Physician values in alopecia areata treatment decision-making: A qualitative assessment

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Background: Alopecia areata (AA) is a disease of hair loss with multiple treatment options. Physicians play an important role in guiding patients during the decision-making process.

Objective: Assess physicians' values and attitudes when helping patients choose an AA treatment.

Methods: Semi-structured qualitative interviews were conducted with dermatologists of varying practice type and location. Each interview was coded independently twice using inductive thematic analysis. Interrater reliability and code frequencies were determined.

Results: Fourteen participants were interviewed. Interrater reliability was κ = 0.85 to 0.97. Dermatologists wanted patients to consider various treatment factors (ie, efficacy, safety, convenience of use, accessibility) and also assessed patients' AA clinical severity and personality traits. Participants often encountered various barriers to effective communication with patients, which may be mitigated by shared decision-making. Shared decision-making tools were perceived to potentially improve patient care and communication, although physicians expressed concern about lack of individualization, limitations of time, and the appropriateness of information.

Conclusion: AA treatment decision-making is a complex process that often utilizes the expertise of a dermatologist, during which shared decision-making tools may be of value to both patients and physicians. (JAAD Int 2023;11:14-23.)

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

INTRODUCTION

Alopecia areata (AA) is an autoimmune disease characterized by non-scarring hair loss. Patients with AA are tasked with making complex treatment decisions that need to account for patient preferences, medication side effect profiles, and medication efficacy data. This decision is often plagued by uncertainty, frustration, and isolation due to the volume of resources and the lack of data and research.[1] This uncertainty is linked to decisional regret, with most patients reporting they would prefer to make decisions in tandem with their physician's expertise and recommendation.[2] Despite these findings, many patients rely on information sources outside the doctor's office to make treatment.[3,4] This suggests a discordance between

physicians and patients during this decision-making process Current physician perceptions and considerations when helping patients choose treatments for AA have not yet been explored and are needed to understand the misalignment that currently exists between patients and physicians. Shared decision-making (SDM), a process where patients and physicians collaborate to come to a mutual decision, has been used in other dermatological diseases and may aid patients in choosing a treatment that aligns with their values and preferences.[5] This study aims to understand factors that dermatologists consider when selecting the appropriate AA treatments together with patients, understand physician preferences for relaying information to patients, and assess the perceived benefits and risks of an AA SDM tool.

CAPSULE SUMMARY

- Alopecia areata treatment decision-making is complex, requiring consideration of treatment and patient factors.

- Communicating information about alopecia areata treatment options to patients is often challenging. Physicians are open to using a shared decision-making tool, especially if it is balanced, time-efficient, and able to be individualized to patients.

METHODS

A convenience sample of physicians of varying practice setting and geographic location were recruited via email and interviewed from September 23, 2020 to January 21, 2021 if they met inclusion criteria of being a board-certified dermatologist that participated in the care of patients with AA. No participants dropped out or refused to participate. The Mass General Brigham institutional review board approved this study. This study meets guidelines defined by the consolidated criteria for reporting qualitative research.[6]

Development of semi-structured interviews

The semi-structured interview guide was developed using a 5-step systematic framework as follows[7]: (1) This study was determined suitable for the semi-structured interview format to allow for the discovery of themes not already identified by the research team.[8] (2) A comprehensive literature review was performed to gather a list of anticipated domains, (J.H., S.L., K.L., P.M.) which were sent for expert review (A.M., L.C., K.H.). (3) A semi-structured interview script using open-ended questions and probes was developed and refined until consensus was reached by all authors. (4) The interview script was pilot tested with 3 dermatologists to check for understanding and clarity of questions.

Conducting interviews

A team of research fellows (J.H., B.K., K.L., K.K.) were trained on usage of the semi-structured interview guides. Pilot interview transcripts were reviewed for consistent usage of the interview script. A total of 14 interviews was then split among the interviewers. None of the participants had a previous relationship with the interviewer. Prior to beginning the interview, participants were informed of the study's purpose and interviewer's role in the study. Participants provided verbal consent to proceed with the one-on-one interview. The interviews were conducted virtually and audio-recorded and were then transcribed verbatim for further analysis. Participants received no monetary compensation. There were no repeat interviews. No field notes were made during interviews and participants did not provide comments or corrections after interview completion as transcripts were not returned to them.

