



## Hidden Struggle; Explaining the Lived Experience of Patients with Alopecia Areata: A Qualitative Study Based on a Phenomenological Approach

Elaheh Hosseini<sup>1\*</sup>, Sadeh Vahabi<sup>1</sup> and Ali Taghipour<sup>2</sup>

<sup>1</sup>Department of Dermatology, Mashhad University of the Medical Sciences, Razavi Khorasan Province, Iran

<sup>2</sup>Department of Epidemiology, Mashhad University of the Medical Sciences, Razavi Khorasan Province, Iran

\*Corresponding author: Elaheh Hosseini, Department of Dermatology, Mashhad University of the Medical Sciences, Razavi Khorasan Province, Iran, E-mail: elahe.hosseini1991@gmail.com

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### Abstract

Alopecia areata is an autoimmune and non-scarring hair loss which has relapsing and remitting periods. It has extensive psychological impacts on affected individuals; like severe depression, anxiety, phobic reaction, paranoia. Also, it can affect the quality of life by lowering self-esteem and self-confidence.

This study considers the psychological and social aspects of the disease and hopes to be effective in promoting the treatment and improvement of the disease and quality of life of patients.

This study has been done with the phenomenology approach on eleven patients in the dermatology clinic of Imam Reza Hospital. In this study, deep interviews were performed using a semi-structured questionnaire. And after interpretation, it was analyzed with MAXqda software.

When the patients first encountered the hair loss, they started to find a reason and justify the condition. Most of them were trying to find an external factor other than believing they have a serious illness. In order to be accepted by other human beings and be a part of human society the individuals at first tried to hide their lesions to be like other members of society since they could not do this satisfactorily, they got a series of complications like depression, anxiety, and loss of self-confidence, and then they would start to hide from others which cause social avoidance in these patients.

Eventually, this situation leads to dysfunction in various aspects of career and academic life, and this causes a vicious cycle in an individual's life.

**Keywords:** Alopecia areata; Qualitative study; Alopecia; Lived experience

### Introduction

Alopecia areata is an autoimmune and non-scarring hairloss which has a relapsing and remitting periods. It is also one of the most common types of non-scarring alopecia and it mostly presents with patchy or round lesions that can be progressive and leads to alopecia totalis (loss of scalp hairs) and universalis (loss of body hairs) [1]. Although it has limited physical discomfort like pruritus or burning sensation [2], the extensive psychological impacts on affected individuals; like severe depression, anxiety, phobic reaction, paranoia, psychosis or suicidal intent [3,4]. Can effect on quality of life by lowering self-esteem and self-confidence [5].

There are evidences that mental disturbances like anxiety or fear and physical traumas and neuroendocrine disturbance might be triggers for the disease [6,7]. In addition to that, the people with a history of autoimmune disease and atopy are more susceptible to this type of alopecia [8], while the exact mechanisms are not fully understood. In spite of all the negative impacts on patients' lives and the extensive damages, there had been limited progression on disease treatment and no absolute treatment was found so far [9].

In a study by colon et al the majority of the examined patients had psychiatric disorders for instance they found a correlation between patchy alopecia areata and generalized anxiety disorder [7]. Also in another study in Oakland university, almost 20% of the study group had neuropsychiatric disorders including-psychoneurosis, personality disorders, or neurotic behavioral traits of a severe nature. Sudden emotional stresses like death of family members and history of intense fear found to be risk factors in a number of patients [10].

The recurrent and chronic nature of alopecia areata, and its deep impact on the appearance of the individual and mental disturbances like severe depression, generalized anxiety and personality disorders leads to an undesirable effect on the person's life as it mentioned above.

One of the most important factors which guide to a better management of this disease is the recognition of our patients' experiences when faced with the disease. Initial studies indicated that limited researches have been carried out in this field.

In addition to that this research is in line with the goal of promoting patient management, not just disease.

This study considers the psychological and social aspects of the disease and hope to be effective in promoting the treatment and improvement of the disease and quality of life of patients.

With more knowledge of patients' course of experiences and having hypothetical picture of their life, we as doctors can play an important role in management of the individuals' disease.

