

# Knowledge, beliefs and perceptions among alopecia areata patients: A cross-sectional study in Faisalabad

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## Abstract

**Introduction** Alopecia areata (AA) is described as a pathological condition with undesirable, non-predictable hair loss. Being a multifactorial disease, many environmental, immunological, psychological and genetic risk factors attribute the onset and progression of AA.

**Objective** Present study was undertaken to assess awareness, social impact, degree of stigma and management approaches among local AA patients.

**Methods** The study was cross-sectional & conducted in Dermatology Department of Government General Hospital, Ghulam Muhammad Abad, Faisalabad. The duration of study was six months i.e. from February 2019 to July 2019 recruiting 50 patients. A questionnaire was designed and distributed among participants recruited through convenient sampling method to collect baseline information such as age, gender, age at onset, duration of AA, marital status, education along with knowledge, perceptions and behavior based-queries.

**Results** With average age of  $27.5 \pm 2.92$  years, 74% participants were male. About 90% participants were married and only 3% were graduates. Majority (62%) had no knowledge about causes of AA. When asked about causative factors, almost 42% of the participants believed that germs and viruses may cause AA. Although family life of 56% respondents was unaffected by disease, yet social life of 66% patients suffered from AA. Depression was experienced by 48% subjects. Availability of economical treatment options was in the knowledge of 50-70% respondents.

**Conclusion** It is concluded that low literacy rate and lack of knowledge about AA can lead to improper treatment options and stress.

## Key words

Alopecia areata, multifactorial, perceptions, stigma.

## Introduction

Alopecia areata (AA) is described as a pathological condition with undesirable, non-predictable hair loss. It can affect any part of body where hair can grow. It has an autoimmune

pathology that intervenes through T lymphocytes that affect hair follicles.<sup>1</sup> Although, only 2% prevalence of AA has been estimated in Europe and United States, it is far less in Pakistan. There are no known ethnic, gender or occupational risk factors.<sup>2</sup>

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Being a multifactorial disease, many environmental, immunological, psychological and genetic risk factors attribute the onset and progression of AA. Moreover, it can be

associated with other diseases. With inconsistent and random progression in each patient, spectrum of clinical manifestation may be patchy hair loss from head, different body parts or complete hair loss from whole body. It can occur in any age but age range of 20-30 years is hypothesized in most of the studies.<sup>3</sup>

Although significant developments have been achieved in understanding pathophysiology, management and treatment strategies, perception of AA, lack of knowledge and behavior of patient are major barriers in successful treatment. One of the major influencer is stress or psychic morbidity that arises due to numerous socio-economic factors. Hair on head and scalp affects one's personality and social interaction.<sup>4</sup> Being a disease of the young, AA can cause significant emotional stress. Coping with hair loss depends on knowledge and perceptions regarding AA and it leads to better adjustment. Whereas, ignorance and irrational behavior enhance the negative impact of AA.<sup>5</sup>

Limited data is available on knowledge, perception and behavior of AA patients in Faisalabad region. Present study was undertaken to assess the clinical features, awareness, social impact, degree of stigma and management approaches among local AA patients.

## **Methods**

**Study Design** Cross-sectional study.

**Setting** Government General Hospital, Ghulam Muhammad Abad, Faisalabad.

**Duration** February, 2019 to September, 2019.

**Sample Size** 50

**Sampling Technique** Convenient sampling techniques was used and consented participants

from dermatology outdoor of Government General Hospital, Ghulam Muhammad Abad, Faisalabad were included.

Diagnosis of alopecia areata was based on previously defined criteria.<sup>6</sup> Demographic parameters such as age, gender, age at onset of AA, duration of AA, marital status and education were recorded. All participants were given a questionnaire to assess their knowledge and perceptions about disease. Patient's conduct during AA was also assessed through same questionnaire.

Before the induction of questionnaire, aims of study were explained to each subject. At the end of data collection, each patient was guided about the influence of studied parameters on health outcomes. AA related medical terms and queries were described in Urdu. Design of questionnaire was understandable to the participants and purpose was to record relevant study data. Prior to induction, proforma queries were tested on convenient sample of 15 patients. Based upon replies, it was further modified and finalized. Along with demographic parameters, responses of 17 queries on causes, severity, associations of AA, effect on family/social life, emotional behavior, stigma, financial consequences, treatment, family/ social support in coping with AA were recorded for each subject.

