

The Bald Truth:  
An Investigation of the Impact that Alopecia Areata has on Women's Self-Esteem,  
Mood and Coping Strategies

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## ABSTRACT

Alopecia Areata (AA) is a chronic, spontaneous, condition characterised by the partial or complete loss of one's hair from their head and/or body. Approximately 2% of the Australian population is diagnosed with AA, and currently there are no cure or effective preventative treatments. Australian research investigating AA is still in its infancy, and although studies worldwide have contributed to our understanding, it remains a poorly understood condition with respect to aetiology, pathogenesis and treatment. Previous research has failed to examine the impact hair loss can have on women's self-esteem, mood and coping simultaneously. Therefore, incorporating a mixed methods design, the current study aimed to investigate the effects AA has on adult Australian women's self-esteem, depression, anxiety and stress levels, by recruiting data from age-matched female controls, to provide a stronger metric of comparison to AA participants. In addition, an exploration into the coping strategies women have implemented overtime in order to manage the condition were discussed, drawing on reoccurring themes attained via semi-structured interviews. It was hypothesised that women diagnosed with AA would exhibit lower self-esteem and elevated levels of depression, anxiety and stress compared to controls. A total of 63 AA participants and 63 controls completed a series of questionnaires, comprising of a demographics survey, the Rosenberg Self-Esteem Scale (RSES), and the Depression, Anxiety and Stress Scale (DASS42). In addition, a smaller sub-sample of 4 women was recruited to partake in interviews, to gain an in-depth subjective view of individuals coping strategies. Both parametric and non parametric analyses were performed, revealing a significant difference between groups, with AA participants reporting significantly higher scores for depression, anxiety and stress. However, no significant differences were found between self-esteem scores and groups. Moreover, 5 common themes emerged in a sequential order previously unidentified throughout past literature, demonstrating a process of coping with hair loss. These strategies included denial and isolation, followed by the use of supportive networks and headwear/wigs, prior to coping through finding a sense of acceptance. Contributing to the body of knowledge, the results of the current study provided valuable insight into the impact AA can have on women. Furthermore, the common coping strategies identified may assist current and/or future sufferers in dealing with and managing the condition throughout their lives.

## DECLARATION

“I, Jessica Katherine Martino, declare that this Bachelor of Psychological Studies (Honours) thesis entitled “The Bald Truth: An Investigation of the Impact that Alopecia Areata has on Women’s Self-Esteem, Mood and Coping Strategies” does not incorporate any materials that were previously written by another person except where due reference is made in the text”

“I further declare that this study has adhered to the ethical principles as established by the Ethics Committee of Victoria University and by the Ethics Committee at the Australian Alopecia Areata Foundation Inc.”

Name: .....

Signature: .....

Date: .....

## DEDICATION

I dedicate this thesis to all the women diagnosed with Alopecia Areata.

Audrey Hepburn once said:

“The beauty of a woman is not in the clothes she wears, the figure that she carries or the way she combs her hair. The beauty of a woman is seen in her eyes, because that is the doorway to her heart, the place where love resides”.

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## LIST OF ABBREVIATIONS

AA Monocularis	Alopecia Areata Monocularis
AA Multilocularis	Alopecia Areata Multilocularis
AA	Alopecia Areata
AAAF Inc.	Australian Alopecia Areata Foundation
AGA	Androgenic Alopecia
AT	Alopecia Totalis
AU	Alopecia Universalis
BAI	Beck Anxiety Inventory
BDI	Beck Depression Inventory
DASS42	Depression, Anxiety and Stress Scale
DLQI	Dermatology Life Quality Index
GAD	Generalised Anxiety Disorder
IPA	Interpretive Phenomenological Analysis
MANOVA	Multivariate Analysis of Variance
MDE	Major Depressive Episodes
MMPI-2	Minnesota Multiphasic Personality Inventory
PUVA	Photochemotherapy
RSES	Rosenberg Self-Esteem Scale
SAL	Social Activity Level
SPSS	Statistical Package for the Social Sciences

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## CHAPTER 1: INTRODUCTION

### 1.1 *Hair is Beauty*

Throughout history, poems and folktales have acknowledged long, lusher, golden hair as a mark of beauty. The loss of hair has been reported since biblical times, resulting in the diminishment of male power (e.g., Samson & Delilah) (Thompson & Shapiro, 1996). Although hair insulates the head under extremely hot conditions, as well as preventing heat loss under colder conditions, realistically it serves little aside from cosmetic purposes.

Nevertheless, the partial or complete loss of one's hair can trigger profound psychological distress (Hunt & McHale, 2007). This may reflect a number of beliefs, such as, that hair symbolises beauty, individuality and/or belonging to a particular social or cultural group (McDonagh & Tazi-Ahnini, 2002). Freedman (1994) stated that, “embodied in the symbolism of hair is a concept of the whole self, a completed person who has the possibility of expressing individualism through the design of their hair” (p. 336).

### 1.2 *Alopecia Areata*

Most people associate hair loss with aging men, unaware of clinical conditions such as Alopecia Areata (AA), which may appear at a very young age and in either gender (Borg & Kennedy, 2012). The term ‘alopecia’ refers to baldness or loss of hair, while the term ‘areata’ refers to loss occurring in patches (Green & Sinclair, 2004). AA is a chronic, non-scarring, inflammatory, hair loss condition and although not life threatening, it often results in adverse psychological and psychosocial consequences (Hunt & McHale, 2007; Shapiro, 2011; Rushton, 2002).

### *1.2.1 Epidemiology*

Recent statistics from the Australian Alopecia Areata Foundation (AAAF Inc., 2013) reported that approximately 2% of the Australian population is diagnosed with AA. With no gender or ethnic preponderance, the majority of literature states that 60% of reported onsets generally occurs before the age of 20 (Hull, Wood, Hutchinson, Sladden, & Messenger, 2003; Mounsey & Reed, 2009; Papadopoulos, Schwarts, & Janniger, 2000; Shallow, Edwards, & Koo, 1992).

### *1.2.2 Aetiology*

Unfortunately the exact cause and subsequent development of AA remains an enigma; however, many aspects of its natural history have been profitably explored and many misconceptions have been eliminated (Sharma, Dawn, & Kumar, 1996; Wang & McElwee, 2011). It has been well documented that several contributing factors including, immunology, genetic predisposition and stressful environmental influences may potentially trigger the onset of AA (Hunt & McHale, 2005a; Jackow et al., 1998; Madani & Shapiro, 2000).

Autoimmune dysfunction activates the body to attack the hair follicles, causing the suppression and/or discontinuation of hair growth (Perret, Weisner-Menzel, & Happle, 1984; Ranki, Kianto, Kanerva, Tolvanen, & Johansson, 1984). Previous research has recognised the clustering of T-Lymphocytes (play a central role in cell-mediated immunity) around affected hair follicles, causing inflammation, followed by hair loss (Khan, 2008; Mounsey & Reed, 2009). Despite the fact that most people living with AA are otherwise healthy, many individuals commonly suffer from co-morbid autoimmune related diseases such as, thyroid, vitiligo or atopy (Friedmann, 1981; Shallow et al., 1992; Thiedke, 2003).

Genetic factors are also considered to play an important role in the origin of AA. Although non-contiguous, Mounsey and Reed (2009) and Yazdan (2012) observed that between 20% and 42% of individuals with AA, reported an additional family member with the condition. Furthermore, Madani and Shapiro (2000) interestingly revealed a significantly higher prevalence of family history in people with a younger age of onset. Authors reported familial incidences of AA in 37% of patients who had their first patch by the age of 30, compared to 7% with their first patch after 30. Although not conclusive, these findings strongly suggested a heredity association of AA development.

Environmental factors such as stressful life events are another commonly cited cause and reason for reoccurring episodes of AA (Tucker, 2009; McGarvey, Baum, Pinkerton, & Rogers, 2001). Although stressful conditions may produce hair loss in anyone, research considers that those prone to AA may be affected to a greater extent. According to Matzer, Egger and Kopera (2011) and Gulic, Tanriverdi, Duru, Saray and Akcali (2004), approximately 75% of individuals experienced stressful situations prior to hair loss. However, in contrast, Tan, Tay, Goh and Giam (2002) reported stressful encounters in only 10% of sufferer's. Therefore, such inconsistencies have yielded the establishment of solid evidence.

### *1.2.3 Clinical Features*

In most cases, AA is usually asymptomatic, as the manifestations of the condition are not visible until an individual's hair physically falls out. The initiation of the condition is usually observed on the scalp, characterised by the sudden appearance of a singular (or several), circular or oval totally smooth bald patch (Khan, 2008, Madani & Shapiro, 2000; Shapiro, 2011), and/or 'exclamation point' hairs (broken or short hairs), generally located at the periphery of the patch



(Bertolino, 2000; Picardi, McMichael, Gallagher, Kalabokes, & Boeck, 2003). In addition, loss may spread to other hair bearing sites such as one's face, limbs and pubic regions (Wasserman, Guzman-Sanchez, Scott, & McMichael, 2007). Changes in one, multiple or all finger/toe nails may also occur, however rarely precedes or follows initial AA onset, rather occurring months or even years later (Sharma et al., 1996).

#### *1.2.4 Diagnosis*

A fundamental responsibility of dermatologists is to differentiate AA from other hair loss conditions such as Androgenic Alopecia (AGA). AGA is commonly referred to as male pattern baldness, although equally occurring in both sexes (Price, 2003). Characterised as progressive, diffuse and symmetric loss of scalp hair, AGA causes hairs to become shorter and thinner, which generally leads to partial or complete scalp baldness (Price, 2003). Given that each of the conditions courses, treatments and psychological impacts are independent of each other, it is vital that individuals are correctly diagnosed (Mounsey & Reed, 2009).

Dermatologists often begin their diagnosis with a physical examination of the affected area(s), investigating crucial factors such as, duration, location and patterns of hair loss (Shapiro Wiseman, & Lui, 2000). Diets, current and past medical conditions and family history must also be taken into consideration (Ito, 2012). Following, a 'pull test' may be conducted, where approximately 60 threads of hair are gently, but firmly pulled. A negative test (6 or fewer hairs removed) indicates normal shedding. Whereas, a positive test (more than 6 hairs removed) indicates a process of active hair shedding, frequently resulting in a diagnosis of AA (Hull et al., 2003; Shapiro, 2011; Tucker, 2009). In addition, scalp biopsies may be required if the diagnosis remains unclear (Shapiro et al., 2000; Thiedke, 2003).

### 1.2.5 *Types*

There are several clinical presentations of AA, subcategorised according to the pattern and severity of hair loss (Borg & Kennedy, 2012). The most common forms of AA, excluding AGA are, Alopecia Areata Monocularis (AA Monocularis), Alopecia Areata Multilocularis (AA Multilocularis), Alopecia Totalis (AT) and Alopecia Universalis (AU) (Gupta & Gupta, 1998; Khan, 2008; Matzer et al., 2011). AA Monocularis is identified by a singular, isolated bald patch on any part of the scalp (See Figure 1), whereas AA Multilocularis is characterised by multiple patches over the scalp (See Figure 2) (Semwal, Agrawal, Singh, Tandon, & Sharma, 2011). Research suggests that between 34% and 50% of individuals diagnosed with AA Monocularis or AA Multilocularis will recover within the first year. However, almost all will relapse experiencing one or more repeated episodes of hair loss across their life span (Tosti, Bellavista, & Lorizzo, 2006). Furthermore, patches may coalesce affecting the entire scalp and/or body (Firooz, Firoozabadi, Ghazisaidi, & Dowlati, 2005; Petukhova, Cabral, Mackay-Wiggan, Clynes, & Christiano, 2011).

Total scalp baldness is the second most extensive form of AA, known as AT (See Figure 3) (Tucker, 2009). The most severe is AU, which affects individual's entire body, including defining facial features such as one's eyebrows and eyelashes (See Figure 4) (Cho, Jo, Paik, Jeon, & Kwon, 2012; Shapiro et al., 2000). AT and AU are estimated to account for between 5% and 30% of all AA cases, and are less responsive to treatments (Hunt & McHale, 2005a; Ito, 2012).



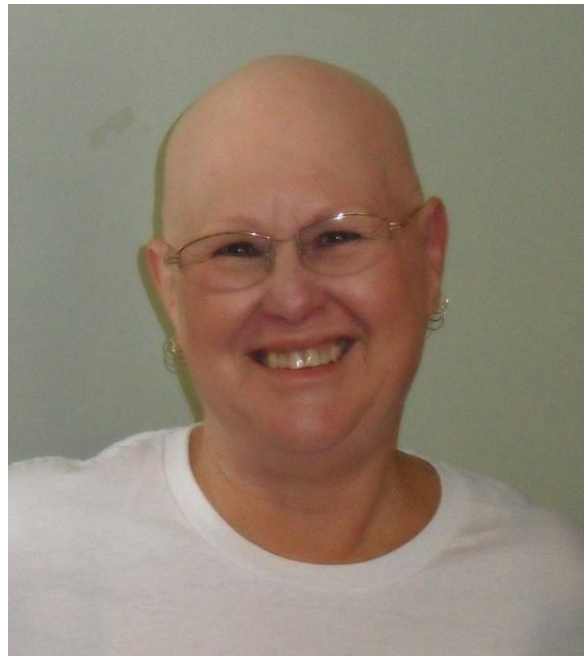
*Figure 1.* Alopecia Areata Monocularis; showing a single patch of hair loss on the scalp (Photo courtesy of the AAAF Inc.).



*Figure 2.* Alopecia Areata Multilocularis; showing multiple patches of hair loss on the scalp (Photo courtesy of the AAAF Inc.).



*Figure 3.* Alopecia Totalis (AT); showing complete loss of scalp hair (Photo courtesy of the AAAF Inc.).



*Figure 4.* Alopecia Universalis (AU); showing complete loss of hair from all parts of the body, including eyebrows and eyelashes (Photo courtesy of the AAAF Inc.).

Tan and colleagues (2002) suggested that elevated depression, anxiety and stress levels are more prone in individuals with severe types of AA, compared to milder types. Based on this notion, researchers categorised the 4 main types of AA into two groups; the limited AA group, represented by singular or multiple patches (i.e., AA Monocularis & AA Multilocularis) and the extensive AA group, represented by complete scalp or body hair loss (i.e., AT & AU). The findings supported Tan et al. (2002) predictions, as 82% of respondents with extensive AA exhibited significantly higher psychological distress throughout their lives, than those with limited AA. Therefore, researchers concluded that as the severity of AA increases, so does the likelihood of individuals developing psychological co-morbid disorders.

Supporting this premises, Fiedler (1992) and Hunt and McHale (2005a) found that extensive AA and its unpredictable course, profoundly impacted the lives of sufferers, as individuals expressed increased feelings of helplessness and lack of control. Therefore, researchers advocated that severe types of AA may not only evoke cosmetic concerns, but induce feelings of vulnerability, lowered self-esteem, alterations in self-perception and psychological anguish.

Furthermore, Al-Mutairi and Eldin (2011) and Sellami, Masmoudi, Mnif, Aloulou, Turki and Jaoua (2012) reported that patients with extensive AA displayed significantly evaluated stress levels and increased mental health concerns. The majority of patients with AT and AU, not only reported psychological suffering, but destructive disturbances in regards to their social lives, physical appearance and identity. In contrast, Matzer et al. (2011) and Cartwright, Endean and Porter (2009) revealed that neither the conditions severity nor status influenced the extent of participants' subjective burden relating to their personal insecurities (i.e., feeling unattractive) or development of depression and anxiety. Nevertheless, the consensus throughout the literature

have stated that due to limited types of AA having greater responsive rates to medical treatments, individuals with extensive AA are more inclined to report lowered self-esteem and develop affective disorders.

### *1.2.6 Duration*

The only predictable aspect regarding the progression of AA is that it is totally unpredictable. Despite minimal research investigating the relationship between the duration of living with the condition and individuals psychological wellbeing, studies have revealed consistent findings. Using the Minnesota Multiphasic Personality Inventory (MMPI-2), Alfani et al. (2012) reported that neither depression nor anxiety scores were significantly correlated with AA duration. However, participants did display elevated scores between the 6 and 11 months periods of having AA, opposed to shorter (i.e., < 6 months) or prolonged (i.e.,  $\geq$  12 months) durations. A possible explanation for these findings could be that by the time individuals reached this phase, they had begun to comprehend the potential negative implications associated with the condition, but had not yet acquired the necessary skills to cope. Moreover, Ghajarzadeh, Ghiasi and Kheirkhah (2011) and Williamson, Gonzalez and Finlay (2001) hypothesised that the duration and location of hair loss would significantly affect the preservation of individual's positive self-concept. However, contradictory to researcher's predictions, no relationship was found. Although similar findings have been reported, they should be interpreted with caution due to the limited adequate investigations on such associations.

### *1.2.7 Treatments*

Currently, there is no cure or effective preventative treatments for AA, with treatments typically producing a 1% recovery rate, which is no better than chance (Hull et al., 2003; Otberg, 2011). Therefore, some researchers have suggested that treatments may only delay a person from focussing on the unenviable task of accepting the loss of their hair, given that AA can persist for many years or even across one's entire lifespan (Alkhalifah, 2011; Hordinsky & Avancini-Caramori, 2008; Shapiro et al., 2000).

Following a clinical diagnosis of AA, individuals may elect to be observed over several months or commence treatment immediately. There is no 'one best' treatment for AA, as strong evidence suggests that drug induced remissions or therapies continue to produce inconclusive results. Therefore, all treatment plans primarily depend on two major factors, the extent of scalp/body involvement, and the age of patients (Prickitt et al., 2004). Nevertheless, for small patches, topical corticosteroids (cream or injections) are usually administered over the bald area/s, which may be continued if regrowth occurs (Ito, 2012; Madani & Shapiro, 2000). However, repeated procedures for prolonged periods of time may induce potential side-effects such as, atrophy, infections and thin or red skin lesions (Hunt & McHale, 2007). Another commonly sought treatment option is Photochemotherapy (PUVA) using ultraviolet lights (Healy & Rodgers, 1993; Sahin, Yalcin, & Karaduman, 1998). Although results are not yet convincing, as clinical trials have reported high relapse rates and fears of induced skin cancer from long-term exposure (Madani & Shapiro, 2000).

Moreover, from a practical standpoint, hair coverage that is deemed by the patient to be cosmetically acceptable seems to be a reasonable end point for treatment. However, given that no current treatment modalities have stood the test of wide spread usage, several new hopes and

research enthusiasms have been inspired (Wasserman et al., 2007). More recently, researchers have experimented with the use of non pharmacological approaches to stimulate regrowth. A longitudinal study by Willemsen, Vanderlinden, Deconinck and Roseeuw (2006) investigated the efficacy of hypnotherapy in the management and recovery of AA. To researcher's surprise, regrowth was observed in 3 patients with AU shortly after commencing hypnotherapeutic sessions. Despite observing continued hair loss in all follow-up periods, for 1 patient relapse did not occur until 4 years after initial hypnotherapy sessions. Furthermore, sessions improved individual's psychological wellbeing, as numerous patients reported significantly reduced depression and anxiety levels.

