

## CLINICAL REPORT

# Psychosocial Stress and Coping in Alopecia Areata: A Questionnaire Survey and Qualitative Study Among 45 Patients

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**The controversial role of psychosocial stress in alopecia areata has been discussed widely, but there has been little research into patients' subjective stress experiences and coping. The aim of this study was to explore general and specific coping strategies in alopecia areata and to assess the role of psychosocial stress in the onset and course of alopecia areata from the patient's viewpoint. Forty-five patients conducted measurements of general coping strategies and body image. Qualitative data analysis was performed referring to interviews of stress experiences before the onset of alopecia areata, stress-reactivity, subjective disease models, consequences of alopecia areata and illness-related coping strategies. Patients do not have dysfunctional coping strategies in general, but they benefit from advantageous strategies in terms of better alopecia areata-specific coping and course of disease after 6 months. Psychological interventions in alopecia areata should focus on training general and alopecia areata-specific coping competences and regulating negative emotionality and insecurity, particularly at the first onset of alopecia areata. Key words: alopecia areata; psychosocial stress; coping; qualitative research; stress regulation.**

(Accepted September 20, 2010.)

Acta Derm Venereol 2011; 91: 318–327.

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The role of psychosocial stress in alopecia areata (AA) is controversial. Regarding the question of psychiatric comorbidity and personality traits in AA, some authors report a clear prevalence of psychiatric comorbidity, in particular anxiety and depression, among patients with AA (1–3). Others conclude that these traits are less important in AA (4, 5). The question as to whether stressful life events are able to trigger episodes of AA has led to lively discussion and inconsistent study results (1, 3, 4, 6–8). However, psychological research on AA has shown that the disease has a dramatic impact on patients' lives (9) and is often associated with adverse effects on psychological well-being and quality of life (4, 10). Interestingly, one study found a higher degree of perceived distress among patients with AA (8), which the authors

attribute to the impact of AA on daily life. According to another study (11) it can be assumed that even if life events and stress experiences play a minor role in the first onset of AA, the disease can lead to higher perceived distress and depression, which could, in turn, negatively affect the course of the disease via stress mediators and psychoneuroimmunological pathways.

Current research on AA concludes that substance P (SP) and nerve growth factor (NGF) are key mediators of stress-induced inhibition of hair growth in mice and appear to be involved in the pathogenesis of AA (12–14). Although it has not yet been proven that psychoemotional stress can trigger AA in humans, neuroendocrine research supports the concept that psychological stress may be able to influence the disease process in AA (15). In addition, patients with AA may have increased activity of the hypothalamic-pituitary-adrenal (HPA) axis, which is involved in stress response, causing an inability to adapt to stressors (14). Therefore, stress management may have an adjunctive benefit in the treatment of AA.

The role of coping in AA has not been studied in depth. It has been suggested that individual susceptibility to AA could be modulated through deficits in emotion regulation or in reduced ability to cope effectively with stress (3), but this has not yet been proven. It can be assumed that, similarly to other chronic diseases, emotional coping as well as social support play a major role in dealing with AA, because the course of AA is highly unpredictable, and problem-oriented coping strategies are therefore limited (16, 17). Advisory literature for patients on coping with AA has been published, concentrating on practical issues, psychosocial aspects, coping with stress and cognitive coping strategies (18, 19). However, evidence of specifically helpful coping strategies in AA is still missing.

The aims of the present study can be classified into three main areas: first, we explore general coping strategies and body image in patients with AA in order to reveal possible maladaptive strategies of stress management in AA. Secondly, we assess the role of psychosocial stress experiences in the onset and course of AA from the patient's point of view. Finally, we explore AA-specific coping strategies and determine whether certain coping strategies might be particularly helpful for different patient subgroups.

## MATERIALS AND METHODS

The study was approved by the ethics committee of the Medical University Graz. The inclusion criteria were: AA, full age ( $\geq 18$  years), and willingness to participate.

As difficulties were expected in obtaining the desired sample size of 60 patients within the given time-frame of 1.5 years, the study was publicized in various ways. The majority of patients ( $n=29$ ) was recruited from the Polyclinic for Hair Diseases at the Department of Dermatology, Medical University Graz. One additional subject was entered by local dermatologists who were informed about the study. Austria's self-help group for AA entered a further 15 volunteers. The survey period was May 2006 to July 2007 and the final follow-up interviews were held in January 2008.

### Study design

The study design combined qualitative and quantitative approaches. The independent variables were demographic parameters and AA-specific data (regrowth of hair; duration, status and severity of AA; and the course of disease after 6 months). Dependent variables were general coping strategies (measured with the stress and coping process questionnaire (UBV)), body concepts (measured with the Frankfurt body concept scales (FKKS)), five rating questions that were included in the interview, and a rating of subjective burden due to AA after 6 months. Qualitative data were collected in interviews and quantified in terms of frequencies of codings per category.

### Subjects

A total of 45 patients with AA participated in the study. The inclusion of a control group was waived, because the questionnaires used in the study were standardized and the interview was specifically aimed at patients with AA.

After being informed of the aims and procedures of the study, participants provided written informed consent. Demographic and illness-specific data were then collected, and half-standardized interviews were conducted. All interviews were carried out by the same interviewer, who had expert knowledge of psychology, AA and qualitative methodology. The interviews were recorded as MP3 files for further transliteration and evaluation. In addition, the rating scales were completed in the interview guideline. The mean duration of interviews was 44 min, ranging from 20 to 84 min. After completing the interview, participants answered the questionnaires, which took at least an additional 50 min.

