

CHALLENGES IN ALOPECIA AREATA AND OPPORTUNITIES TO DRIVE CHANGE

A GLOBAL
MULTI-STAKEHOLDER
CONSENSUS

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ALOPECIA AREATA CONSENSUS TASK FORCE

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EXECUTIVE SUMMARY

Alopecia areata (AA) is an inflammatory autoimmune disease, causing nonscarring hair loss that can significantly impact both the physical and psychological wellbeing of patients.

The condition affects nearly 2% of the general population, with 60% experiencing their first instance of hair loss before the age of 20.¹ Despite its prevalence, the path to diagnosis and treatment presents numerous challenges for people with AA and those caring for them, underscoring a critical need for improved awareness, education, and management of the disease.

This whitepaper presents a comprehensive overview of key challenges and unmet needs in AA, as identified by an international multi-stakeholder group of AA experts, and explores opportunities for enhancing care for those affected by the disease.

¹ Alkhalifah A, Alsantali A, Wang E, McElwee KJ, Shapiro J. Alopecia areata update: part I. Clinical picture, histopathology, and pathogenesis. *J Am Acad Dermatol.* 2010;62(2):177–88.

The paper focuses on three key areas of unmet need:

Delays to diagnosis of alopecia areata

The path to diagnosis of AA is complicated by multiple factors that can hinder patients' presentation to the healthcare system, including limited public awareness and understanding of the disease, socio-economic barriers, and stigma associated with AA. Common misconceptions about the cause of AA or how it can be treated reduces the likelihood of patients consulting appropriate medical specialists for treatment, and some may seek alternative, non-medical methods to address the hair loss. Limited awareness of the symptoms of AA and its holistic impact among primary care physicians and non-specialists can further delay proper referral and diagnosis of patients. Additionally, in many countries AA specialists are lacking or unevenly distributed, further delaying diagnosis, particularly in rural areas. To address these issues and improve the pathway to diagnosis for people with AA, there is a need for increased public awareness, improved education of healthcare professionals, and streamlined referrals and access to specialists.

Unequal and inadequate treatment for alopecia areata

Although the treatment landscape for AA has evolved in recent years, patient access to therapies remains challenging due to the absence of universal disease guidelines and a lack of understanding among dermatologists without specialist AA knowledge. Hesitation amongst some dermatologists to prescribe AA treatments can stem from the limited efficacy of conventional therapies and outdated beliefs about the true cause of the disease. This is compounded by a lack of information on newer therapies in the AA space, coupled with a lack of consensus on treatment approaches among experts. Payer and policymaker perceptions of AA as a cosmetic issue further complicate treatment access, leading to limited coverage and reimbursement. To address these challenges and improve access to treatment for people with AA, there is a global need for comprehensive treatment guidelines, dermatologist education on the latest treatments, and belief and behavior shift among payers and policymakers.

Lowered quality of life for people with alopecia areata and their caregivers

AA can have a considerable impact on the quality of life (QoL) of patients and of those caring for them. Psychosocial co-morbidities, an unpredictable disease course, a lack of public awareness, and stigma associated with the disease, all contribute to this negative impact. Psychosocial support for AA patients is limited worldwide, and inadequate information on the disease and its treatment options often forces patients to rely on unofficial information on the internet, where misinformation can drive common misconceptions about the disease. Enhanced patient and caregiver psychosocial support, increased public awareness, and improved provision of information on AA, are essential to improve the psychological well-being of those affected by the disease globally.

There is a global need for multi-stakeholder collaboration to improve awareness and education of AA as a chronic autoimmune condition, advocate for meaningful policy change in the space, and significantly enhance the level of support and care experience for people living with AA.



Tiffany has since become an advocate and role model for others who suffer from AA

Tiffany was at her hairdressers just after her 44th birthday, when her stylist noted two small bald spots on the back of her head.

She thought perhaps it was winter hair loss, but as the weeks went by, she noticed other spots appearing, and at the urging of her stylist she sought medical help. That's when a dermatologist informed her that she had Alopecia Areata. A couple of steroid injections and everything seemed to go back to normal.

But eventually, the situation worsened. She used hair fibers and hid her condition under hats. Even her family didn't know the extent of her hair loss, and by the time she went to see her doctor the second time, she was nearly bald. The new treatment involved painful injections in her scalp and hip area, along with cortisone cream that did nothing for her hair loss but discolored her face.

In despair, Tiffany finally had her stylist shave her head bald. "My first time back at work, I just sat in the car and prayed," she says.

"I don't know how I'm going to do this." She took off her hat and walked into the main area. Someone walked up to her and commented on her new appearance. "You look so good!"

While the compliment was no doubt heartfelt, it did not diminish Tiffany's pain. "I felt like I was by myself. I didn't see anyone else that looked like me, and I felt like I was an alien. People were staring at me, looking at me like I was going through chemo. I felt really, really alone." Even at church, which had been a source of solace, she felt the isolation of being "other."

For Tiffany, who had already lost a breast to cancer, the loss of her hair was a blow to her concept of what it means to be a woman. "I felt cheated," she says. "I kept asking, why did this happen to me."

Tiffany has since become an advocate and role model for others who suffer from alopecia areata. One woman

in her office pulled her aside one day and told her that it was Tiffany's confidence and beauty that helped her go wigless.

"It's important for people to become more educated and aware of the mental effects," she says. While she has come to terms with her illness, she is keenly aware of the sense of loss and marginalization that AA has on affected men, women and especially children, who face bullying and social ostracism that have lifetime impacts on mental health.

"I kept asking, why did this happen to me?"

DISCLAIMER

This testimonial originates from Tiffany, an actual patient living with AA, and may not represent the experiences of everyone living with the disease. Permissions were obtained for the use of Tiffany's story and picture.

INTRODUCTION

Globally, significant unmet needs remain in alopecia areata due to a widespread lack of awareness and understanding of the disease.¹⁻⁸

This limited recognition extends across the general public and many healthcare professionals, contributing to challenges in diagnosis, treatment, and the overall management of the disease. In line with their ongoing commitment to addressing unmet needs for patients with autoimmune and inflammatory disorders,⁹ Pfizer sponsored and convened an international group of AA experts, including medical professionals, researchers, psychologists, psychiatrists, patients, and patient advocates, to understand the true burden of AA, gain global consensus on the challenges and unmet needs associated with the disease, and identify opportunities to improve care

for those living with it. This global whitepaper explores the perspectives of this expert group, supplemented by available literature on the subject. Throughout this paper, perspectives have been summarized globally where the groups' views were aligned. In these instances, certain terminology and language may not universally resonate at a regional level. Where perspectives in the group differed by country of region, this has been described in the paper and the language and terminology used should more closely reflect local nuance.



METHODS

This whitepaper has been developed using a combination of qualitative and quantitative insights captured between October 2022 and July 2023, via the following methods:

Landscape assessment	Multiple research methods were used to generate unmet need themes for discussion during the advisory board series, including:
Targeted literature review	Based on refined search terms, 369 abstracts were screened, 262 full-texts were reviewed, with a final extraction of 143 articles.
Virtual group interviews	With five representatives from leading AA and dermatology patient advocacy groups.
Review of relevant websites and articles	Including activity from industry, patient advocacy groups (PAGs) and professional associations, and market research.
Pre-meeting survey	Shared with all stakeholders ahead of the advisory boards. Included a mix of multiple choice, rating scale and open text questions, aligned to the unmet need themes identified during the landscape assessment.
Virtual advisory boards	A series of five 3.5-hour virtual meetings to discuss the challenges faced by people with AA, their caregivers, and those managing the condition. Additionally, the meetings explored the opportunities for driving policy change in AA, across three cross-cutting areas: <ul style="list-style-type: none">• Equity of access to care and treatment in AA• Holistic care and support for patients and caregivers• Multi-stakeholder collaboration



The AA Consensus Task Force is an international group of multi-disciplinary AA experts that convened through a series of five advisory boards between May and July 2023 (Table 1). The series included four international stakeholder-specific advisory boards – representing medical professionals, psychologists/psychiatrists, PAGs, and research societies – and one multi-stakeholder advisory board that included all aforementioned stakeholder types from across the Asia-Pacific region, to accommodate time zones.

