



Quality of Life in Women with Alopecia

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Hair loss is a psychologically devastating disorder, causing grave distress to patients of all ages, genders, and nationalities. Due to the visible nature of hair loss, individuals become increasingly self-conscious, and over time may develop anxiety or depression [1]. Furthermore, the psychological stress related to alopecia can impair functioning in social and professional arenas, affecting relationships and creating work related problems [1]. Despite the available treatments for alopecia, their efficacy is not well established and following disease course and treatment success relies on patient perception [2]. Quality of life (QoL) studies are a valuable tool in assessing patient well-being, coping mechanisms, and disease burden on patients' activities of daily living, as well as effects of therapy [2,3].

Previous studies examining alopecia QoL focused on non-scarring conditions such as alopecia areata (AA), telogen effluvium (TE), and androgenetic alopecia (AGA) [1-3]. QoL in cicatricial alopecia is rarely examined, and there has been no comparison with impact of non-scarring alopecias [4]. Our study objective was to determine the impact of hair loss and provided therapies on QoL in patients with scarring (central centrifugal cicatricial alopecia (CCCA), lichen planopilaris (LPP)) and non-scarring alopecia (AA, AGA, and TE).

This study was approved by the research ethics board at Cleveland Clinic and conducted in the Cleveland Clinic Department of Dermatology in Cleveland Ohio. Eligibility criteria included a diagnosis of CCCA, LPP, AA, AGA or TE, age above 18 years, and female gender. Over a 20-month period, 1000 patients seen for hair loss met eligibility criteria. Instructional letters for completing the anonymous online survey were mailed to all eligible patients, and 114 completed the survey. For comparison, a control group of 100 individuals without alopecia were invited to complete the online survey, with 20 individuals participating. QoL data were collected using RED Cap (Research Electronic Data Capture) Survey, a secure, web-based system used to support data collection for clinical

studies [5]. QoL was assessed using Skindex-16, modified to address alopecic disorders, with two additional questions to assess hair loss over the previous month [3].

The data were analyzed using ANOVA. Tukey-Kramer adjustments were used to correct for multiple means pairwise comparisons. Populations were grouped based on the presence or absence of alopecia, non-scarring or scarring type, patient age categories (18-30, 31-45, 46-60, and > 60), and the presence or absence of treatment. Each of the patient population groupings were tested for differences in scores for emotions, function, symptoms, and global domains.

The most common alopecia subtypes were AGA (34%) followed by AA (33%). Of the cicatricial alopecia subtypes, 23% of patients had LPP compared to 2% with CCCA. Most respondents identified as Caucasian (85%) and were between the ages of 46 and 65 (61%). At the time of survey, 83% of respondents were being treated for alopecia.

Patients with alopecia had significant QoL impairment compared to controls ($p < 0.002$, Table 1), and those with scarring alopecia experienced worse QoL impairment compared to non-scarring alopecia, except where symptoms are concerned. No significant differences were found in the QoL scores between patients who were receiving therapy and those who were not. Pairwise comparison demonstrated higher scores in the emotions domain between patients aged 31-45 and 46-65 when compared to patients who are 65 and older ($p < 0.001$ and $p = 0.018$, respectively). Differences among

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Table 1: General comparisons and correlation between single variables and quality of life domains for alopecia patients with scarring and non-scarring subtypes, quality of life by age, and pairwise comparison by age*.