Given that the full recovery from severe forms of AA is unusual, these results were deemed controversial. However, future research is vital as results did indicate something useful. That is, that AA produces hair loss, hair loss induces loads of stress, and stress induces loads of hair loss. However, hypnosis (and other techniques) can reduce stress and hence slow or reverse the loss of hair that is probably caused by the stress itself. Therefore, what remains to be tested, is whether stress reduction has any effect on hair loss associated with AA.

Various treatments may stimulate regrowth; however, many do not alter the conditions course, as upon termination it is not uncommon for hair loss to persist and/or return (Mounsey & Reed, 2009). Therefore, it is imperative that physicians address the psychological impacts AA can impose, thus impeding individual's coping capacities (Alkhalifah, 2011). In addition, this process of coping is made doubly more difficult by society being enamoured with appearance. Hence, the learned associations between beauty (hair), general popularity and wellbeing increase individual's chances of developing poor self-esteem (Kalabokes & Besta, 2001; Sharma et al., 1996).



### 1.3 *Self-Esteem: Am I Worthy of my Hair?*

A significant body of research coincides that, both positive and negative life experiences shape individuals attitudes and perceptions of themselves and the world around them (Robinson, Shaver, & Wrightsman, 1991; Smith & Mackie, 2007). Therefore, a condition like AA has the potential to lower individual's self-esteem, consequently leading to negative behaviours including, social withdrawal, hostility and excessive preoccupation with personal problems (Murk, 2006). Self-esteem is defined as a person's own emotional evaluation of their worth or worthiness, whilst encompassing judgements, attitudes, beliefs and emotions about one's self (Murk, 2006; Robinson et al., 1991; Smith & Mackie, 2007). The importance of self-esteem was first explored by Abraham Maslow (1907-1970), incorporating it within his hierarchy of needs. Maslow (1954) argued that psychological health is impossible, unless the essential core of a person is fundamentally accepted, loved and respected by others, but most importantly by his or her own self.

Although hair loss can be traumatic for either gender, the literature suggests it is substantially more distressing for women (Hunt & McHale 2007). Researchers believed that the socially acceptable attitudes people obtain regarding female baldness, are opposite to those of male baldness, which is now considered 'trendy' (Welsh & Guy, 2009). For women, their hair characterises, femininity, sexuality and personality, whilst providing security and protection (Freedman, 1994; McDonagh & Tazi-Ahnini, 2002; Wasserman et al., 2007). Therefore, females commonly associate hair loss with the abnormality and failure to conform to the norms within society (Welsh & Guy, 2009). Similarly, Liakopoulou et al. (1997) discussed women's sensitivity to unexpected appearance changes and societies expectations, consequently leading to feelings of intense emotional suffering. A respondent in Hunt and McHale's (2005b) study stated

that “*it (AA) has ruined my life to a certain degree, as when a woman loses her hair, which is her crowning glory, it is devastating and one feels like dying*” (pg. 42). Furthermore, many sufferers have expressed the struggles surrounding social interactions, due to the fear being mocked, bullied or centre of attention for the wrong reasons.

Williamson and researchers (2001) recruited 70 AA patients who completed the Dermatology Life Quality Index (DLQI). Based on a thorough analysis, lowered self-esteem was reported in approximately 23% of patients. Findings also revealed that 30% expressed reduced self-confidence as a major consequence associated with having AA. Researchers further concluded that the uncontrollable loss of hair adversely affected individual’s psychological wellbeing, evoking feelings of vulnerability and the loss of one’s identity. Thus participants regularly resorted to disguising their condition with headwear items (i.e., wigs).

Similar concerns emerged amongst AA sufferers over an 18 month period in a US web-based support group (Fox, 2003). Almost 26% of discussions expressed feelings of fear associated with the unpredictability of the condition, looking different, lowered self-esteem and reduced self-confidence. A further 29% of discussions were related to the emotional struggles associated with AA including issues of, trust, isolation, despair, uncertainty and anger, as well as addressing issues surrounding individuals desires to search for a ‘new self’.

The results of Williamson et al. (2001) and Fox (2003) were further supported by Firooz and colleagues (2005). Aiming to assess cause, consequences and cure/control, researchers investigated the illness perception of 80 individuals with AA, aged between 13 and 56 years old. Results showed that more than half of the sample believed AA was accompanied by major life consequences such as, lowered self-esteem. These findings further confirmed the relationship between psychological issues and hair loss.

Contradictory to the majority of studies, Alfani and colleagues (2012) used the MMPI-2 to examine the psychological status and personality traits of 73 AA patients and 73 age and sex matched controls. Although depression, anxiety and social conflict scores were significantly higher in AA patients, there were no reported differences between groups and self-esteem. Despite these inconsistent results, researchers were able to define a profile of the domains in which patients with AA seem to experience elevated distress. In addition, the findings helped identify appropriate means of coping, thus providing a comprehensive insight into the complex situations of individuals experiencing hair loss.

Overall it is apparent, that a visible condition like AA can influence the way individuals view themselves and others. In spite of this, the psychological and emotional consequences that accompany the condition still remain under researched, as they are often secondary to investigating medical cures. However, given that the majority of treatments thus far have proven to be largely inconclusive, the exploration into the implications hair loss can have on individual's psychological wellbeing should be a main focus of research. Nevertheless, numerous studies have acknowledged that it is not uncommon for individuals with AA to develop co-morbid affective disorders such as, depression and/or anxiety, as well as experiencing elevated stress levels (Hunt & McHale, 2007; Kökçam, Akyar, Saral, & Oguzhanoglu, 1999; Koo, Shellow, Hallman, & Edwards, 1994).

#### *1.4 The Association between Alopecia Areata, Affective Disorders and Stress*

Affective disorders are commonly referred to as negative psychological states that may develop in reaction to an experience or event, and surface from no apparent external cause

(Tucker, 2009). Research suggests that the two most common mood disorders associated with AA are depression and anxiety (Koo et al., 1994; Manolache & Benea, 2007).

Depression is universally defined as feelings of sadness, hopelessness, worthlessness and guilt, which has a high co-morbidity rate with Generalised Anxiety Disorder (GAD) (Hunt & McHale, 2007; Kessler et al., 1994). Anxiety is described as a negative emotional state, characterised by high physiological arousal, sleep disturbances, feelings of tension and inner turmoil (American Psychiatric Association, 2013). Individuals with depressive symptoms and GAD may additionally develop social or specific phobias, experience panic attacks and elevated stress levels (Hunt and McHale, 2007). According to Hunt and McHale (2005a) AA has few harmful physical effects; however, the psychological repercussions can be quite severe. Colón and colleagues (1991) found that individuals with AA displayed a higher lifetime prevalence rate of major depressive episodes (MDE) (39%) and GAD (39%), with 74% of sufferers having experienced one or more lifetime psychiatric disorders.

Suplimentary research by Koo and colleagues (1994) expanded on Colón et al. (1991) findings, investigating the development of psychiatric co-morbidity in individuals with AA. Researchers examined 294 community based sufferers medical, social, environmental and psychological states. Depression, anxiety, social phobias and paranoia were all significantly higher in AA patients compared to the general population. MDE was reported by almost 9% of AA patients, compared to a prevalence rate of between 1% and 4% within the general population. In addition, GAD was eight times more common in those with AA.

Furthering this notion, Kökçam and colleagues (1999) revealed elevated depression levels in 36% of individuals with AA, as well as significantly higher interpersonal difficulties, anxiety, phobic reactions and stress levels. Williamson et al (2001) additionally found that 74%

of AA patients reported clinical depression, which was negatively associated with life quality, reflecting poor self-worth and self-confidence. Similarly, Hunt and McHale (2007) and Sellami and researchers (2012) identified statistically significant differences between sufferers and controls, as individual with AA exhibited a greater prevalence of depression, anxiety and stress.

Although much of the research examining the prevalence of psychological co-morbidity in individuals experiencing hair loss is compelling, findings remain controversial. Gupta and Gupta (1998) examined the frequency of depression among 480 individuals with a range of dermatological conditions (i.e., psoriasis & acne). From the total sample, 45 were diagnosed with AA, revealing no differences between depression scores and groups. Using the Beck Depression Inventory (BDI) and Beck Anxiety Inventory (BDA), Gulic et al. (2004) and Cordan-Yazici et al. (2006) further supported these findings identifying no differences in depression and anxiety levels between AA participants and controls.

Despite these conflicting results, overall the prevailing position of research elucidates the profound impact AA can have on individual's psychological wellbeing (Hunt & McHale, 2005a; Tan et al., 2002). In addition, due to the conditions unpredictable nature, there is emerging evidence that particular challenges commonly arise surrounding the complexities involved in coping, given that there is no existing cure (Welsh & Guy, 2009).

### *1.5 Coping with Alopecia Areata*

Based on a review of the literature, it is apparent that research regarding coping with AA is lacking. Therefore, investigations are essential to increase the prosperity of identifying effective strategies that may assist individuals in dealing with the intrusive feelings, thoughts and distressing concerns commonly affiliated with the condition.

Worldwide women take pleasure in flaunting their beauty, confidence and femininity through their hair (Draelos, 2011). Therefore, a diagnosis of AA takes the phase ‘bad hair day’ to a whole new meaning. One of the most interesting clinical entries concerning AA was an exploratory study by Freedman (1994), where women expressed that the loss of their hair was psychologically more demanding, compared to the loss of a breast. Researchers advocated that these feelings may have emerged as hair loss is outwardly visible to others, ultimately affecting individual’s abilities to cope.

By definition coping refers to expending conscious efforts to solve personal and/or interpersonal problems, whilst seeking mastery to minimize or tolerate stress and conflict (Folkman, Lazarus, & Dunkel-Schetter, 1986). All individuals encounter challenging obstacles throughout their lives and employ independent ways of coping (Borsellino & Young, 2010). In spite of there being no precise way to manage hair loss, Taylor (1983) proposed that effectively coping involves positive strategies incorporating, the search for meaning, coupled with the exploration of control, followed by a process of rebuilding one’s self-esteem and managing unwarranted thoughts through self-enhancement.

### *1.5.1 Positive Coping Styles*

Most researchers acknowledge that individuals diagnosed with AA implement both positive and negative coping styles (Garcia, 2010; Papadopoulos & Bor, 1999). However, Harries, Sun, Paus and King (2010) found that individuals who employed constructive strategies are more inclined to manage the condition through gaining a sense of control.

According to McKillop (2010), individuals diagnosed with AA should concentrate their efforts on establishing acceptance for the condition, through maintaining a strong wellbeing and

healthy relationships. Hunt and McHale (2005b) and Thomson and Shapiro (1996) supported this notion, further advocating that successful coping largely amounted to approval of their diagnosis, new appearance and openness to amalgamate existing and necessary lifestyle modifications.

An additional optimistic approach, related to individuals candidly in establishing solid supportive networks, as they have a considerable healing power, through facilitating a sense of normalization, understanding and acceptance (Cartwright et al., 2009; Kalabokes, 2011). Hull and colleagues (2003) and McKillop (2010) examined AA sufferers coping capacity when contact was made with others in a similar situation. Researchers acknowledged that although individuals embark on their own journey of experiences, for many, simply belonging to a fellowship provided them with the non judgmental, accommodating and compassionate environment they required. Furthermore, reassurance was commonly developed through embracing the sharing of experiences and gaining advice from those who have struggled. Similarly, Kalabokes (2011) and Rumsey and Harcourt (2004) stated that support groups allowed people to grow and become stronger. However, interestingly, Prickitt and colleagues (2004) revealed that sufferers who did not attend support groups, often sought special consideration and exaggerated sympathy from others.

In addition to establishing supportive networks, women frequently invested in headwear accessories such as, wigs, hats, bandanas and/or scarves (Harries et al., 2010). McKillop (2010) suggested that headwear increased females comfort levels and self-control, whilst reducing anxiety. When asked “What, if anything, helped you to manage your anxiety regarding hair loss?” 83% of respondents indicated shopping for headwear items (Borsellino & Young, 2010), as it masked the conditions from the others, reducing the awkward stares and stigma of sickness. Williams, Wood and Cunningham-Warburton (1999) additionally revealed that headwear items

were associated with identity restoration, as some individuals created a bond with their wig that persisted even if regrowth occurred.

Alternatively, a number of sufferers have expressed regret towards purchasing wigs, as they were expensive or useless, as a result of inducing feelings of embarrassment (Borsellino & Young, 2010). Hunt and McHale (2005b) similarly uncovered that the maintenance of this ‘new’ appearance was mentally exhausting and physically draining for individuals.

Although it takes time for individuals to find their own styles, pragmatic coping approaches facilitate the restoration of self-confidence (Draelos, 2011; Kalabokes, 2011). Numerous researchers believe that positive strategies desensitize the impact of hair loss, assist in maintaining a stable psychological wellbeing, whilst decreasing the likelihood developing allied psychological disorders (Borsellino & Young, 2010; Cartwright et al., 2009; McGarvey et al., 2001).

### *1.5.2 Negative Coping Styles*

Coping strategies vary, and while some approaches may be more effective, others are considered less beneficial, often leading to future repercussions (Fox, 2003; McKillop, 2010; Papadopoulos and Bor, 1999). Garcia (2010) and Reid et al. (2010) believe that some individuals with AA often utilise maladaptive thoughts and behaviours (i.e., substance abuse, disengagement, self-blame, suicide and/or participation in high risk sexual activities) with the intention of suppressing the negative impacts associated with hair loss. However, Folkman and colleagues (1986) argued that such methods elevated individual’s tendencies of implementing negative coping strategies such as, denial and isolation.

Denial is often a survival reaction to loss, and thought process frequently employed to



ignore a problem/s, hoping it will disappear or solve itself (Cartwright et al., 2009). For individuals with AA, denial is often an initial strategy used to numb the experiences and to protect one's self from intensive shock of losing their hair (Fox, 2003; Garcia, 2010; McKillop, 2010). However, Reid and colleagues (2010) claimed that individuals who retain such a pessimistic state frequently develop isolative coping behaviours.

Isolation is the process of separating somebody (or something) from others with the intention of merely wanting to be alone (McKillop, 2010). For individuals with AA, isolation is generally achieved by means of removing one's self from their secure family networks and/or society, by immersing themselves in work, school or other activities (i.e., video games, reading) (Reid et al., 2010). McKillop (2010) claimed that withdrawing one's self from their usual environment is often accompanied with immense psychological and psychosocial consequences. Conducting a comparison study between 21 outpatients experiencing recent AA onset and 102 outpatients affected by other skin conditions, researchers identified that patients with AA exhibited more isolative behaviours towards relationships (i.e., husband/wife or partner) and society.

An important milestone associated with managing hair loss is recognising that the mourning of individuals 'normal' appearance may be necessary; however, only for a short-term basis (Papadopoulos & Bor, 1999). Grieving the loss of one's hair for long-term periods may hinder an individual's ability to implement effective coping strategies (McKillop, 2010). Therefore, Kalabokes and Besta (2001) emphasised the importance of understanding, discussing and exploring individual's concerns and affiliated psychological issues upon initial diagnosis.

## 1.6 *Rationale*

Australian research investigating AA is still in its infancy, and although worldwide studies have attempted to recognise the profound psychological and psychosocial concerns associated with hair loss, findings remain contentious. Nevertheless, the traumatic impact AA can have on both sexes has been acknowledged, however researchers have concluded that women become substantially more distressed compared to men. Therefore, given that numerous gender comparison studies have already been conducted, the current study will exclusively recruit a female sample. It is envisioned that such methods will provide novel insights into understanding the impact AA has on women's self-esteem, mood and coping strategies simultaneously.

Thus far, previous research has examined AA and individual's self-esteem levels using chemotherapy-induced AA samples. However, the generalisations of these findings were deemed controversial, based on the sampling criteria. Therefore, the present study will add to the breadth of research through investigating the self-esteem scores of women with AA who have no additional existing and/or prior medical or psychiatric conditions. In addition, the findings will aim to contribute to the body of knowledge and elucidate misconceptions regarding AA and the development of co-morbid disorders such as, depression, anxiety and elevated stress levels.

The loss of one's hair is a sensitive topic that commonly creates feelings of increased vulnerability and uncertainty. Therefore, incorporating a mixed methods design, it is anticipated that the current study will exemplify the importance of specific coping research relating to individuals diagnosed with AA through semi-structured interviews. Previously, researchers have inadequately acknowledged the subjective significance of coping and failed to illuminate individual's experiences and interpretations. Rather, pursuing a traditional objective-positivist

stance, through measuring predefined variables that inhibit the exploration and obscure in-depth understandings.

It is envisioned that the data gathered will lead to subsequent research focusing on the development of effective intervention programs, in addition to educating sufferers and increasing community awareness. Findings will further assist organisations such as the AAAF Inc. in understanding the relationship between AA, psychological wellbeing and coping. The current study has the potential to identify specific coping strategies and promote supportive relationships between sufferers and their families, friends and medical practitioners, through giving a voice to those whose views are rarely heard.

### *1.7 Aims*

The aims of the present study were six-fold.

The first aim was to investigate whether there was a significant difference between self-esteem, depression, anxiety and stress scores in participants with limited AA and extensive AA.

The second aim was to investigate whether there was a relationship between participant's duration of living with AA and self-esteem, depression, anxiety and stress.

Using the Rosenberg's Self-Esteem Scale (1965), the third aim was to compare the self-esteem scores of a sample of adult Australian women diagnosed with AA, to a control group of adult Australian women.

The fourth aim was to compare the scores of adult Australian women diagnosed with AA on the Depression, Anxiety and Stress Scale (DASS42), to a control group of adult Australian women.

The fifth aim was to examine whether there is a relationship between self-esteem,

depression, anxiety and stress in adult Australian women diagnosed with AA.

The final aim was to explore the coping strategies of a smaller sub-sample of adult Australian women diagnosed with AA, through identifying themes within semi-structured interview responses.

### *1.8 Hypotheses*

The present study sought to test the following hypotheses.

It was hypothesised that there would be a significant difference between self-esteem, depression, anxiety and stress scores in participants with limited and extensive AA.

It was predicted that there would be no relationships between the duration of living with AA and self-esteem, depression, anxiety and stress.

With reference to the impact AA may have on adult Australian women's self-esteem, it was predicted that scores on the RSES would be significantly lower when compared to controls.

It was hypothesised that adult Australian women with AA would exhibit significantly elevated depression, anxiety and stress scores on the DASS42, compared to controls.

It was further predicted that there would be a significant positive relationship between AA participants and controls and self-esteem, and a significant negative relationship between AA participants and controls and depression, anxiety and stress.

It was hypothesised that there would be a significant negative relationship between the RSES measuring self-worth of individuals with AA, and the domains of the DASS42, measuring mood and stress, and a significant positive relationship between depression, anxiety and stress.

Finally, through the exploration women's lived experiences of having AA, it is assumed that specific coping strategies will emerge regarding the management of the condition.