## Methods and Materials

### Place and date of execution

This study has been done since April 2018 in dermatology clinic of imam Reza hospital.

### Materials and equipment used/subjects

In this study, deep interviews were performed using a semi-structured questionnaire and the interviews continued to saturate the data (not finding a new concept and repeat the previous findings) and after interpretation and typing, it was analyzed with MAXqda software.

### Study design

This qualitative study has been done with the phenomenology approach.

### Method and steps of implementation

The semi-structured interview that begins with the question of the patient's first understanding of the early symptoms of the disease which was included exploratory questions among the researcher's general questions that was identified and used further during the interview or after the interview analysis.

Data analysis in phenomenological research such as qualitative research is a regular pattern of replication and simultaneous data analysis. This model often goes through stages of data collection analysis, data gathering until data saturation. We used Colaizzi's method in our data analysis.

### Statistical methods and sample size

This study has been performed with a phenomenological approach on eleven patients (including eight female and three men) referring to the dermatology clinic of Imam Reza Hospital with definitive diagnosis of Alopecia areata.

In this study, patients were interviewed in-depth using a semi-structured questionnaire (general questions and finding exploratory questions).

Interviews continued until data saturation (lack of new concept and repetition of previously acquired concepts).after typing, interviews were analyzed with MAXqda software.

### Inclusion criteria

- Patients with clinically diagnosed alopecia areata.
- In cases of suspicion with confirmation of pathological examination.

### Exclusion criteria

- Other types of alopecia.
- Having a comorbid psychological disease.
- Children or teenagers who are not able to be interviewed.
- Patient unwillingness.

## Results

We interviewed 11 individuals with alopecia that were referred to imam Reza dermatology clinic for treatment courses.

The sample for this study was 11 participants. The age ranges were 10 to 40, eight participants were female and three were male.

We conducted 11 face-to face interviews of individuals, six patients were single including three men and three women and the remaining five were married women.

After recording the interviews, the data were coded by MAXQDA software. We found 5 themes including (justifying, inhibition, hiding, psychopathy, avoidance) and 19 sub-codes which was in the face-to-face interviews which were performed on individuals with alopecia areata, we concluded that the patients had a common course in their disease. first of all they were trying to justify the disease and find a reason for it then they were struggling for the inhibition of the disease and after they failed to control the disease they started to hide it from others, as a result of these consecutive struggles and failures they might be exposed to mental problems and disappointments, at the end all this process caused them to get away from the society and isolation which we will describe them in details later.

### Justifying

When the patients first encountered the hair loss they started to find a reason and justify the condition. Most of them were trying to find an external factor other than believing they have a serious illness, one participant mentioned;

"When I was a child I got something called scabies, or maybe it was for my long and twisted hair" (p1) #female.

"I have cystic fibrosis and at first I thought that my hair shedding was a result of drugs I used"(p7) #male.

"When my first daughter was taken from milk, my hair began to shed. Maybe it was because I got weakened, then it got better for a while, but after giving birth to my son, my hair became more and more mumble. Every time it got better, another area was started to shed"(p8) #female.

Two patients described they had their first episode after a car accident;

"When I was a little child I had a head trauma in a car accident and my head was swollen and after that I noticed that my hair was started to shed"(p9) #female.

Another patient was believed family problems as a cause of his illness;

"When my hair started to shed for the first time, I was in a severe family crisis"(P2) #male.

### Illness inhibition

Patients started to think that their disease is not a temporary result of a trauma or stress and might be something more serious, in that case they visited multiple doctors and using the drugs and despite all the efforts they found no cure and the hair loss was still with them day and night. after trying modern medicine and visiting dermatologists and using drugs such as corticosteroids, minoxidil and mesotherapy and getting no result they looked after traditional medicine such as herbal medicine, leech therapy ,and acupuncture, they still didn't find it satisfying;

**New medicine:** "I have visited many doctors and I used minoxidil and other drugs, they had no effect "(p1) #female.

**Traditional medicine:** "I went to a doctor and he gave me corticosteroid injections, it was effective at first then after 2 or 3 months it started to shed again, I visited as many doctors as I could, I did mesotherapy and I did everything doctors told me to do, but it was all for nothing and I got no result, it has been five years that I lost my scalp's hair I even tried bleaching therapy but I found no result in that either".