| QOL comparing alopecia and non-alopecia patients | | | | | | |
|--|---------------------------------------|-------------------|-----------------------|---------------|----------|----------|
| | | Alopecia group | | Control group | | |
| | | Mean | Std. Dev | Mean | Std. Dev | |
| Symptoms | Itching | 37.43 | 33.7 | 4.2 | 9.2 | |
| | Burning/Stinging | 13.01 | 23.4 | 0 | 0 | |
| | Hurting | 14.47 | 25.1 | 0 | 0 | |
| | Irritation | 29.50 | 30.6 | 0.8 | 3.7 | |
| Emotion | Persistence/Reoccurrence of hair loss | 65.35 | 35.4 | 5.8 | 12.4 | |
| | Worry | 81.12 | 30.6 | 1.7 | 5.1 | |
| | Appearance | 78.65 | 29.5 | 4.2 | 12.0 | |
| | Frustration | 79.09 | 31.7 | 4.2 | 12.0 | |
| | Embarrassment | 74.85 | 31.9 | 2.6 | 11.5 | |
| | Annoyance | 79.35 | 30.6 | 4.4 | 12.2 | |
| | Depression | 65.19 | 34.8 | 0 | 0 | |
| Function | Interactions with others | 54.53 | 35.6 | 0.8 | 3.8 | |
| | Desire to be with people | 47.51 | 38.0 | 0.8 | 3.7 | |
| | Show affection | 37.28 | 38.8 | 0 | 0 | |
| | Daily activities | 44.10 | 39.4 | 4.2 | 11.9 | |
| | Work or enjoyment | 41.82 | 40.0 | 0 | 0 | |
| Global | | 52.7 | 40.6 | 2.1 | 8.0 | |
| QOL comparing scarring and non-scarring alopecia | | | | | | |
| | | Scarring subgroup | Non-scarring subgroup | P-value | | |
| Symptoms | | 21.9 | 28.7 | 0.038 | | |
| Emotions | | 77.5 | 66.6 | < 0.0001 | | |
| Functions | | 49.0 | 32.8 | < 0.0001 | | |
| Global | | 54.7 | 46.5 | 0.0002 | | |
| QOL comparing current status of therapy | | | | | | |
| | | Yes | No | P-value | | |
| Symptoms | | 24.0 | 21.3 | 0.46 | | |
| Emotions | | 75.1 | 73.2 | 0.54 | | |
| Functions | | 45.0 | 45.3 | 0.95 | | |
| Global | | 52.9 | 51.4 | 0.55 | | |
| QoL comparing age groups | | | | | | |
| | | 18 - 30 | 31 - 45 | 46 - 60 | > 60 | P-value |
| Symptoms | | 17.6 | 23.7 | 22.9 | 29.7 | 0.24 |
| Emotions | | 73.8 | 85.3 | 74.8 | 62.6 | < 0.0001 |
| Functions | | 33.3 | 52.7 | 44.9 | 43.1 | 0.047 |
| Global | | 47.1 | 59.8 | 52.5 | 48.2 | 0.0015 |
| Pairwise comparison between subtype and age group | | | | | | |
| QOL Scale | Age group | Age group | P-Value | | | |
| Emotions | 31 - 45 | 45 - 65 | 0.0047 | | | |
| | 31 - 45 | > 65 | < 0.0001 | | | |
| | 46 - 65 | > 65 | 0.0018 | | | |
| Functions | 18 - 30 | 31 - 45 | 0.029 | | | |
| Global | 18 - 30 | 31 - 45 | 0.01 | | | |
| | 31 - 45 | 46 - 65 | 0.025 | | | |
| | 31 - 45 | > 65 | 0.004 | | | |

*A greater score indicates greater QoL impairment.

QoL domains by alopecia subtype are presented in [Figure 1](#).

Our findings demonstrate that hair loss patients have a lower quality of life in the emotional and functional QoL parameters. Usage of Skindex-16 allows us to compare QoL of patients with alopecia and other skin dis-

orders. In comparison with alopecia, atopic and contact dermatitis showed similar global scores, while vitiligo had lower scores [6,7]. In fact, functioning and emotional aspects were worse among alopecia patients than those with non-melanoma skin cancers [8].