## CHAPTER 2: METHOD

### 2.1 *Participants*

#### 2.1.1 *Alopecia Areata Group*

A total of 66 participants were recruited via the AAAF Inc. There were 3 participants excluded, as they were unsuccessful in responding to questionnaires to their entirety, or had a previous/existing psychological illness, leaving a smaller sample of 63 participants. The inclusion criteria for participation was, female, aged 18 years or above ( $M = 41.87$  years;  $SD = 12.92$ ;  $Range = 21$  to  $71$  years), with a clinical diagnosis of AA. All participants had one or more of the following types of AA including, 9% with AA Monocularis, 24% with AA Multilocularis, 18% with AT and 30% with AU. The remaining 19% of participants reported having multiple forms of AA.

#### 2.1.2 *Control Group*

A control group was recruited as researchers aimed to compare the AA sample to an adult Australian women community sample. A total of 63 female participants, aged 18 years or above ( $M = 40.29$  years;  $SD = 12.20$ ;  $Range = 20$  to  $70$  years), were randomly selected from the Western suburbs of Melbourne, Victoria, Australia. Controls were excluded if they had existing or past psychological, medical or physical illnesses. All AA participants and controls were matched according to age, reporting no significant differences between groups ( $p = 0.48$ ) (See Table 3).

### 2.1.3 Interviewees

A purposive volunteer sample of 4 women with AA (minimum duration of 6 months) participated in semi-structured interviews. This allowed researchers to explore the coping strategies women have utilised to manage the condition overtime. Each of the women were diagnosed with the following AA subtypes, AA Monocularis, AA Multilocularis, AT or AU. Women were aged between 26 and 46 years old, with AA durations between 2 and 40 years (Summarised below in Table 1).

Table 1

*Summary of Interview Participant's Demographic Characteristics Including, Type of Alopecia Areata, Age, Age of Onset and Duration of Living with the Condition*

Pseudonyms	Age*	Types of AA	Age of Onset*	Duration*
V	45	AA Multilocularis	16	29
S	26	AT / AU	7	19
D	42	AU	2	40
M	46	AA Monocularis	44	2

\*In Years

## 2.2 Apparatus

### 2.2.1 Information to Participants Form

Information to Participants Forms (See Appendix A) invited potential participants to partake in the current study. In addition to outlining research aims, the form provided detailed descriptions regarding eligibility criteria and participation instructions. Supplementary information addressed the potential benefits and risks associated with participation. Researchers contact details were also supplied for those wanting to express interest, seek further information or for those who encounter any issues throughout the research process.

### 2.2.2 *Consent Form*

A standard Victoria University Consent Form (See Appendix B) was used to obtain informed consent from participants involved in the study. All participants were required to print and sign their name, and record their suburb/town and date accordingly. Consent forms additionally contained the contact details of a registered psychologist who agreed to provide support to any participants that may become distressed as a result of their involvement.

### 2.2.3 *Demographics Questionnaires*

A demographics questionnaire was developed for AA participants to capture an array of information. Data gathered related to participant's age, gender, relationship status, occupation, relevant medical history (for exclusion purposes), duration and type of AA and Social Activity Level (SAL) (See Appendix C). In addition, controls completed an altered version, collecting data regarding age, gender and relevant medical history (for exclusion purposes) (See Appendix D).

### 2.2.4 *Rosenberg's Self-Esteem Scale (RSES)*

The RSES is the most widely used instrument measuring global self-esteem (Blascovich & Tomaka, 1993) (See Appendix E). The RSES consists of 10 items, scored on a four-point likert scale, where 1 indicates "Strongly Agree", 2 indicates "Agree", 3 indicates "Disagree" and 4 indicates "Strongly Disagree". The 10 items reflect individual's overall emotional evaluation of their own worth, by measuring positive and negative feelings reflecting one's self. Five items were positively worded statements (i.e., On a whole I am satisfied with myself) and five items

were negatively worded (i.e., I wish I could have more respect for myself). Items required reversing to aid dealing with position-response biases.

The RSES is generally self-administrated, taking approximately 5 minutes to complete. A summed score incorporating all item responses were totalled. Positively worded items 1, 3, 4, 7 and 10 were awarded 3 points for “Strongly Agree” responses, 2 points for “Agree”, 1 point for “Disagree” and 0 points for “Strongly Disagree”. Reversed items 2, 5, 6, 8 and 9 were awarded 0 points for “Strongly Agree”, 1 point for “Agree”, 2 points for “Disagree” and 3 points for “Strongly Disagree”. Scores on the RSES range between 0 and 30, with scores between 15 and 25 indicting normal self-esteem. Whereas, scores below 15 suggest low self-esteem and scores above 25 indicate high self-esteem.

The original sample used in development of the RSES consisted of 5,024 high-school juniors and seniors from 10 randomly selected schools within New York City. The scale is a reliable and valid quantitative tool for the assessment of males, females, adolescents, adults and elderly populations, across a large number of different samples (i.e., substance abusers, clinical groups and research). According to Blascovich and Tomaka (1993) the RSES test-retest reliability typically falls within the ranges of 0.82 to 0.88, and Cronbach's alpha for internal consistency commonly ranges between 0.77 and 0.88 (Rosenberg, 1965). Reliability was assessed for the current sample and based on Cronbach's Alpha the measures of the questionnaire fell within the literatures consistently reported ranges, exhibiting high reliability ( $\alpha = 0.87$ ).

#### 2.2.5 *Depression, Anxiety and Stress Scale (DASS42)*

Designed to screen and measure the negative psychological states of depression, anxiety



and stress, Lovibond and Lovibond (1995) developed the DASS42 (See Appendix F). The DASS42 is a self-report inventory scale, comprised of three subscales, consisting of 42 items (a shorter version is also available DASS21). Each of the three subscales contains 14 items, which are further divided into subscales of 2 to 5 items based on similar content, with no items referring to suicidal tendencies.

The depression scale assesses dysphoria, hopelessness, devaluation of life, self-deprecation, lack of interest/involvement, anhedonia and inertia (i.e., I couldn't seem to experience any positive feelings at all). The anxiety scale assesses autonomic arousal, skeletal muscle effects, situational anxiety and subjective experiences of anxious affect (i.e., I was worried about situations in which I might panic and make a fool of myself). Sensitive to levels of chronic non-specific arousal, the stress scale assesses difficulty relaxing, nervous arousal, being easily upset/agitated, irritable/over reactive and impatient (i.e., I find it difficult to relax).

Items on the DASS42 reflect the current emotional state of individuals, as respondents are required to rate the extent to which they have experienced symptoms of depression, anxiety and stress over the past week. Scores are recorded using a 4-point likert scale of severity/frequency, where each of the items are scored as, 0 (did not apply to me at all), 1 (applied to me to some degree, or some of the time), 2 (applied to me to a considerable degree, or a good part of the time) or 3 (applied to me very much or most of the time).

Taking approximately 10 minutes to complete, the DASS42 may be administered individually (research purposes) or in group/clinical settings. Its development was based on a non-clinical sample, therefore it is a suitable tool for screening normal adolescents and adults. However, it is important to note that although the DASS42 may be administered and scored by

non-psychologists, decisions regarding particular scoring profiles should only be made by experienced clinicians, who have carried out the appropriate clinical examinations.

The DASS42 is scored by totalling responses on the applicable 14 items in each of the three subscales. The depression subscale consists of items 3, 5, 10, 13, 16, 17, 21, 24, 26, 31, 34, 37, 38 and 42. The anxiety subscale includes items 2, 4, 7, 9, 15, 19, 20, 23, 25, 28, 30, 36, 40 and 41. The stress subscale comprises of items 1, 6, 8, 11, 12, 14, 18, 22, 27, 29, 32, 33, 35 and 39. The totalled scores across each of the three subscales were evaluated as per Lovibond and Lovibond (1995) developed severity rating index (See below Table 2).

Table 2

*Severity Ratings Index of Depression, Anxiety and Stress (DASS42)*

	Depression	Anxiety	Stress
Normal	0-9	0-7	0-14
Mild	10-13	8-9	15-18
Moderate	14-20	10-14	19-25
Severe	21-27	15-19	26-33
Extremely Severe	28+	20+	34+

Lovibond and Lovibond (1995) psychometric analyses of reliability using a large non-clinical sample indicated acceptable Cronbach's Alpha values for depression, anxiety and stress (0.91, 0.84 & 0.90, respectively). From a clinical sample of 437, the results of Brown and researchers (1997) further supported its internal consistency (0.96, 0.89 & 0.93, respectively). In both reliability assessments, the depression and stress scales met the standard threshold requirement of 0.9 for research; however, the anxiety scale still met the 0.7 threshold for clinical applications. Reliability was conducted for the DASS42 on the current sample with Cronbach's Alpha meeting acceptable values for depression ( $\alpha = 0.95$ ), anxiety ( $\alpha = 0.91$ ) and stress ( $\alpha = 0.93$ ).

### 2.2.6 *Qualitative Design and Materials*

The current studies epistemological underpinning was constructionism. According to Crotty (1998), constructionists claim “that meaning comes into existence in and out of our engagements with the realities in our world” (p.8), that is, both the researcher and subject emerge as partners in the generation of meaning. Constructionism allowed the researchers to gain an in-depth, ideographic understanding of participant’s beliefs, perceptions and/or accounts regarding their coping strategies, through a means of interpretation. Following, the theoretical framework embedded in the current study was Interpretive Phenomenological Analysis (IPA), to elicit individual’s reflections regarding living with AA. Furthermore, to explore emerging themes surrounding participants coping strategies, thematic analysis enabled the development of analytical categories derived directly from the data, rather than preconceived concepts or hypotheses (Willig, 2008). The current study incorporated thematic analysis through a means of semi-structured interviews.

### 2.2.7 *Interview Questions*

Interview schedules were informed by relevant literature and questions were refined through discussions and feedback with colleagues. Open-ended questions (See Appendix G) further allowed researchers to enter the participant’s worlds, whilst creating rapport and a flexible atmosphere for the exploration of theoretical avenues, with researchers taking care to check and clarify the meanings of any unclear experiences (Smith, 1995).

### 2.3 *Procedure*

Ethics approval was obtained from the Victoria University Human Research Ethics Committee (approved on the 8<sup>th</sup> of April, 2013; Application ID: HRE13-061; See Appendix H), and the AAAF Inc. (Approved on the 27<sup>th</sup> of March, 2013; See Appendix I). Following, the sourcing, recruiting and gathering of data commenced, which extended to the 17<sup>th</sup> of September, 2013. Through various conversations and arranged meetings with the AAAF Inc. president, permission was granted to post research advertisements on their official website ([www.aaaf.org.au](http://www.aaaf.org.au)), social networking groups (i.e., facebook) and to approach members affiliated with the foundation. Potential participants were provided with an Information to Participants Form.

Individual's seeking participation contacted researchers via email or phone for a thorough briefing of the research. Participants were informed that their participation was entirely confidential and voluntary, and that withdrawal from the study could occur at their preference. Following, researchers posted or electronically sent out ethical consent forms.

To enhance recruitment, researchers were introduced to potential participants at various AAAF Inc. charity events (i.e., trivia nights & wig sales). Likewise, those who expressed interest were given a verbal briefing and forms to take home. In both recruiting situations, if participants volunteered to be a part of the study, details for the return of consent forms was available on the information provided. Upon receipt of the signed consent forms, each of the participants was sent a questionnaire package, with an enclosed reply-prepaid envelope or had the option of requesting electronic copies. The questionnaire packs included a copy of the demographics questionnaire, RSES and DASS42. Participants were invited to ask questions and raise any concerns, in addition to remaining in contact with researchers throughout the course of the study.

Similar recruitment procedures were as above for interviewees. Once interest was expressed and consent forms returned, both the researcher and participants arranged a time and place of mutual convenience for the interviews to commence (approximately 1 hour duration). Interviews were audio-taped only if participant's approval was granted, which allowed researchers to perform a comprehensive analysis, drawing on reoccurring themes from combined interviews. Following the interviews, participants were debriefed and informed of their right to withdraw their data. Due to the sensitive nature of the topic, researchers had the AAAF Inc. contact details available for support.

## CHAPTER 3: RESULTS

### 3.1 *Analysis*

#### 3.1.1 *Power Analysis*

The aim of the current phase of data collection was to obtain data from age-matched healthy controls, to provide a stronger metric of comparison to AA participants.

A power analysis using Cohen's (1988) power tables was conducted to calculate the minimum sample size necessary to achieve a given level of power for the current studies statistical procedures. Based on Cohen's (1988) guidelines and the recommended level of 80% power (to ensure reliably at 0.5 using with  $\alpha = .01$ ), a minimum of 41 participants per group was estimated. However, to account for possible attrition of data, researcher aimed to recruit a minimum of 60 participants per group.

#### 3.1.2 *Quantitative Statistical Analysis*

Raw data obtained from the questionnaires were number coded to ensure participants confidentiality. Following, completed questionnaires were scored according to the relevant coding procedures outlined in the methods chapter. All outcome measures were then entered into the Statistical Package for the Social Sciences (SPSS-Version 21) for subsequent analyses.

Prior to conducting the main analyses, descriptive statistics were computed for all variables to check for accuracy, and to ensure that all the data was within the specified ranges. Cases with missing values were retained whenever possible and identifiable using a codified value. The data collected was unsuitable for factor analysis due to the small sample size; however, reliability was met for all assessment tools (Refer to methods chapter).

The normality of the data was examined through the inspection of histograms, probability plots, and skewness/kurtosis statistics. Due to the assumption of skewness and kurtosis not being met (exceeding 3 to -3) for some variables, the analyses were performed using both parametric and non-parametric testings.

Using a number of demographic variables, the totals, percentages and frequencies were recorded to characterise the participants in the AA and control groups. Following, several Multivariate Analysis of Variance (MANOVA) were performed to examine any differences across the dependent variables, self-esteem, depression, anxiety and stress and SAL and type of AA (limited AA & extensive AA). Additional MANOVA's were conducted to examine whether there was significant differences between the AA and control groups and self-esteem, depression, anxiety and stress scores. Preliminary assumption testings were conducted to check for normality, linearity, univariate and multivariate outliers, homogeneity of variance-covariance matrices and multicollinearity, with no serious violations noted.

To examine the strength of associations between the duration of living with AA and self-esteem, depression, anxiety and stress, Spearman's correlations were conducted. For parametric variables, Pearson's correlations were performed to examine the relationship between each of the variables. Point biserial correlations were also carried out to investigate the relationship between the dichotomous variable of participants belonging to the AA or control groups and self-esteem, depression, anxiety and stress. All correlations used an alpha of 0.05, and were both one-tailed and two-tailed, as significant directions (according to the hypotheses) were predicted. Preliminary analyses were performed to ensure no violations of outliers, normality, linearity and homoscedasticity.

### 3.1.3 *Qualitative Analysis*

Each interview was transcribed verbatim and was analysed by using the guidelines of Willig (2008). Immersing themselves in the data, researchers examined the interviews independently, noting significant comments, followed by critically reflecting, re-reading, and verifying the emergent thematic phrases. The repeated crosschecking between transcripts ensured that themes were derived directly from the text. Finally, the lists of themes from all interviews were reviewed, thus establishing superordinate themes and sub-themes. All participants were allocated pseudonyms and any personally identifying information was excluded from illustrative quotes.



### 3.2 Quantitative Findings

#### 3.2.1 Demographics

The current sample consisted of 63 adult women diagnosed with AA and a control group of 63 adult women matched appropriately on age. The means and standard deviations of age for both groups are shown in Table 3.

Table 3

*Means, Standard Deviations, Ranges and p-values of an Independent Samples T-test for Age between the Alopecia Areata and Control Groups*

Variable	AA Group <i>n</i> = 63	Control Group <i>n</i> = 63	<i>p</i>
Age			
<i>M</i> ( <i>SD</i> )	41.87 (12.92)	40.29 (12.20)	0.48
<i>Range</i>	21 to 71	20 to 70	

The mean age of the AA participants was 41.87 years (*SD* = 12.92; *Range* = 21 to 71 years) and the mean age of the controls was 40.29 years (*SD* = 12.20; *Range* = 20 to 70 years), all participants were female. An independent samples *t*-test revealed that the small difference in age was not significant ( $t = 0.709$ ,  $df = 124$ ,  $p = 0.48$ ).

The participant's mean age of AA onset and duration of living with the condition are displayed in Table 4.

Table 4

*Means, Standard Deviations and Ranges for Alopecia Areata Onset and Duration of Living with the Condition in Years*

Variable	AA Group <i>n</i> = 63
Age of AA Onset	
<i>M (SD)</i>	28.78 (15.86)
<i>Range</i>	2 to 60
Duration of AA	
<i>M (SD)</i>	13.26 (13.54)
<i>Range</i>	0.2 to 65

Participants average age of AA onset was approximately 29 years old (*SD* = 15.86; *Range* = 2 to 60 years old). The average duration of living with the condition was just over 13 years (*SD* = 13.54; *Range* = 0.2 to 65 years).

A number of demographic variables were recorded to characterise participants in the AA group. The participant's relationship status, occupation and SAL are summarised in Table 5.

Table 5

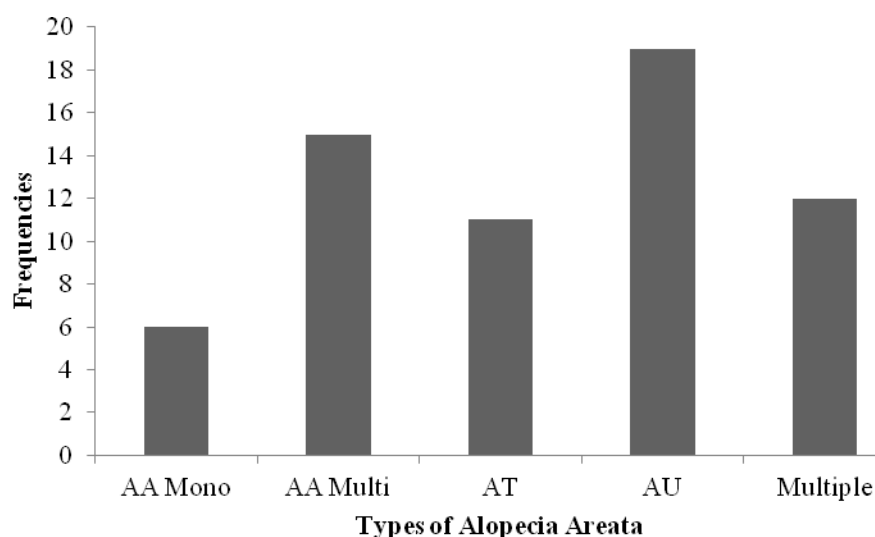
*Demographic Variables for the Alopecia Areata Group*

Variables	AA Group <i>n</i> (%)
Relationship Status	
Single	12 (19)
Relationship	16 (25)
Married	34 (54)
Engaged	1 (2)
Occupation	
Unemployed	2 (3)
Causal	5 (8)
Part-time	16 (26)
Full-time	26 (41)
Other	14 (22)
SAL	
Low	16 (25)
Medium	41 (65)
High	6 (10)

*Note.* SAL = Social Activity Level; Other = Student, Retired or Privately Owned Business  
*n* = 63

Table 5 shows that 54% of the AA respondents were married, 25% were in a relationship, but not married, 19% were single and 2% reported being engaged. Of the participants, 41% were employed full-time, 26% were employed part-time, 22% reported other (student, retired or privately owned business), with the remaining 11% causal or unemployed. With regards to SAL, the majority of the AA participants reported medium activity (65%), followed by low (25%) and then high (10%).

