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BRIEF COMMUNICATION

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Patient Perspectives and Attitudes Toward the Diagnostic Process for Central Centrifugal Cicatricial Alopecia

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INTRODUCTION

Central Centrifugal Cicatricial Alopecia (CCCA) is a progressive form of scarring alopecia that primarily affects women of African descent.[1] CCCA can be diagnosed clinically through scalp examination and trichoscopy. Scalp examination typically reveals the classic distribution of hair loss, beginning at the vertex of the scalp with progressive, symmetric centrifugal evolution. Trichoscopy may show a peripilar gray or white halo around the base of the hair follicles.[2] However, CCCA may also present with atypical distributions of hair loss, such as patchy, temporal, occipital, and frontal-parietal patterns, which pose a diagnostic challenge.[3-5] In such cases, scalp biopsies are crucial for accurate and timely diagnosis of CCCA, as they minimize further hair loss and associated morbidity. Despite their clinical value, patients may be hesitant to undergo scalp biopsy due to concerns about side effects, scarring, or the potential for additional hair loss.

Patient perspectives on biopsies have been studied in other contexts (eg, breast cancer, colon cancer); however, no research has focused on patient perspectives regarding the scalp biopsy process for hair loss, particularly in those with CCCA. Therefore, a qualitative, cross-sectional study was designed to assess patient perspectives on scalp biopsies to diagnose CCCA. An anonymous survey was distributed to patients with CCCA at University of Pennsylvania-affiliated dermatology clinics, including those who had and had not undergone a scalp biopsy. Patient knowledge, attitudes, and concerns regarding scalp biopsies and factors influencing their decision-making were evaluated.

Among biopsy patients (*n=30*), 90% agreed that a biopsy was necessary to confirm their diagnoses, compared to just 30% of non-biopsy patients (*n=10*) (see Table 1). Similarly, 83% of biopsy patients strongly preferred biopsy over diagnostic uncertainty, highlighting its perceived value in clarifying disease status. Notably, provider education and communication played a critical role. Over 85% of biopsy patients felt their dermatologist adequately explained the procedure and clearly communicated the results. In contrast, 70–90% of non-biopsy patients reported neutral responses regarding biopsy purpose, treatment implications, and overall understanding. This suggests that refusal of biopsy may reflect gaps in patient education rather than true opposition.

Despite these gaps, 68% of all participants indicated willingness to undergo biopsy if their condition worsened, emphasizing a potential openness to the procedure when supported by a clear rationale or need (see Table 1). Importantly, no respondents reported feeling coerced, reinforcing that patient autonomy was preserved during all visits. Additionally, 77% of biopsy patients conducted independent research after diagnosis, indicating an area for improvement in post-diagnostic counseling and education (see Table 2).

Our study highlights the crucial role of effective clinician-patient communication in shaping attitudes toward scalp biopsy for CCCA. Patients who undergo biopsy demonstrate greater understanding, trust, and willingness to accept diagnostic interventions, whereas those who decline often lack the information needed to make informed choices. Enhancing patient education and offering accessible, vetted resources could bridge this divide. By positioning the biopsy as a tool for early intervention, dermatologists can support shared decision-making and improve diagnostic outcomes in this patient population.

TABLE 1.

Patient Perspectives and Attitudes Toward the Role of Scalp Biopsy in Diagnosing Central Centrifugal Cicatricial Alopecia (CCCA). Survey responses are presented from patients who underwent a scalp biopsy (*n=30*) and those who did not undergo a biopsy (*n=10*). Responses are shown as both numerical values and percentages.

