The Impact of Alopecia Areata on Sexual Quality of Life

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ABSTRACT

Background: Alopecia areata (AA) is an autoimmune disease characterized by patches of hair loss that can cause decreased quality of life. This study evaluates the sexual quality of life for patients with AA. Methods: We surveyed patients in the National Alopecia Areata Foundation patient registry using an online version of the validated Sexual Quality of Life for Females (SQOL-F) and Sexual Quality of Life for Males (SQOL-M) questionnaires. Main Outcome Measures: Patient sexual quality of life was measured using the SQOL-F and SQOL-M instruments. Results: Eighty-one participants with AA (64 females and 17 males) completed the surveys. The mean age was 39.7 ± 13.8 years for women and 37.4 ± 9.9 years for men. Women had a decreased sexual quality of life with mean SQOL-F score of 51.3 ± 22.9. Men had a decreased sexual quality of life with mean SQOL-M score of 62.7 ± 33.9 (higher scores indicate greater sexual quality of life). No statistical difference was found between these two cohorts (P = 0.12). In discussing negative aspects of their sexuality, women strongly identified with emotional statements such as “I feel embarrassed” (n = 48, 75.0%) while men strongly identified with emotional statements such as “I feel anxious” (n = 7, 46.7%). Both cohorts strongly identified with “I feel like I have lost something” (n = 48, 76.2% and n = 7, 43.8%, respectively). Conclusions: This study demonstrates that AA has a negative impact on the patient’s sexual quality of life.

Key words: Alopecia, alopecia areata, hair loss, sexual quality of life

INTRODUCTION

Alopecia areata (AA) is a genetic, immune-mediated hair loss condition characterized by patches of nonscarring hair loss that affects approximately 1.7% of the global population.[1] The loss of hair in AA is associated with psychological distress, including loss of self-confidence, low self-esteem, heightened self-consciousness, and poor health-related quality of life.[1] Women with cancer-related hair loss report poorer self-concept and poorer body image, and men with male pattern hair loss report that balding makes them less attractive and desirable sexual partners for women.[2,3] In this study, we explore the impact of AA on sexual quality of life.

METHODS

Participants

We administered an online survey to a convenience sample of adults with a diagnosis of AA from the National Alopecia Areata Foundation (NAAF) patient database between March 2018 and May 2018. NAAF is a nonprofit organization with an AA patient registry. Patients accessed the anonymous survey link through the NAAF social media posts. We excluded non-English-speaking patients, those who did not have AA, and those under 18 years of age. This study was approved by the Partners Human Research Committee’s Institutional Review Board.

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How to cite this article: Li SJ, Huang KP, Joyce C, Mostaghimi A. The impact of alopecia areata on sexual quality of life. Int J Trichol 2018;10:271-4.
Survey administration

Demographic data were obtained from the online survey including age, sex, race, ethnicity, and employment status. We administered the Sexual Quality of Life for Males (SQOL-M) and Sexual Quality of Life for Females (SQOL-F) questionnaire. The SQOL-M (11 items) and SQOL-F (18 items) are validated questionnaires that assess the social, emotional, and psychological aspects of sexual health. Responses for each item are scored on a 6-point Likert Scale (1 = completely agree, 2 = moderately agree, 3 = slightly agree, 4 = slightly disagree, 5 = moderately disagree, and 6 = completely disagree). Total scores standardized to range from 0 to 100, with higher scores indicating greater sexual quality of life. All surveys were completed online and hosted by Qualtrics (Qualtrics LLC, Provo, Utah, USA).

Outcome measures and statistical analyses

Descriptive statistics regarding patient’s characteristics and SQOL-F and SQOL-M scores were calculated overall and by gender. The Wilcoxon rank-sum test was performed to test for differences in SQOL scores for men and women with AA. Exact Cochran–Armitage tests for trend were used to compare the 6-point questionnaire items by gender. Analyses were performed using SAS 9.4 (SAS Institute, Cary, NC, USA).