Participant's clinical presentations of AA are illustrated in Figure 5 (See below). This analysis was conducted to determine the frequencies and breakdowns of the sample on the basis of particular types of AA.

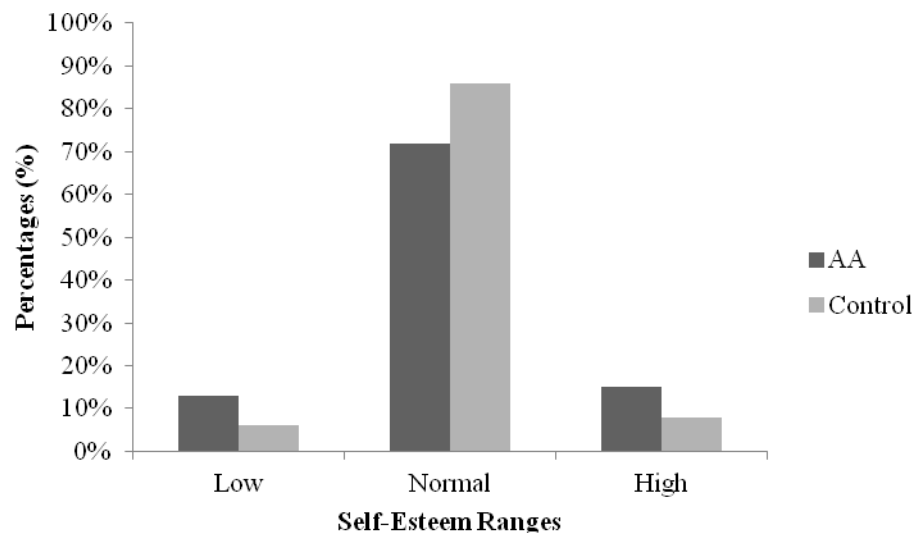


*Figure 5.* Frequency of Alopecia Areata Types

*Note.* AA Mono = Alopecia Areata Monolocularis; AA Multi = Alopecia Areata Multilocularis; AT = Alopecia Totalis; AU = Alopecia Universalis; Multiple = Several Types of AA.

Of the participants, 6 were formally diagnosed with AA Monolocularis, 15 with AA Multilocularis, 11 with AT, and 19 with AU. The remaining 12 participants reported having multiple types of AA across their lifespan.

Using Rosenberg's (1965) interpretation guide, the self-esteem totals and percentages of participants from both the AA and control groups were categorised into either the low, normal or high range. This examination was performed for purposes of comparison and clarification (See Figure 6).



*Figure 6.* Percentages of Alopecia Areata and Control Participants within each of the Self-Esteem Ranges

The majority participants in the AA group (72%) fell within the normal range of self-esteem, followed by 15% in the high range and 13% in the low range. Similarly, the majority of controls (86%) fell within the normal range of self-esteem, with 8% falling within the high range and 6% in the low range.

A frequency comparison of self-esteem scores between both groups revealed that although the majority of participants from either groups fell within the normal range of self-esteem, there was a larger number of controls ( $n = 54$ ) compared to AA participants ( $n = 44$ ). Furthermore, 8 participants in the AA group fell within the low self-esteem range, doubling the amount of controls ( $n = 4$ ). However, more AA participants fell within the high self-esteem range ( $n = 9$ ) compared to the control group ( $n = 5$ ).

Using Lovibond and Lovibond (1995) interpretation guide, the depression, anxiety and stress totals and percentages of participants from both the AA and control groups were categorised into either the normal, mild, moderate, severe and extremely severe ranges. This examination was performed for purposes of comparison and clarification (See Table 6).

Table 6

*Percentages of Alopecia Areata and Control Groups within each of the Depression, Anxiety and Stress Ranges*

	Normal <i>n</i> (%)	Mild <i>n</i> (%)	Moderate <i>n</i> (%)	Severe <i>n</i> (%)	Extremely Severe <i>n</i> (%)
AA Group					
Depression	40 (64)	8 (12)	7 (11)	2 (3)	6 (10)
Anxiety	41 (67)	6 (10)	2 (3)	4 (6)	8 (14)
Stress	40 (65)	6 (11)	7 (11)	5 (8)	3 (5)
Control Group					
Depression	54 (87)	3 (5)	5 (8)	0 (0)	0 (0)
Anxiety	48 (80)	4 (7)	5 (8)	2 (3)	1 (2)
Stress	49 (78)	6 (9)	6 (9)	1 (2)	1 (2)

The majority of AA participants in the AA group fell within the normal range for depression (64%), anxiety (67%) and stress (65%). Furthermore, there was between 2 and 8 participants in the remaining ranges, mild, moderate, severe and extremely severe across the three domains. Similarly, the majority of controls fell within the normal range for depression (87%), anxiety (80%) and stress (78%). With between 0 and 6 participants falling in the remaining ranges.

A frequency comparison between AA participants and controls revealed that although the majority of participants from either groups fell within the normal range of depression, there was a larger number of controls ( $n = 54$ ) compared to AA participants ( $n = 40$ ). Likewise, for both

the anxiety and stress domains, as 48 controls fell within the normal range of anxiety compared to 41 AA participants, and 49 controls fell within the normal range of stress compared to 40 AA participants. These frequencies revealed a common trend regarding the mild, moderate, severe and extremely severe ranges, with more AA participants reporting higher levels of depression, anxiety and stress than controls. Furthermore, across the DASS42 domains, only 2 controls fell within the extremely severe range, compared to 17 AA participants.

### 3.2.2 Differences between Self-Esteem, Depression, Anxiety and Stress on Social Activity Level and Types of Alopecia Areata

Several Multivariate Analysis of Variance (MANOVA) were conducted to explore the differences in AA participants demographic characteristics regarding SAL (See Table 7) and AA types (See Table 8) on multiple dependent variables; self-esteem, depression, anxiety and stress.

Table 7

*Means and Standard Deviations of Social Activity Level for Self-Esteem, Depression, Anxiety and Stress*

Variable	Social Activity Level					
	Low		Medium		High	
	<i>M</i>	( <i>SD</i> )	<i>M</i>	( <i>SD</i> )	<i>M</i>	( <i>SD</i> )
Self-Esteem	16.53	(3.83)	20.30	(5.41)	22.50	(5.90)
Depression	13.93	(10.87)	8.54	(9.08)	4.17	(4.79)
Anxiety	10.67	(11.67)	5.68	(6.00)	5.50	(9.81)
Stress	17.27	(10.43)	12.62	(9.49)	10.67	(7.06)

Table 7 results indicated no significant effect between SAL (low, medium, high) on combined dependent variables  $F(8, 104.00) = 1.37, p = 0.22$ , Wilks' Lambda = 0.82, partial  $\eta^2 = 0.10$ . Follow up univariate analyses of each dependent variables, using a Bonferroni adjusted alpha level of 0.013, showed that there was no contributions of anxiety,  $F(2,55) = 2.09, p = 0.13$ , partial  $\eta^2 = 0.07$  or stress,  $F(2,55) = 1.58, p = 0.22$ , partial  $\eta^2 = 0.05$ . However, the three groups did significantly differ in terms of self-esteem,  $F(2,55) = 4.02, p = 0.02$ , partial  $\eta^2 = 0.13$  and depression,  $F(2,55) = 2.90, p = 0.05$ , partial  $\eta^2 = 0.10$ . *Post-hoc* testing amongst the four dependent variables using Dunnett's procedure revealed a significant difference between the low and high levels for both self-esteem and depression, (all at  $p < 0.05$ ). Comparisons for remaining combinations were not significant.



Table 8

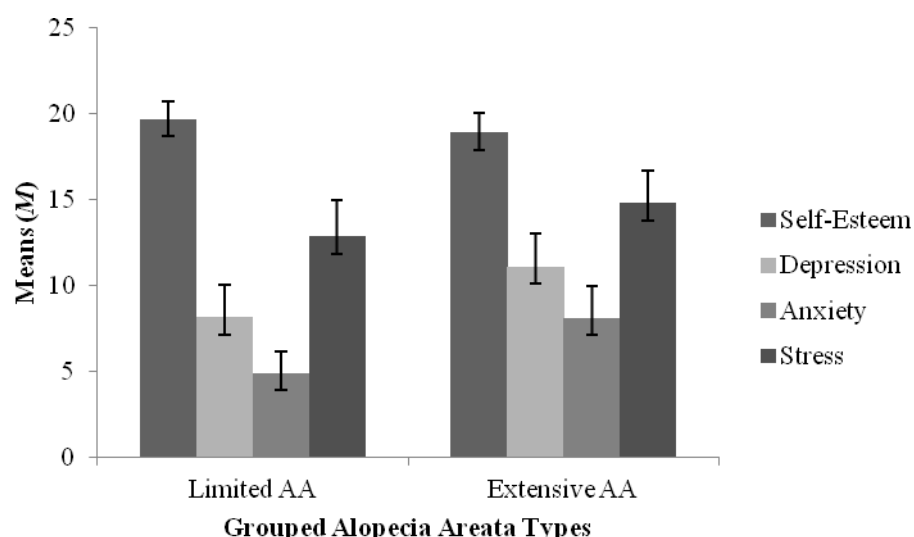
*Means and Standard Deviations of Types of Alopecia Areata for Self-Esteem, Depression, Anxiety and Stress*

Variable	Type of Alopecia Areata			
	Limited AA		Extensive AA	
	<i>M</i>	( <i>SD</i> )	<i>M</i>	( <i>SD</i> )
Self-Esteem	19.70	(4.68)	18.93	(6.04)
Depression	8.15	(8.75)	11.11	(10.29)
Anxiety	4.90	(5.75)	8.11	(9.79)
Stress	12.85	(9.93)	14.82	(9.85)

*Note.* Limited AA = Alopecia Areata Monocularis & Alopecia Areata Multilocularis; Extensive AA = Alopecia Totalis & Alopecia Universalis

Table 8 results indicated no significant effect between the types of AA (limited or extensive) on combined dependent variables  $F(4, 43) = 0.52, p = 0.72$ , Wilks' Lambda = 0.95, partial  $\eta^2 = 0.05$ . Follow up univariate analyses of each dependent variables, using a Bonferroni adjusted alpha level of 0.013, showed that there was no contributions of self-esteem,  $F(1,46) = 0.22, p = 0.64$ , partial  $\eta^2 = 0.005$ ; depression,  $F(1,46) = 1.09, p = 0.30$ , partial  $\eta^2 = 0.02$ ; anxiety,  $F(1,46) = 1.72, p = 0.20$ , partial  $\eta^2 = 0.04$  or stress,  $F(1,46) = 0.46, p = 0.50$ , partial  $\eta^2 = 0.01$ . Given that these results were not significant, *post-hoc* analyses was not required.

Although no significant differences were found between the limited and extensive AA groups on self-esteem, depression, anxiety and stress scores, the means of participants within each group were categorised into either the low, normal or high ranges using Rosenberg's (1965) self-esteem interpretation guide. Similarly using Lovibond and Lovibond (1995) interpretation guide for depression, anxiety and stress, the means of participants with limited and extensive types of AA were categorised into either the normal, mild, moderate, severe and extremely severe ranges. This examination was performed to further illustrate comparisons (See Figure 7).



*Figure 7.* Means and Standard Error of Self-Esteem, Depression, Anxiety and Stress for Limited and Extensive Alopecia Areata

*Note.* Limited AA = Alopecia Areata Monocularis & Alopecia Areata Multilocularis; Extensive AA = Alopecia Totalis & Alopecia Universalis  
Error Bars (represent the standard error of the mean)

Results showed that both the limited and extensive AA groups fell within the normal range for self-esteem. However, for depression, anxiety and stress, the limited AA group fell within the normal range, whereas the extensive AA group fell within the mild range across all three domains.

### 3.2.3 *Relationship between Duration of living with Alopecia Areata and Self-Esteem, Depression, Anxiety and Stress*

Spearman's correlations were conducted to examine the relationship between the duration of living with AA and the following variables; self-esteem, depression, anxiety and stress (See Table 9).

Table 9

*Spearman's Correlation Coefficients for the Relationships between Duration of Alopecia Areata, Self-Esteem, Depression, Anxiety and Stress*

Variable	$r_s$	$p$
Self-Esteem	-0.10	0.48
Depression	-0.11	0.39
Anxiety	0.03	0.87
Stress	-0.02	0.89

There was no significant correlations between the duration of AA and self-esteem,  $r(n = 63) = -0.10$ ,  $p = 0.48$ , depression,  $r(n = 63) = -0.11$ ,  $p = 0.39$ , anxiety,  $r(n = 63) = 0.03$ ,  $p = 0.87$ , and stress,  $r(n = 63) = -0.02$ ,  $p = 0.89$ .

### 3.2.4 Group Differences between Self-Esteem, Depression, Anxiety and Stress

To investigate the hypothesis that women with AA would have significantly lower self-esteem and exhibit significantly higher depression, anxiety and stress scores compared to the control group, a MANOVA was preformed (See Table 10).

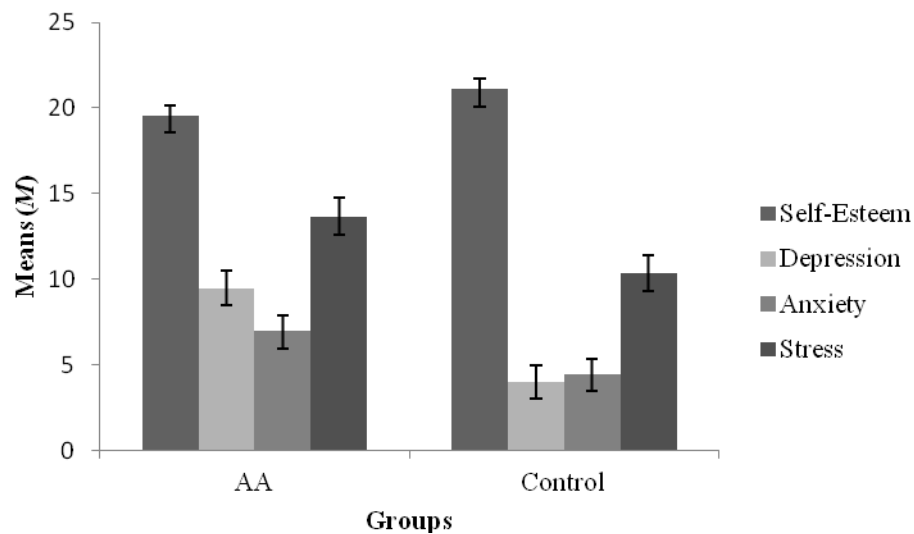
Table 10

*Differences in Self-Esteem, Depression, Anxiety and Stress between the Alopecia Areata and Control Groups*

Variable	AA Group ( <i>n</i> = 63)		Control Group ( <i>n</i> = 63)		<i>F</i> ( <i>df</i> )	<i>p</i>	$\eta^2$
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>			
Self – Esteem	19.55	5.37	21.11	4.06	3.23(1)	0.08	0.03
Depression	9.48	9.59	4.02	4.95	15.51(1)	0.0005	0.12
Anxiety	6.95	8.34	4.46	5.26	3.83(1)	0.05	0.03
Stress	13.62	9.65	10.33	7.24	4.47(1)	0.04	0.04

There was a significant effect between groups (AA & control) on combined dependent variables  $F(4, 114.00) = 4.18, p = 0.003$ , Wilks' Lambda = 0.87, partial  $\eta^2 = 0.13$ . Follow up univariate analyses of each dependent variables, using a Bonferroni adjusted alpha level of 0.013, showed that there was no contribution of self-esteem,  $F(1,117) = 3.23, p = 0.08$ , partial  $\eta^2 = 0.03$ . However, the two groups differed in terms of depression,  $F(1,117) = 15.51, p = 0.0005$ , partial  $\eta^2 = 0.12$ ; anxiety,  $F(1,117) = 3.83, p = 0.05$ , partial  $\eta^2 = 0.03$  and stress,  $F(1,117) = 4.47, p = 0.04$ , partial  $\eta^2 = 0.04$ . *Post-hoc* testing amongst the four dependent variables could not be performed due to having only two groups.

Although no significant difference was found between self-esteem and groups, the overall frequency of self-esteem scores were lower for the AA group ( $M = 19.55$ ;  $SD = 5.37$ ) than the control group ( $M = 21.11$ ;  $SD = 4.06$ ). Across the three domains, depression, anxiety and stress, scores were significantly higher for the AA group ( $M = 9.48$ ,  $SD = 9.59$ ;  $M = 6.95$ ,  $SD = 8.34$ ;  $M = 13.62$ ,  $SD = 9.65$ ) compared to controls ( $M = 4.02$ ,  $SD = 4.95$ ;  $M = 4.46$ ,  $SD = 5.26$ ;  $M = 10.33$ ,  $SD = 7.24$ ). Results are further illustrated in Figure 8.



*Figure 8.* Differences in Self-Esteem, Depression, Anxiety and Stress between the Alopecia Areata and Control Groups

Error Bars (represent the standard error of the mean)

### 3.2.5 Relationship between Groups and Self-Esteem, Depression, Anxiety and Stress

Following, point biserial correlations were conducted to investigate the relationships between the dichotomous variable of participants belonging to the AA or control groups, and self-esteem, depression, anxiety and stress (See Table 11).

Table 11

*Point Biserial Correlations between Alopecia Areata and Control Groups and Self-Esteem, Depression, Anxiety and Stress*

Variable	AA Group or Control Group	
	$r_{pb}$	$p$
Self-esteem	0.16	0.04
Depression	-0.35	0.0005
Anxiety	-0.20	0.01
Stress	-0.20	0.02

There was a significant weak, positive correlation between self-esteem and the AA and control groups,  $r_{pb}(n = 126) = 0.16, p = 0.04$ , one-tailed. This relationship showed that if group membership proceeded from 1 (AA group) to 2 (control group) self-esteem scores would significantly increase.

A significant weak, approaching moderate, negative relationship was identified between depression and the AA or control groups  $r_{pb}(n = 126) = -0.35, p = 0.0005$ , one-tailed. This relationship showed that if group membership proceeded from 1 (AA group) to 2 (control group) depression scores would significantly decrease.

There was a significant weak, negative relationship between anxiety  $r_{pb}(n = 126) = -0.20, p = 0.01$ , one-tailed, and stress  $r_{pb}(n = 126) = -0.20, p = 0.02$ , one-tailed and the AA and control groups. These relationships showed that if group membership proceeded from 1 (AA group) to 2 (control group) both anxiety and stress scores would significantly decrease.

To examine the relationships between variables, self-esteem, depression, anxiety and stress in AA participants, Pearson's correlations were performed (See Table 12).