Table 1: Members of the AA Consensus Task Force

	MEETING 1 MEDICAL PROFESSIONALS*	MEETING 2 PSYCHOLOGISTS AND PSYCHIATRISTS†	MEETING 3 PATIENTS AND PAGS††	MEETING 4 RESEARCH SOCIETIES‡
AUSTRALIA	✓	✓§	✓	✓
ARGENTINA	✓		✓	
BRAZIL	✓	✓	✓	✓
FRANCE			✓	
GERMANY	✓	✓	✓§	✓
HONG KONG	✓			
ITALY	✓		✓§	✓
JAPAN	✓		✓§¶	✓
MALAYSIA	✓			
SINGAPORE	✓			
SPAIN	✓	✓	✓§	✓
TAIWAN	✓			
TURKEY	✓		✓§	
UAE	✓			
USA	✓	✓§	✓	✓

* Included nine dermatologists and one dermatology nurse
 † Included one dermatologist with expertise in mental health in AA, two psycho-dermatology experts and three mental health experts
 †† Included 11 PAG representatives, five of whom were AA patients, and one a dermatologist
 ‡ Included seven research specialists, five of whom were dermatologists and six research society members
 § Stakeholder was also an AA patient
 ¶ Stakeholder was unable to attend advisory board due to unforeseen circumstances and contributed insights via the pre-meeting survey only

GLOSSARY OF TERMS

- AA Alopecia areata
- CoE Center of excellence
- DLQI Dermatology Life Quality Index
- HCP Healthcare professional
- JAK Janus kinase
- PAG Patient advocacy group
- PCP Primary care physician
- QoL Quality of life
- QPL Question prompt list
- SALT Severity of Alopecia Tool

OBJECTIVES

This whitepaper aims to explore three key challenge areas for people with alopecia areata, as identified by the Alopecia Areata Consensus Task Force

1. Delays to diagnosis of alopecia areata
2. Unequal and inadequate treatment for alopecia areata
3. Lowered quality of life for people with alopecia areata and their caregivers

The paper will discuss the drivers behind each challenge, outline a series of tangible actions to address each, and identify opportunities for improving multi-stakeholder collaboration to drive change.



BACKGROUND

Globally, skin diseases are the fourth leading cause of non-fatal disease burden, affecting nearly four billion people in the world, according to recent studies.¹⁰⁻¹¹

Skin diseases have wide-ranging impacts because they not only affect the physical and psychosocial wellbeing of patients, but also have indirect effects on caregivers and family members.¹² AA is a complex systemic autoimmune disease in which the immune system attacks hair follicles, resulting in hair loss without scarring of the skin.¹³

The condition may occur in patches on the scalp, affect all of the scalp hair (alopecia totalis), or affect all of the scalp and body hair (alopecia universalis), including loss of eyebrow and eyelash hair. In some cases, nails are also affected.¹³

Approximately 2% of the general population will develop AA at some point in their lives, with around 60% of patients developing their first patch before the age of 20 years.¹⁴

Various autoimmune and allergy-related conditions, such as asthma, allergic rhinitis, atopic dermatitis, thyroid disease, psoriasis, and rheumatoid arthritis, are commonly associated with AA.¹³ Furthermore, several studies demonstrate higher rates of psychosocial comorbidities in people with AA, particularly depression and anxiety, compared with those unaffected by the disease.^{5,7,19-20}

AA can considerably affect patients' quality of life (QoL),^{8,17-18} and people with AA are more likely to withdraw from social and leisure activities and exhibit higher rates of school or work absenteeism compared with those without the disease.^{5,7,19-20}

While there is no known cure or standardized care for AA, treatments are used to help with hair regrowth in both adults and children.²¹⁻²³ Various options, including topical treatments, intralesional steroid injections,

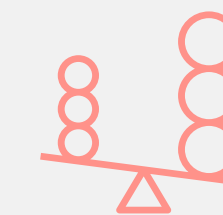
systemic immunomodulators, and Janus Kinase (JAK) inhibitors can be used to treat AA. However, JAK inhibitors remain the only option approved by the regulatory authorities (U.S. Food and Drug Administration and European Medicines Agency)^{13,23} and significant unmet treatment needs remain for AA, including those related to effectiveness, safety, and accessibility.²¹⁻²³

The impact of chronic skin conditions, such as atopic dermatitis, psoriasis, AA, and vitiligo, may be overlooked by many because they are non-life threatening.¹⁰⁻¹² Nevertheless, skin diseases place substantial burden on patients, caregivers, and healthcare systems, and there remains an urgent need to address the multiple challenges that exist for people with AA to enhance their care and improve their overall QoL.

CHALLENGES IN ALOPECIA AREATA AND OPPORTUNITIES TO DRIVE GLOBAL CHANGE



DELAYS TO DIAGNOSIS OF ALOPECIA AREATA



UNEQUAL AND INADEQUATE TREATMENT FOR ALOPECIA AREATA



LOWERED QUALITY OF LIFE FOR PEOPLE WITH ALOPECIA AREATA AND THEIR CAREGIVERS



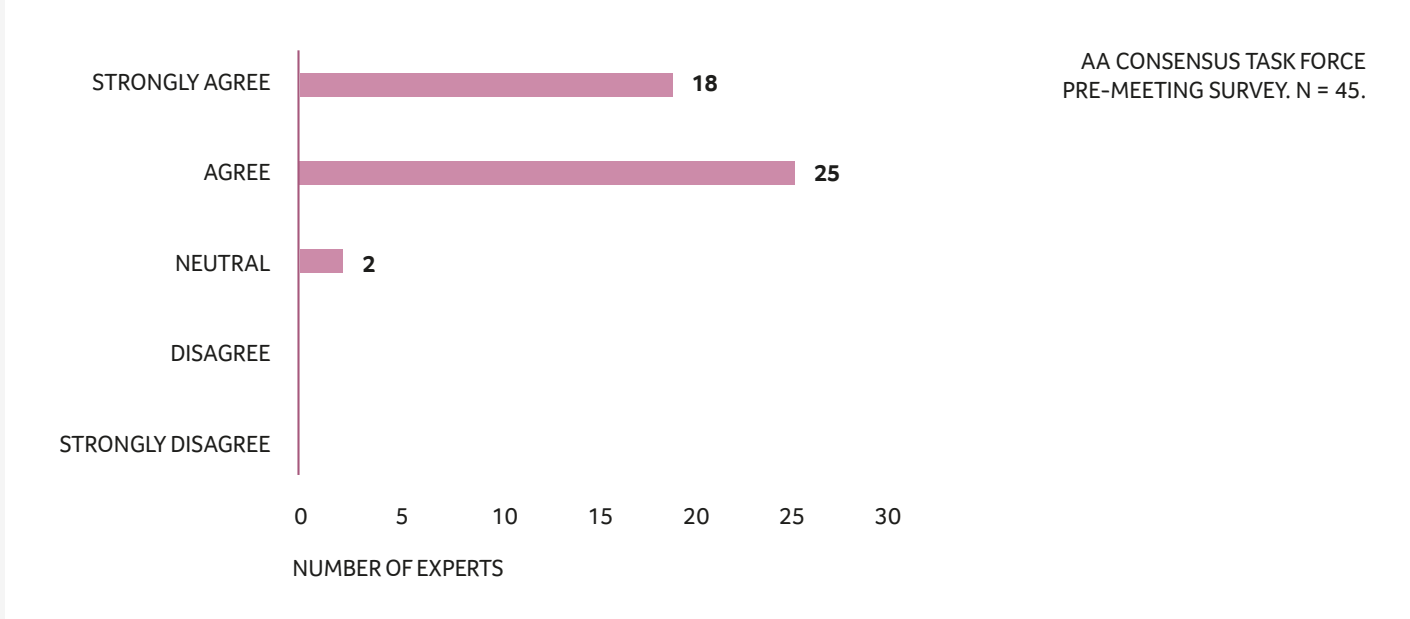
DELAYS TO DIAGNOSIS OF ALOPECIA AREATA

Before people with suspected AA can receive medical support for their symptoms, they must present to a healthcare professional (HCP) with expertise in the diagnosis of hair loss conditions. Typically, dermatologists are responsible for diagnosis, which involves a clinical examination, an evaluation of the patient’s medical history, and, on occasion, a scalp biopsy.^{13,22} Despite the perception that diagnosis of AA is generally straightforward,²⁴ when surveyed prior to the advisory boards, the experts in the AA Consensus Task Force agreed that barriers to both diagnosis and treatment of the disease represent an unmet need in AA (Figure 1). Barriers to treatment will be explored further in the next section.

Figure 1: Global multi-stakeholder expert opinion on barriers to AA diagnosis and treatment

To what extent do you agree that the following statement represents an unmet need in alopecia areata?

