



# The Open Public Health Journal

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## RESEARCH ARTICLE

### The Lived Experience of Women with Alopecia: A Qualitative Study Investigating the Psychological, Social and Emotional Impact of Alopecia in a Sample of Greek Women

Paraskevi Katara<sup>1</sup>, Dimitris D. Vlastos<sup>1,2</sup> and Paraskevi Theofilou<sup>2,3,\*</sup>

<sup>1</sup>Department of Psychology, SCG - Scientific College of Greece, Athens, Greece

<sup>2</sup>SCG Lab of Experimental and Applied Psychology, SCG – Scientific College of Greece, Athens, Greece

<sup>3</sup>School of Social Sciences, Hellenic Open University, Patra, Greece

#### Abstract:

#### Background:

Alopecia is the most frequent cause of hair loss, burdening the patient's psychology through the aesthetic appearance and quality of life.

#### Aims:

The present research attempted to investigate the changes in the socio-emotional world of women with alopecia and their adaptation to all aspects of everyday life.

#### Methods:

A thematic qualitative analysis (with semi-structured interviews) was performed on 10 women with alopecia without any other underlying disease. The aim of the study is to record the experiential experience of each participant in order to enrich the literature on the quality of life of women with alopecia.

#### Results:

The overarching themes that emerged are four and include women's functioning and adaptability, environmental attitudes and expectations, women's attitudes towards treatment and, finally, the impact of the disease.

#### Conclusion:

In conclusion, although alopecia is not life-threatening, it seems to modify, at least initially, the way in which women re-adapt to their daily lives, to how they perceive social and partner relationships and themselves in terms of part of the work.

**Keywords:** Lived Experience, Alopecia, Women, Qualitative Study, Psychological, Social, Emotional, Quality of Life.

#### Article History

Received: June 16, 2023

Revised: August 22, 2023

Accepted: August 30, 2023

## 1. INTRODUCTION

Alopecia areata is a chronic inflammatory condition that affects the scalp with sudden localized or generalized hair loss. The loss usually begins in the form of a well-circumscribed area, the diameter of which ranges from small or medium to quite large. In some cases, it can develop into diffuse alopecia. It is an autoimmune mechanism transmitted by T-lymphocytes and occurs in genetically predisposed individuals or is expressed

in them due to environmental factors [1, 2]. As mentioned, Alopecia areata is considered an autoimmune disease, which may be due to a genetic predisposition. In addition, there are factors that may trigger the onset of the disease in genetically predisposed individuals, such as psychological trauma, severe mental fluctuations as well as medication or infections due to streptococcus [1]. However, more psychosocial problems are observed, compared to men, in women, as according to cultural standards, female attractiveness - femininity does not equate to hair loss.

Alopecia areata, as it appears in the literature, is the most

\* Address correspondence to this author at the School of Social Sciences, Hellenic Open University, Patra, Greece; E-mail: [pardrothe@gmail.com](mailto:pardrothe@gmail.com)

common cause of hair loss due to inflammation. Although there are no clear and targeted statistical data for Greece, research shows that in the USA, there are 4,500,000 people with alopecia [3], thus increasing the probability that someone will suffer from Alopecia Gyroids to approximately 1.7% [3, 4]. Alopecia affects people of all ages, regardless of hair color or gender, although adult males are more affected than females. The age of onset of the disease is not specific. However, more than half of patients (66%) manifest alopecia at an age younger than 30 years, with the first episode occurring at a younger age than 20 years, while in a smaller percentage of patients (22%) alopecia may appear after 40 years [5 - 7].

The first research on the quality of life of people with alopecia begin to be published in 2000 onwards. Comparing the number of published studies, around alopecia areata, there is a relative lack of attention to the effect of the disease on female grief. The psychological and social problems of women due to alopecia areata have been informally described and few studies in the international literature refer to its effect on their quality of life [8]. In a quantitative study, thirty-two women suffering from alopecia were evaluated by a psychiatrist. 20% had chronic family and sexual problems and two were markedly depressed [9]. In the comparison (using psychometric instruments), women with alopecia and those without, as well as men with male alopecia, increased low self-esteem and social inadequacy scores compared to women with non-visible dermatological problems. In addition, women with alopecia were found to have higher scores on disability, stiffness, injury, and overall psychological maladjustment, with lower self-rated scores compared to men with androgenetic alopecia. Shi *et al.* [10], using special tools to determine the quality of life of 532 women with alopecia concluded that a percentage greater than 50% had a significantly low quality of life, which ranged from anxiety to the change in appearance due to the loss of hair (whether total or partial) could lead to a deterioration of their social and professional presence. While at the same time, it became clear that the female gender as well as an age range between 20-50 years are risk factors for an even lower quality of life, although the image presented to them by the treating doctors is comparatively positive (as it is not a fatal disease). In conclusion, women suffering from alopecia tend to suffer more psychological problems due to their hair loss compared to other people [11].

