

Healthcare Barriers and Quality of Life in Central Centrifugal Cicatricial Alopecia
Patients
Lisa Akintilo
Thesis for Consideration of MPH Degree

ABSTRACT

Central Centrifugal Cicatricial Alopecia (CCCA) is a condition known for delayed presentation and treatment. Identifying barriers to care may shorten this delay and improve outcomes. Understanding how CCCA specifically impacts quality of life is also important. Many barriers prevent women with CCCA from obtaining effective dermatological care. Moreover, this condition has a significant impact on patients' quality of life. The objectives of this pilot study were: 1) to elucidate the experience of initial diagnosis for CCCA patients, and 2) to understand how CCCA hair loss affects quality of life.

CCCA patients completed a 53-item cross-sectional survey (CCCA Barriers to Care and Quality of Life Survey—CBCQLS) developed by the study investigators. The CBCQLS measured how alopecia was initially discovered, what factors were most important when seeking medical care, how patients felt about their physicians, and how hair loss created challenges in self-esteem and activities of daily living.

The CBCQLS was completed in person or by telephone by English-speaking, adult, African-American female patients diagnosed with CCCA at the Northwestern University Department of Dermatology between 2011 and 2017. Participants included 34 African-American women ranging in age from 28 to 79. Respondents' median age was 46 (range 28-79); the median age at CCCA diagnosis was 42 (range 15-73). Most ($n=22$, 65%) first noticed their hair loss themselves, while 15% reported their hairstylist was the first to notice signs of alopecia. Nearly all respondents ($n = 31$, 91%) recommended that other women with hair loss immediately go see a dermatologist. Some respondents ($n=13$, 38%) reported their physician's experience with Black hair and CCCA was most

important to them as they sought medical care for hair loss. The majority (n=30, 88%) reported their hair loss bothered them. Median QOL score was 4 on a five-point scale, corresponding with an “Agree” response to statements including “I feel embarrassed, self-conscious, or frustrated about my hair loss” and “My hair loss bothers me.”

CCCA presents a unique set of challenges for women to obtain care. Lack of physician experience with Black hair and CCCA is a barrier to care for many with this disease. Self-esteem of CCCA patients is affected by hair loss.

INTRODUCTION

Many researchers have studied the etiology of Central Centrifugal Cicatricial Alopecia (CCCA), a clinical and histological pattern of hair loss on the central scalp. This disease is chronic and progressive with extensive follicular destruction and eventual burnout.^{1,2} CCCA is most commonly seen in patients of African descent and has been shown to be one of the five most common dermatologic diagnoses made in Black patients.^{3,4} The top five dermatologic diagnoses within this population include acne vulgaris with a frequency of 28.4%, dyschromia (19.9%), eczema (9.1%), alopecia (8.3%), and seborrheic dermatitis (6.7%).⁴ The incidence rate of CCCA is estimated to be 5.6%.^{3,5} Most patients are women with onset between the second and fourth decades of life.⁶

CCCA treatment efficacy is inversely correlated with disease duration. The primary goal of treatment is to prevent progression. Efforts are made to stimulate regrowth in areas that are not permanently scarred. When patients present with a significant amount of scarring hair loss, dermatologists are often limited in their ability to achieve a cosmetically acceptable pattern of growth. Generally, hair is connected to a sense of self-worth in Black women and any type of hair loss has been shown to lead to frustration and decreased self-esteem⁷—a 1994 study⁸ showed that 75% of women with androgenetic alopecia had decreased self-esteem and 50% had social challenges.

The purpose of this pilot study was: 1) to determine what personal, historical, logistical, or environmental factors preclude women from obtaining medical care for CCCA; and 2) to investigate how CCCA affects quality of life (QOL) and psychological well-being.

