# Understanding the experiences of skin conditions and living with visible difference

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This thesis is submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology

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**List of Abbreviations**

**ACT** Acceptance and Commitment Therapy

**BPS** British Psychological Society

**GP** General Practitioner

**HCPC** Health and Care Professionals Council

**HRA** Health Research Authority

**IPA** Interpretative Phenomenological Analysis

**NHS** National Health Service

**NICE** National Institute for Health and Care Excellence

**REC** Research and Ethics Committee

**UK** United Kingdom

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**Acknowledgements**

Firstly, I wish to thank the participants for taking the time to share their experiences with me and to the staff in the dermatology clinics who supported the recruitment process.

I would like to thank my research team, Dr Kate Martin and Dr Carolyn Gordon for all the help, support and wisdom they have provided throughout the research process.

Finally, I wish to thank my fiancé, family and friends for their undying support, love and encouragement as without them, this would not have been possible. They have always been able to shine a light even on the greyest of days.

**Declaration**

I wish to declare my thesis as an original piece of work. All chapters have been prepared under my authorship which have been completed under the supervision of my research team, Dr Carolyn Gordon (Clinical Psychologist, Coventry University) and Dr Kate Martin (Clinical Psychologist, Heart of England NHS Foundation Trust). My thesis has not been submitted for another degree, at another University or other institution. The systematic literature review and the empirical paper have been prepared for submission to the British Journal of Psychology.

**Summary**

This thesis contributes to the understanding of the psychosocial factors associated with skin conditions and the lived experience of visible difference. Chapter one is a systematic literature review that identifies the psychosocial factors associated with the onset and living with alopecia for children and young people. A systematic review of the literature indicated relational factors and frequency of negative life events were associated with the onset of alopecia for young people. Although the findings into the psychosocial factors associated with living with alopecia are mixed, anxiety was the most frequently reported factor for children and young people. The quality of the papers included in the review are mixed, with varying population samples, measures and methodological limitations. Clinical and research implications are discussed.

Chapter two is a qualitative research study that explored the lived experience of six women with rosacea using interpretative phenomenological analysis (IPA). Participants' experiences of rosacea were characterised by an internal struggle to feel in control of their skin condition whilst externally, learning to navigate complex social interactions. Clinical and research implications are discussed.

Chapter three is a reflective account of the researcher's experiences during the research process. The researcher's reflections have been structured around the Acceptance and Commitment Therapy (ACT) Hexaflex model. Particular attention has been paid to the experiences that reflect the researcher's values, cognitive defusion, acceptance, contact with the present moment, self as context and committed action.

**Overall Word Count: 18,592**

# Chapter 1: Literature Review

## The psychosocial factors related to alopecia in young people: A systematic review of the literature

Written in preparation for submission to the *British Journal of Psychology*

(See Appendix A for author guidelines for submission)

Chapter word count (excluding tables, figures and references): 7,918

**1.0 Abstract:**

*Aim:* The pathogenesis of alopecia is complex and the inclusion of various age ranges in previous systematic reviews has made it difficult to understand the psychosocial factors related to young people with the condition. This review aims to identify the psychosocial factors associated with onset and living with alopecia for children and young people.

*Method:* A systematic review of the literature was completed across eleven databases, together with the use of reference and citation searches. A web search engine was also searched to identify relevant grey literature. A total of nineteen studies were identified.

*Results*: Relational factors and number of negative life events were associated with the onset of alopecia. Anxiety was the most frequently reported factor for young people living with the condition. Other factors discussed included quality of life, self-esteem, systemic difficulties and coping strategies.

*Conclusion:* The quality of the papers are mixed with varying population samples, measures and methodological limitations. The review highlights the importance of a holistic assessment of needs and the use of services to support young people and their families. Other research and clinical implications are discussed.

*Key words: Alopecia, young people, psychosocial factors, review*

## 1.1 Introduction:

### 1.1.1 Alopecia

It is widely acknowledged that hair follicles have important physiological functions particularly within temperature regulation, obtaining sensory and tactile information and protection from UV light (Blume-Peytavi, Kanti & Vogt, 2016). For humans, hair has also become a symbol of great psychological and social importance, playing a key role in the development of self-identity, social interaction, sexual attraction and communication (Blume-Peytavi et al., 2016; Farrant & McHale, 2014). Within the literature, research into conditions that cause visible hair loss, particularly on the scalp suggests it can have a devastating impact on psychological and social wellbeing (Hunt & McHale, 2005b).

Alopecia is a term often used to define a broad range of hair loss conditions which are typically grouped into two main categories: non-scarring and cicatricial (scarring) alopecia (American Skin Association, 2012). Although the estimated prevalence rates and symptom trajectory varies between the two categories, broadly speaking both are marked by the thinning or loss of hair that has arisen from a disruption to the hair growth cycle (Bouhanna, 2016). For both categories of alopecia, the pathogenesis of the condition is complex, with various inflammatory, autoimmune, genetic, hormonal and psychosocial factors implicated in the

aetiology of the condition (Dinh & Sinclair, 2007; Madani & Shapiro, 2000; McElwee et al, 2013).

Non-scarring forms of alopecia are the most prevalent forms of hair loss and are defined by a reduced hair density on the scalp (androgenetic alopecia), loss of hair in patches (alopecia areata), across the whole scalp (alopecia totalis) and across the scalp and body (alopecia universalis) (Delamere, Sladden, Dobbins & Leonardi-Bee, 2008). As the hair follicle can re-grow, the majority of people living with the condition will experience reoccurring episodes of hair loss across their lifespan (Messenger, McKillop, Farrant, McDonagh & Sladden, 2012; Papadopoulos, Schwartz & Janniger, 2000). Whilst the two categories of alopecia are largely distinct, over time, it is possible for non-scarring alopecia to develop a biphasic pattern similar to the trajectory of hair loss associated with cicatricial alopecia (Somani & Bergfeld, 2008).

Although the understanding of cicatricial alopecia is limited, in these cases the processes that are thought to cause the hair loss also destroy the hair follicle and lead to the surrounding skin to become scarred (Price & Mirmirani, 2011). Unlike non-scarring alopecia, this prevents any opportunity for hair re-growth, leading to the permanent loss of hair on the scalp (Chiang & Al-Niaimi, 2012). Whilst both cicatricial and non-scarring alopecia have a minimal effect on general physical health, they

pose a significant challenge to clinicians as they are difficult to treat, often chronic in nature and are associated with a number of social and psychological factors (Messenger et al., 2012; Pradhan, D'Souza, Bade, Thappa & Chandrashekar, 2011).

### 1.1.2 Pathogenesis of alopecia

Research into the onset of alopecia has predominantly focused on understanding the different biological and medical factors that underpin the hair loss (Delamere et al., 2008). Preliminary research into the mind-body link indicates that the presence of psychosocial factors can mediate the biological mechanisms responsible for inhibiting hair growth (Arck, Slominski, Theoharides, Peters & Paus, 2006; Garcia-Hernandez, Ruiz-Doblado, Rodriguez-Pichardo & Camacho, 1999). More specifically, it is the presence of stressful life events (Brajac, Tkalcic, Dragojevi & Gruber, 2003), affective disorders (Gupta, Gupta & Watteel, 1997), lack of attachment security (Schmidt, 2003) and personality characteristics (Willemsen, Haentjens, Roseeuw & Vanderlinden, 2009) which have been associated with triggering the onset of alopecia and/or the aggravation of pre-existing symptoms. Whilst this suggests an association between the onset of alopecia and the presence of a psychosocial factor, the pathogenesis of alopecia is complex, with studies reporting conflicting results across a broad range of population samples and age range of participants (Picardi et al., 2003; Van Der Steen, Boezemann, Duller & Happle, 1992). Despite the

methodological limitations of the literature, the conflicting research findings indicate further investigation is required in order to broaden the understanding of the association between psychosocial factors and the onset of alopecia that occurs across the life span.

### 1.1.3 Psychosocial Factors and Alopecia

The psychosocial factors associated with living with non-scarring alopecia in adults is well documented with anxiety, depression, obsessive compulsive disorder , poor self-esteem and poor quality of life frequently documented (Alfani et al., 2012; Al-Mutairi & Eldin, 2011; Chu et al., 2011; Hunt & McHale, 2005a,; Masmoudi et al., 2013; Sellami et al., 2014). Although research into cicatricial alopecia is still in its infancy, poor health-related quality of life, emotional distress, anxiety and depression have also been associated with living with this condition (Chiang, Bundy, Griffiths, Paus & Harries, 2015; Katoulis et al., 2015; Pradhan et al., 2011).

Due to the volume of research on alopecia areata, a number of systematic reviews have been completed. These reviews consistently make reference to the presence of depression, anxiety and poor health related quality of life (Fricke & Miteva, 2015; Ghanizadeh & Ayoobzadehshirazi, 2014; Hunt & McHale, 2005a; Liu, King & Craiglow, 2016; Tucker, 2009). Whilst these reviews help to synthesise the literature, they do not incorporate a quality

assessment framework, with some reviews providing limited information on the studies they investigated. This can make it difficult to compare and critique the quality and findings of the studies and improve future psychological research in the topic area (Moher, Liberati, Tetzlaff & Altman, 2009; NICE, 2012). Furthermore, the majority of the research in this area has focused on the adult population and as such the reviews are limited in their ability to portray the psychosocial factors associated with living with alopecia in young people.

### 1.1.4 Alopecia and Young People

Alopecia can develop at any age and although the prevalence rates vary within the literature, some types of non-scarring alopecia are more likely to develop before adulthood (NICE, 2014b). The age at which the condition develops is considered to be an important risk factor in the trajectory of the condition, as children with alopecia are more likely to have extensive hair loss across the lifespan compared to adults who develop the condition (Fricke & Miteva, 2015).

Childhood and adolescence is usually defined as a time of physical change, sexual maturation and social development (Cote & Levine, 2016). Typically, this stage of life is characterised by the increasing focus on the exploration of values and beliefs, seeking more autonomy and focusing on peer relationships (Erikson, 1968; Sharma & Lucchetta, 2007). Integral to child

development is the importance that is placed on physical appearance, particularly within the formation of identity, body satisfaction and youth culture (Coleman & Hendry, 1999; Harter, 1999; Holmbeck, 2002). As such, visible differences which alter physical appearance can present as an additional challenge for a young person to navigate, as it can disrupt the trajectory of typical social development (Empson, Nabuzoka & Hamilton, 2004).

Within the literature, there seems to be an assumption that the psychosocial factors associated with alopecia in adults mirror those of children and young people (Smith, 2001). However, in light of the importance of appearance within normal social developmental processes, it is perhaps unsurprising that young people with alopecia areata may have higher rates of self-reported depression and anxiety levels compared to adults living with the condition (Ghanizadeh & Ayoobzadehshirazi, 2014). This indicates further research is needed to explore the psychosocial factors associated with alopecia for different age categories, in particular, factors specifically related to children and young people.

### 1.1.5 Rationale and Aims

Several literature reviews on the psychosocial factors associated with alopecia have been conducted (Cash, 2001; Ghanizadeh &

Ayoobzadehshirazi, 2014; Hunt & McHale, 2005a; Tucker, 2009). However, the inclusion criteria of these reviews have led to participant samples of widely varying age ranges ; making it difficult to understand the psychosocial factors specific to children and young people with alopecia. In addition, the systematic reviews completed in this area do not consistently include a quality assessment framework which presents a challenge in establishing the quality and findings of the current literature (Moher et al., 2009; NICE, 2012). To the author's knowledge there has yet to be a systematic literature review which has investigated the psychosocial factors associated with the onset and living with alopecia for children and young people. The current review will therefore explore and critically evaluate the current literature base to address the following aims:

- What are the psychosocial factors associated with the onset of alopecia in children and young people?

- What are the psychosocial factors associated with living with alopecia for children and young people?

## 1.2 Method

### 1.2.1 Ethical Considerations

The systematic literature review protocol was developed and conducted in concordance to British Psychological Society (2009) and

Health and Care Professionals Council (HCPC) Guidelines (2016) for Ethical Human Research and Conduct. The research protocol was also submitted and approved by the Coventry University Ethics Committee (see Appendix B).

### 1.2.2 Searches

#### 1.2.2.1 Database search

A scoping search of the literature was completed in August 2016. Discussions with a Consultant Dermatologist and Clinical Psychologist working in the NHS and librarians from the University established relevant search terms, databases and differences in spelling of the key terms across different countries. The primary and meta electronic databases that were searched were Academic Search Complete, Allied and Complementary Medicine Databases (AMED), Applied Social Sciences Index and Abstracts (ASSIA), Cumulative Index to Nursing and Allied Health Literature (CINAHL), EMBASE, Medline, Psych Articles, PSYCH info, PROQUEST, Scopus and Web of Science. Google Scholar and Open DOAR were also included in the review for the purpose of searching for grey literature.

The key search terms used in the database search are included in Table 1.1. In order to improve the accuracy of the database searches, free

text, subject heading terms and Boolean operators were used (Dundar & Fleeman, 2014). Whilst a search string was used as consistently as possible, at times the search string and use of Boolean operators had to be modified in order to comply with the design of some of the databases.

Table 1.1 Database search strategy

| **Concepts** | **Variation/Synonym** |
|---|---|
| Alopecia | Alopecia* OR Childhood alopecia OR "androgenetic alopecia" OR "hair shaft abnormalities" OR "tinea capitis" OR "traction alopecia" OR "androgenic alopecia" OR "female pattern hair loss" OR "female pattern baldness" OR "hair loss" OR "hair thinning" OR baldness OR "telogen effluvium" OR "cicatricial alopecia" OR "non scarring alopecia" OR “non-scarring alopecia” OR "scarring alopecia" |
| Age | Child* OR “young person” OR “young people” OR adolescent OR teenager OR youth |
| Psychosocial factors | "psychosomatic" OR "psychological cause" OR "psychosocial factors" OR "psychological factors" OR "self esteem" OR psycho* OR psychosocial* OR "quality of life" OR mental* OR anxiety OR depression OR "psychological distress" OR |

| | |
|---|---|
| | "emotional response" OR "lived experience" OR mood OR social avoidance OR social interaction |
| Excluded from the review | drug* OR oral* OR chemo* OR cancer OR "leukemia" OR "leukaemia" |

In line with previous systematic reviews on alopecia, the term, 'psychosocial factors' was operationalised in the current review as "any negative outcomes that affect patients either emotionally, psychologically, or socially" (Tucker, 2009, p.143). Although there are no specific guidelines on the recommended use of search filters, the parameters used in the current review were considered in context of balancing the sensitivity and precision of the search strategy (Brettle, Long, Grant & Greenhalgh, 1998: Jenkins, 2004). This included limiting the key terms to article abstracts that were peer reviewed and available in the English Language. Furthermore, a date limit was not included in the search parameters in order to identify as much information as possible in the context of the broad aims of the review.

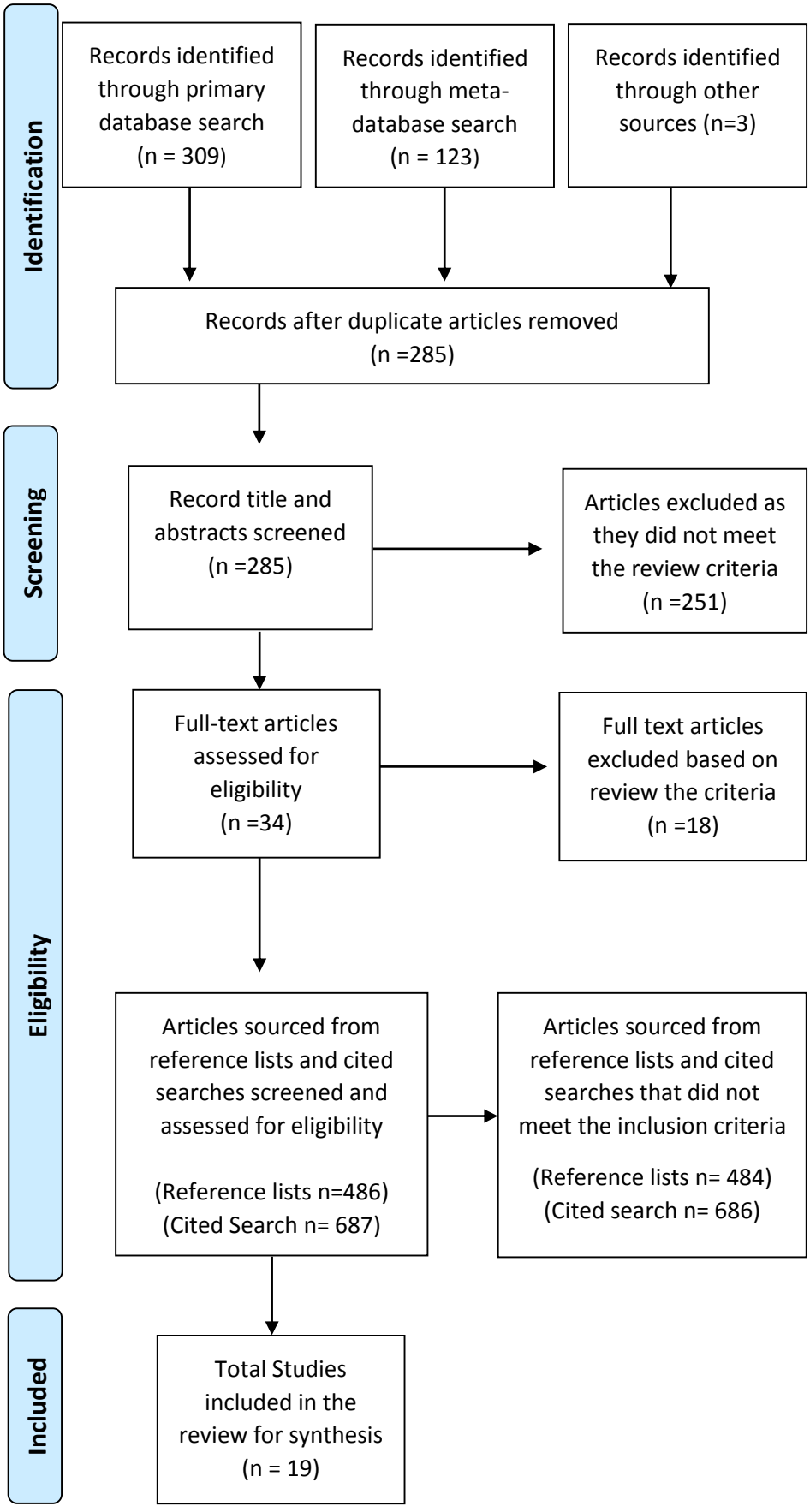
Using the key search terms, a systematic search of the literature was completed between January and February, 2017. The titles and abstracts of papers identified within the stated databases were screened against the criteria and those that did not meet the inclusion

criteria were discarded (see Table 1.2). Following this, the paper's full text was evaluated against the criteria through which they were either excluded or included in the review (see Figure 1.1). Consistent with the research proposal, three papers were discussed with the supervisory team as to whether they met the criteria.

#### 1.2.2.2 Manual Search

The reference lists of the articles that met the inclusion criteria were examined in order to identify other papers that were not captured in the search. In line with good practice guidelines, a cited search on the full text articles that met the inclusion criteria was also completed (NICE, 2014a). Titles and abstracts of the articles sourced from reference lists and cited searches were initially screened against the inclusion/exclusion criteria, followed by a full text review to ensure the articles met the criteria of the review. As it is essential for systematic reviews to be "thorough, transparent and reproducible" (NICE, 2012), Figure 1.1 highlights the search strategy that was completed based on the Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) diagram (Moher et al., 2009).

Figure 1.1 Search Strategy Flow Diagram



### 1.2.3 Selection Criteria

#### 1.2.3.1 Inclusion Criteria

The inclusion/exclusion criteria for the review is included in Table 1.2. As alopecia can affect individuals of all ethnicities, cultures and gender (Messenger et al., 2012), the criteria for the participant samples were kept broad. In order to be consistent with the operational definition of a 'young person' recommended by the World Health Organisation (1986), the current review included papers involving participants up to the age of 25. Both quantitative and qualitative methodologies were included as the synthesis of articles from a range of methodological approaches can enrich the current understanding of physical health conditions (Mays, Pope & Popay, 2005).

The inclusion of grey literature was considered as a criteria in order to reduce possible article selection bias and to help identify additional articles that have yet to be published (Hopewell, McDonald, Clarke & Egger, 2007; McAuley, Tugwell & Moher, 2000). For the purpose of the review, grey literature was defined as "that which is produced on all levels of governmental, academics, business and industry in print and electronic formats, but which is not controlled by commercial publishers" (Hopewell et al., 2007, p.2). Any grey literature included in the review will be discussed as part of the quality assessment as without this, its inclusion can lead to additional bias (Dundar & Fleeman, 2014).

Table 1.2 Inclusion /exclusion criteria

| Inclusion Criteria | Exclusion Criteria |
|---|---|
| • Studies that explore the psychosocial factors associated with the onset and/or living with alopecia<br>• Participants aged up to 25 years old and/or their parents<br>• Studies that include common types of non-scarring and scarring alopecia<br>• Original research that is peer reviewed and/or contained within grey literature<br>• Full text available in English language | • Studies where young people's data cannot to be separated from adult data or other medical conditions<br>• Studies that that use alopecia as a control group to explore other medical conditions<br>• Articles, reviews and opinion pieces |

#### 1.2.3.2 Exclusion Criteria

Studies in the search were limited to the inclusion of full text availability in the English Language. Whilst this may exclude additional information

which could help with the precision and applicability of the findings, in many cases the effect of this exclusion criterion has had a minimal practical difference on the overall research findings (Juni, Holenstein, Sterne, Bartlett & Egger, 2002). Studies that combined the results of participants with alopecia and causes of hair loss from other physical health conditions, medical treatment and mental health difficulties were excluded from the current review. This was to ensure the presence of contextual factors that are commonly associated with psychological and social wellbeing in other causes of hair loss were excluded in the current review (Flessner et al., 2008; Williams, Wood & Cunningham-Warburton, 1999).

