ARC Journal of Dermatology
Volume 8, Issue 3, 2025, PP 37-43
ISSN No. (Online) 2456-0022
DOI: https://doi.org/10.20431/2456-0022.0803004
www.arcjournals.org

A Characterization of Disparities in Published Alopecia Quality of Life Studies

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Received: 03 March 2025 Accepted: 18 March 2025 Published: 29 March 2025

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Abstract

Alopecia is a heterogeneous disease characterized by hair loss from parts or all of the body. This study aims to characterize the patient demographics and funding sources included in alopecia quality of life (QOL) research. We performed a retrospective analysis of 982 published, peer-reviewed QOL studies on various types of alopecia, identifying 100 articles that met our inclusion criteria. Systematic reviews and abstracts were excluded. For each included study, we recorded the type of alopecia, participant demographics, and funding sources. The most commonly studied forms of alopecia were alopecia areata (51 studies), androgenic alopecia (33 studies), and alopecia universalis (7 studies). Overall, alopecia studies were significantly less likely to report patient race than patient sex (OR=0.2094, p<0.0001, 95%CI=0.1150 to 0.3814). Racial demographics were reported in 22 studies, with 18 including Black patients and 20 including White patients. Studies that included Black patients had an average of 12.1 participants, significantly lower than those including White patients, which averaged 139 participants (p=0.018). Additionally, studies on alopecia areata were significantly less likely to include black patients than any other racial group (OR=0.3321, p=0.018, 95%CI=0.1332 to 0.8280). Furthermore, alopecia QOL studies that included black patients were statistically less likely to receive funding compared to those including other racial groups (OR=0.1765, p=0.0039, 95%CI=0.0543 to 0.5737). These findings highlight significant racial disparities in alopecia research, emphasizing the need for increased funding and diversity in participant recruitment to better assess the disease's impacts on quality of life in minority populations.

1. INTRODUCTION

Alopecia, a condition characterized by hair loss from areas of the body where hair typically grows, affects millions of individuals worldwide and manifests in diverse clinical forms.(1,2) Major types of alopecia include androgenetic alopecia (AGA), alopecia areata (AA), telogen effluvium (TE), cicatricial alopecia, traction alopecia, and chemotherapy-induced alopecia. Its complexity arises from its diverse underlying causes, including autoimmune, mechanical, and hormonal factors. The prevalence and distribution of alopecia types differ across populations, influenced by genetic, cultural, and behavioral factors. Understanding the intersection of alopecia and demographic factors is crucial for developing research and interventions that address the specific needs of diverse patient groups. Although alopecia is not life-threatening, its profound impact on physical appearance can lead to significant psychological and social challenges. The psychosocial burden of alopecia is well-documented, encompassing emotional distress, social withdrawal, and diminished self-esteem.(3-7) These impacts can be assessed using quality of life (QOL) measurement tools such as the Dermatology Quality of Life Index (DLQI), Alopecia Areata Severity Scale, and the Hairdex (Haralstad, Wahl).

Research has shown that demographic factors, such as gender, can influence quality of life in dermatologic diseases. For example, a 2022 study found that female psoriasis patients were more likely to report depression than their male counterparts[11]. Additionally, a systematic retrospective review of psoriasis QOL research found that female patients reported significantly lower QOL than male patients in 75% of included QOL studies[12]. Researchers suggest that hormonal differences, societal gender norms, and disparities in healthcare access may contribute to these differences in reported QOL among psoriasis patients (Guillet, Seeli, et al, 2022).

Another key factor that influences QOL in dermatology patients is race. A project by the National Psoriasis Foundation found that 72% of non-Black psoriasis patients reported an impact on their QOL, compared to only 54% of White patients[13]. Four additional studies concluded that Black and Hispanic psoriasis patients have a worse QOL than White patients[14-17]. Even when psoriasis severity was controlled for, non-Black patients continued to report lower dermatology QOL scores. Researchers suggest that cultural differences, socioeconomic status, and disparities in healthcare access may contribute to these variations in self-reported QOL. These findings highlight the urgent need for comprehensive QOL research to better understand and address the impact of dermatologic diseases across diverse populations.

