The Parent-Child Experience of Pre-adolescent Alopecia Areata

By

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Declaration

I declare that this work has not been submitted for any other degree at the University of

Sheffield, or any other institution. The work presented is original and all other sources

have been referenced accordingly.

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Structure and Word Counts

Section One: Literature Review

Excluding references and tables   7981

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Section Two: Research Report

Excluding references and tables   7980

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Overall Abstract

Alopecia areata (AA) can lead to total loss of hair on the scalp and body. It most often begins before the age of 20 and there is no cure. Changes to appearance can have a negative psychosocial impact on people living with AA, and anxiety and depression have been found to be the most common psychological difficulties. Despite the frequency of onset in childhood, most of the psychological research into AA has been conducted amongst adults. There is also a gap in the literature for studies examining the psychological impact of childhood AA on parent and child, as well their joint experience.

The aim of this thesis was to examine what is known about anxiety and depression in AA through reviewing the adult literature, and to explore the lived experience of children with AA and their parents. It is hoped that the findings will inform the development of psychological interventions and resources for individuals living with AA, as well as those supporting children with AA.

A systematic literature review of anxiety and depression in adults with AA was conducted to gain a better understanding of the measures that have been used to assess these constructs, and to understand more about the symptoms of anxiety and depression in people with AA, relative to healthy and clinical controls; as well as their relationship to other variables.

Interpretative Phenomenological Analysis (IPA) was used to explore the experiences of children with AA and their parents as well as the joint parent-child experience of adjusting to the condition. Semi-structured interviews were conducted with four parent-child dyads and data analysed systematically. Steps were taken throughout to ensure research quality.

The narrative systematic review revealed that a broad range of measures have been used, reporting point prevalence rates of 4% to 63% for anxiety and 7.4% to 56%

for depression. Rates of anxiety and depression were generally higher in adults with AA than in healthy controls. Higher anxiety and/or depression was found to be associated with; greater severity of AA, a higher level of education, poorer quality of life, worse illness adjustment, certain illness perceptions, alexithymia, patchy episodes of AA, shorter to intermediate duration of AA, being female and being unmarried. Findings highlight the need for more rigorous research in this area and the potential for targeted psychological interventions.

The IPA study revealed four super-ordinate themes; 'discovering alopecia', 'a shared experience', 'secrecy and disclosure' and 'towards acceptance'; and fourteen subordinate themes. Dyads underwent a similar sequence of stages. Parents felt dismissed by doctors and were prone to self-blame. A key source of distress for parents and children was real and anticipated experiences of stigmatisation. There was a particular burden for female participants related to wig use. Parental adjustment set the tone for how well children coped. There was also a mutually protective parent-child dynamic. Findings highlight the need for parent, teacher and child specific psychoeducational resources providing greater clarity about AA and what to expect, as well as how to deal with experiences of stigmatisation.

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Section One: Literature Review

A Systematic Review of Anxiety and Depression in Alopecia Areata

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Abstract

Objective: This systematic review aimed to gain an understanding of how anxiety and depression have been measured in adults with AA, and what is known about their symptoms, including comparisons with healthy controls and other dermatological conditions; and to examine relationships with other variables.

Method: A systematic literature search was conducted in Scopus, PsycINFO and MEDLINE. Search terms related to alopecia areata, psychological factors, anxiety and depression were used. All included studies were subjected to a quality appraisal.

Results: Twenty-two studies met inclusion criteria. Studies utilised a broad range of self-report measures and clinician led diagnostic tools reporting point prevalence rates of 4% to 63% for anxiety and 7.4% to 56% for depression. In AA patients, rates of anxiety and depression were generally higher than in healthy controls. Higher levels of anxiety and/or depression were found to be associated with; greater severity of AA, a higher level of education, poorer quality of life, worse illness adjustment, certain illness perceptions, alexithymia, patchy episodes of AA, shorter to intermediate duration of AA, being female and being unmarried.

Conclusion: The findings should be treated with caution as studies were mainly of low quality. The review highlights the need for more rigorous research in this area, as well as routine psychological screening and the provision of targeted psychological interventions.

Practitioner Points

- Routine screening of patients with AA for anxiety and depression is recommended and those reporting high levels of distress should be referred for psychological intervention.

- Psychological interventions could target self-conscious emotions such as shame and social anxiety.

- Cognitive behavioural therapy (CBT) may be beneficial for working with illness perceptions and acceptance based approaches may be helpful for individuals in the intermediate stages of AA.

- A key limitation of this review was that the majority of studies were of low quality with small sample sizes.

- Participants in the studies were typically seeking medical or social support which limits our understanding of the prevalence of distress in those with AA not receiving active treatment.

Introduction

Alopecia Areata (AA) is a chronic inflammatory disease characterised by patches of non-scarring hair loss on the head that can develop to total loss of head hair, Alopecia Totalis (AT) or loss of all body hair including the eyebrows and eyelashes, Alopecia Universalis (AU) (Messenger, McKillop, Farrant, McDonagh, & Sladden, 2012). The lifetime incidence of AA globally is reported to be close to 2% (Wang & Christiano, 2017) and the condition affects men and women equally (Fricke & Miteva, 2015). The aetiology of AA is unknown, although the majority of evidence points to it being an autoimmune condition, to which both genetic predisposition and environmental factors contribute (McElwee et al., 2013).

The visual changes associated with AA can have a significant psychosocial impact (Hunt & McHale, 2005). Indeed, research has shown that living with AA puts individuals at a greater risk of developing depression, anxiety and social phobia than the general population (Colon, Popkin, Callies, Dessert, & Hordinsky, 1991; Koo, Shellow, Hallman, & Edwards, 1994; Ruiz-Doblado, Carrizosa, & Garcia-Hernandez, 2003). The occurrence of Generalised Anxiety Disorder (GAD) in people with AA has been linked to chronic environmental stress and worry about social acceptance (Kuty-Pachecka, 2015). It has also been suggested that higher rates of social discomfort, anxiety, anger, fear and low self-esteem in people with AA compared to controls, may lead to depression (Ghanizadeh & Ayoobzadehshirazi, 2014). There have been a number of general reviews of psychological factors and psychiatric comorbidities associated with AA, which have been mostly narrative (Garcia-Hernandez, Ruiz-Doblado, Rodriguez-Pichardo, & Camacho, 1999; Ghanizadeh & Ayoobzadehshirazi, 2014; Kuty-Pachecka, 2015; Sharma et al., 2015), however two reviews by Hunt and McHale (2005) and Tucker (2009) describe adopting a systematic approach. Hunt and McHale (2005) synthesised the findings of 34 studies published between 1980 and 2005 that included

participants with AA and chemotherapy-induced alopecia, and Tucker's (2009) review included 19 studies published between 1984 and 2006 that focused solely on the psychosocial consequences of AA. However, neither systematic review utilised the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) procedure (Moher, Liberati, Tetzlaff, Altman, & PRISMA Group, 2009) or conducted any appraisal of the quality of the extant literature. Current reviews agree that psychological distress increases with severity of hair loss in AA, and that females may be more affected than males by the condition due to gendered differences in appearance-related pressures (Hunt & McHale, 2005; Tucker, 2009). Moreover, anxiety and depression are consistently reported to be the most common psychological difficulties associated with AA (Ghanizadeh & Ayoobzadehshirazi, 2014).

Psychological factors are also implicated in both the cause and development (etiopathogenesis) of AA, due to their potential influence on immune functioning (Wang & McElwee, 2011). There has been some evidence linking stress and traumatic life events to the onset of AA (Garcia-Hernandez et al., 1999) and it has been postulated that depression may moderate this relationship (Gupta, Gupta, & Wateel, 1997). It is also said that prolonged anxiety and sadness related to stigmatisation may exacerbate symptoms of AA (Kuty-Pachecka, 2015). Hence, addressing psychological distress in people with AA may not only be important to subjective wellbeing but might also benefit prognosis.

Applying current findings to clinical practice might also help individuals with AA adjust to their condition (Karia, De Sousa, Shah, Sonavane, & Bharati, 2015). In fact, the United Kingdom (UK) guidelines for the management of AA (Messenger et al., 2012) recommend that patients who are profoundly upset by their alopecia may need psychological support. In addition, evaluating the effectiveness of psychological

therapies for people with AA has been identified as a top research priority by the James Lind Alliance's Alopecia Areata Priority Setting Partnership (Macbeth et al., 2017). However, there remains a need for the development of specific psychological treatment strategies for people with AA (Hunt & McHale, 2005; Montgomery, White, & Thompson, 2017). This requires a proper understanding of the main psychological difficulties in AA, namely anxiety and depression. No systematic review to date has focused on anxiety and depression in people with AA. Since service delivery models differ for adults and children, and the majority of psychological research related to AA has been carried out in adult populations (Hunt & McHale, 2005, Tucker, 2009; Welsh & Guy, 2009), this systematic review will focus on anxiety and depression in adults with AA.

Review Questions

This review aims to examine what the current literature tells us about anxiety and depression in adults with AA, to inform future research and clinical practice. For the purposes of this review anxiety and depression are conceptualised as affective states or traits that can arise from the perception of threat (Epstein, 1985) or loss (Beck, 1976) and result in negative emotional, cognitive, physiological and behavioural changes. Studies will be included in this review if they have measured anxiety or depression using a validated scale, or diagnostic tool such as the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V; American Psychiatric Association [APA], 2013) or International Statistical Classification of Diseases, Tenth Edition (ICD-10; World Health Organization [WHO], 1993).

The review will focus on the following questions:

- How has anxiety and depression been assessed within the adult AA research?

- What do we know about symptoms of anxiety and depression in adults with AA including comparisons with healthy individuals and patients with other dermatological conditions?

- What is known about relationships between anxiety and/or depression in adults with AA and other variables?

Method

Search strategy

A systematic literature search was conducted using the electronic databases Scopus, PsycINFO, and MEDLINE from their inception to December 2017. The search was updated from Jan 2018 to current date on October 27th, 2018.

The search terms used were used:

'alopecia OR "alopecia areata" OR "alopecia universalis" OR "alopecia totalis" OR "hair loss" OR bald* AND psychosocial OR psychological OR "psychological impact" OR "psychological factors" OR psychiatric OR experience AND anxiety OR depression AND NOT cancer OR chemotherapy'

Subject heading and keyword searches were conducted in PsycINFO and MEDLINE in line with best practice, (Centre for Reviews and Dissemination; CRD, 2008). This process involved selecting other terms for anxiety and depression (See Appendix A).

Eligibility Criteria

Articles were considered eligible for inclusion in the review if they met the following criteria: 1. Written in English; 2. Peer reviewed articles available in full text version; 3. Use of a valid measure of anxiety and/or depression; 4. The sample was aged

16 or over; 5. The sample included people with AA or its more progressed forms, i.e.,

AT or AU. The exclusion criteria were: 1. No clearly defined sample or subsample of

adult participants with AA or 2. The aims were not focused on anxiety and/or

depression.

Screening and selection

Electronic searches yielded 893 records, of which 158 were duplicates and

therefore removed. The remaining 735 records were screened for relevance to the

research question by title and abstract, resulting in the exclusion of a further 689

records. Of the remaining 46 records, 21 met eligibility criteria after screening of full

text articles (See Appendix B for references of excluded studies). Reference checking of

these articles and of existing reviews (backwards searches) led to the discovery of one

further article that met eligibility criteria, therefore the final number of articles included

in the review was 22. The PRISMA procedure (Moher et al., 2009) was adopted to

describe this process (See Figure 1).

Identification

Scopus
(*n* = 602)

PsycINFO
(*n* = 83)

MEDLINE
(*n* = 208)

Total records identified through database search
(*n* = 893)

Screening

Records after duplicates removed
(*n* = 735)

Duplicates
(*n* = 158)

Full text articles reviewed for eligibility
(*n* = 46)

Records excluded after screening by title and abstract
(*n* = 689)

Eligibility

Articles added from bibliography search
(*n* = 1)

Studies meeting inclusion criteria
(n= 21)

Full text articles excluded with reasons:
(*n* = 25)
No clearly defined AA sample (*n* = 6)
Aims not anxiety and/or depression in AA (*n* = 5)
Single case/case reports & no measures (*n* = 4)
Not a peer reviewed article (*n* = 2)
No valid measure of anxiety or depression (*n* = 2)
Unable to separate out adults (*n* = 2)
Article not available in English (*n* = 1)
No age details provided (*n* = 1)
Dermatological outcomes only (*n* = 1)
No AA patients in dermatology sample (*n* = 1)

Included

Studies included in the review
(*n* = 22)

Figure 1. PRISMA diagram displaying the flow of articles through the review

Quality assessment

Eligible articles were quality appraised using the Downs and Black (1998) checklist which has been rated by Deeks et al. (2003) as one of the fourteen best tools for evaluating bias in non-randomized studies. Downs and Black (1998) reported adequate internal consistency (KR-20 = 0.89), test-retest reliability (r = 0.88), inter-rater reliability (r = 0.75) and criterion validity for the checklist. The original scale provides a total score out of 32 points. A modified version was applied here whereby, as in previous studies (Larson, Vos, & Fernandez, 2013; Samoocha, Bruinvels, Elbers,

Anema, & van der Beek, 2010) item 27, the power question was simplified. A single

point was awarded if the study included a power calculation. After modification the

maximum score was 28 (See Appendix C). If a question did not apply to a study no

points were awarded for that question. Each paper was assigned a quality grade in

accordance with the following cut offs: low quality = <14, fair quality = 14-18,

moderate quality = 19-23 and high quality = 24-28 (O'Connor et al., 2015) (See

Appendix D). An independent trainee clinical psychologist rated a random selection of

20% ($n = 4$) of the included articles, which yielded an intra-class correlation coefficient

(ICC) of 0.915 indicating strong inter-rater reliability. Disagreements were resolved

through discussion. Due to the limited evidence base, a decision was made not to

exclude any articles on the basis of quality, in order to maximise awareness of the extent

and quality of the entire field of available studies. Table 1. provides a summary of data

derived from studies that were eligible for inclusion in this review ($N = 22$) ordered by

their quality analysis score.

Table 1. *Studies examining anxiety and depression in people with Alopecia Areata ordered by Downs and Black Score*

Author (s) Country	Study design	Sample	Aim of study	Measures	Description of Findings	Quality rating
Devar. (1983) India	Case-Control	*30 Male patients with AA* *30 Male patients with Tinea Versicolor of the face* *30 Male 'normal' controls* (Non-medical friends of the author) Inclusion criterion: Age ranging between 18 - 48	To compare antecedent psychosocial stress, *anxiety*, *depression*, hostility and personality factors in the three study groups	TMAS BDI	Patients with AA were more anxious and depressed than 'normal' controls: TMAS: AA ($M = 24.60$ $SD = 10.90$) Control ($M = 16.37$ $SD = 4.4$) $p < 0.01$ BDI: AA ($M = 20.47$ $SD = 13.08$) Control ($M = 2.20$ $SD = 2.02$) $p < 0.001$	6
Chaudhury et al. (2001) India	Case-Control	*50 Patients with AA* Female = 2 Male = 48 *50 'Normal' controls* Female = 1 Male = 49	Psychiatric evaluation of patients with AA and control group	Standard psychiatric interview SAS CRSD SIS	AA patients obtained significantly higher scores for anxiety and depression than controls. SAS: AA ($M = 27.36$ $SD = 16.14$) Control ($M = 17.70$ $SD = 16.18$) $p < 0.05$ CRSD: AA ($M = 8.40$ $SD = 4.87$) Control ($M = 1.13$ $SD = 0.46$) $p < 0.05$ Psychiatric Interview: 14% of patients with AA had adjustment disorder with depressed mood ($n = 7$) and 4% had dysthymia ($n = 2$). SAS: In AA patients revealed depressive content, hostility, feelings of insecurity, emotional blocking, a lot of inner cry, conflicts in relation to the opposite sex and unhealthy body imagery and a preoccupation with symptoms of hair loss. Depressive symptoms preceded the onset of AA in only two of the patients with depressive disorders.	7

Author (s) Country	Study design	Sample	Aim of study	Measures	Description of Findings	Quality rating
Ataseven et al. (2011) Turkey	Case-Control	*27 Adult AA patients (over the age of 16) were assessed for depression and Anxiety as part of this study* 43 AA patients (including 9 children). Male = 31 Female = 12 30 Healthy controls (including 9 children) Male = 19 Female = 11	The aim of this study was to evaluate possible associations between AA and depression, anxiety and serum levels of cytokines interleukin (IL)-1ß, IL-6, IL-8 and IL-10	HAM-D HAM-A	9 Adult AA patients showed mild depression (33.3%), 5 showed moderate depression (18.5%) 2 showed severe depression (7.4%) and 17 showed anxiety (63%). Overall levels of anxiety and depression were higher in AA patients than controls (includes children so these findings were not included in the synthesis of findings)	8
Bashir et al. (2010) Pakistan	Cross-sectional	*3 Patients with AA* out of a consecutive sample of 114 adult male dermatology outpatients.	To detect the presence of depressive features in patients having various dermatological conditions at the study centre	GHQ12 (Urdu version) and PSE together with the ICD10	1 patient with AA had depression (33.3%)	8
Montgomery et al. (2017) UK	Cross-sectional	*279 Individuals with AA* AA (n = 114) AU (n = 106) AT (n = 59) Total sample size = 338 (includes other forms of alopecia) Majority adults = 98.5% Female = 329 Male = 5	To examine levels of social anxiety, anxiety and depression and associations with wig use. To also report on associations between wig behaviours and psycho-social distress	SPIN PHQ-9 GAD-7	47.5% reported social anxiety, 35.5% anxiety and 29% depression in the clinical range. Participants who reported worries about not wearing a wig reported significantly higher levels of depression, anxiety and social anxiety $p \leq 0.001$	9

Author (s) Country	Study design	Sample	Aim of study	Measures	Description of Findings	Quality rating
Gupta and Gupta (1998) Canada	Cross-sectional	*45 AA patients* AA = 13 AT = 3 AU = 28 Male = 11 Female = 34 *72 Patients with Acne (Acne)* *140 Patients with Atopic Dermatitis (AD)* *217 Patients with Psoriasis* split into two sub-groups: *138 Inpatients (PI)* *79 Outpatients (P0)*	To examine the prevalence of depression, wishes to be dead and suicidal ideation among patients with a range of dermatological disorders that are typically associated with cosmetic disfigurement and body image problems.	CRSD	Lowest mean CRSD score in AA sample: PI = 13.4 ± 8.0, Acne = 11.2 ± 6.8, PO = 8.6 ± 6.5, AD = 7.6 ± 6.2, AA = 7.5 ± 7.3, $p < 0.001$ Lowest percentage who answered 'No' to 'I feel that life is still worth living' in AA sample: PI = 10.3%, PO = 5.1%, AD = 3.4%, AA = 2.2% and Acne = 1.4%, $p = 0.098$ Lowest percentage who answered 'Yes' to 'I have been thinking about trying to kill myself' in AA sample: PI = 7.2%, Acne = 5.6%, PO = 2.5%, AD = 2.1% and AA = 0%, $p = 0.03$	10
Aghaei et al. (2014) Iran	Case-control	*40 AA patients* Male = 44.8% Female = 56.2% *40 Volunteer controls*	The purpose of this research is to assess the frequency of psychological disorders in patients with alopecia areata in comparison with normal subjects.	BDI BAI	Higher rates of anxiety ($p = 0.003$) and depression ($p = 0.008$) in AA patients than controls. Prevalence rates calculated from graph: Anxiety = 45% ($n = 18$) Depression = 48% ($n = 19$) Facial involvement had a significant relationship with depression ($p = 0.020$) and anxiety ($p = 0.019$).	10
Karia et al. (2015) India	Cross-sectional	*50 AA cases* Male = 33 Female = 17 *50 Psoriasis cases* Male = 35 Female = 15 *50 Healthy controls* Male = 14 Female = 36. All 18 - 65 years	To determine the psychiatric morbidity and the Quality of life (QoL) in patients suffering from AA and psoriasis and to examine various factors related with psychiatric morbidity.	Diagnostic interview and DSM IV HAM-D HAM-A	2 AA patients had Anxiety Disorder (4%) 9 AA patients had depression (18%) In AA patients there was a significant correlation of QOL with anxiety (-0.490, $p < 0.001$) and depression (-0.473, $p = 0.001$) i.e. Quality of life was poorer in patients with anxiety and depression.	10

Author (s) Country	Study design	Sample	Aim of study	Measures	Description of Findings	Quality rating
Colon et al. (1991) USA	Cross-sectional	*31 Patients with AA aged 17-59* Male = 9 Female = 22	To evaluated a consecutive series of patients with patchy and extensive alopecia areata in order to clarify the nature and prevalence of psychiatric disorders in this population.	DIS and a semi-structured interview	Life-time prevalence rates: Major Depression = 39% GAD = 39% Phobic disorder = 23%. Patients with phobic disorder tended to have an earlier mean age of onset of AA than those without. Subjects reported high rates of psychiatric disorders amongst their first degree relatives, i.e., 58% anxiety disorders, 35 % mood disorders. Of the 23 subjects who had $\geq$ 1 episode of patchy AA, 12 (52%) had a lifetime diagnosis of GAD compared to 8 subjects who never had a patchy episode ($p = 0.029$) Of the 12 patients with major depression, 6 had onset of depression pre AA onset, 5 post AA onset and 1 coincident with AA onset. Of the 12 patients who had GAD, 5 had onset of GAD, pre AA onset, 5 post AA onset and 2 coincident with AA onset Of the 7 patients with phobic disorder, 4 had onset of phobia pre AA onset and 3 had onset post AA onset. The 4 cases with a life-time diagnosis of panic disorder had a shorter mean duration than those without panic disorder, i.e., 4.8 versus 15.2 years, $p = 0.05$ 3 patients (10%) identified depression as causing their etiology	10

