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## Psychosocial burden of FFA: a qualitative interview study

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Frontal Fibrosing Alopecia (FFA) is an immune-mediated cicatricial alopecia that affects the frontotemporal hairline and facial hair, with 80% of those affected having eyebrow involvement. FFA mainly occurs in post-menopausal women and has been associated with hormonal, genetic, and environmental factors, although a definitive etiology remains unclear. Past studies have illustrated the large negative impact various forms of alopecia can have on patients' quality of life; however limited studies have focused on FFA specifically. Through qualitative interviews, we sought to better understand the burden of FFA on patients' lives. We recruited and interviewed 14 women who were established patients at the Atrium Health Wake Forest Baptist Dermatology clinics. Each interview was then transcribed and underwent independent review and coding using an inductive and constant comparative technique. A data dictionary and common coding system were created based on the transcripts, and codes were assigned to relevant text by the investigators. The average age of participants was 66.9 years old with a mean age of diagnosis of 49.4 years old. Seven themes were identified from the data including hair styling practices, the psychosocial burden of FFA, delay in diagnosis of the disease, selfacceptance, fatigue from chronic management of disease, etiology, being cared for by a hair expert, and longing for a cure. Participants in our cohort felt like they lost a part of their identity with their hair loss and also felt ostracized from society. FFA had a negative impact on participants' social and professional lives and participants were often distressed from the lack of disease understanding and the unknown future of disease progression. Misdiagnosis and delay in diagnosis were common occurrences amongst participants. Our study builds upon the limited data available on the effect of FFA on patients' quality of life and emphasizes that the emotional impact of FFA should not be overlooked by physicians when managing the disease.