The patient sample included 10 males and 35 females; mean age 38 years (range 22–77 years). All participants had reached secondary education level. The following levels of education were found within the sample: lower secondary education ( $n=2$ ; 4.4%), higher secondary education ( $n=18$ ; 40%), post-secondary education (equivalent to qualification for university entrance;  $n=14$ ; 31.3%) and higher education (equivalent to a university degree;  $n=11$ ; 24.4%). The duration of AA (time since first onset) ranged from 1.5 months to 40 years, with mean of 10.6 years. Three groups were defined concerning the status of disease: 19 patients were classified as having their *first episode* of AA, lasting a maximum of 2 years. Patients were classified as having a *chronic* state of AA if the present episode had lasted for more than 2 years ( $n=21$ ). *Relapse* meant a longer duration of AA, with the present episode lasting less than 2 years ( $n=5$ ). Due to the inhomogeneous group sizes, the groups *chronic* and *relapse* were combined for further comparison. The following degrees of severity of AA were found: AA monolocularis ( $n=12$ ), AA multilocularis ( $n=10$ ), confluent AA ( $n=4$ ), AA totalis ( $n=2$ ), AA universalis ( $n=16$ ) and AA barbae ( $n=1$ ). For statistical analysis two severity groups were compared: total and universal

AA ( $n=18$ ) vs. the lesser forms ( $n=27$ ). The course of the disease after 6 months was assessed via telephone interviews: 22 patients reported an improved course of the disease, 16 participants reported a steady state of AA severity, and five experienced a worsening of AA symptoms. Two participants could not be contacted for the telephone interview.

### Half-standardized interviews

Interview guidelines were designed for the study. First, demographic (gender, age, level of education) and illness-specific data (regrowth of hair, duration, status and severity of AA) were collected. Subsequently, six topics were covered, and then the sequence of topics was adapted to the course of conversation. In order to initiate new subjects, open and standardized questions were posed. If participants had difficulty comprehending a question, more detailed standard explanations were given. Patient-oriented communicative strategies (e.g. active listening, repeating phrases, giving a résumé, using open questions to close a topic) were used during the interview to encourage participants' reports. Five topics included an additional rating question, which was answered on a quantitative scale (0–10). The interview topics were:

- i. stress experiences up to 6 months before the onset of AA;
- ii. stress experiences at the time of the interview;
- iii. self-experienced stress-reactivity of AA (the extent to which patients believe stress to trigger or maintain episodes of AA);
- iv. subjective disease models;
- v. consequences of AA on patients' life; and
- vi. AA-related coping strategies.

The rating questions affected all topics except subjective disease models (*iv*) and included: rating of subjective stress experiences (*i*) before the onset of AA and (*ii*) at the time of the interview, (*iii*) stress reactivity of AA, (*v*) experienced subjective burden due to AA, and (*vi*) subjective competence in coping with AA.

### Stress and coping process questionnaire

UBV (20–22) aims at the multidimensional assessment of different components of coping with stressful episodes. On different scales (4–6 point scales) a person's situational appraisals, emotional reactions, coping objectives and coping behaviours (self-directed and environment-directed) are evaluated. In the short form with a duration of approximately 30–45 min four prototypical stressful situations are presented and evaluated in three stages (begin, continuation and positive or negative outcome). For example, subjects are instructed to imagine the following stressful situation:

*Begin: Previous relations with your boss have been quite complicated. Now your boss gives you a task on which you are supposed to work for the next 2 days. This job is very inconvenient for you because you have a lot of routine work to do at the moment. Continuation: Your boss tells you that your routine work also has to be done. As you begin work on the new task, it becomes evident how difficult and time-consuming it really is. It seems that you will only finish it if you ignore your other work, and even then you may have to do overtime on it. Negative outcome: You didn't carry out the job in the assigned time. Also, a lot of routine work remained unfinished.*

With this structure causal attribution styles of (un)successful coping also can be measured. At all stages, different components of coping are evaluated, e.g.:

- Emotional reactions, anxiety: *In this situation I feel ...* (6-point scale ranging from "very nervous/anxious" to "very calm/composed").

- Situational appraisals, belief in controllability: *The chances that I can influence this situation for the better are...* (6-point scale ranging from “very small” to “very large”).
- Coping goals, emotional equilibration: *In this situation my intention is to remain calm and composed...* (4-point scale ranging from “not important at all” to “very important”).
- Self-directed coping, re-evaluation: *I make clear to myself that this situation is not as straining/important as other problems...* (5-point scale ranging from “not at all” to “certainly”).
- Environmental-directed coping, passive behaviour: *I behave passively or wait for something to happen...* (5-point scale ranging from “not at all” to “certainly”).

There are norm tables for the German version for all scales except attribution styles. The scales of the UBV are listed in Table I.

#### Frankfurt body concept scales

The Frankfurt body concept scales (FKKS) (23) are self-rating instruments that assess different aspects of the body concept of a person. Two scales out of nine were chosen for this study, measuring self-acceptance of the body (6 items, e.g. *I am not bothered if my bodily appearance differs from others; I am content with my looks*) and the acceptance of one's body by others (4 items, e.g. *If somebody bashes my physical appearance, I feel worthless; I don't seem attractive to others*). The level of agreement with each statement is rated on a 6-point scale (ranging from “very much” to “not at all”), resulting in two sum-scores of body concept. Higher scores signify a better body concept. There are norms for both scales and additional predisposed intervals for a negative, neutral and positive body concept.