According to Renez *et al.* [12], it emerged from 2530 patients with alopecia that on an emotional and social level, they had a very low quality of life, while in this research it also emerged the positive effect of wearing a wig. Consistent with the findings of the above research is the study by Montgomery *et al* [13], who wanted to evaluate the quality of life of people with alopecia who use wigs during social events. It was found that social anxiety, anxiety (in general) and depression showed remarkably high rates. However, wearing a wig socially increased their self-confidence, with 46% reporting a positive effect of this choice on everyday life in general.

In summary, it is understood that although we are not talking about a life-threatening disease, its impact on the social and personal life of patients, especially women, and the drastic effect it has on their self-image, self-confidence and

psychological composition, affects in significantly their emotional and mental health as well as their social adjustment. Since the progression of the disease cannot be predicted with a high rate of success and coupled with the fact that several treatments, especially if the disease has spread or worsened, are not effective, it is important to consider the possible psychological and social effects with in order to enable patients to obtain a better standard of living.

From the above, it becomes clear that the rationale of the present research could contribute to the evaluation and emergence of possible correlations of the quality of the socio-emotional life of women with alopecia areata. Through the present research, the interpretation and understanding of the emotional world of the participants in depth and how they experience and perceive their own reality will allow the acquisition of a more refined knowledge regarding the Greek population.

The purpose of the research is to investigate and interpret the personal experiences of women with alopecia. More specifically, based on the above literature, the following research questions arise:

1. How do women experience and perceive their functionality and adaptability in relation to the disease?
2. How do they experience the effect of their current situation based on the subjective (feelings of mental health) and the objective criteria (abilities and possibilities of the individual's access to opportunities and resources) resulting from the external conditions?

## 2. METHOD

### 2.1. Participants and Sample

In the qualitative methodology, there is no specific number that concerns the participants. The research itself and its demands are what define him. In contrast to a quantitative methodology, where the generalizability of the results plays an important role and therefore, a large sample number is necessary, in the qualitative one, the researcher aims to highlight the subjective characteristics of the participants' experience [14, 15].

In this research study, the sample was chosen intentionally (purposive sampling) based on the subjective knowledge of the researcher who has consulted the literature on the characteristics of people with alopecia, wanting to give more thorough and in-depth answers to the research proposal. In the present research study, the sample consists of 10 women with alopecia, aged from 20 to 55 years, with obvious problems of chronic alopecia without burdened medical history. These women live both in large urban centers and in provincial towns and islands where they either work or study. The sample cannot be considered representative as there was no intention to generalize the results but an attempt to understand in depth the experiences of the participants [15].

### 2.2. Data Collection Method

The interviews were organized based on the semi-structured interview format and consisted of 15 questions in

total. The semi-structured interview offers flexibility, as although there is a framework of basic questions in line with the research questions, there is the possibility of additional clarifying and probing questions that are tailored to each participant so that they have the opportunity to share their experience as uniquely as they lived it and the perceived [16]. Therefore, although the basic framework of the questions was common to all participants, the supplementary questions were adapted to the experiences and descriptions of each case. The interviews were conducted online *via* Skype and Viber after the researcher (Ms Paraskevi Katara, with experience in conducting interviews) obtained signed information and consent forms, again clarifying the research topic and confidentiality issues. The interviews were recorded directly on a tape recorder and then transcribed in written form for analysis.

### 2.3. Research Process

The final research proposal received approval with protocol number TER2023194 from the Ethics Committee of the SCG College. Helsinki Declaration has been followed for involving human subjects in the study. After the researcher searched the internet for groups of women with alopecia she sent a message - inviting the women to the present research process. The women who responded were informed about the nature of the work, its topic and the fact that their participation would be voluntary. They then completed the ethics forms as sent to them by the researcher, and interviews were scheduled online after she received the signed forms. The women chose a pseudonym that was used during the interviews instead of their real name in order to protect their privacy. Each interview lasted on average 50' and after recording, it was transcribed in the form of a written text.