## Hiding

When patients did not succeed in treating their illness in spite of all the efforts and also when they found that their disease is not curable and they most live their whole life with the current condition, they started to find another ways to improve their situation; in that case they often tend to cover the lesion. (P10) #female.

**Covering with remaining hair:** If it was possible, most of them covered the bald area with the remaining hair, but as we know it is not possible for individuals with universalis alopecia so it would be much harder for them;

"I don't think too much about it now and I try not to go in front of mirror too much, god gave it and he got it back! When I go to a ceremony, I just try to cover it with the remaining hair."(p2) #male.

**Scarf:** It was not that hard for women to cover their baldness from the eyes of strangers Because of the specific laws of our country that women have to cover their hair with scarf in public but almost all of them were concerned about covering their baldness in family ceremonies, one of them expressed that she wears scarf even in family ceremonies;

"I don't wear wigs or anything else I just wear scarf in ceremonies"(p6) #female.

## Wigs

The rest of the patients used wigs apart from men;

"I use wigs, the last one I bought is very natural and nobody can recognize it from the real hair"(p10) #female.

Men almost were not interested in using wigs they expressed that they should accept themselves as they are;

"I did not think about using wigs, this is my real self"(p5) #male.

"I don't like to wear wigs, I thought once but it is not really nice, when I don't have real hair I don't like to have artificial one either, I prefer to wear hat"(P5) #male.

One of the women said that she always wears wigs in front of her children because she believed that being bald in front of her children might make them nervous or might upset them;

"I have two kids and I am always wearing wigs in front of them, they tell me to take it off and be comfortable but I cannot be like that in front of them I don't want to bother them"(p10) #female.

"When I am alone at home I don't wear wigs but when my husband comes home I always wear wig I don't want him to see me like this"(P11) #female.

Most patients were talking about covering their baldness at work and they believed that it might impact on their job and their relationship with the clients;

"I am a tailor and I have my clients, I don't like to be apart from the society and I always tried to behave like normal people, because of that I use wigs and the one that I use is so natural, and I don't think anybody would distinguish it from a real one and also I don't want it to affect my job and relationships"(p10) #female.

## Hat

"...specially at work, when you want to work somewhere it is very uncomfortable, you need to wear hat always, mostly in summer it is so hot"(p5) #male.

One of the patient complains about using wigs especially in summers;

"I have used more than three or four wigs, when you use them too much specially in hot weathers since they have dermal contact they get sweaty and you must wash them very often"(p10) #female.

And she was also upset about wearing wigs in ceremonies;

"When you are going to a ceremony you are always stressful that maybe somebody's hand stick in your hair and take it off or people might say something that hurts my feelings since our people are paying so much attention to appearances"(p10) #female.

Eyebrows and eyelashes are essential part of the face and the lack of them affects the beauty of the face and also they are part of the bodies that covering them is hard and for men, it almost impossible. This powerlessness in hiding the lesion and the role of these parts in facial beauty brings more fear for individuals than losing scalp's hair. And most likely the fear is always with them;

"People mostly do not pay attention to my baldness but their reaction to see me without eyebrows is almost bothering especially when a kid passes by" (p2) #male.

It appears that Lacking Eyebrows as an important part of the face beauty influences on individual's self-confidence;

"Last year my eyebrows and eyelashes were intact and I had more confidence for example, I did not wear a hat, I would go everywhere, but this time, because it lasted too much and I lost my eyelashes and eyebrows, I have less hope and energy and I lost my confidence."(P7)#male.

"When I had eyebrows and eyelashes, it was easier to tolerate the condition"(p5) #male.

## Tatoos

One patient tattooed her eyebrows before losing it;

"Thanks god I didn't lose my eyelashes, and I tattooed my eye brows before they start to shed"(P10) #female.

"I don't feel good about wigs but I may tattoo my eyebrows in future"(p2) #male.

In contrary, another male patient was believed that tattoo is too visible and may not be a good solution.

In spite of this, the concern of men and women were not much different, both sex were thinking that it would be easier for them to endure the condition. If they had the opposite gender [11,12].