#### Follow-up telephone interview

Six months after the interview study participants were contacted by telephone. In a short interview subjects described their current disease status (regrowth of hair, severity and localization). The course of AA since the first interview was then classified into three stages: improved, no change, or worse. Additionally, participants rated their current burden due to AA on a quantitative scale (0–10).

#### Missing data

Interview data and the rating questions were received by all 45 participants. Three participants did not answer the two questionnaires, and one person answered only the body image scales. Due to inconsistent response behaviour the UBV of another person had to be removed prior to statistical analysis.

#### Statistical analysis

To analyse the qualitative questions, a qualitative data analysis (QDA) with an additional frequency analysis was conducted, following established procedures. The MP3 files of the 45 interviews were transliterated and imported to the statistical software programme MAXqda 2007 (24, 25). The coding framework was a combination of the grounded theory approach and thematic coding (25, 26): The six interview topics composed the first categorical level. All categories of the second and third level were drawn inductively out of the texts.

Statistical analysis of quantitative data was conducted with SPSS 15.0 following statistical guidelines of Bortz (27). Data is described by absolute frequencies or by means and standard deviations. For comparing questionnaire results with the norm, Stanine (STANDARD NINE) and percentile rank (PR) were used. Group comparisons of continuous variables were conducted using an independent sample *t*-test. Comparisons between dependent categorical variables were

made using a McNemar's test for dependent samples. Correlations were calculated by Pearson's product-moment correlation analyses. A *p*-value of less than 0.05 was considered significant.

## RESULTS

### General coping and body image in alopecia areata

We hypothesized that patients with AA would have worse general coping strategies and a worse body image than the norm sample and that patients with AA with advantageous general coping strategies would benefit in terms of better AA-specific coping and a milder course of disease. Patients with AA did not differ from the norm sample in their general coping strategies, as measured with the UBV (Table I, second column), thus disproving our first hypothesis. Describing our sample's general coping pattern, patients with AA can be characterized by rather neutral and passive coping behaviours. They show low levels of aggression and the primary coping goals of avoiding conflicts and emotional equilibration. Self-directed coping includes suppression of information and the technique of re-evaluating stressors, while active, environmental-directed coping is rather low.

In addition, we hypothesized that patients with good general coping strategies would benefit in terms of better AA-specific coping and better course of disease. All participants rated their competence in coping with AA on a rating scale. Table I also shows group comparisons between patients who rated their own AA-specific coping competence as high (rating 7–10, *n* = 24) and those who rated their own coping competence as low to medium (rating 0–6, *n* = 16). Patients with good illness-specific coping competence also showed better general coping strategies, and in particular less negative emotional reactions to stressors, less passive/evasive strategies and less assignment of guilt.

In addition, participants with a better course of disease after 6 months differed from those with a constant or worse course of disease in terms of less aggression ( $T(36) = 2.172$ , *p* = 0.037) as an emotional reaction to stressors and in terms of a higher belief in changeability of stressors ( $T(36) = 2.543$ , *p* = 0.015).

Participants did not differ from the norm sample in the FKKS, relating to self-acceptance of the body (PR = 42.79, standard deviation (SD) = 32.327) and acceptance of one's body by others (PR = 48.88, SD = 30.90). However, higher scores in the two body concepts were related to better coping competence with AA (self-acceptance:  $R = 0.336$ , *p* = 0.030; acceptance by others:  $R = 0.312$ , *p* = 0.044).

### Stress experiences in the onset of alopecia areata

When rating their subjective stress levels on the 0–10 scale, patients with AA experienced in retrospect high-

Table I. Comparison of general coping strategies (measured with the Stress and coping process questionnaire, UBV) between the alopecia areata (AA)-patient sample and the norm (second column). Differences in general coping strategies between patients with AA-specific high vs. low/medium coping competence

Scales of the UBV	STANINE <sup>1</sup> Mean ± SD	Coping competence <sup>2</sup>		Statistics ( <i>t</i> )	<i>p</i> -value
		Low/medium Mean ± SD	High Mean ± SD		
<b>Emotional reactions<sup>3</sup></b>					
Anxiety	5.20 ± 1.71	1.66 ± 0.58	2.10 ± 0.60	-2.341	<b>0.025</b>
Depressiveness	5.55 ± 2.00	1.78 ± 0.60	2.32 ± 0.59	-2.800	<b>0.008</b>
Aggression	5.93 ± 1.79	1.98 ± 0.69	2.49 ± 0.62	-2.492	<b>0.017</b>
Mean score of negative emotionality	5.48 ± 1.74	1.80 ± 0.52	2.30 ± 0.52	-2.959	<b>0.006</b>
<b>Situational appraisals</b>					
Belief in changeability	4.65 ± 2.14	1.44 ± 0.66	1.40 ± 0.76	0.681	0.191
Belief in controllability	5.10 ± 2.45	2.75 ± 0.68	3.16 ± 0.66	-1.908	0.066
Negative valence	4.85 ± 2.25	3.14 ± 0.70	2.76 ± 0.63	1.807	0.079
Familiarity	5.63 ± 2.45	2.34 ± 0.95	2.34 ± 0.96	0.000	1.000
<b>Coping goals</b>					
Influencing stressor	5.18 ± 2.15	2.22 ± 0.38	2.37 ± 0.35	-1.303	0.201
Avoiding conflicts	5.95 ± 2.08	2.56 ± 0.45	2.19 ± 0.59	2.112	<b>0.041</b>
Emotional equilibration	5.80 ± 1.52	2.31 ± 0.50	2.30 ± 0.51	0.096	0.924
Self-esteem equilibration	5.55 ± 1.66	2.30 ± 0.48	2.45 ± 0.44	-1.054	0.299
<b>Self-directed coping</b>					
Suppression of information	6.25 ± 2.01	1.39 ± 0.48	1.08 ± 0.65	1.658	0.106
Palliation	5.15 ± 2.14	2.20 ± 0.94	1.96 ± 0.81	0.858	0.396
Search for information	4.25 ± 2.01	2.95 ± 0.53	3.07 ± 0.60	-0.687	0.496
Re-evaluation	5.80 ± 1.96	2.21 ± 0.48	2.06 ± 0.71	0.731	0.469
Blame of others	4.60 ± 2.07	2.28 ± 0.76	1.80 ± 0.64	2.096	<b>0.045</b>
Self-blame	5.30 ± 2.28	2.03 ± 0.39	1.30 ± 0.64	4.066	<b>&lt;0.001</b>
<b>Environmental-directed coping</b>					
Passive behaviour	5.68 ± 2.01	1.78 ± 0.64	1.24 ± 0.57	2.808	<b>0.008</b>
Evasive behaviour	5.73 ± 2.18	1.57 ± 0.70	0.95 ± 0.49	3.274	<b>0.002</b>
Active influence	4.28 ± 2.11	2.59 ± 0.55	2.93 ± 0.59	-1.807	0.079