Table 1: Demographics

| n | 81 |
|---|---|
| Age, mean (SD) |
| Female | 40 (13.8) |
| Male | 37 (9.9) |
| Employment status, n (%) |
| Employed | 64 (79.0) |
| Unemployed | 17 (21.0) |
| Race, n (%) |
| Caucasian | 70 (86.4) |
| African American | 4 (4.9) |
| Asian | 1 (1.2) |
| Native Hawaiian or Pacific Islander | 1 (1.2) |
| American Indian or Alaska Native | 1 (1.2) |
| Other | 4 (4.9) |
| Ethnicity, n (%) |
| Hispanic/latino | 6 (7.4) |
| Not hispanic/latino | 75 (92.6) |

A Wilcoxon rank sum test was performed to compare SQOL score for males and females with alopecia areata. SD – Standard deviation; SQOL-F – Sexual Quality of Life for Females; SQOL-M – Sexual Quality of Life for Males; IQR – Interquartile range

RESULTS

Eighty-one complete responses were collected in total, most of which were women (79%, n = 64) [Table 1]. Over half of respondents were younger than 40 years old (59.3%, n = 48). These respondents were predominantly Caucasian (86.4%, n = 70). Women and men with AA had mean scores of 51.3 ± 22.9 (SQOL-F) and 62.7 ± 33.9 (SQOL-M), respectively. No statistical difference was found between these two cohorts (P = 0.12, Figure 1).

In discussing negative aspects of their sexuality, women strongly identified with emotional statements such as “I feel embarrassed” (75.0%, n = 48), “I feel like less of a woman” (n = 41, 64.1%), and “I lost confidence in myself as a sexual partner” (64.1%, n = 41). Furthermore, compared to men, women were significantly more likely to report feeling frustrated (P = 0.012), feeling embarrassed (P = 0.001), and feeling as though they lost something (P = 0.035). Men strongly identified with statements such as “I feel anxious” (46.7%, n = 7) and “I worry about the future of my sexual life” (43.8%, n = 7).

Both cohorts strongly identified with “I feel like I have lost something” (76.2%, n = 48 and 43.8%, n = 7, respectively).

DISCUSSION

Our findings suggest that patients with AA have decreased sexual quality of life in AA. Women with AA were significantly more likely to report feeling frustrated, embarrassed, and that they lost something. Overall, most respondents identified with negative statements when discussing their sexuality, with the most common being “I feel like I lost something.” These lower SQOL-F and SQOL-M scores suggest that this patient population experiences poor sexual quality of life, similar to findings in other forms of hair loss.

Studies have explored the association of dermatologic conditions on sexual functioning, but few have analyzed the impact of dermatologic conditions on sexual quality of life. For context, despite the physical limitations of genital and nongenital psoriasis, men with these conditions report greater sexual quality of life on the SQOL-M, (76.1 ± 24.4 and 77.8 ± 24.1, respectively) in comparison to our cohort of patients. This observation highlights the emotional impact of AA on sexual quality of life, as there are no physical symptoms or limitations for intercourse. Interestingly, men with nondermatologic conditions such as cancer, diabetes, and obesity also report great sexual quality of life (68.4 ± 20.9) compared to our cohort of patients.
### SQOL-F RESPONSES

| Statement                                                                 | Completely agree | Moderately agree | Slightly agree | Slightly disagree | Moderately disagree | Completely disagree |
|---------------------------------------------------------------------------|------------------|------------------|----------------|-------------------|---------------------|---------------------|
| I am satisfied with the frequency of sexual activity                       | 17.2%            | 15.6%            | 14.1%          | 18.8%             | 15.6%               | 18.8%               |
| *I feel like I have lost something*                                       | 38.1%            | 25.4%            | 12.7%          | 4.8%              | 16.6%               | 17.5%               |
| I worry that my partner feels hurt or rejected                             | 12.9%            | 14.5%            | 17.7%          | 6.5%              | 17.7%               | 30.7%               |
| *I feel guilty*                                                           | 14.1%            | 4.7%             | 18.8%          | 17.2%             | 14.1%               | 31.3%               |
| I try to avoid sexual activity                                            | 16.1%            | 9.7%             | 21.0%          | 8.1%              | 8.1%                | 37.1%               |
| I feel that I can talk to my partner about sexual matters                  | 35.9%            | 20.3%            | 18.8%          | 12.5%             | 9.4%                | 3.1%                |
| *I feel embarrassed*                                                      | 28.1%            | 26.6%            | 20.3%          | 4.7%              | 6.3%                | 14.1%               |
| I have lost pleasure in sexual activity                                   | 9.7%             | 14.5%            | 17.7%          | 9.7%              | 12.9%               | 35.5%               |
| I worry about the future of my sex life                                    | 19.1%            | 22.2%            | 17.5%          | 4.8%              | 15.9%               | 20.6%               |
| I feel close to my partner                                                | 31.3%            | 18.8%            | 20.3%          | 15.6%             | 4.7%                | 9.4%                |
| I feel angry                                                              | 17.5%            | 19.1%            | 11.1%          | 20.6%             | 11.1%               | 20.6%               |
| I feel anxious                                                            | 23.4%            | 20.3%            | 18.8%          | 18.8%             | 6.3%                | 12.5%               |
| I have lost confidence in myself as a sexual partner                       | 21.9%            | 21.9%            | 20.3%          | 4.7%              | 17.2%               | 14.1%               |
| I feel good about myself                                                  | 10.9%            | 25.0%            | 15.6%          | 23.4%             | 17.2%               | 7.8%                |
| I feel like less of a woman                                               | 29.7%            | 25.0%            | 9.4%           | 6.3%              | 10.9%               | 18.8%               |
| I feel depressed                                                          | 23.4%            | 14.1%            | 12.5%          | 10.9%             | 25.0%               |                     |
| *I feel frustrated*                                                       | 20.3%            | 21.9%            | 21.9%          | 15.6%             | 4.7%                | 15.6%               |
| it is an enjoyable part of my overall life                                 | 26.2%            | 20.0%            | 32.3%          | 7.7%              | 13.9%               |                     |