### 2.4. Data Analysis

When designing a survey, an important question that arises is whether to choose a quantitative or qualitative methodology for data analysis. These two methods approach the subject under study differently and, by extension, the research questions are the ones that provide the solution to this concern [17]. In this particular research, qualitative methodology was used as the question is the experience of women with alopecia and therefore, it was useful to study how the world is conceived and interpreted by the participants themselves [18].

For the safe interpretation of the data, a qualitative and specifically thematic analysis was carried out with the aim of identifying, analyzing and reporting patterns (themes) within the data. This process allows the creation of a dialogic relationship between the researcher and data. This method is widely used in qualitative research and is considered particularly important for the new researcher, as it provides basic skills that are also useful for conducting more specialized approaches to qualitative analysis [19]. Also, "thematic analysis concerns the systematic identification, organization and understanding of repeated patterns of meaning in a set of data" [20], while at the same time, the research questions help to guide the specific process. The thematic analysis enables a relative "freedom" as it is not necessary for the researcher to focus on ontological searches, as is the case in other qualitative

analyses, however there is a scientific basis here as well [20]. In this way, the researcher manages to produce, organize and interpret the repeated meanings, of the whole of the data [21].

More specifically, the data analysis will result from the semi-structured interviews with the participants. The empirical data is recorded and after the end of the process, is recorded and transcribed in the form of a written text by the researcher [22]. Then, the key elements that answer the research questions are coded in the form of short phrases, words or theoretical concepts. Then, the researcher groups, compares and merges the coding with similar content, formulating autonomous conceptual entities, that constitute the themes according to his subjective judgment [21]. This particular analytical process is called coding and helps the researcher identify patterns of meaning in their data [20].

In summary, the above process allows the researcher to conduct the thematic data analysis, providing answers to the research questions collected from the participants.

In the context of the specific educational process, the sample consists of 10 sick women and is considered sufficient for the preparation of the specific research, which aims at the quality, appropriateness and adequacy of the information. The participation criteria were the gender of the participants (women), their age (20 - 55 years) and the fact that they suffer from alopecia.

## 3. RESULTS

From the analysis of the interviews, four main thematic axes emerged that answer the research questions formulated above: the functionality and adaptability of women with alopecia, the attitude that their environment maintains towards them and the expectations it allegedly has, the attitude of women towards existing treatments for alopecia and the effect the disease has on various aspects of their lives as the participants themselves would describe it. The themes mentioned as well as their sub-themes, emerged during the analysis and are detailed below.

### 3.1. Functionality and Adaptability

The first thematic axis was formed by the first research question that was formulated, it refers to how women with alopecia experience and adjust the visible signs of the disease in their social life. Three subthemes emerged: adaptability to social life, wearing a wig, and feeling from wearing a wig.

#### 3.1.1. In Social Life

As found in the literature, Shi *et al.* [10], through specific tools to determine the quality of life, concluded that a percentage higher than 50% of the women with alopecia who participated had a significantly low quality of life, which resulted from the anxiety that the loss of hair could lead to a degradation of their social presence. Something related also emerges from the present study. The vast majority of women reported difficulties in readjusting to their social life after the onset of the disease, which were very intense, especially during the first period. Indicatively it was mentioned:

"I was locked inside (...) at first I said... I don't want to see anyone"

“Initially it affected me yes, the first time. Because I didn't want to go out, I didn't feel comfortable...”

“Poor thing...she is very ugly. It's very tiring because I look strong, but seven times out of ten I'm not as strong as I look. In other words, I have told everyone that I will never accept this...”

In addition, in some cases, the social environment played an important role in the gradual restoration of women's social life as the change in appearance due to hair loss was an isolating factor.

“That is, my girlfriends were the reason that motivated me to go out to sea, without my hair... in general, my girlfriends have played a very important role in my social life.”