Coding

Inductive thematic analysis was used to create the codebook (J.H., K.L.) using the first 4 interviews transcripts. The codebook used themes identified during interview script development, supplemented with additional themes derived from the interviews. The first interview was independently coded by 4 researchers (J.H., K.L., B.K., K.K.) to determine discrepancies in interpretation of the codebook. Subsequent interviews were split among researchers and each interview was independently coded twice. Novel codes were determined by consensus among coders. The last 7 interviews presented with no novel codes and were determined to have reached thematic code saturation.

Statistical analysis

Continuous variables were summarized with means and SDs. Categorical variables are reported as proportions and percentages. Coding frequency using reconciled coded interviews and interrater reliability (Cohen κ coefficient) were determined using NVIVO software v1.3 (QSR International). Discrepancies with <90% agreement were discussed among coding teams to establish consensus.[9]

RESULTS

A total of 14 participants were enrolled. Mean interview duration was 24.1 minutes (SD: 8.3). The mean age was 41.6 years (SD: 10.5), 50% of participants were female, and majority (12, 85.7%) were Caucasian. 57.1% of participants practiced in an academic setting and have been in practice for a mean of 10.2 years (SD: 11.7) (Table I).

The interrater reliability of coding teams was κ = 0.85 and κ = 0.97, indicating almost perfect agreement.[5] Table II displays code frequencies and representative quotes for each code.

Factors considered when helping a patient choose an AA treatment

When asked "When helping a patient choose an AA treatment, what factors about the treatment do you want them to consider or be aware of?" all participants mentioned treatment benefit (14, 100%), most often referring to the ability of a treatment to achieve hair regrowth (12, 85.7%) or ability to meet patient expectations (11, 78.6%). All participants also wished for patients to consider the safety of a treatment (14, 100%) such as side effect profile (13, 92.9%) and contraindications (9, 64.3%). Another common consideration was accessibility (13, 92.9%), such as costs to the patients and insurance coverage (11, 78.6%). Participants also wanted patients to consider the treatment's convenience (7, 50.0%).

When determining what patients' factors, they consider when recommending treatments, participants most commonly mentioned patient demographic characteristics (13, 92.9%) and severity or chronicity of patients' AA (10, 71.4%). Other significant themes included the ability of a patient to adhere to a medication (10, 71.4%) and the degree of psychosocial burden of AA on the patient (8, 57.1%). Physicians also considered personality traits of patients (8, 57.1%) such as anxiety and risk aversion.

Sharing information with patients

The most common preferred sources that dermatologists wanted patients to learn about AA treatments were from professional dermatological organizations (13, 92.9%) and physicians (11, 78.6%). Patient testimonials (7, 50.0%) or the internet (9, 64.2%) were also acceptable sources of AA treatment information. Participants determined sources to be credible based on their ability to recognize

Table I. Participant demographics

Characteristics	*N* (%) Overall (*n* = 14)
Age, mean (SD)	41.6 (10.5)
Sex	
Male	7 (50.0%)
Female	7 (50.0%)
Race	
White	12 (85.7)
Asian	2 (114.3)
Ethnicity	
Hispanic or Latino	0 (0)
Not Hispanic or Latino	14 (100)
Years in practice, mean (SD)	10.2 (11.7)
Practice setting	
Academic	8 (57.1%)
Non-academic	6 (42.9%)
Duration of interviews, min (SD)	24.1 (8.3)

N, Entire sample.

the authors or institution (8, 57.1%) or if the source was associated with a professional organization (11, 78.6%).

When relaying information about AA treatments to patients, participants preferred oral (14, 100%) to visual (9, 64.3%) methods of communication. The most popular method was in-person oral communication (12, 85.7%). Participants perceived patients to prefer visual communication, most often in the form of a printed handout (9, 64.3%).