Table 12

*Relationship between Self-Esteem, Depression, Anxiety and Stress in Alopecia Areata Participants*

AA Group	Self- Esteem		Depression		Anxiety		Stress	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
Self-Esteem			-0.48	0.0005	-0.45	0.0005	-0.50	0.0005
Depression	-0.48	0.0005			0.72	0.0005	0.80	0.0005
Anxiety	-0.45	0.0005	0.72	0.0005			0.73	0.0005
Stress	-0.50	0.0005	0.80	0.0005	0.73	0.0005		

There were significant moderate, negative correlations between self-esteem and depression in the AA group,  $r(n = 63) = -0.48, p = 0.0005$ , one-tailed, and between self-esteem and anxiety in the AA group,  $r(n = 63) = -0.45, p = 0.0005$ , one-tailed. Such results demonstrated that higher levels of self-esteem were associated with lower levels of depression and anxiety.

A significant strong, negative correlation was found between self-esteem and stress for the AA group,  $r(n = 63) = -0.50, p = 0.0005$ , one-tailed. This demonstrated that higher levels of self-esteem were associated with lower levels of stress.

Furthermore, there was a significant strong, positive correlation between depression and anxiety for the AA group,  $r(n = 63) = 0.72, p = 0.0005$ , one-tailed. This demonstrated that higher levels of depression were associated with higher levels of anxiety.

A similar relationships was found between depression and stress for the AA group,  $r(n = 63) = 0.80, p = 0.0005$ , one-tailed and between anxiety and stress for the AA group,  $r(n = 63) = 0.73, p = 0.0005$ , one-tailed. These results demonstrated that higher levels of depression and anxiety were associated with higher levels of stress.

### 3.3 *Qualitative Findings*

The interviews yielded data pertinent to the aim of exploring individuals coping strategies in managing the incurable condition of AA. In addition, the data gathered reflected the importance of coping research within the context of AA, through highlighting participant's journeys and struggles.

Using the thematic analysis approach, 5 superordinate themes emerged from the interviews in a previously unidentified sequential order of occurrence compared to past literature. This process of coping commenced with strategies incorporating thoughts of denial and period/s of isolation, followed by the implementation of pragmatic coping strategies such as, supportive networks and investing in headwear/wigs, prior to coping through finding a sense of acceptance for the condition. In addition, 11 sub-themes were identified through employing thematic colour coding systems that grouped responses according to the major themes (See below Table 13).



Table 13

*Superordinate Themes and Sub-Themes Regarding Coping with Alopecia Areata*

Superordinate Themes	Sub-Themes
Denial	- Continuous Searching for Answers - Blocking Out
Isolation	- Physical - Emotional
Supportive Networks	- Groups - Family and Friends
Headwear/Wigs	- Security Blanket - Conforming to Societies Expectations
Acceptance	- Change of Perspectives - I'm not Dying - It's a Journey

Quotes obtained from the interviews served to crystallise the themes and strengthen the quality of the data. It is important to note that due to the small sample size, superordinate themes only emerged if addressed or mentioned by all participants.

### 3.3.1 Denial

All participants articulated denial as an initial strategy towards coping with AA. However, given that denial is perceived as a negative form of coping, participants expressed that it was a short-term approach. Women further mentioned that refusing to acknowledge that their hair might or is falling out commonly occurred through creating maladaptive thoughts,

encouraging the continuous searching for answers and blocking out their situation all together.

#### *Continuous Searching for Answers*

Given that AA has the potential to cause partial or complete hair loss, some women felt it was necessary to constantly search for answers, whilst trying to seek other diagnosis alternatives:

*“I wanted to get another opinion because I didn’t believe him (dermatologist)... I can’t lose my hair, I’m a woman” (M)*

*“I exhausted all my options, I rang hair companies, dermatologists, clinics ... I couldn’t settle with the idea of losing my hair” (D)*

#### *Blocking Out*

Women also expressed denial through totally block out the reality of losing their hair. Participants expressed that ignoring its (AA) presence was attempted through keeping busy:

*“For me I had to fully block it (AA) out, the thought alone was painful enough” (S)*

*“I had to keep myself very occupied... If I had no time to think about it then I could forget about it” (D)*

### *3.3.2 Isolation*

Following a phase of denial, the next major theme derived from the data highlighted participants need for period/s of isolation. This theme emerged from the accounts that women attempted to cope with hair loss through merely wanting to be alone. All participants recalled engaging in both physical and emotional avoidant behaviours.

#### *Physical*

Given that a woman’s capacity to accept AA is commonly embedded in social definitions of hair and beauty, all participants mentioned a fear towards being rejected or stigmatised by

others based on the visibility of the condition. Participants initially believed that having AA would prevent them from participating in normal social interactions. Therefore, this notion often resulted in withdrawal from their community and loved one's to help manage the condition:

*"I became very withdrawn and wanted to be on my own, I didn't want to talk to anyone" (M)*

*"I avoided society... I had lots of friends but I just shut them out and shut myself down" (D)*

*"I hid myself away from everyone to avoid the social stigma... I started to feel apathetic and unmotivated to go out, I even stopped playing sports I absolutely loved" (V)*

Furthermore, it was apparent that hair loss was initially linked to feelings of distress. Women expressed that their hair was a key signifier of their femininity, which was evidently compromised by the condition:

*"I miss getting dolled up, styling my hair and feeling like a complete woman" (D)*

*"It's hard to feel pretty and like a real woman" (M)*

### *Emotional*

Women additionally expressed secluding themselves from their partners and established relationships on an emotional level as a form of coping. Participants feared that they would be perceived as ugly and unlovable:

*"When I was diagnosed I didn't what to go near him (Husband)... I felt unattractive and thought he was going to leave me" (M)*

*"I hated him (husband) touching me, I would constantly snap at him and avoid such situations" (D)*

### 3.3.3 Supportive Networks

Subsequently, support was another major coping strategy that emerged. The interview responses added weight to the argument that supportive systems increased women's self-worth and encouraged participation in social activities. Women illustrated that participating in support groups and confiding in family/friends were their main structures that aided coping with AA.

#### *Groups*

Support groups can play a salient role in assisting individuals to cope with hair loss. With the intention of empowering members through meetings, women appreciated the lenient and uplifting environments, as they felt encouraged to openly discuss and explore of their insecurities:

*"Socially I was lost and pushed away a lot of people. Tapping into support groups helped me on my road to recovery" (V)*

*"AA is mentally exhausting. Groups were important as they allowed me to discuss and raise concerns in a non-judgmental setting" (D)*

Such support groups further assisted women in coping as they were able to meet others who have found a sense of acceptance and moved on with their lives. All participants discussed that the obstacles hindering effective coping were more likely to be overcome largely due to realising they were not alone:

*"What was missing was someone knowing the overall picture of what I was going through" (D)*

*"They (groups) were very important, because when you first start to realise the impact it (AA) can have, knowing you are not alone is vital. Healthy people often tell me they understand, but deep down they don't because they have hair" (S)*

Fortunately, all women described supportive groups as a positive coping experience, as they encouraged increased feelings of self-confidence and self-worth:

*“They (groups) definitely helped boost my self-esteem and confidence, whilst giving me a sense of comfort” (S)*

#### *Family and Friends*

Moreover, all participants spoke very highly of the support they received from their family, partners and friends. An important aspect of these networks was related to participants feeling accepted for who they were, irrespective of their appearance. The process of adaption and acceptance has been clearly ameliorated by the support these women have received:

*“Having people who whole heartedly accept you and just love you for who you are helped me to accept myself too. I was lost within myself, but with their support I was beginning to find myself again” (S)*

*“My families support and acceptance is the reason I can be as strong as I am” (D)*

Supportive groups and family networks were essential in assisting participants with coping. Women strongly articulated that the support they required was emotional, compassionate and genuine. Although participants did not recall receiving pitiful support, they all expressed their objections towards the thought of gaining special consideration based on their condition:

*“The one thing I didn’t want was pity, it was the emotional support I needed” (V)*

*“I didn’t want pity or special consideration, what’s happened has happened” (D)*

#### *3.3.4 Headwear/Wigs*

Continuing on their coping journeys, women discussed wearing headpieces/wigs, as they appeared to increase women’s comfort levels and reduce the risk of developing co-morbid

disorders. All participants had invested in headwear items with the intention of managing their AA, as they acted as a security blanket and enable women to conform to societies expectations.

### *Security Blanket*

Most participants talked a great deal about attempting to conceal their hair loss in order to facilitate coping. In such attempts, the most common items used included:

*“I wear wigs, hats, beanies, scarfs and/ or bandanas” (S)*

For women the above items were relatively effective in disguising their hair loss. Participants often expressed that because they are defined by their hair; wearing wigs gave them a greater sense of comfort and self-assurance:

*“When I’m wearing my wig I feel comfortable, I really enjoy the way they make me feel as a person” (D)*

*“Wearing a wig gave me the confidence I needed to cope” (S)*

This sense of self-enhancement helped all women feel better about themselves. Some women reported wearing headpieces/wigs almost continually to points of necessity, expressing their inability to be seen without them:

*“I never go anywhere without my wig or beanie... It is nice to blend in and not have people stop you in the street and comment” (S)*

*“Without my wig I feel terrible and very unattractive... Whenever I go out I must wear my wig” (D)*

### *Conforming to Societies Expectations*

It was apparent that at some stage throughout participant’s lives, all had worn headwear/wigs to conform to the expectations set by society. Given that AA is a visible condition, wigs allowed women to avoid unwanted attention from others:

*“I tried to fit being the bald person, but I was a complete outcast. Wearing a wig made things much easier. I began to feel a part of society and be accepted” (S)*

*“I really wanted to fit in, but without hair I felt like a walking target” (D)*

Society’s views and attitudes regarding baldness are very different in terms of gender. All women believed that a bald woman is often perceived as socially unacceptable, compared to a bald man:

*“As a woman, I’m not comfortable with myself within the greater society” (D)*

*“Being a bald woman in society is very confronting. However I feel it’s completely opposite for men, as a bald man isn’t looked at twice” (V)*

### 3.3.5 Acceptance

All participants had established either partial or complete acceptance as a form of coping with the loss of their hair. Women reported that this was the final strategy they required in order to feel positive about overcoming the profound difficulties associated with AA. The means in which acceptance was established was exemplified through, changing their perspectives, acknowledging that they are not dying and understanding that AA takes them on a journey.

#### *Change of Perspectives*

Most participants recalled needing to change their outlooks on life in order to reach acceptance. Women discussed redirecting their focus, by concentrating on the important things that define who they are, and what they want from life, rather than on the hair loss itself:

*“I have started to see things differently... I now know that I am not my hair, and that it doesn’t define who I am” (M)*

*“Not having hair will not stop me from doing what I want in life” (S)*

These independent changes of focus commonly led to modifications in the way participants believed to be viewed by others. Women realised that acceptance not only incorporated their own thoughts, but the thoughts of society, irrelevant of whether they were positive or negative:

*“It (AA) is who I am, who cares if someone is going to accept me, because in the end they can only accept me for who I am and whatever comes along with me” (S)*

*“I realised you cannot worry about what everyone else is thinking, or I would be spending my life very unhappy” (V)*

A strategy encouraging acceptance was often associated with taking control. Some women found it easier to cope with having AA through shaving off their remaining hairs:

*“My condition is not changing, and my hair will probably never grow back, therefore I just shaved it all off. I wanted to be in control, not letting it (AA) be in control of me. Because when my hair falls out I have no control over it, but when I shave it off, then I am the one in control” (S)*

This led participants to acknowledge that the unpredictability of the condition is inevitable:

*“It is what it is, whatever happens, happens and I have accepted it” (S)*

*“It (AA) was easier to accept rather than continuing to hold on to all its baggage, because I never knew what was around the corner” (V)*

### *I’m Not Dying*

An interesting concept that emerged from the participant’s accounts regarding coping through a means of acceptance, was that many women made comparisons between AA and more serious conditions. Participants emphasised that AA posed no real threat to their health when compared to people with life threatening illnesses:



*“I’m actually a healthy person and my condition is not life threatening. I have known people who have died from far more severe conditions... sometimes I thank god that I only have AA” (V)*

*“I’m healthy and I’m happy and I don’t have any hair, well too bad, life could be worse” (M)*

### *It is a Journey*

Based on the profound psychological and psychosocial consequences associated with AA, all participants expressed feeling distressed and overwhelmed throughout the early episodes of hair loss. However, a dominate attitude that surfaced was the need to embark on a journey of grief, prior to finding acceptance.

*“You will feel worse before you feel better” (M)*

*“I had to allow myself to feel sorry for myself and be upset, but after that I had to move on... That was the start of my journey towards coping” (S)*

## CHAPTER 4: DISCUSSION

AA is a debilitating, chronic condition that causes partial or complete scalp and body hair loss (Green & Sinclair, 2004). However, the precise nature of the psychological and psychosocial consequences associated with AA still remains controversial. Therefore, using a mixed methods approach, the aims of the current study was to expand upon the findings reported in the AA literature, whilst providing novel insights into the impact hair loss can have on women's self-esteem, mood and coping strategies simultaneously.

### 4.1 *Group Differences on Social Activity Levels*

Although not hypothesised, there was a significant difference between self-esteem and depression scores on participants SAL. These findings indicated that participants who reported being more socially active had higher self-worth, compared to participants who reported lower social interactions. This variation was similarly found between depression and SAL, however, depression levels increased in participants who reported minimal social involvement, compared to those more socially active. Given that these differences were not addressed throughout this paper, it is difficult to make an assumption as to why this was the case. However, due to previous research investigating the struggles 'bald' women often endure whilst trying to fit into society, this discrepancy may not be as surprising (Hunt & McHale, 2007; Liakopoulou et al., 1997; Welsh & Guy, 2009). Therefore, it may be of worth for future studies to evaluate such associations, thus increasing community awareness regarding the consequences linked to their attitudes. It is anticipated that a reduction in society's negative perceptions and stigmatization of women with AA, may enhance individual's acceptance of the condition, fundamentally leading to more positive means of coping.

#### 4.2 *Group Differences on Types of Alopecia Areata*

Although, participants with extensive AA (i.e., AT & AU) reported more frequencies of low self-esteem and elevated depression, anxiety and stress levels compared to participants with limited AA (i.e., AA Monocularis & AA Multilocularis), the hypothesis that there would be a significant difference between groups was not supported. Such results were contrary to researcher's expectations and the majority of reported literature, who have found that psychological adversity such as lowered self-esteem, alterations in self-perception and mental health problems were more prevalent in those with extensive AA (Al-Mutairi & Eldin, 2011; Fiedler, 1991; Hunt & McHale, 2005a; Kushon et al., 1996; Sellami et al., 2012; Tan et al., 2002). Although it is difficult to state why no differences occurred within the current sample, it is plausible to suggest that it may be related to the fact that when individuals exhibit complete hair loss, they are better able to recognize the rarity of treatment responses. Therefore, individuals with extensive AA may be more inclined to rapidly understand, adjust and accept the importance of openly and actively managing the condition. This may additionally lead to more effective coping strategies, rather than being concerned about re-growth or whether their remaining hairs were going to fall out (more probable in individuals with limited AA). Furthermore, due to the availability of cosmetic wigs now days, sufferers can easily disguise their condition irrelevant of experiencing single, multiple patches or total hair loss. These assumptions are supported by the findings of Mazter et al. (2011) and Cartwright et al. (2009) where neither AA severity nor status influenced participant's quality of life, mood and self-worthiness.

#### 4.3 *Relationship between Duration of Living with Alopecia Areata and Self-Esteem, Depression, Anxiety and Stress*

Moreover, the hypothesis that there would be no relationships between the duration of living with AA and self-esteem, depression, anxiety and stress was supported. These findings were consistent with those of Ghajarzadeh et al. (2011), Williamson and colleagues (2001) and Alfani et al. (2012), who reported no significant associations between the length of AA diagnosis and psychological and psychosocial repercussions. Despite these findings, it may seem logical that individuals with prolonged durations of hair loss will exhibit a reduction in psychological consequences, as Cartwright and colleagues (2009) and Kalaboke (2011) suggested that overtime living with no hair generally facilitates acceptance and the implementation of other effective coping strategies. However, what needs to be taken into consideration is the reality of having no hair, no cure and the conditions unpredictable course. These factors often act as a constant reminder for individual's misfortunes, ultimately causing eternal adverse psychological angst. In addition, given that complete re-growth and/or repeated remissions is not unusual, it may be difficult for researchers to obtain an accurate representation of participants' AA duration. Future studies should consider comparing the psychological impact between initial onset and grouped participants with moderate and longer AA durations, as the current study only investigated the relationship due to participants unbalance lengths of AA.

#### 4.4 *Group Differences on Self-Esteem*

Furthermore, it was predicted that self-esteem scores on the RSES would be significantly lower in adult Australian women with AA, compared to controls. Despite a higher frequency of AA participants reporting decreased overall self-esteem (13%) than controls (6%), the hypothesis

was rejected, as no significant group differences were found. Although these findings were similar to Alfani and researchers (2012), the consensus throughout the literature have consistently reported significantly reduced self-esteem scores indicating increased vulnerability, social withdrawal and decreases self-confidence in individuals with AA (Cartwright et al., 2009; Firooz et al., 2005; Fox, 2003; Hunt & McHale, 2005b; Williamson et al., 2001). Therefore, the lack of difference between the groups in the present study may be attributed to the small sample size obtained. Researchers anticipate that a larger sample may have, as evidence suggests, reflected lower self-esteem scores in participants experiencing hair loss, as it is arguable that the group differences were approaching significance ( $p = 0.08$ ). A further explanation to why this discrepancy may have occurred relates to the current studies methodological procedures. The majority of participants were recruited via the AAAF Inc. who encourages the use of their ambassadors, supportive networks and charity awareness events. Therefore, it is presumed that if individuals were experiencing such symptoms, the organisation may have already been aware and possibly assisted individuals by suggesting and providing the appropriate referrals and information packs. Hence, it is possible that the scores attained may underestimate the actual impact AA can have on individual's self-esteem and further research in this area is required.

#### 4.5 *Group Differences on Depression, Anxiety and Stress*

The hypothesis that adult Australian women with AA would exhibit significantly elevated depression, anxiety and stress levels compared to the control group on the DASS42 was supported. Importantly, neither sample demonstrated pathological levels of depression, anxiety and/or stress; however, AA participants did display increased mild to extremely severe scores across all three domains in comparison to fewer controls. These findings add support to previous

studies, identifying a higher prevalence of affective disorders suggesting that individual encountering hair loss experience increased sadness, hopelessness, physiological arousal, tension and amplified stress levels (Colón et al., 1991; Hunt & McHale, 2007, Kökçam et al, 1999; Koo et al., 1994; Picardi et al., 2003; Sellami et al., 2004). Despite such consistencies, the results of Cordan-Yazici and colleagues (2006), Gulic et al. (2004) and Gupta and Gupta (1998) continue to raise controversy, concluding no significant differences between the psychological states of people with AA and controls. However, it is suspected that these discrepancies emerged based on the selection criteria of researchers control samples. Past studies have frequently compared AA subjects to age-matched individuals either diagnosed with more severe conditions such as, psoriasis and acne or hospital staff, working in strenuous, fast passed environments for extensive hours. Therefore, it is assumed that if a heterogeneous control groups was recruited, this might have yielded different results and fallen in alignment with the majority of studies. Nevertheless, the DASS42 has captured a fairly acute picture of mood states associated with AA within the current sample. The results provide additional support for the assertion that the depression, anxiety and stress scales are a sensitive measure of present affective disorders in AA participants. The clinical significance of these findings is that the development of co-morbid disorders can be quickly screened using the appropriate measures. Hence, individuals exhibiting unexpected hair loss can then be referred for more detailed clinical assessments.