This research is relevant to public health by aligning the science behind a particular dermatological condition in skin of color patients with the patient-reported needs of the community. Elucidating the obstacles CCCA patients face within the healthcare system and the psychosocial impact of their disease is critical in developing sustainable and effective community health programming. The lessons learned from this study can be used to influence future health programs focused on skin of color patients. Results from this study will be shared via publication in a nationally recognized dermatology journal and multiple national presentations; furthermore, all participants will be notified of the key conclusions from this project. By sharing the results of this study with key stakeholders including CCCA patients, dermatologists, and even hair stylists, my hope is for positive changes in patient-physician interactions to become a reality. Even just small patient-centered improvements in initial evaluation of patients with hair loss can reap huge gains in patient satisfaction and thus perhaps decrease some barriers to effective healthcare.

METHODS

The investigators designed a survey study of adult, English-speaking, Black women diagnosed with CCCA at the Northwestern Department of Dermatology between 2011 and 2017. Patients were selected from the Electronic Data Warehouse compiled by the Department of Dermatology. All surveys occurred from fall 2016 to spring 2017 and took 10 to 15 minutes to complete. The research was approved by the authors' institutional review board (IRB ID STU00203449).

Survey Instrument: The CCCA Barriers to Care and Quality of Life Survey (CBCQLS) is a novel 53-item survey instrument created to measure two aspects of CCCA hair loss: barriers to medical care and quality of life. The initial set of questions pertained to initial hair loss discovery and the number of physicians, both dermatologists and otherwise, seen for hair evaluation. Participants then rated their physician interactions on an ordinal Likert scale (1=poor, 2=fair, 3=good, 4=very good, 5=excellent). If subjects saw more than one dermatologist or non-dermatologist physician, ratings for each provider were included in our analysis. Participants listed the top three factors they considered when seeking medical care for their hair loss in order of importance. Participants also indicated how much they agreed with QOL statements on a Likert scale (0=not at all, 1 = a little bit, 2=somewhat, 3=quite a bit, 4=very much).

Data Analysis: Analyses were completed using data analysis software JMP Pro13 and a Microsoft Excel spreadsheet. Continuous data were presented as mean, standard deviation, median, minimum, and maximum. Categorical data were presented as counts and percentages. Nine quality of life items were aggregated into a “self-esteem” category (Q30-38). Cronbach’s alpha, a statistical measure of internal consistency and how closely related items are in a group, was used to evaluate internal consistency reliability; values of 0.70 or greater indicate acceptable reliability.

RESULTS

Thirty-four CBCQLS surveys were completed of 501 individuals contacted (7% completion rate). Non-respondents included 7 who refused to participate and 460 who were unable to be contacted. All respondents self-identified as Black women. Median age

at time of survey administration was 46 (range: 28 to 79); median age at CCCA diagnosis was 42 (range: 15 to 73). Respondents did not significantly differ in age from non-respondents ($P=.46$). The majority of participants had an associate's degree, bachelor's degree, or advanced degree of education (MA, MD, JD, PhD); exceptions include eight who reported completing some college, one who reported completing high school, and one who reported no schooling. Three respondents had no health insurance.

Initial Hair Loss:

The majority of respondents ($n=22$, 65%) were first to notice their hair loss, while a few ($n=5$, 15%) reported hair stylists as the initial discoverer. Some respondents ($n=12$, 35%) initially went to a physician to learn why they were losing hair; six (18%) instead utilized hairstylists or the Internet. Some women ($n=15$, 44%) waited more than 1 month up to 6 months after noticing hair loss before seeing a physician instead of going immediately within a four-week period; others ($n= 16$, 48%) waited 1 year or more.

Non-Dermatologist Consultation:

About half (48%) of the women ($n=16$) consulted a non-dermatologist physician regarding their hair loss. Half ($n=8$, 50%) reported their physician did not examine their scalp. Three (19%) reported their physician offered a biopsy; no patients reported their physician diagnosed them with CCCA. The median patient rating of their non-dermatologist physicians was "Good" (3 of 5-point scale). Table 1 and Figure 1 show responses to individual items.

Dermatologist Consultation:

Majority of respondents ($n=22$, 64%) saw either one or two dermatologists for their hair loss. Three (9%) reported their dermatologist did not examine their scalp.

