

Needs Assessment to Enhance Knowledge of People in Puerto Rico Living with Alopecia Areata

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Objective: Alopecia areata (AA) is an autoimmune condition which affects hair follicles provoking their loss. Although the cumulative incidence of AA in the United States is estimated at 2.1%, the number of people living with this condition in Puerto Rico is unknown. In addition, little has been published about people in Puerto Rico who have this condition and its impact on health. We conducted a needs assessment study to help reduce this information gap and address the perceived needs of people living with AA in Puerto Rico.

Methods: A needs assessment study was conducted with a non-experimental, descriptive, transversal design. A 40-item questionnaire was available through the Google Forms platform. Descriptive analysis was conducted.

Results: Most of the participants were women, had AA universalis, were diagnosed (on average) at 19 years of age, and were receiving treatment at the time of the survey. Most of the participants reported having both access to information or education about alopecia and the support of their family and friends but professed needing informational support. In particular, they wanted to find out about treatment options for their alopecia.

Conclusion: Gender and time since the onset of AA appear to be important variables that must be considered when conducting future studies and interventions with this population. These future studies and interventions should address the informational support needs of people living with AA. [*P R Health Sci J* 2021;40:147-150]

Key words: Alopecia areata, Needs assessment, Web-based questionnaire

Alopecia areata (AA) is an autoimmune condition that affects hair follicles provoking its loss (1, 2). This condition might also be influenced by the stressful events of daily life (3) and environmental aspects (4). Alopecia areata has 3 clinical representations: hair loss in specific areas (patchy AA), complete head hair loss (AA totalis), and entire body hair loss (AA universalis) (5). Though AA is a non-life-threatening condition, it can have a direct bearing on the psychosocial well-being of the person who suffers from it (e.g., his or her personal appearance, emotional health, and the quality of their social interactions) (6). Studies have pointed out the relationship between living with AA and high levels of depression, insecurity, and anxiety; low self-esteem; and reduced quality of life (7, 8). Given the negative cultural attitudes about hair loss, people living with AA tend to engage in social avoidance and try to hide or “camouflage” their condition (9).

Overall, updated epidemiological data on AA are lacking (9). Two population-based studies suggest that there are no gender, age, or hair-color differences when it comes to the lifetime risk or incidence of AA (10). There seems to be a higher probability of AA's manifesting in African Americans than in whites (11). African American and Hispanic/Latina women have higher odds of having AA compared to white women (9). Although

the cumulative incidence of AA in the United States is estimated at 2.1% (12), the number of people living with this condition in Puerto Rico is unknown.

A needs assessment study was the first step in addressing this information gap. This type of assessment is a decision-oriented, evaluation study carried out at a single point in time to understand “protection issues, availability of resources, sources of problems and their impact on the affected population” (13).

Materials and Methods

A needs assessment study was conducted (IRB A7080116) with a non-experimental, descriptive, transversal design (21). The inclusion criteria were that each participant must be 21 years old or older; have a diagnosis of AA, be the support person of

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someone with AA, or have a child with AA (this last including parents who are also in the support groups of their children with AA); and live in Puerto Rico. If the person who had AA was a minor, the questionnaire was answered by one of the parents or legal guardians, who provided the minor’s point of view. People who live with some type of alopecia other than patchy AA, AA totalis, or AA universalis (e.g., traction, cicatricial, androgenetic) were excluded from the study.

The following strategies were used to recruit participants: distributing flyers, calling people on the contact list of the Sin Límites con Alopecia foundation (SLcA), placing recruitment announcements in dermatologists’ offices and on the Facebook pages of collaborating organizations, snowball sampling with the study participants, and setting up promotions in activities supported by collaborating organizations. A total of 51 people living with AA who were part of SLcA’s contacts were called. A list of 72 dermatologists in Puerto Rico was obtained via the internet and from newspaper ads from the Puerto Rican Dermatology Society. An envelope with study materials (an informative letter describing the study, 10 promotional color flyers, two legal size promotional posters about the study, a letter of collaboration, and a pre-paid envelope) was sent to all the dermatologists on the list who had a physical address (n = 52). Six providers sent back the prepaid envelope with the letter of collaboration signed (12%). We also tried to contact the Dermatological Society of Puerto Rico and other clinical groups, organizations, and associations, but little support was received. Three organizations that provide services to people living with AA in Puerto Rico posted the study’s promotional flyer on their Facebook pages: (a) the Sin Límites con Alopecia foundation, (b) Alopecia PR, and (c) the National Alopecia Areata Foundation-Puerto Rico. Flyers and other informational materials about the study were available at four social activities supported by the organizations previously mentioned.