*t*-test for independent samples, *p* < 0.05.

Levene's test for homogeneity of variances: *p* > 0.05.

<sup>1</sup>STANINE: STANDARD NINE norms of the UBV, values 4-6 are considered as average in comparison to the norm sample.

<sup>2</sup>Self-rated coping competence on a quantitative scale (0-10; high; rating 7-10, low/medium; rating 0-6).

<sup>3</sup>Higher rating implies lower emotional reactions.

UBV: Stress and coping process questionnaire; SD: standard deviation.

her stress levels before the onset of AA (mean ± SD 7.02 ± 2.659) compared with the period of examination (4.42 ± 2.08; *t*(44) = 5.75, *p* < 0.001). Qualitative data analysis revealed that participants described their life situation before the onset of AA in retrospect in categorical terms of: (i) a normal/positive life situation (*n* = 13), (ii) mental and/or physical illness (*n* = 12), (iii) daily hassles (*n* = 29), (iv) general life changes without emotional burden (*n* = 16), and (v) emotional distress (*n* = 37). At the time of the interview the descriptions of the actual life situation had changed and these differences were evaluated with a McNemar's test. Changes in patients' descriptions of their lives are shown in Fig. 1. They involved more normal/positive characteristics (*n* = 29; *p* = 0.002), and less illness (*n* = 4; *p* = 0.039), daily hassles (*n* = 15; *p* = 0.011), life changes (*n* = 5; *p* = 0.013) and emotional distress (*n* = 18; *p* < 0.001).

### Stress reactivity of alopecia areata

In the interview participants were asked to describe whether they experienced stressors that influenced the outbreak and/or course of AA. In QDA three categories

were extracted, which were not mutually exclusive: (i) no stress reactivity of AA, (ii) high stress level in terms of a lack of recreational phases, and (iii) emotional distress. One-third of participants (33%) did not see

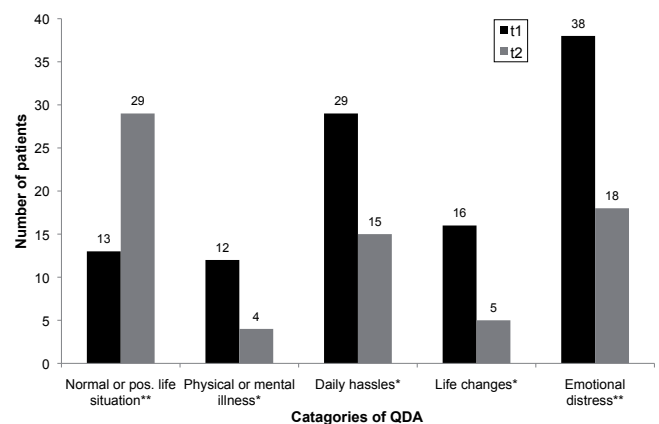


Fig. 1. Changes in the description of life in terms of stress before the onset of alopecia areata (t1 (refers to a description given in retrospect at the same time of examination)) and during examination (t2). McNemar's test for dependent samples, \**p* < 0.05, \*\**p* < 0.01. QDA: qualitative data analysis.

their AA linked to stressors. Another 38% felt that a high stress level in terms of a lack of recreational phases was influencing their AA. Finally, 60% of patients with AA thought that some kind of emotional distress was influencing the course of AA.

When patients rated the extent of stress reactivity of AA on a 10-point scale, the mean stress reactivity was medium-high ( $M=5.96$ ,  $SD=3.3$ ). By forming groups with low (0–3), medium (4–6) and high (7–10) stress reactivity, 29% were found to experience low, 18% medium and 53% high stress reactivity of AA.