Twelve participants (35%) reported their dermatologist did not offer a biopsy. Twenty-one patients (62%) reported a CCCA diagnosis from the first dermatologist they saw. Twenty-three respondents (68%) were diagnosed by dermatology hair experts. Sixteen (47%) were diagnosed by dermatologists within a skin of color center. Fourteen (41%) initial dermatology consultations were race-concordant. The median patient rating of their dermatologists was “Excellent” (5 of 5 point scale). Table 2 and Figure 2 show responses to individual items. Participants saw an average of 3 different providers, both dermatologists and otherwise.

Waiting to see a Dermatologist:

Nearly all respondents ($n = 31$, 91%) recommended that other women with hair loss immediately go see a dermatologist.

Barriers to Care:

The top five factors reported as most important when initially seeking care include the physician’s experience with Black hair and CCCA, the patient’s personal hair styling practices, the physician’s ethnicity, availability of effective treatment options, and treatment cost. Table 3 shows frequency counts for these freely reported factors.

Quality of Life:

The median score on nine aggregated self-esteem items was 4 on a five-point scale, representing an “Agree” response to statements such as “I feel embarrassed, self-conscious, or frustrated about my hair loss” ($n=28$, 82%) and “My hair loss bothers me” ($n=28$, 82%) (Table 4). Cronbach’s alpha for self-esteem survey items was 0.7826.

For the non-aggregated items, many participants reported “strongly disagree” to statements pertaining to activities of daily living, including “I take care of where I sit or

stand at social gatherings due to my hair loss” ($n=18$, 53%), “My hair loss makes it difficult for me to go to the grocery store” ($n=29$, 83%), “My hair loss makes it difficult for me to attend faith-based activities” ($n=30$, 88%), “My hair loss makes it difficult for me exercise” ($n=23$, 68%), “My hair loss makes it difficult for me to go to work and/or school” ($n=24$, 71%), “My hair loss makes it difficult for me to go out with a significant other” ($n=24$, 71%), “My hair loss makes it difficult for me to spend time with family” ($n=27$, 79%), and “My hair loss makes it difficult for me to go to a hair stylist” ($n=16$, 47%).

DISCUSSION

The majority of participants were the initial discoverers of their hair loss. Harbingers of CCCA hair loss include paresthesias, tenderness, and itch⁶, symptoms hard to ignore. Unfortunately, many patients notice hair thinning years after the scarring process has begun and a significant amount of hair has already been lost.^{6,9}

Fifteen percent of respondents learned about their hair loss from their hair stylist. Women of African descent often maintain hairstyles that require frequent interactions with a haircare professional.^{7,10} Because of this, hair stylists are at the forefront of early alopecia detection and are a valued resource in the Black community. Open dialogue between dermatologists and hair professionals could funnel women with hair loss into treatment before extensive damage.

Fifteen (44%) participants recalled a waiting period of several months and sixteen (48%) reported waiting more than an entire year before seeking medical assistance. However, 91% of participants stated women with hair loss should immediately see a

physician for evaluation. Thus, participants' experiences underscore the importance of early treatment. In the authors' experience, many patients wait years prior to presenting to a physician. Some first work with their stylist to address the issue, while others do not realize how significant the loss has become. Some have a negative experience with one provider or are told there is nothing that can be done and then wait many years to see a second provider. Proper education of the patient, physicians, and stylists is important in the identification and prompt treatment of this condition.

It is perhaps to be expected that participants rated interactions with dermatologists as "Excellent" and "Very Good" more frequently than interactions with non-dermatologists. This may be due to an absence of thorough hair evaluation—participants reported that only half of non-dermatologist providers actually examined their scalp during an initial encounter. However, both physician groups had the lowest frequencies of "Excellent" and "Very Good" ratings on "Understanding of your Hair" (Tables 1, 2). Patients with hair loss seek immediate answers, and often it is the specialist that can give them a firm diagnosis as opposed to a primary care provider. The fact that dermatologists and non-dermatologists alike scored poorly on patient-perceived understanding of CCCA indicates an area for improvement within patient-physician interactions and physician knowledge.