Author (s) Country	Study design	Sample	Aim of study	Measures	Description of Findings	Quality rating
Yazici et al. (2006) Turkey	Case-Control	*43 Patients with AA* Male = 26 Female = 17 AA = 41 AT = 2 Mean age 33.8 ± 10.02 Mean duration of illness (months) 54.83 ± 101.37 *53 Control participants* Male = 28 Female = 25 Mean age 30.8 ± 11.70	To detect whether psychiatric symptom frequency is higher in AA patients than in healthy controls	HADS Turkish Version	No difference in anxiety and depression was detected between patients and controls HADS anxiety scores were > 11 (clinical cut-off) in 10 (23.8%) AA patients HADS depression scores were > 8 (clinical cut-off) in 13 (31%) AA patients	11
Sayar et al. (2001) Turkey	Case-Control	*31 Male Turkish Soldiers with AA* The patients had 1-8 discrete patches with surface areas ranging from 2-150cm2. Mean age 23.8 ± 2.5. *40 Controls* - Healthy soldier volunteers from the same military background, with a mean age of 22.7 ± 2.3.	To assess the prevalence of depression, anxiety, hopelessness, psychological distress and alexithymia in young Turkish soldiers with AA compared to a health control group from the same military background.	BDI validated in a Turkish population BHS STAI-1 STAI-2	Patients with AA scored significantly higher than 'normal' controls on all measures. BDI: AA (M = 21.0 SD = 10.2) Control (M = 15.2 SD = 8.5) $p < 0.05$ BHS: AA (M = 9.9 SD 5.4) Control (M = 5.1 SD = 3.4) $p < 0.01$ STAI-1: AA (M = 46.0 SD = 10.7) Control (M = 39.5 SD = 5.2) $p < 0.01$ STAI-2: AA (M = 51.5 SD = 9.0) Control (M = 47.0 SD = 6.5) $p < 0.05$ 55% of AA patients were in the range of clinical depression and 32% displayed hopelessness. Depression was found to be associated to global distress, trait anxiety and hopelessness.	11
Gupta et al. 1997 Canada	Cross-sectional	*44 AA dermatology outpatients* AA= 13 AT = 3 AU = 28 Mean age 44.7 ± 11.6 years Males = 11 Females = 33	To determine the dermatologic and psychologic characteristics of patients who reported an association between stress and their AA (stress reactivity) versus those that did not report such an association.	BSI STPI CRSD	High stress reactivity in AA was associated with significantly higher depression scores (p = 0.0001) which were in the range for a major depressive disorder.	11

Author (s) Country	Study design	Sample	Aim of study	Measures	Description of Findings	Quality rating
Baghestani et al. 2015 Iran	Case-control	*68 AA patients* Male = 72% Female = 18% Mean age 35.4 ± 7.6 Age range 19-64 *68 Healthy controls* Male = 72% Female = 18% Mean age 33.8 ± 8.1 Age range 20-63	To investigate the severity of anxiety and depression in patients with AA.	HAM-A HAM-D Persian versions	Mean anxiety and depression scores were higher in the patient sample: HAM-A: 12.76 ± 7.21 vs 8.54 ± 6.37, $p = 0.003$. HAM-D: 12.84 ± 4.03 vs 6.22 ± 4.95, $p = 0.001$. Odds ratio analyses revealed that patients with AA were exposed to anxiety and depression approximately three and five times more than normal people respectively. 32 patients with AA suffered with anxiety (47%) and 38 suffered with a degree of depression (56%) Mean scores for anxiety ($p = 0.038$) and depression ($p = 0.041$) in patients with AA increased significantly with increasing disease severity. The prevalence of anxiety ($p = 0.012$) and depression was significantly ($p = 0.023$) higher in patients with AA who had received a secondary level of education compared with those who had only received a primary level of education	11
Alfani et al. 2012 Italy	Cross-sectional	*73 AA patients* AA = 45 AT = 19 AU = 9 Male = 33 Female = 40 Mean age 35.2 ± 9.2 Age range 18-73, *73 healthy controls* Male = 33 Female = 40 Mean age 35.1 ± 9.1	The present study evaluated the personality traits and psychological status of patients with alopecia.	MMPI-2 Italian version in addition to a psychologic al interview	AA patients had higher proportions of above cut-off scores particularly on the anxiety ($p = 0.001$), depression ($p = 0.001$), and family problems ($p = 0.028$) scales compared with the controls. Patients scoring high on the depression scale were often described as depressive, sad, tense, weak, and self-doubting. They might have pessimistic worries, show a lack of interest, involvement and initiative, and have feelings of in-efficiency, somatization and indirect expressions of approval being characteristic, and may feel stressed by their general psychosocial environment. Higher scores for depression were observed for patients with an intermediate duration of disease (i.e. 6–11 months)	11
Gulec et al. (2004)	Case-Control	*55 AA patients* AA = 49 AT = 2	To determine the significance of psychological factors, such as stressful life events as triggers in	BDI BAI	No significant difference between patient and control groups with regard to depression and anxiety.	12

Author (s) Country	Study design	Sample	Aim of study	Measures	Description of Findings	Quality rating
Turkey		AU = 1 Males = 34 Females = 18 Mean age 31.53 ± 12.61 (range 18-65 years) *52 Controls (hospital staff)* Males = 34 Females = 18 Mean age 31.90 ± 12.33 years (range 18-62 years)	the onset and/or exacerbation of AA. Depression and anxiety levels of AA patients were also investigated as well as the impact of the disease on HRQoL			
Ruiz-Doblado et al. (2003) Spain	Cross-sectional	*32 Patients with patchy AA* Male = 15% Female = 85% Age range 16-67 years	To evaluate the psychiatric comorbidity of patients with AA (patchy form), as well as the repercussions in their everyday lives and their adaptation to the illness To determine the variables affecting patients' positive and negative adaptation to the illness.	SCAN and the ICD10	Adjustment disorders with anxiety and depressive symptoms (25.9%), GAD (22.2%) and depressive episodes (7.4%) were the most prevalent psychiatric diagnoses in AA patients. Social Phobia = 7.4%. The presence of generalised anxiety ($p = 0.003$) or a depressive episode ($p = 0.020$) was associated with worse adjustment.	12
Kose et al. (2000) Turkey	Intervention	*18 Male patients with AA* recruited from a military hospital Mean age 21.3 Age range 20 - 26	To evaluate patients with AA psychometrically before and after dermatological treatment and investigate the impact of dermatological recovery on the psychological well-being of the patients.	BDI Total BHS STAI BSI	No significant effect of intervention on psychometrics. Depression was found to be associated with alexithymia, global distress, state and trait anxiety and hopelessness. Hopelessness was associated with depression and state anxiety. State anxiety was associated with all of the indices whereas trait anxiety was unrelated to alexithymia	12
Saleh et al. (2008) Egypt	Cross-sectional	*50 AA patients* Males = 28 Females = 22 *50 Psoriasis Patients* Males = 25 Females = 25 *50 Vitiligo Patients* Males = 25 Females = 25 Age range 18-65	To determine the psychiatric morbidity and quality of life in vitiligo, psoriasis and AA in Egyptian patients attending an outpatient clinic.	GHQ TMAS SDS	Anxiety was detected in 24% of AA patients, 12% of psoriasis patients and 14% of vitiligo patients Depression was detected in 16% of AA patients, 30% of psoriasis patients and 24% of vitiligo patients (No statistical differences found in anxiety or depression between groups) Suicidal thoughts occurred in 6% of vitiligo patients, 8% of psoriasis patients and 8% of AA patients. Suicidal attempts occurred in 2% of vitiligo patients, 4% of psoriasis patients and 2% of AA patients respectively.	13

Author (s) Country	Study design	Sample	Aim of study	Measures	Description of Findings	Quality rating
					There was no significant difference in suicidal attempts. Suicidal thoughts were significantly related to disease severity in the 3 groups ($p < 0.05$) In the AA group married patients had significantly less psychiatric morbidity compared to unmarried patients ($p < 0.05$). There was a highly significant relation between poorer QoL and depression ($p < 0.05$) and anxiety ($p < 0.05$) in all groups.	
Sorour et al. (2017) Egypt	Cross-sectional	*208 AA patients* out of a sample of 1042 patients with different chronic dermatological diseases. Males = 122 Females = 86 Inclusion criterion: Age range 17-60	To present an analysis of psychiatric morbidities associated with chronic dermatologic diseases among a group of dermatology outpatients in 3 of the busiest clinics in Cairo.	Psychiatric evaluation using the DSM IV	115 AA patients (55.29%) were diagnosed with depression, 41 (19.71%) were diagnosed with anxiety, 80 (38.46%) expressed suicidal ideation, 9 (4.33%) had attempted suicide and 6 patients (2.88%) were diagnosed with obsessive compulsive diseases.	14
Brajac et al. (2003) Croatia	Case-control	*45 patients with patchy AA* Males = 17 Females = 28 Mean age 40.24 ± SD 13.01 Age range 20-65 Divided into two groups: A1: 1st onset AA = 26 RA: Recidivism of AA = 19 *45 patients with benign scalp lesions* being treated at the same hospital Males = 22 Females = 23 Mean age 40.04 ±SD 10.83 Age range 18-65	To further explore the role of psychosocial factors in the onset and course of AA by examining the relationship between various psychosocial variables and AA, and the role of trait anxiety in patients with first onset of AA as well as recidivism of AA	MSP (to measure emotional aspects of distress) STAI[2]	A significantly higher degree of trait-anxiety was observed among patients in both AA subgroups than in the control group. A1: $M = 31.27 ± 14.22$, Control: $M = 21.11 ± 11.20$, $p = 0.004$ RA: $M = 33.42 ± 12.71$, Control: $M = 21.11 ± 11.20$, $p = 0.002$	14
Sellami et al. (2014) Tunisia	Case-control	*55 patients with AA.* Male = 24 Female = 26 Mean age 32.92 SD 11.81 Age range 18-60 *50 healthy controls* recruited from hospital staff	To investigate a possible relationship between AA and alexithymia as well as two other emotional dimensions, anxiety and depression.	HADS	Anxiety was detected in 31 patients (62%). Depression was detected in 19 patients (38%) The patient group had significantly more anxiety ($p = 0.005$) and depression ($p = 0.047$) than the control group Anxiety was responsible for 14.7% of variation in Alexithymia (14.7%) Depression was significantly more frequent in women with AA compared to men (odds ratio [OR] = 4.433, $p = 0.016$)	15

Author (s) Country	Study design	Sample	Aim of study	Measures	Description of Findings	Quality rating
Yu et al. (2016) China	Cross-sectional	*130 AA patients* Male = 54 Female = 76 Mean age 31.78 ± 10.34 years *212 patients with Androgenetic Alopecia (AGA)* Mean age 30.43 ± 7.8 years Male = 133 Female = 79	The aim of the present study was to provide more information on the role of illness perception in AGA and AA patients in China, and to further investigate the relationship of illness perception with psychological disorders and dermatological QoL	SAS[2] SDS BIPQ	Unmarried patients with higher depression scores had a significantly higher risk for having AA compared to those who had lower depression scores OR = 3.939, $p = 0.024$) The prevalence of clinical depression and anxiety might have been higher in the AGA group. Depression: AGA = 17% AA = 14.6% $p = 0.036$ Anxiety: AGA = 18.9% AA = 13.8% $p = 0.023$ Emotional representation, concern, consequence and identity items on the illness perception measure (BIPQ) were associated with anxiety, depression and QoL in both groups.	15

Notes. BAI: Beck Anxiety Inventory. BDI = Beck Depression Inventory. BHS = Beck Hopelessness Scale. BIPQ = Brief Illness Perception Questionnaire. BSI = Brief Symptom Inventory. CRSD = Carroll Rating Scale for Depression. DIS = Diagnostic Interview Schedule. DSM IV = Diagnostic and Statistical Manual of Mental Disorders 4th Edition. GAD-7 = Generalised Anxiety Disorder Questionnaire. GHQ = General Health Questionnaire. GHQ12 = General Health Questionnaire - 12 item. HAM-D = Hamilton Rating Scale for Depression. HADS = Hospital Anxiety and Depression Scale. HAM-A = Hamilton Rating Scale for Anxiety. ICD-10 = International Classification of Disease 10th Edition. MMPI-2 = Minnesota Multiphasic Personality Inventory-2. MSP = Lemyre and Tessier's Mesure de Stress Psychologique. PHQ-9 = Patient Health Questionnaire-9. PSE = Present State Examination. SAS = Sinha's Anxiety Scale. SAS[2] = Self-rating Anxiety Scale. SDS = Self-rating Depression Scale. SCAN = Schedules for Clinical Assessment in Neuropsychiatry. SIS = Somatic Inkblot Series. SPIN = Social Phobia Inventory. STAI = State Trait and Anxiety Inventory. STAI-1 = State Anxiety Inventory. STAI-2 = Trait Anxiety Inventory. STAI[2] = Speilberg's Trait Anxiety Inventory. STPI = Speilberger State-Trait Personality Inventory. TMAS = Taylor' Manifest Anxiety Scale.

Results

Overview of data

This review included data for 1363 adults with AA from 22 papers describing samples from 21 studies with one overlapping sample, and AA sample sizes ranging from 3 (Bashir, Dar, & Rao, 2010) to 279 (Montgomery et al., 2017). The same data for 44 AA patients was used by two studies in this review (Gupta et al, 1997; Gupta and Gupta, 1998), which has been accounted for in the total figure. Studies were conducted in 13 different countries around the world and published between 1983 and 2017. Most of the studies in this review measured both anxiety and depression, however two studies focused solely on depression (Bashir et al., 2010; Gupta & Gupta 1998). Two studies included findings for suicidal ideation (Gupta & Gupta 1998; Saleh, Salem, El-Sheshetawy, & El-Samei, 2008).

Study designs and sample characteristics

Of the 22 studies included in the review, 11 were cross-sectional, 10 were case-control and one was a non-randomised intervention study that investigated the impact of recovery from AA post dermatological treatment on psychological wellbeing (Kose, Sayar, & Ebrinc, 2000). Five studies included only an AA sample, whilst nine studies also included a healthy control sample, and two studies included an AA sample, another dermatology patient sample and a healthy control sample (Devar, 1983; Karia et al, 2015). Eight studies included patients with other dermatological conditions including tinea versicolor, psoriasis, vitiligo, benign scalp lesions, atopic dermatitis, acne and androgenetic alopecia (AGA).

Most studies included both male and female participants with AA, however four studies focused on men with AA (Devar, 1983; Bashir et al., 2010; Kose et al., 2000; Sayar, Kose, Ebrinc, & Setin, 2001). Twenty of the studies in this review took place in dermatology outpatient clinics, two of which were based in military hospitals (Kose et

al., 2000; Sayar et al., 2001). One study merged data from several studies, involving

patients with acne, atopic dermatitis, psoriasis and AA for the purposes of comparison

(Gupta & Gupta, 1998), and one study employed a survey to the mailing list of Alopecia

UK (Montgomery et al., 2017).

Measures

Studies utilised a broad range of self-report measures and clinician led

diagnostic tools. Table 2. provides summary of the frequency of use of different

measures.

Table 2. Frequency of use of different measures

Combined Measures of Anxiety and Depression/General Measures	No. of studies
Brief Symptom Inventory (BSI)	2
General Health Questionnaire (GHQ/GHQ-12)	2
Hospital Anxiety and Depression Scale (HADS)	2
Lemyre and Tessier's Mesure de Stress Psychologique (MSP)	1
Minnesota Multiphasic Personality Inventory-2 (MMPI-2)	1
Present State Examination (PSE)	1
Somatic Inkblot Series (SIS)	1
Speilberger State-Trait Personality Inventory (STPI)	1
Depression Specific Measures	**No. of studies**
Beck Depression Inventory (BDI)	5
Carroll Rating Scale for Depression (CRSD)	3
Hamilton Rating Scale for Depression (HAM-D)	3
Beck Hopelessness Scale (BHS)	2
Self-rating Depression Scale (SDS)	2
Patient Health Questionnaire-9 (PHQ-9)	1
Anxiety Specific Measures	**No. of studies**
Hamilton Rating Scale for Anxiety (HAM-A)	3
Becks Anxiety Inventory (BAI)	2
State Trait and Anxiety Inventory STAI (includes STAI-1 and STAI-2)	2
Taylor' Manifest Anxiety Scale (TMAS)	2
Generalised Anxiety Disorder Questionnaire -7 (GAD-7)	1
Sinha's Anxiety Scale (SAS)	1
Self-rating Anxiety Scale (SAS[2])	1
Social Phobia Inventory (SPIN)	1
Speilberg's Trait Anxiety Inventory (STAI[2])	1
Diagnostic Tools	**No. of studies**
Diagnostic and Statistical Manual of Mental Disorders IV (DSM IV)	2
International Classification of Disease-10 ICD10	2
Diagnostic Interview Schedule (DIS)	1
Schedules for Clinical Assessment in Neuropsychiatry (SCAN)	1

Note: STAI-1 = State Anxiety Inventory. STAI-2 = Trait Anxiety Inventory.
GHQ-12 = General Health Questionnaire - 12 item

The most commonly used combined measure of anxiety and depression was the

Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983), which was

used in two studies, one of which utilised the Turkish version (Aydemir, Guvenir, Kuey, & Kultur 1997). The most commonly used anxiety specific measure was the Hamilton Rating Scale for Anxiety (HAM-A; Hamilton, 1959), which was used in three studies, and the most commonly used depression specific measure was the Beck Depression Inventory (BDI; Beck, Ward, Mendelson, Mock, & Erbaugh, 1961) which was used in five studies, one of which used the Turkish version (Hilsi, 1989).

The most commonly used clinician led diagnostic tools were the ICD-10 (WHO, 1993) and the DSM-IV (APA,1994), both of which were used in two studies. Clinician led diagnostic tools were either used alongside a structured clinical interview, self-report measures, or both, and in one study the Minnesota Multiphasic Inventory-2 Italian version (MMPI-2; Hataway & McKinley, 1995) was used as a combined measure of anxiety and depression in conjunction with a psychological interview.

Prevalence Rates

Studies reported point prevalence rates of 4% (Karia et al., 2015) to 63% (Ataseven, Saral, & Godekmerdan, 2011) for anxiety, and 7.4% (Ruiz-Doblado et al., 2003) to 56% (Baghestani, Zare, & Seddigh, 2015) for depression. Only one study examined lifetime prevalence, reporting rates of 39% for both anxiety and depression, and 23% for phobic disorder (Colon et al., 1991). Regarding specific forms of anxiety and depression, studies reported the following prevalence rates: Social phobia (7.4%) (Ruiz-Doblado et al., 2003), 'obsessive compulsive diseases' (2.88%) (Sorour, Abdelmoaty, Bahary, & El Birqdar, 2017), adjustment disorder with depressed mood (14%), dysthymia (4%) (Chaudhury et al., 2001) and hopelessness (32%) (Sayar et al., 2001). One study reported rates of depression split by level of severity, i.e. 33.3%, 18.5% and 7.4% for mild, moderate and severe depression respectively (Ataseven et al., 2011) and two studies reported prevalence rates of suicidal thoughts and attempts, that

were 8% and 2% (Saleh et al., 2008) and 38.46% and 4.33% (Sorour et al., 2017) respectively.

The nature of anxiety and depression in AA

Psychosomatic and reactive models of anxiety and depression. Three studies described how their findings support the notion that anxiety and depression occur as a reaction to AA. Baghestani et al. (2015) drew this conclusion based on odds ratio analyses which showed that patients with AA were exposed to anxiety three times more than 'normal' people, and to depression five times more than 'normal' people. In Devar's (1983) study entitled 'Is Alopecia Psychosomatic?', anxiety and depression were found to be significantly higher in patients with AA than in healthy controls. However, when the two groups were compared for factors 'F' and 'O' of Cattell's 16 Personality Factor questionnaire (16PF; Cattell, Eber, & Tatsuoka, 1970), which measure the traits 'depressive agitated anxiety' and 'depressive tendency' no difference was found, which led the authors to conclude that the depression found in AA is a mood state and not a trait, and therefore more likely to be a reaction to AA than a cause. In a similar vein, Chaudhury et al. (2001) deduced that since the AA patients in their study were symptomatic at the time of evaluation, and depressive symptoms preceded the onset of AA in only two of nine patients found to have depressive disorders, it is likely that anxiety and depression in AA patients is secondary to hair-loss. Data supporting a 'reactive theory' of depression and anxiety was however limited and of poor quality, i.e., based on small sample sizes and retrospective speculation, without consideration of confounding variables (or biological indicators).

Yazici et al. (2006) concluded that anxiety and depression did not appear to play a role in the pathogenesis of AA, since they found no difference in anxiety and depression scores between AA patients and healthy controls or higher risk for having AA, in patients with anxiety and depression.