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### SQOL-M RESPONSES

| Statement                                                                 | Completely agree | Moderately agree | Slightly agree | Slightly disagree | Moderately disagree | Completely disagree |
|---------------------------------------------------------------------------|------------------|------------------|----------------|-------------------|---------------------|---------------------|
| I feel as if I have lost something                                        | 18.8%            | 25.0%            | 12.5%          | 18.8%             | 25.0%               |                     |
| I worry that my partner feels hurt or rejected                             | 6.3%             | 18.8%            | 12.5%          | 6.3%              | 56.3%               |                     |
| I feel guilty                                                             | 6.3%             | 6.3%             | 18.8%          | 6.3%              | 6.3%                | 56.3%               |
| When I think about my sexual life, I am embarrassed                        | 6.3%             | 18.8%            | 6.3%           | 12.5%             | 56.3%               |                     |
| I worry about the future of my sexual life                                 | 12.5%            | 12.5%            | 18.8%          | 6.3%              | 6.3%                | 43.8%               |
| I feel angry                                                              | 12.5%            | 6.3%             | 12.5%          | 12.5%             | 50.0%               |                     |
| I feel anxious                                                            | 13.3%            | 13.3%            | 20.0%          | 20.0%             | 6.7%                | 26.7%               |
| I have lost confidence in myself as a sexual partner                       | 18.8%            | 12.5%            | 12.5%          | 12.5%             | 37.5%               |                     |
| I feel less of a man                                                       | 13.3%            | 13.3%            | 6.7%           | 13.3%             | 6.7%                | 46.7%               |
| I feel depressed                                                          | 6.3%             | 6.3%             | 18.8%          | 18.8%             | 43.8%               |                     |
| I feel frustrated                                                         | 6.3%             | 12.5%            | 12.5%          | 6.3%              | 25.0%               | 37.5%               |

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**Figure 1:** The percentage breakdown of the Sexual Quality of Life for Females and Sexual Quality of Life for Males answers. The top statements that females agreed with are “I feel like I have lost something,” “I feel embarrassed,” “I feel that I can talk to my partner about sexual matters,” and “It is an enjoyable part of my overall life” (76.2%, 75%, 75%, and 78.5%, respectively). The top statements that males agreed with include “I feel as if I have lost something,” “I worry about the future of my sexual life,” and “I feel anxious” (43.8%, 43.8%, and 46.6%, respectively). *Statistically significant (P < 0.05) compared to Sexual Quality of Life for Males.

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*International Journal of Trichology / Volume 10 / Issue 6 / November-December 2018 273*
These results must be considered in the context of our study design, which is limited by a sample size of 81 respondents. Most study participants are women, and as such we were underpowered to detect potential differences by gender if they exist. Patients were obtained from the NAAF patient registry, which limits generalizability. Given the method of using a convenience sample, we are unable to calculate a response rate, and there may be response bias.

Sexual quality of life has been shown to be a significant predictor of mental and physical well-being. Accordingly, this domain of health-related quality of life is particularly important for patients with AA, who are more at risk psychological disorders such as anxiety and depression. These findings, which suggest lower sexual quality of life among both men and women with AA, should be confirmed in additional studies, and efforts to quantify and mitigate this dimension of disease impact should be incorporated into clinical practice and trials.

**Financial support and sponsorship**

Nil.

**Conflicts of interest**

Drs. Huang and Mostaghimi have received royalty payments from Pfizer for licensing of the ALTO tool and have participated in clinical trials related to alopecia from Incyte and Aclaris. In addition, Dr. Mostaghimi has received consulting fee from Pfizer.

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