Various barriers existed for physicians when relaying information to patients about AA treatments, such as lack of time to appropriately counsel patients (4, 28.6%) as well as factors intrinsic to the patient such as low health literacy (11, 78.6%) and preconceived fears about treatment (4, 28.6%).

Utility of a decision aid

A decision aid was then defined to physicians as "a tool to inform patients about the pros and cons of different treatment options" with a goal to "help patients choose a decision that is right for them." Perceived benefits of an AA decision aid were improvements in patient care (13, 92.9%), by helping patients develop a preliminary understanding of treatments, breaking down complex information to help facilitate conversations, and providing a structure to decision-making. Participants also believed the decision aid could improve communication between the patient and physician (4, 28.6%). The greatest perceived risk of the AA decision aid was the inability to personalize it to each individual patient (10, 71.4%). Other risks included having an inappropriate amount of information in the decision aid (9,

Table II. Code frequencies and representative quotes

Code	Quote	Frequency *n* (%)
Theme: Treatment factors physicians considered when helping patients choose an AA therapy		
Code: Treatment benefit		14 (100)
Subcode: Ability to achieve hair regrowth	"I would be hoping to see hair regrowth."	12 (85.7)
Subcode: Ability to meet patient expectations	"What it really comes down to is what the patient's goals are…So I mean, one patient might be happy as long as they can just regrow all the eyebrows and one patient might not be happy."	11 (78.6)
Code: Safety of the treatment		14 (100)
Subcode: Local side effects	"Locally in terms of skin thinning or breakdown, or …is the patient having any irritant dermatitis or a bad local reaction."	14 (100)
Subcode: Systemic side effects	"I think people are worried about effects on their body…Side effects like … hepatotoxicity."	13 (92.9)
Subcode: Contraindications to treatment	"What their individual risk is on top of whatever that medication is that you're starting. So eg, if you have a patient who has a history of a kidney transplant and is already on multiple immunosuppressants, then you're not going to probably reach for something like tofacitinib for him because he's already on a number of other immunosuppressant medications and probably can't afford to be on something that lowers his immune system further."	9 (64.3)
Code: Convenience		14 (100)
Subcode: Planning required for appointment	"Their ability to take time off from work for treatments."	12 (85.7)
Subcode: Frequency of clinic visits	"It's just frequent visits for them. They may not need as frequent visits if they're doing a systemic treatment."	12 (85.7)
Subcode: Route of treatment administration	"The route of administration, whether we're talking topical, oral, or injectable."	12 (85.7)
Subcode: Pain or discomfort associated with treatment administration	"Some of the treatments are a little bit painful, so would the pain be worth the treatment?"	9 (64.3)
Subcode: Frequency of treatment administration	"I think about is the ability of the patient to do anything that requires repeated applications because a lot of my patients don't want to have to be bothered with putting something, applying it on twice a day consistently."	9 (64.3)
Subcode: Duration of treatment use	"The likelihood that they would need ongoing treatment."	8 (57.1)
Subcode: Ease of use	"Just how easy it is for the patient. So a lot of times I do intralesional Kenalog for limited disease because it's just very easy. They don't have to remember to use anything at home…And so I think I oftentimes choose that over things like squaric acid or even like topical steroids at home, just because it's a lot easier."	5 (35.7)
Code: Accessibility		13 (92.9)