These findings are supported by the results of QDA of patients' subjective disease models. Overall, 70% of patients with AA had psychosocial disease models (emotional burden, stress overload, discontentment). Fig. 2 shows the main categories of QDA concerning subjective disease models and gives comparisons between patients with different status and severity of AA. In general, 40% of the patients thought that physical factors (autoimmune processes, hormones, genetic factors, lack of sleep or physical illness) cause AA. Approximately 30% were insecure about factors causing AA. Finally 18% gave "meaning" to AA in terms of taking the disease as an opportunity to change certain aspects of their lifestyle. When looking at differences in disease models in relation to different status and severity of AA, statistical comparisons with  $\chi^2$  tests were difficult to interpret due to in homogenous cell frequencies. Therefore we obtained only a statistical tendency for this. However, it is obvious that patients with a relapse or chronic condition of AA may have more physical disease models than patients with a first onset of AA (Pearson's  $\chi^2 = 3.411$ ;  $p = 0.065$ , statistical tendency) and they seem to be more insecure about causalities.

### Stress experiences in the course of alopecia areata

Relating to stress experiences in the course of AA, we concentrated on the burden that patients with AA expe-

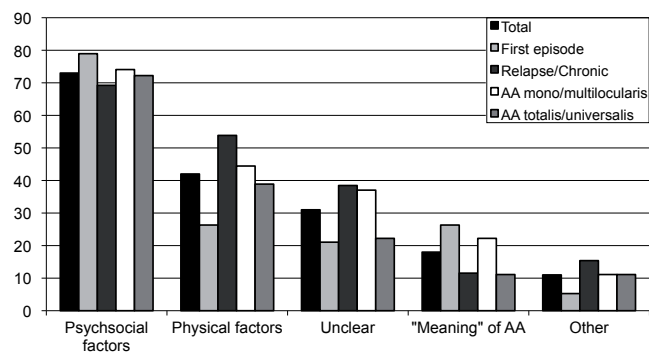


Fig. 2. Main categories of qualitative data analysis concerning subjective disease models of alopecia areata (AA). Percentages are shown for the total sample and patient subgroups with a different status of disease (first episode vs. relapse/chronic state) and different severity of AA (AA mono/multifocalis vs. AA totalis/universalis).

rienced due to the disease itself. In general participants rated their subjective burden due to AA as medium-high ( $4.51 \pm 2.7$ ) on the rating scale. Six months after the interview this subjective burden had decreased significantly ( $3.1 \pm 2.9$ ;  $T(42)=3.20$ ,  $p=0.003$ ). Overall, women ( $4.9 \pm 2.90$ ) felt more stressed due to AA than did men ( $3.10 \pm 0.99$ ;  $T(41.3)=-3.11$ ,  $p=0.003$ ). On the other hand, subjective burden was lower in patients with regrowth of hair ( $3.50 \pm 2.263$ ) compared with those without regrowth ( $5.48 \pm 2.778$ ;  $T(43)=2.613$ ,  $p=0.012$ ). Neither status of disease nor severity of AA influenced the extent of subjective burden.

QDA of the consequences of AA on patients' lives revealed nine main categories with a total of 588 codings. The majority (84%) mentioned emotional distress, such as subjective insecurity, anxiety, depression or feeling shocked at the beginning. The same proportion of participants also described a burden due to their changed body image (feeling unattractive, unprotected or even alienated from themselves). Most participants (80%) also described social discomfort such as problems in the own family or partnership, irritated or negative reactions by others and social withdrawal. For 76% stress caused by the treatment itself was also demanding. This included discontentment with therapy, time-consuming and costly options and adverse effects of wearing wigs. Approximately 60% of patients with AA mentioned that the unpredictable course of the disease was an additional burdening factor. In addition, fixation on the bald spots with accordant checking behaviour (40%) and adverse effects of AA itself or its therapy (31%), such as corticosteroid treatment, were described as problematic. Finally, some participants even experienced discrimination (11%) due to hairlessness (for example in the job market or in being verbally attacked) and another 7% felt stressed by the enduring search for explanations.

Fig. 3 shows the main categories of QDA concerning consequences of AA on patients' lives for the total sample as well as for patients with different status and severity of AA.

### Coping with alopecia areata

When rating their own competences in coping on the rating scale (0–10), overall participants felt fairly confident in coping with AA ( $6.98 \pm 2.23$ ).

QDA about AA-specific coping behaviours revealed 29 categories with 836 codings, resulting in five main categories: (i) Treatment of AA, (ii) Social coping, (iii) Active coping, (iv) Cognitive coping and (v) Passive coping. Table II shows the frequencies of all categories found in QDA and gives short descriptions of those.

For further quantitative analysis the qualitative categories with their number of codings were treated as new variables.

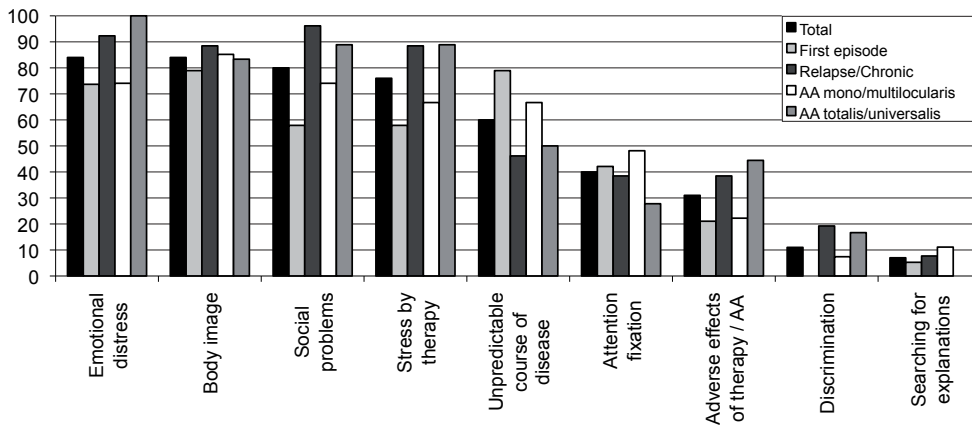


Fig. 3. Main categories of qualitative data analysis concerning consequences of alopecia areata (AA) on patients' lives. Percentages are shown for the total sample and patient subgroups with a different status of disease (first episode vs. relapse/chronic state) and different severity of AA (AA mono/multifocalis vs. AA totalis/universalis).