The top five factors important to participants when obtaining medical care included the physician's experience with Black hair and CCCA, the patient's personal hair styling practices, the physician's ethnicity, availability of effective treatment options, and treatment cost. CCCA patients seeing dermatologists may discern a lack of experience with ethnic hair that leads to doubt in the providers' ability to provide

adequate care and decreased shared decision-making.^{11,12} These patient perceptions are not unfounded; a 2008 study showed dermatology residents are not uniformly trained in diseases pertaining to patients with skin of color.¹³ Incorporation of skin of color education in dermatology training programs is critical.

Finally, hair loss patients often have concerns regarding how medical therapeutics could adversely affect personal hair care regimens, including washing and styling practices. Current research demonstrates that patients consider both treatment effectiveness and the ability to be integrated into daily routines after establishing medical care. The present study shows that some CCCA patients contemplate how well a therapy will work *before* seeking medical care.¹⁴ Consideration of treatment effectiveness is important for both patients and providers, as there is currently minimal evidence behind CCCA management practices. The ability for treatments to be easily integrated into daily haircare habits is important to maintain patient compliance.

Participants' median self-esteem scores indicate the impact of CCCA on morale and self-perception. Items scrutinizing this construct had acceptable internal consistency reliability. It is interesting to note that activities of daily living were not impacted by hair loss. Examination of self-esteem is important in the alopecia population because the effect of hair loss on mental status is well documented.¹⁵⁻¹⁷ Low self-esteem has been reported as a prospective risk factor for clinical depression.¹⁸⁻²⁰ In the African-American population depression rates surpass those of Hispanics and non-Hispanic white persons.²¹ Dermatologists must consider the psychological status of all patients, particularly populations at risk of severe disease.

Limitations of this study include the small and mostly highly educated sample size, limited survey validity, and potential participant bias. Because many patients changed address and/or phone number in the time between CCCA diagnosis and the present study, we were left with a small pilot study that minimizes the impact of our findings. Furthermore, our survey was created by a single expert's opinion and modeling from pre-existing alopecia questionnaires¹⁶; full validity procedures analyzing face, content, and criterion validity were not undertaken. Finally, majority of participants were patients of one of the study's authors, which could influence survey responses. The fact that some providers were hair experts and some were race-concordant with their patients also has potential impact on the responses received; this was not analyzed in the present study. Future studies with more participants from multiple providers would help clarify our preliminary findings.

CONCLUSION

Analysis of barriers to care and quality of life in skin of color patients is an essential addition to dermatological discourse. Alopecia is particularly important to investigate, as past research has found it to be one of the top five diagnoses made in skin of color patients.^{3,4} Past literature has shown alopecia as a notable negative contributor to quality of life.^{15,22,23}

The findings of this study will be communicated to relevant stakeholders by means of journal publication, poster presentations, oral presentations, and direct emails sent to all participants. Our goal is for dermatologists, primary care physicians, haircare professionals, and laypeople alike to be informed about the challenges of healthcare

access for patients with CCCA and how the disease can have an impact on one's psychological well-being. We hope that by bringing more attention to this disease process more research will be undertaken regarding the etiology, identification, and management of this particular form of alopecia. Steps have already been taken regarding the creation of programming for haircare professionals in the community to improve their hair loss detection skills and increase the number of dermatology referrals. Structured pipeline programs utilizing hair salons and barbershops for a host of conditions common in those with skin of color, both dermatological and otherwise, is a definite public health need that is starting to be addressed by physicians and public health workers across the country.

This study, although limited by small sample size, suggests CCCA is also a contributor to self-esteem challenges, similar to other forms of hair loss. Patient-physician interactions and personal hairstyling practices are prominent barriers to care for CCCA patients, demonstrating the need for quality education on skin of color and cultural competency in dermatology residencies across the country.

