-event average Likert score	Postevent average Likert score	z score	P value ^a
I am aware that hair loss is an important topic and impacts many women from all ethnicities	4.8	4.97	−1.57	.1164
I am familiar with the efforts to increase awareness around hair loss in women of color	3.71	3.79	−0.45	.6527
I am familiar with the various treatments and specific resources for hair loss in women of color	2.99	3.57	−3.34	.0008
I feel comfortable reaching out to my state representative regarding legislation that may impact me	3.48	3.71	−1.51	.1310
I feel empowered to speak up about hair loss and make a difference for myself and others	3.70	4.21	−3.55	.0004

^aP<.05 was considered statistically significant.

implementation phases to ensure that the community's most pressing needs are addressed. Dermatologists possess the knowledge and influence to serve as powerful advocates and champions for health equity. As physicians on the front lines of dermatologic health, we are uniquely positioned to engage and partner with patients through educational and advocacy events such as ours. Similarly, informed and empowered patients can advocate for policies and be proponents for greater research funding.⁵ We call on the AAD and other dermatologic organizations to expand community outreach and advocacy efforts to include underserved and underrepresented populations.

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