Table II. Cont'd

Code	Quote	Frequency *n* (%)
Subcode: Cost of treatment	"The ability for a patient to pay for a medicine that's over the counter… Also patients' ability to have medical coverage… Oral JAK inhibitors is extremely difficult to get covered by insurance right now because it would be off label and some patients or most patients cannot afford oral JAK inhibitors. And if that's completely paid out of pocket, the cost could be several 1000, if not more."	11 (78.6)
Theme: Patient factors physicians considered when helping patients choose an AA therapy		
Code: Demographic characteristics		13 (92.9)
Subcode: Age	"One has to consider how old the patients are."	13 (92.9)
Subcode: Gender	"I have a lot of male patients… 'Whatever, I'm used to going bald'… and then for female patients it has a greater impact on quality of life."	5 (35.7)
Code: AA characteristics	"Depending on how extensive the disease is and what has been the course of disease."	12 (85.7)
Code: Patient's ability to adhere to a medication regimen		10 (71.4)
Subcode: Tolerance for medication use	"Using a topical medication twice a day, eg, we may think is not a big deal, but…it can get to be a little frustrating, messy, and it could interfere with your day."	7 (50.0)
Subcode: Lifestyle factors	"So let's say they were in a line of work such that they're unable to get to clinic…Then, potentially, we'd want to consider medications that would allow them to do a majority of their treatment at home…If someone is unable to make those appointments on a regular basis, it may not necessarily be very worthwhile to kind of initiate it if they're only able to come in, say, every you know 6 to 12 months or something like that."	6 (42.9)
Code: Psychosocial burden of AA on patient	"Have a sense of how much the disease has mentally affected the patient and what are going to be the consequences of not optimally treating a patient."	8 (57.1)
Code: Personality traits	"You get to know your patients in terms of their own risk tolerance."	8 (57.1)
Theme: Sources dermatologists prefer patients to learn about AA treatments		
Code: Professional organizations	"I would be aiming for professional organizations that can provide helpful patient information, whether that be through…Up-to-Date, or you know anything that would be a professional organization such as the AAD."	13 (92.9)
Code: Physicians	"The dermatologist because as specialists of the hair, skin and nails, I think we have the most information."	11 (78.6)

Table II. Cont'd

Code	Quote	Frequency *n* (%)
Code: Internet	"I usually like them to visit a website. I often use a website out of New Zealand called DermNet.NZ…The British Association of Dermatologists also has a website."	9 (64.3)
Code: Other patient testimonials	"Patients have support groups and I do think actually support groups are a great option for patients to kind of hear about treatment options."	7 (50)
Theme: Factors that make information sources credible to physicians		
Code: Associated with a professional organization	"Affiliated with some university hospital."	11 (78.6)
Code: Source is recognizable	"If it's a blog by a guy I've never heard of, then maybe it's a great site, but I don't really know that. I probably wouldn't direct a patient there, but if it's like the Alopecia Areata Foundation that might be some place that I would be more comfortable with."	8 (57.1)
Theme: Physicians' preferred method of relaying AA treatment information to patients		
Code: Oral communication		14 (100)
Subcode: In person	"Just simply discussing it in clinic."	12 (85.7)
Code: Visual communication		9 (64.3)
Subcode: Handout	"I personally like giving like handouts or written instructions to a lot of my patients."	8 (57.1)
Subcode: Internet based	"I tell them that there are online, different AA organizations that they can look at."	3 (21.4)
Theme: Dermatologists' perception of how patients prefer to learn about AA treatments		
Code: Oral communication		10 (71.4)
Subcode: In person	"My experience is that they want directly face to face ask questions to the provider."	6 (42.9)
Subcode: Virtual or telephone	"A lot of patients like to communicate via like what we call patient gateway… So you know that's the primary route or via phone."	3 (21.4)
Code: Visual communication		11 (78.6)
Subcode: Handout	"I have some [patients] who would prefer something on a piece of paper and writing."	9 (64.3)
Subcode: Internet based	"We have a patient instruction thing through Epic."	6 (42.9)
Theme: Barriers physicians face when relaying AA treatment information to patients		
Code: Low health literacy of patients	"There are other patients where I feel like I'm going around in circles and they're just not understanding it, and it has to do with their underlying background, whether it's medical or just literacy in general."	11 (78.6)
Code: Language barriers	"Language barriers."	6 (42.9)
Code: Poor communication between patient and physician	"I guess the biggest barrier is just educating them and having them understand exactly what they should be doing and then also understanding."	5 (35.7)