REFERENCES

1. Ogunleye TA, McMichael A, Olsen EA. Central centrifugal cicatricial alopecia: what has been achieved, current clues for future research. *Dermatologic clinics*. 2014;32(2):173-181.
2. Sperling LC. Scarring alopecia and the dermatopathologist. *Journal of cutaneous pathology*. 2001;28(7):333-342.
3. Halder RM, Grimes PE, McLaurin CI, Kress MA, Kenney JA, Jr. Incidence of common dermatoses in a predominantly black dermatologic practice. *Cutis*. 1983;32(4):388, 390.
4. Alexis AF, Sergay AB, Taylor SC. Common dermatologic disorders in skin of color: a comparative practice survey. *Cutis*. 2007;80(5):387-394.
5. Olsen EA, Callender V, McMichael A, et al. Central hair loss in African American women: incidence and potential risk factors. *Journal of the American Academy of Dermatology*. 2011;64(2):245-252.
6. Gathers RC, Lim HW. Central centrifugal cicatricial alopecia: past, present, and future. *Journal of the American Academy of Dermatology*. 2009;60(4):660-668.
7. Gathers RC, Mahan MG. African american women, hair care, and health barriers. *The Journal of clinical and aesthetic dermatology*. 2014;7(9):26-29.
8. Van Der Donk J, Hunfeld JA, Passchier J, Knegt-Junk KJ, Nieboer C. Quality of life and maladjustment associated with hair loss in women with alopecia androgenetica. *Social science & medicine (1982)*. 1994;38(1):159-163.
9. Sperling LC, Sau P. The follicular degeneration syndrome in black patients. 'Hot comb alopecia' revisited and revised. *Archives of dermatology*. 1992;128(1):68-74.
10. Gathers RC, Jankowski M, Eide M, Lim HW. Hair grooming practices and central centrifugal cicatricial alopecia. *Journal of the American Academy of Dermatology*. 2009;60(4):574-578.
11. Harvey VM, Ozoemena U, Paul J, Beydoun HA, Clemetson NN, Okoye GA. Patient-provider communication, concordance, and ratings of care in dermatology: Results of a cross-sectional study. *Dermatology online journal*. 2016;22(11).
12. Laveist TA, Nuru-Jeter A. Is doctor-patient race concordance associated with greater satisfaction with care? *Journal of health and social behavior*. 2002;43(3):296-306.
13. Nijhawan RI, Jacob SE, Woolery-Lloyd H. Skin of color education in dermatology residency programs: does residency training reflect the changing demographics of the United States? *Journal of the American Academy of Dermatology*. 2008;59(4):615-618.
14. Suchonwanit P, Hector CE, Bin Saif GA, McMichael AJ. Factors affecting the severity of central centrifugal cicatricial alopecia. *International journal of dermatology*. 2016;55(6):e338-343.
15. Williamson D, Gonzalez M, Finlay AY. The effect of hair loss on quality of life. *Journal of the European Academy of Dermatology and Venereology : JEADV*. 2001;15(2):137-139.

16. Fabbrocini G, Panariello L, De Vita V, et al. Quality of life in alopecia areata: a disease-specific questionnaire. *Journal of the European Academy of Dermatology and Venereology : JEADV*. 2013;27(3):e276-281.
17. Ramos PM, Miot HA. Female Pattern Hair Loss: a clinical and pathophysiological review. *Anais brasileiros de dermatologia*. 2015;90(4):529-543.
18. Sowislo JF, Orth U. Does low self-esteem predict depression and anxiety? A meta-analysis of longitudinal studies. *Psychological bulletin*. 2013;139(1):213-240.
19. Steiger AE, Allemand M, Robins RW, Fend HA. Low and decreasing self-esteem during adolescence predict adult depression two decades later. *Journal of personality and social psychology*. 2014;106(2):325-338.
20. Wegener I, Geiser F, Alfter S, et al. Changes of explicitly and implicitly measured self-esteem in the treatment of major depression: evidence for implicit self-esteem compensation. *Comprehensive psychiatry*. 2015;58:57-67.
21. Pratt LAB, D.J. *Depression in the U.S. Household Population, 2009-2012*. 2014.
22. Schmidt S, Fischer TW, Chren MM, Strauss BM, Elsner P. Strategies of coping and quality of life in women with alopecia. *The British journal of dermatology*. 2001;144(5):1038-1043.
23. Hunt N, McHale S. The psychological impact of alopecia. *BMJ : British Medical Journal*. 2005;331(7522):951-953.

