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## Quality of Life in Patients with Central Centrifugal Cicatricial Alopecia: A Preliminary Study

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### Dear Editor,

Central centrifugal cicatricial alopecia (CCCA) is a type of scarring hair loss that predominantly affects women of African and/or Caribbean descent, with limited treatment options focused on preventing the progression of disease<sup>1</sup>. There are limited data measuring the hair-related quality of life (HRQL) among patients with CCCA. The purpose of this study is to understand the impact of CCCA on patient HRQL, and identify specific concerns with increased influence on overall HRQL.

Patients were recruited via non-random convenience sampling of all patients over the age of 18 attending a University of Pennsylvania dermatology clinic since January 2016 with a biopsy-proven diagnosis of CCCA. The CCCA Quality of Life Index (CCCA-QLI) Questionnaire was used to assess the impacts of subjective symptoms, relationship issues, and objective signs on overall HRQL. This survey was initially designed and validated among a population of Italian patients, and then administered again in a population of South African patients. A target number of 50 subjects was chosen based on previous administration in Italy and South Africa. The HRQL was calculated using a hierarchical

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structural equation model (SEM) with Partial Least Squared – Path Modelling. HRQL index (QLI) scores and analyzed in  $R^2$ . Loading values, and path coefficients were calculated using statistical modelling with scores expressed on a scale of 0 (best HRQL) to 100 (worst HRQL). This model also provided the relationship between each subcategory of the survey and the overall QLI. A QLI score  $> 50$  was considered as significant impairment of quality of life based on original survey validation done by Fabbrocini et al. against the well-known Dermatology Life Quality Index<sup>3</sup>.

In total, 56 patients completed the survey and were included in the analysis. All patients identified as African-American, and 98% (55/56) were women. The average CCCA-QLI score was 53.31 (Figure 1). Among the three areas in which the CCCA-QLI is divided, ‘subjective symptoms’ and ‘objective signs’ had section scores indicating significantly impaired quality of life (77.02 and 60.69, respectively; Figure 1). Although these two categories had the highest QLI scores, ‘relationship issues’ had the lowest average score, but the highest impact on the overall score with a Cr R2 value of 52.40% (Figure 1).

Our patient population was found to have a significantly impaired HRQL. The mean CCCA-QLI score in this population was similar to the results in other papers using the same survey and SEM analysis in populations of Italian patients (54.94) and South African patients (67.3)<sup>3,4</sup>. Broken down by category, both subjective symptoms of the condition and objective measurements of disease severity had a high number of negative responses. Additionally, because of its high impact on overall CCCA-QLI, the low number of negative responses within the ‘relationship issues’ category had a protective effect against worsening CCCA-QLI among our population, identifying the role that individual connections and larger communities play in mitigating the negative effects of this condition. Literature supports the role of appropriate mental health interventions in addressing the psychosocial consequences of dermatologic issues<sup>5</sup>.

A major strength of this study was the use of a validated questionnaire adapted for CCCA and the use of modelling to further breakdown scores that allowed for the assessment of major contributors to overall decreased quality of life. This allowed the development of scores that were specific to our population of respondents, and allowed for the identification of issues of increased concern in our population. However, the loading values and path coefficients would require updates specific to other populations if administered elsewhere. Additionally, although the two previous studies were also done in specialty hair clinics, recruitment of our study population from a specialty clinic could be a source of selection bias in our responses. Overall, our analysis demonstrates that CCCA has a significant negative impact on HRQL, and dermatologists caring for patients with CCCA should remain sensitive to the emotional and psychological toll this diagnosis has on its patients, and provide appropriate resources to better support patients with this diagnosis.