#### *4.6 Relationship between Groups and Self-Esteem, Depression, Anxiety and Stress*

It was predicted that there would be a significant positive relationship between AA participants and controls on self-esteem. It was further hypothesised, that there would be a significant negative relationship between groups on depression, anxiety and stress. Both these

hypotheses were supported, indicating that lowered self-esteem and elevated scores across the three domains were significantly associated with individuals experiencing hair loss. Furthermore, it is likely that adverse self-esteem, depression, anxiety and stress scores may emerge concurrently in individuals with AA (Colón et al., 1991; Hunt & McHale., 2007; Kessler et al., 1994; Koo et al., 1994). These findings are of great importance for sufferers, associated physicians and loved ones, as increased awareness is presented regarding the high prevalence and potential development of multiple co-morbid disorders.

Furthering this notion, the subsequent hypotheses was also supported, revealing a significant negative relationship between the RSES measuring self-worth of individuals with AA, and the domains of the DASS42, measuring mood and stress levels, and a positive relationship between depression, anxiety and stress. These findings indicated that as a result of losing one's hair, lowered self-esteem would be associated with higher depression, anxiety and stress levels, and elevated depression, anxiety and stress levels would be correlated with each other. These relationships reported in the current study are consistent with the theory in regards to the impact that AA may have on individual's psychological wellbeing (Colón et al., 1991; Hunt & McHale, 2007; Kessler et al., 1994; Kökçam et al., 1999; Koo et al., 1994; Welsh & Guy, 2009). Therefore, it is reasonable to assume that individuals diagnosed with AA may additionally experience identity issues, deliberated self-confidence and negative body image perceptions as such feelings are commonly linked to reduced self-esteem and affective disorders (Cartwright et al., 2009; Williamson et al., 2001). However, these relationships must be interpreted with caution, as everyday activities such as, hobbies, work and/or academic requirements may have also influenced the results, and be a plausible explanation for significant findings.

#### 4.7 *Alopecia Areata and Coping Strategies*

A range of topics and nature of discussions support the view that AA has a significant impact on individual's lives. However, to date existing assessment tools have provided limited attention and insight towards the degree and diversity of these effects. The following section is a commentary on the current studies aim to explore the coping strategies of women diagnosed with AA. Through the exploration of women's lived experiences, it was assumed that specific strategies would emerge that have assisted participants in managing the condition. Researchers further endeavored to interpret and discuss the reported qualitative findings, whilst focusing on the primary themes that transpired (denial, isolation, supportive networks, headwear/wigs and acceptance) and making comparisons with previous literature.

In accordance with Garcia (2010) and Papadopoulos and Bor (1999), the current study highlighted the importance of positive and negative coping strategies that assist individuals experiencing hair loss. However, unlike what has been reported throughout the literature, the current sample appeared to go through a sequential order of specific strategies in attempting to come to terms with the condition. This process involved; experiencing initial maladaptive thoughts and avoidant behaviours, followed by implementing pragmatic strategies, which subsequently encouraged acceptance and moving on with their lives.

Similar to the findings of Fox (2003) and McKillop (2010), participants expressed denial towards their hair falling out as the initial stage of coping. This strategy was encouraged by maladaptive thoughts including, continuously searching for answers and blocking out reality. However, these findings were contrary to those reported by Garcia (2010) and Reid et al. (2010) who stated that participants attempted to cope through means of disruptive behaviours such as, smoking, substance abuse or expressing suicidal intentions. Although it is difficult to state



exactly why these differences exist, it is suspected that individual's personal lives, environmental stimuli and surrounding peers may contribute to their decisions. Furthermore, it is possible that because denial often serves as a numbing reaction to intense shock, it is not uncommon for individuals to be influenced by external factors manipulating their choices.

Following, participants explained that a state of denial was commonly accompanied by isolative behaviours. In line with Picardi et al. (2003) and the findings of Reid and colleagues (2010), participants expressed both physical and emotional withdrawal from their loved ones and society as a means of coping. The current studies participants expressed an immense fear towards, being rejected or stigmatised by their community, having their femininity compromised and concerned about ending up alone. This was partially supported by Freedman (1994) and McGarvey et al. (2001) who acknowledged participants worries regarding society's exploitation of bald women, commonly leading to a sense of diminished femininity. Therefore, such insights play an essential role in highlighting the importance of educating others about the condition and the severe compelling psychological and psychosocial consequences. Researchers advocate that increasing community awareness may additionally reduce some of the distress individuals with AA face, whilst retracting the implementation of negative coping strategies (i.e., denial & isolation).

In correspondence with the literature, participants expressed the implementation of negative coping strategies only for a short period of time (McKilliop, 2010). It is assumed that this phase incorporates overwhelming feelings, as individuals find it difficult to tackle the concept of 'no cure'. Therefore, it is anticipated that a process of mourning may be necessary to allow sufferers to embark on their journey towards acceptance.

Subsequently, further themes emerged surrounding the use of pragmatic coping strategies such as, supportive networks (i.e., groups & loved ones) and investing in headwear/wigs. The theory suggests that the cultivation of a supportive, nonjudgmental and understanding environment is crucial for those with AA (Thompson & Shapiro, 1996). As reported in Kalabokes and Besta (2011) and reinforced throughout the current study, individuals expressed that these environments facilitated self-growth, self-confidence and self-worth, as women mentioned feeling liberated to discuss their insecurities. In addition, supportive networks allowed participants to have a voice and meet others who have reached a sense of acceptance and were moving on with the condition, rather than against it (Fox, 2003; Hull et al., 2003; McKillop, 2010; Runsey & Harcourt, 2004). Contradictory to the works of Prickitt et al. (2004) participants also highlighted the need for emotional, compassionate and genuine support from their loved ones. Interestingly participants mentioned that pity or dispensation was unnecessary, as they wanted to be treated as 'normal'. However, Prickitt and researchers (2004) reported that often sufferers sought excessive sympathy and used their unfortunate circumstances as an excuse for special consideration. Although it difficult to discern the extract reason behind this discrepancy, it may be due to individuals not receiving the initial support they had hoped for, thus needing to seek support rather than receiving it unconditionally. Therefore, given that all current participants expressed an ongoing strong supportive network of family and friends from the time of diagnosis, sympathetic support may not have been considered.

In the current study, the wearing of headpieces such as, wigs, hats, beanies and/or scarfs emerged as an investment to aid coping with hair loss. This is compatible with the research by Draelos (2011), McKillop (2010) and Williamson et al. (2001) who stated that headwear

increased individuals comfort levels, reduced psychological distress and enable society's acceptance through disguising the condition and unwarranted stigmatisation.

Despite these findings, Borsellino and Young (2010) and Hunt and McHale (2005b) reported that some individuals often focused on the negative aspects of headwear including, finances, maintenance and restricting participation in certain activities (e.g., swimming). Again, although it is difficult to determine exactly why this was not evident within the current sample, as a multitude of factors require further exploration. Participants only expressed the benefits related to headwear, which suggests that the sense of self-enhancement wigs provided outweighed any consequences. Therefore, an opportunity exists for future research to investigate the impacts of AA in sufferers who wear wigs, and those who do not.

Continuing in the light of this concept, multiple studies supported the notion of a coping process which is at near completion upon reaching a sense of acceptance for one's self, the condition and all of its entity (Cartwright et al., 2009; Hunt & McHale, 2005b; Kalabokes, 2011; Thompson & Shapiro, 1996). Participants expressed their ability to develop an appropriate attitude about the loss of their hair through deliberating changing their perspectives, by comparing their circumstance to people living with more serious health conditions and through being able to understanding the journey of mixed feelings associated with AA. In accordance with the majority of research, participants reached their stage of acceptance through focusing on who they are and what they want from life, by taking control over the condition, and acknowledging that the unpredictability of hair loss is inevitable (Harries et al., 2010; Hunt & McHale, 2005b; Papadoulous & Bor, 1999; Welsh & Guy, 2009). Furthermore, participants found acceptance through understanding AA as a benign cosmetic problem and although linked to a

variety of psychological consequences, fortunately they are not dying (Fox, 2003; Hunt & McHale, 2007; McKillop, 2010; Thompson & Shapiro, 1996).

It is important for individuals with AA to understand that there is no correct way to cope (Borsellino & Young, 2010). Inevitably all individuals will refine, eliminate and/or manipulate a variety of strategies to tailor a coping process right for them, in order to achieve a personally acceptable perspective of themselves and sense of control over the condition. It appears reasonable to presume that if individuals can maintain effective coping strategies, then they may be less incline to suffer from reduced self-worth and co-morbid disorders. Therefore, rather than treating the impacts hair loss can impose, the first stage of assistance should be devoted to implementing coping interventions tailored specifically to each individual diagnosed with AA. This approach may prevent the risk of sufferers feeling extreme sadness, worry, tension and self-doubt as a result of losing their hair. Nevertheless, the current explorations should not be viewed as the mandatory process of coping or refute the value of other strategies not mentioned, but rather provide essential knowledge that can assists current and/or future sufferers who may be struggling to reached a form of acceptance. It is also acknowledged that individuals coping choices could additionally be influenced by uncontrollable factors such as, the location and amount of hair loss. In spite of this, the findings of the current study have expanded on previous research and provided novel insight into the personal and subjective experiences of women with AA.

#### 4.8 *Strengths and Limitations*

The current study is one of the first to simultaneously investigate the psychological and psychosocial wellbeing of a sample of adult Australian women diagnosed with AA. Examining

self-esteem, depression, anxiety and stress allowed researchers to emphasise the traumatic impact hair loss can have on women and identify effective coping strategies to support this particular group of individuals. Exploring these 4 variables simultaneously was beneficial, as it permitted for the identification of symptom patterns, whilst understanding the possible associations between particular psychological implications. Furthermore, these findings contributed to the body of knowledge and encourage others to be more aware and accepting of bald women within society. Researchers yearn that the current study will reduce women's risks of developing co-morbid disorders and self-image concerns.

The coping processes of individuals with AA can hardly be assessed using standardised questionnaires. Therefore, another advantage of the current study was the incorporation of a mixed methods design. This allowed researchers to explore, identify and discuss the subjective and detailed views of participants coping strategies. Furthermore, given that individuals overcome the challenges associated with hair loss in both similar and different ways (reflected in our results), it was of great importance that thorough knowledge and awareness was obtained from the multiple realities of current sufferers. Although this volunteer sample may typify people who were successfully managing the loss of their hair, their accounts still illustrate the complexities of the coping process. In addition unfortunately in the case of AA, the aetiological aspects are not fully understood, therefore, individuals seeking information and answers are left without clear understandings regarding the condition.

Notably, AA is often medically viewed as a relatively mild dermatological condition, yet those diagnosed consider it to be more serious, causing major personal and life difficulties. Therefore, based on such discrepancies physicians (i.e., dermatologists) often lack empathy and are unable to handle patients break downs (Papadopoulos & Bor, 1999). From a practical point

of view, the current findings can assist dermatologists and associated professionals to realise the vulnerability of patients and simplicity of underestimating the severity of AA. Thus, encouraging them to facilitate meaningful coping interventions, whilst providing the guidance and support individuals may require.

Statistically, the current sample size is considered small, which may have precluded the ability to draw strong inferences. However, clinically a sample size of 63 adult women is considered rather large, given that AA is a rare condition. In fact, the current sample compares favourably to most studies, as previous researchers have obtained samples as small as 12 (Welsh & Guy, 2009) and as large as 80 (Firooz et al., 2005), although taking into account both genders and all ages. While the capacity to generalise the current findings to all individuals with AA may be limited, innovating information is provided regarding the psychological aspects and coping strategies for adult women. In addition, the recruitment of a generalisable control group (gender and age matched) added weight, allowing for the comparison of scores between AA participants and healthy individuals.

Whilst this investigation attempted to address and control for a range of potential extraneous variables, several limitations should be considered. Given that the selection of participants was not randomised, with most of the recruitment occurring via the AAAF Inc., the findings could represent an underestimation of participants' true self-esteem, depression, anxiety, and stress scores. It is assumed that participants prior knowledge received based on their relationship with the organisation, and established support systems may have encouraged a ceiling effect when completing the questionnaire measures and interviews.

In addition, the research was based in Melbourne while the recruitment of individuals was Australia wide. Sourcing the location of specific individuals diagnosed with AA may have

been otherwise unattainable without the assistance of AAAF Inc. due to a lack of connections, time and sensitive nature of the condition. Therefore, future studies may consider advertising in clinics, schools, wig shops and newspapers, as an additional method of recruitment to strengthen research outcomes. Nevertheless, the unusually high response rate in this study would have been practically impossible without assistance from the AAAF Inc.

A further concerning limitation surrounded the smaller sub-sample of interviewees, who formed the basis of the qualitative section. Due to the limited time frame, only 4 participants were obtained, which may have restricted the attainable in-depth exploration into the multiple realities of individuals coping strategies. Future studies should aim for a sample size between 8 and 10 participants (Willigs, 2008), which would allow for a thorough understanding, from a larger variety of sufferer's, thus different and/or additional superordinate themes and sub-themes may emerge.

Moreover, data collection on the basis of personal interviews had the potential to cause methodological biases, as the information obtained may have been influenced by the researcher's characteristics. Such interviewer effects are well known and difficult to avoid in qualitative studies. However, as researcher's main goal was to obtain differentiated and authentic information detailing participants coping strategies, they were extra conscious of their possible influences. Therefore, it was imperative that an undisturbed, relaxed and trustworthy atmosphere was created. Despite such precautions, potential interviewer effects cannot be completely excluded without additional time and resources.

A final limitation was the restricted generalisability of findings to the general population of individuals with AA, as researchers elected to investigate adult female sufferers. However, given that numerous gender comparison and adolescents studies have been conducted,

researchers wanted to focus on consequences AA has on women solely, in addition to providing the needed information regarding specific coping strategies. The rationalisation for this decision was based on the evidences that AA is psychological more distressing for females compared to males, and for adults who have established the foundations of their life, rather than adolescents who are still finding their identity and pathways.

#### *4.9 Future Research Directions and Conclusion*

In spite of the mentioned limitations, this study confirms that AA can be problematic for women in a variety of ways. Combined with previous research, the current study has contributed a considerable amount of valuable information regarding the associations between hair loss and psychological wellbeing, in addition to presenting some compelling directions for future research.

Future studies should seek to measure the effects of AA with valid, reliable and responsive questionnaires specifically designed for individuals with AA. This would allow for supplementary comparisons between individuals with AA and the general population. Furthermore, ongoing attention should be given to ensure a sufficient sample size is obtained to facilitate the exploration of all potential confounding factors. Researchers could also consider focusing on the particular types of AA independently, as well as making appropriate comparisons. Moreover, due to the limited literature available regarding the duration of living with AA, future studies may elect to categorise participants according to their length of diagnosis to investigate whether duration results in psychological and psychosocial divergences.

Furthermore, future investigations may focus on stress reduction interventions specific to individuals with AA. Previous research has highlighted the strong relationship between stress



and AA onset, as well as the impact it can have on continued hair loss (Mounsey & Reed, 2009). For such reasons, measuring pre and post stress levels of AA sufferers and its impacts on hair regrowth and/or loss, in addition to the effects interventions have on their psyche, may be beneficial in assisting them live life to the fullest. Potential stress reduction techniques may include, meditation classes, hypnotherapy session, or listening to relaxation recordings. According to Thompson and Shapiro (1996) relaxation of the body and mind provides individuals with inner peace and the mental strength required to support coping with AA.

The current study achieved its original aims and has in consequence made a contribution to the profound psychological and psychosocial implications hair loss can have on women. Incorporating a mixed methods design helped conceptualise the affects AA has on women's self-esteem, mood, stress and coping simultaneously. Results coincide with previous research, supporting the notion that sufferers are at a higher risk of developing psychiatric disorders compared to healthy individuals. Although self-esteem did not significantly differentiate between groups, additional research is essential. In addition, the current study opposed measuring coping using predefined variables through standard measures, rather qualitatively exploring individual's subjective coping strategies. This approach, added in-depth information into participants coping processes, experiences and obstacles that endeavours to assist current and/or future sufferers. Throughout history, individuals have ascribed great importance to their physical appearance. Even to the present day society continues to impose certain trends and norms of what is 'physically attractive' which is partially determined by one's hair.

## REFERENCES

- Alfani, S., Antinone, V., Mozzetta, A., Pietro, C., Mazzantp, C., Stella, P., Raskovich, D., & Abeni, D. (2012). Psychological status of patients with alopecia areata. *Archives of Dermatology*, 92,304-306.
- Alkhalifah, A. (2011). Topical and intralesional therapies for alopecia areata. *Dermatologic Therapy*, 24, 355-363.
- Al-Mutairi, N., & Eldin, O. N. (2011). Clinical profile and impact on quality of life: Seven years experience with patients of alopecia areata. *Indian Journal of Dermatology*, 77(4), 489-493.
- American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders* (5<sup>th</sup> Ed.). Arlington, VA: American Psychiatric Publishing.
- Australian Alopecia Areata Foundation*. (2013). Retrieved February 23<sup>rd</sup>, 2013, from <http://www.aaaf.org.au>.
- Bertolino, P. (2000). Alopecia areata: A clinical overview. *Postgraduate Medicine*, 107(7), 81–85.
- Blascovich, J., & Tomaka, J. (1993). Measures of Self-Esteem. In J. P. Robinson, P. R. Shaver., & L. S. Wrightsman (Eds.). *Measures of Personality and Social Psychological Attitudes*. (pp. 115-160). Ann Arbor: Institute for Social Research.
- Borg, L., & Kennedy, A. G. (2012). Coping and the psychosocial impact of alopecia areata in young Australians: An exploratory study. Unpublished Honours Thesis, Victoria University, Victoria, Australia.

- Borsellino, M., & Young, M. M. (2010). Anticipatory coping: Taking control of hair loss. *Clinical Journal of Oncology Nursing*, 15(3), 311-315. doi: 10.1188/11.CJON.311-315.
- Brown, T. A., Chorpita, B. F., Korotitsch, W., & Barlow, D. H. (1997). Psychometric properties of the Depression Anxiety Stress Scales (DASS) in clinical samples. *Behaviour Research and Therapy*, 35(1), 79-89.
- Bull, R., & Rumsey, N. (1988). *The social psychology of facial appearance*. New York: Springer.
- Cartwright, T., Endean, N., & Porter, A. (2009). Illness perceptions, coping and quality of life in patients with alopecia. *British Journal of Dermatology*, 160, 1034-1039.
- Cho, H. H., Jo, S. J., Paik, S. H., Jeon, H. C., & Kwon, O. S. (2012). Clinical characteristics and prognostic factors in early-onset alopecia totalis and alopecia universalis. *Journal of Korean Medical Science*, 27, 799-802. doi: 10.3346/jkms.2012.27.7.799.
- Colón, E. A., Popkin, M. K., Callies, A. L., Dessert, N. J., & Hordinsky, M. K. (1991). Lifetime prevalence of psychiatric disorders in patients with alopecia areata. *Comprehensive Psychiatry*, 32(3), 245-51.
- Cohen, J. (1988). *Statistical power analysis for the behavioural sciences* (2<sup>nd</sup> Ed.). Lawrence Erlbaum Associates, NJ: Hillsdale.
- CordanYazici, A., Basterzi, A., Tot-Acar, S., Ustyunsoy, D., Ikizoglu, G., Demirseren, D., & Kanik, A. (2006). Alopecia areata and alexithymia. *Turkish Journal of Psychiatry*, 17(2), 1-6.
- Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. Crow's Nest, NSW, Australia: Allen and Urwin.