Table 1. Respondent Ratings of Non-Dermatologist Physicians (Frequency, Percentage, 95% CI)

Survey Item	Excellent	Very Good	Good	Fair	Poor
Willingness to listen carefully to you	7, 44% (23-67)	1, 6% (1-28)	4, 25% (10-50)	-	4, 25% (10-50)
Understanding of your hair	2, 13% (4-36)	1, 6% (1-28)	3, 19% (7-43)	5, 31% (14-56)	5, 31% (14-56)
Taking time to answer your questions	6, 40% (20-64)	1, 6% (1-30)	2, 13% (4-38)	2, 13% (4-38)	4, 27% (11-52)
Ability to explain things in a way you could understand	6, 40% (18-61)	4, 25% (10-50)	-	-	6, 40% (18-61)
Instructions regarding treatment or follow-up care	6, 40% (18-61)	2, 13% (4-36)	1, 6% (1-28)	1, 6% (1-28)	6, 40% (18-61)
Thoroughness of examination	3, 20% (7-45)	2, 13% (4-38)	2, 13% (4-38)	2, 13% (4-38)	5, 33% (15-58)

Table 2. Respondent Ratings of Dermatologist Physicians (Frequency, Percentage, 95% CI)

Survey Item	Excellent	Very Good	Good	Fair	Poor
Willingness to listen carefully to you	17, 50% (34-66)	4, 12% (5-27)	3, 9% (3-23)	4, 12% (5-27)	6, 18% (8-34)
Understanding of your hair	14, 41% (26-58)	1, 3% (1-15)	5, 15% (5-30)	9, 26% (15-43)	5, 15% (5-30)
Taking time to answer your questions	17, 50% (34-66)	2, 6% (2-19)	6, 18% (8-34)	4, 12% (5-27)	5, 15% (5-30)
Ability to explain things in a way you could understand	18, 53% (37-69)	3, 9% (3-23)	5, 15% (5-30)	3, 9% (3-23)	5, 15% (5-30)
Instructions regarding treatment or follow-up care	14, 41% (26-58)	6, 18% (8-34)	4, 12% (5-27)	5, 15% (5-30)	5, 15% (5-30)
Thoroughness of examination	16, 47% (31-63)	6, 18% (8-34)	2, 6% (2-16%)	2, 6% (2-16%)	8, 24% (12-40)

Table 3. Factors Most Important to CCCA Patients When Seeking Care

Factor	Number, Percentage
Physician's experience with Black hair and CCCA	17, 50%
Personal hair styling practices	9, 26%
Physician's ethnicity	8, 24%
Availability of effective treatment options	8, 24%
Treatment cost	8, 24%

Table 3. Participants were asked to self-describe the three most important factors were to them when initially seeking medical assistance for alopecia. “Personal hair styling practices” refers to patients’ concerns that medical therapy for alopecia would affect or change their daily hair care maintenance routines.

Table 4. Percentage of Participants Who “Agreed” or “Strongly Agreed” with Self-

Esteem OOL Statements

Statement	Frequency, Percentage (95% CI)
“I believe hair forms a major expression of oneself”	26, 76% (60-88)
“I believe hair is a major factor in female appearance”	33, 97% (85-99)
“I believe hair loss is a handicap”	16, 47% (30-65)
“My hair loss bothers me”	30, 89% (73-95)
“I feel embarrassed, self-conscious, or frustrated about my hair loss”	28, 82% (66-92)
“I feel less attractive because of my hair loss”	18, 53% (35-70)
“I feel less confident because of my hair loss”	17, 50% (32-68)
“I feel old because of my hair loss”	13, 38% (22-56)
“I feel anxious or worried about my hair loss”	23, 68% (51-81)