‘The AA care pathway is fragmented and there are multiple barriers to diagnosis and treatment’



CHALLENGE 1

Limited public awareness and understanding of AA, socioeconomic barriers, and stigma associated with the disease can hinder patients' presentation to the healthcare system

Globally, experts agreed that awareness of AA among the public, including its recognition as a medical autoimmune condition, is generally low. However, data to illustrate the extent of low awareness are limited.¹⁻³ Without sufficient awareness or understanding of AA, people experiencing hair loss are unlikely to make a connection between their symptoms and the disease. Low public awareness of AA may result in signs of the disease going unrecognized or, in cases where appearance of hair loss is diffuse, it may be mistaken for other more common hair loss disorders for which many patients do not usually seek treatment.²⁵⁻²⁶ Furthermore, hair loss is often not considered a significant concern, with some people perceiving it to be 'just a hair issue' and not worthy of seeking medical help. The Task Force experts highlighted that this low public awareness and lack of understanding of AA are major barriers to initial

presentation of patients to the healthcare system, with most patients not having heard of the disease until their diagnosis.

Even when patients suspect they might have AA, limited understanding of the disease etiology may lead them to seek alternative approaches before accessing medical expertise, according to experts. For example, a common misbelief, often exacerbated by misinformation on the internet, is that AA is caused by stress or may be improved by changes to their diet.²⁷⁻²⁹

This may drive patients to explore dietary changes or supplements that have no evidence for efficacy, rather than seeking appropriate medical help. Experts reported that some patients actively choose homeopathic or herbal treatments over medical therapies to manage their disease, and data suggests that use of alternative medicine is particularly high among individuals with skin conditions.³⁰

Preference for alternative treatments may be especially prevalent in countries such as Taiwan, where traditional medicine is commonplace even in hospital settings.³¹

A Taiwanese study of psoriasis, another autoimmune dermatological condition with comparable impact on QoL to AA, found that over half of participants used solely traditional Chinese medicine for their condition.³² According to the Task Force, another common belief is that AA is a cosmetic rather than medical condition, with experts in Turkey and Brazil suggesting that patients may explore cosmetic approaches from hair centers or beauticians instead of seeking medical help, thereby delaying diagnosis. This lack of understanding of the cause of AA can also delay diagnosis in countries where patients are able to present directly to specialists, leading them to visit physicians who specialize in areas other than dermatology. For example, in Taiwan, where allergy, immunology and rheumatology fall within the same department, patients may first see a rheumatologist.



An individual may not understand what the disease they have is... or who to go to

PATIENT ADVOCATE, USA

Furthermore, patient confusion around other types of hair loss may lead them to visit hair transplant surgeons, hair restoration centers, or trichologists who may lack the knowledge to differentiate AA from other forms of hair loss and refer to the appropriate specialists. Experts in Brazil stated that the lack of regulation governing trichologists has resulted in varying expertise across the profession, which can hinder the referral of patients to specialists.

Socioeconomic status may also discourage patients from seeking a diagnosis due to expenses associated with specialist care. According to experts, this issue is particularly true in Latin American countries where there are large disparities in the level of care offered between public and private healthcare systems, with limited access to specialists and treatment through the public system.³ Several published studies support this notion, including a recent study in Asia that used the Global Burden of Skin Diseases dataset and found a positive correlation between AA

It never occurs to them to consult a dermatologist... they do not believe it's a dermatological disorder

DERMATOLOGIST, JAPAN

prevalence and country income.³³ An independent study using self-reported and clinician-reported cases of AA to estimate prevalence demonstrated a positive correlation with individuals' health insurance coverage or household income. This may indicate a relationship between patients' ability to afford healthcare and their presentation to healthcare systems.³⁴

Finally, stigma associated with AA may also be a barrier to patient presentation to the healthcare system. The expert Task Force believe that societal perception and judgment surrounding AA can affect patients' self-esteem, leading some to believe that they are 'undeserving of treatment', making them hesitant to approach HCPs. This, in turn, may lead patients to conceal hair loss, further dissuading them from pursuing a diagnosis. For those patients for whom hair holds significant cultural and religious significance, this stigma is often exacerbated, further impacting presentation to HCPs.



CHALLENGE 2

Low awareness and understanding of alopecia areata among primary care physicians may lead to dismissal of symptoms and delays to specialist referral

Once patients have recognized the need to seek help from a medical professional, the type of physician they first present to varies by country and healthcare system, depending on whether access to a specialist is direct or if referral is required. In most countries, AA is diagnosed by a dermatologist, which requires a referral if patients first present to a primary care physician (PCP) or other specialist. Experts confirmed that in Australia patients are required to first present to a PCP, while in Taiwan and the UAE patients can access dermatologists directly. In countries where direct access is feasible, it relies on patients being aware of whom to present to. In the US, the ability to directly consult a dermatologist may be contingent on a patient's healthcare coverage, often necessitating an initial

visit to a PCP before being referred onwards. Globally, children or adolescents with suspected AA usually present first to a pediatrician. Patient presentation may vary within countries as well as between them, often driven by differences between public and private healthcare systems.

When referral to a dermatologist is required, PCPs can act as a barrier to the diagnosis of AA. Most experts agreed that many first-line physicians do not have adequate information on AA, and their low awareness and understanding of the disease and its symptoms can make diagnosis challenging. This is supported by regional studies in Latin America demonstrating that low awareness of AA among PCPs may impede diagnosis.^{3,35}

For some non-specialists, the overlapping symptoms of AA with other forms of hair loss, particularly for those with diffuse AA, can present an additional barrier to diagnosis.^{13,36}

According to experts in Brazil and Australia, some PCPs believe AA to be a cosmetic issue, further decreasing the likelihood of correct referral and diagnosis. Furthermore, experts agreed that PCPs can overlook the holistic burden of AA, dismissing patients' symptoms and experiences. This dismissal may leave some patients to believe that there are no treatment options available. These barriers to AA diagnosis at the primary care level mean that patients often require multiple physician opinions before receiving an appropriate specialist referral and eventual diagnosis.



The true problem is not delayed diagnoses but delayed referral to dermatologists... diagnosis is fast and easy when a dermatologist is consulted

DERMATOLOGIST, SPAIN

Patients who I see have traversed a long and tortuous journey to access care

DERMATOLOGIST, USA

CHALLENGE 3

A lack and unequal distribution of alopecia areata specialists worldwide further delays diagnosis of the disease

Even following referral or direct access to a dermatologist, patients may encounter challenges in finding a specialist with specific expertise in AA. The AA Consensus Task Force highlighted a lack of dermatologists with specialist knowledge and understanding of AA across several regions, including the US, Australia, Italy, Japan, and Argentina. Where specialists exist, they are often unevenly distributed, with many patients finding it difficult to access AA expertise outside of larger cities. This distribution of specialists can be a barrier to the timely diagnosis of AA for patients living in rural areas, with experts in Japan and Australia reporting the lack of dermatologists in non-urban areas to be a challenge in their countries.

Furthermore, experts in Germany and Australia reported long wait times to see an AA specialist. Patient access to specialist dermatologists may also differ depending on the healthcare system or their level of health coverage, with experts from Brazil highlighting that access to board-certified dermatologists is limited for those who do not have private healthcare, potentially delaying diagnosis for these patients.

It is important to note that while the challenge of access to specialists was highlighted by many of the Task Force globally, experts in the UAE and Taiwan reported an easier experience for patients in their countries.



OPPORTUNITIES TO IMPROVE THE PATHWAY TO DIAGNOSIS FOR PEOPLE WITH ALOPECIA AREATA

Each opportunity in this whitepaper is intended to be led either by a singular group of stakeholders or as a collaborative initiative, involving different groups working together to achieve it.

The role of each stakeholder group is outlined within each opportunity.

Drive public awareness of alopecia areata to increase presentation of patients to the healthcare system

Deliver educational campaigns to improve public awareness of AA, recognition of symptoms, and appropriate presentation to healthcare systems.

Campaigns providing comprehensive and accessible information to the public may help to encourage timely diagnosis through fostering a deeper understanding of AA as a disease and its impact on individuals' lives. Such campaigns could leverage sponsored video content distributed on popular social media platforms (e.g., TikTok, Instagram, Facebook, and Snapchat) and PAG websites, to ensure maximum reach. Key topics could include the autoimmune nature of AA, its symptoms, and the importance of seeking a diagnosis from a medical professional. Campaigns should be easily comprehensible, medically accurate, and highly

impactful. Including AA influencers in these awareness efforts is likely to enhance their reach and impact. Campaigns could be driven by collaboration between PAGs and medical professionals, with carefully considered financial support from industry.

Conduct targeted outreach to increase awareness of AA among hair and skin professionals who may encounter patients through their day-to-day work and can encourage prompt referral to dermatologists.

Hair and skin professionals, such as hairdressers and beauticians, specialist trichologists, and those who work in hair transplant and restoration centers, may encounter AA patients in their day-to-day work. These stakeholders are uniquely positioned to be able to identify AA and signpost

patients to appropriate medical support and diagnosis. Increasing awareness of AA and its symptoms among these professionals could have substantial positive impact on the diagnosis of people with AA. These outreach efforts should be coordinated by professional organizations and PAGs, who could develop and distribute information leaflets, as well as conduct seminars or training on the key signs and symptoms of AA. Such outreach should be tailored to the type of professional it is targeting, with the approach to reaching hairdressers likely to be very different to that used for hair transplant surgeons, for example. Once educated, these professionals could support with enhancing awareness of AA among the public by clearly displaying its symptoms in their places of work.