### 3.1.2. *Using a Wig*

Another issue that arose is whether women with alopecia choose to wear wigs in their daily lives or not. Unlike the male appearance, where the feature of partial or complete hair loss is not the subject of discussion and gazes, long hair on a woman is socially a sign of femininity and self-confidence. Research results emphasize the positive effect of wearing a wig on restoring the social life of women with alopecia [12, 13]. Most of the participants mentioned the use of a wig or even a headscarf almost right from the start: “okay, I've also been wearing wigs (...) But the whole point is to accept yourself and your problem and move on” and “one with handkerchiefs... one with a wig, one without”. In some cases, this choice emerged gradually as the new reality became more acceptable: “I'm late to put on a wig.”, while only one participant referred to the fact that the wig, although it has been purchased, is neither part of her daily life nor does she feel the need to include it in it. As he characteristically stated: “As a rule, I don't wear it”.

### 3.1.3. *Feeling of Wearing a Wig*

As wig use is almost universal among the women interviewed, it was important to also explore how they feel about this new addition to their lives. In some cases (almost half of the participants) they seem to resent wearing the wig, as either the feeling is strange or even tiring, specifically: “I didn't like it. And now you ask me I don't like it. I don't like the feeling in my head. (...), and “the wig tires me, I don't want it”, or the wig is quite restrictive in movements, as was typically mentioned: “with the wig and I don't feel that freedom, that's the freedom I miss.”.

However, the rest of the women seem to agree with the findings of the study by Montgomery *et al* [13], who wanted to assess the quality of life of people with alopecia who wear wigs during social events. Rates of anxiety as well as unpleasant feelings arising from insecurity during social events due to hair loss were reduced by wearing a wig as they increased their self-confidence. They typically refer to the fact that the wig completes their professional appearance or they don't feel as exposed without it, and furthermore that it is a move that makes them feel good, for example: “I don't feel comfortable without it” “I feel... naked”.

“I don't like the scarf with work clothes... I'll have to say something to him. Whereas now I don't do that.” and “I don't attract attention”.

“I will give my money to buy wigs to feel beautiful”.

## 3.2. *Environmental Attitude and Expectations*

The present thematic axis arose in order to examine the attitude of the close family circle of women with alopecia as well as their partner, as well as their social environment, since the fact that they themselves are experiencing an unprecedented situation may also affect the treatment of those around them. Below, the close environment and the social environment will be analyzed separately, as well as the reaction that women with alopecia expect to receive.

### 3.2.1. *Family and Partner*

As is known from the existing literature, although alopecia is not included in the malignant diseases, the fact that it is not possible to precisely determine the cause of its occurrence, combined with the limited (or even no) effectiveness of the known treatments, causes significant effects both in the emotional world of individuals and in their psychosynthesis [23]. In this case, the family and partner's coping with the new reality plays an important role in the women's own experience. In some cases, the family and partner were particularly supportive by maintaining a neutral attitude that did not burden the participants emotionally, for example:

“From the beginning, my people were... well, how can I tell you, as if they didn't care and they passed this on to me too” and “with the husband let's say... Not even, he didn't even care, I had it I didn't have it”.

“My family, because they lived through it with my sister, who didn't go out anywhere, they also make the effort. He is next to me”.

“My mother may be in some distress. My kids not at all... maybe because I don't have too much anxiety and I haven't communicated it to them.”.

In addition, in one case, the participant seems to recognize how the new reality she was called to live has affected her parents emotionally, however they never allowed anything to be seen that would burden her emotionally: she characteristically states: “they felt what I felt I... in them they would certainly be sad”.

Of course, there were also cases among the participants where the behavior of the close family circle changed and “adapted” to the alopecia, something that was noticeable: “I think they were sad (...) they shouldn't spoil me for the sake of my hair falling out again”.

In one case, the family's refusal to accept the new situation and support the participant caused even more intense irritation and unpleasant feelings: “I was more annoyed that they basically couldn't accept it, that is, my mother couldn't accept it more this saddened me more”.

### 3.2.2. *Social Environment*

An additional basis that emerged for the investigation of the experience of women with alopecia was the treatment of the outside world in this change. Several referred to looks that sometimes concealed the intent to comment, while others

perceived them as more sympathetic. For example: “when I first put on a wig (...) they looked to gossip.”, as well as “I often feel looks (...) they want to help”.

Although the majority of women reacted positively to the resulting comments and stares, stating during the interviews how: “I think they treat me (the world) as I treat myself” and “Little girl, when they were looking at me, I went and told them what are you looking at me for?” (...) or I smiled at them when they looked at me”, some shared unpleasant experiences, as they received a feeling of pity towards their face: “that they feel sorry for me” and “there is too often the look of regret.”.