Two studies discussed how their findings neither supported an etiologic or reactive role of anxiety and depression in AA. In one study by Colon et al. (1991), although three of the 31 patients with AA identified depression as causing the onset of their AA, the authors found an almost equal onset of major depression, GAD and phobic disorder before and after the emergence of AA. In the same study, individuals with AA reported high rates of anxiety (58%) and mood disorders (38%) amongst their first degree relatives, which led the authors to speculate about a possible increased risk for AA in patients with a positive family history of these psychiatric disorders. In Kose et al.'s (2016) intervention study in which levels of anxiety and depression did not change following successful treatment of AA, the authors concluded that recovery of AA symptomatology might be independent of psychological variables, and that their findings pointed towards a biological mechanism in AA rather than a stress model.

The experiential nature of depression and anxiety. One study in this review utilised a mixed-methods design (Montgomery et al., 2017). One of the participants in this study described how having to wake up and put a wig on every morning; and feeling unable to take off a wig in front of someone new, caused feelings of depression; and 65% of participants worried about affording new wigs. The majority of participants in this study (82.6%) had AA, however it was not possible to cross-reference qualitative feedback to type of alopecia. Nonetheless, these findings provide an indication of experiences that may give rise to anxiety and depression in individuals with AA who use wigs to conceal their hair loss.

Chaudhury et al.'s (2001) assessment of patients with AA using the Somatic Inkblot Series (SIS: Cassell & Dubey, 1997), a structured, projective, diagnostic procedure revealed, in the authors' own words, 'depressive content, hostility, feelings of insecurity, emotional blocking, lot of inner cry, conflicts in relation to opposite sex and

unhealthy body imagery with preoccupation with his symptoms of hair loss'. The SIS is normally used as an adjunct to therapy, during which responses can be further explored to elicit deeply defended material. In the absence of more detailed information about the outcome of this procedure, the reader is left with a somewhat generic description of the patient experience.

Finally, in a study of the psychological status of patients with AA, Alfani et al. (2012) reported that patients who scored high on depression, hysteria, psychopathic deviance, psychasthenia (a disorder characterised by phobias, obsessions, compulsions and excessive anxiety) and schizophrenia scales, were often described as 'depressive, sad, tense, weak, and self-doubting. They might have pessimistic worries, show a lack of interest, involvement and initiative, and have feelings of in-efficiency, somatization and indirect expressions of approval being characteristic, and may feel stressed by their general psychosocial environment'. However, it is not possible to ascertain which observations relate to anxiety and depression per se.

Comparisons with healthy controls

Ten studies compared anxiety and depression in adult AA patients and healthy controls based on mean scores (Bhagestani et al., 2015; Chaudhury et al., 200; Devar, 1983; Gulec, Tanriverdi, Duru, Saray, & Akcali, 2004; Sayar et al., 2001) or percentage prevalence rates (Aghaei, Saki, Daneshmand, & Kardeh, 2014; Alfani et al., 2012; Karia et al., 2015; Sellami et al., 2014; Yazici et al., 2006). Of these, seven found significantly higher levels of anxiety and depression in patients with AA compared with healthy controls (Aghaei et al., 2014; Alfani et al., 2012; Bhaghestani et al. 2015 Chaudhury et al; 2001; Devar, 1983; Sayar et al., 2001; Sellami et al.), two found no difference (Yazici et al., 2006; Gulec et al., 2004) and one study reported no difference for anxiety, i.e. a 4% prevalence rate of anxiety disorder in both groups, and higher levels of

depression in AA patients, i.e. an 18% prevalence rate of depression in patients with AA versus no cases of depression in healthy controls (Karia et al., 2015).

Comparisons with other dermatological conditions

The eight studies that examined anxiety and depression in patients with AA and other dermatological conditions reported mixed findings. One study found trait anxiety to be higher in AA patients (first onset and recidivism) than in a control group of patients with benign scalp lesions (Brajac, Tkalcic, Dragojevic, & Gruber, 2003). Two studies found no difference in anxiety and depression between patients with AA and those with tinea-versicolor of the face (Devar et al., 1983) psoriasis and vitiligo (Saleh et al., 2008). Saleh et al. (2008) also found no difference in rates of suicide attempts between patients with AA, psoriasis and vitiligo. Similarly, Yu, Tan, Song and Yang. (2016) found no difference in mean anxiety and depression scores between patients with AA and those with AGA, however when these groups were compared based on prevalence rates of anxiety and depression, these were found to be significantly higher in the AGA group. A study by Gupta and Gupta (1998) found that patients with AA reported lower levels of depression and suicidal ideation than those with psoriasis, acne and atopic dermatitis.

In three cross-sectional studies, differences in co-morbidy between patient groups were not analysed for statistical significance. Karia et al. (2015) reported higher rates of anxiety and depression in AA than in psoriasis, whilst Sorour et al. (2015) reported higher rates of depression but lower rates of anxiety in patients with AA compared to those with psoriasis, chronic urticuria, atopic dermatitis and acne. Bashir et al. (2010) on the other hand, reported lower rates of depression in AA compared with a range of other dermatological conditions, however their sample of 113 male dermatology outpatients only included three patients with AA, of whom one received a diagnosis of depression.

Relationships with other variables

Demographic variables. Two studies reported gender differences in the prevalence of anxiety and depression. One study reported that females were differentiated from males by a higher prevalence of anxiety and depression, however the authors did not report whether this difference was statistically significant (Baghestani et al., 2015). Another study found that depression was significantly more frequent in women with AA compared to men, and that unmarried patients with higher depression scores were at a significantly higher risk of having AA compared to those who had lower depression scores (Sellami et al., 2014). Baghestani et al. (2015) reported that the prevalence of anxiety and depression was significantly higher in patients with AA who had received a secondary level of education compared with those who had only received a primary level of education.

Clinical and appearance related variables. Three studies reported relationships with severity of AA. Baghestani et al. (2015) found a significant increase in mean scores for anxiety and depression in AA patients with greater severity of hair loss. Saleh et al. (2008) found that suicidal thoughts were significantly related to greater severity of AA, vitiligo and psoriasis. In more severe forms of AA, individuals lose their facial hair, including eyebrows, eyelashes, beard and nose hair. Aghaei et al. (2014) reported that in patients with 'facial involvement' of AA, there were significantly higher rates of depression and anxiety. However, it would have been helpful to the reader for the authors to clearly define 'facial involvement', as there were also categories for 'eyelash involvement' and 'eyebrow involvement' in their study.

In Colon et al.'s (1991) study of the lifetime prevalence of psychiatric disorders in patients with AA, a significant relationship was found between the experience of patchy episodes of AA and a lifetime diagnosis of generalised anxiety disorder (GAD).

Of the 23 patients who had experienced ≥ one episode of patchy AA, 12 (52%) had a lifetime diagnosis of GAD, compared to none of the eight patients who had never had a patchy episode. However, these findings are difficult to interpret without a proper understanding of the course and severity of AA in patients who never had a patchy episode. Presumably for these patients hair-loss was more sudden and therefore less unpredictable.

Another clinical variable found to be associated with anxiety is duration of AA. Colon et al. (1991) reported that the four AA patients with a lifetime diagnosis of panic disorder in their sample of 31 AA patients, had a shorter mean duration of AA than those without (4.8 versus 15.2 years), although the authors themselves acknowledged that this sub-sample was too small to allow for generalisation. Similarly, Alfani et al. (2012) found significantly higher scores for Psychasthenia (an anxiety disorder) in patients with an intermediate duration of AA (6–11 months) compared with shorter periods (< 6 months) and longer periods (≥ 12 months).

Finally, in Montgomery et al.'s (2017) study in which 83% participants had AA, participants who reported worries about not wearing a wig had significantly higher levels of depression, anxiety and social anxiety.

Quality of life (Qol) and adjustment. Two studies reported a relationship between anxiety and depression in patients with AA and poorer quality of life. However, the studies differed in terms of the statistical analyses and QoL measures they used, making the findings difficult to compare. Karia et al. (2015) found a significant negative correlation of QoL with anxiety, using the World Health Organisation Quality of Life assessment (WHO-QOL BREF; Skevington, Lotfy, & O'Connell, 2004), and Saleh et al. (2008) reported a significant relationship between poorer QoL and anxiety and depression using the Dermatology Life Quality Index (DLQI; Finlay & Khan, 1994)

and PCASEE scale (Bech, 1996) to compare mean QoL scores of AA patients who were positive and negative for anxiety and depression,.

In patients with patchy form AA, the presence of generalised anxiety and depression has also been associated with worse adjustment to illness (Ruiz-Doblado et al., 2003) as measured using the Psychological Adjustment to Illness Scale (PAIS; Derogatis, 1986).

Psychological variables. Two studies reported findings related to patients' perceptions of their illness. Gupta et al. (1997) found that high stress reactivity, i.e. the degree to which patients felt a stressful situation made their AA worse, on a scale of 1-10, was associated with significantly higher depression scores, that were in the range for a major depressive disorder. Yu et al. (2015) found that aspects of illness perception, as measured by the Brief Illness Perception questionnaire (BIPQ; Broadbent, Petrie, Main, & Weinman, 2006) correlated with anxiety and depression in patients with AA. Namely, 'identity', i.e., how much patients felt they experienced the symptoms of their illness and 'emotional representation', i.e., how much patients felt their illness affected them emotionally; both measured on a scale of 1-10.

Relationships were also found with alexithymia, which is as a deficit in the awareness and identification of emotional states. One study reported that anxiety was responsible for 14.7% of the variation in alexithymia, in a sample of 55 patients with AA (Sellami et al., 2014). Another study reported an association between pre-treatment scores for depression and state anxiety in patients with AA and alexithymia (Kose et al., 2000). However, the sample was small, all male and recruited from a military hospital, thereby limiting the generalisability of this finding.

Kose et al. (2000) also observed inter-relationships between different forms of anxiety and depression present in AA patients prior to treatment, and found that trait

anxiety was not related to alexithymia. The authors took this to mean that the distress associated with AA must be reflected in state anxiety, which may in turn influence other psychological variables. Another study in this review conducted by the same authors, which also took place in a military setting, found that depression was associated to global distress, state anxiety, trait anxiety, and hopelessness, corroborating the notion of inter-relationships between different forms of anxiety and depression in AA (Sayar et al., 2001), albeit with similar limitations around generalisability.

Methodological critique of studies

Scores on the Downs and Black (1998) checklist for the studies in this review ranged from six (low quality) (Devar, 1983) to 15 (fair quality) (Sellami et al., 2014; Yu et al., 2016) however, 18 of the 22 studies were rated low quality (See Appendix D). These ratings should be considered in light of the fact 21 studies were cross-sectional and cohort designs and one was a non-randomised intervention study. Questions related to randomisation and follow up periods were not applicable to most of the studies in this review, however scores provide an indication of general methodological quality, and the quality of studies relative to one another.

Another key limitation is that AA samples were recruited almost exclusively from dermatology outpatient settings, apart from one study that utilised the mailing list of Alopecia UK (Montgomery et al., 2017). Participants were therefore not representative of people with AA who do not seek support, limiting the generalisability of findings. Also, no studies provided an indication as to whether their AA sample was representative of either the source population from which it was recruited, or people with AA in the local population, and only one study provided details of percentage response rate (Gupta & Gupta, 1998), creating a high risk of non-response bias.

In cross-sectional studies, where data was recorded at a snapshot in time, it is not possible to make temporal associations, or to infer any cause and effect relationships, only associations. Furthermore, only two case-control studies utilised both a clinical and healthy control group (Devar, 1983; Karia et al., 2015) of which only one attempted to control for clinical variables, such as itching, which might in themselves cause anxiety or depression.

The studies were conducted in 13 different countries which may influence the cross-cultural validity of findings. For example, as Sellami et al. (2014) point out, in Islamic countries such as Tunisia or Egypt, women sometimes cover their hair, which may have had an impact on psychological outcomes. However, efforts were made to use language-adapted versions of outcome measures.

Other factors which may limit the generalisability of findings relate to the selection of participants and consideration of confounding variables. Many studies either did not describe how participants were selected (Ataseven et al. 2011; Chaudhury et al. 2001; Gupta & Gupta, 1998; Saleh et al. 2008) or simply stated that samples were recruited consecutively or randomly, without providing any details of how this was carried out, increasing the risk of selection bias. Control groups were generally matched for age, gender, and sometimes other variables, but the criteria for matching was not always provided. Inclusion and exclusion criteria either varied greatly across studies or were not specified. Not all studies excluded participants with other chronic health conditions or who were taking medication, and some studies excluded patients with more severe forms of AA, i.e. AT and AU. These inconsistencies and confounds make meaningful comparisons between the findings of different studies problematic.

A number of studies described the distribution of their AA participants according to degree of hair-loss, as determined by clinical examination or assessment

using the Severity of Alopecia Tool (SALT; Olsen et al., 1999), however noticeably few studies controlled for severity of AA as a potential confounding variable.

The three most recent studies in this review had the largest AA sample sizes of 279 (Montgomery et al. 2017), 208 (Sorour et al., 2017) and 130 (Yu et al., 2016) perhaps indicating attempts to improve on the methodology of earlier studies. However, in general sample sizes were small, and no studies conducted a power calculation. Four studies included all male AA samples, two of which took place in a military setting, where soldiers were reportedly under constant stress, and some AA samples were gender skewed. These factors further limited the generalisability of findings.

Discussion

The first aim of this review was to investigate how anxiety and depression has been assessed in adults with AA. It found that studies have utilised a broad range of self-report measures and clinician led diagnostic tools making it difficult to meaningfully compare their findings. The most commonly used combined and specific measures of anxiety and depression were the HADS (Zigmond & Snaith, 1983), the HAM-A (Hamilton, 1959) and the BDI (Beck et al., 1961). The most commonly used clinician led diagnostic tools were the ICD-10 (WHO, 1993) and the DSM-IV (APA, 1994). It has been argued that the nine-item Health Questionnaire (PHQ-9; Kroenke, Spitzer, & Williams, 2001) and seven-item Generalised Anxiety Disorder Assessment (GAD-7; Spitzer, Kroenke, Williams, & Lowe, 2006) might be a pragmatic option to assess depression and anxiety in people with dermatological conditions, as they are free and widely used in primary care (Thompson, Kent, & Smith, 2002). Indeed, these measures were used in the most recently published study in this review (Montgomery et al., 2017). Moreover, both are based on DSM-IV criteria.

The second aim of this review was to gather information about symptoms of anxiety and depression in people with AA, including comparisons with healthy individuals and patients with other dermatological conditions. Measures revealed point prevalence rates of 4% to 63% for anxiety and 7.4% to 56% for depression. Findings also suggest that levels of anxiety and depression in people with AA are higher than in healthy individuals. In comparison, Koo et al. (1994) who evaluated psychiatric comorbidity in 294 community-based AA patients of all ages, reported rates of generalised anxiety and major depression of 18.2% and 8.8% respectively compared with 2.5% and 1.3 to 1.5% in the general population. Koo et al.'s (1994) findings also suggest that people with AA experience anxiety and depression more than healthy individuals, however the prevalence rates reported in this review are much broader in range. This is most likely due to the smaller sample sizes of studies in this review, for example the highest rate of 63% for anxiety was calculated in a sample of 27 adults with AA. It might also be due to studies conceptualising anxiety and depression in different ways, as with the highest rate of 56% for depression, which was based on 38 out of 68 patients with AA suffering with some degree of depression; or the use of different measures. It is worth noting that only one study in this review examined lifetime prevalence as opposed to point prevalence, reporting a life-time prevalence rate of 39% for both anxiety and depression, and 23% for phobic disorder (Colon et al., 1991). A recent review of the epidemiology and burden of AA by Fricke and Miteva (2015) cited a 38% to 39% lifetime prevalence of depression and a 39% to 62% prevalence of GAD in people with AA. The highest prevalence rate for anxiety of 62% reported by Fricke and Miteva (2015) is in line with the findings of this review.

Studies were reviewed for their views on the role of anxiety and depression in the etiopathogenesis of AA, as well as any findings regarding the qualitative experience of anxiety and depression in adults with AA. Findings were mixed but leaned towards a

view of anxiety and depression occurring as a reaction to AA, as concluded by three studies. (Baghestani et al., 2015; Devar et al., 1983; Chaudhury et al., 2001). This highlights the need for a better understanding of the psycho-neuro-immunological basis of AA, as has been suggested previously (Hunt & McHale, 2005), which may require greater research collaboration between medical and psychological professionals. The predominant view of anxiety and depression as reactive provides support for the need to screen for psychological difficulties that arise as a result of AA.

Less information was available about the experiential nature of anxiety and depression in AA due to most studies being purely quantitative. However, one mixed methods study revealed that the need to conceal hair-loss on a daily basis might contribute to feelings of anxiety and depression (Montgomery et al., 2017). This finding is corroborated in a study by Wiggins, Moore-Millar and Thomson (2014) which suggests that the daily work put into managing the noticeability of wigs is in itself a huge psychological burden for individuals, and one that is under-estimated. Further qualitative exploration of anxiety and depression in people with AA is recommended.

Studies comparing AA with other dermatological disorders reported mixed findings that may have been related to differences in the way between-group comparisons were conducted, i.e., whether they were based on mean scores for anxiety and depression or prevalence rates. Studies reported lower mean scores for depression and suicidal ideation in patients with AA than in patients with psoriasis, acne and atopic dermatitis (Gupta & Gupta, 1998) and lower prevalence rates of anxiety and depression in patients with AA than in those with AGA, a type of alopecia characterised by diffuse and progressive hair-loss (Yu et al., 2016). This may have been due to the presence of physical discomfort in other skin disorders, as research has shown that the degree of itching in patients with psoriasis and atopic dermatitis is strongly correlated to depressive psychopathology (Gupta, Gupta, Shork, & Ellis, 1994). In Yu et al.'s (2016)

study patients with AGA were more likely to experience scalp itchiness, but also felt they had lower personal control and lesser helpful treatment than AA patients, factors that may have caused greater distress in this patient group. To control for the influence of factors such as itchiness, Brajac et al. (2003) purposefully chose patients with benign scalp lesions as their clinical comparator group and discovered higher levels of trait anxiety in patients with AA, providing some support for the potential influence of physical discomfort on the findings of Gupta and Gupta (1998) and Yu et al. (2016).

The third aim of this review was to investigate what is known about relationships between anxiety and/or depression in adults with AA and other variables. In terms of demographic variables, significantly higher levels of depression were reported by women with AA and unmarried AA patients (Sellami et al., 2014). The latter observation was corroborated by Saleh et al. (2008) whose study reported that married patients had significantly less psychological morbidity in general than unmarried patients. The association with gender may be due to the aesthetic stress placed on women in society (Baghestani et al., 2015) and the symbolic importance of hair to the identity of women (Hunt & McHale, 2005; Synnott, 1982). Whilst both men and women with AA have been found to experience reduced self-esteem, women also report relationship, marital and career difficulties (Schmidt, 2003; Hunt & McHale, 2005). Regards marital status, it is possible that an un-established personal and social-life in people with AA who are unmarried, might lead to greater concerns about the future, causing increased anxiety and depression (Sellami et al., 2014). One study found that anxiety and depression was higher in AA patients who had received a secondary versus a primary level of education (Baghestani et al., 2015). This may have been linked to differences in literacy and comprehension of the outcome measures, or in personal thresholds for wellbeing related to socio-economic factors.

With respect to clinical variables, increased severity of AA (Baghestani et al., 2015) and AA with facial involvement (Aghaei et al., 2014), were found to be associated to higher levels of anxiety and depression. One or more patchy episodes of AA (Colon et al., 1991) and a shorter to intermediate duration of AA (Colon et al., 1991; Alfani et al., 2012) were found to be associated to greater anxiety. With increasing hair loss, and in turn increasing disfigurement, challenges to concealment and identity also become greater, which is likely to be emotionally distressing. As the pattern of hair loss in AA is highly unpredictable, it is easy to see how this might provoke increased anxiety. In particular, the recurrence of episodes can give rise to continuing feelings of anxiety and loss (Hunt & McHale, 2005). Research has shown that as the use of problem-oriented strategies becomes more limited, people with AA evolve towards embodied acceptance (Welsh & Guy, 2009). It is possible therefore that at shorter to intermediate duration time-points, patients begin to realise the impact of AA, but have not yet developed the necessary emotional-coping strategies. Anxiety and depression were also found to be associated with poorer quality of life (Karia et al., 201; Saleh et al., 2008), and worse illness adjustment (Ruiz-Doblado et al., 2003) in patients with AA, highlighting the need for psychological support.

Psychological variables found to be associated with anxiety and depression in AA were illness perceptions (Gupta et al., 1997; Yu et al., 2015) and alexithymia (Kose et al., 2000; Sellami et al., 2014). The types of illness perception that appeared to be deleterious were stress-reactivity, identity and emotional representations (described earlier). These types of perceptions have been found to be common in patients with AA (Firooz, Firoozabadi, Ghazisaidi, & Dowlati, 2005) highlighting the need to provide people with AA with clear information about the condition, and the potential for psychological therapies to help identify unhelpful thoughts and reframe experiences. Alexithymia is defined as difficulty being aware of, recognising, differentiating, and

defining emotions (Sifneos, 1988) and is thought to increase the likelihood of psychosomatic disorders (Kuty-Pachecka, 2015). The association with alexithymia may be due to a lack of social support due to individuals with AA being unable to describe their emotional state.