Instrument

The questionnaire was accessed electronically using the Google Forms platform. Upon entering, the survey taker was asked to sign an informed e-consent; followed by a 15-minute-long questionnaire. The instrument had five sections: demographics, support network, diagnosis, treatment and relationship with doctor, and an exploration of services needed.

Data analysis

The data collected was exported to IBM SPSS Statistics 20. A descriptive analysis and a comparison between groups were conducted. A t-test was specifically used to explore whether there were differences when comparing the identified needs of people who had been living with AA for five years or less, with those of people who had been living with AA for more than five years. We found only one study that we could use as benchmark for comparing groups based on time since onset of AA (22). This study used “2 years or less since diagnosis” and “more than 2 years since diagnosis.” We decided to use “5 years

or less since diagnosis” and “more than 5 years since diagnosis” for our cohorts since we had only two participants with an onset of AA equal to or less than two years.

Results

After a period of 3 years of actively promoting the study, we were able to recruit 49 people, mostly females (Table 1). Of them, 39 lived with AA (80%) and 10 were members of support networks (20%). Seven people reported on children aged 6 to 17 years. The average age of the participants who were adults living with AA was 35 years; for the members of the support networks, the average age was 44 years.

Table 1: Type of Participant by Gender

Type of participant	Gender		Total n (%)
	Male n (%)	Female n (%)	
Adults living with AA	2 (4%)	30 (61%)	32 (65%)
Minors living with AA	4 (8%)	3 (6%)	7 (14%)
Support network	1 (2%)	9 (18%)	10 (20%)
Total	7 (14%)	42 (85%)	49 (100%)

Support network

Of the 10 support network participants, seven were family members and three were friends. Family members identified themselves as mothers (n = 3), siblings (n = 2), and partners/“other” (n = 2). Members of the support networks reported providing emotional support (n = 8) followed by informative support (n = 2).

People who live with AA

Ninety-two percent of the participants with AA were diagnosed by a doctor, at an average age of 19 years. Most had AA universalis (n = 14), followed by patchy AA (n = 13) and AA totalis (n = 5). Eighty-eight percent (n = 33) of the participants had received treatment to manage their AA, which included having tried one or more home remedies (Table 2). A large minority of participants (44%) affirmed having sought alternative medicine to help handle issues related to their AA. Of those that had a doctor who treated their AA, most reported having a good (n = 9) or excellent (n = 5) provider-patient relationship; but some reported having fair (n = 4) or bad relationship (n = 1). When asked, whether they thought their doctor provided them with adequate guidance regarding their AA, 10 answered “No” and nine answered “Yes.”

When asked whether they had sought help from an individual or individuals other than their doctor to handle situations related to their AA, 14 participants (44%) answered “Yes”. Of these, 10 had sought help from a psychologist or psychiatrist, eight

Table 2: Treatments and Remedies for Managing AA

Treatment/Remedy	n
Injectable corticosteroids	22
Topical creams/immunotherapy	21
Radiation	4
Cryotherapy	3
Natural treatments with garlic	2
Hair-loss shampoo	2
Biotin	1

from a priest or spiritual guide, three from a naturopath, and three from a counselor (these options were multiple choice). Other professionals mentioned were acupuncturists (n = 1), chiropractors (n = 1), and aestheticians (n = 1).

At the time of taking the survey, people living with AA reported to have needed (in the 30 days prior) the following: relevant nutritional information (59%), information about medical or alternative treatments for AA (56%), and information regarding recent AA-related scientific discoveries (56%). Of the participants who reported needing this information, the majority were from the group that had AA for five years or less, compared to the group of more than five years (although not statistically significant).

Twenty-seven participants reported having received support from their families (84%) and 22 from their friends (69%). Family support was received from a sibling or siblings (63%; n = 20), his or her mother (59%; n = 19), a partner (56%; n = 18), his or her father (47%; n = 15), a child or children (31%; n = 10), and one or both grandparents (n = 1). The type of support received was mostly emotional (n = 18), followed by informative/evaluative (n = 7) and instrumental (n = 2). Most of the participants who reported to have not received support from their family nor friends, have lived with AA for less than 5 years; nevertheless, this difference was not statistically significant.