- Draelos, Z. D. (2011). Camouflage techniques for alopecia areata: What is a patient to do? *Dermatologic Therapy*, 24(3), 305-310. doi: 10.1111/j.1529-8019.2011.01417.x.
- Fiedler, V. C. (1992). Alopecia areata. A review of therapy, efficacy, safety and mechanisms. *Archives of Dermatology*, 128(11), 1519-1529. doi: 0.1001/archderm.1992.016802-10097016.
- Firooz, A., Firoozabadi, M. R., Ghazisaidi, B., & Dowlati, Y. (2005). Concepts of patients with alopecia areata about their disease. *BioMed Central Dermatology*, 5(1). doi:10.1186/1471-5945-5-1.
- Folkman, S., Lazarus, R. S., Dukel-Schetter, C. (1986). Dynamics of a stressful encounter: Cognitive appraisal, coping and encounter outcomes. *Journal of Personality and Social Psychology*, 50, 992-1003.
- Fox, J. (2003). Case study of alopecia universalis and web-based news groups. *British Journal of Nursing*, 9, 550-558.
- Freedman, T. G. (1994). Social and cultural dimensions of hair loss in women treated for breast cancer. *Cancer Nursing*, 17, 334-341.
- Friedmann, P. S. (1981). Alopecia areata and auto-immunity. *British Journal of Dermatology*, 105, 153-157.
- Garcia, C. (2010). Conceptualization and measurement of coping during adolescence: A review of the literature. *Journal of Nursing Scholarship*, 42(2), 166-185. doi:10.1111/j.1547-5069.2009.01327.x.
- Ghajarzadeh, M., Ghiasi, M., & Kheirkhah, S. (2011). Depression and quality of life in Iranian patients with alopecia areata. *Iranian Journal of Dermatology*, 14, 140-143.

- Green, J., & Sinclair, R. D. (2004). Alopecia totalis incognito. *The International Journal of Dermatology*, 43, 919-921.
- Gulic, A. T., Tanriverdi, N., Duru, C., Saray, Y., & Akcali, C. (2004). The role of psychological factors in alopecia areata and the impact of the disease on the quality of life. *International Journal of Dermatology*, 43, 352-356.
- Gupta, M. A., & Gupta, A. K. (1998). Depression and suicidal ideation in dermatology patients with acne, alopecia areata, atopic dermatitis and psoriasis. *British Journal of Dermatologists*, 139, 846-850.
- Harries, M. J., Sun, J., Paus, R., & King, L. E. (2010). Management of alopecia areata. *British Medical Journal*, 341, 242-246. doi:10.1136/bmj.c3671.
- Healy, E., & Rodgers, S. (1993). PUVA treatment for alopecia areata: Does it work? A retrospective review of 102 cases. *British Journal of Dermatology*, 129(1), 42-44.
- Hordinsky, M., & Avancini-Caramori, A. P. (2008). Alopecia Areata. In A. J. McMichael & M. K. Hordinsky (Eds.). *Hair and scalp diseases: medical, surgical, and cosmetic treatments* (pp. 91 - 105). doi: 10.3109/9781420018660.007.
- Hull, S. P. M., Wood, M. L., Hutchinson, P. E., Sladden, M., & Messenger, A. G. (2003). Guidelines for the management of alopecia areata. *British Journal of Dermatology*, 149, 692-699.
- Hunt, N., & McHale, S. (2005a). The psychological impact of alopecia. *British Medical Journal*, 331, 951- 953.
- Hunt, N., & McHale, S. (2005b). Reported experiences of persons with alopecia areata. *Journal of Loss and Trauma*, 10, 33-50. doi: 10.1080/15325020490890633.

- Hunt, N., McHale, S. (2007). The psychological impact of alopecia. *The Psychologist*, 20(6), 362-364.
- Ito, T. (2012). Advances in the management of alopecia areata. *Journal of Dermatology*, 39, 11-17. doi: 11.11/j.1346-8138.2011.01476.x.
- Jackow, C., Puffer, N., Hordinsky, M., Nelson, J., Tarrand, J., & Duvic, M. (1998). Alopecia areata and cytomegalovirus infection in twins: Genes versus environment? *Journal of American Academy Dermatology*, 38(3), 418-425.
- Kalabokes, V. D. (2011). Alopecia areata: Support groups and meetings- how can it help your patients? *Dermatologic Therapy*, 24, 302-304.
- Kalabokes, V., & Besta, R. M. (2001). The role of the National Alopecia Areata Foundation in the management of alopecia areata. *Dermatologic Therapy*, 14(4), 340-344.
- Kessler, R. C., McGonagle, K. A., Zhao, S., Nelson, C. B., Hughes, M., Eshleman, S., Wittchen, H. U., & Kendler, K. S. (1994). Lifetime and 12-month prevalence of DSM-III-R psychiatric disorders in the United States: Results from the National Co-morbidity Survey. *Archives of General Psychiatry*, 51, 8-19.
- Khan, S. A. (2008). Alopecia areata. *Physicians Academy*, 2(11), 110-112.
- Kökçam, I., Akyar, N., Saral, Y., & Oguzhanoglu, N. K. (1999). Psychosomatic symptoms in patients with alopecia areata and vitiligo. *Turkish Journal of Medical Sciences*, 29, 471-473.
- Koo, J. Y., Shellow, W. V., Hallman, C. P., & Edwards, J. E. (1994). Alopecia areata and increased prevalence of psychiatric disorders. *International Journal of Dermatology*, 33(12), 849-850.

- Kushon, D., McCown, W., Ditre, C., Posa, J., Hines, J., & Williams, L. (1996). Stressful life events and alopecia areata. *Loss, Grief and Care*, (7)3-4, 87-103.doi: 10.1300/J132v07n03\_08.
- Liakopoulou, M., Alifieraki, T., Katideniou, A., Kakourou, T., Tselalidou, E., Tsiantis, J., & Stratigos, J.(1997). Children with alopecia areata: Psychiatric symptomatology and life events. *Journal of American Academy Child and Adolescents Psychiatry*, 36, 678-684.
- Lovibond, S. H., & Lovibond, P. F. (1995). *Manual for the Depression Anxiety Stress Scales*. (2<sup>nd</sup> Ed.). Sydney: Psychology Foundation.
- Madani, S., & Shapiro, J. (2000). Alopecia areata update. *Journal of the American Academy of Dermatology*, 42, 549-566. doi:10.1067/mjd.200.103.909.
- Manolache, L., & Benea, V. (2007). Stress in patients with alopecia areata and vitiligo. *European Academy of Dermatology and Venereology*, 21, 921-928.
- Maslow, A. H. (1954). *Motivation and personality* (3<sup>rd</sup> Ed.). NY: Harper & Row.
- Matzer, F., Egger, J. W., & Kopera, D. (2011). Psychosocial stress and coping in alopecia areata: A questionnaire survey and qualitative study among 45 patients. *Acta Dermato-Venereologica*, 91, 318-327. doi:10.2340/00015555-1031.
- McDonagh, A. J. G., & Tazi-Ahnini, R. (2002). Epidemiology and genetics of alopecia areata. *Clinical and Experimental Dermatology*, 27, 409-413.
- McGarvey, E. L., Baum, L. D., Pinkerton, R. C., & Rogers, L. M. (2001). Psychological sequelae and alopecia among women with cancer. *American Cancer Society*, 9(6), 283-289.
- McKillop, J. (2010). Management of autoimmune associated alopecia areata. *Journal of Art and Science Dermatology*, 24(36), 42-46.

- Mounsey, A. L., & Reed, S. W. (2009). Diagnosing and treating hair loss. *American Academy of Family Physicians*, 80(4), 356-362.
- Murk, C. J. (2006). *Self-esteem research, therapy and practice: Towards a positive psychology of self-esteem* (3<sup>rd</sup> Ed.). NY: Springer Publisher Company.
- Otberg, N. (2011). Systemic treatment for alopecia areata. *Dermatologic Therapy*, 24, 320-325.
- Papadopoulos, A. J., Schwartz, R. A., & Janniger, C. K. (2000). Alopecia areata: Pathogenesis, diagnosis and therapy. *American Journal Clinical Dermatology*, 1(2), 101-105.
- Papadopoulos, L., & Bor, R. (1999). *Psychological approaches to dermatology*. Leicester: BPS Books.
- Perret, C., Wiesner-Menzel, L., & Happle, R. (1984). Immunohistochemical analysis of T-cell subsets in the peribulbar and intrabulbar infiltrates of alopecia areata. *Acta Dermato-Venereologica*, 64(1), 26-30.
- Petukhova, L., Cabral, R. M., Mackay-Wiggan, J., Clynes, R., & Christiano, A. M. (2011). The genetics of alopecia areata: What's new and how will it help our patients? *Dermatologic Therapy*, 24, 326-336.
- Picardi, A., Pasquini, P., Cattaruzza, M. S., Melchi, C. F., Papi, M., Camaioni, D., Tiago, A., Gobello, T., & Biondi, M. (2003). Psychosomatic factors in first-onset alopecia areata. *Academy of Psychosomatic Medicine*, 44(5), 375-374.
- Price, V. H. (2003). Androgenetic alopecia in women. *The Society for Investigative Dermatology*, 8, 24-27.
- Prickitt, J., McMichael, A. J., Gallagher, L., Kalabokes, V., & Boeck, C. (2004). Helping patients cope with chronic alopecia areata. *Dermatology Nursing*, 16(3), 237-241.



- Ranki, A., Kianto, U., Kanerva, L., Tolvanen, E., & Johansson, E. (1984). Immunohistochemical and electron microscopic characterization of the cellular infiltrate in alopecia (areata, totalis, and universalis). *Journal of Investigative Dermatology*, 83(1), 7–11.
- Reid, E. E., Haley, A. C., Borovicka, J. H., Rademaker, A., West, D. P., Colavincenzo, M., & Wickless, H. (2010). Clinical severity does not reliably predict quality of life in women with alopecia areata, telogen effluvium, or androgenic alopecia. *American Academy of Dermatology*, 66, 97-102. doi: 10.1016/j.jaad.2010.11.042.
- Robinson, J. P., Shaver, P. R., & Wrightsman, L. S. (1991). *Measures of Personality and Social Psychological Attitudes*. United States of America: Academic Press.
- Rosenberg, M. (1965). *Society and the adolescent self-image*. Princeton, NJ: Princeton University Press.
- Rumsey, N., & Harcourt, D. (2004). Body image and disfigurement: Issues and interventions. *Body Image*, 1, 83-97.
- Rushton, D. H. (2002). Nutritional factors and hair loss. *Clinical and Experimental Dermatology*, 27, 400-408.
- Sahin, S., Yalcin, B., & Karaduman, A. (1998). PUVA treatment for alopecia areata. *Dermatology*, 197, 245–247. doi: 10.1159/000018005.
- Sellami, R., Masmoudi, J., Mnif, L., Aloulou, J., Turki, H., Jaoua, A. (2012). The psychological impact of alopecia areata: A case-control study of 50 patients. *European Psychiatry*, 27, 1-3. doi: 10.1016/S0924-9338(12)75041-1.
- Semwal, B. C., Agrawal, K. K., Singh, K., Tandon, S., & Sharma, S. (2011). Alopecia: Switch to herbal medicine. *Journal of Pharmaceutical Research and Opinion*, 1(4), 101-104.

- Shallow, W., Edwards, J. E., & Koo, J. Y. M. (1992). Profile of alopecia areata: A questionnaire analysis of patient and family. *International Journal of Dermatology*, 31(3), 186-189.
- Shapiro, J. (2011). Dermatologic therapy: Alopecia areata update. *Dermatologic therapy*, 24(3), 301. doi: 10.1111/j.1529-8019.2011.01422.x.
- Shapiro, J., Wiseman, M., & Lui, H. (2000). Practical management of hair loss. *Canadian Family Physician*, 46, 1469-1477.
- Sharma, V. K., Dawn, G., & Kumar, B. (1996). Profile of alopecia areata in Northern India. *International Journal of Dermatology*, 15(1), 22-27.
- Smith, E. R., & Mackie, D. M. (2007). *Social Psychology* (3<sup>rd</sup> Ed.). Philadelphia, PA: Psychology Press.
- Smith, J. A. (1995). Semi-structured interviewing and qualitative analysis. In J. A. Smith, R. Harre., & L. Van Langehove (Eds.). *Rethinking Methods in Psychology*. (pp. 9-26). London, UK: Sage Publications.
- Tan, E., Tay, Y., Goh, C., & Giam, Y. C. (2002). The pattern and profile of alopecia areata in Singapore: A study of 219 Asians. *International Journal of Dermatology*, 41, 748-753.
- Taylor, S. E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. *American Psychologist*, 38, 1161-1173.
- Thiedke, C. C. (2003). Alopecia in women. *American Academy of Family Physician*, 67(5), 1007-1014.
- Thompson, W., & Shapiro, J. (1996). *Alopecia Areata understanding and coping with hair loss*. Baltimore, Maryland, United States of America: Johns Hopkins.
- Tosti, A., Bellavista, S., & Lorizzo, M. (2006). Alopecia areata: A long term follow up study of 191 patients. *Journal of the American Academy of Dermatology*, 55, 438-441.

- Tucker, P. (2009). Bald is beautiful: The psychosocial impact of alopecia areata. *Journal of Health Psychology, 14*(1), 142-151. doi: 10.1177/1359105308097954.
- Wang, E., & McElwee, K. J. (2011). Etiopathogenesis of alopecia areata: Why do our patients get it? *Dermatologic Therapy, 24*(3), 337-347. doi: 10.1111/j.1529-8019.2011.01416.x.
- Wasserman, D., Guzman-Sanchez, D. A., Scott, K., & McMichael, A. (2007). Alopecia areata. *International Journal of Dermatology, 46*, 121-131.
- Welsh, N., & Guy, A. (2009). The lived experience of alopecia areata: A qualitative study. *Body Image, 6*, 194-200. doi: 10.1016/j.bodyim.2009.03.004.
- Willemsen, R., Vanderlinden, J., Deconinck, A., & Roseeuw, D. (2006). Hypnotherapeutic management of alopecia areata. *American Academy of Dermatology, 55*, 233-237. doi: 10.1016/j.jaad.2005.09.025.
- Williams, J., Wood, C., Cunningham-Warburton, P. A. (1999). A narrative study of chemotherapy-induced alopecia. *Oncology Nursing Forum, 26*(9), 1463-1468.
- Williamson, D., Gonzalez, M., & Finlay, A. Y. (2001). The effect of hair loss on quality of life. *Journal of European Academy of Dermatology and Venerology, 15*, 137-139.
- Willig, C. (2008). *Introducing qualitative research in psychology* (2<sup>nd</sup> Ed.). Buckingham, UK: Open University Press.
- Yazdan, P. (2012). Update on the genetics of androgenetic alopecia, female pattern hair loss and alopecia areata: Implications for molecular diagnostic testing. *Seminars in Cutaneous Medicine and Surgery, 31*, 258-266. doi: 10.1016/j.sder.2012.08.003.

## APPENDIX A: Information to Participants Form



### INFORMATION TO PARTICIPANTS INVOLVED IN RESEARCH

#### **You Are Invited to Participate**

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You are invited to participate in a research project to investigate the impact alopecia areata has on women's self-esteem, depression, anxiety, stress and coping strategies. The study is entitled "The Bald Truth: An Investigation of the impact that Alopecia Areata has on Women's Self-Esteem, Mood and Coping Strategies".

This project is being conducted by a student researcher, Jessica K. Martino as part of an Honours Degree in a Psychology course at Victoria University, under the supervision of A/Prof. Gerard A. Kennedy from Victoria University.

The purpose of this study aims to examine the effect alopecia areata has on women's self-esteem, depression, anxiety and stress levels, in addition to exploring coping strategies sufferers utilise to facilitate managing the condition throughout their lives.

#### **Project Explanation**

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Previous research has demonstrated the possible risk of individuals with alopecia areata developing other health issues such as depression and anxiety. In addition, research has demonstrated that alopecia areata can negatively impact individual's self-esteem. Literature regarding coping strategies is still in its infancy, therefore coping strategies sufferer implemented will be explored.

The aim of this study will be to examine self-esteem, depression, anxiety and stress levels as well as coping, in women (18+ years old) with alopecia areata. In order to assess these issues, participants are required to complete a series of questionnaires. This research is also seeking participants to partake in an interview to gain a more in-depth analysis based on the research aims. This will allow for further exploration regarding women impacted by the condition and the effects on their self esteem, mood and coping.

The research also aims to identify factors that may assist people with alopecia areata to cope better with the condition.

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### **What Will I be Asked to Do?**

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You will be requested to complete a series of questionnaires: (1) Demographics Questionnaire (2) Rosenberg's Self-esteem Scale, (3) Depression, Anxiety and Stress Scale (DASS42), which are designed to measure self-esteem, depression, anxiety, stress, respectively. The completion of the questionnaires should take approximately 20 minutes. Interested participants should contact a member of the research team (see contact details below) to arrange delivery of questionnaire packages so you can complete the questionnaires in your own time. Participants can return completed questionnaires via regular post using an enclosed reply-paid envelope. In addition, if you would prefer to receive the questionnaire package electronically (e.g., via email), please contact researchers and supply your email address. You can return the completed questionnaires via regular mail or email. Note, any identifying information in an email to us will be deleted and we will only retain your completed questionnaires, to maintain anonymity of your responses.

Researchers are additionally seeking participants to partake in an interview. Interested participants will be further contacted by researchers to decide on a time and place of mutual convenience to collect interview data.

### **What Will I Gain From Participating?**

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You will assist research that may identify possible effective coping strategies and the psychological risks associated with alopecia areata. It is anticipated that by participating in this study, the information collected will promote beneficial coping strategies utilised by alopecia areata sufferers, in addition to enhancing self-esteem and reducing the risk of developing co-morbid disorders such as depression and/ or anxiety.

### **How Will the Information I Give be Used?**

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The data collected will be for research purposes and the completion of an Honours degree. The research will be published in a thesis, journal article/s, and poster format and presented during conference presentation/s. The research data will also be used to inform practice at Australian Alopecia Areata Foundation Inc. (AAAF Inc.). No personally identifying information will be used and any data that is reported will be as summary results across all participants.