Respondent Ratings of Non-Dermatologist Physicians

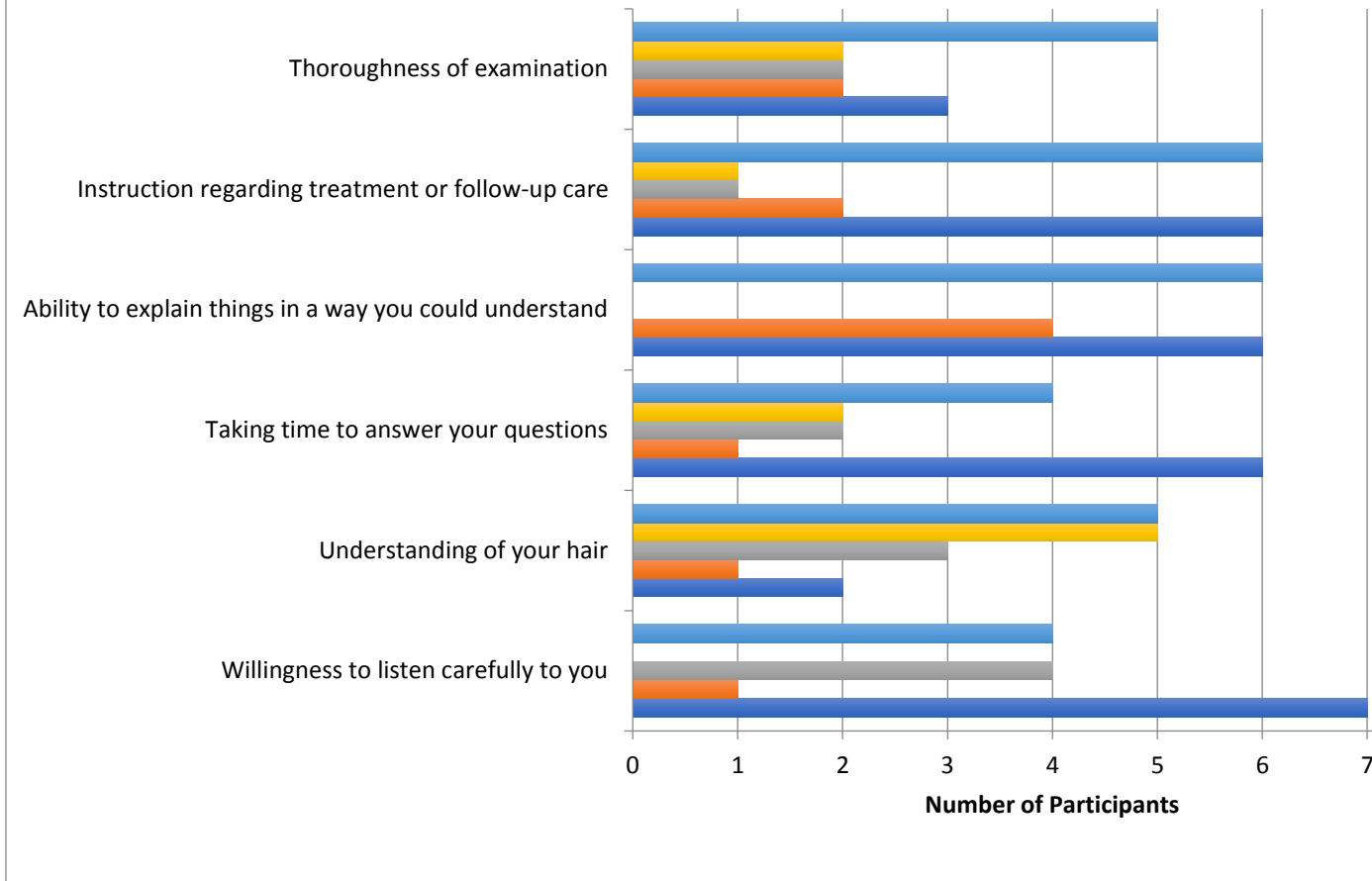


Figure 1. Participants were asked to rate their non-dermatologist physician, seen during an initial hair loss evaluation, on six distinct items. Physicians were rated most poorly on “Instructions regarding treatment or follow-up care”, “Ability to explain things in a way you could understand”, “Thoroughness of examination”, and “Understanding of your hair.”