### 1.2.4 Quality Assessment

The inclusion of quality assessments is considered to be an essential component of systematic reviews as they help to evaluate the methodological quality of the current literature and minimise bias within a project (Sanderson, Tatt & Higgins, 2007). As there is currently no recommended 'gold standard' critical appraisal tool, careful consideration is required to ensure the most appropriate quality appraisal tool is chosen in relation to the reviewed studies (Katrak, Bialocerkowski, Massy-Westrop, Kumar & Grimmer, 2004; Sanderson et al., 2007). In light of this, papers included in the current review were subject to the quality assessment tool devised by Caldwell, Henshaw and Taylor (2005, 2011). (See Appendix C). This tool was chosen as it incorporates both generic and

specific concepts designed to be relevant to the qualitative, quantitative and mixed method approaches and range of research designs used within health research (Caldwell, Henshaw & Taylor, 2011).

As the framework does not provide a quality rating score, a scoring system was devised comprising: two points were awarded to a paper where quality criteria were fully met; one point for partially met quality criteria; 0 points for quality criteria not being met (See Appendix D for all quality assessment scores). Each study was therefore given an overall total score which was converted into a percentage quality score. Due to the limited volume of research, studies were included in the review regardless of their quality assessment score. This can support the generation of new insights into a topic area (Noyes et al., 2013). Whilst the literature does not provide a universal threshold score to classify 'high' and 'low' quality papers, (Whiting, Harbord & Kleijnen, 2005) for the purpose of the current review a paper with a quality rating score of below 50% was deemed to be poor quality. The quality rating score for each study is included in Table 1.3.

### 1.2.5 Quality Assessment Analysis

Inter-rater reliability testing for the quality assessment framework was completed on a random selection of five papers included in the review. A summary of the Cohen's Kappa reliability coefficient for these papers is

included in Table 1.3 (See Appendix E for Kappa coefficient data). The co-efficient scores varied from 0.79-0.91 with an overall Kappa reliability co-efficacy score of k=0.86. This indicates strong inter-rater reliability (Altman, 1999). Discrepant findings were discussed. Where divergence occurred it seemed to result from a lack of familiarity with the existing literature on the part of the rater.

### 1.3 Review of the literature

Nineteen papers were identified in the search and a summary of the papers is provided in Table 1.3. All papers recruited participants with non-scarring alopecia (alopecia areata, alopecia totalis and alopecia universalis). Three papers explored factors associated with the onset of alopecia, twelve papers focused on factors associated with living with the condition and four papers investigated both aspects. The majority of the studies (n=16) used quantitative, rather than qualitative (n=2) methodologies. One study used mixed methods.

Studies included in the review involved participants between the ages of 1-21 years. Research was completed across eleven different countries, with most papers being conducted in America (n=6). Information on participants' ethnicity and cultural backgrounds was inconsistently reported.

The findings have been structured to address the aims of the current review, exploring the psychosocial factors associated with the onset of alopecia, followed by the factors associated with living with alopecia. As none of the papers recruited participants with scarring alopecia, for ease of reading in the results and discussion section of the current review the term alopecia has been used to refer to participants with alopecia areata, alopecia totalis and alopecia universalis.

Table 1.3 Data log of the 19 papers in the review

| Author, Date, Location | Aim | Methodology and Method of data collection | Participant Information and Sampling Method | Main Findings | Quality Assessment Score |
|---|---|---|---|---|---|
| Al-Okali, El-Sourbagy & Wassif, 2008<br><br>Location: Libya | To compare depression and anxiety in children with skin diseases | Methodology: Quantitative<br>Design: Case Control Design<br>Measures: 1) D Test, 2) Anxiety Manifest Scale, 3) MMPI Psychiatric evaluation, 4) Medical history/ clinical examination | Sampling method: Not reported<br>Recruitment: Outpatient dermatology<br>Participants: aged 6-14 years<br>n = 50 'healthy' control group<br>n= 50 participants with skin conditions including n=10 with AA (6 males, 4 females) | 1) No significant difference *(p*=>0.05)* in the mean depression score between AA ( *M*=9.6, *SD*= 5.2) and control group (M=9.7, *SD*= 3.3)<br><br>2) AA group significantly higher mean (*M*= 20.2, *SD*= 6.6), anxiety score (*M*=13.2, *SD*=5.6) compared to control group (*p*= <0.01)* | 42% |
| Andreoli et al, 2002.<br><br>Location: Rome | To explore the onset of AA and stressful events | Methodology: Quantitative<br>Design: not reported<br>Measures: 1) Clinical interview, 2) Paykel's scale of stressful events, 3) HTP, 4) Rorschach diagnostic test | Sampling Method: Not reported.<br>Recruitment: Inpatient dermatology<br>Participants: N= 180 with AA, AT, AU. 54% male, 46% female. Age range 5-16 years, mean age =9.7 years. | 1) 81% of participants reported stressful event prior to AA (e.g. relational problems, pressure of expected performance, sibling rivalry).<br>2) 45% reported one stressful situation/event | 44% |
| Beattie & Lewis-Jones, 2006<br><br>Location: UK | To compare HRQOL scores in children with skin conditions | Methodology: Quantitative<br>Design: Not reported<br>Measures: 1) CLQI, 2) CDLQI | Sampling: Not reported<br>Recruitment: Outpatient dermatology<br>Participants: N= 379 aged 5-16 years with chronic skin condition and diseases. AA group n=11 (7 male, 4 female) | 1) Parents scored AA to have the 5th highest impact on child QOL compared to 11 skin conditions<br>2) Parents QOL score for child higher (18.7%) than AA participants score (10%)<br>2) Teasing/ bullying the most frequently reported in AA compared to 11 other skin conditions. | 58% |

Abbreviations:
*Quality of life measures:* QOL = Quality of Life, HRQOL= Health related quality of life, CLDQI= Children's Dermatology Life Quality Index, CLQI= Children's Life Quality Index, LECL = Life Events Checklist, LES=Life Events Scale, FES= Family Environment Scale, PedsQL= Paediatric Quality of Life Inventory
*Mental Health: CAMHS*= Child and Adolescent Mental Health Service, RCAMS= Revised Children's Manifest Anxiety Scale, RCADS= Revised Child and Anxiety and Depression Scale, STAI= State Trait Anxiety Inventory, CDS= Children's Depression Scale, CDRS= Children's Depression Rating Scale-Revised, CDI= Child's Depression Inventory, CBCL= Child Behaviour Checklist, CMAS = Child Manifest Anxiety Scale, HTP= Graphic House Tree Person Test, SCL-90-R= Symptom Checklist-90 Revised
*Medical terminology:* AA= Alopecia Areata, AT= Alopecia Totalis, AU= Alopecia Universalis, AD= Atopic Dermatitis, SALT= Severity of Alopecia Tool
** = Author observed the paper did not provide full statistical analysis data and/or participant information*

| Author, Date, Location | Aim | Methodology and Method of data collection | Participant Information and Sampling Method | Main Findings | Quality Assessment Score |
|---|---|---|---|---|---|
| Bilgic, et al, 2014<br><br>Location: Turkey | To assess depression, anxiety and QOL of young people with AA. | Methodology: Quantitative<br>Design: Not reported<br>Measures: 1) CDI, 2) STAI, 3) PedsQL, 4) Demographic form, 5) SALT | Sampling method: Not reported<br>Recruitment: Outpatient dermatology<br>Participants: Age range 8-18 years.<br>n=40 AA Child group<br>n=34 AA Adolescent group<br>n=33 Child control group<br>n=32 Adolescent control group | 1) State ($t$=3.16, $p$<.001) and Trait ($t$=2.95, $p$ <.001, two-tailed)* anxiety scores significantly higher in child AA group than control group.<br>2) Parents scored children with AA to have significantly lower HRQOL scores than control group ($U$= -2.63, $p$<.001, two -tailed)*<br>3) State anxiety significantly higher in adolescent AA group than control group ($t$=4.04, $p$<.001, two-tailed)*<br>4) No significant difference between parent's HRQOL scores of adolescents with AA and control group ($t$=-2.34, $p$<.02, two-tailed)* ($P$ value set at <.01) | 64%<br><br>(k=0.91) |
| Coulacoglou, Tchinou, & Michopoulou, 2001<br>Location: Greece | To evaluate personality structure of children with psychosomatic symptoms. | Methodology: Quantitative<br>Case Study: Case Report<br>Measures: 1) Fairy Tale Test (FTT), 2) Somatic Inkblot Series (SIS), 3) Family Drawing Test | Sample: Not reported<br>Recruitment: Not reported<br>Participant: n=1 10 year old male with AA, n=1 11 year old female with headaches and vomiting | 1) Low self-esteem (T=14.6)* stress and depression (T=78)* in child with AA.<br>2) Psychosomatic symptoms reflected in the avoidance of body imagery. | 17% |
| De Waard-Van Der Spek, Raeymaecker, Koot, & Oranje, 1994<br><br>Location: Netherlands | To establish psychological and social factors in the pathogenesis and prognosis of AA in childhood | Methodology: Quantitative<br>Design: Not reported<br>Measures: 1) CBCL, 2) Coddington Life Event Scale, 3) Physical examination and blood tests | Sampling Method: Not reported<br>Recruitment: Outpatient dermatology<br>Participants: n=17 AA/AT group (11 male, 6 female, age range 4-21).<br>n=15 AD "Reference group" (7 male, 8 female, age range 5-16) | 1) AA Group scores were significantly lower on social competence measure than normative values ($t$= -2.35, $p$ <.05)*<br>2) 75% of AA group scored below the cut off score for clinical psychopathology.<br>3) No significant difference in number of life events between AA group and normative values (data not provided)* | 44% |

| Author, Date, Location | Aim | Methodology and Method of data collection | Participant Information and Sampling Method | Main Findings | Quality Assessment Score |
|---|---|---|---|---|---|
| Diaz-Atienza & Gurpegui, 2011<br><br>Location: Spain | To investigate environmental conditions, subjective and physiological state of AA children | Methodology: Quantitative<br>Design: Case Control<br>Measures: 1) Clinical interview, 2) CDI, 3) STAI, 4) Scale of Life Events, 5) Personality questionnaire, 6) FES, 7) Blood and urine samples | Sampling method: Not discussed<br>Recruitment: Outpatient dermatology, neuropediatric and neurology clinic<br>Participants: age range 7-19 years. n=31 AA (AT/AU) Group (16 male 15 female), n=23 Control Group 1(epilepsy), n=25 Control group 2: (healthy siblings) | 1) No significant difference in personality variables*, state $F(2,76)= 0.28$, $p=.75$, trait anxiety $F(2,76)= 1.28$, $p=.28$, depression scores $F(2,76)=0.24$, $p=.98$ between AA and control groups<br>2) AA families had more environmental factors than control group 1 ($\chi^2(1)=4.23$, $p=.04$) and more stressful life events prior onset of alopecia | 61% |
| Elkin, Hiker & Drabman, 2006<br><br>Location: USA | To explore behavioural intervention with a child with anxiety and AA | Methodology: Quantitative<br>Design: Case Report<br>Measures: 1) CDI, 2) RCADS, 3) CBCL | Sampling: Not reported<br>Recruitment: Psychology CAMHS<br>Participant: n=1, 13 year old female with AA. | 1) Parent and child scores within normal range (only raw scores provided)*<br>2) Mother reported higher perceived child anxiety than participant<br>3) Results support use of behavioural techniques for anxiety arising from the onset of AA | 42% |
| Farajzadeh et al, 2013<br><br>Location: Iran | To evaluate the clinical profile of AA in children | Methodology: Quantitative<br>Design: Cross Sectional Survey<br>Measures: 1) SALT, 2) Physical assessment, 3) Clinical Interview | Sampling Method: Not reported<br>Recruitment: Paediatric dermatology<br>Participants: N=100 (57 males, 43 females) with AA/AT. Age range 1-16 years | 1) 33% reported stress prior to onset of AA<br>2) Age of onset, socioeconomic and parent educational status significantly associated with severity of young person's hair loss. ($p<.05$)* | 78% |
| Ghanizadeh, 2008<br><br>Location: Iran | To understand the prevalence of lifetime comorbid psychiatric disorders in AA. | Methodology: Quantitative<br>Design: Survey<br>Measures 1) Standardised clinical interview 2) Psychiatric assessment | Sampling: Not reported<br>Recruitment: CAMHS inpatient<br>Participants: N=14 with AA, mean age, 11.66 years (age range not reported) | 1) 78% had one or more lifetime psychiatric disorders. Depression most frequent disorder (50%).<br>2) 71% met DSM-IV criteria for current psychiatric diagnosis. | 44% |
| Hankinson, McMillan, Miller, 2013<br><br>Location: USA | Explore the perception and attitudes of children towards AA | Methodology: Quantitative<br>Design: Not reported<br>Measures 1) Research Interview, 2) Observation of behaviour | Sampling: Not reported<br>Recruitment: Not reported<br>Participants: N=123 aged 5-14yers | 1) 42% young children (5-9 years) and 54% older children (10-14 years) perceived AA child was sick, dying or contagious.<br>2) Children (5-9 years) interviewed in pairs were five times more likely to feel scared to form a relationship with a peer with alopecia compared to older children (10-14 years) | 31% |

| Author, Date, Location | Aim | Methodology and Method of data collection | Participant Information and Sampling Method | Main Findings | Quality Assessment Score |
|---|---|---|---|---|---|
| Karambetsos, et al, 2013<br><br>Location: Greece | To assess mental health of children with AA and AD reported by parents. | Methodology: Quantitative<br>Design: Cross Sectional Survey<br>Measures: 1) CBCL, 2) Symptom Checklist-90-Revised (SCL-90-R), 3) Clinical Interview | Sampling: Not reported<br>Recruitment: Outpatient Dermatology<br>Participants:<br>n= 51 Parents of children with AA (6-14 years)<br>n = 14 Parents of children with AD (6-14 years)<br>n= 12 Control group | 1) Anxiety, depression and social problem scores significantly higher in AA group compared to control group ($p$<.01)*<br>2) Maternal education status was significantly lower in AA group than control group ($p$<.01)* | 69% |
| Liakopoulou, et al., 1997<br><br>Location: Greece | To investigate psychopathology, QOL, frequency of life events in children with AA | Methodology: Quantitative<br>Design: Not reported<br>Measures 1) The Child Psychiatric Interview, 2)CBCL , 3) CMAS, 4) CDI, 5) LES | Sampling Method: Not reported<br>Recruitment: Outpatient dermatology and paediatric clinic<br>n=33 AA Group 1 mean age 10.5 years<br>n=16 AA Group 2 mean age 4.6 years<br>n=30 Control Group 1 mean age 10.6 years<br>n=16 Control Group 2 mean age 4.2 years | 1) Parents of AA groups scored their children significantly higher scores on anxious/depressed subscale of CBCL than parents of control groups ($F$(1.59) = 49.04, $p$<0.01)<br>2) No significant difference in CDI depression scores between AA group 1 and control group ($z$= 1.1248, $p$=.26)*<br>3) AA group 1 scored significantly higher on 4 anxiety subscales compared to control group ($p<0.05$)*<br>4) No significant difference in number of negative life events between AA Group 1 and 2 and control groups ($\chi^2$ (1)= 2.97, $p$=.08) | 61% (k=0.82) |
| Manolache, Petrescu-Seceleanu, & Benea,2008<br><br>Location: Bucharest | To examine relationship between AA and stressful events in children | Methodology: Quantitative<br>Design: Case Control Design<br>Measures: Clinical interview | Sampling Method: Not reported.<br>Recruitment: Dermatology department<br>Participants: N=86, <14 years old<br>n= 43 AA Group (18 males, 25 females).<br>n=43 Control Group (other skin conditions) | 1) Mean AA group scores on stressful events prior to AA onset was significantly higher compared to control group ($\chi^2$ =-14.36, $p$<.01)*, OR 7.14(95%CI, 2.59-19.63).<br>2) 88% of participants with AA reported a single stressful event | 28% |
| Mehlman & Griesemer,1968<br><br>Location: USA | To investigate relationship between child AA and emotional state. | Methodology: Qualitative/Descriptive<br>Design: Case Report<br>Measures: Clinical Psychiatric Interview | Sampling: Not reported<br>Recruitment: Outpatient Paediatric clinic<br>Participants: N=20 AA, AT, AU (7 male, 9 female, age range 2.5-18) * | 1) Traumatic weaning, abandonment, “neurotic anxiety”, birth of sibling and loss occurred two weeks prior to AA onset | 33% |

| Author, Date, Location | Aim | Methodology and Method of data collection | Participant Information and Sampling Method | Main Findings | Quality Assessment Score |
|---|---|---|---|---|---|
| Rafique & Hunt, 2015<br><br>Location: Pakistan | To understand adolescent's experiences of living with AA | Methodology: Qualitative, Interpretative Phenomenological Analysis (IPA)<br>Method: Semi structured interviews | Sample method: Not reported<br>Recruitment: Outpatient dermatology<br>Participants: N=8 (3 male, 5 female, age range 16-19).<br>n=3 developed interview schedule and included in analysis. | 1) 4 super ordinate themes, 16 subordinate themes. Super ordinate themes: 1) Loss, 2) Concerns, 3) Negative (emotions/thoughts), 4) Coping styles<br>2) Males and females expressed different coping behaviour | 86%<br><br>(k=0.85) |
| Reeve, Savage & Bernstein, 1996<br><br>Location: USA | To identify psychiatric diagnoses and life stressors in children with AA | Methodology: Quantitative<br>Design: Cross Sectional Survey<br>Measures: 1) Standardised clinical Interview, 2) RCAMS, 3) CDS, 4) LECL, 5) CDRS-R, 6) Piers-Harris Children's Self-Concept Scale<br>7) FES, 8) CBCL, 9) SCL-90-R | Sampling method: Not reported<br>Recruitment: Outpatient dermatology<br>Participants: N=12 with AA, age range 6-14 years. Sex distribution not reported. | 1) n=7 met diagnostic criteria for anxiety in clinical interview<br>2) Group mean scores were in the non-clinical range for depression (*M*=26, *SD*=7.6) and anxiety (*M*=62, SD=6.4)<br>3) Group mean self-concept scale score (T=64.6) indicated a high positive self-concept (93rd percentile) and above the normative value. | 56%<br><br>(k=0.82) |
| Toback & Rajkumar, 1979<br><br>Location: USA | To assess the "psychodynamics" in children with AA, AT and trichotillomania | Methodology: Quantitative<br>Design: Not reported<br>Measures: 1) Wechsler Intelligence Scale, 2) Geometric forms test, 3) Goodenough draw a man test, 4) Bender gestalt test, 5) Picture vocabulary test, 6) Clinical Interview | Sampling method: Not reported<br>Recruitment: Paediatric Ambulatory service<br>Participants:N=15 (9 male, 6 female, age range 3-12)<br>n=8 AA Group<br>n=2 AT Group<br>n=5 Trichotillomania Group | 1) AA group: n=3 "moderate emotional disturbance", n=5 "mild emotional disturbance"<br>2) AT group: n=1 "moderate emotional disturbance", n=1 "severe emotional disturbance" | 25%<br><br>(k=0.79) |
| Wolf, 2014<br><br>Location: USA | To explore factors that impact young people with AA and use of coping strategies | Methodology: Quantitative/Qualitative<br>Design: Mixed methods<br>Measures 1) Survey Questionnaire (created by the researcher), 2) Semi Structured Interview | Sampling Method: Purposeful<br>Recruitment: Charity database, social media, websites & conventions<br>Participants:<br>Quantitative: N=237 with AA (77 male, 160 female, age range 10-19)<br>Qualitative: N=11 with AA (6 male, 7 female age range 12-18) | Quantitative: Impact factors associated with AA 1) self-esteem, 2) psychological effects, 3) appearance/acceptance, 4) socialization, 5) communication<br>Coping strategies associated with AA: 1) physiological, 2) avoidance, 3) outside support, 4) social support<br>Qualitative: 3 main themes: 1) Acceptance, 2) Social issues 3) Coping | 44% |

### 1.3.1 Findings

#### 1.3.1.1 *Aim: What are the psychosocial factors associated with the onset of alopecia in children and young people?*

Out of the 19 papers included in the review, a total of 7 studies explored the psychosocial factors associated with the onset of alopecia. Within these papers, the presence of relational, social factors and the frequency of events emerged as key themes.

##### 1.3.1.1.1 Relational and Social Factors

In a descriptive study exploring psychosocial factors for young people with alopecia aged 5-16 years, 81%, of parents and children reported a relational difficulty to have occurred within six months prior to the development of alopecia (Andreoli et al., 2002). The majority of these difficulties centred on experiencing the separation from important attachment figures, separation anxiety and relationship discord within the family and school systems (Andreoli et al., 2002). The researchers concluded difficulties within the family system were more likely to occur during the pre-alopecia phase compared to events that are commonly associated with stress, such as the birth of a sibling and beginning of school. The loss of attachment, emotional security and family discord prior to the development of alopecia is also reiterated in the findings of other papers (Mehlman & Griesmer, 1968). However, in contrast, common stressful events in childhood such as traumatic weaning and birth of siblings were considered to be

important life events that occurred during the pre-alopecia phase (Mehlman & Griesmer, 1968). Drawing upon their findings within their clinical practice, the researchers hypothesised that rather than the type of relational difficulty, the association with the onset of alopecia is likely to be dependent on the child's subjective perception of a situation and whether it poses a threat to their emotional wellbeing (Mehlman & Griesmer, 1968). Although Andreoli et al (2002) and Mehlman and Griesmer (1968) make reference to a possible association between relationship difficulties and alopecia, they do not include a comparative control group, with the method of data collection focused on the use of unstructured interviews and observations in clinical practice. As highlighted in the quality assessment scores of these studies, they did not employ a control group or conduct a statistical analysis on the findings and as such, it is difficult to draw any firm conclusions in relation to the strength of the observed association.