Enhance PCP understanding of alopecia areata and the associated holistic patient burden to improve referral to dermatologists

Create educational programs for PCPs to increase understanding of AA and improve referral to dermatologists for diagnosis.

PCP education on the symptoms of AA, its holistic patient burden, and the importance of referral to specialists, may help expedite the referral process for formal diagnosis and treatment. An increased PCP understanding on the burden faced by people with AA may enhance initial patient–doctor interactions by fostering increased PCP empathy and reducing their dismissal of symptoms. Educational materials could include a simple AA symptom identifier, an AA referral pathway resource, and a HCP–patient discussion guide. These materials would help to ensure that PCPs can identify the signs of AA, have clarity on the process and timelines for referral to dermatologists, and that appropriate questions are asked during consultations with patients, thereby speeding up referral and diagnosis. Co-creation of such resources between PCPs and dermatologists, with support from the pharmaceutical industry, would ensure medical accuracy, wide distribution through the primary care network, relevance to the end user, and optimal uptake.

Develop a question–prompt list (QPL) to enhance patient–physician information flow during primary care consultations.

A QPL may help to equip patients with the knowledge and confidence to ask relevant questions during discussions with their PCP, as well as help them to understand the type of information to share with their physician during initial consultations. This tool may also empower patients to advocate for specialist referral, thereby contributing to timely AA diagnoses. PAGs could lead on development of the tool, engaging with patients and caregivers to contribute their own experiences and ensure it addresses questions they feel are important. PAGs can play a crucial role in the distribution of the tool by making it available for download on their websites.

UNEQUAL AND INADEQUATE TREATMENT FOR ALOPECIA AREATA

In recent years the treatment landscape for AA has evolved, marking a transformation in the management of this condition which has historically had very limited effective treatment options.⁴

Notably, targeted treatments in a new therapeutic class have recently received U.S. Food and Drug Administration and European Medicines Agency approval for treatment of AA, presenting patients with additional therapeutic options.³⁷⁻⁴⁰

Despite these advances, challenges persist globally in patient access to AA treatment.

CHALLENGE 4

Limitations in some dermatologists' understanding of alopecia areata and its treatment options can hinder patient access to appropriate therapy

Aside from recently approved systemic therapies, many of the more conventional AA therapies have low or variable efficacy, unpleasant side effects, and are not suitable for long-term use. In addition, relapse frequently occurs following cessation of treatment for AA.^{4,22}

A stagnated treatment development landscape has, until recently, left dermatologists with limited treatment options to explore for AA.⁴ Notably, as newer therapies are not yet approved in many regions, dermatologists often rely on these older treatments in their approach to patient care. While this is not representative of all regions, experts from several countries described ways in which dermatologists may be hesitant to prescribe medication for AA.

Experts from Brazil and Taiwan stated that in some cases, a perceived lack of long-term efficacy and side effects associated with treatment, results in a

lack of receptivity to treat AA among some dermatologists. Indeed, another expert from Australia described a 'look and see' approach that is employed by some dermatologists, whereby they wait for spontaneous remission before considering treatment for AA.

Experts from Spain and the US felt that the holistic burden faced by patients (see Challenges 7-9) can be dismissed by dermatologists, which may enhance hesitation to offer systemic medication to their patients. Furthermore, according to medical AA experts from Brazil, Australia, and Turkey, entrenched outdated beliefs mean that some dermatologists continue to believe that AA is caused by stress, which may further limit their ability to recognize the need for therapeutic options.

Even if dermatologists are motivated to prescribe treatment for AA, not all have up-to-date information and understanding of how best to treat

the disease, according to medical experts in the US, Australia, Japan, and Italy. The global prevalence of AA (2.11%)⁴¹ is low compared with many other dermatological conditions, such as psoriasis and atopic dermatitis, and several experts felt that dermatologist training and clinical experience tends to focus on these more common conditions,³⁵ thereby limiting their opportunity to gain a deep understanding of AA. Furthermore, the changing therapeutic landscape and variable efficacy of AA treatments can make it challenging for some dermatologists to keep abreast of available therapeutic options and when to use them.

The barriers described above can result in patients experiencing multiple referrals before visiting a specialist with sufficient knowledge of AA to provide them with optimal care, as highlighted by experts in the US, France, and Argentina.



Many clinicians are not comfortable with treating AA as they may see it as cosmetic and believe they should not use such potent drugs

DERMATOLOGIST, BRAZIL

Not all dermatologists are current in treatment options for AA

PATIENT ADVOCATE, USA

CHALLENGE 5

Up-to-date universal disease guidelines on the treatment and holistic management of alopecia areata are lacking

Disease management guidelines are important to ensure that physicians have access to standardized, evidence-based protocols and best practices on how to diagnose, manage, and treat conditions.^{24,42-43} This is particularly pertinent for AA, which often has an unpredictable disease course and varying presentation that makes it difficult to treat.²² Although there have been notable efforts to develop a global expert consensus on the diagnosis and treatment of AA,⁴²⁻⁴³ these have been hindered by the lack of robust evidence from randomized controlled trials for many conventional AA therapies, a lack of expert consensus on certain treatment approaches, and limited information on treatment outcomes with newer therapies such as JAK inhibitors.

While local guidelines or consensus statements have been developed in some countries, such as Italy, Japan, Australia, and Brazil,^{22,44-46} they are lacking in many others, which experts

suggested may drive disparities in care for patients in countries where guidelines are not available. Experts in Singapore noted that the absence of country guidelines or a consensus approach has led to guideline development at the individual hospital level, which may limit awareness of best practice among dermatologists at a regional level.

With new therapy approvals, the development of updated guidelines will be key to guide dermatologists on their use. Experts indicated that new guidelines are currently under development in Taiwan and Germany, while in Japan and Italy existing guidelines are being updated to include the newly emerged JAK inhibitor class of drugs.

In addition, the American Academy of Dermatology (AAD) has recently published peer reviewed educational guidance in the form of a continuing medical education supplement on hair loss disorders, which included AA.⁴⁷

Despite the advancement of country-specific guidelines, a lack of universal, consensus guidelines present a challenge in countries where local guidelines do not yet exist.

Physicians practicing in these countries must manage AA patients without clear guidance, resulting in some using guidelines developed outside of their region. The use of non-local guidelines may present challenges based on differences in local therapy approvals, reimbursement status, and preferences.

Where guidelines and consensus statements do exist, relatively few describe the need for psychological support to be integrated into the treatment of AA,^{22,45} despite the profound psychosocial burden often experienced by people living with AA.^{15,19,48} Psychotherapy, hypnotherapy, mindfulness-based practices, collocated behavioral health treatment, and cognitive behavioral

therapy have all been explored in pilot studies as useful tools to reduce this burden on patients.⁴⁹

However, experts agreed that this support is rarely provided to patients with AA as part of the standard treatment approach and more extensive investigation of the utility of these methods in larger cohorts for widespread integration into clinical practice is needed.⁴⁹



For AA, we have no guidelines, we don't know the standard treatment protocol

DERMATOLOGIST, SINGAPORE

We need to have international guidelines to pressure the system

RESEARCHER AND DERMATOLOGIST, BRAZIL

Expert opinion on the challenges associated with universal AA disease management guidelines:

There is no 'one-size-fits-all' treatment approach and treatment decisions must consider individual patient factors (e.g., the extent, position, and duration of hair loss, age, and comorbidities), as well as the risk of potential side effects.

There is no consensus among HCPs on the preferred treatment choice, dosage, and duration of therapy across countries.

Global variation in the approval of JAK inhibitors and the use of alternative medicine makes it difficult to standardize a treatment approach worldwide.

Where JAK inhibitors are approved, there may be multiple types to choose from, targeting different JAK isoforms (i.e., JAK-1, JAK-2, JAK-3), adding further complexity.

Current measures of AA severity used to determine treatment eligibility, such as the Severity of Alopecia Tool (SALT) are not universally adopted and do not accurately reflect the holistic patient burden of AA.

Information on adverse events associated with AA treatments, including side effects and the psychological impact of relapse while on treatment, and the subsequent impact of these on treatment adherence, is lacking.