Compared to psoriasis and other dermatologic conditions, there is a significant paucity of data on how race and sex influence QOL in alopecia patients. A retrospective review of eleven published alopecia QOL studies found that female patients reported worse QOL than male patients in only two studies[18]. Notably, to our knowledge, no retrospective study has directly compared QOL outcomes among alopecia patients of different racial backgrounds, despite evidence from other diseases suggesting these disparities exist. Furthermore, many alopecia studies underrepresent certain populations(8), including gender-diverse individuals, older adults, and economically disadvantaged groups. A comprehensive understanding of alopecia requires an in-depth analysis of its subtypes, their associations with different populations, and their broader implications for QOL.

Additionally, funding disparities further exacerbate these gaps in research. Funding is critical for advancing clinical trials, developing innovative treatments, and assessing their real-world impact on diverse patient populations. Without inclusive QOL research, it remains unclear whether existing and emerging treatments effectively address the needs of underrepresented groups. Therefore, advancing QOL research in alopecia requires a deliberate focus on inclusivity. By identifying and addressing underrepresented populations and underfunded research areas, the dermatology community can move toward more comprehensive, patient-centered care. This study aims to bridge these gaps by critically analyzing existing alopecia QOL research, and highlighting key disparities.

2. METHODS

This project was a retrospective review of 982 published, peer reviewed articles. Research articles were queued using an Embase search for the following key terms: “Health Related Quality of Life”, “Quality of Life”, “Alopecia”, “DLQI” (dermatology quality of life index), “Hair-Specific-Skindex-29”, “HAIRDEX”, “Alopecia Areata Symptom Impact Scale”, “Alopecia Areata Quality of Life”, and “Alopecia Areata Quality of Life Index”. To meet inclusion criteria, articles had to be peer-reviewed and published, assess alopecia-related quality of life as a primary outcome, and utilize clearly defined and objective criteria for quality of life assessment. Additionally, articles were required to include one of the following diagnoses in the title or keywords: Alopecia Areata, Female Pattern Alopecia, Male Pattern Alopecia, Androgenetic Alopecia, Scarring Alopecia, Cicatricial Alopecia, Central Centrifugal Cicatricial Alopecia, Lichen Planopilaris, Frontal Fibrosing Alopecia, Chemotherapy-induced Alopecia, Telogen Effluvium.

For each included article, we recorded the following variables: publication year and country, study type, alopecia subtype, sample size, participant demographics, and the QOL assessment tool used. We additionally documented whether each study reported a funding source and categorized the funding sources as government, institutional, industry-sponsored, foundation, or privately funded. Statistical analysis was conducted through student’s t-tests, Chi-squared analysis, odds ratios, and ANOVA.

3. RESULTS

A total of 100 articles met the inclusion criteria, excluding abstracts and systematic reviews. The most frequently studied type of alopecia was alopecia areata (51 studies), followed by androgenetic alopecia (33 studies), female pattern hair loss (5 studies), alopecia universalis/totalis (7 studies), and chemotherapy-induced alopecia (7 studies). The most common study design was cross-sectional (70 studies), followed by cohort studies (9 studies) and clinical trials (9 studies). The US contributed the highest number of studies (17), followed by China (7) and the United Kingdom (6). Demographic information of the included studies is featured in Table 1. Only 12 studies reported both race and sex data, while 28 studies included information on the race of patients included within the studies , and 60 studies included sex data. Among studies reporting race, 18 included Black patients, 20 included White patients, and 16 included Asian patients. Notably, the average number of Black patients per study was 12.1, significantly lower than the average of 139 White patients per study (p=0.018), while studies including Asian patients had an average of 135 participants.