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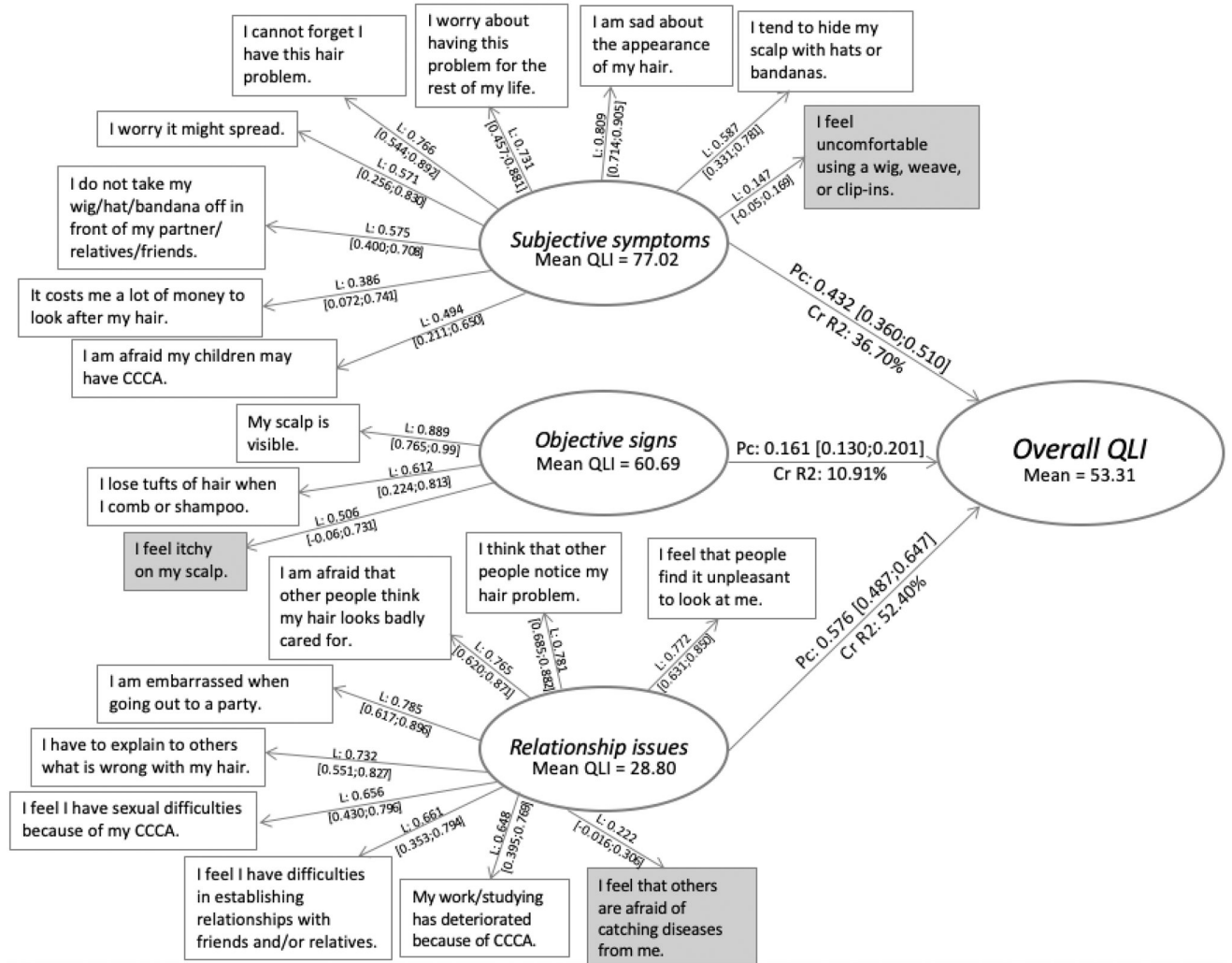
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## Data availability:

Data available on request from the authors.

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**Fig 1. Path Diagram – Partial Least Squared – Path Modelling**

Summary of structural equation model for quality of life in CCCA, indicating the impact and relative weighting of each of the three latent variables subjective symptoms, relationship issues, objective signs, and 21 manifest variables. *l* = manifest variable loading, *pc* = path coefficient, *Cr R2*: Contribution to *R*<sup>2</sup>; [*x*<sub>1</sub>, *x*<sub>2</sub>] = confidence intervals. Criteria used to assess structural fit of the model included goodness of fit (0.66), significance of path coefficients and level of *R*<sup>2</sup> values. The *R*<sup>2</sup> coefficients, using the Repeated Indicator Approach, is 1. All path coefficients were positive and significant with positive Bootstrap confidence intervals. The three items in the figure that are shaded grey had values that did not contribute to the estimated QLI and were therefore excluded from the final analysis.