The association between the subjective state of young people with alopecia and environmental stressors within the family system has also been explored using case control designs. Research completed by Diaz-Atienza and Gurpegui (2011) found children (aged 7-19 years) with alopecia had significantly more environmental stressors ($\chi^2(1)=4.23$, $p=.04$) than age and sex matched control group of children with epilepsy. With an odds ratio of 7.6 [95%CI, 1.5-38.2] children with alopecia reported more family conflict and separation from an attachment figure (migration, marital separation and death) (Diaz-Atienza & Gurpegui, 2011). Furthermore, compared to the control group, families of a child

with alopecia were significantly less expressive of their emotions, indicative of alexithymia traits ($\chi^2(1)= 4.20$, $p=.04$) (Diaz-Atienza & Gurpegui, 2011). Whilst the power of the results are questionable due to the sample size of participant groups (Diaz-Atienza & Gurpegui, 2011), in light of the method of data analysis and use of a control group, it could be hypothesised the lack of emotional expression between family members and separation from an attachment figure could influence how the family system responds to and manages stressful situations. These findings highlight the importance of considering the difficulties within the family and social systems during the pre alopecia phase, rather than limiting the focus to just individual factors.

Similar to Diaz-Atienza and Gurpegui (2011) findings, research completed by Manolache, Petrescu-Seceleanu and Benea (2009) found a significant difference in the number of relational and social factors experienced by young people in the pre alopecia phase compared to control groups ($\chi^2 =-14.36$, $p<.01$). The odds ratio indicated children with alopecia below the age of 14 years were seven times more likely to experience social and relational difficulties, compared to children in the control group who only reported the presence of social factors. The most common stressful trigger reported by all participants was in relation to starting school and changes at school. However, children with alopecia also reported family problems such as trauma, financial worries and family disputes (Manolache et al., 2009). As reflected in the quality assessment score (28%), the limited information provided on the population sample and method of data collection restricts the ability to understand the observed differences between

participants with alopecia and the control group. However, one hypothesis may be the accumulation of difficulties at school and within the family that may be important factors.

#### 1.3.1.1.2 Frequency of life events

The findings into the number of negative and stressful events in the pre alopecia phase are mixed, with some studies reporting a single stressful event whilst others report the occurrence of multiple events (Andreoli et al., 2002; Diaz-Atienza & Gurpegui, 2011; Farajzadeh et al., 2013; Manolache, et al., 2009). Research completed by Andreoli et al (2002), concluded it is the duration of a single event during the pre alopecia phase that is important, rather than the number of stressful events. In contrast to these findings, other papers allude to the presence of multiple stressful events with parents of young people of alopecia reporting a significantly higher number of stressful events during the pre alopecia phase compared to control groups $H(2)=23.11$, $p<.001$) (Diaz-Atienza & Gurpegui, 2011). Furthermore, other studies have not found a significant difference in the number of negative life events between young people with alopecia, control groups and normative data for life events scales (De Waard-Van Der Spek, Raeymaecker, Koot & Oranje 1994; Liakpoulou et al., 1997). However, unlike the other papers included in the review, research completed by Liakpoulou et al (1997) found children with alopecia significantly reported fewer positive life events ($\chi^2(1)= 6.23$, $p=.01$) than control groups prior to the onset of alopecia. These findings are suggestive of the need to focus not only on the frequency of

the negative life events within the family system, but also on the presence of positive events in order to support the psychosocial understanding in the onset of alopecia in young people.

#### 1.3.1.1.3 Summary

Overall, quality research into the psychosocial factors associated with the onset of alopecia in young people is limited, with over half of the papers (n=4) receiving a poor quality assessment score (<50%). In particular, the methodological limitations associated with the use of small sample sizes and descriptive analysis, (Barker, Pistrang & Elliott, 2015) could impact the power and validity of the findings and increase the possibility of a Type II error occurring. As highlighted in Table 1.3, several methods of data collection are used in the papers including the use of self-report measures and non-standardised clinical interviews. As the method of data collection can influence what information is obtained, it can make it difficult to compare findings across studies which use various techniques to collect participant data (Wethington, Brown & Kessler, 1995). The reliance on interviews and inconsistent definition of a psychosocial factor, are also likely to increase possible researcher bias in the method of data collection. Furthermore, it could increase the subjectivity in the interpretation of participant information and rigour of analysis in the data that is collected.

One of the main considerations of these papers is the reliance on retrospective data which is likely to have been impacted by the varying length of time between the onset of alopecia for participants and date the study was completed. It is possible participants recall of events was biased, which could impact the overall findings of the papers. Regardless of these methodological limitations, overall, the findings indicate a number of psychosocial factors could be associated with the onset of alopecia. In particular, social situations commonly associated with stress and difficulties in the family system, such as loss of attachment, may signal a threat to a young person's emotional wellbeing. The duration of a negative life event, how families express their emotional state and lack of positive events may also be important factors to consider. The pathogenesis of alopecia in young people is complex and this is reflected in the mixed results of the papers. It is therefore important to consider these psychosocial factors in context of the biological and environmental factors that could trigger the onset of alopecia in young people.

#### 1.3.1.2 *Aim: What are the psychosocial factors associated with living with alopecia for children and young people?*

Within the 19 papers included in the review, a total of 16 studies explored the psychosocial factors associated with living with alopecia for young people. Four key themes emerged from the literature: 1) mental health difficulties (depression and anxiety) 2) self-esteem and quality of life, 3) social factors, 4) psychosocial intervention and coping strategies.

#### 1.3.1.2.1 Depression

For some papers in the review, mental health difficulties were associated with children living with alopecia. In particular, parents of children with alopecia scored their children to have significantly higher levels of depression, anxiety and somatic complaints compared to parents of children with atopic dermatitis and the control group ($p$=<.01) (Karambetsos et al., 2013). Furthermore, research completed by Ghanizadeh (2008) reported half of children with alopecia who met the criteria for a psychiatric disorder had a major depressive disorder. However, for other papers, a significant association between depression and young people living with alopecia was not found (Al-Okali, El-Shourbagy & Wassif, 2008; Bilgic et al., 2014; Diaz-Atienza & Gurpegui, 2011). Whilst the findings into the association between depression and young people living with alopecia is mixed, it is possible these inconsistencies result from children and parent's perspectives being analysed separately or combined in the same results. This is highlighted in the research completed by Liakpoulou et al (1997) where they found parents scored their child with alopecia to have significantly higher scores on the anxious/depressed subscale, compared to parents in the control groups ($F$(1.59)= 49.04, $p$<0.01). However, separate analysis of the measures completed by young people indicated that depression scores were not significantly different compared to those of the control group ($z$=1.1248, $p$=.26).

#### 1.3.1.2.2 Anxiety

The majority of the papers in the review found an association between anxiety and young people living with alopecia, with significantly higher anxiety scores reported by both young people with alopecia and their parents compared to control groups (Al-Okali et al., 2008; Liakpoulou et al., 1997). Furthermore, research that separated data from child and adolescent participants found state ($t$=3.16, $p$<.001) and trait ($t$=2.95, $p$ <.001) anxiety to be significantly higher for children (8-12 years) compared to scores provided by the control group (Bilgic et al., 2014). However, for adolescents, (13-18 years) only state anxiety scores were significantly higher compared to the age matched control group ($t$=4.04, $p$<.001) (Bilgic et al., 2014). The findings from the qualitative research included in the review supplements quantitative results as participants reported experiencing anxiety towards future concerns, self-identity and appearance (Rafique & Hunt, 2015).

Not all of the papers included in the review draw the same conclusions, with some studies reporting mixed findings (De Waard-Van Der Spek et al., 1994). For example Reeve, Savage and Bernstein (1996) found anxiety scores to be within normative range on self-report measures that were completed by participants. However, in structured interviews with the same participants and their parents, 7 out of the 12 participants met the diagnostic criteria for anxiety disorders (Reeve et al., 1996). Whilst Reeve et al (1996) concluded this discrepancy highlighted the

child's minimization of their difficulties and the parent's ability to over identify anxiety in their child, due to the small sample size (N=12) and lack of statistical analysis, it questions the credibility of the findings. Other research into anxiety has also shown no significant difference in anxiety scores between children with alopecia, epilepsy and 'healthy' sibling control groups (Diaz-Atienza & Gurpegui, 2011). However, as the researchers also found young people with alopecia showed biological markers of stress (increased sympathetic tone), they concluded participants could have "dissociated from conscious experience" of their physical state (Diaz-Atienza & Gurpegui, 2011, p.106). Whilst this could account for the differences in the findings across the papers, the researchers also reiterated participant's use of medication and medical treatment could be confounding variables that were not accounted for (Diaz-Atienza & Gurpegui, 2011).

#### 1.3.1.2.3 Self-esteem and quality of life

The earliest paper to be published that is included in the review found young people with alopecia had a "mild-moderate emotional disturbance" due to a "poor adjustment" at home and at school (Toback & Raikumar, 1979, p.115-116). A case report also reported similar findings for a young male who had difficulties with school, low self-esteem and stress (Coulacoglou, Tchinou & Michpoulou, 2001). Although the results of these papers should be held in context of their quality assessment scores (25% and 17% retrospectively), research with more rigorous methodology also found adolescents living with alopecia experienced difficulties with self-esteem (Rafique & Hunt, 2015). The qualitative methodology

of this paper enabled participants to report the context surrounding their low self-esteem, which included difficulties associated with identity formation, concerns about the future and themes associated with loss (Rafique & Hunt, 2015). Whilst these results indicate self-esteem is an important factor to consider, research completed by Reeve et al (1996) found the self-esteem scores for participants with alopecia were above the normative value (93$^{rd}$ percentile) and thus, indicated a high positive self-concept. Furthermore, research completed by Wolf (2014) found the scores provided by children with alopecia for confidence and self-esteem was significantly higher ($F(2,234)=12.076$, $p<.001$) than the scores provided by adolescent participants.

Only two studies explored quality of life. These papers reported that parents perceived alopecia to have a greater detrimental effect on their child's quality of life compared to the scores provided by their child (Beattie & Lewis-Jones, 2006; Bilgic et al, 2014). This discrepancy between child and parent perspective was found to be more prominent for children aged eight to twelve years compared to the quality of life scores provided by parents and adolescents (Bilgic et al, 2014). However, some consistency between parent and young people's perspectives was found. This occurred in questions related to the frequency of bullying and teasing, as both the young person and their parent rated this to be an area of concern (Beattie & Lewis-Jones, 2006). The findings of these two papers provide a preliminary understanding of quality of life for young people with alopecia. As highlighted by Beattie and Jones, (2006) quality of life measures commonly include questions about family and peer relationships and as such, the presence

of social factors should also be considered in order to gain a holistic understanding of the quality of life for young people (Beattie & Lewis-Jones, 2006).

#### 1.3.1.2.4 Social factors

Although research into the social factors related to alopecia is limited, the social competence (e.g. social relationships, school performance) scores of young people was found to be significantly lower the expected normative value ($t$=-2.35, $p$<.05) (De Waard-Van Der Spek et al., 1994). Hankinson, McMillan and Miller (2013) also explored social relationships from the view of children between the ages of 5-14 years without alopecia. The authors found nearly half of participants thought a child with alopecia was contagious or sick (Hankinson et al., 2013). Furthermore, compared to older children (10-14 years), young children (5-9 years) interviewed in pairs were five times more likely to be fearful of developing a relationship with a child who had alopecia (Hankinson et al., 2013). Whilst the findings of these papers should be considered in context of their quality score (44%, 31% respectively), they suggest the perception of alopecia within a young person's peer group could shape the opportunities available for social skill development.

The demographic information of families living with alopecia was also considered as a social factor related to young people living with the condition. Families who participated in research tended to be from low socio-economic groups with

parents having a lower education status (Farajzadeh et al., 2013; Karambetsos et al., 2013; Reeve et al., 1996). As well as the demographic information, parents' mental health was also explored within the literature. Findings are mixed, with some papers reporting the presence of depression for parents (Elkin, Hiker & Drabman, 2006; Karambetsos et al., 2013) and other papers finding a non-significant relationship (Farajzadeh et al., 2013; Reeve et al., 1996). Despite the limited number of papers, the findings highlight the importance of exploring wider systemic factors, as they are likely to impact on the availability of social support and the types of coping strategies employed by young people living with alopecia.

#### 1.3.1.2.5 Psychosocial intervention and coping strategies

Qualitative research exploring coping strategies found young people used practical and 'action-orientated' ways of coping with alopecia (Rafique & Hunt, 2015; Wolf, 2014). This included the use of homemade remedies, wearing hats/scarfs as well as self-distraction, use of humour and drawing strength from religion and social relationships (Rafique & Hunt, 2015). Both papers reported sex differences in coping behaviours, with males employing the use of humour and females tending to use self-distraction (Rafique & Hunt, 2015). Wolf (2014) concluded the findings of the differences in coping behaviours indicated female participants experienced more difficulty in living with alopecia compared to male participants. However, as the paper completed by Wolf (2014) was sourced from grey literature, it has not been subjected to a peer review. As such, the findings

should be considered in light of this as well as the existence of heterogeneity within the participant sample.

Only one study explored psychosocial interventions for young people with alopecia. Based on the findings of this case report, Elkin et al (2006) concluded the use of a behavioural intervention was an effective method for supporting anxiety arising from the onset of alopecia. However, in light of the chosen methodology, the quality assessment score (42%) and lack of statistical analysis, questions the validity and generalisability of their findings.

#### 1.3.1.2.6 Summary

Overall, the findings of the review indicate anxiety is an important factor for young people living with alopecia. Whilst the results were mixed, quality of life, self-esteem and systemic difficulties were also highlighted as possible factors associated with the condition. Within the papers, a disparity was found in the perception of mental health difficulties and quality of life between young people and their parent's. Liakpoulou et al (1997) and Reeve et al (1996) concluded this reflected the differences in coping with the impact of alopecia, with children using minimisation and parents trying to seek additional support. However, based on the findings of Bilgic et al (2014) the differences found between parent, child and adolescent scores indicates puberty may influence the experience of psychosocial factors for young people. However, it is difficult to generalise and

compare the findings across the papers as the variety of measures used differed in their psychometric properties, reliability and validity.

The quality of the papers that explored the psychosocial factors related to living with alopecia in young people are mixed, ranging from 17-86%. As highlighted within the quality assessment framework (see Appendix D), the main difficulties included the limited justification of the chosen methodology and lack of adequate information relating to data collection, sampling strategy and population sample. Without this information, it is unclear if the recruitment process was compromised by a selection bias and whether the participant sample was representative of the population. Furthermore, of the papers that used quantitative methodologies, 13 studies did not use age and gender matched control groups. As such, it questions the internal validity of their findings (Barker et al., 2015).

### 1.4 Discussion

The aim of this review was to explore and critically appraise the literature that explored psychosocial factors associated with alopecia in children and young people. The papers report mixed findings. However, relational difficulties and the experience of emotionally difficult life events maybe important factors to consider in the onset of alopecia in young people. An association between anxiety and living with alopecia for young people was found in a number (n=7) of papers

included in the review. The strength of this association varied across the findings and methods of data collection. Other psychosocial factors that were reported included poor health related quality of life, difficulties with social competence, family and peer relationships and parental socio-economic and mental health status. Although the findings highlight research into the coping strategies and psychological interventions for young people with alopecia is limited, some differences in coping strategies were found between males and females.

Within the review, no studies were conducted with young people with cicatricial or androgenetic alopecia. This is likely to reflect the predominant focus towards alopecia areata in adult literature and the complexities associated with the pathogenesis of scarring alopecia. Although children and young people can develop cicatricial alopecia and androgenetic alopecia, (Gonzalez, Cantatore-Francis & Orlow, 2010; Ross, Tan & Shapiro, 2005), the current findings within the literature are unable to address the possible psychosocial factors related to these types of alopecia for children and adolescents.

Some of the findings of the current review mirror research completed within the adult population. In particular, research into the presence of alexithymia personality traits and stressful life events during the pre-alopecia phase in adults has also reported mixed findings (Gulec, Tanrierdi, Duru, Saray & Akcali, 2004; Manolache & Bearea, 2007; Picardi et al., 2003). Furthermore, previous systematic reviews have also indicated a number of personal, social functioning

factors for adults living with alopecia (Hunt & McHale, 2005a; Liu et al., 2016; Tucker, 2009).

Previous research has highlighted that the age alopecia develops can determine the severity and longevity of the condition (Fricke & Miteva, 2015). Although the findings in the current review are mixed, they also suggest the age of onset is associated with the parents' perception of their child's mental wellbeing. Furthermore, the divergence that was found between child and parental quality of life scores was greater on subjective domains compared to more objective factors such as the frequency of bullying and teasing by others (Beattie & Jones, 2006). As such, it is likely these differences reflect the tension between the parents' anxieties about their child's future and the child's desire to keep their internal experiences private "in a quest for normality" (Baca, Vickrey, Hays, Vassar & Berg, 2010; Verhey, Kulik, Ronen & Streiner, 2009:409).

The findings of the current review are in contrast to research completed by Chu et al (2011) who found young people living with alopecia (aged below 20 years) were more likely to develop major depressive disorder and for people aged between 20 and 59 years, they were more likely to develop anxiety compared to the population sample. As their study was completed with Taiwanese participants recruited from a national database, the differences in the findings compared to the current review could result from the different population samples and method of participant recruitment.

### 1.4.1 Limitations of the review

There are a number of limitations to the review. During the database search, three studies whose full text was not available in English were excluded. Whilst this may have omitted valuable data from the review, research suggests the exclusion of a small number of non-English papers is unlikely to alter the overall results of literature reviews (Juni et al., 2002). As such, it was felt the possibility of language bias did not influence the overall findings.

As the majority of the research employed quantitative methodologies, a meta-analysis was originally considered as a possible review of the literature to increase the generalisability of the findings. However due to the lack of homogeneity in sample population and the variety of measures that were used, the papers did not meet the required criteria.

The varying ages of participant samples used in research was also seen to limit the review as several studies were excluded based on the inability to separate young people's data from adult participants. Despite this limitation, it was felt the inclusion of these studies would have added adult data into the results, increasing the confounding variables in the findings.

### 1.4.2 Research Implications

Research in this area has used a broad range of participant and population samples which indicates people living with alopecia are assumed to be a homogenous group. However, based on the findings of the current review, future research would benefit from separating children and adolescents into separate groups. To enrich the understanding of young people's experiences, parents perspectives towards the psychosocial factors associated with their child should also be sought separately from the young person.

As highlighted in the review, future research would benefit from recruiting age and gender matched control groups, as well as providing an operational definition of the psychosocial factors that are explored. Information on the sampling method and population sample is also recommended to increase the validity and generalisability of future research.

The majority of the studies within the review focused on the use of quantitative methodology. However, this can limit the data that is collected about people's experiences (Yardley, 2000). The use of qualitative methodology could supplement the existing quantitative literature and enrich the understanding of the psychosocial factors related to the onset as well as living with alopecia.

Research in this area has predominately focused on alopecia areata. Future research would benefit from exploring psychosocial factors associated with other forms of alopecia in young people such as cicatricial and androgenetic alopecia. Furthermore, additional research is required into the use of coping strategies and psychological interventions. This would provide clinicians and healthcare professionals with a better understanding in how to support young people and their families with the experience of living with a visible difference.

### 1.4.3 Clinical Implications

To support the effectiveness of medical treatment and intervention, it is important for clinicians to explore the psychosocial factors that may be present for young people with alopecia and the effect the condition could have on the family system. More specifically, the use of routine, validated screening tools or outcome measures for both the parent and young person with alopecia could be helpful in understanding their perspectives towards current difficulties and whether any differences exist between the difficulties that are reported by the parent and young person. Furthermore, it may provide additional insight into where psychological support should be focused, in terms of working with a young person directly, their parents or to address wider systemic issues.

Whilst only one paper explored psychosocial interventions, the range of factors highlighted within the review indicates the need for clinicians to adopt a holistic

approach to supporting young people living with alopecia. More specifically, the findings suggest the importance for clinical psychologists to consider the use of systemic ways of working to ensure the perspective of the child, their parents and the wider psychosocial factors are considered within a young persons' formulation and therapeutic intervention.

As the papers in the review used a broad range of outcome measures to explore psychosocial factors, it suggests there is no single measure that is recommended for young people with alopecia. However, clinicians may wish to consider the Revised Child Anxiety and Depression Scale (RCADS child and parent version) and the children's dermatology life quality index (CDLQI). These measures are considered to have appropriate psychometric properties for use with children, adolescents and their families and are widely used within research and services supporting young people (Chorpita, Ebesutani & Spence, 2015; Ebesutani, Bernstein, Nakamura, Chorpita & Weisz, 2010; Olsen, Gallacher, Finlay, Piguet & Francis, 2016).

Although NICE guidelines advocates clinicians to consider the psychosocial needs of people with alopecia (NICE, 2014b), they are limited in addressing how clinicians such as consultant dermatologists and general practitioners should approach conversations about mental health with service users. This can be a particularly challenging conversation for clinicians to have with clients in the context of the time they are commissioned for each appointment (Burns, Greenwood, Kendrick & Garland 2000; Gordon-Elliott & Muskin, 2013; McCabe &

Leas, 2008). Training, supervision and consultation in communication skills, screening for psychological distress and mental health could be beneficial for clinicians to develop their skills in exploring young people and their family's mental health. This may be helpful in supporting clinicians to recognise when to refer service users to appropriate mental health services for timely support and psychological intervention.

### 1.4.4 Conclusion

Research indicates psychosocial factors are associated with both the onset and living with alopecia for children and young people. The findings highlight the need for high quality studies to be completed to enhance the understanding of the experiences of young people with alopecia and the generalisability of the findings. Clinical implications indicate medical clinicians may benefit from additional training, supervision and consultation in order to support the psychosocial factors associated with alopecia in young people.

