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Identification and characterization of alopecia areata subgroups regarding quality of life impairment based on demographic, clinical, psychological, and social factors

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ABSTRACT

The benign dermatological hair condition Alopecia Areata (AA) is known to impair Quality of Life (QoL), especially mental and social health, due to the accompanying visible appearance changes. Previous studies have identified demographic, clinical, social, and psychological variables related to QoL. Yet, the novelty of this study lies in examining how QoL differences in AA relate to (combinations of) these variables. The aim of the current study is to identify and characterize subgroups of AA persons with less or more QoL impairment by means of (combinations of) demographic, clinical, psychological, and social factors, including both potential risk (perceived stigmatization, avoidant coping, physical identity definition) and protective factors (disclosure, social support, emotion-focused coping and non-physical identity definition). An online questionnaire was filled out by 322 persons with AA, including the Dermatology Life Quality Index (DLQI) as QoL measure, Perceived Stigmatization Questionnaire (FSQ), brief COPE, Social Support Survey, a newly developed identity-definition measure, clinical characteristics, and demographics. Classification and Regression Tree (CART) analysis identified subgroups based on QoL outcome. Lowest QoL impairment was found in persons with low feelings of being flawed combined with low secretiveness. Low QoL impairment was also found in persons feeling flawed combined with low avoidant coping, low sensitivity to others' opinions and older age. QoL impairment was intermediate in persons perceiving more social support in those with a younger age, and defining identity less on physical appearance in those sensitive to others' opinions. Highest QoL impairment was characterized by feeling flawed combined with an avoidant coping style. Current findings provide indications for the identification of risk and protective profiles for QoL impairment and which factors to address in interventions to improve QoL in AA.

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Introduction

Alopecia Areata (AA) is a dermatological disorder with an autoimmune etiology, unpredictable course and multiple presentations (Rajabi et al., 2018). It has a lifetime-estimated risk of 2%, affects both genders equally, and has an average age of onset of 33 years (Liu et al., 2016; Toussi et al., 2021). Persons with AA experience rapid, sudden hair loss in round patches to sometimes total baldness, including eyebrows and eyelashes (Liu et al., 2016). The autoimmune etiology makes it difficult to cure AA, and relapse rates are high (Lintzeri et al., 2022). Although AA is a benign condition, it impairs health-related quality of life (HRQoL) (van Dalen et al., 2022), especially mental and social health due to accompanying appearance changes (Aldhouse et al., 2020; Liu et al., 2016). Despite a growing recognition that psychological and social factors (e.g. stigma, coping) are related to psychological burden in AA (e.g. Mesinkovska et al., 2020; Tucker, 2009), conflicting results have been found regarding the relation between psychological burden and the clinical (AA-severity, AA-duration) and demographic (age, gender) factors (e.g. Liu et al., 2016; Rencz et al., 2016). Furthermore, studies on factors directly related to QoL in AA are still limited. Identifying which (combination of) factors are related to better or worse QoL in AA helps determining risk groups for QoL impairment, and suggests which factors to address to enhance QoL.

The majority of research that has focused on QoL in AA was either focused on comorbid psychiatric disorders such as depression and anxiety (e.g. Titeca et al., 2020; Vélez-Muñiz et al., 2019), or were qualitative studies (Aldhouse et al., 2020; Barkauskaite & Serapinas, 2020; Matzer et al., 2011; Welsh & Guy, 2009). The few quantitative studies that have examined psychological factors related to QoL in AA focused on only a few variables (Willemse et al., 2019; Yu et al., 2016). These studies have identified potential risk factors for QoL, such as an avoidant coping style and a negative perception of the condition (the illness perception *identity*) (Willemse et al., 2019; Yu et al., 2016). An additional factor that might relate to lower QoL in AA is perceived stigmatization. Research in related chronic dermatological conditions such as psoriasis and eczema (sharing AA's unpredictable nature, visibility and autoimmune etiology) confirmed a relationship between stigmatization and QoL (Jankowiak et al., 2020; Kowalewska et al., 2020). Up to now, no clear insight has been provided into how the above factors combine to characterize different QoL subgroups within the AA population.