CHALLENGE 6

Payer and policymaker perception of alopecia areata as cosmetic issue drives a lack of treatment coverage and reimbursement

Although many dermatological conditions are associated with substantial patient burden,^{10,50} data capturing their full impact on patients are lacking, which means they are often overlooked by payers and policymakers for resource allocation.^{35,50-53} This issue extends to AA where, until recently, tools to accurately measure the holistic patient burden of the disease have also been lacking.⁵⁴⁻⁵⁵

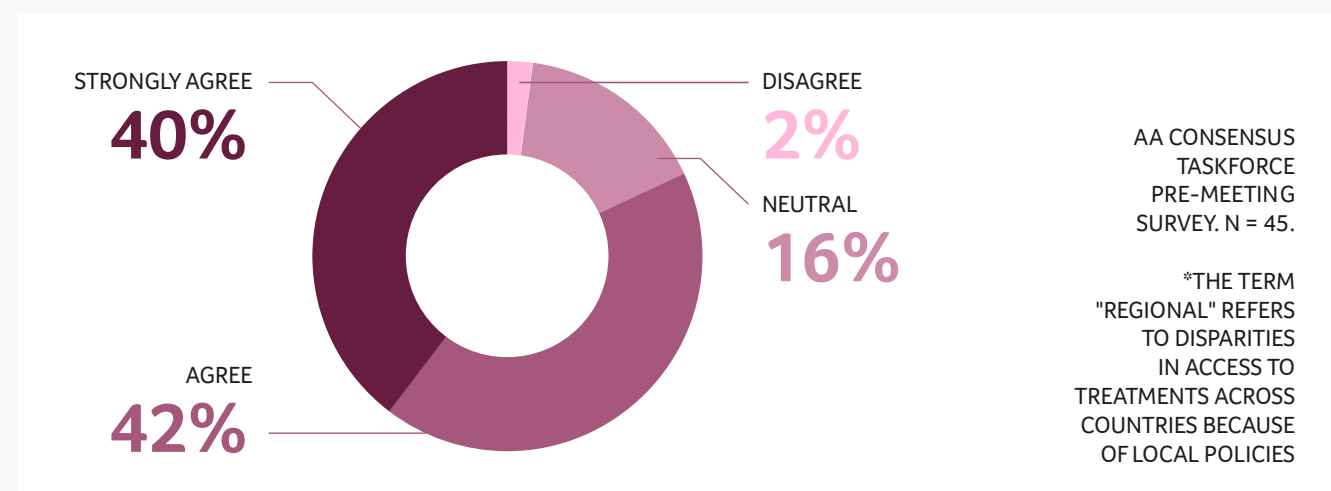
According to experts, this lack of payer understanding of AA and the perception that it is mainly a cosmetic issue can limit their willingness to cover therapies (Figure 2). Many of the Task Force experts, particularly those who are patients or patient advocates, felt that payer and policymaker receptivity to the implementation of new treatments and policies in AA was low in their countries. This may drive policies that limit access to treatment, with some insurance providers fully excluding AA treatments, and others

restricting reimbursement to a set percentage. According to experts, a lack of disease guidelines makes it difficult to illustrate the need for AA treatment to healthcare providers or governments. As such, they may not recognize the urgency of allocating resources for its management.

Figure 2: Access to treatments and payer and policymaker perception

To what extent do you agree that the following statement represents an unmet need in alopecia areata?

'Access to treatment is low, driven by payer perceptions, inadequate coverage, and market & regional* disparities'



The perception by the insurance companies and healthcare institutions can be that it is not life threatening and does not have significant bearing on health outcomes and hence is a more cosmetic problem

DERMATOLOGIST, HONG KONG

A lack of reimbursement is a key barrier for patient access to treatment for AA, and discussion from experts highlighted that reimbursement pathways and restrictions vary widely both within and between different countries.

According to experts, health insurance coverage for AA treatments can be limited, as is the case in Turkey, or completely lacking, as in Malaysia, Singapore, and Taiwan. In countries such as the US, healthcare coverage for AA treatments may vary,⁶ and in Latin American countries, patients with public insurance have limited access to many AA treatments.³ It should also be noted that in Germany federal law excludes some medications, such as those with a focus on improving patients' QoL and those that improve hair growth, from statutory health insurance.⁵⁶ Across geographies, limitations in coverage for AA therapies can leave patients with significant out-of-pocket costs, often restricting access to those who can afford to pay.⁵⁷⁻⁵⁹

The financial burden of AA extends to caregivers and family members of patients and can have a significant impact on their QoL.⁸ Experts described how the chronic and relapsing nature of AA, and the necessity for long-term treatment, can exacerbate the financial burden, with patients and caregivers often worrying about the lasting financial impact of the disease.

In addition to medical therapies, wigs, makeup, microblading, scarves, and

weaves are often used by people with AA to hide hair loss,^{5,57-58,60-61} but cost also remains a major barrier to patient access to such items. Wigs are often classed as cosmetic items and not covered by insurance providers, which limits access to those who can afford to pay out-of-pocket.^{57,60,62-63} In the US, coverage of wigs can vary among different insurance providers or plans, and some only provide reimbursement for chemotherapy-associated hair loss.⁶³ Even where partial coverage is provided, patients may still be left with significant cost,⁶³ further adding to their financial burden.^{5,57-58}

Where treatment coverage is available, barriers to access remain for many patients. Until recently, there have been no approved therapies for AA, meaning many patients use off-label treatments to manage their disease. Off-label use of treatment is commonly declined by insurance companies when first requested and often requires a complex and lengthy process to obtain coverage.^{6,64} Furthermore, experts reported that both patients and dermatologists can lack the time and knowledge needed to complete the required paperwork for reimbursement of AA treatments, thereby limiting access to therapies for these patients if they cannot afford to pay out-of-pocket.

Experts also discussed how existing reimbursement pathways are often restrictive. For example, in some cases, reimbursement of novel treatments (such as JAK inhibitors) may be limited to after multiple rounds of other

failed therapies. This was felt to be problematic as early intervention is associated with better outcomes for patients, although this hypothesis requires further research.⁶⁵ In addition, experts shared that treatment coverage is often limited to those patients with the most severe physical symptoms. Experts mentioned that some insurance providers in the US require patients to have a high SALT (Severity of Alopecia Tool; commonly used to measure AA vseverity) score for treatment reimbursement to be considered, thereby limiting the number of eligible patients. In addition, SALT only measures scalp hair loss and therefore does not capture other aspects of hair loss, including its location or visibility, duration, or the presence of eyebrow or eyelash loss.⁶⁶

The significance of taking into account the psychosocial burden is widely recognized in assessing disease severity and determining treatment eligibility.⁶⁶ However, the Dermatology Life Quality Index (DLQI) tool does not accurately capture disease-specific domains for QoL in AA, and AA-specific QoL assessment tools require further development to validate their use in routine clinical practice, including input from patients globally.⁵⁴ A lack of validated disease-specific tools to accurately measure the holistic impact of AA on those affected and define severity makes it challenging for reimbursement assessments to establish patients' need for treatment.

OPPORTUNITIES TO IMPROVE PATIENT ACCESS TO TREATMENT FOR ALOPECIA AREATA

Improve the adequacy of alopecia areata treatment by enhancing HCP understanding of the treatment landscape

Establish comprehensive, universal disease guidelines, co-created with a global multi-stakeholder steering committee.

Standardized guidelines will help to ensure that HCPs across geographies are aware of the latest treatment options for AA and prescribe appropriate treatments to patients. Such guidelines should be collaboratively developed by a multi-stakeholder group of AA experts, including dermatologists, dermatology societies, and PAGs, using the available clinical evidence to create a standardized treatment approach. Key considerations include

accommodating regional variation in therapy approvals, adopting flexible measures of disease severity, considering the extent, duration, and presentation of hair loss, and addressing the accompanying psychosocial burden. While guideline development could be supported by industry from a financial and logistical standpoint, providing the platform and resources to bring stakeholders together, it is recommended that such support occurs through a coalition involving multiple companies.

This approach helps prevent the perception of the activity being promotional for specific therapies.

BEST PRACTICE EXAMPLE



Resolution and Global Report on Psoriasis by the World Health Organization (WHO)

The International Federation of Psoriatic Disease Association's engagement with the WHO and United Nations (UN) Economic and Security Council led to the opportunity to put psoriasis on the agenda at key events such as the World Health Assembly.⁶⁷

Efforts culminated in the adoption of a resolution on psoriasis at the 67th WHO General Assembly in 2014, where member states recognized the significant burden associated with the disease and were encouraged to contribute to advocacy efforts to fight stigma and raise awareness.⁶⁸ The resolution led to preparation of a WHO global health report on psoriasis, and recognition of unmet needs associated with the disease by the WHO. This provided a global platform for policymaker prioritization of psoriasis in member states, with lobbying by patient advocates being essential to this process.

Shift payer perception of alopecia areata from believing it to be a cosmetic condition to understanding that it is a chronic autoimmune disease

Conduct patient surveys to generate data illustrating the holistic burden of AA that can be distributed to payers and policymakers.