Review strengths and limitations

No previous review has specifically focussed on anxiety and depression in adults with AA. The findings of this review enable the development of hypotheses that might be tested more rigorously in future research and support the need for psychological support for people with AA. A systematic and comprehensive literature search was performed however a limitation was the absence of grey literatures searches. A meta-analysis could have been conducted to statistically pool data from the different studies in this review and arrive at combined prevalence rates. This might also have allowed for relationships between levels of anxiety and/or depression and different variables to be examined, such as findings based on self-report versus clinical diagnosis, as measures of symptoms are not the same as assessment of clinical depression and anxiety. However, conducting a meta-analysis was decided against, as pooling results obtained from diverse, non-randomised, poor quality studies is not recommended, and can be misleading as the process of synthesis can compound errors or biases in individual studies (CRD, 2008). The heterogeneity of measures used and absence of mean and standard deviation scores for anxiety and depression in a number of studies also did not lend well to conducting a meta-analysis.

The Downs and Black (1998) checklist may not have been the most appropriate quality appraisal tool to use for cross-sectional and case-control studies as a number of the checklist items were not applicable to these study designs. Further modification of the checklist, or the use of a tool such as the Newcastle Ottawa Scale (NOS) (Wells et al., 2016) may have been preferable. The NOS has been adapted for use with cross-

sectional as well as case-control studies (Herzog, 2013) and might have enabled a greater focus on risk of bias, however the review included one intervention study, and Downs and Black ratings were considered helpful in providing a view of the general methodological quality of the articles.

Implications for future research

The findings of this review highlight a paucity of high quality studies examining depression and anxiety in individuals with AA. Future research should consider using larger more representative AA samples, providing greater clarity around how samples are selected and paying greater attention to potential confounding variables including protective factors. The use of a multi-site case-control design would help reduce the risk of local bias, and future studies might consider using a longitudinal cohort design in order to explore the role of anxiety and depression in the onset and development of AA. The review also highlights a gap in the literature for studies evaluating the effectiveness of psychological interventions on anxiety and depression in adults with AA. Given the unpredictable and chronic nature of AA, it is recommended that such studies include a follow-up period. Montgomery et al.'s (2017) mixed methods study illustrated the value of qualitative enquiry for gaining insight into the issues that might give rise to anxiety and depression in this population. Such information would inform the development of targeted psychological interventions.

Clinical Implications

This review highlights that although AA is not considered to be life threatening it can be accompanied by high levels of anxiety and depression and in some cases suicidal ideation, particularly amongst those seeking help. Despite the methodological limitations of the studies, findings suggest the need for a more integrated model of care.

It is important that the psychological impact of AA be taken seriously by GPs, dermatologists and other healthcare professionals. Routine screening of patients with AA who present to dermatology out-patient clinics using simple tools such as the PHQ-9 and GAD-7 has been suggested by Alfani et al. (2012). There is also scope for the involvement of liaison psychiatrists or psychologists in the management of AA, to assist with further evaluation or to supervise the provision of psychological support by the dermatologist; and patients with high levels of anxiety or depression should be referred for psychological intervention (Chaudhury et al., 2001; Ruiz Doblado et al., 2003).

Montgomery et al. (2017) highlight the importance of wigs to the social and emotional wellbeing of individuals with alopecia. Psychological interventions could target self-conscious emotions such as shame and social anxiety. The high level of concern about the cost of wigs also has important implications related to wig provision in the UK National Health Service, and the development of affordable products.

Approaches such as cognitive behavioural therapy (CBT) may be beneficial for working with illness perceptions. Acceptance and Commitment Therapy (ACT) may be helpful for individuals in the intermediate stages of AA and therapy might also be used to facilitate the identification of emotions in AA patients who may be alexithymic in structure and struggle to reach out for social support.

Conclusion

A broad range of measures have been used to examine anxiety and depression in people with AA, revealing point prevalence rates of 4% to 63% for anxiety, 7.4% to 56% for depression, 8% to 38.46% for suicidal thoughts and 2% to 4.33% for suicidal attempts. In general anxiety and depression were found to be higher in AA patients than in healthy controls. In adults with AA, higher levels of anxiety and depression were found to be associated with greater severity of AA, having a secondary versus primary

school level of education, poorer quality of life, worse illness adjustment, certain illness perceptions and alexithymia; greater anxiety was found to be associated with experiencing patchy episodes of AA, and a shorter to intermediate duration of AA; and greater depression has been linked to being female and being unmarried. The notion that anxiety and depression occur as a reaction to AA as opposed to being involved in the onset and development of the condition, received the greatest support. Challenges related to concealing hair-loss may lead to anxious and depressive emotions. Due to the methodological limitations of the studies included in this review findings need to be treated with caution. They suggest the need for more rigorous research in this area and the development of a referral pathway to psychological services for adults with AA.

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Appendix A: Search Strategy

Multi-field Search in Scopus

alopecia OR "alopecia areata" OR "alopecia universalis" OR "alopecia totalis" OR "hair loss" OR bald*

AND

psychosocial OR psychological OR "psychological impact" OR "psychological factors" OR psychiatric OR experience

AND

anxiety OR depression

AND NOT

cancer OR chemotherapy

Limit to 2017

Limit to:

English

Example of full search strategy in PsycINFO

Date range 1860 - 2017 limit to English

An advanced search was carried out using mapped subject headings

The **Explode** function was used to search for articles with the mapped subject heading as well as any more specific terms related to that subject heading.

The **Focus** function was used to search for articles in which the mapped subject heading is considered to be the primary focus of the article.

Free-text searches were combined with subject-heading searches by using the 'search as keyword' function as illustrated below.

The table below shows the free-text words and subject headings used. *Explode and focus were used at the same time for all subject headings* (in order to look for all of the exploded terms and also retrieve articles in which any one of the terms had been designated as the main focus of the article).

Component of Research Question	Free-Text Words	Subject Headings
Terms for Alopecia Areata	Alopecia	Alopecia
	Alopecia areata	
	Alopecia universalis	
	Alopecia totalis	
	Hair loss	
	Bald	
	Balding	
Terms for Psychological Impact	Psychosocial	Psychosocial Factors
	Psychological	Psychological Assessment Psychological Consequence
	Psychological Impact	Psychological Stress Emotional Adustment Mental Health Wellbeing
	Psychological Factors	Psychosocial Factors Anxiety
	Psychiatric	Psychiatric Evaluation Psychiatric Symptoms
	Experience	
Terms for Anxiety and Depression	Anxiety	Anxiety Generalised Anxiety Disorder Social Anxiety Anxiety Sensitivity Anxiety Management Taylor Manifest Anxiety Scale State Trait Anxiety Inventory Anxiety Disorders

	Depression	Depression (Emotion)
		Recurrent Depression
		Major Depression
		Beck Depression Inventory
		Treatment Resistant Depression

The focus function is useful for reducing the number of irrelevant articles, however the author is aware of the limitations of using this function in terms of narrowing the search. Practice searches were carried out to gage the impact of using the focus function on the relevance and number of articles retrieved.

The Boolean operator 'OR' was used to combine search results for different terms for 'Alopecia Areata', 'Psychological Impact' and 'Anxiety and Depression' and the boolean operator 'AND' was used to combine the search results for each component of the research question.

Subject heading and keyword search in MEDLINE

Date range 1860 - 2017 limit to English

The same process was followed in MEDLINE as in PsycINFO. Subject Headings in MEDLINE are referred to as **MeSH terms**. Additional MeSH terms used in MEDLINE were: 'Alopecia', 'Alopecia Areata', 'Adaptation, Psychological', 'Mental Disorders', 'Post-traumatic', 'Psychology', 'Psychiatry', 'Depressive Disorder' and 'Test Anxiety Scale'.

Supplementary search 2018

The search was updated for each database from 2018 to October 27th 2018, however no additional articles met criteria for inclusion in this review.

Appendix B: Excluded Full Text References

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Lyketsos, C. G., Lyketsos, G. C., Richardson, S. C., & Beis, A. (1987). Dysthymic states and depressive syndromes in physical conditions of presumably psychogenic origin. *Acta Psychiatrica Scandinavica*, *76*, 529-534.

Lyketsos, G. C., Stratigos, J., Tawil, G., Psaras, M., & Lyketsos, C. G. (1985). Hostile personality characteristics, dysthymic states and neurotic symptoms in urticaria,

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androgenetica patients* (Doctoral dissertation, Saint Louis University).

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Appendix C: Downs and Black (1998) Quality Checklist

Reporting

1. *Is the hypothesis/aim/objective of the study clearly described?*

yes	1
no	0

2. *Are the main outcomes to be measured clearly described in the Introduction or Methods section?* If the main outcomes are first mentioned in the Results section, the question should be answered no.

yes	1
no	0

3. *Are the characteristics of the patients included in the study clearly described?* In cohort studies and trials, inclusion and/or exclusion criteria should be given. In case-control studies, a case-definition and the source for controls should be given.

yes	1
no	0

4. *Are the interventions of interest clearly described? Treatments and placebo (where relevant) that are to be compared should be clearly described?* Treatments and placebo (where relevant) that are to be compared should be clearly described.

yes	1
no	0

5. *Are the distributions of principal confounders in each group of subjects to be compared clearly described?* A list of principal confounders is provided.

yes	2
partially	1
no	0

6. *Are the main findings of the study clearly described?* Simple outcome data (including denominators and numerators) should be reported for all major findings so that the reader can check the major analyses and conclusions. (This question does not cover statistical tests which are considered below).

yes	1
no	0

7. *Does the study provide estimates of the random variability in the data for the main outcomes?* In non-normally distributed data the inter-quartile range of results should be reported. In normally distributed data the standard error, standard deviation or confidence intervals should be reported. If the distribution of the data is not described, it must be assumed that the estimates used were appropriate and the question should be answered yes.

yes	1
no	0

8. *Have all important adverse events that may be a consequence of the intervention been reported?* This should be answered yes if the study demonstrates that there was a comprehensive attempt to measure adverse events. (A list of possible adverse events is provided).

yes	1
no	0

9. *Have the characteristics of patients lost to follow-up been described?* This should be answered yes where there were no losses to follow-up or where losses to follow-up were so small that findings would be unaffected by their inclusion. This should be answered no where a study does not report the number of patients lost to follow-up.

yes	1
no	0

10. *Have actual probability values been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?*

yes	1
no	0

External validity

11. *Were the subjects asked to participate in the study representative of the entire population from which they were recruited?* The study must identify the source population for patients and describe how the patients were selected. Patients would be representative if they comprised the entire source population, an unselected sample of consecutive patients, or a random sample. Random sampling is only feasible where a list of all members of the relevant population exists. Where a study does not report the proportion of the source population from which the patients are derived, the question should be answered as unable to determine.

yes	1
no	0
Unable to determine	0

12. *Were those subjects who were prepared to participate representative of the entire population from which they were recruited?* The proportion of those asked who agreed should be stated. Validation that the sample was representative would include demonstrating that the distribution of the main confounding factors was the same in the study sample and the source population.

yes	1
no	0
Unable to determine	0

13. *Were the staff, places, and facilities where the patients were treated, representative of the treatment the majority of patients receive?* For the question to be answered yes the study should demonstrate that the intervention was representative of that in use in the source population. The question should be answered no if, for example, the intervention was undertaken in a specialist centre unrepresentative of the hospitals most of the source population would attend.

yes	1
no	0
Unable to determine	0

Internal validity – bias

14. *Was an attempt made to blind study subjects to the intervention they have received?*
For studies where the patients would have no way of knowing which intervention they
received, this should be answered yes.

yes	1
no	0
Unable to determine	0

15. *Was an attempt made to blind those measuring the main outcomes of the
intervention?*

yes	1
no	0
Unable to determine	0

16. *If any of the results of the study were based on "data dredging", was this made
clear?* Any analyses that had not been planned at the outset of the study should be
clearly indicated. If no retrospective unplanned subgroup analyses were reported, then
answer yes.

yes	1
no	0
Unable to determine	0

17. *In trials and cohort studies, do the analyses adjust for different lengths of follow-up
of patients, or in case-control studies, is the time period between the intervention and
outcome the same for cases and controls?* Were follow-up was the same for all study
patients the answer should yes. If different lengths of follow-up were adjusted for by,
for example, survival analysis the answer should be yes. Studies where differences in
follow-up are ignored should be answered no.

yes	1
no	0
Unable to determine	0

18. *Were the statistical tests used to assess the main outcomes appropriate?* The
statistical techniques used must be appropriate to the data. For example nonparametric

methods should be used for small sample sizes. Where little statistical analysis has been undertaken but where there is no evidence of bias, the question should be answered yes. If the distribution of the data (normal or not) is not described it must be assumed that the estimates used were appropriate and the question should be answered yes.

yes	1
no	0
Unable to determine	0

19. *Was compliance with the intervention/s reliable? Where there was non-compliance with the allocated treatment or where there was contamination of one group, the question should be answered no.* For studies where the effect of any misclassification was likely to bias any association to the null, the question should be answered yes.

yes	1
no	0
Unable to determine	0

20. *Were the main outcome measures used accurate (valid and reliable)?* For studies where the outcome measures are clearly described, the question should be answered yes. For studies which refer to other work or that demonstrates the outcome measures are accurate, the question should be answered as yes.

yes	1
no	0
Unable to determine	0

Internal validity

21. *Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population?* For example, patients for all comparison groups should be selected from the same hospital. The question should be answered unable to determine for cohort and case-control studies where there is no information concerning the source of patients included in the study.

yes	1
no	0
Unable to determine	0

22. *Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time?* For a study which does not specify the time period over which patients were recruited, the question should be answered as unable to determine.

yes	1
no	0
Unable to determine	0

23. *Were study subjects randomised to intervention groups?* Studies which state that subjects were randomised should be answered yes except where method of randomisation would not ensure random allocation. For example alternate allocation would score no because it is predictable.

yes	1
no	0
Unable to determine	0

24. *Was the randomised intervention assignment concealed from both patients and health care staff until recruitment was complete and irrevocable?* All non-randomised studies should be answered no. If assignment was concealed from patients but not from staff, it should be answered no.

yes	1
no	0
Unable to determine	0

25. *Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?* This question should be answered no for trials if: the main conclusions of the study were based on analyses of treatment rather than intention to treat; the distribution of known confounders in the different treatment groups was not described; or the distribution of known confounders differed between the treatment groups but was not taken into account in the analyses. In nonrandomised studies if the

effect of the main confounders was not investigated or confounding was demonstrated but no adjustment was made in the final analyses the question should be answered as no.

yes	1
no	0
Unable to determine	0

26. *Were losses of patients to follow-up taken into account?* If the numbers of patients lost to follow-up are not reported, the question should be answered as unable to determine. If the proportion lost to follow-up was too small to affect the main findings, the question should be answered yes.

yes	1
no	0
Unable to determine	0

Power

27. Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%?

yes	1
no	0

Appendix D: Downs and Black (1998) Quality Appraisal of Included Studies

Authors	Downs and Black (1998) Checklist Items																											Total Score
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	
Devar. 1983	1	1	1	0	0	1	1	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	6
Chaudhury et al. 2001	0	1	1	0	1	1	1	0	0	0	0	0	0	0	0	1	0	0	0	1	0	0	0	0	0	0	0	7
Ataseven et al. 2011	1	1	1	0	2	1	0	0	0	0	0	0	0	0	0	1	0	0	0	1	0	0	0	0	0	0	0	8
Bashir et al. 2010	1	1	1	0	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	1	1	1	0	0	0	0	0	8
Montgomery et al. 2017	1	1	1	0	2	1	0	0	0	0	0	0	0	0	0	1	0	1	0	1	0	0	0	0	0	0	0	9
Gupta and Gupta 1998	1	1	1	0	2	1	1	0	0	1	0	0	0	0	0	0	0	1	0	1	0	0	0	0	0	0	0	10
Aghaei et al. 2014	1	1	1	0	1	1	0	0	0	1	0	0	0	0	0	1	0	1	0	1	0	1	0	0	0	0	0	10
Karia et al. 2015	1	1	1	0	2	1	1	0	0	0	0	0	0	0	0	1	0	1	0	0	1	0	0	0	0	0	0	10
Colon et al. 1991	1	1	1	0	1	1	0	0	0	1	0	0	0	0	0	1	0	1	0	0	1	1	0	0	0	0	0	10
Cordan Yazici et al. 2006	1	1	1	0	2	1	1	0	0	1	0	0	0	0	0	1	0	1	0	1	0	0	0	0	0	0	0	11
Sayar et al. 2001	1	1	1	0	2	1	1	0	0	0	0	0	0	0	0	1	0	1	0	1	1	0	0	0	0	0	0	11
Gupta et al. 1997	1	1	1	0	1	1	1	0	0	1	0	0	0	0	0	1	0	1	0	1	0	0	0	1	0	0	0	11
Baghestani et al. 2015	1	1	1	0	2	1	1	0	0	1	0	0	0	0	0	1	0	1	0	0	0	0	0	1	0	0	0	11
Alfani et al. 2012	1	1	1	0	2	1	0	0	0	1	0	0	0	0	0	1	0	1	0	1	0	1	0	0	0	0	0	11
Gulec et al. 2004	1	1	1	0	2	1	0	0	0	0	0	0	0	0	0	1	0	1	0	1	0	1	0	1	0	0	0	12
Ruiz-Doblado et al. 2003	1	1	1	0	1	1	1	0	0	1	0	0	0	0	0	1	0	1	0	1	1	0	0	1	0	0	0	12
Kose et al. 2000	1	1	1	1	2	1	1	0	0	0	0	0	0	0	0	1	0	1	0	1	1	0	0	0	0	0	0	12
Saleh et al. 2008	1	1	1	0	2	1	1	0	0	0	0	0	0	0	0	1	0	1	0	1	1	1	0	1	0	0	0	13
Sorour et al. 2017	1	1	1	0	1	1	0	0	0	1	0	0	0	0	0	1	0	1	0	1	1	1	0	1	1	0	0	14
Brajac et al. 2003	1	1	1	0	2	1	1	0	0	1	0	0	0	0	0	1	0	1	0	1	1	1	0	1	0	0	0	14
Sellami et al. 2014	1	1	1	0	2	1	1	0	0	1	1	0	0	0	0	1	0	1	0	1	1	1	0	1	0	0	0	15
Yu et al. 2016	1	1	1	0	2	1	1	0	0	1	1	0	0	0	0	1	0	1	0	1	1	1	0	1	0	0	0	15

Note. Questions that were not applicable received a score of 0. Scores of: <14 = low quality (red); 14-18 = fair quality (blue); 19-23 = moderate quality (no studies); 24-28 = high quality (no studies)

Section Two: Research Report

The Parent-Child Experience of Pre-adolescent Alopecia Areata

An Interpretative Phenomenological Analysis Study

Abstract

Objective: Alopecia areata (AA) can lead to total loss of hair on the scalp and body and most often begins before the age of 20. There is a gap in the literature on the parent and child experience of pre-adolescent AA. This study aimed to explore the psychosocial experiences of children with AA and their parents as well as their joint experience; including how parents and children naturalistically respond to the condition.

Method: The study used Interpretative Phenomenological Analysis. Four parent-child dyads were recruited via Alopecia UK. Semi-structured interviews were carried out with each parent and child. Steps were taken to ensure research quality, which included conducting an audit of the analytic process.

Results: Analysis revealed four super-ordinate themes; 'discovering alopecia', 'a shared experience', 'secrecy and disclosure' and 'towards acceptance', and fourteen subordinate themes. A key source of distress for parents and children was real and anticipated experiences of stigmatisation. There appeared to be a particular burden for females related to wig use. Parental adjustment set the tone for how well children coped but there was also a mutually protective parent-child dynamic.

Conclusion: This is the first study to investigate the parent-child experience of alopecia areata. The results demonstrated that with time parents and children largely coped well, but also highlight opportunities for psychoeducational/psychological intervention.

Practitioner Points

- Practitioners are encouraged to acknowledge the emotional impact of AA and be more transparent about the nature of the condition, albeit in a sensitive manner.

- There is scope for the development of psycho-educational resources to help parents and teachers better understand the child's experience of AA and to help children deal with intrusive questions, teasing and bullying.

- Dermatologists/practitioners are encouraged to screen for anxiety and depression and refer children with AA and/or their parents, who show signs of significant distress, to psychology support.

- A key limitation of this study was that participants were all recruited through a non-NHS source and were all white British.

- The small sample size allowed for in-depth exploration of the aims but findings will only be transferable to individuals with similar characteristics.

Keywords. Alopecia areata, alopecia, hair-loss, child, parent, qualitative research, interpretative phenomenological analysis.

Introduction

Alopecia areata (AA) is a chronic inflammatory condition characterised by round or oval patches of non-scarring hair loss (Colon, Popkin, Callies, Desert, & Hordinsky, 1991). The majority of evidence suggests that it occurs in response to an autoimmune reaction that develops when genetically predisposed individuals are exposed to an unknown trigger (Mulinari-Brenner, 2018). Its estimated lifetime incidence is 2.1% and it does not discriminate by gender or ethnicity (Mirzoyev, Schrum, Davis, & Torgerson, 2014). The course of the disease is unpredictable. Around 14% - 25% of patients progress to alopecia totalis (AT), total loss of scalp hair, or alopecia universalis (AU), loss of entire scalp and body hair, at which point full recovery is rare (Darwin et al., 2018). There are treatments for AA but no long-term cure, and negative side effects need to be considered, particularly in children (Harries, Sun, Paus, & King Jr, 2010). The onset of AA most often occurs prior to the age of 20 (Price, 1991) and it is the third most common dermatosis in children (Wohlmuth-Wieser et al., 2018).