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# Chapter 2: Empirical Paper

Exploring the lived experience of women with rosacea: visible difference, diagnosis and treatment

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**2.0 Abstract**

*Aim:* The psychological understanding of rosacea is limited. Findings from quantitative studies indicate women living with the condition can encounter various psychological and social difficulties. The aim of the paper is to explore the lived experiences of women with rosacea.

*Method:* Semi-structured interviews were completed with six adult women with rosacea. Interpretative Phenomenological Analysis (IPA) methodology and ideologies were employed throughout the development of the research, data collection and analysis of participants' transcripts.

*Results:* Two super ordinate themes emerged from the findings: 'concealment' and 'it's a battle, isn't it'. The experiences of participants was characterised by an internal struggle to feel in control of their skin condition, whilst externally learning to navigate complex social interactions.

*Conclusion:* Within clinical practice, the psychosocial factors associated with rosacea need to be considered. Other research and clinical implications are discussed.

*Key words: Rosacea, lived experience, women, IPA*

## 2.1 Introduction

### 2.1.1 Rosacea

Rosacea is an inflammatory facial skin condition that is estimated to affect between 1-20% of the population (Tan & Berg, 2013). Symptoms typically include erythema (persistent redness), pustules, telangiectasia (small dilated blood vessels), inflammation of the eye lids and phymatous (enlargement of facial features) (Starr & Macdonald, 1969; Steinhoff, Schauber & Leyden, 2013). These symptoms can cause pain, burning sensations and in severe cases, visual impairments (Wilkin et al., 2002). A variety of medical treatments for managing rosacea are available, all of which are limited in their effectiveness, with the majority only providing temporary symptom reduction. (Van Zuuren, Fedorowicz, Carter, Van der Linden & Charland, 2015). Whilst the etiopathogenesis of the condition is relatively unknown, the condition is chronic, causing individuals to experience multiple symptoms that can increase in severity over time (Spoendlin, Voegel, Jick & Meier, 2012; Wilkin et al., 2002). The lack of clarity regarding the condition's aetiology has meant rosacea symptoms are often mistaken by others for signs of alcohol misuse and poor personal hygiene which can lead to psychological distress for people living with the condition (Barankin, 2003; Blount & Pelletier, 2002).

It is estimated that the majority of people living with rosacea are undiagnosed and only seek medical support when they perceive their symptoms to be severe or when they have a detrimental effect on mental wellbeing and quality of life (Abram, Silm, Maaroos & Oona, 2009; Wehausen, Hill & Feldman, 2016). For

clinicians, recognising the psychosocial factors associated with rosacea can be challenging as the objective severity of a visible difference does not correlate with the lived experience (Clarke, 1999). This has meant psychosocial factors related to rosacea can be overlooked within professional practice (Huynh, 2013).

### 2.1.2 Psychosocial factors associated with rosacea

Although the findings are limited, quantitative research has consistently reported the presence of anxiety, depression, social difficulties and decreased quality of life for participants living with rosacea (Egeberg, Hansen, Gislason & Thyssen, 2016; Gupta, Gupta, Chen & Johnson, 2005; Moustafa, Lewallen & Feldman, 2014; Su & Drummond, 2012). A recent systematic review of the literature also found rosacea to have a detrimental effect on perceived quality of life (Van Der Linden et al., 2015). Within this review, the impact on perceived quality of life was more prominent for young people with rosacea and participants with severe forms of the condition (Van Der Linden et al., 2015).

As well as individual factors, research into societal perception of rosacea found 'healthy' participants scored faces with erythema as less trustworthy, healthy and fun compared to the same face without persistent redness (Dirschka et al., 2015). Furthermore, a recent survey found nearly a third of participants reported feelings of stigmatisation which included being subjected to rude comments or jokes about their skin condition (Halioua, Cribier, Frey & Tan, 2017). These feelings of stigmatisation were found to be a mediating factor for anxiety and

depression in participants living with rosacea (Bohm, Schwanitz, Gissendanner, Schmid-Ott & Schulz, 2014).

The majority of research into the psychosocial factors associated with rosacea has employed quantitative methodology and cross sectional survey designs. More recently, research has employed qualitative methodologies to analyse unscripted comments posted on online support forums. Themes highlighted within their findings indicate people living with rosacea wish to seek information about medical treatment and support for difficulties associated with depression, anxiety, confidence and self-esteem (Alinia et al., 2016; Cardwell, Farhangian, Alinia, Kuo & Feldman, 2015). Whilst these papers provide an indication of the topics that are important to people with rosacea, the papers do not report details on the method of qualitative analysis which can limit the credibility of the findings (Yardley, 2000). Moreover, they are unable to provide an in-depth account of the lived experience of rosacea due to the chosen method of data collection.

### 2.1.3. Sex differences and rosacea

Women are two-three times more likely to develop rosacea and are more likely to develop the condition at an earlier age compared to men (Wollina, 2011). Males who are diagnosed with rosacea usually experience symptoms associated with the phymatous subtype which is managed through the use of medication and surgical procedures (Powell, 2015; Wollina, 2014). However, in contrast,

females typically experience multiple symptoms across different subtypes which can be more resistant to medical intervention and harder to treat (Goldgar, Keahey & Houchins, 2009; Tisma et al., 2008).

Research into the psychosocial factors associated with rosacea for men and women has reported inconsistent findings (Van Der Linden, et al., 2015). Whilst one study reported higher levels of depression and lower quality of life for men with rosacea (Bohm et al., 2014), other findings indicate women with rosacea have a higher risk of depression and anxiety and lower quality of life compared to men (Aksoy, Altaykan-Hapa, Egemen, Karagoz & Atakan, 2010; Egeberg et al., 2016).Whilst it is unclear whether men or women are more likely to be impacted by rosacea, the literature indicates possible sex differences in the lived experience of the condition. This suggests the inclusion of men and women with rosacea in the same group in research studies could increase the heterogeneity of the participant sample and thus, indicates the merit of exploring the experiences of rosacea from a gender specific focus.

### 2.1.4. Rationale and aim

The etiopathogenesis of rosacea is largely unknown. However, a number of psychosocial factors have been associated with the condition (Powell, 2005; Sowinska-Glugiewicz, Ratajczak-Stefanska & Maleszka, 2004). Research into rosacea has employed a range of questionnaires and surveys which vary in their reliability, validity and sensitivity (Van der Linden et al., 2015). It is therefore possible the psychological needs of people living with rosacea could be under

estimated within the literature. Research has also been conducted on a variety of population samples, consisting of different ages, sexes, cultures and clinical samples. As such, this can make it difficult to compare research findings (Bessell & Moss, 2007).

The use of quantitative methods have dominated research into the psychosocial factors associated with rosacea. However, this methodology is unlikely to reflect the complexity of the emotions, cognitions and overall experiences associated with living with visible differences (Collins & Nicolson, 2002; Thompson & Kent, 2001). A phenomenological, idiographic approach to explore the subjective experience of a homogenous sample of participants with rosacea could help address this gap within the literature as it provides an in-depth account of lived experience that quantitative measures are unable to address (Brocki & Wearden, 2006). The research aims to provide an exploratory account of the experiences of women living with rosacea. In particular, the research aims to gain an understanding of the lived experience of visible difference, conceptualisation of rosacea and the process of receiving a clinical diagnosis and treatment. These aspects merit particular consideration as they are clinically salient and could potentially be important to understanding the lived experience of women with rosacea.

## 2.2 Methods

### 2.2.1 Research Design

In accordance with the research aims, a qualitative methodology was chosen. Interpretative Phenomenological Analysis (IPA) was selected due to its focus on exploring participants' experiences, cognitions and how they make sense of their world (Larkin, Watts & Clifton, 2006). IPA is considered to be an effective approach in understanding the subjective experience of physical health conditions and is widely used within health psychology research (Brocki & Wearden, 2006). The idiographic and hermeneutic ideology that underpins this methodological approach provides a balance between understanding the meaning attached to personal experience and acknowledging the role of the researcher in making sense of an individual's narrative (Smith, 2004).

### 2.2.2 Procedure

#### 2.2.2.1 Ethical Procedures

A research project proposal was reviewed and approved by Coventry University Ethics Committee, NHS Research and Ethics Committee (REC), Health Research Authority (HRA) and the local NHS Research and Development Department (See Appendices F-I). In addition, the British Psychological Society (BPS) code of ethics and conduct (2009), and code of human research ethics (BPS, 2010) were also adhered to throughout the research project.

#### 2.2.2.2 Materials

A semi structured interview was employed as they are seen as archetypal method of IPA (Smith & Osborn, 2007). One to one interviews were chosen to allow a rapport to develop and provide a space for participants to describe their experiences and perceptions of their world (Smith, Flowers & Larkin, 2009). The interview schedule (see Appendix J) contained eight questions with the use of prompts to allow for an exploration of participant experience and intensify the richness of the collected data (Smith, 2004). The interview questions were developed by exploring themes within the literature relating to other acquired facial disfigurements. Discussions with the supervision team also supported this process and ensured the interview schedule maintained a degree of flexibility to allow participants to express their thoughts and experiences.

#### 2.2.2.3 Recruitment

Purposive sampling was used in the project. This included service users who were accessing support or had done so previously from three identified NHS research sites. Service users were initially screened against the inclusion criteria by Dermatologists working at the research sites. Dermatologists were chosen as they had access to information relating to the inclusion criteria as part of their routine clinical contact with clients. Dermatologists discussed the research with service users and provided them with a participant information sheet (see Appendix K). Clients who wished to register their interest in participating in the project or receive additional information were provided with the researcher's contact details

and a consent form (see Appendix L) by the dermatologist. Thirteen people provided consent to be contacted by the researcher, after which four people declined to participate and three chose not to get back in contact with the researcher. A total of six people participated.

#### 2.2.2.4 Interview Procedure

Prior to the interviews, participants signed a written consent form (see Appendix M) and completed a demographic information sheet (see Appendix N). The majority of the interviews took place at the research site (n=5) and one took place in the participants home (n=1). All interviews were recorded via dictaphone. Interview length ranged from 38 minutes to 72 minutes, averaging 57 minutes. Following the interview, participants were provided with a debrief information sheet (see Appendix O) and opportunity to ask any further questions about the research. Participants were also asked if they wished for their General Practitioners (GP) to be sent a letter to inform them of their participation in the research project (See Appendix P). All participants reported they wished for a copy of the overall findings once the research had been completed.

### 2.2.3 Participants

Participants who met all the inclusion criteria outlined in Table 2.1 were considered for the research project. As highlighted in the table, the age of participants was limited to individuals aged 20 years and above in order to capture participants who

are representative of the clinical population (Berth-Jones, 2010; Wollina 2011). In order to allow sufficient time for participants to have a lived experience of rosacea, the criteria of having rosacea for more than six months was included.

Table 2.1: Participant inclusion and exclusion criteria

| | |
|---|---|
| Inclusion Criteria | • Female aged 20 years old and above<br>• Clinical diagnosis of rosacea<br>• Lived with rosacea for more than 6 months |
| Exclusion Criteria | • Male<br>• Females aged under 20 years old<br>• Visible difference caused by other health conditions Diagnosis of body dysmorphic disorder<br>• Lived with rosacea less than 6 months<br>• Non English Speaking |

A total of six participants with a clinical diagnosis of rosacea were recruited. All participants were Caucasian ethnicity and the majority identified themselves as British (n=5), one described themselves as Polish. The average age of participants was 54 years and the average duration of living with rosacea was 11 years. Demographic information of participants is included in Table 2.2.

Table 2.2 Participant demographic information

| **Participant Pseudonym** | **Age** | **Duration of Rosacea** | **Rosacea Subtype** |
|---|---|---|---|
| Edith | 49 | 10 years | Unknown |
| Hannah | 69 | 10 years | Unknown |
| Grace | 32 | 10 years | Papulopustular |
| Lucy | 56 | 1 year | Unknown |
| Nicole | 64 | 10 years | Unknown |
| Gemma | 53 | 24 years | Unknown |

Whilst there is no set sample size for IPA, the methodology focuses on a smaller data set to avoid losing the "subtle inflections of meaning" (Collins & Nicolson, 2002, p.626; Smith et al., 2009). As such, the number of participants included in the research was considered to be suitable for IPA methodology.

### 2.2.4 Analysis

Each interview was transcribed verbatim and identifiable information was removed. Participant's transcripts were analysed in line with IPA research guidelines (Smith et al., 2009) (see Appendix Q). Extracts of participant's transcripts can be found in the appendices (see Appendix R). In the initial stages of analysis, each transcript was explored separately. This involved a line by line analysis to identify emerging themes for each participant. The initial themes that emerged

from each participant's transcripts were then clustered together in order to identify super-ordinate and sub-ordinate themes that summarised participants' lived experiences (see Appendix S).

#### 2.2.4.1 Research credibility

The credibility of the research was considered in line with Elliott, Fischer and Rennie's (1999) quality assessment guidelines. These guidelines are considered to be an effective and pragmatic approach for evaluating qualitative research in health psychology (Smith, 2003). Each step of analysis from the transcripts through to final themes was discussed and reflected on with the supervisory team. A peer on the doctorate course initially coded an extract of a participant's anonymised transcript for verification of the credibility of the analysis. The similarities and differences between the two perspectives were explored and reflected upon (Yardley, 2000).

#### 2.2.4.2 Researchers position

Credibility of the research was also considered within a reflexive account of the researcher's position towards the project. The researcher was a trainee clinical psychologist and was on placement in the service where participants were recruited from. The researcher felt this was helpful to develop an awareness of the project within the NHS department as well as increasing the rapport with the

dermatologists involved in screening possible participants against the inclusion criteria.

The role of the researcher is a key consideration within IPA methodology as they influence the dynamic process of understanding and making sense of participant's personal worlds (Pietkiewicz & Smith, 2014). Prior to the interviews, the bracketing process highlighted the researcher's assumption that rosacea would be a negative experience for participants. This assumption was likely to have been developed from a review of the literature on the psychosocial factors associated with rosacea, as well as the researcher's own personal experiences of living with a visible difference. Without an awareness of this assumption, it could have influenced the researcher's ability to be open to participant's experiences, particularly towards exploring their strengths or positive experiences of living with a visible difference. A reflective diary was used throughout the research and reflections on the interview process was discussed with the supervisory team.

**2.3 Results**

Two superordinate and seven subordinate themes emerged from the analysis of the data. As shown in Table 2.3, the superordinate themes consist of; '*Concealment'* and '*It's a battle isn't it'*. Verbatim extracts of participant's transcripts are used to highlight each theme as well as the convergence and divergence that occurred within participant experiences.

Table 2.3 Superordinate and subordinate themes

| Superordinate Themes | Subordinate Themes |
|---|---|
| Theme 1: Concealment | 1a) The need to conceal<br>1b) Being exposed<br>1c) Putting on a brave face |
| Theme 2: "It's a battle, isn't it" | 2a) "Keeping it at bay"<br>2b) Costs of the battle<br>2c) Finding a cause<br>2d) Personal Strength |

### 2.3.1 Theme 1: Concealment

All participants described concealing their experiences of rosacea from other people. Three subordinate themes emerged; *the need to conceal, being exposed* and *putting on a brave face*. Within each of these subordinate themes, concealment seemed to be dependent on the perception of rosacea and the social environment.

#### *2.3.1.1 Theme 1a: The need to conceal*

All participants described concealing rosacea by wearing make-up or avoiding triggers that increased the visibility of their skin condition. Three participants reflected how their use of cosmetics enabled them to conform to the social construction of beauty and femininity.

> "I mean regardless of the rosacea anyway, I would wear make-up because that's what women do"
>
> (Grace, line 401-402)

Grace described how her rosacea "adds another level" to her make-up use, expressing the need to conceal her skin condition in order to "fit in with everybody else". The frustration this caused was emphasised through her tone of voice.

> "you've got people that have got really, really bad skin conditions and they're battling away, behind-the-scenes going oh, you know, I've gotta plaster myself with make up today just to look normal"
>
> (Grace, line 179-181)

For Lucy, rosacea acted as a misrepresentation of her identity, causing her to feel "embarrassment" and "shame". The incongruence between her internal self and the external representation of her identity was emphasised by describing her body as a "shell".

> "It's like people have got this perception that they'll meet you and within three seconds they'll decide what you, who you are like, or what you are and it actually isn't and it's just a shell"
>
> (Lucy, line 260-262)

This seemed to force Lucy to use make-up to hide her rosacea from other people in order to conform to the social expectation of concealing visible differences.

> "I think, that [make-up] will feel like a chore because it doesn't come natural to do it, erm, and, that I'll forget I've got it on and wipe something and I'll realise I've got a white top on, and, you know, because I've-I've not been that way inclined in the past, erm, but I think to a degree, people expect you to hide it. (Pause). There's an expectation from other people to keep it covered and for you to look your best, every day as you go to work or whatever and, erm, I can see me falling into that"
>
> (Lucy, line 331-335)

Lucy's reflections seemed to resonate within Edith's experiences as she reflected on how she did not like make-up, but felt she had to use it "every morning, every evening". For Edith, she described the need to conceal her skin condition as it made her feel "like a second class of people". During times when she was unable to hide her rosacea, she described being rejected by other people based on her physical appearance.

> "But anyway, it would be nice to look normal so people don't erm. I remember as I said how people look at me, with err, erm, how to say, that I look disgusting, for-for myself as well anyway"

(Edith, line 149-151)

In contrast, Hannah described “everybody” to perceive her rosacea to be “just one of those things”. At times, Hannah shared this co-construction of rosacea, stating “it was fine, I coped it wasn’t a really major problem”. However, at other times, she expressed an annoyance towards the minimisation of her skin condition “coz you think well it’s not one of those things to me”. Her reflections imply that, at times, Hannah experienced a struggle between the personal experience of rosacea and her friends and family’s understanding of her skin condition. This, along with the impact it had on her confidence, may be why she felt the need to physically conceal her symptoms.

> “Sometimes my husband says to me you know, “I don’t know why you’re worrying because it’s not that bad”, and (whispers) oh I know, but I just want to make sure this wasn’t showing. You know, if I-I have been on-on occasions gone out with him and if I feel like we’ve gone somewhere and we’ve gone – I’ve gone all hot, and I’m thinking, saying do you know (whispers) are my spots showing? [husband] No (elongated pronunciation).”

(Hannah, line 427-431)

#### *2.3.1.2 Theme 1b: Being Exposed*

All participants except Hannah made reference to rosacea placing them within a disempowered position, regarding which aspects of their identity they could keep private and what was made public for other people to see and critique. Lucy likened this as "opening up your soul" to other people, increasing a sense of vulnerability and "exposing too much" of her sense of self. Lucy described how her feelings of exposure were exacerbated when a photograph was taken of her face without make-up. Her use of the words, "whole naked body" implies without make-up, she felt stripped back, defenceless and unable to protect herself from the judgement of other people.

> "It's exposing yourself, even though it's on the skin, that's exposing me, my vulnerability and I felt vulnerable and that's really weird, all I'm doing is showing the skin on my face but I feel like I, I might as well have exposed my whole naked body to you"
>
> (Lucy, line 574-577)

For Nicole, she described how other people mistook her rosacea symptoms to represent feelings of embarrassment. Her elongated pronunciation and observed changes in the intonation of her voice emphasised how this exposed her to judgement and mockery of other people and in turn, led her to feel embarrassment and frustration.

> "When I worked it was a lot more embarrassing when I worked, erm, you know, just people seeing you and saying look at it (high pitch). Why you red like that. Aww (elongated pronunciation), Nicole's really embarrassed of, you know, something was said, and I only laughed, do you know what I mean, I wasn't particularly embarrassed but they'd automatically take it that I was embarrassed because I'd colour up that much".
>
> (Nicole, line 83-87)

Edith described how her skin condition not only exposed her own feelings of "disgust" towards her rosacea, but also revealed her social positioning to be on the "lower shelf" in comparison to "normal" people. This seemed particularly poignant when she described her daughter's "honest" comments about rosacea, reflecting the loss and sadness she experienced due to feeling rejected as a mother based on her physical appearance.

> "It hurt me. Err, sometimes it erm, make me feeling that she would prefer another mother, nicer younger. I don't, I don't know why. Sometimes her behaviour or sometimes she doesn't like kiss, I don't know, because of this (points to face). Erm. Err, I notice in other kids they love their mother however they look, but she sometimes say oh she look nicer than you."
>
> (Edith, line 606- 609)

Grace described when her rosacea symptoms increased in severity, her facial appearance became “the pinnacle of awful” and she was unable to conceal her rosacea with make-up. During this time, she reflected on the responses towards her rosacea from members of the public. The religious connotations highlighted by the word “hell” and use of a simile emphasised the shock of “the people” towards her appearance as well as exposing her struggle to perceive her face to be “normal”.

> “I think I looked like I got leprosy or something, like, it-it would just be, the people would just judge you on your face, basically, just look- take one look and go what the hell is the matter with that girl-”
>
> (Grace, line 195-197)

Gemma described how other people mistook her symptoms to signal “stress” and being “embarrassed”. Her reflections implied at her workplace, these emotive states were associated with an exposure of incompetence and weakness, causing her to use “war paint” to “stand out” against other people’s interpretations of her emotional state.

> “I was trying to pass a catheter and one of the staff nurses said to me, you don’t, you shouldn’t be embarrassed at looking at bodies, you know, you’ve chosen this profession and it was, you know, quite, I found that

quite hard coz, you know, I'd had four babies, I know, I know what bits and pieces look like"

(Gemma, line 47-50)

As well as the exposure of negative responses, Grace and Lucy also described how rosacea exposed other people's compassion and sympathy. This was revealed by offering treatment suggestions and wanting to learn more about the lived experience of rosacea.

"My friends mum's got it and so were having the discussion going oh my mums tried this cream why don't you try this or oh she got this from this pharmacy online and it worked for her, erm, so, so yeah that-that was recently actually we were discussing that with one of my close friends, so, erm and their like oh someone else has got it and, so it's nice to know that with even your own circle of friends people are aware of what it is"

(Grace, line 792-796)

#### *2.3.1.3 Theme 1c: Putting on a brave face*

The accounts of five participants reflected the importance of masking their difficulties from other people. In her struggle to keep her difficulties with rosacea "private", Lucy described wearing an "emotional mask" for individuals she considered to be "on the periphery" of her life.