Annual patient surveys driven by PAGs may support the generation of important data demonstrating the challenges faced by people with AA. Sharing this information with payers and policymakers may help to shift their perceptions on the disease and influence decisions on treatment reimbursement and access. This approach could offer a richer insight into the lived experiences of AA patients, enhancing understanding of its impact on their QoL and underscoring the necessity for treatment access and support. In addition, these insights could support the development of a new Quality of Life Index (QLI) tool that could be used by physicians to assess the impact on AA on patient QoL (see point below).

Create a new psychosocial assessment tool to accurately capture the holistic burden of AA on patients and caregivers.

Accurate measurement of the psychosocial burden of AA and QoL impact on patients may contribute to the use of more holistic disease severity measures to determine treatment eligibility and reimbursement for AA. Development of a psychosocial assessment tool could also help to facilitate widespread data collection, creating a body of evidence that could be used to persuade payers and policymakers that AA is not a cosmetic issue. Such a tool could also be used to capture the impact of treatment on QoL and demonstrate their value to payers

and policymakers to support reimbursement decisions. Creation of the tool could be led by psychological experts and dermatologists, and could build on previously developed QLI tools.⁵⁴ Evaluating use in global patient populations and gathering input from patients will be crucial for development. Data from global patient surveys (see point above) may be used to shape domains for the assessment tool and could help to facilitate local adaptation based on cultural needs.

Leverage the patient voice to lobby policymakers through increasing presence at multi-disciplinary international events.

The presence of patients and/or PAGs representing AA at multi-disciplinary conferences and events (e.g., the World Health Assembly) may help to enhance the visibility of AA among payers and policymakers and increase awareness of the holistic burden of the disease. This may help to humanize the condition and support with lobbying of policymakers to make AA a priority.

While good examples of integration of the patient voice into international events via PAGs exist, such as the National Alopecia Areata Foundation (NAAF) activity at US Capitol Hill Day, many countries lack the presence of a strong patient body to help place AA on governments' agendas. Industry and professional organizations could play an important role in facilitating this activity, particularly in regions where local PAGs do not exist.



LOWERED QUALITY OF LIFE FOR PEOPLE WITH ALOPECIA AREATA AND THEIR CAREGIVERS

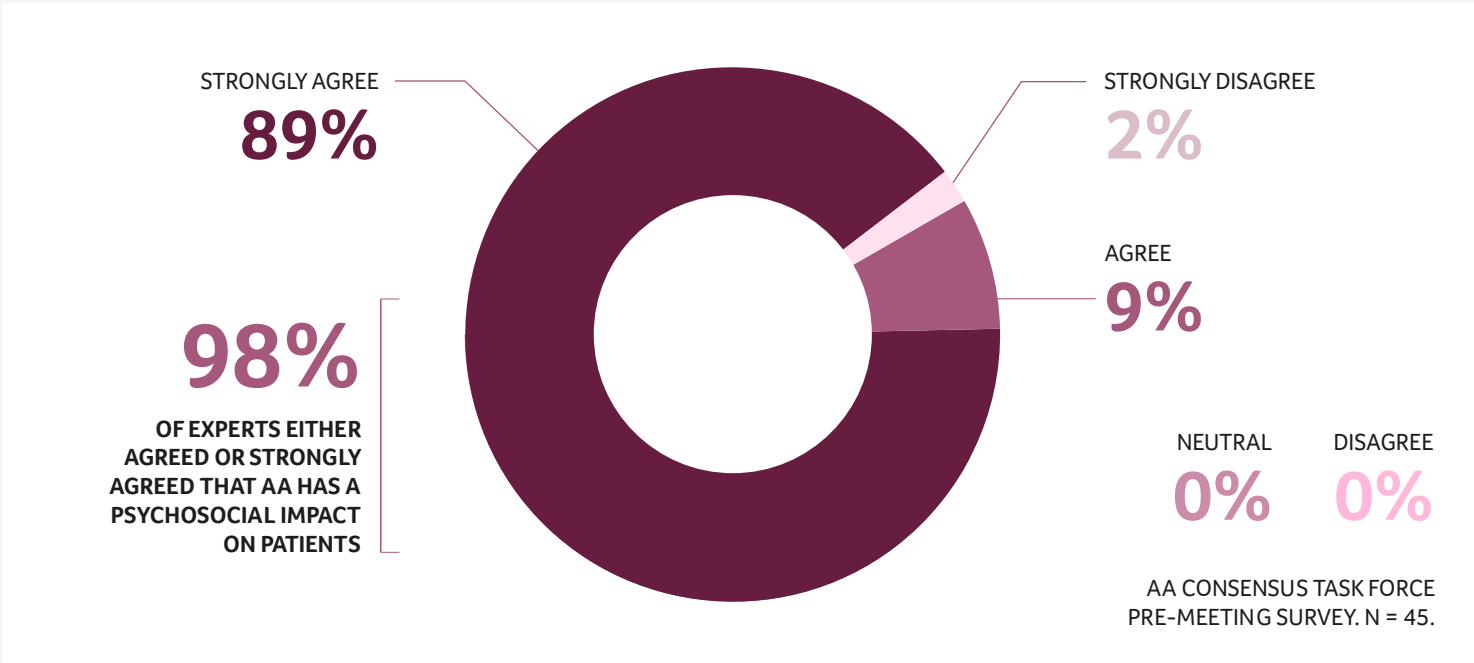
Many studies have demonstrated the considerable impact of AA on the QoL of patients.^{17,20,48,69} In addition to uncomfortable secondary symptoms, such as eye and nose irritation, poor thermoregulation, and sunburn,^{5,19} hair loss can lead to significant psychosocial burden in turn affecting the QoL of patients.^{15,20,48}

When surveyed prior to the advisory boards, 98% of the AA Consensus Task Force experts agreed or strongly agreed that AA has a psychosocial impact on patients and associated comorbidities that negatively affect QoL (Figure 3).

Figure 3: Expert alignment on the psychosocial impact of AA on patients

To what extent do you agree that the following statement represents an unmet need in alopecia areata?

'AA has a psychosocial impact on patients and associated comorbidities that negatively affect QoL'



CHALLENGE 7

A lack of public awareness of alopecia areata, its unpredictable course, and stigma associated with the disease often contribute to lowered quality of life for both patients and caregivers

This whitepaper highlights that a lack of awareness and understanding of AA can lead the public to perceive the disease as unimportant (trivialization), and foster negative attitudes and stereotypes towards people with the disease (stigmatization). This public perception, if internalized by individuals (self-stigmatization), can further exacerbate the psychosocial burden of the disease.

According to experts in the AA Consensus Task Force, people with AA often face uncomfortable interactions with the public, including intrusive questions, excessive pity, assumptions about the cause of hair loss (e.g., cancer or stress), double-takes, strange looks, or fears of contagion, and these types of interactions have also been documented in previous studies.^{1,7,19} Stigma associated with the disease may also be exacerbated by cultural norms that place hair in high

regard in terms of beauty and personal identity.^{7,20} In Japan, experts shared that hair loss is sometimes ridiculed by local media, and others stated that it can be perceived as unattractive or repulsive.

Children and adults with AA may experience bullying by classmates and colleagues respectively, intensifying the psychosocial burden of the disease.⁷⁰⁻⁷¹ This may be an issue for younger patients, particularly during puberty, who often face unique social pressures and a battle for acceptance and belonging among their peers.

Strikingly, the impact of childhood bullying can be life-long, with adults who experienced bullying as a child often continuing to experience negative psychosocial and physical outcomes later in life.⁷²



‘Black beautiful hair’ is traditionally highly regarded

DERMATOLOGIST, JAPAN

It is important when we talk about stigma to talk about the ignorance about AA, people do not understand the nature and the causes which can contribute to the stigma

DERMATOLOGIST, SPAIN

[You often hear] I’ve lost my identity because I’ve lost my hair

PSYCHOLOGIST AND AA PATIENT, AUSTRALIA

Experts also discussed how gender has a complex role in influencing the impact of AA on QoL. Although many females identify more strongly with their hair than males, they often possess greater adaptability in concealing hair loss or altering their appearance, such as using makeup or hairstyling. The influence of gender on the psychosocial impact of AA has been researched in the literature. Several studies indicate that females are impacted more severely than males,^{17,48,73} while other research suggests a comparable impact on both genders.^{19,69}

