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

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### INTRODUCTION

- Frontal Fibrosing Alopecia (FFA) is an immunemediated scarring alopecia first described in 1994 that has increased in prevalence over the past thirty years.<sup>1</sup>
- It is predominantly limited to the frontotemporal hairline and affects the eyebrows in 80% of cases.<sup>2,3</sup>
- It mainly occurs in post-menopausal women and has been associated with hormonal, genetic, and environmental factors, although a definitive etiology remains unclear.<sup>4</sup>
- Both scarring (cicatricial) and non-scarring types of alopecia have a negative effect on patients' overall quality of life (QOL).<sup>4–6</sup>
- Scarring alopecias potentially have greater psychological impact, leading to higher levels of anxiety and depression than non-scarring types.<sup>7</sup>
- 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

When my eyebrows fell out, I told a doctor or two about it, but no one caught that it might be the first sign of this autoimmune disease. It went untreated for many years really, until I began to lose my scalp hair. (Participant 10)

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The frustrating part is that these people did not diagnose me fast enough for it to have done good and help me keep my hair. (Participant 4)

It's helping a lot. She [my hair specialist] has a great personality, and she treats me with great respect and kindness and not pity. And she told me she had some other things to try if this stops working, so I feel like I've got a big ally. (Participant 4)

She's [my hair specialist] my only glimmer of hope. (Participant 14)

If there was a cure, how much do I pay for it? My life savings. Everything I've got if I could have great hair. Everything I've got. (Participant 14)

I would pay \$20,000 today at the most. And if it is going to grow my hair back, I would just look at my bank account and see how much I have extra. It is worth a lot of money to me. Maybe \$50,000. (Participant 4)

I'm embarrassed not to have hair, I feel cheated. (Participant 4)

Your source of confidence is taken away and you feel just a little lacking kind of vulnerable just in your appearance. Are you always looking your best? Does it show today? Will the wind blow and undo what I've done this morning? (Participant

was a teacher. And right before I retired, one student started making jokes about me and my hair loss. And I had a coteacher, a male, who also had hair loss and he made up funny names for the two of us. And at the time it did make me laugh, and I blew it off. But I was happy to get out of teaching. I felt like "you know, I think I'm done with this and working with kids." And that's one thing where I feel like, yes, it [FFA] did affect my choice. It expedited my retirement. (Participant 12)

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It's changed my bedtime routine, because there's things to paint on my eyebrows, there's medicine to put all around my scalp. And it's just something else to do. And something else to take medicine for. I really didn't take a lot of medicine at all. And now I take two prescription pills by mouth, I take some different vitamins and biotin plus special shampoo. And it's just a lot to remember to take those meds. It's not something that I've been in the habit of doing all my life. I've been relatively healthy. And so now I have a pill pack. It just seems like a very senior adult thing to have to have. (Participant 10)

> Well, it's an ongoing battle. / mean, I medicate every day for *it.* (Participant 2)

It's not life threatening or anything so you don't want to give a lot of credence to that. But it still affects your overall morale (Participant 2)

> Well, it's just one of those things that happens as we get older. It's just something extra we have to deal with but it's not life threatening. (Participant 6)

I have a sense of regret that I maybe made medical decisions that led to me losing my hair, especially a lot of my hairline. (Participant 12)

What's the reason that I have it? I have no idea. I don't know, luck of the draw. I don't know. (Participant 14)

It makes me feel regretful that I didn't appreciate my hair. Boy I would've styled it more. I would have just enjoyed my hair more. (Participant 12)

I like to wear my hair up in a ponytail when I'm exercising or something, but I can't do that. And I've decided that I'm not going to chemically treat my hair any longer because I don't think that's a good idea with this type of condition. So, I have to wear my hair natural which is kind of difficult at times. I can't wear my hair the way I want to wear it. I have to be selective about hairstyles. (Participant 5)



# 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.<sup>8</sup>
- Consequently, hair loss can be an extremely traumatic and impactful experience for individuals.<sup>9</sup>
- 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
- O Although FFA is now the most prevalent scarring alopecia, many physicians are still unfamiliar with the disease.<sup>10</sup>
- Misdiagnosis of scarring alopecia has been associated with increased rates of anxiety and depression, and increased severity of disease.<sup>11</sup>
- 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 <sup>11,12</sup>

### CONCLUSION

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- 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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