The qualitative studies reflect the results of the quantitative studies in that perceived stigmatization, illness identity, and avoidant coping are identified risk factors for psychological burden in AA (Aldhouse et al., 2020; Barkauskaite & Serapinas, 2020; Mesinkovska et al., 2020). They also indicate how combinations of these and other factors, such as AA-duration and age, could be important in explaining QoL. For example, coping was less avoidant and more acceptant in older persons and in those who dealt with AA for a longer time, which seemed to have a positive effect on their well-being (Barkauskaite & Serapinas, 2020; Welsh & Guy, 2009). In addition to risk factors, these qualitative studies provide insight into potential protective factors in AA, such as disclosure, social support, and accepting.

An additional important theme arising from the qualitative studies is a sense of change in identity. Losing hair was seen as losing part of one's identity (Barkauskaite & Serapinas, 2020; Hunt & McHale, 2005; Mesinkovska et al., 2020). Placing less value on

physical appearances when defining identity could be a protective factor associated with better QoL. Establishing the role of physical appearance in defining identity in persons with AA was mentioned as important for future research (Hunt & McHale, 2005), but no studies have yet included this theme.

The aim of the current study is to identify and characterize subgroups of AA persons with less or more QoL impairment by means of (combinations of) demographic, clinical, psychological, and social factors, including both potential risk and protective factors. A decision tree approach is applied, which allows for exploration on how the QoL subgroups could be characterized and identify the most important (combination of) factors related to QoL in AA. This identification can provide direction for interventions to improve QoL in AA, and also help medical professionals working with AA patients to screen for the most relevant risk factors for QoL impairment.

Materials and methods

Procedure

The current study is part of a larger research project on possible QoL determinants in AA. Participants completed an online survey. For this study, data on QoL, stigmatization, disclosure, social support, coping, identity definition, and demographic & clinical characteristics were analyzed. The two inclusion criteria were: having received the AA diagnosis by a dermatologist or a general practitioner, and being ≥16 years old. Recruitment was through (inter)national Alopecia support groups. These organizations introduced the study-information with survey link to their members via their social media websites. The survey was available in English and Dutch. Of the 353 participants who started the survey, 322 participants (91.2%) completed the relevant measurements and were included in the analyses. The 33 dropouts did not differ significantly from the completers in age ($p = .07$), AA-duration ($p = .72$), gender ($p = .97$) and AA-severity ($p = .31$).

Measures

Quality of Life was assessed using the Dermatology Life Quality Index (DLQI), a 10-item disease-specific questionnaire (Finlay & Khan, 1994). The DLQI is the most widely reported QoL instrument used in AA and has been found reliable and valid for the AA population (Chernyshov et al., 2021; Rencz et al., 2016; van Dalen et al., 2022). Higher scores indicate more QoL impairment.

Perceived stigmatization was assessed using the Feelings of Stigmatization questionnaire (FSQ). This 32-item questionnaire measures six stigmatization subscales: anticipation of rejection, feeling flawed, sensitivity to others' opinions, guilt & shame, positive attitudes (reverse-scored), and secretiveness. Higher mean scores indicate more perceived stigmatization (Ginsburg & Link, 1989; Wittkowski et al., 2007). Due to conceptual overlap of the subscales guilt & shame, and anticipation of rejection with DLQI-items, these subscales were excluded from analysis.

Coping was assessed using the brief COPE which consists of 14 coping scales, each with 2 items (Carver, 1997). Based on previous research (Cartwright et al., 2009; Días

et al., 2012; Poulus et al., 2020), the 14 scales were grouped into three main coping strategies: *problem-focused, emotion-focused*, and *avoidant*. Higher mean subscale scores indicate larger use of that main coping strategy. The brief COPE, with this three-category division, has proven to be valid and reliable (Días et al., 2012; Poulus et al., 2020).

Identity definition was measured using a self-designed questionnaire to measure the importance participants place on physical appearance when defining identity compared to other (more global) attributes. Participants were asked the following: *'How important is it for you to be judged positively by others with regard to your . . . .?'* The 10 items include: *physical attractiveness, intelligence, overall presentation, health, humor, social skills, youthfulness, empathic skills, reliability*, and *charm*. Each attribute is scored on a 7-point Likert scale from 1 (not at all) to 7 (very much). The importance on appearances level is the participants' score on the item '*physical attractiveness'* minus their mean on the other items. The higher this score, the more value is placed on appearances in comparison to the other attributes.