In one case the participant was confronted with a very aggressive comment that hurt her deeply and as she said: “I will remember it forever”. The comment is quoted in the following quote: “what did you go and shave your hair like that dude, you look like a Mongolian?”. This phrase will never leave my head because it was the first time I cried when someone insulted me so badly”.

### 3.2.3. *Expected Reaction from the Social Environment and Partner*

The fact that alopecia is a disease that, especially in Greece, is not particularly widespread and therefore, there is insufficient information as to what is happening. Comparing the number of published studies, around alopecia areata, there is a relative lack of attention to the effect of the disease on women's grief [8] therefore, it is the sufferers themselves who can guide those around them as to what attitude to take. must comply with them. Therefore, what they are looking for from their social environment is a bit more targeted information and, for the most part, discretion:

“Let them spend it a little more indifferently”.

“There should be more information, if there is information they will not look anyway”.

“To be a little more discreet... so that the other person does not feel that you feel sorry for him”.

Moving on to the part of the partner, the women who were in a relationship referred to the need they felt to be treated in the same way by their partner as before the appearance of alopecia, it was typically mentioned: “to do what he did before, not to change at all”.

“By not caring if our image has changed... also having the same behavior as before... which I think is very difficult for someone to do that.”.

While in the cases where the women who participated in the interview were free, they wished to feel supported and above all alopecia was not a deterrent for a potential partner, showing how the essence of creating a healthy relationship lies in other things and not in the appearance of the hair.

“I would like it not to be so intense... the look, that I am different... but the negative look that because you don't have hair, I am tearing down all the rest”.

“To have the man who will embrace her, the man who will listen to her, who will not care”.

### 3.3. *Attitude towards Treatment*

The specific thematic axis arose from the fact that known existing treatments, such as those mentioned in the literature review (cortisone injection, minoxidil, irritants and surgery) have limited or no efficacy, which is usually proportional to the predisposition and stage involved. alopecia is found [24 - 26]. Furthermore, we studied whether the women were on continuous treatment from the initial onset of alopecia, whether they were eventually distanced from treatment as and how they would react to the prospect of a stabilized treatment.

#### 3.3.1. *Continuous Treatment*

Despite the fact that, as mentioned, the effects of the treatments are limited, a small percentage of the women who participated in the study entered and remained in treatment from the onset of alopecia, maintaining a feeling of optimism about its outcome. Specifically:

“I never lost it, I always waited for a drug to come out and believed that my hair would grow back.”.

Also, one participant, whose initial choice after a period of continuous treatment with constant disappointments as the effect was only temporary, referred to her parents' persistent motivation and constant need to continue treatment. As she said: “basically what they don't accept is that I give up. I tell them that if it is to come out, it will come out by itself... I tell them that we will discuss it again and that's it. They stop after that but inside... they don't like that I'm not working to solve it. That is, whatever is good will be for my own good.”.

#### 3.3.2. *Distancing*

The fact that a specific and permanent treatment for alopecia is not yet known, combined with the fact that the participants have been dealing with the present condition for several years, has been a factor in their distancing from existing treatments. The trial of cortisone, vitamins, alternative treatments and even substances that cause a burn to the head although they have been tried, gradually over the years the need to stay committed to the treatment process and accept the new condition has decreased. Thus, although they had chosen the treatment, they now seem unwilling to continue. Features mention:

“No, I stopped... just fine”.

“In the first decade I was constantly treated (...) now not even vitamins”,

“I did and stopped”.

#### 3.3.3. *Willingness for Stabilized Treatment*

In the course of the interview, it also emerged how they would react if a treatment appeared that promised how it would stabilize and therefore perhaps get rid of alopecia. Some were particularly positive about such a prospect, for example:

“I would enter yes... without a second thought”.

Although a larger percentage, they would start the treatment after it was first confirmed that there would be no side effects and that the results would be positive:

“I would enter yes if I first saw, did a research and saw that there is a result”.

“if there are no unwanted side effects, of course I would”.

However, there were participants who, because of the suffering they have suffered from the ongoing treatment and the consequences it has had on their body and soul, would hardly choose to start over even if they eventually faced alopecia, thus showing how potentially they have accepted the situation. As mentioned by them:

“Now in the phase I'm in no... for now that is”.