> "I'd like an easy life but life is never easy but I don't want stuff to beat me the vast majority of times so I put this mask on then, I'll probably crumble somewhere else, erm, but I've forced myself to do it. And I-I don't like other people to know unless they're really close to me. - But apart from that it's, oh yeah everything's fine, that was my word, yeah fine, and that's one of my mask words, fine."
>
> (Lucy, line 361-366)

For Grace, Edith and Hannah, they minimised the impact of their rosacea by comparing the condition with other physical health problems.

> "Rosacea's annoying, but it's not life-threatening and it's not, erm, you know, it's one of those things, that you get on with but it's not, err, a massive medical problem that's going to kill you is it".
>
> (Grace, line 693-695)

Whilst this provided participants with a wider context to their conceptualisation of rosacea, for Hannah, her reflections indicated that this minimisation restricted her capacity to acknowledge the challenges her skin condition had caused her.

> "Why was I the one that sort of this-this happened to. But. But as I say, its-it's not you know, I'd have something to complain about if it was a, you know, a real disability that I'd got, then, so, it-it's nothing compared to that" (Hannah, line 102-104)

For Edith and Nicole, they described using humour in social situations with other people. Nicole's intake of breath is suggestive of masking her feelings related to the unpredictability of being "red".

> "I-I know I'm red and I say am I red, she'll [sister] say a bit. And I get my mirror out and have a look and I'll say, (big in-take of breath) I look at my mirror and look at her face and say I'm as red as your lipstick (laughs)"
>
> (Nicole, line 108-110)

However, Edith's account also highlighted the emotional toll of masking her difficulties through the use of humour. This was highlighted when she described a time when she "tried to be fun" with her daughter.

> "For example, I tried to be, err, I am full of energy, and I tried to smile and after like this I feel like an old woman. And my own daughter doesn't like me. (Tearful, long pause). As I said the most you cry if you are unhappy with your life"
>
> (Edith, line 623-625)

### *2.3.2 Theme 2: "It's a battle, isn't it"*

All participants described rosacea to be a condition that required the continuous use of treatments and skincare products. Participants discussed the limited effectiveness of their treatments and the variety of methods they have used to manage rosacea. Within their treatment journey, the struggle for power and

control over their rosacea was evident across four subordinate themes; "*keeping it at bay", costs of the battle, finding a cause* and *personal strength*.

#### *2.3.2.1 Theme 2a: "Keeping it at bay"*

Participants often externalised rosacea, referring to their skin condition as "it". Grace described living with rosacea to be a "battle", trying a variety of methods to "keep it at bay". For Gemma, the unpredictable nature of her rosacea "flare-ups" emphasised her struggle in keeping her symptoms at bay.

> "You can't predict how it's gonna be, I mean it could be, I could walk in here, one day and my skin would all just flush and it could be something as simple as like if there's a plug-in on the wall or you know, those sort of things tend to irritate it as well kind of almost like a chemical attack, if you know what I mean, so you just don't know what you're walking into and what could trigger it"
>
> (Gemma, line 190-193)

Edith also described the management of her skin condition to be a continuous "fight", feeling more empowered and in control when her symptoms had improved and she had lost weight.

> "I was like I can do everything. And I remember I still, I had-I had a lot of power because I was lighter, I felt very, very attractive"

(Edith, line 389-390)

However, on days when her skin condition had increased in severity, her account reflected feeling defeated and powerless, impacting several aspects of her life.

> "When I was with these problems, you could see my eyes like dead. Just, (sighs) sometimes still I feel like this err, that if I am-if I am in bad mood and bad condition and everything and my daughter and face and everything. Just I, if I walk you can see in my eyes no-no life."

(Edith, line 413-415)

Edith's reflections were reiterated in Lucy's account as she described feeling "on a high" when her treatment was keeping "on top of it". However, prior to seeing a consultant, she also described how her symptoms felt unmanageable, causing "a negative thought spiral" and invoking feelings of hopelessness.

> "-you look in the mirror you don't think your good, good enough for people to look at and it just then starts tipping you down, even lower, erm, and it's like, erm, like a hole with a ladder in and you're on the edge of the hole when you're not feeling good and then you look in the mirror and think oh god there's another one there and another one there, so you down a rung and then somebody will have looked at you at work quite

> deeply, and it's obvious they are looking at your face so you go down another rung on the ladder"
>
> (Lucy, line 621-627)

Three participants described how their experiences with General Practitioners (GP) had made it difficult to keep rosacea at bay. For Gemma, she described how her GP considered rosacea to be unimportant, perceiving them to provide her with a prescription whilst thinking "that'll probably fix it, go away". This was reiterated by Grace who described a time when her rosacea symptoms "flared up" due to her GP refusing to provide her with any medication to "get it under control".

> "I had to go cold turkey with absolutely no alternative that they could offer me. Erm, and my face just, absolutely I think it was the hormones or something but the worst it's ever been, absolutely flared up ridiculously, erm, to the- and then I went back to the GP and they washed their hands saying look it's so bad we don't want to prescribe anything without you seeing a dermatologist because, erm, we don't want to make it worse"
>
> (Grace, line 47-51)

In contrast, Hannah described how her GP encouraged her to try multiple treatment options to manage her rosacea. The repetition of "let's try" implied treating rosacea was a choice for Hannah, rather than a necessary process.

> "I've taken lots of different types of medication, different types of creams, because the doctor kept saying well let's try this one, let's try this one-"
>
> (Hannah, line 10-12)

However, Hannah's reflections also implied an internal battle between feelings of guilt for accessing NHS services "just because I've got a few spots" and being "relieved that at least something could possibly be done about it". This suggests she may have found it difficult to express the importance she placed on treating her rosacea.

#### *2.3.2.2 Theme 2b: Costs of the battle*

The accounts of five participants expressed feeling frustrated about the financial cost of trying a variety of medical treatments and cosmetic products.

> "The creams on the market are very expensive and generally don't work (laughs). For, erm, very well anyway and I just like, it's an expens-err, an expensive waste of time, basically. Until you do find one that perhaps works for you, but then I've had to spend hundreds of pounds to get to that point"
>
> (Grace, line 462-465)

Although Gemma described finding an effective make-up product “changed my life”, Gemma and Lucy also expressed feeling guilty about the amount of money they had spent on their physical appearance.

Social difficulties arising from the management of rosacea was expressed by Edith. She described a conflict between her desire to protect her daughter from the harmful effects of her medication and feeling like a “cold mother”. Edith’s tearful presentation and softer tone of voice emphasised the sadness at the loss of intimacy with her daughter.

> “Yeah she, I tried to you know be close to her but err, sometimes I notice last time, don’t touch me because I have medicine. (Whispers) Don’t touch me.”
>
> (Edith, line 352-353)

The relational consequences of treatment was reiterated by Gemma, who described experiencing difficulties within her relationship due to her night time skin regime.

> “He was saying to me, oh my God, you know, you’ve always got stuff all over your face, you don’t need that, you know, you don’t need to go to bed covered in loads of cream, so he wasn’t, his lack of empathy and understanding didn’t help with our relationship”

(Gemma, line 142-145)

In addition to the social factors, four participants reflected concerns about the side effects associated with their medical treatments. Whilst Grace and Nicole both reflected feeling concerned they could become anti-biotic "resistant", Nicole also described the physical health risks associated with her search for an effective treatment method.

> "there's things saying, that it could, you know, you have to really watch the sun, it could cause, they can cause skin cancer and, different things and I do go away on holiday quite a lot so and that concerned me and I didn't find they worked"

(Nicole, line 287-290)

#### *2.3.2.3 Theme 2c: Finding a cause*

The uncertainty towards the cause of rosacea was reflected within all participants lived experiences. "Parasites", difficulties with the "immune system", "hormones", "pregnancy", "genetics", "old age" and "god" were all indicated as factors associated with the onset of the condition. For Hannah, she described always looking after her skin which made it difficult to understand the development of rosacea, creating a sense of unfairness and frustration.

> "So, I just think sometimes well err, I've-I've-I've always, as far as I'm concerned, you know did everything that I had to-to keep my skin clean and, you know erm. Make-up remover and everything else and you think

> well, why is it- you know, you just can't understand if you do everything you feel is necessary to have your skin without spots, you know. Why does-why does it happen?"
>
> (Hannah, line 148-152)

Whilst Edith described feeling "scared" following her diagnosis of rosacea, Grace described her diagnosis experience to be "positive", providing her with an "official label" that helped her to make sense of her skin condition. However, Grace's experiences also expressed an internal struggle to sit with the uncertainty that surrounded the cause of her skin condition.

> *"*I like to have a reason for things and if you-you haven't got a reason for it you just kind, of always thinking in your head (pause) why? Or why is it? Or could it be this, or could it be that or if I try this, if I cut out this in my diet, would that help? You always want to try and strive to-to get a reason. And it's hard when there isn't one"
>
> (Grace, line 245-248)

The difficulty in not being able to find out the aetiology of her rosacea, seemed to be associated with Grace's motivation to seek more information and try different strategies to alleviate her symptoms. Prior to Lucy's diagnosis, she described feeling she was "to "blame" for the onset of her rosacea, causing her to feel embarrassed and avoid social situations.

> "I just felt too embarrassed about the way I looked, erm, and to a degree, I think I felt ash-ashamed of the way I looked because I felt in a way until I knew it was rosacea that I blame myself, it's something I've done."
>
> (Lucy, line 213-216)

When Lucy described her experience of being diagnosed with rosacea, she reflected how it had provided her with a sense of empowerment and relief, despite the restrictions in the length of the appointment.

> "And in that seven minutes, I learnt more and felt a lot better than I had done in two or three years"
>
> (Lucy, line 75-76)

#### *2.3.2.4 Theme 2d: Personal strength*

The need to have personal strength and resilience to live with rosacea was reflected in five participants' experiences. For Grace, she described herself to be a "resilient person" and by having a "thick skin" she was able to "just get on with life" despite receiving judgemental comments from other people.

> "So, I was just like, forget this, I don't care anymore, I'm just gonna take to, wear it, to give my skin a break and just go out without make-up and, erm, and just get on with it, so. Whereas, I think probably other people

would probably lock themselves away, the way I looked, (laughs). And just go I never wanna go out again err, because it was so, it was very, very bad."

(Grace, line 253-256)

The need for personal strength to live with rosacea echoed within Gemma's experiences. By comparing herself to other people, Gemma emphasised the strength of her personal attributes and how it has helped her to live with her skin condition.

"I'm quite a stoic person but I can see why somebody would get desperate"

(Gemma, line 395-396)

For Hannah, she described herself as an "out-going" person whereby "nothing sort of holds me back". Throughout her experiences, Hannah reiterated how she "coped" with rosacea. This implied the strength of her character was an important component of her experiences and towards her construct of rosacea.

" It's just how I am personality wise I just, you know, just get on with things and cope as best as I can"

(Hannah, line 46-47)

In contrast to the experiences of other participants, Lucy described her personal strength to develop following the onset of her skin condition, through a process of "learning to manage" her symptoms. The development of her resilience and empowerment was reiterated through her tone of voice and use of short sentences.

> "There's only you that can climb yourself back up with the assistance from other people, so and like, being able to say, yeah that's ok. I've got rosacea. This is it. This is me. Erm. I'm dealing with it"
>
> (Lucy, line 627-629)

## 2.4 Discussion

The research aimed to provide an exploratory account of the lived experiences of women who had a diagnosis of rosacea. Two superordinate themes emerged from the data and will be considered in relation to existing literature. Research limitations, as well as implications for further research and clinical practice will also be discussed.

### 2.4.1 Discussion of the findings

#### 2.4.1.1 Theme 1: Concealment

Participants' lived experience of rosacea reflected feelings of low mood, anxiety, shame and difficulties with confidence. Participants' accounts were consistent with findings from quantitative research which has found participants with

rosacea experienced anxiety and depression (Egeberg et al, 2016; Moustafa et al 2014; Su & Drummond, 2012). However, participants' also described the importance of minimising their emotional difficulties and concealing them from other people. Whilst it is recognised the findings of the current research are based on a small sample size, it is possible other people with rosacea may also minimise the difficulties they experience. Furthermore, if participants' minimised their difficulties on the self-report measures used within quantitative research, it could indicate the psychosocial factors associated with rosacea are under-reported within the literature.

Physical appearance played a key role in the external representation of participant's identity. Participant's described the need to conceal their skin condition through the use of make-up in order to prevent rosacea becoming part of their self-image. It is possible, their use of concealment and minimisation of their experience of rosacea reflected a coping process that enabled participants to adjust to living with a visible difference. The association between physical appearance and identity has also been reflected within the experiences of people living with other visible differences (Thompson & Broom, 2009). Furthermore, the need to conceal differences in appearance is consistent to research that has explored the lived experience of people with vitiligo (Thompson, Kent & Smith, 2002). However, in contrast to the current study, the social support provided to people with vitiligo was a central theme to their experiences and for some

participants, it supported the acceptance of their skin condition (Thompson et al., 2002).

The majority of participants' in the current study expressed feelings of embarrassment within social situations and reflected on the challenges to "fit in" with society and conform to social norms. The emotional difficulties described by participants' seemed to be more pronounced during times of increased symptom severity. These reflections are consistent with quantitative research that found a negative association between symptom severity and perceived quality of life (Van der Linden et al., 2015). However, the accounts of participant's' experiences enrich the current understanding as they also described feelings of powerlessness and exposure to social judgement when their rosacea symptoms increase.

The nature of participants' social interactions contributed to the way they conceptualised their skin condition. The majority of participants' described receiving judgemental comments and being "stared at" by other people which led to feelings of rejection, embarrassment and low mood. These findings are consistent with other research which found that feelings of stigmatisation increased the likelihood of developing anxiety and depression in people living with rosacea (Bohm et al., 2014). However, Grace and Lucy also described other people to show sympathy and compassion for their skin condition, offering support and advice on treatment. This suggests both positive and stigmatising social factors are important to consider in understanding the lived experience of rosacea.

#### 2.4.1.2 Theme 2: "It's a battle, isn't it"

Research into the factors associated with rosacea have predominantly focused on understanding the effectiveness of medical treatments, (Powell, 2005; Van Zuuren et al., 2015) rather than exploring the experiences of those treatment methods. Whilst findings from qualitative research suggest people with rosacea primarily use online forums to discuss treatment options (Alinia et al, 2016), the current findings extend the understanding within the literature, as participant's described their struggle to keep rosacea symptoms at bay in context of the limited effectiveness of medical treatments. Furthermore, participant's reflections enrich the understanding of the treatment process as the range of skin care products and medical treatments participants tried seemed to be driven by feelings of powerlessness, embarrassment and hope for a 'cure'.

Through the use of IPA methodology, participants were able to express their experiences of healthcare services. Divergence was found in their experiences of being diagnosed with rosacea. For some participants, being diagnosed with a "label" provided them with relief, hope and validation. However, other participants described their diagnosis as unhelpful. It is possible the differences in the diagnosis experience reflects the individual differences and needs of participants. However, it could also suggest the way in which a diagnosis is provided is key to the conceptualisation of rosacea, service user satisfaction and towards the management of the skin condition (Halioua, Fournier, Bourcier & Alvarez, 2014). Divergence was also found in how participants experienced the

support offered by their GP's. It is possible these differences could reflect the current inconsistencies in funding, resources and specialist training for skin conditions across primary care services (APPGS, 2013; Krasuska, Millings, Lavda & Thompson, 2016).

Personal strength and resilience featured in participant's accounts of the management of rosacea. Whilst this has not been reported in studies that have explored the psychosocial factors associated with rosacea, personal growth, use of humour and inner strength have been found in the adjustment of other visible differences (Egan, Harcourt & Rumsey, 2011). It has been argued that resilience and personal strength are important factors to consider as they provide a more balanced and enriched perspective into the lived experiences of visible difference (Rumsey & Harcourt, 2004). Furthermore, a systematic review found resilience to be positively associated with perceived quality of life and management of physical health conditions (Cal, Ribeiro De Sa, Glustak & Santiago, 2015). As such, this suggests, an individual's resilience is an important factor to consider and monitor in the provision of medical treatment.

### 2.4.2 Methodological Limitations

The findings of the current study should be considered in light of several methodological limitations. All participants were from a Caucasian ethnicity which limited the understanding of the lived experience of rosacea from other ethnicities and cultural backgrounds. Whilst the sample size was consistent with the chosen methodology, the majority of the research exploring rosacea

employed quantitative methods and as such, the results of the current findings are difficult to compare to the current literature.

The parameters of the inclusion criteria meant that the duration of rosacea varied from one-twenty four years which created a richness to the data in the length of time participants lived with the condition. More specifically, it provided the opportunity for some participants to reflect on their conceptualisation of rosacea and use of different treatment methods across a number of years. However, the variation in the duration of rosacea may also have caused a difference in the lived experience of the condition.

Triangulation of data can be achieved through a variety of methods, all of which aim to increase the credibility of research findings (Tonkin-Crine et al., 2016). Although triangulation of data was considered within the current research, due to time constraints and difficulties experienced in the recruitment process, it was not possible to offer participants the opportunity to be included within the triangulation process.

### 2.4.3 Research Implications

To address the gaps within the literature, the exploration of the lived experience of men with rosacea, as well as people from a range of different ethnic and cultural backgrounds should be considered. Future research into the diagnosis experience provided by GPs and by dermatologists would be helpful in gaining an

understanding of the lived experience of rosacea across different services. Furthermore, based on the limitations of the current research, future studies should consider the duration of rosacea as an inclusion criteria.

### 2.4.4 Clinical Implications

Participant experiences highlight the importance for clinicians to be mindful of the psychosocial factors that can occur for people living with rosacea. This could be supported by the use of mental health and quality of life outcome measures in order to detect any changes in client's emotional wellbeing during the treatment of rosacea. Alternatively, clinicians could ask clients to provide a subjective unit of distress score (SUD) at each appointment which can be helpful in monitoring treatment outcomes (Kaplan & Smith, 1995). Furthermore, due to participant's minimisation of their difficulties in living with rosacea, GP's may benefit from training and consultation to support the exploration of psychosocial factors, screening for and supporting people with psychological distress and signposting to appropriate services.

The reflections within the subordinate themes of 'the need to conceal' and 'being exposed' indicate medical professionals could provide service users with the option of being referred to make-up camouflage services. These services aim to help individuals "gain self-confidence and independence" in living with visible differences (Changing Faces, 2017). However, consistent with other skin

conditions, referral to camouflage services need to be carefully considered and need to be broached with clients in a sensitive, compassionate manner.

Participants' motivation to try a variety of treatments indicates the treatment process can be therapeutic, providing a sense of empowerment to service users. However, participants' lived experiences also highlight the need for clinicians to carefully consider the ethical implications associated with continuously providing a variety of treatment options that are ineffective for service users. Whilst a conversation about the prognosis of rosacea and the limited effectiveness of treatment may be challenging, clinicians may find it helpful to reflect on this with service users at diagnosis and/or early on in the treatment process. Furthermore, additional supervision and communication skills training could be beneficial for clinicians.

As the leading organisations for supporting rosacea are predominantly based within America, (National Rosacea Society, 2017) the development of a UK based support group for people with rosacea could help individuals to feel supported, increase social networks and share knowledge of helpful ways to manage rosacea.

**2.5 Conclusion**

The current study provided an exploration of the lived experiences of women with rosacea. The idiographic and phenomenological approach enriched the current understanding of the conceptualisation of rosacea, diagnosis and

treatment experience. The clinical and research implications indicate medical practitioners need to consider the psychosocial factors associated with living with rosacea in order to address any unmet needs.

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## Chapter 3: Reflective Paper

# ‘Dancing around the Hexaflex’: My reflections on the research journey

Not intended for publication

Overall word count (excluding references): 2685

## 3.0 Introduction

Reflexivity is a key part of the research process, starting from the formulation of a research question to the conclusion of a project (Berger, 2015). However, reflexivity within qualitative research is complex and requires the researcher to reflect on their own beliefs and assumptions as well as the interpretation of participant's lived experiences (Mayhut & Morehouse, 1994). As researchers are recommended to "see themselves in fundamentally the same way as they see the people they are studying", (Proctor, 2009, p. 93) the use of a psychological model can be an effective method to support reflexivity within a research project. Acceptance and Commitment Therapy (ACT) is a trans-diagnostic model that is widely used within psychological services and is considered to be an effective method for supporting a range of mental health difficulties and physical health conditions (A-Tjak et al., 2015; Dahl, 2009). In addition to its use with clients, the ACT model also provides a useful framework for clinicians to consider their own values and difficulties (Harris, 2009; Levin & Hayes, 2009).

The aim of this paper is to provide a reflective account of the research experiences captured within the reflective journal I completed throughout the research process. To support psychological flexibility, my reflections are structured within the six key dimensions of the ACT Hexaflex model; values,

cognitive defusion, acceptance, contact with the present moment, self as context and committed action (Harris, 2009).

### 3.1 Moving towards my values

Individual core values are considered to be life's compass, providing a sense of meaning, purpose and motivation (Harris, 2009). Based on an individual's values, their behaviour can be understood as either a helpful process that enables them to 'move towards' their values or signal a 'movement away' from achieving their desired goals (Harris, 2009). Prior to deciding on my research question, I recall feeling overwhelmed by the number of possible areas I could complete my research within. This was exacerbated by having discussions with clinicians and an exploration of the literature in several topic areas. At the time, my decision to complete my research within dermatology seemed to have occurred through a process of chance and opportunity.