The impact of the disease on a person's physical appearance can have significant psychosocial consequences. It has been found to negatively impact upon self-esteem, quality of life, body image, educational progress, work-life and marital relationships; and people with AA often report experiences of stigmatisation (Hunt & McHale, 2005; Tucker, 2009). Research has shown that individuals with AA are at a greater risk of developing depression, anxiety and social phobia than the general population (Colon, Popkin, Callies, Dessert, & Hordinsky, 1991) and that the risk of depression is greater below the age of 20 (Chu et al., 2012). Psychological distress has been found to increase with severity of hair loss (Tucker, 2009) and to be greater in females than males (Hunt & McHale, 2005; Rafique & Hunt, 2015; Tucker, 2009; Wolf & Hudson Baker, 2018).

This may be due to concerns associated with being bald, given the level of importance placed on appearance by society (Rumsey & Harcourt, 2014). Moreover, hair is deeply symbolic (Synnott, 1987) and imbued with cultural and personal meanings related to gender, identity, sexuality and attractiveness (Cash, Price, & Savin, 1993). Females may be at greater risk of self-objectification (Frederickson & Roberts, 1997) due to media influence (Harper & Tiggemann, 2008). Recent theoretical accounts suggest that appearance concern arises when appearance is more salient (important) to an individual's overall self-concept, negatively valenced (evaluated) by the individual (Clarke et al., 2013), and discrepant with internally held ideals (Moss & Carr, 2004) that are informed by the cultural milieu and become internalised over time (Altabe & Thompson, 1996; Thompson & Kent, 2001; Tiggemann, 2012). The 'beauty is good' stereotype emerges in childhood with young people preferring attractive peers as friends (Dion, 1973). Having a disfigurement is more likely to elicit teasing at school (Kish & Lansdown, 2000) and increase the risk of a child developing negative self-perceptions, problems with body image and general psychological disturbances (Rumsey & Harcourt, 2014). However, relatively little is known about how early experience of having a visible condition might influence the development of the wider self-concept.

What is apparent from the psychological literature is that despite the frequency of onset of alopecia in childhood and adolescence, and the unique developmental challenges that occur at these life stages (Erikson, 1963; Hearst, 2007), research has been conducted predominantly in adult populations (Hunt & McHale, 2005; Tucker, 2009; Welsh & Guy, 2009). In a study conducted by Hunt and McHale (2004), 20% of 162 participants who reported personal experiences of AA were young people. Adolescents described difficulties sustaining intimate relationships and implications for their social lives, whilst children were more distressed about having to accommodate changes in their appearance and being teased at school.

Several studies have examined psychiatric diagnoses and symptomology in young people with AA (Bilgic et al., 2013; Ghanizadeh, 2008; Liakopoulou et al., 1997; Reeve, Savage, & Bernstein, 1996). In those conducted amongst children and adolescents, Ghanizadeh (2008) reported a high percentage (78%) of current and past psychiatric disorders, although this finding was based on diagnostic interviews with only 14 participants who had been referred to a psychiatric unit. In a larger sample of 74 young people with AA, Bilgic et al. (2013) found higher self-reported anxiety and lower parent reported quality of life, compared to healthy controls, as well as evidence linking depression to AA in children, but not adolescents. The difference in findings for children and adolescents was attributed to adolescents having more mature coping skills. However, participants were recruited from a dermatology outpatient clinic and may have been experiencing exacerbations of their hair loss during evaluation. In child focused studies, Liakopoulou et al. (1997) found that children with AA were more anxious, depressed, withdrawn, aggressive, and delinquent than clinical controls. Girls in particular found it more difficulty to adjust to their new self-image and had problems with self-esteem. These findings were based on a combination of child psychiatric interviews and self-report measures, but the sample of 33 children was again too small to allow for generalisation. Reeve et al. (1996) on the other hand found that based on structured diagnostic interviews with children and parents, seven out of twelve children with AA met criteria for anxiety disorders, however the results of self-report rating scales indicated no significant psychopathology. This may have been due to parents over-identifying with symptoms or children under-reporting them. Nonetheless, the discrepancy highlighted the need to consider the parent-child relationship. In general, the reliance of these studies on diagnostic and quantitative measures could result in an over simplification of experiences and insufficient attention being paid to protective mechanisms in children with AA.

In a recent mixed methods study, Wolf and Hudson-Baker (2018) identified five key factors that impact children and adolescents with AA, namely, 'confidence/self-esteem', 'psychological effects', 'appearance/acceptance' and 'socialisation and communication'. Their study used exploratory factor analysis to analyse survey data for 267 participants aged nine to 19, of whom 106 volunteered to carry out follow-up interviews. Most interviewees reported being psychologically affected by AA but had a positive attitude about themselves. The predominantly positive self-appraisals may however have been due the self-selected nature of this sub-sample. A study by Rafique and Hunt (2015) used interpretative phenomenological analysis (IPA) to explore the experiences of eight adolescents with AA in Pakistan. Using IPA allowed the researchers to explore psychosocial difficulties associated with AA as differentiated from those that may already be present due to puberty. The study identified themes of 'loss' (self/social), 'concerns' (physical/future), 'negative' (emotions/thoughts) and 'coping styles' (adaptive/maladaptive) and found that only females reported feelings of shame and guilt. The coping mechanisms of participants changed and improved with time in line with Cash, Santos, and Williams's (2005) three-pattern framework of body image coping; avoidance, appearance fixing and acceptance.

Only one study has discussed the parental experience of AA, and impact of the parent-child relationship on adjustment to the condition. In Elkin, Hilker, and Drabman's (2006) case study of Christy, an adolescent with AA and her mother, it became apparent that Christy's mother was significantly more anxious than her daughter about Christy's ability to cope with AA. The authors hypothesised that this may have caused Christy to be more socially anxious, thereby maintaining her mother's concerns. Both received behavioural intervention which resulted in reductions in Christy's social anxiety, but treatment became increasingly focused on Christy's mother and her own adjustment. These findings, although not generalisable highlight how

parental adjustment and beliefs can affect a child's ability to cope with appearance change. In a study amongst 50 parents of children with chemotherapy-induced alopecia, nearly half reported that their child's alopecia had been a traumatising painful experience, and most wanted more alopecia education from doctors (Gunawan et al., 2016)

There is a paucity of studies on the psychological and social impact of AA in young people, particularly children. There is also a gap in the literature on the parental and family experience of AA. This is important to understand as children's AA might also affect their parents, who may need support. Furthermore, children's views about appearance, and ability to adjust are likely to be shaped by the attitudes and behaviours of their parents (Kearney-Cooke, 2002).

The current study used a qualitative methodology in order to gain an understanding of the emotional and social experiences of children with AA and their parents, which would not be possible using quantitative methods. Interpretative Phenomenological Analysis (IPA) (Smith, Flowers, & Larkin, 2009; Larkin & Thompson, 2012) with a 'multi-perspective design' (Smith et al., 2009, pp. 52) was chosen, in order to build a 'multi-perspectival view' of the child and parental experience of and adjustment to AA, as well as develop an understanding of the relational impact.

Aims

The aims of this study were:

(1) To explore the psychological and social experiences of children with AA and their parents.

(2) To explore how children with AA and their parents naturalistically respond to the psychosocial aspects of the condition.

(3) To generate a joint perspective from dyadic interviews, so as to develop a picture of the joint parent-child experience of pre-adolescent AA.

Method

Design

This study used Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009) with a 'multi-perspectival view' (e.g. Larkin & Griffiths, 2004) to explore and 'give voice' to the subjective experiences of children with AA and their parents. IPA was deemed appropriate due to its idiographic focus and concern with meaning, i.e., understanding the *particular* experiences of individuals while holding an appreciation for wider contextual factors (Moran, 2000). The 'double hermeneutic' stance in IPA (Smith & Osborn, 2003) involves the researcher *making sense* of the participant *making sense* of their own experience, by drawing on psychological theory to offer interpretations whilst developing findings that can contribute to theory (Larkin & Thompson, 2012). Multi-perspectival IPA is an emerging development of this methodology, which offers powerful insights into the potential for overlap and divergence between how similar events are experienced by different people (Larkin & Thompson, 2012).

Participation of Alopecia UK

Two representatives of Alopecia UK were consulted during the development of the research, both of whom have lived experience of AA. They provided feedback on the research protocol, specifically the aims and design of the study, development of semi-structured interviews, interview scripts, participant information sheets and recruitment procedures.

Ethical Considerations

The study gained ethical approval from the University of Sheffield Department of Psychology Ethics Committee (Reference number 012373) following an internal review process (Appendix A). Research governance approval was obtained from the University of Sheffield (Appendix B). The researcher followed the University's guidelines on data storage and transcription (Appendix C). Informed written consent was sought from parents and assent from children (Appendix D and E), and treated as "processual" (Rosenblatt, 1995). Ethical dilemmas related to the researcher holding a 'dual-role' were anticipated and the 'researcher' role was explained clearly prior to conducting interviews (Thompson & Russo, 2012). Participants were advised to consult a general practitioner if issues of a psychological need arose or a dermatologist for queries related to AA. A process was in place for addressing safeguarding issues that was commensurate with NHS guidelines and mandatory training had been undertaken on this.

Recruitment

In order to gain detailed accounts of the individual experience of a small group of people who shared a similar experience, recruitment was purposive (Thompson, Smith, & Larkin, 2011). An advert for the study was posted on the Alopecia UK Website and via the email list of one of their regional child support groups. Potential participants who contacted the researcher by email to express an interest were screened according to the inclusion and exclusion criteria listed, by completing an eligibility form (Appendix F) via email or over the telephone. All eligible dyads were sent parent and child information sheets (Appendices G and H). For those who agreed to take part, interviews were arranged at a time and place that was convenient to them. All participants chose

their home address. The 'readability statistics' tool in Microsoft Word was used to ensure the language used in the child information sheet was age appropriate.

Inclusion criteria:

- Child aged between 8 and 12

- Child's AA present for at least 6 months

- Child and parent/guardian both English language speakers

Exclusion criteria:

- Child having diagnosis of another chronic physical health problem

- Child or parent/guardian having a significant psychological condition unrelated to AA

Data Collection

There were two stages to the data collection process. Firstly parent and child were asked to review their respective participant information sheets and invited to provide informed consent and assent. Following this demographic and contextual information were gathered including; age and ethnicity of parent and child, marital and employment status of parent, age of onset and severity of child's AA, and the impact of AA on the quality of life of parent and child. The last question on the Alopecia Areata Symptom Impact Scale (AASIS: Mendoza, Osei, Shi, & Duvic, 2013) was used to capture the severity of AA (Appendix I), and the Family Dermatology Life Quality Index (FDLQI: Basra, Sue-Ho, & Finlay, 2007) and Child Dermatology Life Quality Index (CDLQI: Lewis-Jones & Finley, 1995) modified to refer to "alopecia" or "hair loss" in place of "skin disease" or "skin" were used to capture the impact of the condition (Appendices J and K). The DLQI has been used previously in AA populations

(Finlay & Khan, 1994) and both versions have good psychometric properties (Basra, Sue-Ho, & Finlay, 2007; Salek et al., 2013). This stage of data collection was also used to build rapport with parent and child. Secondly, semi-structured interviews were conducted with each of the parents and children separately. Interviews lasted between 35 and 69 minutes and were audio-recorded using encrypted digital recorders. An interview script was developed to guide the first stage of data collection (Appendix L) and interview schedules were developed for the second stage (Appendices M and N). Table 1 shows a summary of the interview schedules.

Table 1. Child and Parent Interview Schedules

Child

Q1. Can you tell me a little bit about yourself 'name of child?'

Q2. Can you tell me when you first started losing your hair?

Q3. Can you tell me a bit about school and hobbies?

Q4. How has life been since your hair loss?

Parent

Q1. When did 'name of child's' alopecia start? Can you tell me about this time?

Q2. Can you tell me about what it is like being 'name of child's' mum/dad?

Q3. Can you tell me about 'name of child's' school life?

Q4. How has life been since 'name of child's' alopecia?

After completing the interviews the researcher noted down brief field notes and a record of any thoughts or feelings that arose for her during the interviews. Recordings

were transcribed verbatim by the researcher, and a university approved transcriber who signed a confidentiality agreement (Appendix C). Transcriptions included details of pauses and speech dynamics where appropriate and were checked against recordings for accuracy after completion (Smith et al., 2009)

Participants

Four dyads took part in the study, all of whom were recruited via the online advert. Tables 2 and 3 outline demographic and contextual data collected for all participants.

Table 2. Child demographics (n=4)

Characteristic	Number
Gender	
Male	2
Female	2
Age	
8-9 years	1
10-12 years	3
Ethnicity	
White British	4
Age at onset of alopecia areata	
0-3 years	2
8-12 years	2
AASIS Score	
1	
2	2
3	
4	1
5	
6	1
CDLQI Score (Impact of condition)	
No effect	1
Small effect	2
Moderate effect	1

Note. CDLQI = Child Dermatology Life Quality Index; AASIS = Alopecia Areata Symptom Impact Sale Score.

Table 3. Parent demographics (n=4)

Characteristic	Number
Gender	
Female	4
Age	
30-39 years	3
40-49 years	1
Ethnicity	
White British	4
Marital Status	
Married	4
Employment Status	
Employed	4
FDLQI Score (Impact of condition)	
Small effect	3
Large effect	1

Note. FDLQI = Family Dermatology Life Quality Index

Analysis

Analysis was conducted systematically using IPA as outlined by Smith et al. (2009). Transcripts were first read and re-read alongside listening to recordings to facilitate immersion in the data. Line by line noting was then conducted by making hand-written comments in the right hand margin of transcripts relating to observations, reflections, interpretations and anything of significance about the interview experience. Attention was paid to participants' use of *descriptive, linguistic* and *conceptual* comments, using colour coding to aid this process.

The researcher then identified emerging themes, which were not only grounded in the narrative but in the researcher's interpretations, and encapsulated into short phrases hand-written into the left-hand margin of each transcript. Emergent themes were structured hierarchically and recorded in a format that enabled them to be moved into new groupings as well as linked back to source data. The researcher then searched for connections across emergent themes as well as patterns of similarity and divergence, developing a set of superordinate and subordinate themes. This process was repeated for each transcript, taking care to maintain the integrity of each, and then for each parent-child dyad. A similar type of within-group analysis was utilised in a multi-perspectival study by Rostill-Brookes, Larkin, Toms, and Churchman (2010), which looked at children and social workers' experiences of foster-placement breakdown. Overall themes from parent-child dyads were then combined to develop a master set of themes.

Analysis then progressed to a more theoretical level, drawing on psychological theory and exploring participant data in terms of what it might 'mean' (Larkin & Thompson, 2012). This led to further refinement and development of a final set of themes. Analysis was a cyclical rather than a linear process, taking care throughout to check interpretations remained true to the data.

Quality Control

The quality of qualitative research can be assessed based on its contribution, credibility and rigour (Spencer & Ritchie, 2012). Demographic details about the sample have been provided so it is clear to whom the research is applicable (Lewis & Ritchie, 2003). Examples of narrative for each theme identified are also included in the results section to ensure the reader can evaluate the fit between the data and the researcher's interpretation of it. Details of the data analysis process were recorded to illustrate that the development of themes was grounded in participants' accounts and based on an adequate number of instances of data (Appendix O). The analytic process was audited by a peer (Appendix P). The researcher also consulted with the research supervisor throughout to verify the rigour of the analytic process.

Reflexivity

The researcher is a female clinical psychology trainee who has androgenetic alopecia (AGA). She acknowledged that her visible hair-loss may have affected the views expressed by participants (Faulkner, 2012) and that her personal experience of AGA, which started in adolescence, had the potential to influence interpretations. The researcher documented any personal experiences, preconceptions and pre-existing theoretical knowledge that may have generated interpretative biases (Appendix Q). The use of a reflexive journal, which included thoughts, feelings and contextual information helped the researcher 'bracket off' or at least 'hold awareness of' her own worldview, while attempting to be open to perceiving another (Husserl, 1931) (Appendix R). Interpretations were also discussed with the research supervisor to facilitate reflexivity, the aim of which was to guard against undue bias but also strengthen the analytic process.

Results

Multi-perspectival analysis led to the emergence of four superordinate themes and fourteen subordinate themes. These are summarised in Table 4 with details of which participants contributed to each theme. Children differed in age, gender, and the duration and severity of their AA. These differences will be commented on where relevant. All participants' qualitative experiences corresponded with their quantitative ratings.

Table 4. Summary of themes and participant contributions

Super-ordinate	Sub-ordinate	P1	P2	P3	P4	C1	C2	C3	C4
1. Discovering Alopecia	1a. Initial reactions to alopecia	✓	✓	✓	✓	✓	✓	✓	✓
	1b. Searching for answers	✓	✓	✓	✓	✓	✓	✓	
	1c. Exploring solutions	✓	✓	✓	✓	✓	✓	✓	✓
	1d. Questioning why	✓	✓	✓	✓	✓	✓		✓
	1e. Alopecia and cancer	✓	✓		✓	✓		✓	✓
2. A Shared Experience	2a. It's what *we* have to live with	✓	✓	✓	✓	✓	✓	✓	✓
	2b. Alopecia getting in the way	✓	✓	✓	✓	✓	✓	✓	✓
	2c. Experiences of stigmatisation	✓	✓	✓	✓	✓	✓	✓	✓
	2d. Loss and grief	✓	✓	✓		✓	✓	✓	
	2e. Living with uncertainty	✓	✓	✓	✓	✓	✓		
3. Secrecy and Disclosure	3a. Hiding the shame of hair-loss	✓	✓	✓	✓	✓	✓	✓	✓
	3b. Managing other people's reactions	✓	✓	✓	✓	✓	✓	✓	
4. Towards Acceptance	4a. Going it alone and seeking support	✓	✓	✓	✓	✓	✓	✓	✓
	4b. Growing stronger	✓	✓	✓	✓	✓	✓	✓	

1. Discovering Alopecia

This superordinate theme describes how families experienced a similar sequence of stages and emotional journey of discovery early on.

1a. Initial reactions to alopecia

Most participants described their initial reaction to discovering bald patches as not being one of great concern. This was because patches were not noticeable or hair temporarily grew back. A lack of awareness of the condition led parents to assume patches were either benign or caused by something non-medical. Only one parent anticipated the worst and felt overwhelmed with anxiety. This may have been due to her placing a greater level of importance on physical appearance or other predisposing factors.

> P2: *"At first I thought because she had a bath erm, … at first it looked like she had scalded her head, so the hair had fallen out, erm … but deep down I knew the worst was going to happen, erm my feelings, I cried, close to a breakdown."*

1b. Searching for answers

When patches became more noticeable parents grew concerned and looked to medical professionals for answers but generally felt dismissed. There were long waits to see a dermatologist while children's hair loss progressed. This led to feelings of anxiety, frustration, anger and helplessness as parents began to lose faith in the likelihood of timely intervention. Some parents felt like they had to battle to be taken seriously.

> P4: *"So then we got referred to a dermatologist … and he was very flippant and said yes, it's alopecia … but it will grow back and be fine."*

P1:   *"... it was just constant us battling ... to get her seen, to get some ... kind of answers to what was going on, or what she was going through or what could be done."*

The three children who lost most of their hair described feeling shocked, upset and not knowing what to think. Parents differed in their ability to contain their own anxieties. This was reflected in children's narratives, suggesting that children looked to their parents to make sense of their hair-loss. While parents contemplated what being bald would mean for their child's future, children remained focused on how to conceal their hair-loss and deal with questions from peers. Children's tendency to remain in the 'here and now' appeared to be psychologically protective.

1c. Exploring Solutions

Parents eventually discovered that little could be done to treat their child's alopecia beyond the application of steroid creams, which they were apprehensive about due to fears of toxicity and burning. This led to dyads exploring alternative 'cures' such as oils, nutritional supplements and going gluten free. One parent tried applying olive oil mixed with lavender oil to her son's head, which developed into a relaxing pre-bedtime ritual and an opportunity for parent-child bonding.

P3:   *"... we usually have like a little talk of a night when I'm putting stuff on his head ... that would be the time when if he's got anything to tell me it probably comes out then."*

Girl dyads described frustrating experiences with wigs, false eyelashes and micro-blading (eyebrow tattooing). Getting wigs to look not "too wiggy" took a lot of time and patience. One girl was able to see positives in being able to try out different wigs and hairstyles. Parents of girls commented on wigs being expensive. Boys used

hats to conceal their hair loss and as their safety behaviour. One parent described how her son always wore the same hat, as if were a type of security blanket.

1d. Questioning why

As doctors were unable to provide parents with any definitive cause for their child's alopecia, participants began forming their own hypotheses, which included stress, genetics, a family history of autoimmune conditions and diet. Parents experienced feelings of guilt and self-blame as they questioned whether something they did or didn't do may have caused their child's alopecia.

C4:   *"Does chewing have anything to do with it?"*

C2:   *"Lots of the doctors say it's oh, its generic [meaning genetic], its generic because my granddad, he had it, and then my two aunties had it and um ... yeah."*

Children's hypotheses were based on their parents, although one of the older children in the sample also questioned "why me?" Two parents recounted stressful incidents that occurred in their child's life prior to the onset of alopecia, which they felt may have been a trigger. This made them feel angry and attribute some blame to others.

1e. Alopecia and Cancer

All participants discovered that alopecia is often mistaken for cancer. This was a frustrating experience for children who regularly had to explain that they were not sick. This inevitably led to more questions, which they found tiresome. One child described how he attributed these experiences to a lack of awareness of alopecia in others.