As expected, the self-rated coping competence was highly negatively correlated with the subjective burden due to AA ( $R = -0.699, p < 0.001$ ).

In a next step, correlations between self-rated coping competences, respectively, self-rated burden due to AA and the corresponding AA-specific coping strategies (only second-level categories) were explored. As different levels of severity and status of AA supposedly require different coping strategies, these correlations were calculated for patients with different status and severity of AA.

Concerning the status of AA, the following findings were made. Patients with first onset of AA felt less burdened due to AA when they had an attitude of *waiting for regrowth* ( $R = -0.479, p = 0.038$ ). No correlations between self-rated coping competence and the strategies applied could be found. For patients with a relapse or chronic state of AA the coping competence correlated positively with the *amount of coping behaviours* ( $R = 0.419, p = 0.033$ ), *sending open messages* ( $R = 0.440, p = 0.024$ ) and *acceptance of AA* ( $R = 0.427, p = 0.030$ ). Correspondingly, self-rated subjective bur-

Table II. Categorical system and frequencies of the qualitative data analysis (QDA) concerning alopecia areata (AA)-specific coping strategies

Categories of AA-specific coping in QDA	Description of categories	Codings in QDA	n (%)
Total		836	45 (100)
Treatment		318	45 (100)
Corticoids	Different corticoid treatments	73	36 (80)
Other treatment	Vitamins, trace elements, lotions, phototherapy, etc.	58	30 (67)
Outpatient departments	Dermatological outpatient departments	35	29 (64)
Dermatologists	Dermatologists in private practice	33	25 (56)
Alternative medicine	Acupuncture, homeopathy, kinesiology	53	25 (56)
DCP-therapy	Treatment with diphenylcyclopropenone	20	14 (31)
Other medical specialists	General practitioners, gynaecologists, neurologists, internists, etc.	13	11 (24)
Esotericism and other treatment	Energetic treatment, pendulum work, replacing amalgam inlays, treatment with oscillators, etc.	14	11 (24)
Psychological treatment	Psychiatrists, psychologists, psychotherapists	19	10 (22)
Social coping		130	41 (91)
Social support	Social support from family, partner, friends, colleagues, etc.	61	35 (78)
Sending open messages	Speaking openly about AA, showing baldness in private and/or public	36	18 (40)
Contact with others	Contact with other people with AA, visiting self-help-groups	33	18 (40)
Active coping		178	41 (91)
Cosmetic procedures	Wearing wigs, hats or shawls, hairstyle covering bald spots	76	40 (89)
Stress management	Relaxation, managing stressors	45	21 (47)
Elimination of "causes"	Changing relevant psychological triggers	38	12 (27)
Humour	Humorous, playful handling of AA	19	8 (18)
Cognitive coping		152	41 (91)
Relativizing AA	Putting AA into perspective	45	24 (53)
Acceptance	Acceptance of AA and integration into one's life	62	24 (53)
Calming down	Calming oneself down, hoping for spontaneous regrowth	29	17 (38)
Information	Searching information about AA and its treatment	16	12 (27)
Passive coping		58	29 (64)
Distraction	Ignoring AA, distraction	19	12 (27)
Keeping a secret	Concealing AA from others	19	11 (24)
Waiting for regrowth	Awaiting spontaneous regrowth	13	10 (22)
Self-pity	Feeling sorry for oneself	7	7 (16)

den was associated with *keeping AA a secret* ( $R=0.407$ ,  $p=0.039$ ) and little effort to *eliminate the "causes"* ( $R=-0.389$ ,  $p=0.050$ ).

Correlations were also calculated for participants with different severity of AA, while results seem most interesting for patients with AA totalis/universalis. This patient group rated their coping competence higher when they had applied many coping behaviours ( $R=0.640$ ,  $p=0.004$ ). Subjective competence was correlated with the strategies of *sending open messages* ( $R=0.509$ ,  $p=0.031$ ), *social support* ( $R=0.508$ ,  $p=0.032$ ), *humour* ( $R=0.491$ ,  $p=0.039$ ) and *acceptance* ( $R=0.532$ ,  $p=0.023$ ). Subjective burden in this group was related to little *social support* ( $R=-0.482$ ,  $p=0.043$ ) and *keeping AA a secret* ( $R=0.667$ ,  $p=0.002$ ).

