doi.org/10.58931/cdt.2025.62139

ABOUT THE AUTHOR

Anastasiya Muntyanu, MD, PhD, FRCPC, FAAD

Dr. Anastasiya Muntyanu is a Canadian and US board-certified dermatologist, currently practicing in Toronto. She completed her medical school training at the University of Ottawa and graduated from the University of Toronto Dermatology Residency Program. She completed her PhD, which focused on studying environmental triggers of autoimmune and inflammatory skin diseases including psoriasis, systemic sclerosis, atopic dermatitis. She has over 40 publications in high impact journals and has received numerous awards including the Canadian Institutes of Health Research award, Canadian Dermatology Association, and American Dermato-Epidemiology Network. During her residency she was the co-chair of the Canadian Dermatology Association’s Resident and Fellow Society and was a resident representative on numerous academic committees for which she received the Resident Leadership Award and the Resident Teaching Award from the Canadian Dermatology Association. Dr. Muntyanu’s clinical areas of interest include medical and surgical dermatology with a focus on psoriasis, eczema, systemic sclerosis and morphea, and skin cancer.

Affiliations: Women's College Hospital, Toronto, ON
Canadian Dermatology Center, Toronto, ON
St. Joseph's Hospital, Toronto, ON

Bare Realities: Uncovering the Life-Altering Impacts of Alopecia Areata

Anastasiya Muntyanu, MD, PhD, FRCPC, FAAD

Hair plays a pivotal role in shaping personal and group identity, conveying messages about age, gender, culture, ethnicity, and social status. The vast economic impact of the hair care industry—reflected in billions of dollars spent on products and hair salon treatments—highlights its cultural and societal importance.

The versatility of hair, in terms of style and appearance, has long symbolized power, transformation, and self-expression across various cultures and histories.[1] *Whether through myths, religious texts, or modern media, well-groomed hair is celebrated and often equated with attractiveness and social status.*

For patients with alopecia areata (AA), hair loss carries heavy public and self-imposed stigma. The impact on self-esteem and identity is profound, with many patients experiencing deep feelings of loss, grief, and shame. It is important to explore the impact of AA on a patient’s life in many domains. Holistic management, which combines effective medical treatments with mental health support and effective camouflage strategies is needed, with the ultimate aim of improving the quality of life (QoL) for those affected by AA.

Introduction

AA is an autoimmune disease that targets hair follicles and affects approximately 2% of the population.[2] It can develop at any age and affects patients of any gender and ethnicity. Clinically, it presents in many different forms, including the patchy (or localized) subtype observed in approximately 70% of cases, alopecia totalis (loss of all scalp hair) or universalis (loss of all body hair) observed in 15–25% of cases, and more rare patterns such as diffuse, reticular (extensive confluent patches), ophiasis (band-like, peripheral pattern), and sisaipho forms. Nails are affected in approximately 30% of patients (e.g. pitting and trachyonychia), which confers a worse prognosis.[4]

The Severity of Alopecia Tool (SALT) is a commonly used tool in clinical trials to grade the extent of hair loss across the scalp, ranging between 0%–100%.[5] A SALT score of >50 is typically defined as severe disease and is often an indication for systemic therapy.[5] Although several other clinical assessment tools are available, most do not take into consideration the impact on a patient's QoL. The QoL is an important indicator, as two patients with identical SALT scores can experience significant differences in QoL impacts. Therefore, it is important to consider the patient's perspective when assessing disease severity.

Impact on Quality of Life

AA has a significant impact on QoL in both adults and children, with more than 75% of patients experiencing some level of impairment and up to a third reporting extremely severe effects.[6,7] Compared to conditions such as androgenetic alopecia and psoriasis, for example, AA shows a markedly worse impact on QoL. In addition to the loss of hair, functional impairments can also occur, such as increased sensitivity to weather with risk of sunburn to the scalp and ocular irritation from the loss of eyebrows and eyelashes.

The impact of AA on QoL is influenced by several demographic and clinical factors. Younger patients and women tend to experience a lower QoL. Factors such as the severity and extent of hair loss, including more widespread involvement, longer disease duration, multiple recurrences, and hair loss involving the eyebrows and eyelashes are associated with worse outcomes.[7] Interestingly, discrepancies between patient and physician assessments have been noted, with patients' self-rated severity being a more accurate predictor of QoL impairment. This indicates that the negative impact on self-image plays an important role in the patient's perceived burden of the disease.

The emotional and social dimensions of QoL metrics are particularly affected by AA. Both adults and children with AA often report challenges in mental health, social interactions, and familial relationships. This impact extends beyond the patient to family members, as seen by the significant impact on parental QoL.[8] AA patients often struggle with initiating and maintaining romantic relationships and may camouflage their condition due to fear of rejection or negative perceptions. In fact, up to a third of individuals have ended their relationships due to AA.[9] All of these factors contribute to social withdrawal and isolation, highlighting the need for improved disease awareness and support systems within both the medical community and society at large.