Survey Question		Number (N) / frequency (%)		
		Biopsy (*n=30*)	No Biopsy (*n=10*)	Total (*n=40*)
"Do you agree that it was necessary for the doctor to obtain a scalp biopsy to confirm your diagnosis of CCCA?"	Strongly Agree	17 (56.7%)	2 (20.0%)	19 (47.5%)
	Agree	10 (33.3%)	1 (10.0%)	11 (27.5%)
	Neutral	2 (6.7%)	6 (60.0%)	8 (20.0%)
	Disagree	0 (0%)	0 (0%)	0 (0%)
	Strongly Disagree	0 (0%)	0 (0%)	0 (0%)
	No Answer	1 (3.3%)	1 (10.0%)	2 (5.0%)
"Scalp biopsies are necessary to diagnose CCCA and other hair loss disorders."	Strongly Agree	16 (53.3%)	1 (10.0%)	17 (42.5%)
	Agree	10 (33.3%)	3 (30.0%)	13 (32.5%)
	Neutral	0 (0%)	6 (60.0)	6 (15.0%)
	Disagree	2 (6.7%)	0 (0%)	2 (5.0%)
	Strongly Disagree	0 (0%)	0 (0%)	0 (0%)
	No Answer	2 (6.7%)	0 (0%)	2 (5.0%)
"I would rather get a scalp biopsy instead of being unsure of what type of hair loss I have."	Strongly Agree	19 (63.3%)	2 (20.0%)	21 (53.5%)
	Agree	6 (20.0%)	2 (20.0%)	8 (20.0%)
	Neutral	0 (0%)	3 (30.0%)	3 (7.5%)
	Disagree	3 (10.0%)	2 (20.0%)	5 (12.5%)
	Strongly Disagree	1 (3.3%)	1 (10.0%)	2 (5.0%)
	No Answer	1 (3.3%)	0 (0%)	1 (3.5%)
"There are other ways besides the scalp biopsy to decide if you have CCCA."	Strongly Agree	2 (6.7%)	1 (10.0%)	3 (7.5%)
	Agree	9 (30.0%)	4 (40.0%)	13 (32.5%)
	Neutral	13 (43.3%)	5 (50.0%)	18 (45.0%)
	Disagree	3 (10.0%)	0 (0%)	3 (7.5%)
	Strongly Disagree	0 (0%)	0 (0%)	0 (0%)
	No Answer	3 (10.0%)	0 (0%)	3 (7.5%)
"My dermatologist provided enough information about the scalp biopsy for me to make an informed decision on the procedure."	Strongly Agree	9 (30.0%)	2 (20.0%)	11 (27.5%)
	Agree	11 (36.7%)	1 (10.0%)	12 (30.0%)
	Neutral	1 (3.3%)	0 (0%)	1 (3.5%)
	Disagree	1 (3.3%)	3 (30.0%)	4 (10.0%)
	Strongly Disagree	7 (23.3%)	0 (0%)	7 (17.5%)
	No Answer	1 (3.3%)	4 (40.0%)	5 (12.5%)
"My dermatologist did a good job educating me on the procedure of a scalp biopsy"	Strongly Agree	15 (50.0%)	1 (10.0%)	16 (40.0%)
	Agree	11 (36.7%)	1 (10.0%)	12 (30.0%)
	Neutral	1 (3.3%)	7 (70.0%)	8 (20.0%)
	Disagree	1 (3.3%)	0 (0%)	1 (3.5%)
	Strongly Disagree	0 (0%)	0 (0%)	0 (0%)
	No Answer	2 (6.7%)	0 (0%)	2 (5.0%)

TABLE 1. (CONTINUED)

Patient Perspectives and Attitudes Toward the Role of Scalp Biopsy in Diagnosing Central Centrifugal Cicatricial Alopecia (CCCA). Survey responses are presented from patients who underwent a scalp biopsy (*n=30*) and those who did not undergo a biopsy (*n=10*). Responses are shown as both numerical values and percentages.