Table II. Cont'd

Code	Quote	Frequency *n* (%)
Code: Lack of time	"Having limited time. I mean you're in a clinic. Busy, active clinic, and then patients are going to have many questions and you typically have between 15 to 20 minutes per patient. And that's typically not enough to answer questions of a very stressed-out patient who started to overnight lose hair."	4 (28.6)
Code: Patient fears	"Patients' fears about treatments is always a big factor. Fears about what a certain skin change or hair change means for their overall health as well as how that may progress."	4 (18.6)
Theme: Perceived benefits of using a decision aid		
Code: Improved patient care or education	"It could help patients kind of go a yes/no of what works best for them, to kind of navigate the system on their own little bit on their own, or kind of read through the treatment options on their own and kind of get a gestalt for what seems best for them."	13 (92.9)
Code: Improved communication with patient	"I think would be convenient for patients and help facilitate conversations around treatment options"	7 (50.0)
Theme: Perceived challenges and risks associated with using a decision aid		
Code: Lack of personalization of decision to each patient	"It's hard to personalize a decision aid completely to all different types of patients and all different types of background…It would have to be partnered with the conversation to talk about the nuances of each treatment."	10 (71.4)
Code: Having too much or too little information	"Are you going to err on the side of including every single risk associated with it, and every single data point that's out there? Or are you going to try to kind of include as little information as possible?"	9 (64.3)
Code: Prevent the patient from exploring treatment options	"I guess it just totally depends on the aid and the quality of it. Whether it's anchoring somebody on what they think should be done."	7 (50.0)
Code: Challenges specific to the physician		
Subcode: Time consuming	"[The decision aid] can take up a lot of your time, which can put you behind in terms of the other patients you have scheduled for the day."	8 (57.1)
Subcode: Logistical difficulties incorporating a decision aid into practice	"You have to figure out a way to kind of have it go with your clinic flow… You have to logistically figure out how much time it would take to have them review it …Timing might be tough and then I think."	5 (35.7)
Theme: Physicians' preferred medium for a decision aid		
Code: Physical copy	"A laminated flow chart."	8 (57.1)
Code: Online	"Web based or internet based would be ideal."	7 (50.0)
Code: Application	"Sent to patients by gateway."	4 (28.6)

Continued

Table II. Cont'd

Code	Quote	Frequency n (%)
Theme: Physicians' preferred time to use a decision aid		
Code: Before clinic	"Before they even come into your clinic they kind of go through it on their own."	2 (14.3)
Code: During clinic	"We can discuss it at the visit during the clinic time."	11 (78.6)
Code: After clinic	"They'll go home with [the decision aid] and then call me after the fact."	7 (50.0)
Theme: Information that should be included in a decision aid		
Code: Various treatment options	"I would like for it to have the available treatment options."	9 (64.3)
Code: Treatment factors	"It would include… risk benefit, administration schedule, administration mode, vehicle, if it's a topical… individual patient substrate."	9 (64.3)
Code: Interactive tool	"Maybe a brief questionnaire that would assess their preferences and then present them with their two main options."	6 (42.9)
Code: Educational materials	"It should include an understanding of the disease that they have."	2 (14.3)

AA, Alopecia areata; *n*, subsample.

64.3%), potentially causing patients to prematurely anchor on decisions without guidance from a physician (7, 50.0%). Risks to the physician were logistical, such as the decision aid being time consuming (8, 57.1%) or being difficult to use (4, 28.6%).

The preferred medium for a decision aid was a physical copy (8, 57.1%) or online (7, 50.0%), with some participants recommending to incorporating the decision aid into a website (3, 21.4%) or the health record system (5, 35.7%). Participants varied in when they would use a decision aid in their practice, with most either preferring during (11, 78.6%) or after clinic (7, 50.0%).

When asked what information should be included in the decision aid, participants suggested including information about a treatment's benefit (6, 42.9%) and safety profile (8, 57.1%) and thought the decision aid should display various treatment options (9, 64.3%) for the patient to review. Participants also proposed making the decision aid interactive (6, 42.9%) and incorporating additional education for patients such as explanations of AA's disease process (2, 14.3%).