C3:   "... *like people would think that you have cancer or that you had cancer…because it's just, because that's well known, and alopecia isn't, so the first instinct isn't oh, look, he has alopecia…"*

One parent described how rumours that her son had cancer led him to believing he did have cancer and that his parents were keeping it from him. This child's inability to communicate his concerns within the family may have been due to his younger age.

P4:   "*… well, he thought he had cancer … and he would die from it, because the little girls had teased him about it, well, not teased him but it had spread round his class that he had cancer. Um … and I think he thought that … that he did have cancer and we weren't telling him … but he didn't actually say that to … to us or any of us, it was this school teacher … so I was quite taken aback and quite upset"*

One parent's comparison of AA to chemotherapy-induced alopecia suggested she was struggling to reconcile how unfair her daughter's alopecia felt or find any meaning in it.

P2:   "*… if you've got cancer, and I wouldn't wish it off of anyone, and you lose your hair, you know you're losing it while you're having chemo and it will grow back, ninety percent of the time, but this is not a means to an end, this is it."*

2.   A Shared Experience

This superordinate theme describes how parents experienced the practical and emotional burden of alopecia through their children, who relied on them for support.

2a. It's what *we* have to live with

This shared experience was further evidenced in the language used by parents who frequently described their children's experiences using the word 'we' in place of 'I', 'she' or 'he'. There was also a lot of overlap in the narrative within dyads in terms of parents and children recounting the same events. One parent was quite explicit about how enmeshed she felt with her child's experience:

P2:   *"Because it's my daughter, and it's what I have to live with, we have to live with."*

One parent described how not knowing what it felt like to have alopecia left her feeling ill-equipped as a parent. This parent offered to shave her hair off as an act of solidarity. One parent's attempt to put herself in the place of her child may have unintentionally made her child more aware of her mother's distress.

C2:   *"... she like doesn't like washing her hair, because she feels that I'm jealous, but I'm not."*

2b. Alopecia getting in the way

Most participants described how alopecia got in the way of leisure activities and family life. The impact on leisure activities was greater for girls than for boys. Girls withdrew from activities such a dance, trampolining and adventure sports due to concerns about whether their wig would stay in place.

C2:   *"I mean, I used to do a lot more ... cos I would like, for my cousin's birthday, we went up to um ... [name of a trampoline park] but I can't do that now ... unless I like done it without my wig on, or wore a bandana."*

C4: *[A boy in response to being asked whether alopecia had changed anything?] "Um … no, more … people ask me like why have you got spots on the back of your head, but nothing's changed."*

All parents encouraged their children to continue with their activities by "trying to keep things the same", offering moral support and problem solving. Special arrangements were put in place for girls to have their own changing room when they went swimming.

2c Experiences of stigmatisation

Children found being asked questions without consideration of their feelings annoying and were sometimes unsure of how to answer. One child reported having to reassure others that his alopecia was not contagious. Parents also experienced reactions to their child's alopecia in the form of staring or teasing. One dyad described a covert form of bullying that went on for some time, which was particularly distressing.

C1: *"[About a peer at school] … she had really like, really nice lovely long hair down to her waist, and she'd like … urrgh, I can't describe it, she'd just like, she'd look at me and then she'd just flick her hair out as if like look what I've got and you haven't … she used to sit on my table and it was like, … she'd start going to me oh er [big sigh] like isn't it great to have hair, well I just love having my hair, I can do whatever I want with it, I can dye it, I can …'*

All parents experienced anger and/or a heightened sense of protectiveness in response to real or anticipated experiences of their child being teased, bullied or excluded. Children's worst fear was having their wig or hat pulled off, which most had experienced. Parents and children both constantly worried about experiences of

stigmatisation. However, parents sometimes felt as though their children coped better than they did.

> P1: *"... but a couple of hours later ... this girl pulled her wig off, so then it was just pfff you know it's like an explosion, ... I mean we were devastated, so I was absolutely livid, but for C1 it was sort of like...well everybody knows, you know what, what can they say."*

Parents tried to advise their children on retorts or stepped in to protect them but were sometimes unsure of the right approach to take. One child described how she texted her mum throughout the day for emotional support.

> C1: *"... like I used to text my mum always throughout the day, ... I used to just start texting and just like I can't cope, in like lessons cause it just got, it's really really sad ... you see all these other people ... they shouldn't laugh at you, you know so I just got really really sad and like annoyed."*

2d. Loss and grief

Participants reported experiences of loss and grief for 'the child before alopecia' and 'a normal childhood'. One child's expression of grief was particularly powerful, and suggestive of a loss of identity and on-going struggle to feel socially acceptable.

> C1: *"... and like I would rather break my arms and legs than lose my hair."*

Two parents used a similar metaphor to describe how it felt like the child's personality was literally being erased, particularly when eyebrows and eyelashes were lost.

P1:   *"… she felt like she'd been rubbed out, like erm,…like being*

erased,…like her personality was going and her hair was going, and stuff like

that, and she felt like she wasn't herself anymore."

One parent's description of how her child's alopecia triggered memories of earlier losses in her life, demonstrates how alopecia can be experienced as a traumatic event, and how trans-generational issues can influence the parental response.

P2:   *"I can pretend everything's okay, I've had to in my, for other things that*

has happened erm, my best friend died with cancer [welling up] … my adopted

parents split up when I was eight years old … and it was it was a lot of

heartbreak and I've lost two or three very very close friends … but this is the

worst loss ever."

2e. Living with uncertainty

One way that parents and children coped with the uncertainty of alopecia was by secretly holding onto hope that hair would grow back. This led to inner conflict between being optimistic and accepting alopecia in order to move forward with life. One parent rationalised it would be better for her son to accept being bald.

P1:   *"I still hope … that it will grow back, if I'm honest … but I'd hate for it*

to grow back and fall out again, so … and I don't even know why I want it to

grow back, because … he's accepted it and is dealing with it and he looks great,

and … but … I don't know … it's just hair, isn't it, you know … I mean that in a

way of … it's nice having hair."

3. Secrecy and disclosure

This superordinate theme describes the sense of secrecy and shame that accompanied hair-loss and how the daily job of impression management took up a lot of family's emotional resources.

3a. Hiding the shame of hair-loss

Girls were concerned about peers noticing they were wearing a wig. One parent realised how ashamed her daughter felt about being bald after witnessing her get caught 'off-guard' without her wig.

> P1: *"… she always just pops out and puts rubbish in the bins, erm and she did it the other day but someone was walking past from school and she came in and she was like oh God urgh … and I was like okay, she won't even recognise you C1, but after then you could see that she was very like, urrgh she was stressing herself out thinking about going back to school and seeing this girl."*

Most children described how it upset them when peers asked if they were wearing a wig, or why they wore a hat, perhaps because this reinforced their appearance concerns. Peers eventually got used to their alopecia, hence transitioning into a new school year was a particularly difficult time for families.

> C3: *"… but then there's people who just sort of come up to you like randomly like why do you wear a hat? Tell me, tell me, tell me, tell me!"*

3b: Managing other people's reactions

Children described how at times they would decide when, how and to whom they would disclose their alopecia and/or in the case of girls, that they wore a wig. This helped them retain a degree of control over their experience.

4b. Becoming stronger

All parents saw it as their job to help their children grow stronger. Children described using psychological coping strategies such as humour, positivity, and acceptance.

C1:   *"I just got on with the rest of the day, and I tried to stay positive."*

C3:   *"I just thought, well, it's going to be there for a while isn't it, so I might as well just come to peace with it and not care."*

All parents admired their children's strength at dealing with alopecia but there were subtle differences in perspective. Two parents reported occasionally feeling as though 'the roles were reversed'. This was linked to experiences of being comforted or reassured by their children which they found uncomfortable, perhaps because they felt it was their job to be the stronger one. One parent proudly reflected on how her son's experience of alopecia would make him a more resilient adult.

P3:   *"He is a remarkable ... getting a bit emotional now, but he is a remarkable person and I think that he's going to make a great adult. He's going to be able to cope with whatever life throws at him, because he's, he's, done this."*

Discussion

This study sought to explore the psychological and social experiences of pre-adolescent age children with AA and their parents, and to develop a picture of the joint parent-child experience by combining perspectives.

Psychosocial impact and adjustment in children

The key challenge for children with AA was dealing with other people's reactions to their hair loss, such as staring, intrusive questions, teasing and bullying. These

findings fit with the reported experiences of young people with AA in previous studies (Wolf & Hudson Baker, 2018; Hunt & McHale, 2004) and broader research amongst children with facial disfigurement (Kish & Lansdown, 2000). A number of theories might explain why children experienced negative responses (Thompson & Kent, 2001), such as incorrect assumptions being made about AA being contagious (Bernstein, 1976) or representative of lower social rank (Gilbert, 1997). Equally, peers may have been unsure of how to interact (Langer, Fiske, Taylor, & Chanowitz, 1976). While children recognised that questions about their hair loss, wig or hat often arose due to curiosity, they found them annoying, upsetting and tiresome. Macgregor (1990, p.250) describes how people with disfigurements are subjected to 'a level of familiarity from strangers not otherwise dared … that generate feelings of shame, impotence, anger and humiliation in their victims.' All children experienced low mood, loss of self-confidence and feelings of shame and embarrassment, and girls described greater levels of distress than boys. Similar gender differences have been reported by Liakopoulou et al. (1997) and Rafique and Hunt (2015) however, it is worth noting that the the boys in this study may have been less inclined or able to express emotional difficulties, particularly in relation to appearance concerns, due to factors such as age, personality or societal gender expections. A key difference between the experiences of girls and boys however, was the impact of wearing a wig. Girls withdrew from some leisure activities and were provided with a separate changing room when they went swimming. In their study of young people with epidermolysis bullosa, Williams, Gannon, and Soon (2011) suggest that being separated out in this way can lead to further distress and reduced self-esteem. The theme 'secrecy and disclosure' described how children constantly held a secret about why (and in the case of wigs, *whether*) they wore a wig or a hat, but also felt obligated to disclose their true selves to peers. These findings support Goffman's (1959) theory that individuals might want to keep certain facts about themselves secret,

if they think they are incompatible with their self-concept, however they possess a social obligation to present themselves as they truly are. These 'dark secrets' are in fact 'double' because not only are true attributes being kept secret, but the fact that they are, is being kept secret too. Children used a number of different coping mechanisms depending on the situation, as they began to accept AA as a part of their lives, including; denial, avoidance, humour, support seeking and acceptance. This suggests that adjustment was a dynamic process (Leventhal, Suls, & Leventhal, 1993) rather than a linear one. The importance of acceptance has also been discussed in relation to androgenetic alopecia (Kranz, 2011). Involvement with peer support groups and exposure to positive role models with AA were pivotal in helping children adjust to their condition. This corroborates the finding of Compas, Jaser, Dunn, and Rodriguez (2012) that 'accommodative coping', i.e., efforts to adapt to the source of stress are related to better adjustment in young people with chronic illness.

Psychosocial impact and adjustment in parents

All parents were affected by their child's AA but one parent experienced significantly greater levels of anxiety and low mood. This parent's near emotional breakdown upon discovering her child's AA was indicative of a conditioned fear response (Kolb, 1987) that was potentially linked to earlier losses in her life. Most parents felt dismissed by medical professionals, which caused them additional distress. Similar experiences have been reported by adults with AA (Hunt & McHale, 2004) and parents of children with cleft lip (Stock & Rumsey, 2015). Parents also described feelings of guilt and self-blame as they contemplated how they might have played a role in causing their child's AA. Such feelings have also been expressed by mothers of children with atopic dermatitis (Chamlin, Frieden, Williams, & Chren, 2004). The main difficulty for parents was constantly worrying about their child being bullied or teased, and concerns for their future. This supports the findings of Ablett and Thompson's

(2016) review of the family experience of chronic skin conditions. However, parents in this study were not as burdened with the physical management of their child's condition, as AA is painless and treatment is optional. Parents of girls did however find experiences with wigs to be emotionally and financially burdensome. Parents who were less prone to negative attributions, such as viewing their child's appearance-change as an impediment, and more focused on minimising their child's distress, adjusted better; in accordance with Lazarus and Folkman's (1984) transactional model of coping.

The joint experience

The superordinate theme 'a shared experience' captured how AA was experienced both *by the child*, and *by the parent through the child*. This is likely due to parents biological drive to protect their children and children's dependency on their parents. A similar theme, 'what hurts me hurts you' was identified by Ablett and Thompson (2016). A central concern for parents and children was actual and anticipated experiences of stigmatisation. For children fears of discrimination tended to remain in the here and now, however parents also worried about future implications.

The theme 'loss and grief' relates to how parents and children both reminisced about 'the child/self before alopecia', suggesting that the changes caused by AA were too great to be integrated into the child's existing 'self-theory' (Epstein, 1973). This might also have been a defence by both parties, against fully acknowledging the reality of changes. It suggests that dyads chose instead to preserve the 'child before alopecia' as a separate and somewhat idealised entity in the mind. Moreover, due to the uncertain prognosis of AA, parents and children both *privately* fantasised that the 'child before alopecia' might one day return. The role of hope as a coping mechanism is well documented in the physical health literature (Rasmussen, O'Byrne, Vandamente, & Cole, 2017). An interesting finding of this study was that the shared experience of AA

provided opportunities for increased parent-child bonding through facing challenges together, but also manifested in a mutually protective parent-child dynamic.

The findings offer support for the biopsychosociocultural framework (Thompson, 2012 p 103), which considers predisposing factors, beliefs and cognitive processing, behaviours and social context as all potentially contributing to appearance related wellbeing.

Strengths, limitations and future research

The current study addresses a gap in the literature on the individual and joint experiences of children with AA and their parents. The variation in time since onset of alopecia, degree of hair-loss, gender and age of the four children in this study provided interesting insights into the impact of such variables on experiences of AA. Future studies might wish to focus on specific time-points following diagnosis, or follow up on families longitudinally. The results also highlighted the scope for deeper exploration into the particular experiences of boys or girls.

During interviews, the need to converse more flexibly with children in order to engage and maintain their interest had the potential to generate a lot of irrelevant content. Also, due to the more open style of interviewing in IPA, the content of parent's interviews could easily have been dominated by their experiences of accessing healthcare, which they were keen to talk about. This was picked up by the research supervisor when reviewing pilot interviews, enabling the researcher to spend more time building rapport with children prior to beginning recording, and to gently guide subsequent interviews more closely towards the study's aims. Measures were taken in line with the research protocol to refer one parent, who was particularly distressed by her daughter's AA, to appropriate healthcare professionals.

All dyads were recruited through Alopecia UK. In future, it would be interesting to explore the experiences of families recruited from other sources, such as via a dermatology outpatient clinic. Parents who agreed to take part were all mothers and participants were all white British. Future research might consider exploring the perspectives of fathers and/or siblings, or families of a different race.

Clinical Implications

The findings suggest a need for the development of targeted psycho-educational resources related to AA. Parents and teachers might benefit from information about the aetiology and unpredictable nature of AA and guidance on how to support the child. This might help to mitigate parental feelings of helplessness and self-blame. Child-friendly leaflets might cover topics such as 'how to deal with the reactions of others'. There is also an opportunity to build on the nuanced examples of coping provided by participants to develop guidance on dealing with social anxiety related to AA and/or wearing a wig. Such resources could help facilitate conversations between families and healthcare professionals. The study also highlights the potential for healthcare professionals to use brief screening tools to assess the psychological wellbeing of children with AA and their parents, and to onwards refer to psychological services where appropriate.

Results show how alopecia can be experienced as a traumatic event. In such cases there may be a need for more in-depth trauma-focused therapy. It has been argued that there needs to be a shift in the emphasis placed on appearance by society (Rumsey & Harcourt, 2014) and there is a role for psychology in raising awareness of such dynamics. This might help families relinquish appearance ideals and focus on other aspects of the self. The study also demonstrated the importance of acceptance to living well with AA. Acceptance and Commitment Therapy (ACT) is a therapeutic model that

promotes living in line with one's values in spite of problems (Hayes, Strosahl, &

Wilson, 1999) and might also be beneficial in the context of AA.

Conclusion

The results suggest that there is a sequence of stages that families go through,

from discovering alopecia to moving towards acceptance. During this process, children

looked to their parents to make sense of what was happening to them and parents

influenced how well their children coped with AA through their ability to contain their

own anxieties and model (Bandura, Ross, & Ross, 1961) adaptive adjustment. This is

consistent with findings in the wider paediatric health literature that parental adjustment

predicts child adjustment (Drotar, 1997). The parent-child relationship naturalistically

evolved to focus on the new challenges faced by the child because of being visibly

different.

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Appendix A: Ethics Approval Letter

The University Of Sheffield.

Anita Raman
Registration number: 150123750
Psychology
Programme: Doctorate in Clinical Psychology

Dear Anita

PROJECT TITLE: The parent-child experience of pre-adolescent alopecia areata: An interpretative phenomenological analysis
APPLICATION: Reference Number 012373

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 09/01/2017 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 012373 (dated 20/12/2016).
- Participant information sheet 1026119 version 1 (19/12/2016).
- Participant information sheet 1026120 version 1 (19/12/2016).
- Participant consent form 1026122 version 1 (19/12/2016).
- Participant consent form 1026121 version 1 (19/12/2016).

The following optional amendments were suggested:

The following suggestions were offered one of the reviewers, with an eye towards improving the quality of the project. Please consider them if they are useful. 1. The brief overall summary needs relevant references adding - and of course the interviews will be in depth ... 2. Drop social from the aims 3. Considering the amount of quantatative infoirmation being collected - better described as mixed methods? 4. The service users need to review the interview questions ... 5. Needs to have a medical and definitive diagnosis of AA as an inclusion critera. 6. Not currently or previously seen in CAMS as an exclusion criteria. 7. Given that good care has been taken with the wording of the project to ensure child understanding - then the information and consent forms for the children need to be run through the same programme to ensure comprehension ...

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Yours sincerely

Thomas Webb
Ethics Administrator
Psychology

Appendix B: Research Governance Approval

The University Of Sheffield.

Department Of Psychology.
Clinical Psychology Unit.

Doctor of Clinical Psychology (DClin Psy) Programme
Clinical supervision training and NHS research
training & consultancy.

Clinical Psychology Unit
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Project title: The parent-child experience of pre-adolescent alopecia areata: An interpretative
phenomenological analysis

URMS number: 151174

Dear Anita,

LETTER TO OONFIRM THAT THE UNIVERSITY OF SHEFFIELD IS THE PROJEOT'S RESEAROH GOVERNANOE SPONSOR

The University has reviewed the following documents:

1. A University approved URMS costing record;
2. Confirmation of independent scientific approval;
3. Confirmation of independent ethics approval.

All the above documents are in place. Therefore, the University now **confirms** that it is the project's research governance sponsor and, as research governance sponsor, **authorises** the project to commence any non-NHS research activities. Please note that NHS R&D/HRA approval will be required before the commencement of any activities which do involve the NHS.

You are expected to deliver the research project in accordance with the University's policies and procedures, which includes the University's Good Research & Innovation Practices Policy: www.shef.ac.uk/ris/other/gov-ethics/grippolicy, Ethics Policy: www.sheffield.ac.uk/ris/other/gov-ethics/ethicspolicy and Data Protection Policies: www.shef.ac.uk/cics/records

Your Supervisor, with your support and input, is responsible for providing up-to-date study documentation to all relevant sites, and for monitoring the project on an ongoing basis. Your Head of Department is responsible for independently monitoring the project as appropriate. The project may be audited during or after its lifetime by the University. The monitoring responsibilities are listed in Annex 1.

Yours sincerely

Dr Andrew Thompson
Director of Research Training, Clinical Psychology Unit

cc. Supervisor: Andrew Thompson
Head of Department/School: Glenn Waller

To access the University's research governance website go to:
www.sheffield.ac.uk/ris/other/gov-ethics/governance

Monitoring responsibilities of the Supervisor:

The primary responsibility for project monitoring lies with the Supervisor. You agree to:

1. Establish a **site file** before the start of the project and ensure it remains up to date over the project's entire lifetime:
   www.sheffield.ac.uk/ris/other/gov-ethics/governance/rg-forms

2. Provide **progress reports/written updates** to the Head of Department at reasonable points over the project's lifetime, for example at:

   a. three months after the project has started; and
   b. on an annual basis (only if the project lasts for over 18 months); and
   c. at the end of the project.
   See: www.sheffield.ac.uk/ris/other/gov-ethics/governance/rg-forms

3. Report **adverse events**, should they occur, to the Head of Department:
   www.sheffield.ac.uk/ris/other/gov-ethics/governance/rg-forms

4. Provide progress reports to the research funder (if externally-funded).

5. Establish appropriate arrangements for recording, reporting and reviewing significant developments as the research proceeds – i.e. developments that have a significant impact in relation to one or more of the following:

   * the safety or physical or mental integrity of the participants in the project;
   * the project's scientific direction;
   * the conduct or management of the project.
   The Head of Department should be alerted to significant developments in advance wherever possible.

6. Establish appropriate arrangements to record, handle and, as appropriate, store all information collected for or as part of the research project in such a way that it can be accurately reported, interpreted and verified without compromising the confidentiality of individual care users.

****

Monitoring responsibilities of the Head of Department

You agree to:

1. Review the **standard monitoring progress reports**, submitted by the Supervisor, and follow up any issues or concerns that the reports raise with the Supervisor.

2. Verify that **adverse events**, should they occur, have been reported properly and that actions have been taken to address the impact of the adverse event(s) and/or to limit the risk of similar adverse event(s) reoccurring.

