

Factors influencing alopecia areata treatment decisions: A qualitative assessment



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Background: Alopecia areata (AA) is a disease of hair loss in which patients may benefit from comprehensive understanding of AA's disease process and therapeutic options during treatment decision-making.

Objective: Determine factors influencing patients' AA treatment decision-making.

Methods: Qualitative interviews were conducted using semi-structured interview guides. Interviews were coded using inductive thematic analysis.

Results: Twenty-one participants with AA were interviewed. Coding interrater reliability was $\kappa = 0.87$ - 0.91 , indicating strong-almost perfect agreement. Participants faced multiple barriers, including lack of access to health care ($n = 10$, 47.6%) and lack of transparency about their condition and treatment options ($n = 9$, 42.9%). Information about AA was sought from primarily the internet ($n = 15$, 71.4%) and physician recommendation ($n = 15$, 71.4%). When choosing AA treatments, patients often considered treatment efficacy ($n = 21$, 100%), safety ($n = 21$, 100%), and convenience of use ($n = 20$, 95.2%).

Limitations: Referral and regional biases may be present and limit generalizability.

Conclusions: Patients with AA face various challenges including medical uncertainty and lack of information. Patients need trustworthy and accessible sources of information regarding their treatment that also take into consideration their preferences and values. (JAAD Int 2023;10:77-83.)

Key words: alopecia areata; decision aid; hair loss; qualitative; shared decision-making.

INTRODUCTION

Alopecia areata (AA) is a disease of non-scarring hair loss with an unpredictable course. Although the recent Food and Drug Administration's approval of baricitinib marks the first step in introducing new agents in the management of AA, a broad range of treatment options remain available to patients, each with their own risks and benefits.^{1,2} Comprehensive

understanding of these factors are critical for joint decision-making, and patients' attempts to understand their treatment options have resulted in seeking information outside of medical appointments.³

This highlights a continued need to understand how patients make AA treatment decisions, which may provide insight into how to best share

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information with patients. In this study, we aim to understand the factors influencing treatment decision-making among patients with AA, including barriers faced during the decision-making process, information sources utilized to learn about treatment options, and treatment factors themselves.

METHODS

English-speaking patients from Brigham and Women's Hospital dermatology clinic over the age of 18 years with a dermatologist-confirmed diagnosis of AA were interviewed from September 10, 2020 to March 2, 2021. Demographic information and an assessment of patient-reported AA symptom severity and impact on functioning using a validated instrument, the Alopecia Areata Symptom Impact Scale, were collected.⁴ The institutional review board of Mass General Brigham approved this study.

Development and use of the interview guide

A semi-structured interview guide was developed using identified domains from literature review and clinician experience (Fig 1, full version in Mendeley link <https://doi.org/10.17632/7vt4hgcw2f.1>). Specific guidance published by Bredart et al on how to prepare and conduct the interviews was followed while training interviewers.⁵ Patients' medical charts were reviewed to determine AA severity.

Data analysis

Using inductive thematic analysis, a preliminary codebook based on the first 4 interview transcripts was reviewed and refined until discrepancies in the interpretation of the codebook were resolved. Subsequent interviews were split among pairs of researchers and each interview was coded independently twice. Novel codes were determined by consensus. Data were analyzed for thematic saturation in cohorts of 7 interviews.

Coding frequencies using reconciled coded interviews and interrater reliability (Cohen κ coefficient) were determined using NVIVO software v1.3 (QSR International). Codes with less than 90% agreement were discussed to consensus and reconciled. Continuous variables were summarized with means and standard deviations. Categorical variables are reported as proportions and percentages.

RESULTS

A total of 21 participants were enrolled. Most participants were Caucasian ($n = 16$, 76.2%) and female ($n = 18$, 85.7%), with a mean age of 43.2 ± 17.6 years and 42.9% ($n = 9$) patients had alopecia totalis or universalis (Table I).

The interrater reliability rating was $\kappa = 0.87$ - 0.91 , indicating strong-almost perfect agreement.⁶ Code frequencies with representative quotes are in Table II (Mendeley link <https://doi.org/10.17632/7vt4hgcw2f.1>).

Perceived barriers to appropriate care

Participants reported various barriers to appropriate care, with the most common being lack of access to health care ($n = 10$, 47.6%) (ie, insurance [$n = 9$, 42.9%], specialist referrals [$n = 1$, 4.8%]). Lack of information about AA ($n = 8$, 38.1%) was

frequently cited. Participants perceived lack of transparency ($n = 9$, 42.9%) from their physicians regarding treatment options.