Respondent Ratings of Dermatologist Physicians

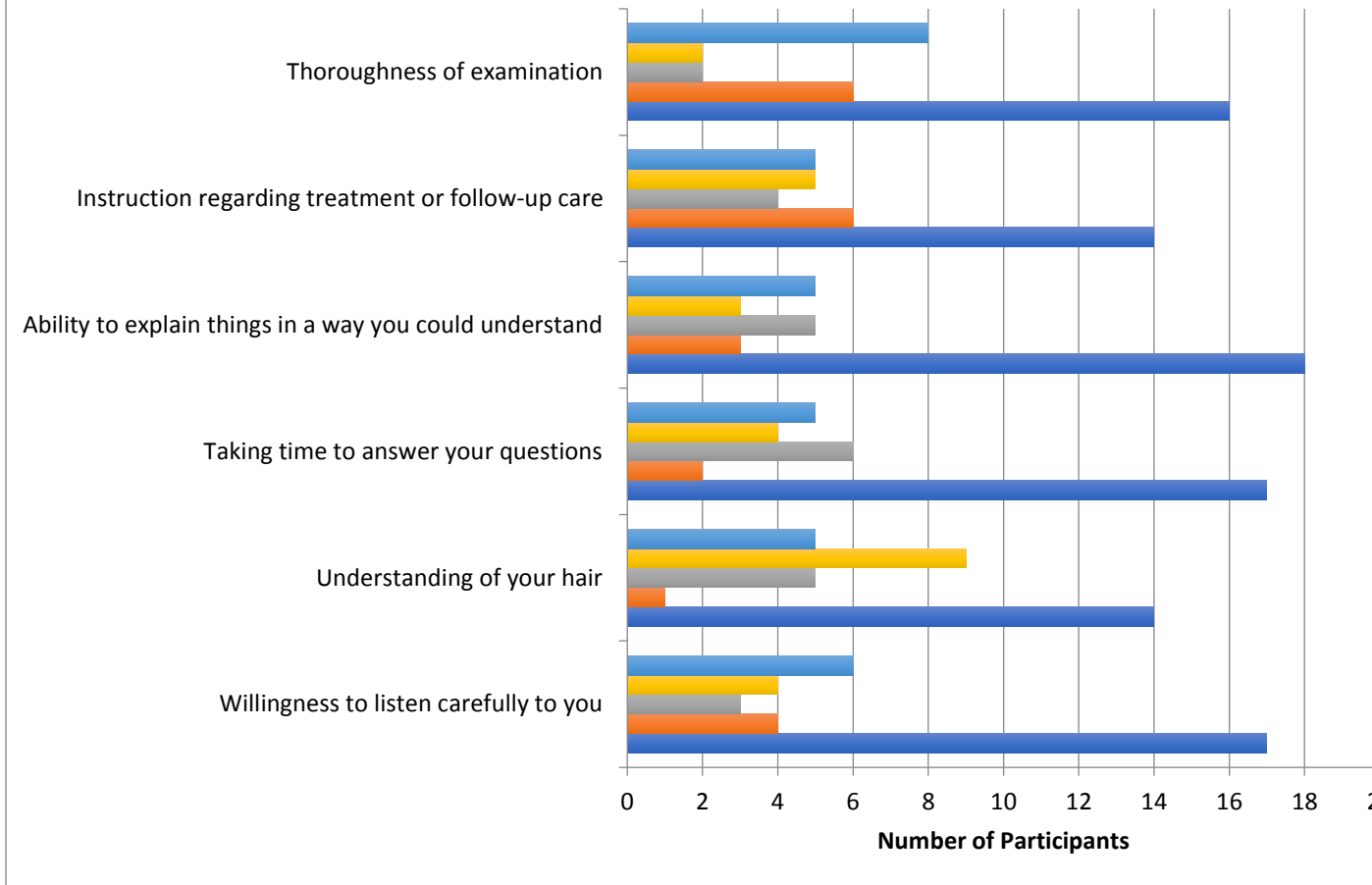


Figure 2. Participants were asked to rate their dermatologists, seen during an initial hair loss evaluation, on six distinct items. Physicians were ranked lowest on “Thoroughness of examination” and “Understanding of your hair.”