Our results allowed us to gain insight into the sub-

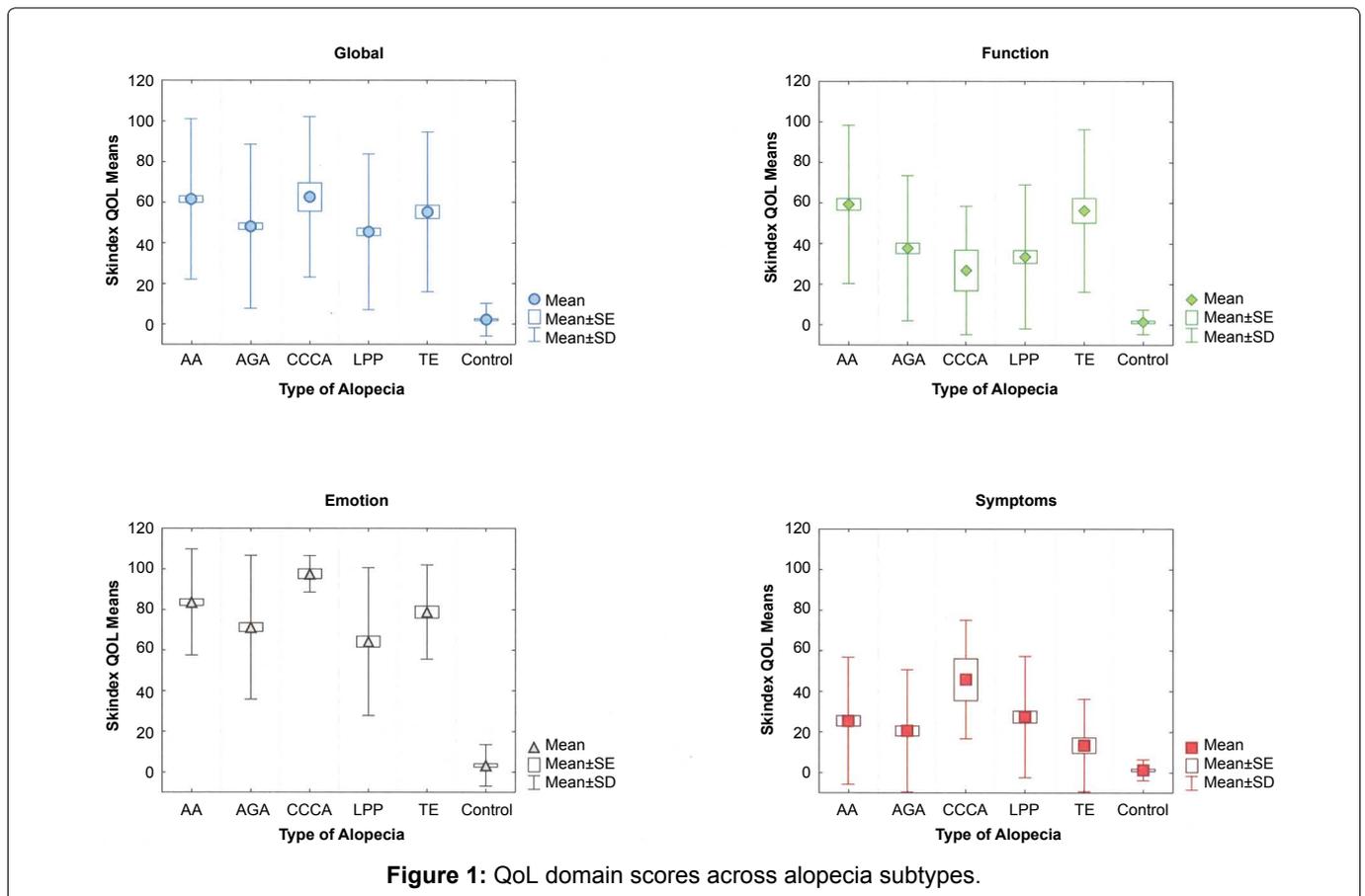


Figure 1: QoL domain scores across alopecia subtypes.

stantial QoL burden of scarring alopecia, as these patients exhibited extensive QoL impairment in the emotions, functions, and global domains. This is possibly associated with the irreversible nature of the condition and lack of effective treatment options. In addition, prior studies have found that patients often feel greater QoL impairment than could be predicted by their symptoms, and a disconnect between patient and physician perception of hair loss [4].

The findings from this study substantiate the broad scope of effects that hair loss causes in the lives of women. Physicians who encounter patients with alopecia should consider the impact of hair loss on QoL during original assessment and follow-up [2]. Larger QoL studies, with better response rates are needed to further address the impact of hair loss.

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