Considering my core values, I began to reflect on my professional practices and the importance I place on appreciating diversity and understanding other people's experiences. I also became aware of the value I place on inclusion and acceptance. These values seemed to be rooted within my own previous experiences of living with a visible difference as well as my employment within several learning disability teams. In context of my values, the decision to work with a population group that are under-represented within the literature and

whose psychological needs have historically been overlooked and minimalised, no longer appears to have happened by chance. Instead, it is more conceivable that my values have not only shaped the development of my research question, but also, my identity as a scientific practitioner.

In clinical practice, I truly value the opportunity to explore the subjective experience of service users, collaborating with clients to jointly make sense of their difficulties. As such, within the empirical paper, the ideologies underpinning Interpretative Phenomenological Analysis (IPA) seemed consistent with my own subjectivist epistemological position. During the research process, I felt passionate about my empirical paper and enjoyed adopting the hermeneutic approach of IPA. Following the completion of the database search within my systematic literature review, I observed a very different emotional response, feeling stuck in the process and at times, overwhelmed with the synthesis of the data. Reflecting on this, I wondered if the predominant focus of quantitative methodologies had initially seemed a 'movement away' from my values and epistemological assumptions.

I observed my perspective to shift when I was on placement within a physical health service as I experienced the importance of quantitative literature reviews within medical settings. More specifically, I became aware of the research-practice link and how the generalisability of quantitative findings can help shape the commissioning bids for services, aid best practice and service development.

Reflecting on the completion of my systematic review, I feel more passionate about the findings. I am more attuned to how the review can be utilised within clinical practice and how the findings can support the needs of young people living with alopecia.

### 3.2 Cognitive defusion versus cognitive fusion

Within the ACT model, being reflective is central to the ability to separate ourselves from our thought processes (Hayes, Luoma, Bond, Masuda & Lillis, 2006). Without reflexivity, we can become wedded to specific ways of thinking and perceive our thoughts and feelings to represent 'truths' that guide our patterns of behaviour (Harris, 2009). Halfway through my interview with one of the participants, Edith, I became aware of my preoccupation with my choice of language, increasing my use of 'erms', and pausing half way through my sentences in order to decide how best to express myself.

Following the interview, I was concerned this had limited my ability to provide her with warmth and compassion, especially during times when she described experiences that were emotive for her. Initially, I found it difficult to reflect on my experiences, perceiving my thoughts to be 'truths' and I began to question my skills as a scientist practitioner. However, when transcribing the interview, I became curious about Edith's description of feeling like a "cold mother" and wondered whether my emotional response reflected the counter-transference within the researcher-participant relationship. Reflecting on this process offered me an alternative perspective on my abilities and skills, and I was able to

reconsider my approach towards Edith. Before the completion of my empirical paper, I had not fully appreciated the personal challenges that can arise within qualitative methodology. Based on my experiences, I am more mindful of the processes that can trigger the vulnerabilities of the researcher, as well as the need to employ reflexivity throughout the research process (Dwyer & Buckle, 2009).

The language that is chosen to construct our reality is an important consideration of the ACT model, and is seen to bridge the gap between the internal experience and the social world (Harris, 2009). Within the interviews, participants described their experience of living with rosacea to be a "battle", and a "fight", requiring the use of "tools" and "war paint". This construction of rosacea was seemingly emphasised by clinicians through the provision of different medical interventions and numerous GP appointments in order to manage the skin condition. Prior to my research journey, I had considered the use of metaphors to be a helpful process in my psychological work with clients. However, it is suggested the use of metaphors and similes can be an unhelpful process, as they can restrict the construction of reality by emphasising a particular way of thinking (Lakoff & Johnson, 2003). Due to this, I wondered about the ramifications of using military terminology to describe the lived experience of rosacea and whether participant's would feel they had 'lost the battle' or been 'defeated' if the severity of their symptoms progressed. Whilst my reflections on the language use of participant's with rosacea are somewhat tentative, they are consistent with research findings

that have explored the use of military language within cancer services (Czechmeister, 1994; Semino et al., 2017). By reflecting on the use of language, I feel it has provided me with a more balanced perspective towards the use of metaphors within my clinical and research practice. As such, I feel more equipped to recognise when they can be beneficial to a client's conceptualisation of their experiences and when they can create additional challenges for service users.

The positive functions of humour are often debated amongst healthcare professionals and largely depend on the clinician's viewpoint (Martin, 1996). Within the interviews with Nicole and Edith, I perceived their use of humour to be self-deprecating, invoking my feelings of compassion and sympathy towards their experiences. Following their interviews, my original assumptions, recorded within my reflective journal, indicated my potential of becoming fused to the idea their humour was disempowering. As such, I was at risk of avoiding other interpretations of their language use. However, by bracketing my original assumptions, my perspective shifted within the coding process. As such, I was able to acknowledge how their use of humour had enriched the descriptions of their experiences. This process has affirmed the importance of not relying upon my assumptions to understand the construction of other people's experiences but rather, to try and understand the meaning behind the use of language and the variety of functions humour can serve (McCreaddie & Wiggins, 2007).

### 3.3 Acceptance

Acceptance is an active and dynamic process where challenging events, thoughts and feelings are embraced without needing to change or avoid them (Hayes et al., 1999; Hayes et al., 2006). During the research process, I was afforded the opportunity to shadow a dermatology hair loss clinic. Within this clinic, I was particularly struck by the emotive content of clients' experiences and in their descriptions of being "ugly", "weird" and "unfeminine". Following the clinic, I began to reflect on my own construction of beauty and upon the social processes that create an 'ideal' beauty for women to strive towards (Gallagher & Pecot-Hebert, 2007). I felt a sense of shame towards my reflections as I wondered if my own conformity played a part in maintaining the rigidity of the social norms of beauty that can cause difficulties for people living with visible differences. Whilst this awareness has been challenging to accept and conflicts with my desire to celebrate diversity, I am more aware of the tension between my own actions and the social processes that are driving them.

### 3.4 Contact with the present moment

Focusing on the 'here and now', rather than ruminating on past and future events is an important part of maintaining psychological flexibility (Harris, 2009). At different points during the research process, I found my thoughts began to ruminate on the time constraints associated with the completion of the thesis. This was especially evident during the process of gaining appropriate ethical approval. Whilst I firmly believe ethical codes of conduct are integral to clinical

and research practices, at times, I found the process challenging to navigate, particularly due to the introduction of gaining HRA approval amidst the submission of my ethics application. Furthermore, my anxieties towards the time frame of my research project was exacerbated by the restructuring of the local research and development team and the length of time they required to process my application.

Overall, I experienced this process to be stressful, causing me to ruminate on possible future consequences and as such, it created a barrier in my ability to be within the present moment. It is likely the difficulties I experienced highlighted a conflict between my value to act ethically and my desire to fulfil the requirements of the doctorate programme and professional training. However, on reflection I feel the ethical approval procedure has increased the rigour of my project and improved the experiences of participants, as it has ensured ethical practices have been thoroughly considered throughout the research process.

The use of bracketing in research can help mitigate the potential influence of unacknowledged research assumptions and allow the researcher to focus on the 'here and now' of participant experiences (Tufford & Newman, 2010). The opportunity to explore my own thoughts and assumptions towards rosacea has been a valuable experience. Prior to conducting the interviews, I was able to acknowledge my beliefs towards visible difference and to understand my assumption that living with rosacea would be a negative experience. I found

bracketing to be a beneficial process as it enabled me to focus on how participant's described their lived experience, remain within the present moment and prevented the direction of the interview being channelled by my preconceived assumptions.

### 3.5 The context of the self

The importance of striking a balance between the 'thinking self' and the 'observing self' is emphasised within the ACT model as it allows individuals to become aware of the distinction between "sensing and what is sensed" (Carrasquillo & Zettle, 2014, p. 660; Harris, 2009; Hayes et al., 1999). Reflecting on participant's difficulties in separating the private and social parts of the self particularly resonated with my experiences of training on the clinical psychology doctorate course. Whilst my experiences have enabled me to foster the development of my 'observing self', at times, my vulnerabilities have felt exposed and open to the judgement and critique of my peers, clinical tutors and supervisors. For trainees, discovering the limitations of beliefs and epistemological assumptions can be challenging (Davidson, Harper, Patel & Byrne, 2007). However, I have also found training to be a rewarding experience and I am more attuned to my identity within my professional practice and in acknowledging my strengths as a clinical and scientific practitioner.

Within qualitative research, the researcher is considered to adopt either an 'insider' or 'outsider' position to the population they are studying (Hellawell, 2006). At the start of my research journey I had assumed a prior knowledge to the topic area due to my previous experiences of living with a visible difference. As such, I considered myself to adopt an 'insider' position. However, during the coding process, I wondered whether participant's had positioned me as an 'outsider' which was reflected within some of their comments "probably you can't imagine because you are- you have normal skin" -"you see people- like yourself you've got nice clear skin"- "do you know what I mean". The differences between my original assumption and participant's experiences of me emphasised the naivety of my original perception. Furthermore, this caused me to feel embarrassment as I had assumed the experiences of all types of visible differences would share some commonalities. Reflecting on this, I wondered if my struggle to understand if I was an 'insider' or an 'outsider' mirrored some of the experiences participants described in their difficulties to "fit in" with society and adhere to social norms. With this in mind, I now perceive my research position to be within "the space between", acknowledging the researcher's membership to the wider group whilst celebrating the differences in the group member's experiences (Dwyer & Buckle, 2009, p.60).

### 3.6 Committed action

The ability to be committed to our actions is an active process that allows our behaviour to be consistent to our values and goals, as well as providing a sense of

meaning (Stoddard, Nilloofar & Hayes, 2014). Before embarking on my research journey, I had not considered the psychological needs of people living with skin conditions, nor was I aware of the limited psychological services that are available within dermatology. Being on placement within the service that participants were recruited from provided me with a deeper understanding of the range of difficulties people living with skin conditions can encounter on a daily basis. My experiences have also increased my awareness of the limited research and best practice guidelines that are specific to psychodermatology and the challenges this can cause, for both clinical work and research practices. Whilst at times these challenges seemed overwhelming and complex, this area of psychology feels like an exciting and valuable area to complete further research within upon qualification. Furthermore, my research journey has affirmed to me my passion and motivation to work within a physical health setting, particularly towards the exploration of the mind-body link. I have become appreciative of what this area of psychology has provided me with and how it has helped marry my professional practice to the personal values I find meaningful.

### 3.7 Conclusion

Overall, my 'dance around the hexaflex' has allowed me to acknowledge my strengths and vulnerabilities, as well as the interplay between my personal and professional practices. I have truly valued this experience and despite the pressures on the NHS, I will continue to develop my reflexive skills to ensure they remain at the heart of my research and clinical practice. Whilst the completion of

my research project symbolises the end of my journey as a Trainee Clinical Psychologist, I believe my experiences have provided me with the necessary tools to ensure upon qualification I will continue to “be present, open up and do what matters most” (Harris, 2013, p.32).

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**Appendix A: Author Guidelines for the *British Journal of Psychology***

Author Guidelines:

The Editorial Board of the British Journal of Psychology is prepared to consider for publication:

(a) reports of empirical studies likely to further our understanding of psychology

(b) critical reviews of the literature

(c) theoretical contribution Papers will be evaluated by the Editorial Board and referees in terms of scientific merit, readability, and interest to a general readership.

All papers published in The British Journal of Psychology are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 8000 words (excluding the abstract, reference list, tables and figures), although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Submission and reviewing

All manuscripts must be submitted via Editorial Manager. The Journal operates a policy of anonymous (double blind) peer review. We also operate a triage process in which submissions that are out of scope or otherwise inappropriate will be rejected by the editors without external peer review to avoid unnecessary delays. Before submitting, please read the terms and conditions of submission and the declaration of competing interests. You may also like to use the Submission Checklist to help you prepare your paper.

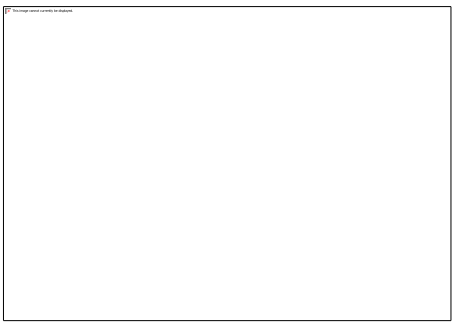
4. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. You may like to use this template. When entering the author names into Editorial Manager, the corresponding author will be asked to provide a CRediT contributor role to classify the role that each

author played in creating the manuscript. Please see the Project CRediT website for a list of roles.

- The main document must be anonymous. Please do not mention author's names or affiliations (including in the Method section) and refer to any previous work in the third person.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensive without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.
- All articles should be preceded by an Abstract of between 100 and 200 words, giving a concise statement of the intention, results or conclusions of the article
- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide DOI numbers where possible for journal articles
- SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association.

**Appendix B: Coventry Ethical Approval for Systematic Literature Review**



# Certificate of Ethical Approval

Applicant:

Carly Jeffery

Project Title:

A systematic review of the psychosocial antecedents and consequences of non-scarring alopecia in young people

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Low
Risk

Date of approval:

15 August 2016

Project Reference Number:

P45389

Sophie Krumins on behalf of ethics.hls

Tue 21/03/2-17 09:43

To: Carly Jeffery <jefferyc@uni.coventry.ac.uk>;

Amendment request form.docx

Hi Carly

Please complete the above form, and confirm if any other changes will need to be made to your application, due to your change in title/focus

Many thanks,

HLS Ethics

Faculty of Health & Life Sciences

Faculty Research Support Hub (RC409)

Coventry University

Carly Jeffery

Tues 21/03/2017 11:26

To: ethics.hls <ethics.hls@coventry.ac.uk>;

Amendment request form docx

Dear HLS Ethics,

Thank you for your email, please find attached my completed amendment request form for my systematic literature review ref: P45389. I look forward to hearing from you as to whether this amendment has been approved by Coventry Ethics. Please do not hesitate to contact me if you require any additional information.

Kind regards

Carly Jeffery
Trainee Clinical Psychologist
Universities of Coventry and Warwick
jefferyc@uni.coventry.ac.uk

Sophie Krumins on behalf of ethics.hls

Tue 28/03/2017 14:00

To: Carly Jeffery <jefferyc@uni.coventry.ac.uk>;

Hi Carly

Thank you for your e-mail and request. The reviewer has approved this and a note has been added to your application.

Please proceed with good ethics and good luck with your study.

Many thanks,

HLS Ethics

Faculty of Health & Life Sciences

Faculty Research Support Hub (RC409)

Coventry University

Appendix C: Quality Assessment Framework (Caldwell, Henshaw & Taylor, 2011)

| Question | Yes (2 points) | Partial (1 point) | No (0 points) |
|---|---|---|---|
| **Q1. Does the title reflect the content?** The title should be informative and indicate the focus of the study. It should allow the reader to easily interpret the context of the study. An inaccurate or misleading title can confuse the reader | | | |
| **Q2. Are the authors Credible?** Researchers should hold appropriate academic qualifications and be linked to a professional field relevant to the research | | | |
| **Q3. Does the abstract summarize the key components?** The abstract should provide a short summary of the study. It should include the aim of the study, outline of the methodology and the main findings. The purpose of the abstract is to allow the reader to decide if the study is of interest to them | | | |
| **Q4. Is the rationale for undertaking the research clearly outlined?** The author should present a clear rationale for the research, setting it in context of any current issues and knowledge of the topic to date | | | |
| **Q5. Is the literature review comprehensive and up to date?** The literature review should reflect the current state of knowledge relevant to the study and identify any gaps or conflicts. It should include key or classic studies on the topic as well as up to date literature. There should be a balance of primary and secondary sources | | | |
| **Q6. Is the aim of the research clearly stated?** The aim of the study should be clearly stated and should convey what the researcher is setting out to achieve | | | |
| **Q7. Are all ethical issues identified and addressed?** Ethical issues pertinent to the study should be discussed. The researcher should identify how the rights of informants have been protected and informed consent obtained. If the research is conducted within the NHS there should be an indication of local research ethics committee approval | | | |

| | | | |
|---|---|---|---|
| **Q8. Is the methodology identified and justified?** The researcher should make clear what research strategy they are adopting, i.e. qualitative or quantitative. A clear rationale for the choice should also be provided, so that the reader can judge whether the chosen strategy is appropriate for the study. | | | |
| **Q9. Quantitative Studies: Is the study design clearly identified and a rationale provided?** The design of the study e.g. survey, experiment should be identified and justified. As with the choice of strategy, the reader needs to determine whether the design is appropriate for the research undertaken | | | |
| **Q10. Quantitative Studies: Is there an experimental hypothesis clearly stated and are the key variable identified?** In experimental research the researcher should provide a hypothesis. This should clearly identify the independent and dependent variable and state their relationship and the intent of the study. In survey research the researcher may choose to provide a hypothesis, but it is not essential, and alternatively a research question or aim may be provided | | | |
| **Q11. Quantitative Studies: Is the population identified?** The population is the total number of units from which the researcher can gather data. It may be individuals, organisations or documentation. Whatever the unit, it must be clearly identified | | | |
| **Q12. Quantitative Studies: Is the sample adequately described and reflective of the population?** Both the method of sampling and the size of the sample should be stated so that the reader can judge whether the same is representative of the population and sufficiently large to eliminate bias | | | |
| **Q13. Quantitative Studies: Is the method of data collection valid and reliable**? The process of data collection should be described. The tools or instruments must be appropriate to the aims of the study and the researcher should identify how reliability and validity were assured | | | |
| **Q14. Quantitative Studies: Is the method of data analysis valid and reliable?** The method of data analysis must be described and justified. Any statistical test used should be appropriate for the data involved. | | | |
| **Q15. Qualitative Studies: Are the philosophical background and study design identified and the rationale for choice evident?** The design of the study e.g. phenomenology, ethnography, should be identified and the philosophical background and rationale discussed. The reader needs to consider if it is appropriate to meet the aims of the study. | | | |
| **Q16. Qualitative Studies: Are the major concepts identified?** The researchers should make clear what the major concepts are but they might not define them. The purpose of the study is to explore the concepts from the perspective of the participants. | | | |

| | | | |
|---|---|---|---|
| **Q17. <u>Qualitative Studies:</u> Is the context of the study outlined?** The researcher should provide a description of the context of the study, how the study sites were determined and how the participants were selected. | | | |
| **Q18. <u>Qualitative Studies:</u> Is the selection of participants described and the sampling method identified?** Informants are selected for their relevant knowledge or experience. Representativeness is not a criteria and purpose sampling is often used. Sample size may be determined through saturation | | | |
| **Q19. <u>Qualitative Studies:</u> Is the method of data collection auditable?** Data collection methods should be described and be appropriate to the aims of the study. The researcher should describe how they assured that the method is auditable | | | |
| **Q20. <u>Qualitative Studies:</u> Is the method of data analysis credible and confirmable?** The data analysis strategy should be identified, what processes were used to identify patterns and themes. The researcher should identify how credibility and confirmability have been addressed. | | | |
| **Q21. Are the results presented in a way that is appropriate and clear?** Presentation of data should be clear, easily interpreted and consistent | | | |
| **Q22. Is the discussion Comprehensive?** In quantitative studies the results and discussion are presented separately. In qualitative studies these may be integrated. Whatever the mode of presentation the researcher should compare and contrast the findings with that of previous research on the topic. The discussion should be balanced and avoid subjectivity | | | |
| **Q23. <u>Quantitative Studies</u>: Are the results generalizable?** | | | |
| **Q24. <u>Qualitative Studies</u>: Are the results transferable?** | | | |
| **Q25. Is the conclusion comprehensive?** Conclusions must be supported by the findings. The researcher should identify any limitations to the study. There may also be recommendations for further research or if appropriate implications for practice in the relevant field. | | | |