## **Data Analysis**

Data in continuous variables was expressed as mean±standard deviation (SD). Frequencies were used to document categorical variables. Data analysis was done by Statistical Package for Social Science (version 17; Chicago, USA). Differences in proportions were assessed using the chi-squared test, and P<0.05 was considered to be significant.

**Results**

Results are summarized in **Table 1**. Average age of subjects was 27.5±2.92 years (minimum: 6 months-58 years maximum). About 74% participants were male and mean age at onset of AA was 21. About 90% participants were married and only 6% were graduates.

**Table 1** Baseline characteristics and distribution of sample based on queries

<i>Parameters</i>	<i>Number (n)</i>
Total participants	50
Mean age (years)	27.5 ± 2.92
Range (min.-max.)	0.5-58
Gender (male/female)	37/13
Age at onset (years)	21
Duration of AA (years)	8
<i>Marital status</i>	
Married	45
Unmarried	5
<i>Education</i>	
Graduate	3
Undergraduate	25
Uneducated	22
<i>Cause of AA</i>	
A health problem	15
Cosmetic problem	3
Both	1
Unknown	31
<i>Is AA a serious health problem?</i>	
Yes	14
No	29
Unknown	7
<i>Is AA related to diet?</i>	
Yes	9
No	39
Unknown	2
<i>What are causes of AA?</i>	
Stress	6
Life style	2
Chance or fate	19
Diet	1
Pollution	1
Germs or virus	21
Genetic	0
<i>Did AA affect your family life?</i>	
Yes	18
No	28
Unknown	4
<i>Did AA affect your social life?</i>	
Yes	33
No	7

Unknown	10
<i>Has AA affected the way people see you?</i>	
Yes	4
No	9
Unknown	
<i>Is it easier to live with AA?</i>	
Yes	18
No	25
Unknown	7
<i>Which emotional behavior is associated with AA?</i>	
Anxiety	8
Depressiveness	26
Aggression	16
<i>Perceived stigma</i>	
Anticipation of rejection	24
Feeling of being flawed	5
Feeling of guilt and shame	8
Optimistic behavior	9
Hiding AA	4
<i>Does AA have serious financial consequences for you?</i>	
Yes	23
No	26
Unknown	1
<i>Is any treatment available for AA?</i>	
Yes	35
No	2
Unknown	13
<i>Will treatment be effective in curing AA?</i>	
Yes	37
No	3
Unknown	10
<i>Are home remedies more effective than physician's prescriptions?</i>	
Yes	7
No	36
Unknown	7
<i>Will AA be cured with time?</i>	
Yes	31
No	2
Unknown	17
<i>Do you receive family support as coping strategy?</i>	
Yes	45
No	5
<i>Do you receive social support as coping strategy?</i>	
Yes	41
No	9

Data is presented as n (number).

Majority (62%) had no knowledge about what causes AA ( $P < 0.05$ ). Although 30% considered it a serious health issue. Significantly ( $P < 0.05$ ) higher number of patients (78%) had the perception that AA has no association with diet. Similarly, when asked about causative factors, almost half (42%) of the participants believed that germs and viruses cause AA. Whereas, 38% declared occurrence of AA as fate or chance, eliminating diet, pollution, life style and family history being the risk factors for AA. While family life of majority (56%) was unaffected by disease, yet 66% patients ( $P < 0.05$ ) stated that their social life suffered from AA. Majority of respondents (74%) did not like the way people observed them and behaved with them. Half of the patients said that living with AA is not easy.

Majority (48%) of the study sample experienced depression and expected disgrace. According to 70% participants ( $P < 0.05$ ), treatment options are available and about 50% said that its cost can be easily managed. Most participants were optimistic about successful (74%,  $P < 0.05$ ) and timely (62%) cure of AA. Effectiveness of home remedies to treat AA was denied by 72% ( $P < 0.05$ ). Almost 80-90% patients ( $P < 0.05$ ) claimed to receive support from family and society during course of therapy.

## **Discussion**

Studies reflecting patient's awareness, opinion and conduct in progression and therapeutic control are generally well documented. However, gap exist in relevant data reports from local population of Faisalabad, Pakistan. Purpose of the study was to provide an insight on AA to minimize paucity of information. Although mortality is not associated with AA, the knowledge, perceptions and behavior of patients are deeply affected by experience of AA and vice versa.