“Difficult, it's soul-destroying”.

### 3.4. Effect of the Disease

The fourth and last thematic axis emerged in order to study the second research question that deals with how they experience the effect of their current situation based on subjective (feelings of mental health) and objective criteria (skills and possibilities of the individual's access to opportunities and resources) arising from external conditions. Below, four levels of impact of the disease will be analyzed: psyche, work, social and partner life.

#### 3.4.1. In the Psyche

Although alopecia, according to research is a psychosomatic disease and is treated as autoimmune, the psychological factors of its occurrence are still under study. Alopecia is a psychosomatic disease as stressful factors predate the exacerbation of the disease, which eventually manifests itself physically. However, the onset of alopecia is not necessarily due to a single or even permanent factor. In some cases, a brief incident of severe stress or a more severe shock is enough to disrupt normal immune function [27]. Just as one participant mentions, the alopecia started after the end of a particularly toxic and stressful relationship:

“Because basically, I had a flare-up of alopecia when I was in a very toxic relationship. That is, through this relationship, there was a lot of stress...sadness”.

Something fairly common that was reported by almost all participants is that they became isolated – at least initially – and wondered if their lives would ever become 'normal' again.

“That summer may be I shut down”.

“At first I didn't feel well (...) I will live like a normal person”.

In the literature review it was mentioned that in several cases, the patients may also suffer from depression or Generalized Anxiety Disorder [28, 29]. Although a body of relevant research suggests that stress may play a minimal role in the initiation and manifestation of the disease [30, 31], even if this is true, the resulting anxiety and depression from the chronicity of the disease significantly affect its outcome and quality of life [32]. This is exactly what is confirmed by some of the participants, as they mentioned their need for psychological support after experiencing a depressive episode due to the exacerbation of the disease. As listed:

“I have gone through a depressive episode”.

“I went to a psychiatrist. At first, he gave me treatment, in the end it wasn't necessary. I mean I haven't taken any medication to fight my anxiety or anything. Only psychotherapy.”.

#### 3.4.2. At Work

Alopecia as it emerged from the interviews, does not seem to affect the professional opportunities of the participants or their development in the work part. In some cases, however, it may initially have been a deterrent for them to claim a job themselves:

“Many times, for me I didn't take or didn't have the courage because I was thinking about how I would be there and what I would do with this matter that not to stand in the way, I have not been accepted”.

On the other hand, some participants were reassured by the fact that they had already been in the same job for years, so their professional life was not affected. Of course, in one case, the participant could only continue working in the same job as long as she wore a wig and therefore, the alopecia was not evident:

“I have thought that it could cause me a problem, but because I am in the same job, it has not caused me any problem at the moment.

“It was not acceptable to go to work without hair”.

#### 3.4.3. In Social Relations

The social part of the lives of women with alopecia, as emerged from the above thematic axis, was to some extent influenced by the women themselves due to the need for isolation that they initially felt. According to Rencz *et al.* [12], it emerged from 2530 patients with alopecia that, on an emotional and social level, they had a very low quality of life. However, in relation to their social environment, there was no change:

“Relationships have not been affected yes”.

There was certainly one case, in which even if she was with friends, the anxiety arising from the alopecia did not allow her to let go and relive social moments as before, describing feelings defined as fatigue. According to the participant:

“When I will not exist in the outside world. When I'm with my cycle I don't feel uncomfortable. When I have to move outside, for example, the wind will blow, don't move her, this anxiety... being a doll like that, a little... it's moments, that is, if we go out for five hours, I can withstand three... the last two I suffer. I want to go home...”.

#### 3.4.4. In Social Life

In terms of partner life, there was a stark contrast in how women who developed alopecia while already in a partner perceived it compared to those who were single. Thus, the former referred to the stability of their partner's behavior even if they themselves felt differently at first and to the fact that he was supportive:

“He was very good... nothing changed”.

“He is much more comfortable than me”.

“Not from my husband's side... from my side. I mean... at

first, I didn't feel like a woman enough...”.

On the contrary, women who were single or at a much younger age when alopecia manifested themselves shared feelings of anxiety, that because of the current situation they would not be able to find a partner easily or even at all:

“I mean, all the years I've had alopecia I can't make a connection. It works very negatively”.