DISCUSSION

The results from our study demonstrate that physicians' factor in multiple variables when helping patients choose an AA treatment. Dermatologists universally wanted patients to consider hair regrowth or efficacy in the context of meeting patient expectations. One participant highlighted the importance of aligning patient goals with the physician's, stating "one patient might be happy as long as they can just regrow all the eyebrows and one patient might not be happy." Safety profile, accessibility, and convenience of use of a treatment were also important considerations among dermatologists.

Dermatologists also considered various patient characteristics when helping patients choose an AA treatment. In addition to clinical features of patients such as age and AA severity, physicians emphasized the importance of the patient's ability to adhere to a treatment regimen, which requires an understanding of a patients' personal characteristics and circumstances. Physicians also acknowledged the variability in emotional burden among patients with AA and its impact on treatment choice: "Some patients just kind of embrace not having hair, and others cannot do that…So there's a lot of talk about their values and life and how much their hair fits into that." Together, these findings highlight the complex role of physicians in guiding the patients through treatment decisions, a process that requires clarification of stakeholder values and expectations.

Physicians preferred patients to learn about AA treatments from dermatologists and reputable sources such as dermatology-specific organizations (ie, the American Academy of Dermatology), although many were also open to patients seeking information from other unvetted sources, such as the internet or support groups. When asked how they preferred to relay information to patients, dermatologists favored

in-person conversations, the default in clinical settings, alluding to their perceptions that it is the fastest, least cumbersome way to communicate with patients.

Limited time per patient was cited as a common barrier and may encourage limiting use of other materials during clinic given the potential for added time, although physicians acknowledged patients may prefer visual learning. Physicians' value of efficient communication was a recurring theme: "You typically have between 15 to 20 minutes per patient. That's typically not enough to answer questions of a very stressed-out patient who started to overnight lose hair." Other barriers such as low health literacy of patients required additional physician guidance and contributed to difficulty in providing comprehensive care. Practical solutions are needed to help alleviate the burden of relaying information off of physicians, which may be addressed with SDM.

Recommended by the American Medical Association, SDM seeks to enhance patients' autonomy by allowing patients to choose options congruent with their values.[10] Recent studies have shown that a majority of patients with AA prefer SDM to physician and patient-only guided treatment decisions.[2] However, dermatology specific SDM resources are sparse, with only 5 published SDM tools available.[5] Furthermore, no SDM tools exist specifically for AA, a condition that ideally requires patient input when choosing a treatment due to the broad range of acceptable options. Lack of SDM tools may be attributable to logistic difficulties as well as preconceived notions that some patients may be unable to, or do not want to participate in SDM.

In order to make SDM a routine part of dermatologic practice, physicians need simple and efficient solutions to supplement the patient-physician interaction. One potential solution may be to utilize balanced, non-biased SDM tools such as decision aids. Dermatology-specific decision aids for psoriasis and acne have been validated among patients and were found to make the treatment decisions easier and decrease decisional conflict.[11,12] Potential pitfalls of a decision aid may include longer clinic visits, overwhelming the patient with too much information, and lack of personalization.[5] However a single decision aid available in multiple formats such as a physical pamphlet or a website and/or handout linked to the after-visit summary in the electronic medical record may be pragmatic approaches. Further research is needed to evaluate the values of patients with AA when choosing a treatment.

Limitations

Our study should be considered in the context of our study design. Although our enrolled sample represents a geographically diverse population of both academic and non-academic practice settings, the majority of our participants were Caucasian. Our results may not represent the potentially broad range of cultural attitudes toward the decision-making process. Many participants also indicated during interviews no prior experience with decision aids, leaving the concept of a decision aid open to interpretation. The lack of familiarity with decision aids may have influenced a participant's attitudes and perceptions toward such a tool.

CONCLUSION

AA treatment decision-making is an intricate process that requires input from both patients and dermatologists. Dermatologists consider a multitude of factors when providing guidance during this process. Barriers to effective communication and the complexity of decision-making may benefit from a SDM tool to allow patients and physicians to work together in making higher quality decisions that align with patients' values and preferences.

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