Negative experiences or anxiety about judgment from others may lead patients to avoid social situations as a coping mechanism.¹⁹⁻²⁰ People with AA have higher rates of work and school absenteeism and unemployment than those without the disease.^{5,20} They may also limit their involvement in physical and leisure activities,^{7,19-20} avoid romantic relationships,^{5,20} and even withdraw from interactions with family and friends.^{5,19-20} This in turn may further add to the sense of isolation and lowered QoL experienced by people with AA.^{5,7,19} Additional factors that may impact psychosocial burden and QoL of patients include the extent of hair loss (severity, eyelash or eyebrow hair loss, and facial hair

loss) and disease duration. Although these factors were mentioned by some experts, their impact was thought to be complex and while some studies support an association with increased psychosocial burden,^{17,20,73} the extent of this association varies between studies.^{48,73}

Research has shown that extent or severity of hair loss as measured by SALT score is not directly associated with lowered QoL.^{20,48,73} In fact, experts shared how patients experiencing patchy or partially recovered AA may feel more anxious about their appearance than those with complete hair loss, although data to demonstrate this is lacking. As such, patients’ self-reported levels of disease severity may be a better indicator of the impact on their QoL, as they are more likely consider factors such as their ability to cover bald patches, and the speed or unpredictability of the disease,⁷³ which can be particularly disturbing and shocking for patients.⁷

Although studies in AA have shown that use of wigs can improve patients’ QoL, fear of their displacement (i.e., shifting of the wig from its intended position on the head) can also add to patients’ anxiety. These fears may result in the avoidance of certain social

or leisure activities.^{7,19,61} They can also bring physical discomfort due to skin irritation, particularly in warmer weather.^{7,61}

Experts stated that the use of concealment methods such as wigs among many patients is driven by pressure to conform to societal norms. In these cases, wearing a wig may perpetuate the feeling that they are ‘living a lie’, further adding to the psychosocial burden on patients whilst also contributing to the lack of awareness among the public.

Finally, the QoL of caregivers and family can also be impacted by AA.^{8,18} For children with AA, their parents may even experience a greater QoL impact than the patients themselves,⁸ with experts sharing that parents often feel responsible for the disease and carry self-blame. Caregivers may also experience concern about treatment side effects and frustration about failed treatment or disease relapse. Finally, experts highlighted the financial burden associated with AA as a key factor contributing to its psychological impact on family members. This is supported by published data indicating that higher treatment expenditure is predictive of poorer QoL outcomes for AA caregivers.⁸



CHALLENGE 8

Inadequate information on alopecia areata and its treatment options can perpetuate misconceptions and further impact patient quality of life

Adequate information on their disease and treatment options is essential for patients' understanding of their disease and involvement in shared decision-making, which itself is associated with better patient-reported outcomes.⁷⁴ Globally, experts reported that the amount and quality of information shared with AA patients is inadequate, often limited by time pressures on HCPs during their consultations with patients. This is supported by literature that describes a lack of time as a key barrier to the implementation of shared decision-making,⁷⁵⁻⁷⁶ and studies showing that many patients believe the information provided by their HCP to be insufficient to meet their needs.^{7,35,77} When surveyed prior to the advisory boards, the majority of experts agreed or strongly agreed that gaps exist globally in the information available to people with AA (Figure 4).



I don't really have an explanation about my condition from any doctor or HCPs that treated me... I have had to search for myself by internet, reading books or talking with other patients to try to understand my disease

PATIENT AND PATIENT ADVOCATE, SPAIN

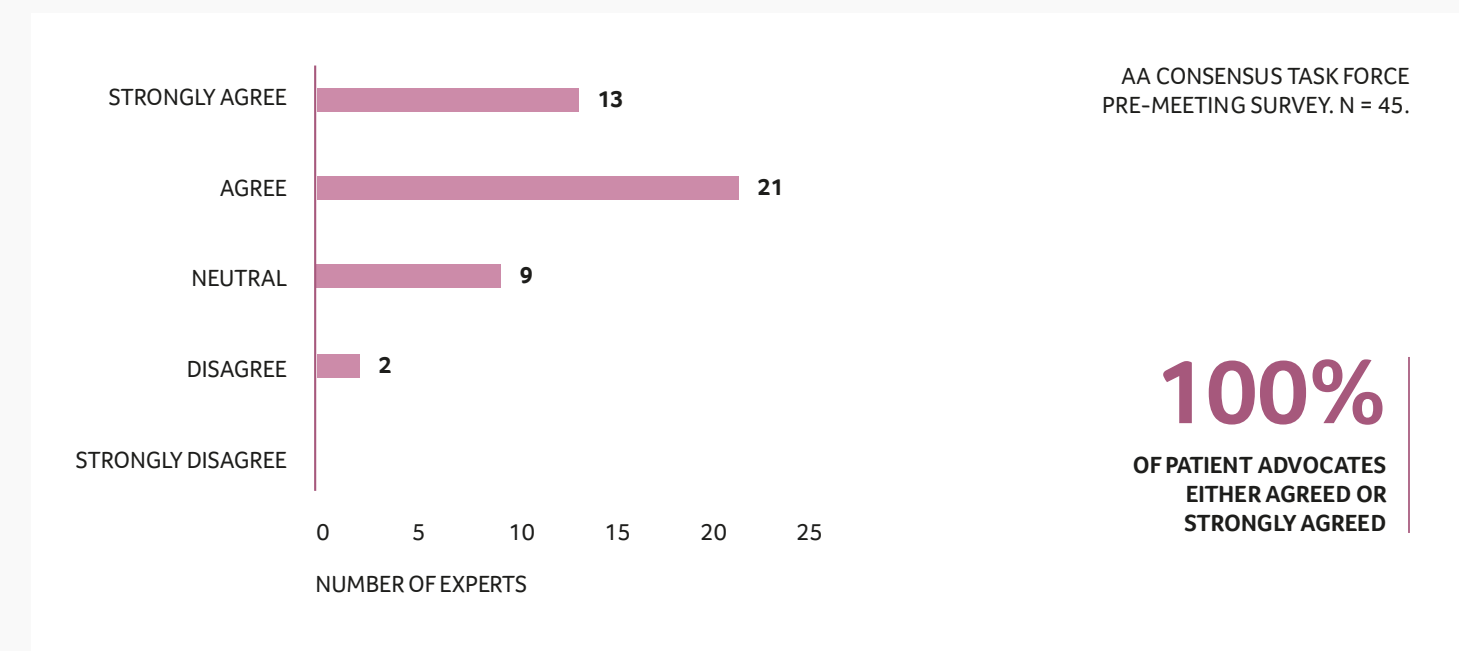
In the medical field, not many people have the time, knowledge, and empathy to succeed in transmitting information

DERMATOLOGIST AND PATIENT ADVOCATE, BRAZIL

Figure 4: Expert opinion on the availability of information for patients

To what extent do you agree that the following statement represents an unmet need in alopecia areata?

'Globally, gaps exist in the information available to patients with AA, with English-speaking patients having broader access to information'



According to experts, information for AA patients is inadequate in several areas:

- Fundamental information is lacking on the complex pathophysiology of AA, the influence of environmental and genetic factors, associated comorbidities, and the autoimmune nature of the disease, all of which are vital for patients and caregivers to be able to dispel common misconceptions and make informed decisions on effective treatment options
- Patients are often not provided with information on the unpredictability of the AA disease course (cycles of relapse and remission), or on disease prognosis including severity and associated outcomes such as holistic burden, which can leave patients and caregivers feeling unprepared and not knowing what to expect
- The availability of patient information regarding the effectiveness and safety of available treatment options for AA is limited. This can hinder patients' ability to make informed treatment decisions, by weighing up the potential risks of side effects versus the effectiveness of therapies, a particular issue for younger AA patients who often underestimate the risks and side effects of AA therapies due to desperation to see hair regrowth

Although some AA patient information resources do exist, often developed by PAGs, accessing them can be challenging for patients. Experts believed that many physicians are not aware of PAG-developed resources and therefore do not signpost their patients to them.⁷ Furthermore, several geographical, educational, or language-related factors present an additional barrier to information for some patients.⁷⁴ Those with lower levels of education may be less likely to access and understand information on their disease and treatment options, and therefore less likely to be able to advocate for treatment where necessary.⁷⁶

Geographical disparities may also impact the availability of patient information, with brochures and leaflets often more likely to be found in larger university hospitals compared with rural areas. Finally, experts believed that non-English speaking patients and caregivers may face additional barriers, with many resources only existing in English-language.

This lack of adequate information from trusted sources can drive AA patients to the internet or social media, where misinformation may perpetuate common misconceptions about the disease,⁷⁸ such as that it is caused by stress or is contagious. Experts discussed how these misconceptions can subsequently contribute to self-stigmatization experienced by patients, further impacting their QoL.