Social support was measured using the Social Support Survey. This questionnaire was designed for patients with chronic conditions and has been found to be a valid and reliable questionnaire (Sherbourne & Stewart, 1991). Higher scores indicate more perceived social support.

Self- disclosure was measured with a short 4-item survey. Respondents were asked: 'How many people in your social environment know about your alopecia?' The 4 items include: *Family and Relatives, Friends, Colleagues or Classmates*, and *Neighbors*. Higher mean scores indicate more disclosure. This measurement was found to be a reliable and valid measurement of self-disclosure in persons with chronic conditions (Gignac & Cao, 2009).

Demographic and clinical characteristics

Sections with questions about: 1) demographics: *gender, age, living and work situation*, and 2) clinical characteristics: *percentage of hair loss (scalp & eyebrows) and AA-duration*, were included. AA-severity was measured according to the investigational guidelines reported by Olsen (Olsen et al., 1999) in which the severity of the condition was rated as extensive in cases of >50% of hair loss, moderate with 20–50% of hair loss, and mild with <20% of hair loss. An additional item was included concerning loss of eyelashes/eyebrows.

Internal consistencies of the multi-item measures in the current sample are reported in Table 2.

Statistical analysis

Descriptive statistics were analyzed and presented as absolute frequencies, means(M) and standard deviations(SD). With regard to the scoring of the scales, a missing value was replaced with the mean of the other items of the scale. Based on the total number of items per scale, 0 (4–7 items) to 2 missings (≥15 items) were allowed. Comparisons between DLQI-completers and non-completers were made using χ^2 tests and ANOVAs. As indicators for normality, skewness and kurtosis values were used (−2 and +2). Above data were computed with SPSS 27 (IBM, 2020).

To model OoL differences, the recursive partitioning and regression trees method in R-software was used. We fitted an Rpart tree, using DLQI score as the dependent variable and a set of 17 variables: *gender, age, working situation, living situation, AA-duration, hair loss severity, eyebrow/eyelash loss severity, disclosure, social support, the three coping styles, four dimensions of perceived stigmatization, and identity definition*, as independent variables. Rpart performs a tenfold cross-validation by default to help evaluate the reliability of the tree model (Therneau et al., 2013). This classification and regression tree (CART) analysis (Breiman et al., 1984; Lewis, 2000), was applied to identify the most important (combination of) factors related to QoL (DLQI) in AA. The CART analysis is well suited to stratify risk groups. It involves the segregation of different values of classification variables through a decision tree composed of progressive binary splits. It splits the sample based on the most useful cutoff score (Breiman et al., 1984; Lewis, 2000). A minimum split size of 30 was imposed. Unlike regression analysis, CART analysis is not affected by strong correlations between variables (Breiman et al., 1984). To obtain effect sizes of subgroup differences on DLQI outcomes, standardized subgroup means based on z-scores were computed.

Results

Demographics

Demographic data are presented in Table 1. The variables representing the psychological and social factors entered in the CART analysis to identify QoL subgroups are presented in Table 2.

Table 1. Demographic and clinical characteristics of the AA participants ($N = 322$).

Variable	*N*	%
Gender		
Male	34	10.6
Female	288	89.4
Hair loss scalp		
>50%	214	66.5
20 – 50%	62	19.3
<20%	46	14.3
Hair loss eyebrows/eyelashes		
>50%	164	51.1
20 – 50%	33	10.3
<20%	124	38.6
Living situation		
With partner/family/friend(s)	270	84.1
Alone	36	11.2
Other	15	4.7
Work situation		
Currently working	222	68.9
Not currently working	75	31.1
	M	*SD*
Age (years)	37.7	13.33
AA Duration (years)	15.5	13.24

Table 2. Distribution and internal consistency of social/psychological variables entered in the classification and regression tree (CART) analysis.