Sixty-nine studies used a survey tool to assess alopecia severity. The most frequently used tool was the Dermatology Life Quality Index (DLQI) (51 studies), followed by SKINDEX (9 studies), HAIRDEX (6 studies), and the Alopecia Areata Severity Index Score (3 studies). Notably, none of the studies utilizing an alopecia-specific severity scale reported racial demographic data.

Studies on alopecia areata were significantly less likely to include Black patients compared to White or Asian patients (OR=0.3321, p=0.018, 95%CI=0.1332 to 0.8280). Additionally, these studies were significantly less likely to report patient race than patient sex (OR=0.2094, p<0.0001, 95%CI=0.1150 to 0.3814).

Of the 28 studies that disclosed funding sources, the most common funding types were government/national funding (14 studies), industry (15 studies), foundation grants (10 studies), institutional funding (4 studies), and private grants (2 studies). Among these studies, 11 included Black patients, 13 included White patients, and 9 included Asian patients. Importantly, studies including Black patients were significantly less likely to receive funding compared to those that did not (OR=0.1765, p=0.0039, 95% CI=0.0543–0.5737). There were no significant differences in funding sources between countries.

4. DISCUSSION

Alopecia significantly affects quality of life, yet previous research has often underrepresented certain populations. This systematic review highlights disparities in study populations, funding allocation, and geographic distribution in alopecia QOL research.

One major finding from this review was that alopecia QOL studies were significantly less likely to report patient race than sex. Existing literature has established that gender significantly influences self-reported QOL in dermatological diseases. Sex-based hormonal differences can affect disease presentation, and patients of different genders have varied experiences with healthcare providers and treatments. For example, one study found that while female psoriasis patients are more likely to seek treatment than males, they are significantly less likely than males to receive biologics or UV therapy, contributing to poorer quality of life[19]. In addition, the strong emphasis on physical appearance in Western culture, as well as the significance of hair in self-identity and individuality, may significantly contribute to differences in quality of life between male and female patients. A 2009 British study found that female alopecia patients reported significantly worse quality of life than male patients, particularly regarding symptoms and emotional distress[20]. These findings highlight the importance of including female patients in QOL studies.

From the beginning of human history, hair has been a key aspect of identity across different racial and cultural groups. For example, enslaved Black Americans used tightly braided hairstyles to not only send messages regarding Underground Railroad passageways, but to store gold, plant seeds, and rice on their escape from plantations. Nowadays, locs and braided hairstyles carry tremendous social and cultural value in black communities[31]. And due to the pressures to conform to eurocentric work and academic places, Black Americans may be more likely to suffer heat damage from repeated hair straightening, or traction alopecia from wearing tight braids underneath a wig or sewn in extensions[31]. Despite this, there is significantly less research on the psychological and social impacts of alopecia in Black versus White patients, compared with studies examining gender-based differences. For example, a clinical study on alopecia areata found that only 15% of studies reported participant race[29]. Another study found that Black alopecia patients were more likely than White patients to experience depression and anxiety disorders, highlighting the role of race and cultural values in patient well-being[21]. These findings emphasize the need for greater racial diversity in alopecia QOL research to ensure a more comprehensive understanding of the disease’s impacts.

Another major finding in this study is that Black patients were significantly underrepresented in alopecia QOL studies compared to patients of other races. This aligns with previous research revealing that Black patients have the lowest enrollment rates in alopecia areata clinical trials[22]. Another study found that Black, Asian, American Indian/Alaskan Native, and Hispanic/ Latino participants were all underrepresented in alopecia clinical trials relative to their population proportions[23]. Finally, a clinical trial on androgenic alopecia revealed that only 8 out of 20 studies included race or ethnicity data, with the majority of participants being White (Aggarwal, 2022). Lower access to transportation, lower socioeconomic status, and lower overall trust in the medical research field likely contribute to decreased levels of participation of black and minority patients in different alopecia studies[30]. Inclusion of Black patients in QOL studies is crucial for assessing whether current treatments are effective across diverse racial populations. Results from these studies can assist dermatologists with better supporting Black alopecia patients by providing insight on how they emotionally cope with the disease.