AA affects all age groups.<sup>7</sup> Although it rarely affects above 60 years of age according to previous studies.<sup>8,9</sup> Age range of AA presentation was between six months to 58 years and mean age was  $27.5 \pm 2.92$  years. The mean onset age was 21.5 yrs which was in accordance with reported by earlier study.<sup>2</sup> Current study reported that AA is more prevalent among the males than females, in contrast to previous studies done by the Sharma and his Colleagues, indicating female predominance by 46% of girls comparable to only 19% of boys.<sup>10</sup> Another survey conducted in Singapore by Tan and his colleagues, also elucidated the female preponderance.<sup>11</sup> However, study conducted in Pakistan by Ejaz and his colleagues, indicated the equal sex distribution to be affected by AA.<sup>2</sup>

Marital status is also one of the considerable factor of AA. Our results are in accordance with recent study<sup>12</sup> that the impact of AA on quality of life was more profound within the married category comparable to unmarried. These results denoted that more responsibilities make them worry leading to psychological distress. In contrary, Masmoudi and his colleagues, reported unmarried to be greatly affected.<sup>5</sup> Education also have a great impact on incidence and manifestation of AA. The results from this survey confirmed the previous study conducted<sup>10</sup> indicated the high proportion of patients with low education level due to unawareness leading to personal and social problems.

Many studies underline, that experience of AA causes psychological disorders leading to personal and social problems.<sup>13,14</sup> AA causes marked disturbances in social life of patients forcing them to avoid social meetings, altering hair style and types of clothing as it is evident from one of study conducted by Christensen and his colleagues, that about 48% patient experienced embarrassment by their society.<sup>15</sup> The results from this survey are in line with the

results of authors reporting the quality of life to be seriously impaired by altering one's self-esteem.<sup>16,17</sup> According to this survey about 66% patients are affected by social behavior and about 74% patients are affected by the way people judge them, some have shown problems in their families and earnings as they couldn't make themselves confident enough to face social behavior that lead to financial consequences.

Different factors involve in aggravation of AA including genetic, viral, life style, diet and stress conditions. This survey elucidated that the major contributing factor of AA is infectious agents affecting almost half of the participants, confirming the earlier work done by Simakou and his colleagues,<sup>18</sup> which indicated *Helicobacter Pylori* and viral agent like swine flu being the leading cause of AA. About 38% of participants believed that AA to be caused by fate or chance with no contribution of genetic factors. In contrast however, study conducted by Juarez-Rendon and his colleagues,<sup>19</sup> elucidated that about 10-42% of the patient are observed with positive family history of AA. Health problems like autoimmune diseases and autopsy have association with the AA as by this survey 30% of AA patients are associated with other health problems.<sup>2</sup> Along with these, cosmetics like bleaching and straightening of hairs by hot wax combing also have little contribution towards AA as reported by Dawber.<sup>20</sup>

Stressful events have profound role in triggering of some episodes of AA as stress mediates the release of stress hormones which facilitate inflammation rather than leading to its direct cause as reported by earlier work.<sup>3</sup> As it is evident from this survey that 12% of participants experienced AA because of stressful events. This survey confirmed the previous study done by York and his colleagues,<sup>21</sup> that women who experienced high stress are 11 times more likely to suffer from hair loss as compared to who

don't report high stress. Other factors like life style and diet has little contribution being a risk factor of AA.

AA is merely seen as a skin disorder but also contribute to perceived stigma because of its association with high level of anxiety, depression and lower self-esteem, leading to habit of hiding hairs and loss of confidence as reported in this survey.<sup>22,23</sup> According to earlier studies women are more concerned about their physical appearance than males so have more negative impact as perceived stigma.<sup>24</sup> As they feel themselves as unattractive.<sup>25</sup>

Various therapeutic approaches including garlic as home remedy is used in India as reported by Hajheydari and his colleagues,<sup>26</sup> and medical treatments involving corticosteroids are carried out for treating AA illustrated by Wesserman and his colleagues.<sup>27</sup> However, this survey reported that home remedies are only 14% effective. AA is not a serious and life time disease, it recovered with the passage of time in most cases as according to this report 62% of patients are recovered with the passage of time.

Coping is implicated as an important factor influencing recovery from illness and mediating the rebuilding of self-esteem and self-confidence by family and social interaction. As this survey elucidated that about 80-90% of patients claimed to receive support from family and society during therapy. Taylor and coworkers,<sup>28</sup> reported that due to unpredictable course coping process will be difficult for the patients of AA without social support.

Hair loss has profound social implications. Social relationships and social support severely impact upon coping with changes in appearance, which may lead to identity change. This article can be a preliminary step towards a psychological understanding of the implications

of alopecia.

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