"If I was a boy, it would be easier for me, but I am a girl and without hair it would be a great pain, for boys it's easier they can wear hat"(p1) #female.

## Psychopathy

It is almost inevitable for patients to completely hide their disease from others especially from family members so they found themselves permanently subject to judgment and this fear of not being accepted in society and being rejected by people leads to a devastating damages on individual's mental health.

**Low self-confidence:** One of the most common consequences of hair loss is loss of self-confidence especially in women [13,14] both men and women were reported that they were not as confident as they were before, one participant said; "the life had become so hard I have no confidence in the way I've had before and I'm not going to any party or family ceremonies and I don't go out like before"(P7) #male.

A thirty year old man was mentioned the disease, as a traumatic event in his life; when it first started it was like a mental trauma gradually I lost my confidence and I really got hurt and it also affects my abilities in a bad ways especially at work "(P5) #male.

Some of them believed that loss of eyebrows and eyelashes have led to a loss in their self-confidence; "last year my eyebrows and eye lashes were intact and I had more confidence for example, I did not wear a hat, I would go everywhere, but this time, because it lasted too much and I lost my eyelashes and eyebrows, I have less hope and energy and I lost my confidence."(P7) #male.

Lack of self-confidence may impact on carrier and educational life of individuals; "I was stressed for lessons and exams I thought that I could not learn anything I read"(P1) #female.

Only one patient was mentioned that she gained her confidence gradually and now she has many friends and is going regularly to the gym with wigs and she believed her good mood is due to the helps of those around her (P8).

**Depressed mood:** Most of the participants had depressed mood, they had diminished interest or pleasure in almost all activities most of the day; "I couldn't do my job, I was very bored and I couldn't enjoy doing anything at all, I barely went out..."(P6) #female.

"I was alone and upset, I wish I could get back to the old days that I had hairs"(P10) #female. "I was depressed. I did not go anywhere; I did not speak to anyone. I had a bad situation. I stuck in a corner."(P6) #female.

"I am always depressed and silent at home and I do not speak to anyone"(P2) #male.

**Thinking too much:** Some of them complained of worrying about future; "I always think about the future, what will happen if my children get married and have wife and husband, what their family would think of us"(p10) #female. And one participant was upset about thinking too much about her situation.

**Being shy:** As hair and body image is one of the important component in self-value most of the participants were upset about being ashamed of their situation; "we have too many ceremonies these days and for every one of them, I have to go to the Hairdresser's and I will be ashamed of my hair loss"(p1) #female.

"I went to the hairdresser, and she told my mom that her hair loss is contagious and it was very embarrassing for me"(p1) #female.

Also one of the patients stated that if she was a boy the situation would be less embarrassing.

It seems that loss of eyebrows and eyelashes are more stressful than loss of scalp's hair for individuals; "thanks god I didn't lose my eyelashes, and I tattooed my eye brows before they start to shed"(P10) #female.

"In the initial course of the disease when I didn't lose my eyelashes and eyebrows it was more tolerable and I was more confident on that time"(p7) #male.

Even though hair loss cause mental and psychological disturbance, ten out of eleven participants were not willing to meet psychologist or psychiatrist; "I don't like to go to a psychologist I am afraid that they may say something that bother me and make me more upset"(P1) #female.

**Fear of cancer:** Younger participants were hiding the fear of cancer in their first episodes when they encountered the baldness, as a thirteen year old girl mentioned that; when I first noticed the disease, I thought it might be cancer and none of the doctors could diagnose it.

## Irritability

Some participants were complained of being irritable after the beginning of the disease; "I became irritable and get upset soon"(P4) #female.

It is too hard for patients to accept the fact that the disease does not have a cure and they must live with it their whole life, one study reported that, personality traits, severity of the condition, and the duration of the disease are all involved in the adaptation process [15].

"I don't think too much about it now and I try not to go in front of mirror too much, god gave it and he got it back, when I go to a ceremony, I just try to cover it with the remaining hair."(p2) #male.

"I just get used to it. I don't have another way because it is not a curable disease and it may last many years"(P9) #female.

It seems that over time patients learn to cope with the disease and find their own ways to manage the situation; "at first I was very upset about it and every time I came to the hospital, I was crying, but now I care less and I learnt not to think about it and it really helps"(P8)#female.