## DISCUSSION

### *General coping and body image in alopecia areata*

No differences were found between patients with AA and the norm sample in terms of general coping strategies (measured with the UBV). However, many studies found high anxiety and depression in the AA-patient group (1–3, 10, 11), and anxiety and depression are highly correlated with dysfunctional coping strategies in the UBV (21). Patients with AA cannot be characterized as a group with dysfunctional coping strategies. Therefore, our first hypothesis was clearly disproved. Previous studies have suggested that individual susceptibility to AA could be modulated through deficits in emotion regulation or reduced ability to cope effectively with stress (3, 13). Our results clearly support this assumption. A better course of disease after 6 months was related to more advantageous coping strategies, particularly to less aggression as an emotional reaction to stressors and to a higher belief in changeability of stressors. High emotional arousal and low self-experienced controllability (or helplessness) might therefore constitute psychological key factors in the modulation of hair growth inhibition in AA. The possible effects of negative emotion and helplessness on psychoneuroimmunological regulation have been described elsewhere (28–30). In addition, high competences in coping with general stressors also benefit AA-specific coping: patients with a high competence in coping with AA were characterized by better general coping strategies, particularly less negative emotional reactions to stressors, less passive/evasive strategies and less assignment of guilt. Therefore, emotion regulation and active coping strategies seem to facilitate the process of coping with AA. We assume that such coping could also reduce the high degree of perceived distress among patients with AA (8) and as a consequence this might even positively affect the course

of disease. However, controlled studies are needed to prove such effects.

Surprisingly, body image (measured with the FKKS) of our sample was not negatively affected in comparison with the norm sample. Previous studies found an impact on body image in chemotherapy-induced hair loss (31, 32), although patients were not compared with healthy controls in these studies. The negative impact of AA on body image has been demonstrated by results of the QDA concerning consequences of AA. We suppose that changes in body image due to AA do not lead to a substandard body image and are limited to specific bodily areas. In addition, higher scores in body concept were related to better coping competence with AA. Patients with a good coping competence eventually manage to maintain a positive body image. Conversely, a good general body image could also facilitate coping with AA.

### *Stress experiences in the onset and course of alopecia areata*

Results concerning stress experiences in the onset of AA were surveyed in retrospect and therefore have to be interpreted with caution. Patients with AA experienced higher stress levels before the onset of AA compared with the period of examination. This finding is well represented by changes in the categorical description of life in terms of stress. Interestingly, a change in subjective stress levels was related to different categories, ranging from physical illness to daily hassles and emotional distress. We see the advantage of our qualitative approach in the possibility of identifying people's individual perceptions and subjective stress experiences, which can hardly be assessed by standardized questionnaires.

These results seem to indicate that high individual stress experiences contribute as a trigger to the manifestation of AA, but our study design does not allow this conclusion to be confirmed. Results could also be influenced by perception errors due to patients' search for explanations.

Regarding stress reactivity of AA, the results indicate that approximately two-thirds of participants thought that stress, primarily emotional distress, was influencing the manifestation and course of AA, and more than half believed stress reactivity to be high. Accordingly, three-quarters of all participants had psychosocial disease models. These results were partly surprising. In 1997 a study by Gupta et al. (11) that also used a rating of stress reactivity from 0 to 10, considered only 16% of patients to experience high stress reactivity. However, this big difference between 53% and 16% is even more remarkable considering the fact that Gupta et al. defined "high stress reactivity" starting from a rating of "5", while in our study it was defined starting from "7". These differences could be explained by an increasing awareness of stress processes and its harmful

effects that has emerged during the last years and that concern both medical professionals and the population. Supporting our results, in a recent study (33) a similar high percentage of patients with AA (77%) thought that psychosocial distress was relevant for the manifestation and course of disease. Interestingly, patients with a relapse or chronic condition of AA had many physical and unclear disease models. It is possible that, in fact, there is a small group of patients with AA in whom distress and psychosocial factors play a minor role in triggering AA, while physical factors are more relevant.

In general, participants rated their subjective burden due to AA as medium-high, while influencing factors were regrowth of hair and gender. Women felt more stressed due to AA. This result could be explained by the fact that in women in particular physical attractiveness contributes highly to a positive body-image and self-esteem (31, 34). Although regrowth of hair was not correlated with a better course of disease after 6 months, it seemed to reduce emotional distress. Furthermore, the subjective burden in the total sample had decreased significantly after 6 months, which can be attributed to spontaneous remission as well as to patients' handling of their first emotional shock reactions. Interestingly, we found that neither the disease status nor the severity of AA influenced the extent of the subjective burden.

Qualitative analysis of the consequences of AA on patients' lives revealed a wide range of categories that were more detailed than categories found in an earlier QDA (9). This confirms that a disease such as AA influences many relevant aspects of patients' lives, ranging from emotional distress to social problems, as well as stress caused by the therapy itself. When interpreting the results it is important to consider that the categories sometimes label a process of dealing with AA and emerging problems. Comparing AA with other chronic illnesses, dealing with negative emotionality poses a big challenge for everyone concerned. While in other chronic illnesses social and job-related functionality often directly deteriorate (17), in AA personal, social and job-related functionality are often "indirectly" concerned due to a high subjective burden and social stigmatizing. Stress due to therapies, an unpredictable course of disease and dealing with possible causes of disease are factors that are also well known in other chronic illnesses. More specific consequences of AA are probably changes in body image, attention fixation on bald spots, which is often related to high distress, as well as discrimination due to changed physical appearance. However, pain or other bodily symptoms are of minor relevance.

#### *Coping with alopecia areata*

All participants had experiences with prior (medical) treatment of AA. Following patients' descriptions of the

treatment process, the majority made use of biomedical diagnostics and therapy in the beginning. Later, if these therapeutic approaches remain without success, many engage in alternative medicine. Psychological/psychotherapeutic/psychiatric treatment of AA was mentioned least often, and in this category medical psychiatric treatment was predominant. The possible potential of psychological and psychotherapeutic treatment of AA therefore still remains unutilized.