## Appendix D: Quality Assessment Scores

| Papers | Title | Authors | Abstract | Rationale | Literature Review | Aim | Ethical Issues | Methodology identified/justified | *Quan:* Study Design *Qual:* Study design | *Quan:* Hypothesis/aim *Qual:* Concepts identified | *Quan:* Population Sample *Qual:* Context of study | *Quan:* Participant Sample *Qual:* Participant Selection | *Quan:* Method of data collection valid/reliable *Qual:* Method of data collection auditable | *Quan:* Method of data analysis *Qual:* Method of data analysis credible | Results | Discussion | *Quan:* Generalisability *Qual:* Transferable | Conclusion | Total Score |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Al-Okali, et al., 2008 | 2 | 1 | 2 | 0 | 0 | 2 | 0 | 0 | 1 | 1 | 0 | 1 | 1 | 1 | 1 | 1 | 0 | 1 | 15/36 |
| Andreoli et al, 2002 | 2 | 2 | 1 | 1 | 1 | 2 | 0 | 0 | 1 | 0 | 0 | 1 | 1 | 0 | 1 | 2 | 0 | 1 | 16/36 |
| Beattie & Lewis-Jones, 2006 | 1 | 2 | 2 | 1 | 1 | 2 | 0 | 1 | 0 | 1 | 2 | 2 | 1 | 1 | 2 | 1 | 0 | 1 | 21/36 |
| Bilgic, et al, 2014 | 2 | 2 | 2 | 2 | 2 | 2 | 1 | 0 | 0 | 1 | 0 | 1 | 1 | 2 | 1 | 2 | 1 | 1 | 23/36 |
| Coulacoglou, et al., 2001 | 2 | 1 | 1 | 0 | 0 | 1 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 6/36 |
| De Waard-Van Der Spek, et al., 1994 | 2 | 2 | 2 | 1 | 1 | 2 | 0 | 0 | 0 | 0 | 1 | 2 | 0 | 0 | 1 | 1 | 0 | 1 | 16/36 |
| Diaz-Atienza & Gurpegui, 2011 | 1 | 2 | 2 | 1 | 2 | 1 | 1 | 0 | 1 | 1 | 0 | 1 | 1 | 2 | 2 | 2 | 1 | 1 | 22/36 |
| Elkin, et al., 2006 | 1 | 2 | 1 | 1 | 1 | 1 | 0 | 0 | 1 | 1 | 0 | 1 | 2 | 0 | 1 | 1 | 0 | 1 | 15/36 |
| Farajzadeh et al, 2013 | 2 | 2 | 2 | 2 | 1 | 2 | 2 | 1 | 1 | 2 | 2 | 1 | 1 | 1 | 1 | 2 | 1 | 2 | 28/36 |

| | | | | | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Ghanizadeh, 2008 | 2 | 2 | 1 | 2 | 1 | 2 | 1 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 2 | 0 | 2 | 16/36 |
| Hankinson, et al., 2013 | 2 | 2 | 0 | 0 | 0 | 2 | 1 | 0 | 0 | 0 | 0 | 1 | 0 | 1 | 1 | 0 | 0 | 1 | 11/36 |
| Karambetsos, et al, 2013 | 1 | 2 | 2 | 2 | 1 | 2 | 1 | 0 | 1 | 1 | 2 | 2 | 2 | 2 | 1 | 2 | 0 | 1 | 25/36 |
| Liakopoulou, et al., 1997 | 2 | 2 | 2 | 2 | 1 | 2 | 0 | 0 | 1 | 1 | 0 | 1 | 1 | 2 | 2 | 1 | 1 | 1 | 22/36 |
| Manolache, et al., 2008 | 2 | 2 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 1 | 0 | 1 | 2 | 1 | 0 | 0 | 10/36 |
| Mehlman & Griesemer, 1968 | 1 | 2 | 1 | 1 | 1 | 1 | 0 | 0 | 0 | 0 | 1 | 1 | 0 | 1 | 1 | 0 | 0 | 1 | 12/36 |
| Rafique & Hunt, 2015 | 2 | 2 | 2 | 2 | 1 | 2 | 2 | 2 | 2 | 2 | 1 | 1 | 2 | 2 | 2 | 2 | 1 | 1 | 31/36 |
| Reeve, et al., 1996 | 2 | 2 | 2 | 1 | 1 | 2 | 1 | 0 | 0 | 1 | 2 | 1 | 1 | 0 | 1 | 2 | 0 | 1 | 20/36 |
| Toback & Rajkumar, 1979 | 1 | 2 | 1 | 1 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 1 | 0 | 0 | 1 | 9/36 |
| Wolf, 2014 | 2 | 1 | 1 | 1 | 1 | 2 | 1 | 2 | Quan:2 Qual: 0 | Quan: 2 Qual:1 | Quan: 1 Qual:1 | Quan: 1 Qual:1 | Quan: 0 Qual:0 | Quan: 0 Qual: 0 | 0 | 1 | Quan: 0 Qual: 0 | 1 | 22/50 |

Scoring: 2 points= criteria fully met, 1 point = criteria partially met, 0 points= quality criteria not met

**Appendix E: Kappa Reliability Co-efficient Data**

Overall Kappa reliability co-efficient

**Symmetric Measures**

| | | Value | Asymptotic Standard Error[a] | Approximate T[b] | Approximate Significance |
|---|---|---|---|---|---|
| Measure of Agreement | Kappa | .863 | .046 | 11.392 | .000 |
| N of Valid Cases | | 90 | | | |

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Bilgic et al., (2014) Kappa reliability co-efficient

**Symmetric Measures**

| | | Value | Asymptotic Standard Error[a] | Approximate T[b] | Approximate Significance |
|---|---|---|---|---|---|
| Measure of Agreement | Kappa | .914 | .037 | 12.052 | .000 |
| N of Valid Cases | | 90 | | | |

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Liakopoulou et al., (1997) Kappa reliability co-efficient

**Symmetric Measures**

| | | Value | Asymptotic Standard Error[a] | Approximate T[b] | Approximate Significance |
|---|---|---|---|---|---|
| Measure of Agreement | Kappa | .827 | .113 | 4.885 | .000 |
| N of Valid Cases | | 18 | | | |

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Rafique and Hunt, (2015) Kappa reliability co-efficient

**Symmetric Measures**

| | | Value | Asymptotic Standard Error[a] | Approximate T[b] | Approximate Significance |
|---|---|---|---|---|---|
| Measure of Agreement | Kappa | .852 | .142 | 3.657 | .000 |
| N of Valid Cases | | 18 | | | |

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Reeve et al., (1996) Kappa reliability co-efficient

**Symmetric Measures**

| | | Value | Asymptotic Standard Error[a] | Approximate T[b] | Approximate Significance |
|---|---|---|---|---|---|
| Measure of Agreement | Kappa | .825 | .116 | 4.821 | .000 |
| N of Valid Cases | | 18 | | | |

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Toback and Rajkumar, (1979) Kappa reliability co-efficient

**Symmetric Measures**

| | | Value | Asymptotic Standard Error[a] | Approximate T[b] | Approximate Significance |
|---|---|---|---|---|---|
| Measure of Agreement | Kappa | .793 | .140 | 3.885 | .000 |
| N of Valid Cases | | 18 | | | |

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Appendix F: Coventry Ethical Approval for Empirical Research


# Certificate of Ethical Approval

Applicant:

Carly Jeffery

Project Title:

Exploring the lived experience of women with rosacea: visible difference, diagnosis and treatment

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as High Risk

Date of approval:

09 March 2016

Project Reference Number:

P41490

Appendix G: NHS Research Ethics Committee Ethical Approval Letter

Health Research Authority

**West Midlands - Coventry & Warwickshire Research Ethics Committee**

The Old Chapel
Royal Standard Place
Nottingham
NG16FS

**Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval**

27 June 2016

Miss Carly Jeffery

Trainee Clinical Psychologist

Coventry and Warwickshire NHS partnership trust

Universities of Coventry and Warwick Clinical Psychology Doctorate Programme,

Coventry University, James Starley Building,

Priory Street, Coventry,

CV1 5FB

Dear Miss Jeffery

| | |
|---|---|
| **Study title:** | **Exploring the lived experience of women with rosacea: visible difference, diagnosis and treatment** |
| **REC reference:** | **16/WM/0218** |
| **IRAS project ID:** | **198968** |

Thank you for your letter of 21 June 2016 responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the

REC Manager, Ms Rachel Nelson,

NRESCommittee.WestMidlands-CoventryandWarwick@nhs.net.

## Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

## Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).*

*Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.*

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of management permissions from host organisations*

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

## Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

| *Document* | *Version* | *Date* |
|---|---|---|
| Covering letter on headed paper [Covering Letter to Dr Brittain] | Version 1 | 21 June 2016 |
| GP/consultant information sheets or letters [Letter to GP] | Version 1 | 20 June 2016 |
| Interview schedules or topic guides for participants [Interview Schedule] | Version 1 | 14February 2016 |
| IRAS Application Form [IRAS_Form_21042016] | | 21 April 2016 |
| IRAS Application Form XML file [IRAS_Form_21042016] | | 21 April 2016 |
| IRAS Checklist XML [Checklist_21042016] | | 21 April 2016 |
| IRAS Checklist XML [Checklist_21062016] | | 21 June 2016 |
| IRAS Checklist XML [Checklist_23062016] | | 23 June 2016 |
| Letter from sponsor [Letter from Sponsor] | 1 | 09 March 2016 |
| Other [Coventry University Ethical Approval Certificate] | 1 | 09 March 2016 |
| Other [GCP Certificate] | 1 | 15 November 2015 |
| Other [Statement of Activities] | 1 | 18 April 2016 |
| Other [Schedule of events] | 1 | 18 April 2016 |
| Other [Indemnity Insurance] | | 09 March 2016 |
| Other [Liability Insurance] | | 09 March 2016 |
| Other [Demographic Information Sheet] | Version 1 | 14 February 2016 |
| Other [Participant Debrief Information Sheet] | Version 1 | 14 February 2016 |
| Other [Consent Form- To be contacted by researcher] | Version 1 | 14 February 2016 |
| Participant consent form [Participant Consent Form] | Version 2 | 20 June 2016 |
| Participant information sheet (PIS) [Participant Information Sheet] | Version 3 | 22 June 2016 |
| Research protocol or project proposal [Research Project Proposal] | Version 1 | 14 February 2016 |
| Summary CV for Chief Investigator (CI) [CI CV] | 1 | 18 April 2016 |
| Summary CV for supervisor (student research) [Carolyn Gordon] | | |
| Summary CV for supervisor (student research) [Kate Martin] | | |

## Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

## After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

## User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

## HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

| **16/WM/0218** | **Please quote this number on all correspondence** |
|---|---|

With the Committee's best wishes for the success of this project.

Yours sincerely

Dr Helen Brittain Chair

Email:NRESCommittee.WestMidlands-CoventryandWarwick@nhs.net

Appendix H: Health Research Authority Ethical Approval Letter

Miss Carly Jeffery
Trainee Clinical Psychologist
Email: hra.approval@nhs.net

Coventry and Warwickshire NHS partnership trust
Universities of Coventry and Warwick Clinical Psychology
Doctorate Programme,
Coventry University, James Starley Building,
Priory Street,
Coventry,
CV1 5FB

30 June 2016

Dear Miss Jeffery

## Letter of HRA Approval

| | |
|---|---|
| **Study title:** | **Exploring the lived experience of women with rosacea: visible difference, diagnosis and treatment** |
| **IRAS project ID:** | **198968** |
| **REC reference:** | **16/WM/0218** |
| **Sponsor** | **Coventry and Warwick University** |

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

### Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

*Appendix B* provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities

- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided. It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

## Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

## After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators"*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.

- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

## Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

## User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at hra.approval@nhs.net. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

## HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is **198968**. Please quote this on all correspondence.

Yours sincerely

Dr Claire Cole

Senior Assessor

Email: hra.approval@nhs.net

Appendix I: NHS Research and Development Ethical Approval Letter

**Research & Development Directorate** **Birmingham Heartlands Hospital**
*MIDRU*
*R&D Office: 0121 424 1633*
*Fax: 0121 424 3167*
Bordesley Green East
Birmingham B9 5SS

Tel: 0121 424 2000
Fax: 0121 424 2200

Ms Carly Jeffery

Trainee Clinical Psychologist

St Michaells Hospital
St Michael's Road

Warwick

CV34 5QW

12 August 2016

Dear Carly,

## Letter of access for research

This letter should be presented to each participating department before you commence your research at this site, Heart of England NHS Foundation Trust

In accepting this letter, each participating department confirms your right of access to conduct research through this organisation for the purpose and on the terms and conditions set out below. This right of access commences on 12 August 2016 and ends on 01 November 2017 unless terminated earlier in accordance with the clauses below.

As an existing NHS employee you do not require an additional honorary research contract with the participating organisation. The organisation is satisfied that the research activities that you will undertake in the organisation are commensurate with the activities you undertake for your employer. Your employer is fully responsible for ensuring such checks as are necessary have been carried out. Your employer has confirmed in writing to this organisation that the necessary pre-engagement checks are in place in accordance with the role you plan to carry out in the

organisation.. Evidence of checks should be available on request to Heart of England NHS Foundation Trust..

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving the organisation(s) permission to conduct the project.

You are considered to be a legal visitor to Heart of England NHS Foundation Trust premises. You are not entitled to any form of payment or access to other benefits provided by Heart of England NHS Foundation Trust to employees and this letter does not give rise to any other relationship between you and Heart of England NHS Foundation Trust, in particular that of an employee.

While undertaking research through Heart of England NHS Foundation Trust you will remain accountable to your employer, Coventry and Warwickshire Partnership NHS Trust but you are required to follow the reasonable instructions of your nominated manager, Dr Kate Martin, Senior Clinical Pyschologist, in this organisation or those given on her behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to cooperate fully with any investigation by West Midlands Ambulance Service NHS Foundation Trust or this organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with Heart of England NHS Foundation Trust policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with Heart of England NHS Foundation Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on Heart of England NHS Foundation Trust premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and Heart of England NHS Foundation Trust, prior to commencing your research role at each site.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

The organisation will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that the organisation accepts no responsibility for damage to or loss of personal property.

This letter may be revoked and your right to attend the organisation terminated at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of the organisation or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you MUST stop undertaking any regulated activity immediately.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or suitability to work with adults or children, or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform the organisation that employs you through its normal procedures. You must also inform the nominated manager in each participating organisation..

Yours sincerely

pp.

Ms Elizabeth Adey

Head of Research,

Heart of England NHS Foundation Trust

Appendix J: Interview schedule

Version 1, Date: 14/02/2016

**Coventry University**
Priory Street, Coventry, CV1 5FB
Telephone 0247688 8328
Fax 024 7688 8702

**Programme Director**
**Doctorate Course in Clinical Psychology**
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF WARWICK

Coventry University

**COVENTRY AND WARWICK CLINICAL PSYCHOLOGY DOCTORATE**

## Interview Structure

**Research Project Title**: Exploring the lived experience of women with rosacea: understanding visible difference, diagnosis and treatment

**Research Project Lead:** Carly Jeffery, Trainee Clinical Psychologist

### Interview schedule:

- Introduce myself to the participant and discuss the aim of the research
- Ensure the participant has read the participant information sheet and ask if they have any further questions regarding the research
- Discuss IPA research and the interview schedule
- Allow a time for the participant to ask any questions
- Complete the participant consent form
- Complete the demographic information sheet
- Ask whether they would like a summary of the project
- Obtain permission to being audio recording of the interview

### Interview questions:

**Question One:** Can you tell me a bit about yourself?

**Question Two:** Can you tell me a bit about when you first noticed the symptoms of rosacea?

*Prompt:* what was that like?

**Coventry University**
Priory Street, Coventry, CV1 5FB
Telephone 0247688 8328
Fax 024 7688 8702

**Programme Director**
**Doctorate Course in Clinical Psychology**
Dr Eve Knight
BSc Clin.Psy.D. CPsychol



**Question Three**: Can you tell me about being diagnosed with rosacea?

*Prompt:* What was it like? Were you expecting a diagnosis? What did the diagnosis mean to you?

**Question Four:** On a day to day basis, what is it like to have rosacea?

*Prompt:* What does it mean to you?

**Question Five:** What does a good day and a bad day with rosacea look like?

**Question Six:** Tell me what it is like in social situations?

Prompt: Has everyone reacted in this way? What have their reactions meant to you? How does it make you feel?

**Question Seven***:* What are your experiences of the management of rosacea?

*Prompts*: What treatment has been offered to you? Is there anything (e.g. medical, emotional, social/ relationships) that helps? Why does that help?

**Question Eight***:* Is there anything else you would like to share with me about your experience of living with Rosacea?

Inform the participant I have finished the questions in the interview schedule and thank them for taking the time to participate in the project.

General Prompts

- Can you tell me more about that?
- What happened?
- How did it make you feel?
- In what way?
- What is that like?
- Can you give me an example?

Appendix K: Participant Information Sheet

IRAS ID: 198968, Version 4.1, Date: 29/06/2016

**Coventry University**
Priory Street, Coventry, CV1 5FB
Telephone 0247688 8328
Fax 024 7688 8702

**Programme Director**
**Doctorate Course in Clinical Psychology**
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

**COVENTRY AND WARWICK CLINICAL PSYCHOLOGY DOCTORATE**

# Participant Information Sheet

**Research Project Title**: Exploring the lived experience of women with rosacea: understanding visible difference, diagnosis and treatment

**Research Project Lead:** Carly Jeffery, Trainee Clinical Psychologist

Email: jefferyc@uni.coventry.ac.uk

General Office Telephone Number: 02476 888328

Address: Clinical Psychology Doctorate Programme, Coventry University, Faculty of Health and Life Sciences, James Starley Building, Priory Street, Coventry, CV1 5FB.

Research is an important part of understanding people's experiences so that professionals can provide the best care possible. I am a second year trainee clinical psychology doctorate student at the Universities of Coventry and Warwickshire and I would like to invite you to participate in the research I am currently conducting which focuses on the lived experience of adult women with rosacea.

The aim of the information below is to help you decide whether or not you would like to take part in the research project.

**What is the aim of the research project?**

In recent years, the research that has investigated rosacea has started to shape the psychological understanding of the condition. However, the lived experiences of people diagnosed with this condition remains a neglected area within the literature. The aim of this project is to explore women's experiences of having rosacea. It is hoped the information that is collected will provide a greater understanding of:

- What it is like to have rosacea
- The experience of being diagnosed with the condition
- The experience of social situations for women with rosacea
- What it is like to try and manage the condition

**Dean of Faculty of Health and Life Sciences**
Professor Guy Daly Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

**Head of Department of Psychology**

**Coventry University**
Priory Street, Coventry, CV1 5FB
Telephone 0247688 8328
Fax 024 7688 8702

**Programme Director**
**Doctorate Course in Clinical Psychology**
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

**Who will be asked to take part?**
Up to eight females aged 20 and above who have had a clinical diagnosis of rosacea for over 6 months will be invited to take part in the research project. Participants need to have previously been or are currently being supported by the Dermatology Services within the Heart of England NHS Foundation Trust.

**Who will decide if I should participate in the research?**
It is your decision whether you participate in the research project or not. Any decision you make will not affect the medical treatment you receive now or in the future. Your information will only be used in the project if you consent to its use.

**If I agree to take part, what is involved in the research project?**
If you wish to participate in the research project, you will be invited to take part in an interview with the project lead. Prior to the interview, you will be asked to complete a consent form and a demographic information sheet which asks you to provide information about your age, ethnicity, date you were diagnosed with rosacea and condition subtype (if known).

The interview
The interview will last approximately 60 minutes and will involve an informal discussion where the researcher hopes to find out about your experiences of living with rosacea. The project lead will ask a range of questions which will cover areas related to this topic. You do not have to answer any questions if you do not wish to and can stop the interview at any time.

If, in the interview you disclose information that is a cause of concern for either your safety or the safety of other people, the project lead will liaise with the appropriate service to provide support. Should this issue arise, it will be discussed with you in more detail.

The interviews will be audio recorded for the purpose of transcription. Once the research project has been marked and approved by Coventry and Warwick Universities, the audio tapes and any confidential information obtained for the purpose of the project will be destroyed.

**Coventry University**
Priory Street, Coventry, CV1 5FB
Telephone 0247688 8328
Fax 024 7688 8702

**Programme Director**
**Doctorate Course in Clinical Psychology**
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

**Will other people be able to identify me in the research?**
All personal information such as name, date of birth, names of friends and family, where you live etc. will not be included in the findings of the research project. Only the project lead will have access to this information and this will be kept separately from the transcripts. Any information that could identify you will be anonymised. You will not be able to be identified in the research project.

The project will use extracts of the transcripts to highlight themes that arise from participant's experiences. A pseudonym will be used, which means the reader would not be able to identify you. Any personal information that could identify you will be kept confidential and will not be included in the findings of the project.

Anonymised transcripts may be shared with the research supervisory team to aid the process of identifying themes that emerge from the information that is provided by participants.

**What are the possible advantages and disadvantages of taking part?**
Advantages: An opportunity to 'give voice' to your experiences of rosacea. It is hoped the information that is provided will add to our understanding of rosacea and inform future practices.

Disadvantages: It is not anticipated you will experience any disadvantages by taking part in this research project. Before you decide whether to take part or not it is important to think about how it may feel to discuss your experience of having rosacea and whether this is likely to be a particularly challenging or difficult experience for you.

**Do I have the right to withdraw my consent?**
If you have previously consented to your information being used in the research project and decide you wish to withdraw your consent, you can do so up to one month after your interview took place. After this time, the data will be analysed in preparation for writing the research project. You can withdraw from the research by contacting the project lead on the contact details listed above.

**Coventry University**
Priory Street, Coventry, CV1 5FB
Telephone 0247688 8328
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**Programme Director**
**Doctorate Course in Clinical Psychology**
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BSc Clin.Psy.D. CPsychol



**What if something goes wrong?**
If you experience any psychological distress during the interview, you will be asked if you would like to have a break or continue with the interview. You will also be reminded of your right to withdraw from the interview at any time.

If you find discussing your experiences of living with rosacea particularly distressing, the project lead will discuss the possible options of support that are available to you. This may include encouraging you to contact your GP to discuss how you are feeling. The project lead may also make a referral with your consent, to an appropriate service for support. After the interview, you will also be provided with a Debrief Information Sheet which will contain information about the available services you can access for advice and support.

**What are the contact details for the Patient Advice and Liaison Service?**
The Patient Advice and Liaison Service (PALS) for the Heart of England NHS Foundation Trust has changed its name to the Patient Services Department. This service provides support to service users, relatives and carers who have concerns, complaints or queries about the service that has been provided to them by the NHS. You can contact the Patient Services Department either via telephone on: 0121 424 0808 or their email address: bhs-tr.Complaints-ConcernsandCompliments@nhs.net

**Will any healthcare professionals involved in my care be made aware of my participation in the research project**?
If you decide to participate in the research project, you will be asked if you would like your General Practitioner (GP) to be informed of your participation in the research project. If you provide your consent, the chief investigator will write to your GP to let them know you are taking part.

**What will happen to the results of this research project?**
It is anticipated the research project will be submitted to a journal article for publication, as well as being presented to staff and colleagues affiliated with the Coventry and Warwick Clinical Psychology doctorate programme and at other appropriate conferences. Feedback on the overall research findings will also be made available to staff within the dermatology department at the Heart of England NHS Foundation Trust.

**Coventry University**
Priory Street, Coventry, CV1 5FB
Telephone 0247688 8328
Fax 024 7688 8702

**Programme Director**
**Doctorate Course in Clinical Psychology**
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

**If I consent, can I have a copy of the results?**
If you consent to participating in the project, before your interview you will be asked whether you would like to have a summary of the overall findings and conclusion of the research project. If you inform the project lead you would like a copy of this summary it will be available once the project has been submitted and approved by the Coventry and Warwick doctorate programme in the summer of 2017.

**Who has approved the research project?**

The research project is sponsored by Coventry University. It has been reviewed and approved by Coventry University ethics committee, NHS research ethics committee and the research and development department for the Heart of England NHS Foundation Trust.