The psychological and support needs of people living with AA were also explored. The greatest needs identified were help to deal with my physical appearance (59%), support from my family (56%), support from my friends (56%), and help understanding or making sense of the fact that I live with AA (56%). For psychological and support needs identified, there were no statistically significant differences when comparing people living with AA for 5 years or less with those of over 5 years.

Discussion

The number of participants was smaller than expected. This could be related both to the low rates of AA in Puerto Rico (when compared with rates of other conditions), and the data collection strategy. Web-based questionnaires can have their advantages (e.g., speed, cost, and quality of data collection) but can result in low participation and response rates (15, 16). Despite this low response rate, the participation was quite

varied in terms of place of residence and age. Recommendations for future research include supplementing with an extended social media campaign and/or radio broadcasting to facilitate recruitment efforts.

In our study, the majority of the participants living with AA had been diagnosed with AA universalis at an early age (~19 years). A higher average age of onset was expected, and we thought that most of the participants would be diagnosed with patchy AA. Most patients develop AA before the age of 40, with the mean age of onset tending to range from 25 to 36 years (17). The condition is typically characterized by a rapid onset, during which patients experience hair loss in well-circumscribed patches; this type (patchy AA) is considered to be the most common form of the condition (17). Although patchy AA is more common than the others, in most cases, it is easier to conceal (camouflage) than are AA totalis and AA universalis.

The treatments mentioned by most participants living with AA coincide with those described in recent literature as being the most common and updated treatments for the condition: injectable corticosteroids and topical creams/immunotherapy (17, 18). In terms of gender, most of the study participants were women. Although AA affects women and men almost equally, adult women are more likely to seek help and support for it (19) and are more affected than adult men in terms of the negative cultural attitudes toward hair loss (20). That is, it is considered culturally acceptable for adult men to be bald, but that is not the case for adult women. In terms of time since onset, it seems to be a variable to consider in future studies, as reflected in the results related to perceived social support and identified needs. A recent study (6) supports these results with the finding that two variables associated with lower quality of life in people living with AA were disease duration and sex.

The needs of people living with AA are divided between informative and supportive. Most say they have no need to access information or education about the condition, rather, they want alternatives to manage it. Among the psychological and support needs, 2 of the most mentioned are related to the experience of living with AA (i.e., accepting how I look and help to understand or make sense of the fact that I live with AA). This finding can also be linked to the same cultural aspects that were previously discussed.

Participants agreed they had good relationships with their doctors but also believed that their physicians did not provide them adequate guidance or orientation regarding their AA. This is particularly important for two reasons: Patient dissatisfaction with the physician diagnosing AA has been linked to a negative impact on quality of life; additionally, referral to a mental health professional in the face of an AA diagnosis (in the clinical setting) is relatively infrequent (14).

As this assessment has found, people living with AA have needs that they perceive to be urgent, particularly in terms of the daily management of their condition. Results also show the relevance and urgency of developing strategies to diversify support networks, increasing referrals to specialized mental

health professionals, improving patient-provider relationships, and enhancing the availability of alternative treatments for AA in Puerto Rico.

Resumen

Objetivo: La alopecia areata (AA) es una enfermedad autoinmune que afecta los folículos del cabello provocando su pérdida. Aunque la incidencia acumulada de AA en los Estados Unidos se estima en 2.1%, se desconoce el número de personas que viven con esta afección en Puerto Rico. Además, existe poca literatura sobre AA en la isla y su impacto en la salud. Realizamos un estudio de necesidades para ayudar a reducir esta brecha de información y abordar las necesidades percibidas de las personas que viven con AA en Puerto Rico. **Métodos:** Se realizó un estudio de necesidades con un diseño no-experimental, descriptivo y transversal. Un cuestionario de 40 reactivos estuvo disponible a través de la plataforma de formularios de Google. **Resultados:** La mayoría de los participantes son mujeres, con AA universalis, diagnosticados a los 19 años (en promedio), y estaban recibiendo tratamiento a la hora de completar la encuesta. La mayoría de los participantes informaron tener acceso a información o educación sobre la alopecia y el apoyo de sus familiares y amigos, pero declararon necesitar apoyo informativo. En particular, querían conocer las opciones de tratamiento para su alopecia. **Conclusión:** El género y el tiempo desde el inicio de la AA parecen ser variables importantes que deben considerarse al realizar futuros estudios e intervenciones con esta población. Estos estudios e intervenciones deben abordar las necesidades de apoyo informativo de las personas que viven con AA.

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