## Avoidance

As we know every single human act is for survival in order to survive in a society we need to be accepted by other individuals since we need their help. good appearance is one of the criteria for being accepted in society and being different in appearance might cause the fear of being judged or rejected by other human beings or, from Darwin's point of view, it might results to get eliminated from nature.

In order to be accepted by other human being and be a part of human society the individuals at first tried to hide their lesion to be like other members of society since they could not do this satisfactorily they got a series of complications as we mentioned above, and then they would start to hide themselves from others

Eventually this situation leads to dysfunction in various aspects of career and academic life and this cause a vicious cycle in individual's life.

Most of the participants avoided to go out especially in places and situations that needs a good appearance like parties, family gatherings, or a job interview.

I haven't gone to the holly shrine for a long time, since 3 years ago a woman saw me there and felt pity for me!(p2) #male.

"I don't like family gatherings also I don't enjoy going to some one's house or having guest I prefer to be with my friends"(P2) #male.

"At first I was depressed I did not go anywhere or talk to anybody I stuck in a corner" (p6) #female.

"I didn't talk too much with others and I tried not to have contact with others because of my condition I thought everyone was looking at me in a bad way"(P6) #female.

"I couldn't do my job, I was very bored and I couldn't enjoy doing anything at all, I barely went out..."(P6) #female.

"the life had become so hard I have no confidence in the way I've had before and I'm not going to any party or family ceremonies and I don't go out like before"(P7)#male.

As we mentioned above the disease had functional disturbance in many participant's life, one of the younger patients abandoned his school after the beginning of the disease and he mentioned that it was stressful for him; I left school because it was stressful for me"(P7) #male. The low attitudes of the community toward these people and the disease also worsen the condition and thus exacerbated patient's avoidance: "I went to the hairdresser, and she told my mom that her hair loss is contagious and it was very embarrassing for me"(P1) female.

"At a time I was bald as a result of hair loss people almost thought that I have cancer or contagious disease they didn't come near me or use my belongings like scarf"(P6) #female.

## Discussion

Consistent to our study Davey et al. in England ,found that negative cultural meaning of hair loss may leads to social avoidance in people with alopecia areata and both studies suggested normalizing interaction with healthcare practitioner, also in 2018 study support groups and online forums was found to be effective.

In another qualitative study by Rafique and Hunt in 2015 which was investigated the coping behavior of patients with AA in Pakistan that was performed on 8 individuals, they found that female experiencing greater feelings of loss and were more concerned about future and their looks and male patients blamed their fate and luck and they recommended that health care practitioners must consider the negative dimension of AA in people's life and provide psychological and social supports. In contrast with the study performed in Pakistan we have not found any significant gender difference in individual's feeling and experience of the disease.

A qualitative study in Austria indicated that in general people with AA don't have dysfunctional coping strategies but for the better management general and specific coping competences must be trained by psychologist and negative emotions should be regulated specially at the first onset of alopecia.

As we recommended in this study a study by Cartwright et al. in London proposed that practitioner must consider the negative psychological impact of AA in their treatment programs.

Also In line with our study, welsh et al demonstrated that the patients at first did not accept their condition as a permanent one and they manage the condition by concealment and over time they found more coping strategies and were becoming more optimistic about their condition.

In this phenomenological study, we show a clear picture of the patient's struggles to cope with the disease In order to counter the physical and mental side effects of the disease .first of all patients were trying to justify the disease and find an external factor for it then they were struggling for the inhibition of the disease and after they failed to control the disease they started to hide it from others and this might lead to a series of mental problems, at last all this process causes social avoidance and functional disturbances in familial and academic life Which ultimately leads to a constant struggle in one's life so We called it a " hidden struggle" as our central core.

## Conclusion

This disease is not only a biologic disease and has many psychological aspects. We need more understanding of the patient and not just the disease and also we have to consider psychosocial aspects of the disease in order to a better management of the disease.

This study recommends cooperation between dermatologist and psychiatrists or psychologist and increasing community awareness especially at schools and special communities like hairdressers'.

Since limited studies had been done so far, further studies should be done in this field.

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