Variable	Subscale	M	SD	Range	Cronbach's Alpha
QoL (DLQI)		8.56	7.08	0 – 30	.87
Social Support		3.72	1.04	1 – 5	.97
Coping	*Problem-focused*	2.44	0.71	1 – 4	.84
	Emotion-focused	2.37	0.49	1 – 4	.70
	Avoidant	1.73	0.55	1 – 4	.71
Stigmatization	*Feeling Flawed*	2.11	1.13	1 – 6	.82
	Sensitivity to the opinion of others	2.86	1.17	1 – 6	.68
	Negative attitudes	2.66	1.10	1 – 6	.50
	Secretiveness	2.21	1.18	1 – 6	.73
Disclosure		3.51	1.15	1 – 5	.87
Identity based on physical attractiveness		−0.17	1.01	−4.4 – 3.2	.93

DLQI = Dermatology Life Quality Index, QoL = Quality of Life.

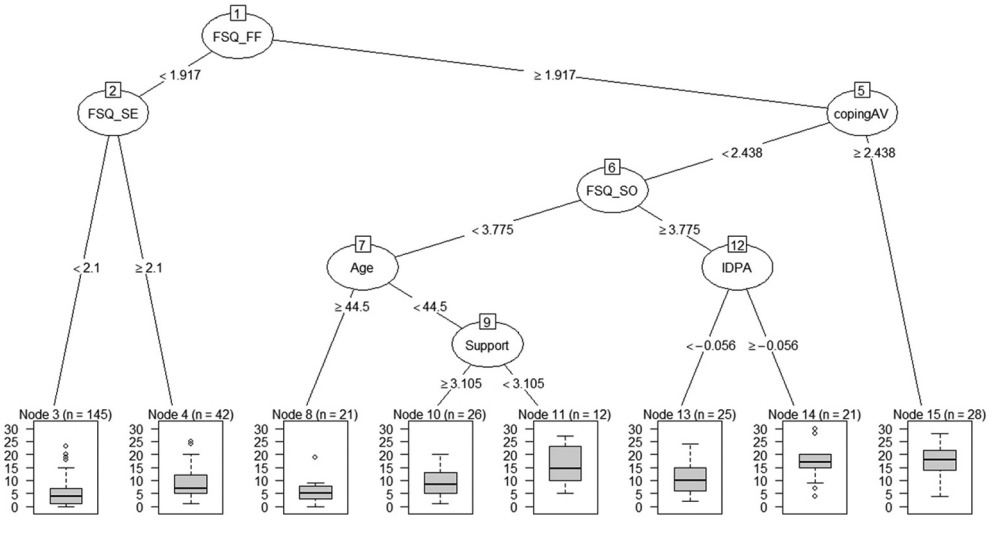

Figure 1. Tree for identifying QoL (DLQI) subgroups in AA participants. Each inner node represents the variable used for splitting, with splitting values below the nodes. The endnotes provide boxplots, representing the distribution of the QoL scores in each of the subgroups (endnodes). FSQ = feelings of stigmatization questionnaire, FF = feeling flawed, SE = secretiveness, so = sensitivity to the opinion of others, copingAV = avoidant coping, IDPA = identity definition based on physical appearances.

Variables characterizing QoL subgroups

Figure 1 shows the CART analysis results. The tree model included seven splits (inner nodes) resulting in eight subgroups (end nodes) with different QoL levels. Two groups were identified with low QoL impairment, three with intermediate QoL impairment, and three with high QoL impairment. Of the 17 variables included in the analysis, seven were identified in characterizing different QoL levels, resulting in the eight subgroups. The stigmatization dimension *feeling flawed* was the first split in distinguishing different QoL levels, followed by splits in the stigmatization dimension *secretiveness*, *avoidant coping*,

Table 3. QoL impairment based on subgroups discerned in classification and Regression Tree (CART) analysis.