Survey Question		Number (N) / frequency (%)		
		Biopsy (*n=30*)	No Biopsy (*n=10*)	Total (*n=40*)
"My dermatologist did a good job educating me on why I needed a scalp biopsy"	Strongly Agree	14 (46.7%)	0 (0%)	14 (35.0%)
	Agree	12 (40.0%)	2 (20.0%)	14 (35.0%)
	Neutral	3 (10.0%)	7 (70.0%)	10 (25.0%)
	Disagree	0 (0%)	1 (10.0%)	1 (3.5%)
	Strongly Disagree	0 (0%)	0 (0%)	0 (0%)
		1 (3.3%)	0 (0%)	1 (3.5%)
"I was educated on how the management or treatment of hair loss would change if I received my scalp biopsy."	Strongly Agree	12 (40.0%)	0 (0%)	12 (30.0%)
	Agree	7 (23.3%)	0 (0%)	7 (17.5%)
	Neutral	8 (26.7%)	9 (90.0%)	17 (42.5%)
	Disagree	1 (3.3%)	1 (10.0%)	2 (5.0%)
	Strongly Disagree	0 (0%)	0 (0%)	0 (0%)
	No Answer	2 (6.7%)	0 (0%)	2 (5.0%)
"If my hair condition continued to worsen after treatment, I would undergo a biopsy [or second biopsy] if recommended by my dermatologist"	Strongly Agree	11 (36.7%)	1 (10.0%)	12 (30.0%)
	Agree	10 (30.0%)	5 (50.0%)	15 (37.5%)
	Neutral	3 (10.0%)	4 (40.0%)	7 (17.5%)
	Disagree	4 (13.3%)	0 (0%)	4 (10.0%)
	Strongly Disagree	1 (3.3%)	0 (0%)	1 (3.5%)
	No Answer	1 (3.3%)	0 (0%)	1 (3.5%)
Did you ever feel pressured or coerced to get a scalp biopsy?	Yes	0 (0%)	0 (0%)	0 (0%)
	No	28 (93.3%)	8 (80.0%)	36 (90.0%)
	No Answer	2 (6.67%)	2 (20.0%)	4 (10.0%)

TABLE 2.

Perceptions of Diagnostic Communication and Engagement with Biopsy-Related Information Among Patients with CCCA. Survey responses are presented from patients who underwent a scalp biopsy (*n=30*), and responses are shown as both numerical values and percentages. "Other" responses (indicated by an asterisk) include self-reported sources such as medical journals, online health libraries, and general search engines (eg, Google, Medline).

Survey Question		Number (N) / frequency (%)
		Biopsy (*n=30*)
Were you offered a copy of your scalp biopsy report?	Yes	21 (70.0%)
	No	7 (23.3%)
	Unsure	2 (6.67%)
	No Answer	0 (0%)
Did you believe that your dermatologist was clear when communicating your scalp biopsy results?	Very Clear	25 (83.3%)
	Somewhat Clear	5 (16.7%)
	Not Clear	0 (0%)
	No Answer	0 (0%)
After receiving your diagnosis did you do any personal research on the results of your scalp biopsy?	Yes	23 (76.7%)
	No	7 (23.3%)
	No Answer	0 (0%)

TABLE 2. (CONTINUED)

Perceptions of Diagnostic Communication and Engagement with Biopsy-Related Information Among Patients with CCCA. Survey responses are presented from patients who underwent a scalp biopsy (*n=30*), and responses are shown as both numerical values and percentages. "Other" responses (indicated by an asterisk) include self-reported sources such as medical journals, online health libraries, and general search engines (eg, Google, Medline).

Survey Question		Number (N) / frequency (%)
		Biopsy (*n=30*)
For respondents that responded yes to the previous question, where did you go to learn more about your results?	Dermatology Websites	17 (56.7%)
	Blogs	5 (16.7%)
	Online Forums	7 (23.3%)
	Social Media	2 (6.67%)
	Family or Friends	2 (6.67%)
	Other Dermatologist	1 (3.33%)
	Other*	8 (26.7%)
	No Answer	0 (0%)

DISCLOSURES

Dr Taylor has served as a consultant, advisory board member, and/or speaker for AbbVie, Arcutis, Armis Scientific, Avita, Beiersdorf, Biorez, Bristol-Myers Squibb, Cara Therapeutics, Dior, Eli Lilly, EPI Health, Evolus, Galderma, GloGetter, Hugel America, Incyte, Johnson & Johnson, L'Oreal USA, MedScape, MJH LifeSciences, Pfizer, Piction Health, Sanofi, Scientis US, UCB, and Vichy Laboratoires. She has received royalties from McGraw-Hill. She has served as an investigator for Allergan, Concert Pharmaceuticals/Sun Pharma, Croma-Pharma GmbH, Eli Lilly, and Pfizer. Dr. Ogunleye has served as a consultant, advisory board member, and/or speaker for Beiersdorf, MJH LifeSciences, Dermatology Times, Veradermics, and Health Central. All other authors have no conflicts of interest to disclose.

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