This review additionally evaluated funding sources for alopecia QOL studies. The most common funding sources were government funding, followed by industry, foundation, institutional, and private grants. Currently, the NIH and the National Alopecia Areata Foundation are among the primary funders of alopecia research in the US[24]. One notable finding was that alopecia QOL studies involving Black patients were statistically less likely to receive funding compared with studies involving other racial groups. This trend mirrors broader disparities in research funding, where Black scientists and researchers have been found to have lower funding success rates[25]. Funding for alopecia research is critical for advancing diagnostic and treatment innovations. Increased funding is particularly needed for studies focusing on Black patients, who are disproportionately impacted by certain types of alopecia such as alopecia areata and traction alopecia due to hair practices [26-27]. Despite the greater disease burden in these populations, Black patients remain underrepresented in studies. Greater funding could lead to improved therapies and a deeper understanding of how alopecia impacts Black patients' psychological well-being, quality of life, and overall patient care.

5. LIMITATIONS

There are several limitations to this study. First, as a retrospective analysis of published studies, the findings are subject to publication bias. Studies with statistically significant results or larger sample sizes are more likely to be published, potentially skewing the findings and failing to capture the full spectrum of alopecia research. The exclusion of abstracts, systematic reviews, unpublished studies, ongoing research, and studies from non-English-speaking countries may have resulted in the omission of relevant alopecia QOL studies.

Another significant limitation is the inconsistency in the reporting of demographic data in the reviewed studies. Only a small number of studies reported both sex and racial demographics, which limited our ability to assess representation. Furthermore, the disproportionate focus on alopecia areata and androgenetic alopecia in the included studies limits the generalizability of the findings to other alopecia subtypes, which may have unique demographic factors. Additionally, many studies lacked complete funding information, affecting the interpretation of potential biases and the generalizability of the results. Future studies should include more diverse data sources and address funding disparities for a more comprehensive understanding of alopecia research.

6. CONCLUSION

This study highlights significant racial disparities in alopecia quality of life research, with Black patients underrepresented in both study participation and funding allocation compared with other racial groups. These gaps underscore the need for more inclusive research practices that more accurately reflect the diversity of individuals affected by alopecia. Furthermore, the study emphasizes the importance of consistent reporting on both sex and race in future QOL studies to enable a more intersectional understanding of alopecia's psychosocial impacts across demographic groups. Future research should examine funding sources within alopecia research to identify gaps and promote more equitable resource allocation. By increasing diversity in alopecia research, the dermatological community can provide more equitable care for minority populations to improve patient outcomes and patient well-being

Table 1. *Demographic Characteristics of Included Studies*

Category	Number of Studies
Number of Articles (excluding abstracts and systematic reviews)	100
Most Common Study Type	Cross-sectional (70 studies)
Most Common Countries	
United States	17
China	7
United Kingdom	6
Brazil	3
Gender Breakdown	
Studies Including Men	62
Studies Including Women	74
Studies Including Both Genders	43
Funded Studies Including Racial Breakdown	28
Studies Including White Patients	13
Studies Including Black Patients	11
Studies Including Asian Patients	9
Most Common Types of Alopecia	
Alopecia Areata	51
Androgenic Alopecia	33
Universalis/Totalis	7
Chemotherapy-induced	7
Female Pattern Hair Loss	5
Telogen Effluvium	4
Cicatricial	4
Traction/Scarring Alopecia	2
General Alopecia	2
Most Common Survey Tools	
DLQI	51
Skindex	9
Hairdex	6
AASIS	3
Most Common Types of Funding	
Industry	15
Government	14
Foundation	10
Institutional	4
Private Grants	2

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Citation: *Sydney DeVore et al. A Characterization of Disparities in Published Alopecia Quality of Life Studies. ARC Journal of Dermatology. 2025; 8(3):37-43. DOI:https://doi.org/10.20431/2456-0022.0803004*

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