Sub-Group (node)	Identified variables with their cut-off values	Low impairment	Intermediate impairment	High impairment	*M*	M_z	*n*
3.	FSQ_FF < 1.92, FSQ_SE < 2.1	X			4.94	−0.51	145
4.	FSQ_FF < 1.92, FSQ_SE ≥ 2.1		X		8.76	0.03	42
8.	FSQ_FF ≥ 1.92, copingAV < 2.44, FSQ_SO <3.87, age ≥ 44.5	X			5.62	−0.41	21
10.	FSQ_FF ≥ 1.92, copingAV < 2.44, FSQ_SO <3.87, age ≥ 44.5, Support ≥ 3.11		X		8.92	0.05	26
11.	FSQ_FF ≥ 1.92, copingAV < 2.44, FSQ_SO <3.87, age < 44.5, Support < 3.11			X	15.75	1.02	12
13.	FSQ_FF ≥ 1.92, copingAV < 2.44, FSQ_SO ≥3.87, IDPA < 0.056		X		10.88	0.33	25
14.	FSQ_FF ≥ 1.92, copingAV < 2.44, FSQ_SO ≥3.87, IDPA ≥ 0.056			X	16.95	1.19	21
15.	FSQ_FF ≥ 1.92, copingAV ≥ 2.44			X	17.35	1.24	28

FSQ = Feelings of Stigmatization Questionnaire, FF = feeling flawed, AV = avoidant, SE = secretiveness, SO = sensitivity to the opinion of others, IDPA = identity based on physical appearances, *n* = corresponding group size, *M* = estimated group means of QoL (DLQI); M_z= group means standardized as a z-score.

the stigmatization dimension *sensitivity to others' opinions*, *age*, *defining identity*, and *social support*. Results of the eight subgroups are presented in Table 3.

Three subgroups (end nodes) stand out due to high positive deviations from the QoL mean: node 15 (mean $z = 1.24$), node 14 (mean $z = 1.19$), and node 11 (mean $z = 1.02$). These subgroups are characterized by higher DLQI scores, indicating high QoL impairment. The subgroup with the highest QoL impairment, node 15, is characterized by high stigmatization on the dimension feeling flawed and by high avoidant coping. Node 14 is characterized by high stigmatization on the dimensions feeling flawed and sensitivity to other's opinion, low avoidant coping, and by defining identity more on physical attractiveness. Node 11 is characterized by again high stigmatization on the dimension feeling flawed and low avoidant coping, combined with low stigmatization on the dimension sensitivity to other's opinion, having a younger age (<44.5), and perceiving less support.

The subgroup with the least QoL impairment, node 3, also shows considerable deviation from the mean (z =-0.51) and was characterized by low stigmatization on the dimensions feeling flawed and secretiveness. Another subgroup with relatively low QoL impairment and considerable deviation from the mean (z =-0.41) is node 8, which is characterized by high stigmatization on the dimension feeling flawed, but low avoidant coping, low stigmatization on the dimension sensitivity to other's opinion, and being 44.5 years or older.

Discussion

In this study, we sought to identify subgroups of persons with AA based on their QoL levels. The primary goal was to identify which (combinations of) demographic, clinical, psychological and social factors could best identify potential risk and protective profiles. The eight subgroups that were identified could be divided into three 'risk' profiles (highest QoL impairment), three profiles with intermediate QoL impairment, and two

'protection' profiles (least QoL impairment). The results highlight the importance of perceived stigmatization in combination with avoidant coping, defining identity on physical appearance, age, and social support in identifying QoL subgroups.

Regarding all profiles, the stigmatization dimension *feeling flawed* was found to distinguish QoL levels most. This dimension of perceived stigmatization reflects feelings of weakness and dirtiness (Ginsburg & Link, 1989), which seems closely linked to what was found in qualitative AA-research in which persons reported experiencing a self-perception of a repellent, inadequate, odd self not worth loving due to appearance changes (Aldhouse et al., 2020; Welsh & Guy, 2009). Feeling more or less flawed *in combination* with other factors in characterizing different QoL levels is a novel finding, and proves to be relevant.

Feeling less flawed in combination with less secretiveness can be seen as the most protective profile. This is in line with research in general populations concluding that when secretiveness is combined with self-concealment, QoL is more strongly affected (e.g. Maas et al., 2019). In those feeling flawed, a protective profile is still evident when avoidant coping and sensitivity to others' opinions are low, and age is over 44.5 years. The effect of age on well-being in AA was conflicting in previous research (Liu et al., 2016; Shi et al., 2013; Yoon et al., 2019). The present study might explain these conflicting results as the potential protective value of older age seems especially apparent in combination with particular psychological and social variables.