“He has been 100% affected in the matter of personal life (...) I feel that he does not accept me as I am... eh, and it is something that unfortunately, will not change. If I don't leave the island, unfortunately, it won't change.”

while the fear that she may never build her own family was also described by one participant:

“That I will stay alone and not have a family. That I will never make my dreams come true in this part...”.

#### 4. DISCUSSION

The present study was conducted with the aim of studying the experience of women with alopecia as well as investigating their psycho-emotional world. The functionality and adaptability of women with alopecia seem to be affected at a social level at least during the initial onset of the disease, while the research is also consistent with the literature regarding wig use. Research results emphasize the positive effect of wearing a wig on restoring the social life of women with alopecia [12, 13]. The majority of women, also in the present research, felt positive about wearing a wig, as this way they felt more confident and did not receive comments as often.

In addition, in relation to the second research question regarding the effect of the disease, both on the psyche and on social, professional and partner life, the research seems to agree with the literature again. Although, as mentioned above, the psychological causes of the disease have not been extensively examined, however, stressful life events play an important role in triggering certain episodes of alopecia. For example, as found in a study of a group of women, those who experienced high levels of stress were 11 times more likely to experience hair loss [33]. Thus, in the present study, some of the women reported stressful situations or a generally stressful perception of life before the first appearance of alopecia. At the same time, the social life of women with alopecia is affected to some extent by the women themselves, due to their initial need for isolation. According to Rencz *et al* [12], it emerged from more than 2000 alopecia patients that they had a very low quality of life on an emotional and social level. However, in relation to their social environment, there was no change at least that resulted from the external factors.

As mentioned, hair is an essential element in shaping the identity of many women. Elements such as attractiveness, femininity and even sexuality are symbolically associated with healthy and long female hair, something that has no counterpart in the male sex [34]. Therefore, hair loss can seriously affect self-esteem and body image which was also seen in the present study, as part of the women looking for a partner showed anxiety about whether the situation they are facing will eventually stand in the way or become acceptable from each partner. Even women in stable relationships reported changes in self-image and thoughts about whether existing relationships would be affected. In a related study of cancer subjects with

and without alopecia, women who had experienced hair loss had poorer body image and self-esteem than women who had not lost their hair [35].

At the same time, it was observed that there is not a large bibliographic scope that refers to the effectiveness of the psychological reinforcement of people with alopecia in order to face the challenges of the situation they experience. A single study described the benefits of a support group in coping with the condition. This group consisted of people with alopecia, nurses and doctors, but the findings regarding the results are not clear [36].

#### CONCLUSION

In conclusion, the analysis of the interviews leads to the fact that women with alopecia experience their disease with relative dynamism, in the face of social imperatives, which want a woman to be considered feminine when she has long and healthy hair, while they deal with their emotional world wisely and based on how they will manage the treatments offered. Although alopecia has not been found to stand in the way of women's professional lives, the issue of appearance seems to be a common fear among single women when they are about to mingle with a potential partner.

#### LIMITATIONS AND SUGGESTIONS FOR FUTURE RESEARCH

First, it is worth noting that an important limitation is the fact that the participants were only women. Based on the literature review, there are gender differences in the type of alopecia, but also how men are treated socially in terms of their perception of their self-image and emotionality [5, 6]. Therefore, the limitation itself could be a trigger for future research in order to study the experience of men with alopecia and other forms of alopecia, even if men ultimately experience the same limitations on a social and romantic level.

#### ETHICS APPROVAL AND CONSENT TO PARTICIPATE

The final research proposal received approval with protocol number TER2023194 from the Ethics Committee of the SCG College.

#### HUMAN AND ANIMAL RIGHTS

No animals were used in this research. All procedures performed in studies involving human participants were in accordance with the ethical standards of institutional and/or research committees and with the 1975 Declaration of Helsinki, as revised in 2013.

#### CONSENT FOR PUBLICATION

Informed consent was obtained from all participants.

#### STANDARDS OF REPORTING

COREQ guidelines were followed.

#### AVAILABILITY OF DATA AND MATERIALS

The data and supportive information are available within the article.

**FUNDING**

None.

**CONFLICT OF INTEREST**

Dr. Paraskevi Theofilou is on the Editorial Advisory Board of The Open Public Health Journal.

The authors declare no conflict of interest, financial or otherwise.

**ACKNOWLEDGEMENTS**

Declared none.

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