

Psychosocial Burden of Frontal Fibrosing Alopecia (FFA): a qualitative interview study

Madison K. Cook BS,¹ Patrick O. Perche BS,¹ Jonathan C. White BS,¹ Steven R. Feldman MD PhD,¹ Lindsay C. Strowd MD¹
Center for Dermatology Research, Department of Dermatology, Wake Forest School of Medicine, Winston-Salem, North Carolina

INTRODUCTION

- Frontal Fibrosing Alopecia (FFA) is an immune-mediated scarring alopecia first described in 1994 that has increased in prevalence over the past thirty years.¹
- It is predominantly limited to the frontotemporal hairline and affects the eyebrows in 80% of cases.^{2,3}
- It mainly occurs in post-menopausal women and has been associated with hormonal, genetic, and environmental factors, although a definitive etiology remains unclear.⁴
- Both scarring (cicatricial) and non-scarring types of alopecia have a negative effect on patients' overall quality of life (QOL).⁴⁻⁶
- Scarring alopecias potentially have greater psychological impact, leading to higher levels of anxiety and depression than non-scarring types.⁷
- Due to the chronicity, lack of approved treatments, and widespread involvement of both scalp and non-scalp hair, we predict FFA has a broad negative impact on participants' lives.

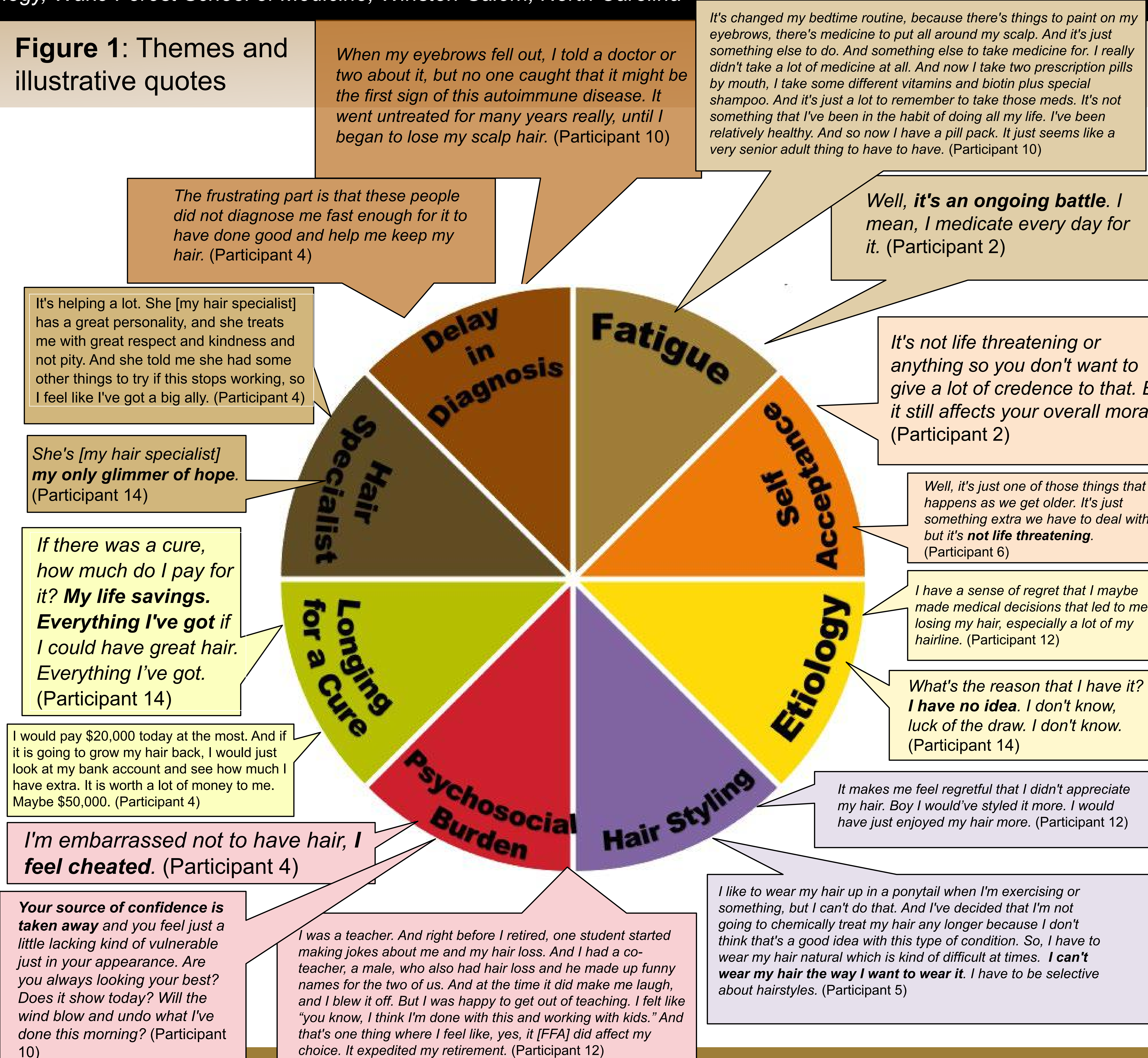
OBJECTIVE

- The objective of our study was to better understand the effects of FFA on patients' lives.

METHODOLOGY

We conducted semi-structured interviews with 14 patients with a diagnosis of FFA from the Atrium Health Wake Forest Baptist Department of Dermatology. A data dictionary and common coding system were created based on the transcripts of interviews, and codes were assigned to relevant text by the investigators.

Figure 1: Themes and illustrative quotes



RESULTS

Participants were a mean age of 66.9 years, 100% female, and had a mean age at diagnosis of 49.4 years. All participants had scalp involvement, and the majority of participants (78.6%) had eyebrow involvement. Our analysis elicited 8 themes (Figure 1).

DISCUSSION

- The cultural importance and value of hair has been pervasive throughout history.⁸
- Consequently, hair loss can be an extremely traumatic and impactful experience for individuals.⁹
- In our cohort, participants with FFA expressed the devastating effects of this progressive disease on many aspects of their lives
- The etiology of FFA is not well understood, and this was distressing to participants in our study
- Although FFA is now the most prevalent scarring alopecia, many physicians are still unfamiliar with the disease.¹⁰
- Misdiagnosis of scarring alopecia has been associated with increased rates of anxiety and depression, and increased severity of disease.¹¹
- In our cohort, the amount of money participants were willing to pay for a one-time cure was considerably greater than for other chronic dermatological conditions such as psoriasis or rosacea.^{11,12}

CONCLUSION

- Our study builds upon the limited data available on the effect of FFA on patients' quality of life
- FFA is associated with a large psychosocial burden

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