3. Verify that a project is complying with any **ethics conditions** (e.g. that the information sheet and consent form approved by ethics reviewers is being used; e.g. that informed consent has been obtained from participants).

4. Introduce a form of **correspondence** (e.g. regular email, annual meeting) with a project's Supervisor, that is **proportionate to the project's potential level of risk**, in order to verify that a project is complying with the approved protocol and/or with any research funder conditions. Whatever correspondence is chosen the Head of Department should, as a minimum, ensure that s/he is informed sufficiently in advance about significant developments wherever possible.

Appendix C: University Guidelines on Data Storage and Transcription

Doctorate in Clinical Psychology, University of Sheffield

Transcribing Confidentiality Form & Guidance Notes

Type of project: Research thesis

Project title: The Parent Child Experience of Pre-Adolescent Alopecia Areata: An Interpretative Phenomenological Analysis

Researcher's name: Anita Raman

The recording you are transcribing has been collected as part of a research project. Recordings may contain information of a very personal nature, which should be kept confidential and not disclosed to others. Maintaining this confidentiality is of utmost importance to the University.

We would like you to agree:

1. Not to disclose any information you may hear on the recording to others,

2. If transcribing digital recordings – only to accept files provided on an encrypted memory stick

3. To keep the tapes and/or encrypted memory stick in a secure locked place when not in use,

4. When transcribing a recording ensure it cannot be heard by other people,

5. To adhere to the Guidelines for Transcribers (appended to this document) in relation to the use of computers and encrypted digital recorders, and

6. To show your transcription only to the relevant individual who is involved in the research project.

7. If you find that anyone speaking on a recording is known to you, we would like you to stop transcription work on that recording immediately and inform the person who has commissioned the work.

Declaration

I have read the above information, as well as the Guidelines for Transcribers, and I understand that:

1. I will discuss the content of the recording only with the individual involved in the research project

2. If transcribing digital recordings – I will only accept files provided on an encrypted memory stick

3. I will keep the tapes and/or encrypted memory stick in a secure place when not in use

4. When transcribing a recording I will ensure it cannot be heard by others

5. I will treat the transcription of the recording as confidential information

6. I will adhere to the requirements detailed in the Guidelines for transcribers in relation to transcribing recordings onto a computer and transcribing digital audio files

7. If the person being interviewed on the recordings is known to me I will undertake no further transcription work on the recording

I agree to act according to the above constraints

Your name __Sharon Keighley___

Signature _____

Date _____24/01/18_____

Occasionally, the conversations on recordings can be distressing to hear. If you should find it upsetting, please stop the transcription and raise this with the researcher as soon as possible.

Guidelines for transcribers

Introduction

The course has created the guidelines below for anyone who is involved in transcribing data for staff or trainees in the Clinical Psychology Unit, University of Sheffield.

In addition to adhering to the following guidelines, **transcribers must sign a confidentiality form** prior to beginning any work. If you are unsure about any of the information given below, or for a copy of the confidentiality form, please contact the relevant trainee/member of staff.

When undertaking transcribing, whether from tapes or digital recording, you must:

- Password protect the computer files you are typing **before you type any text** – this can be done easily in Microsoft Word (instructions below)

- Anonymise any personal information contained in the data you are transcribing as you type e.g. names. Please contact trainee or member of

  staff who transcribing you are doing if you have any queries about this.

- Delete any files from your computer (including from your 'Trash' folder) once you have submitted your completed transcription.

- Keep the tapes/encrypted memory stick in a secure locked place when not in use.

- If transcribing from a digital recording, you must also adhere to the specific guidance on this (appendix 2 of this document).

  Instructions for a password protecting files on a PC

  For Word 2007:

  1) Open a blank Word document

  2) Go to Save As and choose the compatible mode

  3) Click Tools, then select General Options

  4) Enter a password to open the document. You will asked to re-type this, then

     please ensure you click ok before closing the dialogue box.

For Word 2010 onwards:

APPLIES TO: Excel 2016, Word 2016, PowerPoint 2016, Excel 2013, Word 2013, PowerPoint 2013, Excel 2010, Word 2010, PowerPoint 2010, Excel Starter, Office 2010, Word Starter, Word Starter 2010

- In an open document, click **File** > **Info** > **Protect Document**.

  You see the following options.
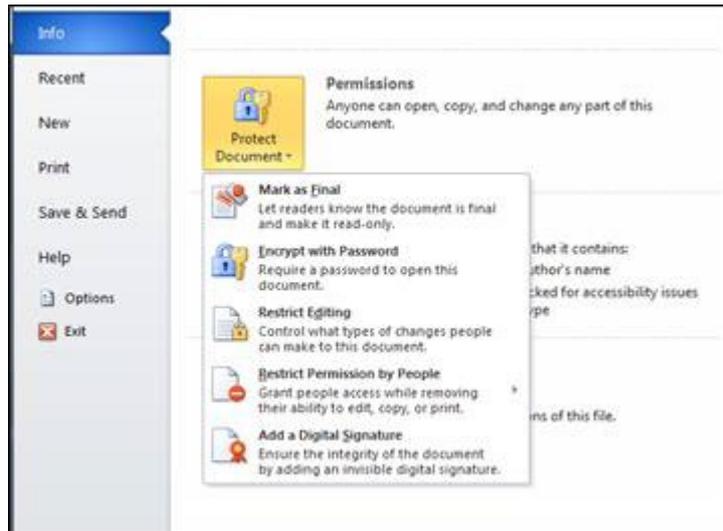
- o **Mark as Final:**   Make the document read-only.

  When a document is marked as final, typing, editing commands, and proofing marks are disabled or turned off and the document becomes read-only. The **Mark as Final** command helps you communicate that you are sharing a completed version of a document. It also helps prevent reviewers or readers from making inadvertent changes to the document.

  When you mark a document as final, Word asks you to save the file. The next time you open it, you will see a yellow **MARKED AS FINAL** message at the top of the document. If you click **Edit Anyway**, the document will no longer be marked as final.

- o **Encrypt with Password:**   Set a password for the document.

  Caution: Keep your password in a safe place. If you lose or forget the password, it cannot be recovered

  When you select **Encrypt with Password**, the **Encrypt Document** dialog box appears. In the **Password** box, type a password, and then type it again when prompted. **Important:** Microsoft cannot retrieve lost or forgotten passwords, so keep a list of your passwords and corresponding file names in a safe place.

- **Restrict Editing:**   Control what types of changes can be made to the document.

  When you select **Restrict Editing**, you see three options:

  - o **Formatting restrictions**   This reduces formatting options, preserving a look and feel. Click **Settings** to select which style are allowed.
  - o **Editing restrictions**   You control how the file can be edited or you can disable editing. Click **Exceptions** or **More users** to control those who can edit.
  - o **Start enforcement**   Click **Yes, Start Enforcing Protection** to select password protection or user authentication. You can also click **Restrict permission** to add or remove editors who'll have restricted permissions.
  - o **Restrict Permission by People:**   Use a Windows Live ID to restrict permissions.

Use a Windows Live ID or a Microsoft Windows account to restrict permissions. You can apply permissions via a template that is used by your organization, or you can add permissions by clicking **Restrict Access.** To learn more about Information Rights Management see [Information Rights Management in Office](#).

- **Add a Digital Signature:**   Add a visible or invisible digital signature.

Digital signatures authenticate digital information such as documents, email messages, and macros by using computer cryptography. Digital signatures are created by typing a signature or by using an image of a signature to establish authenticity, integrity, and non-repudiation. See the link at the end of this topic to learn more about digital signatures.

To learn about digital signatures, see [Digital signatures and certificates](#).

Instructions for password protecting files on a Mac:

1) Open a blank Word document

2) Go to Word on the menu bar and select Preferences

3) Click on Security and insert a password to open the document. You will be

   asked to re-type this, then click ok.

Appendix 2

Additional Guidance for transcribing from digital recordings

Important: Trainees and staff must provide you with recordings via an encrypted memory stick. Do not accept files via any other means.

Installing DSS Player Pro software (you only need to do this once)

In order to transfer audio files to your computer, you will need to have installed the DSS Pro software that comes to the machine. You will only need to do this once, not for each recording.

The procedure is as follows:

On a PC:

1. Insert CD
2. Go to My Computer – select the CD Drive, click on Launcher
3. Install DSS Player Pro programme (NOT the standard DSS Player) – follow the installation instructions as they appear (e.g. agreeing to terms and conditions)
4. You will be asked to provide the License ID number for Windows users- this can be found on the green card in the box.
5. The manual/help instructions for the DSS Player Pro will be automatically downloaded with the programme files.

On a MAC:

1. Insert CD
2. Click on the CD icon – click 'Setup'
3. Install DSS Player programme (Mac users cannot access the Pro version) – follow the installation instructions as they appear (e.g. agreeing to terms and conditions). Your machine will automatically ask you to restart.
4. Once you have restarted, go to the applications menu and select the DSS Player folder. Click on DSS player and you will be asked to provide the License ID number for Mac OS users, this can be found at the bottom of the green card in the box.
5. The manual/help instructions for the DSS Player Pro will be automatically downloaded with the programme files.

To listen/download audio files from a memory stick (once DSS player is installed)

1. Open DSS player programme

2. Plug in encrypted memory stick to USB port

3. Input password to unlock the memory stick

4. In DSS player, click on File/Import Dictation

5. Select the USB memory stick

6. Select the audio file, click ok to upload to DSS file.

7. Exit the memory stick by clicking on 'lock and exit' button – hand this back to the trainee, who will delete the audio file for you (please do not delete yourself)

To open the audio files in order to transcribe

1. Locate the folder within DSS pro player

2. Double click on the audio track within this, a pop up window will prompt you for the password. Enter the password given to you by the trainee

Reminder: ensure you have fully deleted your transcription and the original recordings from your computer once you have passed your transcription to the trainee/member of staff.

The procedure for deleting files from DSS player is as follows:

- Locate the folder in DSS player where the track is saved within DSS player

- Select the individual files of the audio tracks you wish to delete

- Right click over them and select 'delete'

Appendix D : Parent Consent Form

The University Of Sheffield.

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TN   UK

Department Of Psychology.
Clinical Psychology Unit.

Doctor of Clinical Psychology (DClin Psy) Programme
Clinical supervision training and NHS research training
& consultancy.

Telephone:
Fax:
Email:

Version 2 06.03.15
Parent/Guardian Consent form

Participant name...

Participant address..

I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that mine, and my child's participation is voluntary and that we are free to withdraw at any time without giving any reason, and without my child's medical care or legal rights being affected in any way.	
I understand that the interviews with me and my child will be recorded on an encrypted digital recorder and that the files will be deleted after our participation	
I agree to take part in the above study.	
I would like to receive a copy of the study results, once available.	

_____   _____   _____

Name of Participant   Date   Signature

_____   _____   _____

Name of Person taking consent   Date   Signature

2 copies: 1 for participant, 1 for the project notes.

Appendix E : Child Assent Form

Department Of Psychology.
Clinical Psychology Unit.

Doctor of Clinical Psychology (DClin Psy) Programme
Clinical supervision training and NHS research training
& consultancy.

The
University
Of
Sheffield.

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TN UK

Telephone:
Fax:
Email:

Version 2 06.03.15
Child Assent form

Participant name...

Participant address..

I understand what the study is about. I have had the chance to ask questions about it and my questions have been answered	
I know that I can stop being in the study at any time without giving a reason and it will not affect me in any way	
I know that our conversation will be recorded but the recording will be destroyed after it is written up.	
I am happy to take part in the study ☺	
I would like to receive a copy of the study results, once available.	

_____   _____   _____

Name of Participant   Date   Signature

_____   _____   _____

Name of Person taking consent   Date   Signature

Appendix F: Eligibility Form

Eligibility (to be completed via telephone with potential adult participant)

	✓ Yes	X No
Your child:		
Has had alopecia areata for at least 6 months		
Is aged 8-12 years		
Has another chronic health condition (e.g. asthma, diabetes)*		
You:		
Are the parent/primary caregiver (not necessarily mum or dad) of the above child		
You agree to only one parent/caregiver of your child, who is yourself, being involved in the study

To help you decide which parent or caregiver should take part, you might wish to consider which of you is most involved in your child's day-to-day care needs, and/or has been most present through your child's diagnosis of AA. | | |
Both of you:		
You are both English language speakers		
Have a diagnosis of a significant unrelated psychological condition (e.g. psychosis)*		

To be eligible for study all questions must be answered yes, apart from those marked* which should be false.

Appendix G: Parent Information Sheet

The University Of Sheffield.

Department Of Psychology.
Clinical Psychology Unit.

Doctor of Clinical Psychology (DClin Psy) Programme
Clinical supervision training and NHS research training
& consultancy.

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TN UK

Participant Information Sheet (Parent/Carer)

What is the purpose of the study?

This study aims to explore the experiences of children who have alopecia areata and the experiences of their parents/carers.

Who is conducting the study?

This study is being conducted by Anita Raman who is training to be a clinical psychologist. Anita has experience of working in healthcare and is interested in how alopecia affects the lives of children and their parents. The project is supervised by Dr Andrew Thompson Reader in Clinical Psychology.

Who can take part?

We are hoping to speak to children aged 8-12 years who have had alopecia areata for at least the last six months, and one of his or her parents/carers. Alopecia UK has agreed to help us find people to take part in the study. Because the study is focused on alopecia, children with any other chronic health problem, such as asthma or diabetes will not be able to take part.

What will be involved if we take part?

The study will involve an initial meeting with the researcher Anita, so that she can gain some information about you both, and you can get to know each other. This would then be followed by interviews with you and your child, either immediately after, or at a later date if you would prefer. The length of interviews will vary according to the age of your child and the things that you and your child are happy to share. We expect interviews with parents to last a maximum of one hour, and those with children up to 40 minutes. The interviews can take place either at your home or at the University of Sheffield depending on your preference, and we are able to offer a maximum of £10 towards your travel if you travel.

Do we have to take part?

There is no obligation to take part and refusal to do so will not affect your child's treatment in any way. You also have the right to withdraw from the study at any point, even during interviews and up to one month after they have taken place.

What are the benefits?

No one has previously explored the experience of children with alopecia together with that of their parents. We are hoping that the information gathered will help inform future guidance for children with alopecia, their parents and health care professionals.

What happens to the information collected?

The interviews will be recorded on an encrypted digital device, and the files generated will be transcribed by a University of Sheffield employed transcriber who has signed a confidentiality agreement. Sections of the interviews may be used a published article from the study, or included in teaching materials. However, your responses would not be traceable back to you, as no personally identifiable information would be included.

What do we do if we have any complaints?

If you have any complaints about any aspect of the research these can be raised with the academic supervisor Dr Andrew Thompson. Email: a.r.thompson@sheffield.ac.uk Tel: 0114 2226637

What should we do next?

If you and your child would be happy to participate, or if you have any further questions about the study, please email the researcher Anita at araman1@sheffield.ac.uk. If, however, you would rather not take part, thank you for taking the time to read this information.

Thank you for reading this information sheet.

Appendix H: Child Information Sheet

Participant Information Sheet (Child)
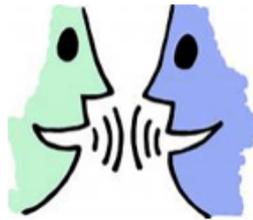
What is the study about?

We would like to know if you would be happy to take part in a study about what life is like for children who have hair loss, and for the people who look after them.

Who can take part?

We are hoping to speak to children aged 8-12 and one of the people who looks after them. That might be mum, dad or someone else.

What will happen if I take part?

Anita will meet with you, and you'll get a chance to get to know her a bit better, and then if you agree, she'll have a chat with you about different parts of your life, and how you feel about your hair loss.

The chat would take 40 minutes at most, depending on how much you want to say. She could come to your home or you could visit her at her University with a parent, or carer (they need to agree too).

Who is doing the study?

Anita is doing the study. She's worked with children before in health care. Anita is really interested in how children with hair loss, and the people who look after them feel about it.

Do we have to take part?

You don't have to take part if you don't want to, and it won't affect anything. You can also change your mind later, even after you have met Anita and started talking, and for up to a month after your chat.

What are the benefits of taking part?

No scientific research has asked children with hair loss, and those who look after them, what it's like for them. What you tell us will help us understand you better and create better support for children with hair loss and their families in the future.

What happens to the information I tell you?

Your chat with Anita will be recorded and typed out later. The study might lead to us writing an article about what you and others have told us, but we would not mention anyone's names, or any details that would make it possible for people to work out who you are.

What should I do next?

If you and your mum or dad, or person who looks after you would like to take part, please email Anita at araman1@sheffield.ac.uk and she will contact you.

If you don't want to take part, that's fine too, and you don't need to do anything.

What should I do if I'm unhappy about something?

If you feel unhappy about something to do with the study, tell your parent, or the person looking after you to let the supervisor of the study Dr Andrew Thompson know. His email address is a.r.thompson@sheffield.ac.uk and his telephone number is 0114 2226637

THANKYOU FOR READING THIS INFORMATION SHEET

Appendix I: Alopecia Areata Symptom Impact Scale (AASIS) - Last Question

Select the current overall condition of your hair loss: Please select one:

1. Episodes of patches of hair loss on scalp or beard that last less than 6 months and completely re-grow to normal hair.

2. One or more episodes of patches of hair loss on the scalp (patchy AA) that last for more than 6 months.

3. Mostly alopecia areata, plus one or more short episodes of AT or AU, last less than 1 year.

4. 100% scalp hair loss (completely bare scalp or AT). Little or no body hair loss for 1 year or more at some time in my life.

5. 100% scalp hair loss and 100% body hair loss (AU) for 1 year or more at some time in my life.

6. None of the above - describe_____

Appendix J: Adapted Family Dermatology Life Quality Index (FDLQI)

The Family Dermatology Life Quality Index (FDLQI)

Name: ....   FDLQI Score

Relationship with patient: ....

Patient's diagnosis (if known): ....   Date: ....

- The questions relate to the impact of your relative/partner's hair loss/alopecia on <u>your</u> quality of life over the <u>last month</u>.
- Please read the questions carefully and tick one box for each.

1. Over the last month how much emotional distress have you experienced due to your child's hair loss (e.g. worry, depression, embarrassment, frustration)?

Not at all/Not relevant ☐   A little ☐   Quite a lot ☐   Very much ☐

2. Over the last month how much has your child's hair loss affected your physical well-being (e.g. tiredness, exhaustion, contribution to poor health, sleep/rest disturbance)?

Not at all/Not relevant ☐   A little ☐   Quite a lot ☐   Very much ☐

3. Over the last month how much has your child's hair loss affected your personal relationships with him/her or with other people?

Not at all/Not relevant ☐   A little ☐   Quite a lot ☐   Very much ☐

4. Over the last month how much have you been having problems with other peoples' reactions due to your child's hair loss (e.g. bullying, staring, need to explain to others about his/her hair loss?)

Not at all/Not relevant ☐   A little ☐   Quite a lot ☐   Very much ☐

5. Over the last month how much has your child's hair loss affected your social life (e.g. going out, visiting or inviting people, attending social gatherings)?

Not at all/Not relevant ☐   A little ☐   Quite a lot ☐   Very much ☐

(Please turn over)

6. Over the last month how much has your child's hair loss affected your recreation/leisure activities (e.g. holidays, personal hobbies, gym, sports, swimming, watching TV)?

Not at all/Not relevant ☐   A little ☐   Quite a lot ☐   Very much ☐

7. Over the last month how much time have you spent on looking after your child (e.g. putting on creams, giving medicines or looking after their skin)?

Not at all/Not relevant ☐   A little ☐   Quite a lot ☐   Very much ☐

8. Over the last month how much extra house-work have you had to do because of your child's hair loss (e.g. cleaning, vacuuming, washing, cooking)?

Not at all/Not relevant ☐   A little ☐   Quite a lot ☐   Very much ☐

9. Over the last month how much has your child's hair loss affected your job/study (e.g. need to take time off, not able to work, decrease in the number of hours worked, having problems with people at work)?

Not at all/Not relevant ☐   A little ☐   Quite a lot ☐   Very much ☐

10. Over the last month how much has your child's hair loss increased your routine household expenditure (e.g. travel costs, buying special products, creams, cosmetics)?

Not at all/Not relevant ☐   A little ☐   Quite a lot ☐   Very much ☐

Thank you for completing the questionnaire.

Appendix K: Adapted Child Dermatology Life Quality Index (FDLQI)

CHILDREN'S DERMATOLOGY LIFE QUALITY INDEX

NHS No
Name: Diagnosis: CDLQI
Age: SCORE:
Address: Date:

The aim of this questionnaire is to measure how much your skin problem has affected you OVER THE LAST WEEK. Please tick one box for each question. Very much = 0 Quite a lot =1, Only a little = 2, Not at all = 3

1. Over the last week, how **itchy, "scratchy"**, sore or **painful** has your hair loss been?
    - Very much ☐
    - Quite a lot ☐
    - Only a little ☐
    - Not at all ☐

2. Over the last week, how **embarrassed** or **self conscious**, **upset** or **sad** have you been because of your hair loss?
    - Very much ☐
    - Quite a lot ☐
    - Only a little ☐
    - Not at all ☐

3. Over the last week, how much has your Hair loss affected your **friendships**?
    - Very much ☐
    - Quite a lot ☐
    - Only a little ☐
    - Not at all ☐

4. Over the last week, how much have you changed or worn **different or special clothes/wigs** because of your hair loss?
    - Very much ☐
    - Quite a lot ☐
    - Only a little ☐
    - Not at all ☐

5. Over the last week, how much has your hair loss affected **going out, playing**, or **doing hobbies**?
    - Very much ☐
    - Quite a lot ☐
    - Only a little ☐
    - Not at all ☐

6. Over the last week, how much have you avoided **swimming** or **other sports** because of your hair loss?
    - Very much ☐
    - Quite a lot ☐
    - Only a little ☐
    - Not at all ☐

7. Last week, was it **school time**?

    If school time: Over the last week, how much did your hair loss affect your **School work**?
    - Prevented school ☐
    - Very much ☐
    - Quite a lot ☐
    - Only a little ☐
    - Not at all ☐

    OR

    was it **holiday time**?