Information source considerations

Participants sought information about AA from publicly available sources ($n = 15$, 71.4%) (ie, academic institutions' websites, PubMed, and Amazon product reviews). The same proportion of patients also relied on their physicians for information ($n = 15$, 71.4%). Participants sought dermatologists who demonstrated evidence of credibility ($n = 8$, 38.1%) and displayed strong interpersonal skills ($n = 7$, 33.3%).

Treatment factors considered

All patients considered treatment benefit when choosing an AA treatment ($n = 21$, 100%). All participants also considered safety profile ($n = 21$, 100%) (ie, potential for side effects, severity of side effects, impact of the treatment on other health conditions, or drug interactions). The convenience of a treatment was also considered during treatment decision-making ($n = 20$, 95.2%).

DISCUSSION

Our findings reflect a broad range of factors influencing patients' AA treatment decision-making. Various systemic and individual-level barriers when

CAPSULE SUMMARY

- Alopecia areata treatment decision-making is complex, requiring consideration of various factors by patients.
- Patients face various barriers to appropriate treatment, including medical uncertainty and lack of transparency. Patients may benefit from solutions to mitigate confusion surrounding their alopecia areata that provide accessible and credible medical information.

Abbreviations used:

AA: alopecia areata
AASIS: Alopecia Areata Symptom Impact Scale
SD: standard deviation

seeking care for their AA were present and patients sought information from various sources. When choosing an AA treatment, patients each had their own unique interpretations of treatment domains and preferences regarding those domains.

One of the most common barriers to appropriate treatment was lack of clarity and understanding

surrounding AA’s disease process, eliciting feelings of frustration, and isolation: “That has been really frustrating is the lack of medications, the lack of research, the lack of data...There is just so much information out there and to do research can be kind of exhausting.”

Physicians played a predominant role in both educating patients and offering emotional support. Patients identified ways to determine physician credibility, citing credentials such as their associated institution and specialization in hair loss. Patients valued a physician’s ability to display empathy, with one patient willing to drive across state lines to be treated by her dermatologist: “It was an

PATIENT QUALITATIVE STUDY SCRIPT

Patient name: _____ **MRN:** _____ **Date:** _____

Interviewer instructions: This is a semi-structured interview.

Questions 1-2: Expand on each ‘domain’ the patient brings up spontaneously. Allow the patient to discuss what they consider in their decision making. Use the probes provided or similar probes to delve deeper into their responses (i.e. It’s important to consider how safe a treatment is—What do you mean by safe?).

Please use the checklist (page 2) below to keep track of what domains the patient spoke about. Additional prompts are available in the table at the end of the script.

This interview should take between ~10-30 minutes.

Introduction:

Hello, my name is (insert name) and I am a research assistant. How is your day going so far?

First, we’d like to thank you for participating in this study today- Your time today will help other people with alopecia areata (AA). Today, I’d like to learn about what matters to you when choosing an AA treatment. We would like to use this information to create a guide for patients to use when choosing an AA treatment.

I will be asking you a series of open-ended questions to facilitate this discussion.

Do you have any questions for me before we begin?

1. What factors about a treatment do you consider when choosing an AA therapy?

Outcome attributes:

- Evidence/ Knowledge
- Treatment Benefit
- Safety

Process attributes:

- Administration
- Convenience/ Accessibility

Other:

- Format/ Information delivery
- Religion
- Culture
- Support
- Barriers

Probes:

- That’s very interesting, can you tell me more about...
- Could you give me an example of...
- So, you mentioned A and B, can you think of any other *** that is important when selecting a medication?
- What do you mean by...
- Would you explain further...
- What would that look like?
- Why is that important to you?
- Is there anything else that you consider when making a treatment decision?

2. Is there anything else we’re missing that you’d like to discuss?

Fig 1. Semi-structured interview script. AA, Alopecia areata.