Moving to the other extreme, the risk profile with the highest QoL impairment is associated with feeling more flawed combined with avoidant coping. Avoidant coping includes behaviors such as denial and disengagement with the goal to avoid having feelings about a stressor (Carver, 1997) and is associated with poorer psychological outcomes in several populations (Livneh, 2019). In the other two risk profiles, which both include more feelings of being flawed, but less avoidant coping, the factor that seems to limit QoL impairment is being less sensitive to others' opinions. When sensitivity to others' opinions is high, less focus on physical attractiveness when defining identity may protect from QoL impairment. When one is less sensitive to others' opinions and under the age of 44.5, perceiving more social support appears to limit QoL impairment.

The fairly new construct *identity definition* and its relevance in characterizing QoL in AA, is an additional novel finding. This form of identity definition seems closely linked to Cash's research who developed the field of body image and examined the consequences of placing (too much) value on 'importance of appearance' (Cash, 2011). Although it is still an understudied area, a more recent review concluded that overall more focus on appearance is related to poorer psychological and behavioral outcomes in both clinical and non-clinical populations (Jarry et al., 2019). As already indicated, losing hair in a short period of time was found to be related to identity loss in AA (Aldhouse et al., 2020; Hunt & McHale, 2005). When the importance of physical appearance is low, losing hair is expected to be less influential for one's identity, and may affect QoL less.

The importance of social support in those younger than 44.5-year old in potentially limiting QoL impairment does not seem specific to AA. Previous research on age differences in perceiving social support during the COVID-19 pandemic also found a protective role of social support in younger persons on mental health (Cao et al., 2022). Younger persons might still be in need of a larger social network to fulfill their need to belong than older persons.

The results of the current study have several practical implications. First, the combinations of factors characterizing QoL subgroups seem in line with the biopsychosocial model, which suggests a more holistic approach to understanding health and illness (Engel, 2012). Second, psychological therapies, such as cognitive behavioral therapy (CBT), may be useful. In particular, the underlying rationale of cognitive restructuring in CBT would be ideally suited to addressing maladaptive beliefs about being flawed while promoting more adaptive beliefs about living with AA and the new self. Additionally, behavior-wise, reducing avoidant behaviors, and actively seeking social support when confronted with AA at a younger age might also be helpful. Third, medical professionals having patients with AA could screen their patients especially on feelings of being flawed, as this factor is related to their quality of life outcomes the most. By paying attention to this aspect, patients may feel better understood and listened to, which could also increase their willingness to accept psychological therapy if necessary.

This study has some limitations. First, its cross-sectional design. A longitudinal study could provide additional insight into causality. Another limitation is the measurement of the construct 'identity based on physical appearance' through a new self-developed questionnaire, which is not yet validated. As the questionnaire has high face validity and the construct was shown in the current study to be related to quality of life in some subgroups of alopecia areata persons, future research into this construct and validation of its operationalization is warranted.

A last limitation is a limited number of males in the current sample. Next, to a potential lack of generalizability, it might also have resulted in an underestimation of the effect of gender. Strengths of the current study include the large international sample, being novel in identifying different subgroups of QoL in AA based on a combination of factors, and highlighting the relevance of the relevant fairly new construct 'identity based on physical appearance'.

Conclusions

Regression tree analysis was applied to generate a decision tree for identifying and characterizing AA subgroups with more or less QoL impairment. In particular, psychological and social factors have a role in identifying these subgroups. Of the demographic variables, only age was found to be of importance. Current findings provide indications for identification of risk and protective profiles for QoL impairment, and for the development of interventions to address QoL improvement in AA.

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Author contribution statement

All authors have accepted responsibility for the entire content of this manuscript and approved its submission. See the author contribution form for the specific contributions for each author.

Ethics approval

The study was approved by the Psychology Research Ethics Committee of Leiden University.

Consent to participate

All participants gave informed consent before the start of the study.

Data availability statement

Data supporting the findings of this study are available from the corresponding author on request.

Disclosure statement

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