### **What Are the Potential Risks of Participating in This Project?**

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By completing the questionnaires and answering interview questions you may become aware of issues concerning alopecia areata and/ or your general health that may be distressing. If you require support, Psychologist Prof. Mark Andersen will be available for assistance (Telephone: (03) 9919 5413).

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## **How Will This Project be Conducted?**

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Questionnaires will be sent to participants via regular post or, if preferred, via email. All email addresses and any personally identifying information provided will be deleted and the researchers will only retain anonymous hard copies of the completed questionnaires.

For consenting participants wanting to partake in an interview, researchers and participants will agree on the appropriate time and location. Participants will be required to answer open ended questions, which will take approximately 1 hour to complete. Participants are free to terminate or refuse to answer any question throughout the interview process.

Participation in the research is voluntary, and if you do choose to be a participant, you are free to choose not to answer any questions in the questionnaire if you would prefer not to. If you are interested in the research outcomes, you can apply to the Chief Investigator for a copy of a summary research report.

## **Who is Conducting the Study?**

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Victoria University

Chief Investigator:

Associate Professor Gerard A. Kennedy. His contact details are (03) 9919 2481 or [gerard.kennedy@vu.edu.au](mailto:gerard.kennedy@vu.edu.au)

Student Researcher:

Miss Jessica K. Martino. Her contact details are 0422 725 873 or [jessica.martino@live.vu.edu.au](mailto:jessica.martino@live.vu.edu.au)

Any queries about your participation in this project may be directed to the Chief Investigator listed above. If you have any queries or complaints about the way you have been treated, you may contact the Research Ethics and Biosafety Manager, Victoria University Human Research Ethics Committee, Victoria University, PO Box 14428, Melbourne, VIC, 8001 or phone (03) 9919 4148.

## APPENDIX B: Consent Form



### CONSENT FORM FOR PARTICIPANTS INVOLVED IN RESEARCH

We would like to invite you to take part in a study which aims to investigate the impact of Alopecia Areata on women's self-esteem and mood states, in addition to exploring coping with the condition.

The purpose of this study will be to examine self-esteem, depression, anxiety and stress levels, and coping strategies utilised to facilitate managing the condition. In order to assess these issues, participants are required to complete a series of questionnaires. This research is also seeking participants to partake in an interview to gain a more in-depth analysis based on the research aims. This will allow for further exploration regarding women impacted by the condition AA and the effects on their self esteem, mood and coping. If interested please contact researchers.

The research also aims to identify factors that may assist individuals with alopecia areata to cope better with the condition.

In giving your consent to participate in this research, you may become aware of issues regarding alopecia areata that were or are distressing. In the event that you require support, Psychologist Prof. Mark Andersen will be available for assistance, telephone: 9919 5413. Links to counselling services will be provided to all participants.

The benefits of participation may increase knowledge for alopecia areata sufferers about the relationship between the condition and combination of the psychological variables, possibly enabling preparedness and awareness of possible risks for mental health concerns. Due to limited research on alopecia areata and self-esteem, mood disorders and coping, this study may promote beneficial coping strategies in addition to increased community awareness of the psychological impact of alopecia areata.

#### CERTIFICATION BY SUBJECT

I, \_\_\_\_\_  
(Full name)

of \_\_\_\_\_  
(Suburb / town)

certify that I am at least 18 years old\* and that I am voluntarily giving my consent to participate in the study:

“The Bald Truth: An Investigation of the impact that Alopecia Areata has on Women’s Self-Esteem, Mood and Coping Strategies”

being conducted at Victoria University by: Jessica K. Martino under the supervision of A/Prof. Gerard A. Kennedy.

I certify that the objectives of the study, together with any risks and safeguards associated have been fully explained to me by:  
Jessica K. Martino,

and that I freely consent to participation involving the below mentioned procedures:

- Questionnaires regarding self-esteem, depression, anxiety and stress with the impact of alopecia areata.
- Partaking in an interview discussing the impact alopecia areata has on self-esteem, depression, anxiety, stress and coping with the condition.

I certify that I have been provided with and have read the document entitled “Information to Participants Involved in Research’ that explains this study,

I agree to the research data from this study may be published or provided to other researchers on the condition that my name is not used and the recording of data will not identify me,

I certify that I have had the opportunity to have any questions answered and that I understand that I can withdraw from this study at any time and that this withdrawal will not jeopardise me in any way.

I have been informed that the information I provide will be kept confidential.

Signed: \_\_\_\_\_

Date: \_\_\_\_\_

Any queries about your participation in this project may be directed to the researcher Associate Professor Gerard A. Kennedy.

Ph: (03) 9919 2481

If you have any queries or complaints about the way you have been treated, you may contact the Research Ethics and Biosafety Manager, Victoria University Human Research Ethics Committee, Victoria University, PO Box 14428, Melbourne, VIC, 8001 or phone (03) 9919 4148.



## APPENDIX C: Demographics Questionnaire (Alopecia Areata)



### Demographics Questionnaire (Alopecia Areata)

“The Bald Truth:

An Investigation of the impact that Alopecia Areata has on Women’s Self-Esteem,  
Mood and Coping Strategies”

1. Age in Years: .....

2. Gender:

☐ Male

☐ Female

3. Relationship Status:

☐ Single

☐ In a Relationship

☐ Married

☐ Other .....

4. Occupation:

☐ Unemployed

☐ Casual

☐ Part-time

☐ Full-time

☐ Other .....

5. Do you have a past or current medical or psychological history?  
(If yes please specify)

☐ No

☐ Yes .....

6. How long have you been diagnosed with having alopecia areata?

.....

7. Type of Alopecia Areata:

☐ Alopecia Areata Monocularis

☐ Alopecia Areata Multilocularis

☐ Alopecia Totalis

☐ Alopecia Universalis

☐ Other .....

8. Social Activity Level (excluding social networking sites / chat sites):

☐ Low

☐ Medium

☐ High

## APPENDIX D: Demographics Questionnaire (Controls)



### Demographics Questionnaire (Controls)

“The Bald Truth:  
An Investigation of the impact that Alopecia Areata has on Women’s Self-Esteem,  
Mood and Coping”

1. Age in Years: .....

2. Gender:

☐ Male

☐ Female

3. Do you have a past or current medical or psychological history?  
(If yes please specify)

☐ No

☐ Yes .....

## APPENDIX E: Rosenberg Self-Esteem Scale (RESE)

### Rosenberg Self Esteem Scale

Circle the appropriate number for each statement depending on whether you strongly agree, agree, disagree, or strongly disagree with it.

	Strongly Agree	Agree	Disagree	Strongly Disagree
On the whole, I am satisfied with myself.	1	2	3	4
At times I think I am no good at all.	1	2	3	4
I feel that I have a number of good qualities.	1	2	3	4
I am able to do things as well as most other people.	1	2	3	4
I feel I do not have much to be proud of.	1	2	3	4
I certainly feel useless at times.	1	2	3	4
I feel that I'm a person of worth, at least on an equal plane with others.	1	2	3	4
I wish I could have more respect for myself.	1	2	3	4
All in all, I am inclined to feel that I am a failure.	1	2	3	4
I take a positive attitude toward myself.	1	2	3	4

## APPENDIX F: Depression, Anxiety and Stress Scale (DASS42)

<b>DASS</b>	<b>Name:</b>	<b>Date:</b>
<p>Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you <i>over the past week</i>. There are no right or wrong answers. Do not spend too much time on any statement.</p> <p><i>The rating scale is as follows:</i></p> <p>0 Did not apply to me at all            1 Applied to me to some degree, or some of the time            2 Applied to me to a considerable degree, or a good part of time            3 Applied to me very much, or most of the time</p>		
1	I found myself getting upset by quite trivial things	0   1   2   3
2	I was aware of dryness of my mouth	0   1   2   3
3	I couldn't seem to experience any positive feeling at all	0   1   2   3
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0   1   2   3
5	I just couldn't seem to get going	0   1   2   3
6	I tended to over-react to situations	0   1   2   3
7	I had a feeling of shakiness (eg, legs going to give way)	0   1   2   3
8	I found it difficult to relax	0   1   2   3
9	I found myself in situations that made me so anxious I was most relieved when they ended	0   1   2   3
10	I felt that I had nothing to look forward to	0   1   2   3
11	I found myself getting upset rather easily	0   1   2   3
12	I felt that I was using a lot of nervous energy	0   1   2   3
13	I felt sad and depressed	0   1   2   3
14	I found myself getting impatient when I was delayed in any way (eg, lifts, traffic lights, being kept waiting)	0   1   2   3
15	I had a feeling of faintness	0   1   2   3
16	I felt that I had lost interest in just about everything	0   1   2   3
17	I felt I wasn't worth much as a person	0   1   2   3
18	I felt that I was rather touchy	0   1   2   3
19	I perspired noticeably (eg, hands sweaty) in the absence of high temperatures or physical exertion	0   1   2   3
20	I felt scared without any good reason	0   1   2   3
21	I felt that life wasn't worthwhile	0   1   2   3

*Reminder of rating scale:*

- 0 Did not apply to me at all
- 1 Applied to me to some degree, or some of the time
- 2 Applied to me to a considerable degree, or a good part of time
- 3 Applied to me very much, or most of the time

22	I found it hard to wind down	0	1	2	3
23	I had difficulty in swallowing	0	1	2	3
24	I couldn't seem to get any enjoyment out of the things I did	0	1	2	3
25	I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	0	1	2	3
26	I felt down-hearted and blue	0	1	2	3
27	I found that I was very irritable	0	1	2	3
28	I felt I was close to panic	0	1	2	3
29	I found it hard to calm down after something upset me	0	1	2	3
30	I feared that I would be "thrown" by some trivial but unfamiliar task	0	1	2	3
31	I was unable to become enthusiastic about anything	0	1	2	3
32	I found it difficult to tolerate interruptions to what I was doing	0	1	2	3
33	I was in a state of nervous tension	0	1	2	3
34	I felt I was pretty worthless	0	1	2	3
35	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
36	I felt terrified	0	1	2	3
37	I could see nothing in the future to be hopeful about	0	1	2	3
38	I felt that life was meaningless	0	1	2	3
39	I found myself getting agitated	0	1	2	3
40	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
41	I experienced trembling (eg, in the hands)	0	1	2	3
42	I found it difficult to work up the initiative to do things	0	1	2	3

## APPENDIX G: Semi-Structured Interview Questions



### Interview Questions

#### GENERAL

What type of AA do you have?

How long have you had AA?

Can to describe how you felt when you first noticed a patch or hair loss?

Can you describe some difficulties you have experienced as a result of being diagnosed with AA?

\*\*\*\*Mental, social, emotional, physical

Can you explain the impact of these difficulties over time?

\*\*\*\*Easier or harder over time?

Can you describe any changes you have made in your family life?

\*\*\*\*Why did you feel you needed to make these change?

\*\*\*\*How did these changes make you feel?

Can you describe any changes you have made in your personal relationships?

\*\*\*\*Why did you feel you needed to make these change

\*\*\*\*How did these changes make you feel?

Can you describe any changes you have made in your social interactions?

\*\*\*\*Why did you feel you needed to make these change

\*\*\*\*How did these changes make you feel?

Can you describe any changes you have made in your Workplace/school/home?

\*\*\*\*Why did you feel you needed to make these change

\*\*\*\*How did these changes make you feel?

Can you describe any changes you have made in your leisure activities?

\*\*\*\*Why did you feel you needed to make these change

\*\*\*\*How did these changes make you feel?

Can you think of any other life changes that you have made?

Are your family / friends aware of your condition?

(If YES) How and when did you tell them?

Was this hard for you?

(If NO) Why?

Can you explain some reasons why you would not tell someone about your condition?

\*\*\*\*How would that make you feel?

Can you provide some examples of when you have not told someone about your condition?

## **COPING**

Can you explain your reaction when you were first diagnosed with AA?

\*\*\*\*How did this make you feel?

\*\*\*\*What did you do?

How did you feel when you were informed that AA has no current cure?

\*\*\*\*How did this make you feel?

Did you find that your doctor/dermatologist supportive and knowledgeable?

(If YES / NO) In what ways?

Did they make the experience better or worse?

What was beneficial?

What could have been better?

Have you sought any treatments for your condition?

(If YES) Why?

\*\*\*\* Did you find it beneficial (why or why not?)

(If NO) Why?

Have you accepted that you have AA?

(If YES) How long did it take you?

What helped you to accept it?

(If NO) Why do you think this is?

Do you feel that you will ever?

Are there any times when you feel you have been less accepting of your condition?

\*\*\*\* Why do you think this occurred?

Can you tell me about any positive adjustments you have made in your life since being diagnosed with AA?



Can you tell me about any negative adjustments you have made in your life since being diagnosed with AA?

Can you describe any practical coping strategies you used to manage AA?

\*\*\*\* What is it like?

\*\*\*\* How does it make you feel?

\*\*\*\* Could you manage without them? Why?

Can you explain any stigmas you felt are attached to your condition?

(If YES) How does this make you feel?

How do you cope with this?

What was the most difficult aspect of being diagnosed with AA?

\*\*\*\* How did this make you feel?

\*\*\*\* Have you overcome this? (How)

Has AA impacted your emotional state?

(If YES) How?

Was / is this difficult to manage?

Has this affected your family, friends, work, or activities

What are some techniques you used to help deal with this emotional impact?

\*\*\*\* Positive / Negative

Can you tell me about any support networks you have utilised as result of your condition?

\*\*\*\* Were they useful? How?

What were your reasons behind using or approaching them?

\*\*\*\* How was it useful?

\*\*\*\* Was it ever not useful?

\*\*\*\* Do you still use (why/why not)

## **SELF – ESTEEM**

Has AA changed the way you view yourself?

(If YES) In what ways, Examples

Are there any ways that AA may make you feel positive about yourself?

(If Yes) Example

Are there any ways that AA may make you feel negative about yourself?

(If Yes) Example

Can you explain how you think AA changes your identity? (Example)

How do you think AA affects your physical appearance? (Example)

\*\*\*\*How does this make you feel?

Has AA has affected your relationships with others? (Family, friends)

\*\*\*\* In what ways? Positive / Negative

In what ways may being diagnosed with AA affect your ability to complete tasks?

\*\*\*\* Positive / Negative

Since being diagnosed with AA, can you describe any examples where you felt less motivated in life?

\*\*\*\* Why do you think this occurred?

Are there any examples where your condition has made you feel unsatisfied with yourself?

\*\*\*\*Why do you think this occurred?

Has being diagnosed with AA ever made you feel hopeless about anything?

(If YES) In what ways? Examples

Do you wish you could have more respect for yourself?

(If YES) In what ways do you feel this would be possible?

(If NO) Are there any way that AA has hindered this respect? Example

Have you ever felt less incline to succeed as a result of AA?

(If YES) In what ways? Examples

## **DEPRESSION, ANXIETY & STRESS**

Can you describe how you felt when you were first diagnosed with AA?

Has your first feeling about having AA changed?

(If YES) In what ways, Examples

(If NO) Why do you think this is?

Can you comment on your frame of mind when you were first diagnosed with AA? (Examples)

\*\*\*\*Positive / Negative

Can you comment on frame of mind now as a result of having AA? (Examples)

\*\*\*\*Positive / Negative

Have you experienced any changes in your mood since being diagnosed with AA?

(If YES) Why do you think this occurred?

How does it make you feel?

How have others reacted to these changes?

Has being diagnosed with AA, ever caused you to feel sad or unhappy?

\*\*\*\*\* Onset or Now

(If YES) Why do you think this occurred?

Has this affected your family, friends, work or activities?

Can you tell me how AA may have impacted the way you think about life? (Examples)

Can you describe how AA may cause you to feel anxious?

\*\*\*\*How did you overcome this feeling?

\*\*\*\*Do you often feel this way?

Can you describe some situation where your condition may have caused heightened anxiety levels?

(If YES) Why do you think this occurs?

Has this affected your family, friends, work, or activities?

Can you provide some examples when AA has caused you to lose interest in something?

\*\*\*\*How did this make you feel?

\*\*\*\*How did you overcome this?

Can you describe whether AA has impacted your stress levels? (Examples)

Can you describe some situations where your condition caused heightened stress levels?

(If YES) Why do you think this occurred?

Has this affected your family, friends, work or activities?

## **CLOSING**

On a whole, can you describe how you view your overall experience of living with AA?

What have you learnt about yourself, since being diagnosed with AA?

What have you learnt about others since being diagnosed with AA?

What words of wisdom or advice would you share with future or current individuals who have AA?

What advice helped you?

\*\*\*\*What advice would have helped you?

\*\*\*\*What advice was less effective?

How would you describe having AA to others who do not have the condition?

Is there anything else you would like to share about your experience?

## APPENDIX H: Victoria University Human Research Ethics Committee Approval

### Ethics Application – Approved

**Quest.Noreply@vu.edu.au**

Mon 8/04/2013 11:38 AM

**To:**

gerard.kennedy@vu.edu.au;

**Cc:**

jessica.martino@live.vu.edu.au;

Dear ASPR GERARD KENNEDY,

Your ethics application has been formally reviewed.

Application ID: HRE13-061

Application Title: Investigating the impact of Alopecia Areata on woman's self-esteem, mood states and coping.

The application has been accepted and deemed to meet the requirements of the National Health and Medical Research Council (NHMRC) 'National Statement on Ethical Conduct in Human Research (2007)' by the Victoria University Human Research Ethics Committee. Approval has been granted for two (2) years from the approval date; 08/04/2013.

Continued approval of this research project by the Victoria University Human Research Ethics Committee (VUHREC) is conditional upon the provision of a report within 12 months of the above approval date or upon the completion of the project (if earlier). A report proforma may be downloaded from the Office for Research website at: <http://research.vu.edu.au/hrec.php>.

Please note that the Human Research Ethics Committee must be informed of the following: any changes to the approved research protocol, project timelines, any serious events or adverse and/or unforeseen events that may affect continued ethical acceptability of the project. In these unlikely events, researchers must immediately cease all data collection until the Committee has approved the changes. Researchers are also reminded of the need to notify the approving HREC of changes to personnel in research projects via a request for a minor amendment. It should also be noted that it is the Chief Investigators' responsibility to ensure the research project is conducted in line with the recommendations outlined in the National Health and Medical Research Council (NHMRC) 'National Statement on Ethical Conduct in Human Research (2007).'

On behalf of the Committee, I wish you all the best for the conduct of the project.

Secretary, Human Research Ethics Committee  
Office for Research  
Email: [researchethics@vu.edu.au](mailto:researchethics@vu.edu.au)

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This is an automated email from an unattended email address. Do not reply to this address.

## APPENDIX I: Australian Alopecia Areata Foundation Research Approval

### RE: Alopecia Areata Research

Chel Campbell [chel@aaaf.org.au]

**Sent:** Wednesday, 27 March 2013 1:12 PM

**To:** Jessica Martino [jessica.martino@live.vu.edu.au]

**Cc:** Gerard Kennedy [Gerard.Kennedy@vu.edu.au]

Hi Jessica,

Your idea was floated at the Committee Meeting and everyone thought that your ideas would generate interest within the community and provide valuable results that we could share.

Cheers,

Chel Campbell  
President  
0412921013  
[www.aaaf.org.au](http://www.aaaf.org.au)