    If holiday time: How much over the last week, has your hair loss interfered with your enjoyment of the **holiday**?
    - Very much ☐
    - Quite a lot ☐
    - Only a little ☐
    - Not at all ☐

8. Over the last week, how much trouble have you had because of your hair loss with other people **calling you names, teasing, bullying, asking questions** or **avoiding you**?
    - Very much ☐
    - Quite a lot ☐
    - Only a little ☐
    - Not at all ☐

9. Over the last week, how much has your **sleep** been affected by your hair loss?
    - Very much ☐
    - Quite a lot ☐
    - Only a little ☐
    - Not at all ☐

10. Over the last week, how much of a problem has the **treatment** for your hair loss been?
    - Very much ☐
    - Quite a lot ☐
    - Only a little ☐
    - Not at all ☐

Please check that you have answered EVERY question. Thank you.

Appendix L: Interview Script for Demographic Data Collection

Preamble

Hello "name of parent and child", my name is Anita. Thank you very much to both of you for agreeing to help with my research, it is lovely to meet you. Have you both had an opportunity to read the information sheets about the study? (*A further copy will be available at interview)*

(Confirm inclusion and exclusion criteria) Do either of you have any questions you would like to ask me? (*Answer questions*). Okay so I hope you feel your questions have been answered.

Now, I have a couple of forms that I will need you to sign to say they you are happy to continue, but would also like to remind you that you are under no obligation, and you are free to withdraw from the study at any time.

(After signing consent and assent forms) Okay, so now I'll explain a little more about what the plan is for today. Firstly, I have some brief questions* and some questionnaires for you both to fill in so that I can get a bit more information about you both.

There is a questionnaire for each of you about how you find different aspects of life since "name of child" lost his/her hair as a result of alopecia**. There is an additional questionnaire for you "name of child" that will ask a few questions about your alopecia***. I'm happy to go through any of the questions with either of you if you would like. Especially the ones about alopecia "name of child" as these can be a little more detailed, and might be a little upsetting to answer.

Once we've completed the questionnaires, if you both feel you are able to carry on, I'd like to chat to each of you separately. "Name of child", your interview should last for up to 45 minutes, but that will depend on how much you'd like to share, which is completely up to you. "Name of adult," your interview will last for up to an hour, and

again, that depends on how much you'd like to say, and where the conversation leads.

Let's see how we get on with the first part, and if you're happy to continue to the

interviews we will do that today. If you feel like you'd like to schedule in a separate

date for the interviews, we can do that also. Also, just to remind you this will all be

confidential and anonymous and no details will be used in the final report that could

identify either of you. If you'd like to see some examples of the way information might

look in the final research report, I have brought some examples along with me.

How does all that sound? Do you have any questions before we get started?

Thank-you both again for your time.

*Demographic questions: Name (both), age (both), parent's/guardian's employment
status, parent's/guardian's marital status, ethnic origin (both), age of onset of alopecia.*

***Family Dermatology Life Quality Index (for parent) and Child Dermatology Life
Quality Index (for child). Both adapted for alopecia.*

**** Alopecia Areata Symptom Impact Scale (for child). Last Question..*

Appendix M: Parent Interview Schedule

Preamble: Okay, so thank-you for completing the questionnaires. As I said earlier, this conversation is for me to find out a little more about your experience of "name of child's" alopecia, so don't worry if you feel like you are doing all the talking. If you would like to stop at any point, or do not feel able to answer a question please let me know. Do you have any questions before we start?

(*Switch tape recorder on*)

1. When did "name of child's" alopecia start? Can you tell me about this time?

  Prompts: What happened? How did you feel? What were you thinking?

2. Can you tell me about what it's like being "name of child's" mum/dad/ 'care-giver's relationship with child'?

  Prompts: Has 'name of child's' alopecia change things in any way? How do you feel/think about those things? What do you think your child feels/thinks about them?

3. Can you tell me about 'name of child's school life?'

  Prompts: Has 'name of child's' alopecia changed things in any way? How do you feel/think about that?

4. How has life been since 'name of child's' alopecia?

  Prompts: What have you found helpful/unhelpful? What have the reactions of other people been like? What have the reactions of people at school/teachers/other family been like? How does that make you feel? What do you think about that?

Thanks & Debrief: How have you found it talking with me? Do you want to add anything or alter anything you said previously? Do you have any questions? Is there anything that you're worried about from our conversation? Is there anything you think I should ask other parents? Are you still happy for this recording to be used in my study?

Appendix N: Child Interview Schedule

Preamble: Okay, so thank-you for filling out those questionnaires for me. So now I'd just like to spend some time talking to you about your experience of alopecia. Some people find it harder than others to talk about this this type of thing, so it's okay to tell me as much as you feel comfortable talking about. Also, don't worry if you feel like you are doing all the talking! I've brought along some drawing materials, because sometimes it's easier to draw things, than say how you feel out loud. You don't have to use these though. I'll let you decide what feels more comfortable as we start talking. Do you have any questions before we start again?

(Switch tape recorder on)

1. **Can you tell me a little bit about yourself "name of child?"**
   Prompts: What do you do for fun? Have you got any brothers or sisters? Can you tell me a little about your friends?

2. **Can you tell me when you first started losing your hair?** *(Check whether child uses the term alopecia)* **OR I wonder if you could draw a quick picture of yourself for me?**
   General Prompts: What happened? How did you feel? What were you thinking?

   Picture Prompts: Can you tell me about your picture? (specific/unclear parts: What is this part? Can you explain what is happening here? What does this bit mean? Can you tell me some more about your picture? What are you thinking/feeling here?)

3. **Can you tell me a bit about school and hobbies? If it's easier to draw you can?**

   Prompts: What is school like? What is it like meeting new people? How do you feel about your friends? How do you think other people feel/think about you?

   Picture Prompts: As above

4. **How has life been since your hair loss? If it's easier to draw you can?**

   Prompts: Has your hair loss changed anything? How have other people been? What have your teachers/friends/people in the family been? How does that make you feel? What do you think about that?

   Picture prompts: As above

Thanks & Debrief: How have you found it talking with me? Do you want to add anything or change anything you said previously? Do you have any questions? Is there anything that you're worried about from our conversation? Is there anything you think I should ask other children? Are you still happy for this recording to be used in my study?

Appendix O: Data Analysis Process

Steps 1 and 2. Transcripts were first read and re-read alongside listening to recordings to facilitate immersion in the data. Line by line noting was then conducted. Highlighting of comments: Yellow = descriptive, green = linguistic and orange = conceptual.

Image removed to protect confidentiality

Step 3. Emergent themes were structured hierarchically and recorded in a format that enabled them to be moved into new groupings as well as linked back to source data.

	A	B
	C2 Themes	**Line numbers**
1	**C2 Themes**	**Line numbers**
2	Dealing with stress and pressure	17-19
3	Discovering alopecia	44-46
4	Noticing alopecia progressing/getting worse	47-48, 49-50, 77-79, 81-82, 85-87
5	Hiding hairloss	48-49, 49-50, 94-96, 284, 341-342
6	Starting to wear a wig	49-50
7	Not knowing what to think	53, 58-59, 75-76
8	Observing parents reponse	53-59
9	Feeling alone	62-67
10	Worry	73-74
11	Uncertainty	73-74
12	Fear	78
13	A shared experience with others	87-91
14	Doctors not doing anything/unable to help	74-75
15	Worry	73-74
16	Uncertainty	73-74
17	Noticing alopecia progressing/getting worse	77-79, 81-82, 85-87
18	Fear	78
19	Experience of wearing a wig	94-96
20	Adjusting to new appearance	100-102
21	Shock	102
22	Frustration related to accessing support	104-109
23	Frustration	119-122
24	Experience of parent seeking support from homeopath	124-125
25	Homeopath not able to help	127-128
26	Experience of parent seeking support from counsellor	129-130
27	Logistical challenges of seeking support	132-134
28	Experience of parent's distress	147-149
29	Examples of parental distress	149-154, 156-157, 160, 180-181, 183-184
30	Experience of treatments not working	167-168, 174
31	Negative experience of wearing a wig	155-157

Study aims | P1 | C1 | P2 | **C2** | P3 | C3 | P4 | C4

C2 Themes	Line numbers
Dealing with stress and pressure	17-19
Discovering alopecia	44-46
Noticing alopecia progressing/getting worse	47-48, 49-50, 77-79, 81-82, 85-87
Hiding hair-loss	48-49, 49-50, 94-96, 284, 341-342
Starting to wear a wig	49-50
Not knowing what to think	53, 58-59, 75-76
Observing parents response	53-59
Feeling alone	62-67
Worry	73-74
Uncertainty	73-74
Fear	78
A shared experience with others	87-91
Doctors not doing anything/unable to help	74-75
Worry	73-74
Uncertainty	73-74
Noticing alopecia progressing/getting worse	77-79, 81-82, 85-87
Fear	78
Experience of wearing a wig	94-96
Adjusting to new appearance	100-102
Shock	102
Frustration related to accessing support	104-109
Frustration	119-122
Experience of parent seeking support from homeopath	124-125

Step 4. Development of superordinate and subordinate themes
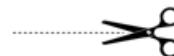
Steps 5. This process was repeated for each transcript then superordinate themes and subordinate themes were developed for each parent-child dyad.

	A	B	C	D	E	F
1	P2		C2		Dyad 2	
2	Superordinate themes	Subordinate themes	Superordinate Themes	Sub-ordinate Themes	Superordinate Themes	
3	Discovering Alopecia	The journey of hairloss	Discovering Alopecia	The experience of alopecia progressing	Discovering Alopecia	The journey of hairloss
4		Negative experiences of healthcare		Ideas about alopecia		Negative experiences of healthcare professionals
5		Making sense of alopecia		Negative experiences of healthcare professionals		Questions about alopecia
6				Negative experiences of treatments		Negative experiences of treatments
7	Coping	Seeking support				
8		Receiving support	Coping	Positive experiences of support	Coping and Support	Positive experiences of support
9		Seeking solutions / Taking control		Negative experiences of support		Negative experiences of support
10				Emotional coping mechanisms		Seeking support and solutions
11	Loss	Loss of normalcy				Emotional coping mechanisms
12		A different child	Other people's reactions	Positive Experiences of other peoples reactions		
13		Grieving the past		Negative experiences of other people's reactions	The emotional impact of alopecia	Feeling upset and frustrated
14				Not knowing		Low mood and Depression
15	Emotional Impact	Feeling upset and frustrated				Fear and worry
16		Low mood and Depression	The emotional Impact of Alopecia	Fear and worry		Dealing with uncertainty
17		Fear and worry		Feeling upset and frustrated		Hope and hopelessness
18		Dealing with uncertainty		Dealing with uncertainty		
19		Hope and hopelessness			A shared experience	Loss (of hair, of normalcy, of person child used to be)
20			Alopecia as a life-changer	Difference and identity		The parent-child relationship (closer together and further apart)
21	Alopecia and parenting	A shared experience		Impact on activities		Dealing with other people's reactions (experiences of bullying)
22		The parent child relationship		Family experience		
23		The role of the parent			Secrecy and disclosure	Hiding hairloss (incl transitioning to a wig)
24		Providing support	Keeping a secret	Hiding hairloss		Managing others
25				Transitioning to a wig		
26	Impact on daily life	Impact on activities			A life-changer	Impact on activities
27		Managing others				Difference and Identity
28		Hiding hairloss				The financial cost of alopecia

P1 | C1 | DYAD1 | P2 | C2 | **DYAD2** | P3 | C3 | DYAD3 | P4 | C4 | DYAD 4 | ALL DYADS | Notes

Overall themes from parent-child dyads were then combined to develop a master set of themes.

	Dyad 1		Dyad 2		Dyad 3		Dyad 4		Final Themes	
	Superordinate themes	Subordinate themes	Superordinate Themes		Superordinate themes	Subordinate themes	Superordinate themes	Subordinate themes	Discovering Alopecia	A journey of discovery
3	Discovering Alopecia	The hairloss jouney	Discovering Alopecia	The journey of hairloss	Discovering Alopecia	A journey of discovery	Discovering Alopecia	Experience of healthcare professionals		Questioning why
4		Negative experiences of healthcare professionals		Negative experiences of healthcare professionals		Experiences of the healthcare system		The journey of hairloss		Alopecia being mistaken for cancer
5		Positive experiences of healthcare professionals		Questions about alopecia		Questioning why		hypothesizing about alopecia		
6		Looking for answers		Negative experiences of treatments		Experiencing physical discomfort		Discovering alopecia	Feeling alone	Negative experiences of healthcare professionals
7		Alopecia and cancer						Learning about alopecia		Finding people who understand
8			Coping and Support	Positive experiences of support	A journey of emotions	A different first year		Alopecia coming and going		
9	A Shared Experience	Experiencing the social impact of alopecia		Negative experiences of support		Holding onto hope		Experience of treatment (cream)	A shared experience	Experiencing the emotional impact of alopecia
10		Experiencing the emotional impact of alopecia		Seeking support and solutions		A sad reality				The parent-child dynamic
11		Loss		Emotional coping mechanisms		Worry	Reactions of others	Alopecia being mistaken for cancer		Loss and grief
12		A few steps forward and a few steps backwards				Grief and loss		Others mistaking alopecia for cancer		
13		Dealing with the reactions of others	The emotional impact of alopecia	Feeling upset and frustrated		Feeling alone		Other people noticing hair loss	Secrecy and disclosure	Hiding hairloss
14		Eliciting curiosity and empathy		Low mood and Depression		Anger		Being asked lots of questions about alopecia		Managing other people's reactions
15		Overt and covert bulling		Fear and worry		The emotional impact of other's reactions		Experience of being teased by sibling		
16		Transitioning to a wig		Dealing with uncertainty		Not knowing what to do			Coping	Seeking solutions
17		The practicalities of wearing a wig		Hope and hopelessness		Feeling inadequate	A shared experience	Alopecia and parenting		Developing a support network
18						Pride and admiration		A shared experience		Psychological coping strategies
19	Coping	Seeking solutions	A shared experience	Loss (of hair, of normalcy, of person child used to be)				feeling protective		Coming to terms with alopecia
20		Developing a support network		The parent-child relationship (closer together and further apart)	Stigmatisation	It's the way people ask questions		Impact on day to day life		
21		Humour		Dealing with other people's reactions (experiences of bullying)		Alopecia being mistaken for cancer		Alopecia not changing things	A life-changer	Impact of alopecia on leisure activities
22		Seking support				Bullying and teasing		Positive experience of teacher with knowledge of alopecia		Stigmatisation
23		Support from friends	Secrecy and disclosure	Hiding hairloss (incl transitioning to a wig)				Support from mum		Visible difference and identity
24		Support from school		Managing others	Coping and support	Building strength				
25		Emotional coping mechanisms				Practical parenting	Coping and concealment	Hiding hairloss		
26		Parental support	A life-changer	Impact on activities		Seeking solutions and support		Ignoring other children's questions as a coping strategy		
27		Finding people who understand		Difference and Identity		Embracing support networks		Experience of others not caring about alopecia		
28				The financial cost of alopecia		Psychological coping strategies		positive experience of teacher with knowledge of alopecia		
29	A life-changer	Impact on activities				Giving support to others with alopecia				
30		The practicalities of wearing a wig				Adjusting to hairloss	Emotional impact	Feeling upset		
31		The parent-child relationship (parent-child role reversal)				Finding others who understand		Feeling alone		
32						Feeling supported		Dealing with uncertainty		
33						The hat as an enabler		Worries and concerns		
34						The hat as an enabler		Sadness		
35										
36					A shared experience	A shared experience				
37						Feeling safe				
38										
39					Finding acceptance	Coming to terms with alopecia				
40						Acceptance				

P1 | C1 | DYAD1 | P2 | C2 | DYAD2 | P3 | C3 | DYAD3 | P4 | C4 | DYAD 4 | **ALL DYADS** | Notes

Step 6. Analysis then progressed to a more theoretical level which led to further refinement and development of the final set of themes described in this study.

Final Themes

Discovering Alopecia	A journey of discovery
	Questioning why
	Alopecia being mistaken for cancer
Feeling alone	Negative experiences of healthcare professionals
	Finding people who understand
A shared experience	Experiencing the emotional impact of alopecia
	The parent-child dynamic
	Loss and grief
Secrecy and disclosure	Hiding hairloss
	Managing other people's reactions
Coping	Seeking solutions
	Developing a support network
	Psychological coping strategies
	Coming to terms with alopecia
A life-changer	Impact of alopecia on leisure activities
	Stigmatisation
	Visible difference and identity

Feeling alone subsumed into other superordinate themes

Themes not conveying the strength and resilience shown by children and picked up on by parents

Life-changing aspects are part of the shared experience

➡️

Final Themes V2

Discovering Alopecia	Initial reactions to alopecia
	Searching for answers
	Comparisons with cancer
A Shared Experience	Alopecia getting in the way
	Stigmatisation
	The emotional impact of alopecia
	Loss
	The parent-child relationship
Secrecy and Disclosure	Hiding hair-loss
	Managing other people's reactions
Coping	Seeking solutions
	Developing a support network
	Psychological coping
Strength and Resilience	

Coping runs through all themes
Strength and resilience need not be a standalone sub-ordinate theme
Look at other ways to describe superordinate themes that encapsulate experiences
Need to get across temporal nature of experiences

⬇️

Final themes V3

A journey of discovery	Initial reactions to alopecia
	Searching for answers
	Questioning why
	Comparisons with cancer
In it together	Alopecia getting in the way
	Experiences of bullying and stigmatisation
	Loss of the child/self before alopecia
	Protecting one another
A pointless battle	Seeking solutions
	Developing a support network
	Growing through adversity
Secrecy and Disclosure	Hiding the shame of being different
	Managing others to protect the self

After revisiting original narrative

Ensuring all experiences covered

After engaging in more interpretation of the results

Applying cognitive behavioural theory

Incorporating knowledge of Goffman's work

Coping theories – dynamic versus staged approaches

Moving towards acceptance common to all dyads in the temporal process

Draw on theory on coping and and resilience and look at the appearance research

Look at review of the family experience other chronic dermatological conditions

Final Themes - Final version

Discovering Alopecia	Initial reactions to alopecia
	Searching for answers
	Exploring solutions
	Questioning why
	Alopecia and cancer
A Shared Experience	It's what we have to live with
	Alopecia getting in the way
	Experiences of stigmatisation
	Loss and grief
	Living with uncertainty
Secrecy and Disclosure	Hiding the shame of hair-loss
	Managing other people's reactions
Towards Acceptance	Going it alone and seeking support
	Growing stronger

Appendix P: Peer Audit of Analytic Process

Peer Audit – The Pre-Adolescent Experience of Alopecia Areata

Data collection

1. Is there evidence that raw data was collected and is appropriate for the research aims? (As evidenced by anonymised transcripts/data etc.)

   (Yes) / Partially / No

2. Has relevant demographic and background information been collected to contextualise the sample (e.g. gender, age, occupation, marital status, severity of AA, quality of life measures)?

   (Yes) / Partially / No

3. Are there reflections/notes/summaries on the data collection process?

   (Yes) Partially / No

Research/analysis process

4. Has the researcher maintained a reflexive journal? (As evidenced by notes kept on pre-existing theoretical knowledge, personal views, thoughts and feelings regarding the researcher's experience of androgenetic alopecia and initial preconceptions.)

   (Yes) Partially / No

5. Has the data been sufficiently coded? (e.g. is all the relevant data coded?)

   (Yes) Partially / No

6. Has the data been systematically coded (e.g. line by line noting, hand-written comments, colour coding of *descriptive, linguistic* and *conceptual* comments and identification of emergent themes.)

   (Yes) / Partially / No

7. Is it clear that the researcher has engaged in a process of refining and redefining superordinate and subordinate themes that are grounded in the original narrative? (Evidence of emergent themes structured hierarchically and recorded in a format that enabled them to be moved into new groupings as well as linked back to source data)

   (Yes) Partially / No

8. Has a multi-perspectival approach been adopted? (Evidence of repeating the process above for each parent and child, and then for each parent-child dyad and developing a final set of themes by combining themes for each parent-child dyad)

   (Yes) / Partially / No

Cross-checks

9. Crosschecking randomly selected excerpts from the interviews against the corresponding coding and themes recorded in excel.

   Are these consistent?

   (Yes) Partially / No

10. Vice-versa crosschecking randomly selected themes and subthemes from Excel against the corresponding data.

    Are these consistent?

    (Yes /)Partially / No

Date of audit:

05/11/2018

Signature of researcher:

███████████████████

Name and job title of auditor:

~~Miss~~ Alexandra Leedham, trainee clinical psychologist and peer IPA researcher
Mrs

Signature of auditor:

███████████

Appendix Q: Personal Experiences and Preconceptions

Removed to protect confidentiality

Appendix R: Examples of Reflexivity

Removed to protect confidentiality