The other four main categories of QDA are not discussed in detail here. Nevertheless, these results indicate that the process of coping with AA includes different levels in order to meet the requirements of persons affected by AA. Of course, coping strategies may also change during the course of disease and depend on the illness severity. After dealing with the first emotional shock, many patients focus on calming themselves down and waiting for spontaneous regrowth. This can be seen as a cognitive coping strategy based on illness-specific knowledge. If spontaneous regrowth fails to appear, many get involved in different (medical) treatment options, but also in social and other coping behaviours. In the best case patients with chronic AA finally manage to accept the disease and integrate it into their daily life, sometimes even in a humorous way.

Patients with first onset of AA felt less burdened due to AA when they had an attitude of *waiting for regrowth*. As mentioned before, this passive strategy can be seen as a cognitive coping strategy based on illness-specific knowledge. Stowell (16) has shown that active coping unfolds its positive effects primarily in highly stressful situations. We conclude that patients with good emotional coping who manage to stay calm at the beginning of AA may benefit, at least in terms of little subjective burden due to AA. Eventually such a low emotional arousal might also positively influence the course of AA.

The most helpful coping strategy for patients with a relapse or chronic state of AA seems to be an active and open handling of AA, as both "eliminating causes" and being open about AA are negatively correlated with subjective burden. In addition, subjective coping competence also increases when patients apply open and active as well as cognitive strategies such as accepting AA. Similar results were found in patients with a high severity of AA, pointing at the importance of dealing openly and actively with AA, receiving social support and acceptance of the symptoms.

#### *Implications for biopsychosocial treatment of alopecia areata*

Illness and health are not defined as "conditions" in the biopsychosocial model, but as dynamic occurrences. Thus, health must be "created" during every second of life (35, 36). Therefore study results such as ours must



be seen as some kind of explanation for a biopsychosocial state and they may hint at some future treatment.

For AA treatment an adequate handling of negative emotionality and insecurity among patients with AA seems to be of particular importance, especially among patients with first onset of AA. Sufficient coping with negative emotionality arising due to the manifestation of AA could increase the chance of spontaneous remission in AA. This conclusion might seem daring and still has to be proven. Yet, our results and psychoneuroimmunological research seem to follow the same track. In this context, awareness of the discrepancy between the low objective medical threat and high psychological strain of AA can facilitate the acknowledgement of negative emotionality in patients with AA and thus reduce negative emotions. In addition, clear information about the disease and limited treatment options and the high rate of spontaneous remission in AA could contribute to better coping with the disease.

We suppose that biopsychosocial history-taking should involve patients' life situations before the onset of AA. If patients experienced many daily hassles, they should be motivated to reduce their stress level. In cases of high emotional distress, referral to specialists in the psychosocial field may be helpful in order to encourage active coping strategies. However, exploration of patients' disease models and their accordant consideration in the treatment plan seem to be important in order to compensate for the broad consequences of AA on patients' lives.

Finally, psychological interventions in AA should focus on the training of general and AA-specific coping competences and techniques of regulating emotionality.

### Limitations

First, the desired sample size of 60 was not attained within the given time-frame of 1.5 years, thus limiting the possibility of statistically measuring small and medium-high effects. This also delimited some group comparisons due to small cell frequencies. However, a sample size of 45 patients with AA can be seen as good average in comparison with other studies with this patient group, and to our knowledge the present study constitutes the broadest and most detailed qualitative analysis of patients with AA.

Secondly, the selection of the sample was not randomized. Patients volunteered to participate in the study, and this could have led to a selection bias of including patients who were more interested in psychosocial aspects and therefore to an overestimation of the relevance of psychosocial triggers in AA. In addition, the sample was recruited from among two main groups (patients of an outpatient Department of Hair Diseases and participants of a self-help group) that had heterogeneous characteristics concerning status and duration

of AA. Patients visiting the outpatient department were mostly experiencing their first episode of AA. In contrast, participants recruited at the self-help group often had a long duration and chronic state of AA and had learned to cope very well with AA. An advantage of this heterogeneous group is the possibility of exploring the coping strategies of those patients with chronic AA who can probably no longer be recruited in the clinical field. The disadvantage can be seen in the fact that some of our questions referred to a time before the first onset of AA and that these time intervals were of very different duration.

Thirdly, we waived the exploration of a control group because the questionnaires used in the study were standardized. As our sample did not differ in body concept and general coping strategies from the norm sample, further studies should include other patient reference groups to better assess the body concept and general coping strategies of patients with AA in relation to other illnesses. Thereafter, it could be interesting to compare our qualitative findings with illness-related burden and coping strategies of patients with other dermatological conditions.

Finally, data collection on the basis of personal interviews can cause a methodological bias, as the data obtained is influenced by the interviewer's characteristics (37, 38). Such interviewer-effects are well known and difficult to avoid in qualitative research. As the main goal of our interviews was to obtain differentiated and authentic information about participants' personal experiences with AA, we chose an interviewer with expert knowledge of psychology and AA, who was experienced in patient-oriented communication. The interviewer was conscious of possible interviewer effects, such as the potential influence of her own verbal and non-verbal behaviour, on participants' answers. Special attention was paid to creating an undisturbed, relaxed and trustworthy atmosphere. Despite such precaution a potential interviewer effect on our data cannot be completely excluded and would require a number of randomly assigned interviewers.

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