**I am interested in taking part, what happens next?**
If you are interested in taking part in the project, you will be provided with a consent form. This form asks for your consent for me to contact you about the project and what your preferred contact details are. You can either post your completed consent forms to me at the address listed above, or, you can contact me directly via email on: jefferyc@uni.coventry.ac.uk

If there is anything that you don't understand about the aims and purpose of the study or you would like more information, please do not hesitate to contact me on the contact details listed above and I would be happy to answer any questions you may have. If you contact me for further information this does not mean that you are obliged to take part in the project.

Thank you for taking the time to read this information and in your consideration of whether you wish to participate in this project.

Appendix L: Consent form 1 (Consent to be contacted by the researcher)

IRAS ID 198968, Version 1.1, Date: 29/06/2016

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**COVENTRY AND WARWICK CLINICAL PSYCHOLOGY DOCTORATE**

## Participant Consent Form- Consent to be contacted by the project lead

**Research Project Title**: Exploring the lived experience of women with rosacea: understanding visible difference, diagnosis and treatment

**Research Project Lead:** Carly Jeffery, Trainee Clinical Psychologist

**Email**: jefferyc@uni.coventry.ac.uk

**Address:** Clinical Psychology Doctorate Programme, Coventry University, Faculty of Health and Life Sciences, James Starley Building, Priory Street, Coventry, CV1 5FB.

**Please read the statements below and if you agree, please initial each box:**

I confirm I have read and understood the participant information sheet for the above project and I am interested in taking part ☐

I am aware by signing below, I am providing my consent for the project lead to contact me to provide more information about the research project and answer any questions or queries I may have about the project ☐

I understand the medical treatment I receive now or in the future will not be affected by my decision to participate/not participate in this research project ☐

**Participant Information:**

Name (Please print):……

My preferred contact details are: ……

Signature: ……

Date: ……

Thank you for registering your interest in the research project, please can you send your completed consent forms to Carly Jeffery (Trainee Clinical Psychologist) at the address listed above. You can also contact me directly via my email address listed above.

**Dean of Faculty of Health and Life Sciences**
Professor Guy Daly Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

**Head of Department of Psychology**

Appendix M: Consent form 2

IRAS ID: 198968, Version 2.1 Date: 29/06/2016

**Coventry University**
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treet Coventry CV1 5FB Tel 024 7679 5805

**Head of Department of Psychology**

**COVENTRY AND WARWICK CLINICAL PSYCHOLOGY DOCTORATE**

# Participant Consent Form

**Research Project Title**: Exploring the lived experience of women with rosacea: understanding visible difference, diagnosis and treatment

**Research Project Lead:** Carly Jeffery, Trainee Clinical Psychologist

Email: jefferyc@uni.coventry.ac.uk

Address: Clinical Psychology Doctorate Programme, Coventry University, Faculty of Health and Life Sciences, James Starley Building, Priory Street, Coventry, CV1 5FB.

**Please read the statements below and if you agree, please initial each box:**

I confirm I have read and understood the participant information sheet for the above project and by signing below I consent to participate in this project ☐

I am aware of what will be involved in the research project and that the interview will be audio recorded and transcribed ☐

I am aware I will be asked to provide demographic information about myself such as my age, ethnicity, date of diagnosis of rosacea and condition subtype (if known) ☐

Any questions I have had about the project have been answered and I am aware who I can contact about the research project if I need to do so ☐

I have been informed participation is the research project is entirely voluntary and I can withdraw the information I provide up to one month after my interview ☐

I understand a pseudonym will be used in the research project and I consent to extracts of my interview being used in the report and in publication ☐

I understand the academic and clinical supervisors of this research may look at the transcripts of the interviews which have been anonymised ☐

I am aware how my data will be treated in the project and I understand my personal information will not be included in the project ☐

I provide my consent for my General Practitioner (GP) to be informed of my participation in the research project ☐

I agree to take part in the research project ☐

| **Participant:** | **Research Project Lead:** |
|---|---|
| Name: | Name: |
| Signature: | Signature: |
| Date: | Date: |

1 copy to participant, 1 copy for researcher site file

**Dean of Faculty of Health and Life Sciences**
Professor Guy Daly Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

**Head of Department of Psychology**

Appendix N: Participant Demographic Information Sheet

Version 1, Date: 14/02/2016

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**Programme Director**
**Doctorate Course in Clinical Psychology**
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**COVENTRY AND WARWICK CLINICAL PSYCHOLOGY DOCTORATE**

## Participant Demographic Information Sheet

**Research Project Title**: Exploring the lived experience of women with rosacea: understanding visible difference, diagnosis and treatment

**Research Project Lead:** Carly Jeffery, Trainee Clinical Psychologist

Email: jefferyc@uni.coventry.ac.uk

Address: Clinical Psychology Doctorate Programme, Coventry University, Faculty of Health and Life Sciences, James Starley Building, Priory Street, Coventry, CV1 5FB.

Name: _____

Age: _____

Ethnicity: _____

Rosacea Subtype (if known): _____

Date received diagnosis of rosacea: _____

**Dean of Faculty of Health and Life Sciences**
Professor Guy Daly Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

**Head of Department of Psychology**

Appendix O: Participant Debrief Information Sheet

Version 1, Date: 14/02/2016

**Coventry University**
Priory Street, Coventry, CV1 5FB
Telephone 0247688 8328
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**Programme Director**
**Doctorate Course in Clinical Psychology**
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

# Participant Debrief Information Sheet

**Research Project Title**: Exploring the lived experience of women with rosacea: understanding visible difference, diagnosis and treatment

**Project Lead:** Carly Jeffery, Trainee Clinical Psychologist

Email: jefferyc@uni.coventry.ac.uk

Address: Clinical Psychology Doctorate Programme, Coventry University, Faculty of Health and Life Sciences, James Starley Building, Priory Street, Coventry, CV1 5FB.

Thank you for taking part in my research project. Within the interview, I asked you a number of questions about your experience of having Rosacea, particularly your thoughts and feelings towards visible difference, diagnosis and management of the condition.

## What happens to the information you have provided

The information provided in the interviews will now be transcribed. All personal information that could identify you will be anonymised and will not be used in the research report. Only extracts of participants transcripts will be incorporated into the report and a pseudonym will be used. This means the reader will not be able to identify you.

In the transcripts, I will look for the main themes that have emerged from the interviews to encapsulate the lived experience of rosacea. The transcripts and audio recording will be destroyed once the research project has been submitted for marking and approved by the Coventry and Warwick Clinical Psychology Doctorate programme.

## How to withdraw your information from the project

If you wish to withdraw the information you have provided in the interview, please contact me using the details listed above. You can withdraw your consent up to one month after your interview took place.

**Dean of Faculty of Health and Life Sciences**
Professor Guy Daly Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

**Head of Department of Psychology**

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Dr Eve Knight
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Findings of the research project

If you have confirmed you would like to know the overall conclusion and findings of the research project, you will be sent a copy once the project has been marked and approved by the Coventry and Warwick
University Doctorate Programme. The research project will be submitted for marking in the summer of 2017.

Support Services:

Whilst it is not the intension of the research project to cause any distress, if you found discussing your experience of rosacea particularly challenging and/or upsetting, you may wish to discuss how you are feeling with someone. You can contact your GP, or alternatively there are a number of services available which you can access for support. I have included the contact details of these services below.

**Changing Faces –** UK based charity which offers practical and emotional support as well as information aimed at supporting individuals and families living with visible difference

Telephone number: 0300 0120 2759 (Weekdays 9am-5pm)

Website: www.changingfaces.org.uk

**Mind-** offers a range of practical advice, information and support for people experiencing mental health difficulties.

Telephone number: 0300 123 3393 (Weekdays 9am - 6pm)
Website: www.mind.org.uk

**Samaritans-** offers a range of services including emotional support, advice and information

Telephone Number: 08457 90 90 90 (available 24 hours)
Website: http://www.samaritans.org

## Thank you again for taking the time to share your experiences

**Dean of Faculty of Health and Life Sciences**
Professor Guy Daly Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

**Head of Department of Psychology**

Appendix P: GP Letter

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Telephone 0247688 8328
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**Programme Director**
**Doctorate Course in Clinical Psychology**
Dr Eve Knight
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Dr …..
GP Address

Date

Dear Dr ,

**Re: Name of Participant, DOB:**

I am writing to you to inform you (name of participant) has provided their consent to participate in a qualitative research project exploring the lived experience of women with rosacea. Within the project, participants will be asked to complete a 60-80 minute semi-structured interview which aims to explore: 1) what it is like to have rosacea, 2) the experience of being diagnosed with the condition, 3) the experience of social situations for women with rosacea, 4) what it is like to try and manage the condition.

The research is being completed as part of the Coventry and Warwick Clinical Psychology Doctorate Course and has been approved by Coventry University ethics committee, NHS research ethics committee and the research and development department for the Heart of England Foundation Trust. (Name of participant) has provided their consent for you to be informed of their participation in the project.

A copy of the participant information sheet has been enclosed with this letter to provide additional information about the research project. This includes information on the aim of the study, method of data collection, inclusion criteria and ethical considerations. If you require any further information regarding the research project, please do not hesitate to contact me using my contact details listed below.

Kind regards,

Carly Jeffery

Trainee Clinical Psychologist

Universities of Coventry and Warwick

Email: jefferyc@uni.coventry.ac.uk

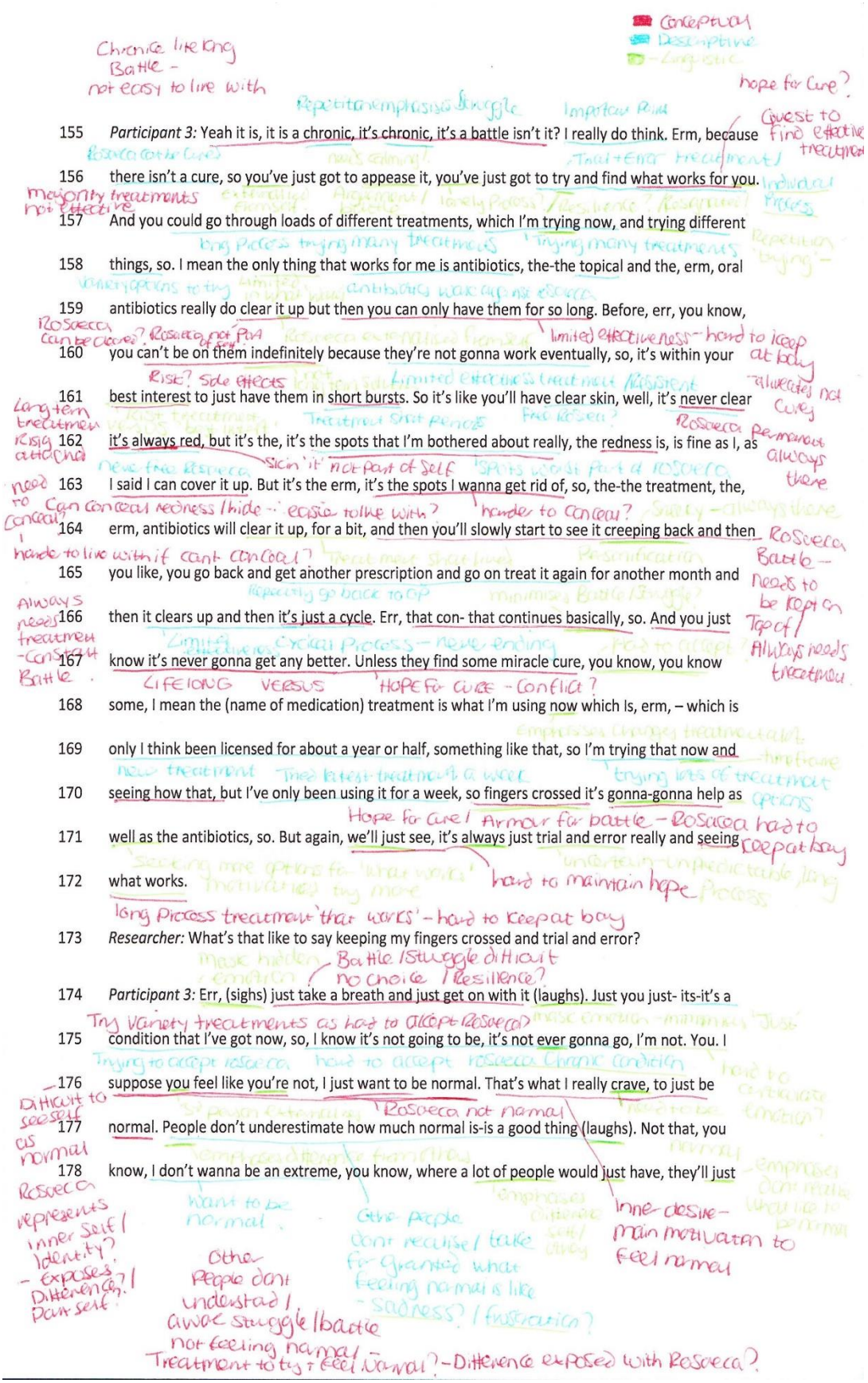
Address: Clinical Psychology Doctorate Programme, Coventry University, Faculty of Health and Life Sciences, James Starley Building, Priory Street, Coventry, CV1 5FB

## Appendix Q: IPA Guidelines (Smith, Flowers & Larkin, 2009)

| Step | Description |
|---|---|
| 1: Reading and re-reading | Reading and re-reading a participant's transcript enabled the researcher to become immersed in the data. This included listening to the audio-recording of the interview while reading the transcript. |
| 2: Initial Coding | A detailed line by line analysis of the transcript was completed to draw out the meaning held within participant's dialogue. This included noting important descriptive, linguistic and conceptual information. |
| 3 Developing emergent themes | This step involved identifying and developing the themes that emerged from the initial coding process of a participant's transcript. |
| 4 Searching for connections across emergent themes | The connections between emergent themes were analysed to develop a structure that reflected the researcher's interpretation of meaningful and important aspects of participant's experiences. |
| 5 Moving to the next case | Following the analysis of a participant's transcript the identified themes were bracketed to prevent the researcher's fore-structure restricting the themes that emerged within other participant's dialogue. Steps 1-5 were repeated for each transcript. |
| 6 Looking for patterns across cases | The themes from participant transcripts were organised into subordinate and super-ordinate themes. Convergence and divergence across participant's subthemes was also considered during this process. |

## Appendix R: Extract of Participant's Transcript Analysis

## Participant 3



155 *Participant 3:* Yeah it is, it is a chronic, it's chronic, it's a battle isn't it? I really do think. Erm, because

156 there isn't a cure, so you've just got to appease it, you've just got to try and find what works for you.

157 And you could go through loads of different treatments, which I'm trying now, and trying different

158 things, so. I mean the only thing that works for me is antibiotics, the-the topical and the, erm, oral

159 antibiotics really do clear it up but then you can only have them for so long. Before, err, you know,

160 you can't be on them indefinitely because they're not gonna work eventually, so, it's within your

161 best interest to just have them in short bursts. So it's like you'll have clear skin, well, it's never clear

162 it's always red, but it's the, it's the spots that I'm bothered about really, the redness is, is fine as I, as

163 I said I can cover it up. But it's the erm, it's the spots I wanna get rid of, so, the-the treatment, the,

164 erm, antibiotics will clear it up, for a bit, and then you'll slowly start to see it creeping back and then

165 you like, you go back and get another prescription and go on treat it again for another month and

166 then it clears up and then it's just a cycle. Err, that con- that continues basically, so. And you just

167 know it's never gonna get any better. Unless they find some miracle cure, you know, you know

168 some, I mean the (name of medication) treatment is what I'm using now which is, erm, – which is

169 only I think been licensed for about a year or half, something like that, so I'm trying that now and

170 seeing how that, but I've only been using it for a week, so fingers crossed it's gonna-gonna help as

171 well as the antibiotics, so. But again, we'll just see, it's always just trial and error really and seeing

172 what works.

173 *Researcher:* What's that like to say keeping my fingers crossed and trial and error?

174 *Participant 3:* Err, (sighs) just take a breath and just get on with it (laughs). Just you just- its-it's a

175 condition that I've got now, so, I know it's not going to be, it's not ever gonna go, I'm not. You. I

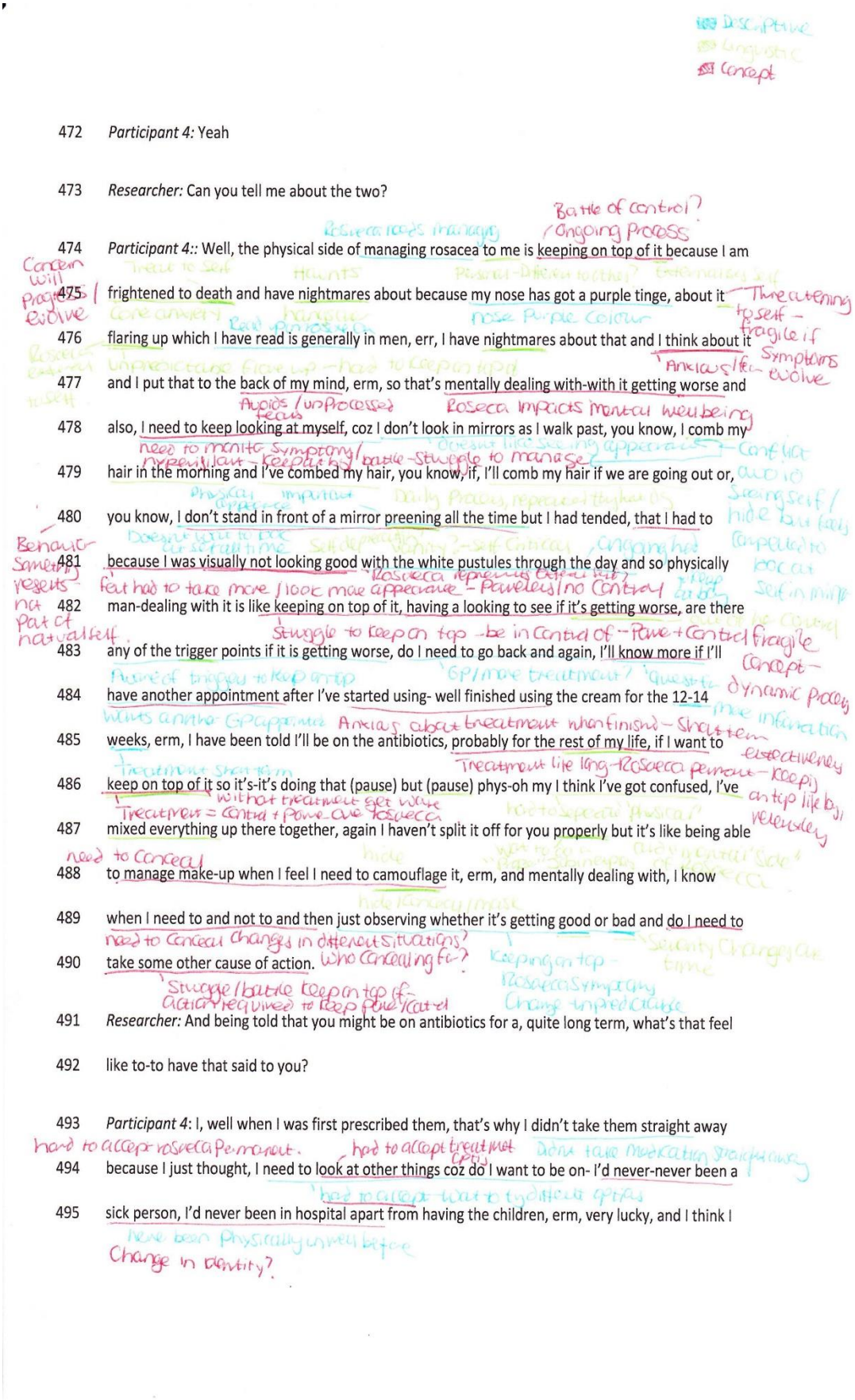
176 suppose you feel like you're not, I just want to be normal. That's what I really crave, to just be

177 normal. People don't underestimate how much normal is-is a good thing (laughs). Not that, you

178 know, I don't wanna be an extreme, you know, where a lot of people would just have, they'll just

Participant 4:

,



472 *Participant 4:* Yeah

473 *Researcher:* Can you tell me about the two?

474 *Participant 4::* Well, the physical side of managing rosacea to me is keeping on top of it because I am

475 frightened to death and have nightmares about because my nose has got a purple tinge, about it

476 flaring up which I have read is generally in men, err, I have nightmares about that and I think about it

477 and I put that to the back of my mind, erm, so that's mentally dealing with-with it getting worse and

478 also, I need to keep looking at myself, coz I don't look in mirrors as I walk past, you know, I comb my

479 hair in the morning and I've combed my hair, you know, if, I'll comb my hair if we are going out or,

480 you know, I don't stand in front of a mirror preening all the time but I had tended, that I had to

481 because I was visually not looking good with the white pustules through the day and so physically

482 man-dealing with it is like keeping on top of it, having a looking to see if it's getting worse, are there

483 any of the trigger points if it is getting worse, do I need to go back and again, I'll know more if I'll

484 have another appointment after I've started using- well finished using the cream for the 12-14

485 weeks, erm, I have been told I'll be on the antibiotics, probably for the rest of my life, if I want to

486 keep on top of it so it's-it's doing that (pause) but (pause) phys-oh my I think I've got confused, I've

487 mixed everything up there together, again I haven't split it off for you properly but it's like being able

488 to manage make-up when I feel I need to camouflage it, erm, and mentally dealing with, I know

489 when I need to and not to and then just observing whether it's getting good or bad and do I need to

490 take some other cause of action.

491 *Researcher:* And being told that you might be on antibiotics for a, quite long term, what's that feel

492 like to-to have that said to you?

493 *Participant 4*: I, well when I was first prescribed them, that's why I didn't take them straight away

494 because I just thought, I need to look at other things coz do I want to be on- I'd never-never been a

495 sick person, I'd never been in hospital apart from having the children, erm, very lucky, and I think I

Appendix S: Photo of data analysis