Table I. Patient characteristics

Characteristics	<i>n</i> (%)
	Overall (<i>n</i> = 21)
Age, mean (SD)	43.2 (17.6)
Sex	
Male	3 (14.3)
Female	18 (85.7)
Race	
White	16 (76.2)
Black or African American	1 (4.8)
Asian	1 (4.8)
Native Hawaiian or other Pacific Islander	1 (4.8)
Other	2 (9.6)
Ethnicity	
Hispanic or Latino	2 (9.6)
Not Hispanic or Latino	18 (85.7)
Data not available	1 (4.8)
Duration of AA (y)	12.4 (14.0)
Severity of AA	
Patchy	12 (57.1)
Totalis	6 (28.6)
Universalis	3 (14.3)
AASIS symptom severity, mean (SD)	
Scalp hair loss	5 (4.5)
Eyelash or body hair loss	3.5 (4.6)
Tingling or numbness of the scalp	1.0 (2.5)
Painful skin	2.0 (2.5)
Irritated skin	1.7 (2.1)
Anxious or worry	4.9 (3.2)
Sad	3.8 (3.1)
AASIS impact on functioning, mean (SD)	
Work	1.7 (3.0)
Enjoyment of life	2.8 (3.4)
Interaction with others	3.2 (3.7)
Daily activity	3.2 (3.6)
Sexual relationship	4.2 (3.8)
Quality of life	3.1 (2.9)
AASIS global (average of all scores), mean (SD)	2.9 (3.6)

AA, Alopecia areata; AASIS, Alopecia Areata Symptom Impact Scale; SD, standard deviation.

8-hour round trip from me to come for this treatment and I felt that it was worth every sensation I had in my scalp.” Perceived transparency from their physicians about treatment options was also important to patients and allowed patients to feel supported to make autonomous treatment decisions.

The major treatment factors patients sought when making an AA treatment decision were also identified: efficacy, safety, and convenience. Patients demonstrated a broad range of interpretations of each of these domains, highlighting the nuances that should be taken into consideration when making AA

treatment decisions. Patients consistently weighed the risks and benefits between these factors: “I do not want to harm myself because at the end of the day, it’s just hair... but at the same time, mentally, it can be really difficult to not have hair.”

These findings provide valuable insight into the heterogeneous factors that patients with AA consider when making treatment decisions. Patients may benefit from a comprehensive, evidence-based information source to supplement traditional in-clinic verbal communication and educational pamphlets. A potential solution would be a shared decision-making tool.⁷ Access to such resources could enhance patients’ sense of control and understanding of their condition and therapeutic options. Although decision aids may not eliminate uncertainty, they would assist physicians in providing a framework to engage patients to participate in treatment management decisions and facilitating a better understanding of treatments to provide better patient-centered care.^{8,9}

Limitations

This study must be considered within the context of its study design, which was done using a convenience sample from an academic center. These patients may differ from patients who seek care at non-academic centers. Due to the geographic proximity of patients to the academic medical center from which they were selected, referral and regional biases may be present, thus limiting generalizability. Our sample was largely Caucasian and female and may not encompass the potentially broad range of cultural attitudes about medical decision-making. Additionally, interviews were conducted during the COVID-19 pandemic which likely impacted patients’ perceived barriers to appropriate treatment.

CONCLUSION

Our findings demonstrated that patients with AA consider various factors when making treatment decisions and relied on not only dermatologists, but information sources outside the clinic. Patients need resources that provide comprehensive information and tools that can help lead them to the optimal individualized treatment plan.

Conflicts of interest

Dr Mostaghimi has received personal fees from Pfizer, hims, and 3Derm and holds equity in hims and Lucid. Dr Huang has received royalty payments for licensing of the ALTO tool, participated in clinical trials related to alopecia from Incyte, Lilly, Concert, and Aclaris, and received consulting fees from Pfizer and Concert. Dr Senna has participated in alopecia clinical trials related from Eli Lilly