Psychiatric Comorbidities

AA carries a significant mental health burden, with numerous studies showing that 30%–68% of adult patients experience anxiety, depression, or other psychological symptoms, and these rates are significantly higher compared to those in age-and gender-matched controls.[7] Notably, receiving an AA diagnosis itself appears to be a risk factor for the development of depression,[10] with patients showing a 30%–38% higher risk of new-onset depression and increased use of antidepressants.[11] These findings are particularly pronounced among women and individuals aged 30–49 years. The severity of depression appears to correlate with the extent of hair loss. AA has also been associated with suicidal ideation in 13%–38.5% of patients and attempted suicide in 4.3%.[7,12]

In addition to depression, AA is associated with several anxiety disorders, including social anxiety (clinically significant in 47.5% of patients) that often leads to significant social withdrawal and isolation.[13] This is associated with a higher rate of anxiolytic prescriptions. A survey-based study reported that all participants disclosed symptoms of anxiety and up to 66% rated it as extremely severe.[14] Pediatric patients with AA also exhibit separation anxiety, generalized anxiety, and social phobia compared to their unaffected peers. Additionally, this group exhibits higher rates of attention-deficit/hyperactivity disorder (ADHD) and obsessive-compulsive disorder (OCD) compared to controls.

In elderly patients, AA has been associated with an increased risk of dementia, possibly related to decreased social involvement.[15] These findings underscore the necessity for dermatologists to consider comprehensive mental health evaluations and support as part of the management strategy for patients with AA.

Impact on Work, School and Beyond

Over two-thirds of patients reported that AA influenced major life decisions, including choices related to relationships, education, and careers.[9] Adults with AA show significantly higher rates of work absenteeism (56%) and unemployment (82%) compared to controls.[9,16] AA also impacts patients' career choices and promotion opportunities. This can result from new-onset mental health disorders, social withdrawal, and the increased scheduling burden of appointments and treatments. Factors that contributed to higher rates of unemployment and work absenteeism include being a woman, having moderate-to-severe disease (as reported by the patient) and facial hair loss.[7] Decreased work productivity was found to be linked to the psychological burden of AA and to physical effects of hair loss (such as eye irritation from eyelash loss).

Similarly, children with AA face considerable challenges in their daily lives. Approximately half of affected children report missing school and experiencing academic difficulties due to the distress associated with their hair loss.[9] The condition also contributes to stigmatization and bullying, particularly among boys and those with localized disease, leading to diminished self-esteem and social isolation.[17] These educational and social setbacks often result in long-term impacts, such as altered career or education plans, as patients adjust their lifestyles to manage the condition.

Due to the burden of AA, most patients (90% of women and 72% of men) focus on camouflage techniques for their hair loss.[9] In fact, wigs are frequently used to mitigate the visible effects of AA, with 86.7% of patients reporting their use for social events and 55.9% wearing them continuously.[13] These strategies are often time-consuming, averaging 10.3 hours of preparation per week and increasing to 13.7 hours during peak disease activity.[9] Despite their utility in avoiding stigmatization, wigs and hairpieces are associated with physical discomfort, high costs, persistent worry about misplacement of the wig, and discovery by others. Additionally, the need to camouflage can lead to reduced physical activity and social engagement, as patients may avoid activities such as swimming, shopping, or simply going out due to anxiety about their appearance.

Financial Burden

Patients with AA face a substantial economic burden, with costs extending beyond direct medical expenses to include lost income (absenteeism), higher insurance premiums, transportation, and expenses for wigs, cosmetic products, and procedures. In the US, annual healthcare costs were estimated to exceed $11,000 USD with even higher costs for patients with alopecia totalis/universalis.[18] Out-of-pocket costs vary widely, with median annual spending of approximately $1,350 USD (medical appointments and supplements),[19] and additional expenses—averaging $2,000 per year—for hairpieces and psychotherapy.[9] Many patients reported using their savings or cutting back on essential expenses (including food and clothing) to manage these costs.

Conclusion

AA is not merely a matter of appearance—it is a life-altering autoimmune disease with wide-ranging impacts on psychological well-being, social functioning, professional and academic achievement, and financial stability. The burden extends across age groups and genders, often with underestimated consequences. Effective care for AA must combine access to evidence-based therapies with comprehensive support that reflects the condition's emotional, social, and financial impact. Only through such an integrative approach can we hope to meaningfully restore not just hair, but also confidence, and QoL for those affected.

Correspondence

Anastasiya Muntyanu, MD, PhD, FRCPC, FAAD
Email: anastasiya.muntyanu@mail.mcgill.ca

Financial Disclosures

A.M.: Consulting Fees: Amgen, Pfizer, Sanofi; **Payment/ Honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events:** Abbvie, Arcutis, Sun Pharma, Galderma, Celltrion

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