CHALLENGE 9

The limited psychosocial support available to alopecia areata patients and their caregivers further exacerbates the impact on quality of life

Experts unanimously agreed that psychosocial support is an important unmet need for patients with AA, worldwide. While access to mental health support is a global issue across many diseases,⁷⁹⁻⁸⁰ experts believed that limited physician awareness and understanding of AA can exacerbate the problem:

- Physician-patient consultations may not allow for AA patients to effectively communicate the emotional toll of hair loss on their wellbeing. This may be due to time pressure, physicians not asking questions on the psychosocial impact of the disease, or physician dismissal of the psychosocial burden
- Physicians may feel ill-equipped to manage the psychosocial burden of AA on patients. Some may lack awareness, or even believe AA

is caused by stress, placing the etiologic onus on patients, and worsening the psychosocial burden

- A lack of physician understanding of the holistic burden of AA may limit their willingness to advocate for payer coverage of a comprehensive treatment plan that includes psychosocial support for patients

Even if physicians recognize the need for mental health support, patient access to appropriate supportive care can be limited. Experts in the US described geographical disparities in the availability of mental health professionals, hindering access to these services in areas where the profession is less represented. Additionally, insurance companies often limit coverage of mental health support, according to experts.

For example, coverage in Germany often requires patients to have been diagnosed with a psychiatric condition, meaning access to mental health support for patients without this diagnosis is limited to those who can afford to pay privately. Where adequate psychosocial support is not provided in standard care pathways, patients may seek alternative support themselves, and research has shown that patients can experience significant out-of-pocket costs for counseling or therapy, contributing to financial burden and impacting QoL.⁵ For those who cannot afford to pay out-of-pocket costs, mental health support often remains inaccessible.

Even when AA patients do receive appropriate mental health referrals, psychologists' understanding of AA pathophysiology can be limited,



Too little attention has been paid to the psychosocial burden and fast and effective psychotherapeutic support

MENTAL HEALTH SPECIALIST, GERMANY

according to experts, which may result in misguided approaches to management of the psychosocial burden.

PAGs play a vital role in addressing psychosocial distress and empowering patients to advocate for themselves, through the provision of informational materials and social support. However, there is a lack of AA PAGs globally, and many countries are completely lacking PAG presence, particularly across the Asia-Pacific and Latin America regions. For some countries, pan-dermatological disease PAGs may cover AA.

Where PAGs and support groups do exist, they are not always known to patients, which may leave many people with AA feeling unsupported and alone in navigating their disease.



OPPORTUNITIES TO REDUCE THE IMPACT OF ALOPECIA AREATA ON PATIENT QUALITY OF LIFE

Increase public awareness and understanding of alopecia areata to reduce the trivialization of the disease and stigma experienced by patients

Create campaigns, leveraging social media and celebrity ambassadors to effectively educate the public and reduce stigma.

Public awareness campaigns may help to combat the stigma and misconceptions surrounding AA by emphasizing that AA is a systemic, autoimmune disease with significant physical and psychosocial burden. Campaigns could be multi-faceted, including presence at large-scale national or international events

(e.g., popular televised sports, sponsored events, dedicated awareness months/days) as well as localized initiatives. Use of social media and celebrity ambassadors could help to increase visibility and reach a wider audience.

Successful implementation of such a campaign relies on collaboration between PAGs and medical societies to communicate the message, highlight the importance of credible information sources, and shape the vision.

Equip patients and caregivers with a deeper understanding of alopecia areata and its treatment options, enhancing feelings of support and empowering self-advocacy

Develop patient-friendly, accessible information resources, co-created by physicians and PAGs.

Information is crucial to ensure patients with AA feel adequately supported. Sharing information on AA and its treatments may help to empower patients and their caregivers to advocate for the best possible care. Information should be packaged in a clear and easy to digest format, such as leaflets or brochures, which can be distributed by HCPs to patients and their caregivers, helping to mitigate potential time constraints during consultations. While physicians should play a role in ensuring the accuracy of the information included in such resources, the selection of topics to cover should be driven by patient preference, and they should be developed in close partnership with PAGs to facilitate this. Finally, in addition to information, resources should signpost patients to local PAGs and psychological support where possible.



Help people with alopecia areata and their caregivers to navigate the psychosocial burden associated with alopecia areata, get adequate support, and improve their quality of life

Establish criteria for AA Centers of Excellence (COEs) that integrate the management of psychosocial comorbidities into AA treatment programs.

Although considerable time and resource would be required to deliver such an initiative, incorporating mental healthcare into the management pathways of AA at COEs may be crucial for enhancing the overall quality of care for patients. Such mental health services could be provided to both patients and their caregivers, aimed at helping them manage the associated psychosocial burden. A first step could be the establishment of COE criteria through partnership with HCPs, PAGs, dermatological societies, psychiatrists, and mental health providers. This should be followed by set up of pilot sites to evaluate effectiveness, implementation guidelines for future sites, and educational resources for HCPs.

Create a mental health question-prompt list to support AA patients in making their HCP aware of essential aspects of their mental health.

Empowering patients with such a tool may facilitate more meaningful patient-physician discussions and ensure that crucial aspects of patient mental wellbeing are addressed during consultations. The question-prompt list could also serve as a valuable resource for caregivers, providing them with a guide so they can actively participate in discussions and advocate for the comprehensive care of individuals they are caring for, potentially contributing to their own mental wellbeing. The question-prompt list should be developed as a collaboration between patient advocates, caregivers and psycho-dermatologists/psychologists, to ensure that the questions promote an accurate assessment of psychosocial comorbidities. Partnering with mental health organizations could also help to disseminate and validate the tool to increase impact.

Generate self-advocacy guidance to empower people with AA to advocate for their own care and support, particularly in countries with no PAG presence.

Self-advocacy guidance resources could help to equip patients and caregivers with the knowledge and understanding to advocate for their own needs. Such guidance could increase the number of patients accessing mental health support, as well as increase the uptake of shared decision-making in clinical practice. Advocacy guidance may include information for patients and their caregivers on how to ensure their needs are met, including specific guidance on how to respond to HCP recommendations, such as the right to challenge or question decisions. Patients and global pan-dermatology PAGs (e.g., GlobalSkin) could play a key role in both development and distribution of such guidance.

EXPERT INSIGHT

Effective multi-stakeholder collaboration is crucial for shaping AA policy and addressing unmet needs.

All experts in the AA Consensus Task Force agreed that multi-stakeholder collaboration will be vital to drive the global belief and behavior change required to influence policy in the AA space. Effective collaboration among different stakeholders is essential for the implementation of the opportunities highlighted in this whitepaper and addressing unmet needs in AA.

The expert group highlighted several barriers to effective multi-stakeholder collaboration worldwide:

- Differing interests, goals and perceived impact of AA among stakeholder groups
- A lack of funding, resources, and platforms for collaboration
- Challenges in time allocation, especially for HCPs
- Geographical, societal, and cultural differences, such as language barriers, differing time zones, and varied healthcare systems
- Reluctance of certain stakeholder groups, such as payers and policymakers, to collaborate
- Achieving multi-stakeholder collaboration relies on the identification of shared objectives between various stakeholder types, despite their potentially differing priorities or cultural nuances. Delineating clear roles and responsibilities, leveraging PAGs to encourage interaction between stakeholders, overcoming barriers such as resource constraints, and streamlining project management processes, are all essential to driving such collaboration
- Information sharing between AA organizations is important, as demonstrated by the Australia Alopecia Areata Foundation Inc. (AAAF) in Australia, who allow localization of their resources by other AA PAGs
- With vast networks, access to data and platforms, and human and financial resources, the pharmaceutical industry is well-placed to help facilitate this important need for multi-stakeholder collaboration

CONCLUSIONS

Multi-stakeholder collaboration and innovative solutions are urgently needed to shift beliefs and behaviors, drive meaningful policy change, and improve the care experience for people living with alopecia areata.

By engaging a diverse group of international AA experts, the AA Consensus Task Force identified key challenges and unmet needs associated with the disease and opportunities to improve care for those living with it. Building tangible solutions from these opportunities to overcome challenges and unmet needs in AA is not the sole responsibility of one stakeholder and should be driven through collaborative efforts between medical professionals, researchers, psychologists, psychiatrists, patients, and patient advocates.

Multi-stakeholder collaboration and innovative solutions are urgently needed to shift beliefs and behaviors, drive meaningful policy change, and improve the care experience for people living with AA. The AA Consensus Task Force calls on all stakeholders to:

- Raise awareness of AA as a chronic autoimmune disease rather than a cosmetic issue, overcome common misconceptions, increase presentation of patients to dermatologists, reduce stigma associated with the disease, and positively influence access to care and reimbursement decisions
- Establish universal guidelines for the holistic treatment of AA that encompass every aspect of patient care, in order to improve equal access to optimal treatment and support for people living with AA worldwide
- Provide AA patients and caregivers with adequate information and support, to increase uptake of shared decision-making, empower patients to advocate for themselves, and ultimately improve both physical and psychosocial outcomes



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