Table II. Code frequencies and representative quotes

Themes	Quote	Freq (%)
Barriers experienced by patients with AA		
Code: access to health care		10 (47.6)
Subcode: coverage by health insurance	"[The treatment] was not going to be covered by insurance...so it's certainly a consideration that I need to really take into account."	9 (42.9)
Subcode: lack of ability to be referred to a specialist	"The issue of, 'Oh, you don't have a primary care physician to then refer you to a specialist.'"	1 (4.8)
Code: physician not offering treatment options	"I was told there's nothing I could do [for my hair loss]."	9 (42.9)
Code: lack of information regarding AA	"There's a lot of unknowns with alopecia areata and no one really knows the exact cause of it."	8 (38.1)
Code: pandemic	"Another barrier was when COVID-19 came. I did not receive treatments for 4 months because it's every 6 weeks."	4 (19.0)
Code: other time commitments (ie, work)	"Luckily, I have a very flexible job...but I could see if I had to go a few times a month to get injections or shots or anything that requires an in-person visit, I could see that being a deterrent."	4 (19.0)
Information sources considered by patients		
Code: physician recommendation	"The doctor's input is first and foremost [important]."	15 (71.4)
Code: internet (ie, websites, Amazon, PubMed)	"I think the internet is a resource for everybody."	15 (71.4)
Factors considered when choosing a doctor		
Code: qualifications of dermatologist		8 (38.1)
Subcode: specialized in hair loss	"When I was researching where to go, I looked at the people that specialize [in hair loss]."	6 (28.6)
Subcode: member of professional associations or highly esteemed institution	"[My doctor] is very qualified...and [she] teaches at Harvard."	4 (19.0)
Code: physician characteristics		12 (57.1)
Subcode: transparency	"My dermatologist told me we could do all sorts of different treatments...having all that information at my disposal ... I felt like that there was not anything that I was missing and I was being presented with all the treatment options that are available to me."	8 (38.1)
Subcode: good bedside manner	"[My dermatologist] was very empathetic and understanding, and that definitely helps to build the trust to feel like your doctor just does not see you as a name on the chart to get through every day."	7 (33.3)
Factors considered when choosing an AA therapy		
Code: treatment benefit		21 (100)
Subcode: ability to achieve hair regrowth	"My idea of success is seeing hair start to grow."	21 (100)
Subcode: magnitude of treatment effect	"I used to have long thick hair so that when it all fell out it was, you know, traumatic and so obviously I want to get back to what I had."	8 (38.1)
Subcode: prevent hair loss	"Stopping the hair from falling out."	6 (28.6)

Continued

Table II. Cont'd

Themes	Quote	Freq (%)
Subcode: ability to treat other comorbidities	"[The topical steroid] was good for the itching that could sometimes come with the eczema, because I also have psoriasis and eczema...It would take care of the itching and it would also help with the [hair] growth."	5 (23.8)
Subcode: time to treatment effect (eg, speed of hair regrowth)	"Whatever is going to work super fast, I was willing to do many at the same time versus try one at a time and wait even though some of [the doctors said] if you try many at the same time, you will not know which one is the one that's working...I do not really care because I just wanted it to go away."	4 (19.0)
Code: safety		21 (100)
Subcode: local side effects (ie, dermatitis)	"[Topical steroids] can thin out your skin and make it more susceptible to dryness, breakage."	19 (90.5)
Subcode: systemic side effects	"I did not want to have anything that was systemic that might impact the rest of my body, so I asked which one would impact like directly on the hair follicle and that's how I chose that treatment."	18 (85.7)
Subcode: contraindications	"I do not want to do anything that otherwise impacts my health and I have borderline high blood pressure, and I have a heart arrhythmia. I was very concerned about the impact of the [treatment] on my existing health."	18 (85.7)
Subcode: overall side effects	"My biggest concern is whether or not it's going to do any harm to me."	17 (81.0)
Subcode: severity of side effect	"Would [the treatment side effects] cause me to be tired to a point where I cannot function? If it causes a noticeable difference, where I can't sleep, tiredness, or noticeable weight gain."	14 (66.7)
Code: convenience		20 (95.2)
Subcode: route of administration (systemic or localized)	"Understanding which [routes of administration] we are looking at and why is it important."	14 (66.7)
Subcode: cost of treatment (ie, medication, copays)	"I don't have unlimited funds..., so it's certainly a consideration that I need to really take into account."	12 (57.1)
Subcode: frequency of medication administration	"If [the steroid shot] was... every single Wednesday morning for 3 mo and you have to come in every other week...that would not be a treatment that I would want to pursue just given how much work time I would miss."	10 (47.6)
Subcode: pain associated with treatment	"[Needles to the scalp] are not fun, so those are sort of always my last resort. I have not had great experiences with those."	8 (38.1)
Subcode: duration of medication administration	"[Minoxidil] grows hair, but you have to use it the rest of your life."	7 (33.3)

AA, Alopecia areata; COVID, corona virus disease.

and Concert, received consulting fees from Concert, and is on the scientific advisory board of Cassiopea. Dr Pérez-Chada reported receiving grants from the National Psoriasis Foundation outside the submitted work. All other authors have no conflicts of interests to declare.

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