

Coping and the Psychosocial Impact of Alopecia Areata in Young Australians: An Exploratory Study

Submitted by

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Abstract

Alopecia Areata (AA) is a chronic condition, causing individuals to lose hair. AA affects approximately 2% of individuals and may have a substantial psychological effect on diagnosed individuals. There has been minimal research conducted in Australia, in regards to coping, quality of life, depression and anxiety simultaneously. The study aimed to determine whether anxiety, depression and stress were elevated in young people with AA in comparison to normative data from the Depression, Anxiety and Stress Scale (DASS42), from a young adult Australian sample and an adult sample from the UK. The study also examined the relationship between quality of life and the psychological state measured in participants with AA. In addition, the study explored coping strategies used by young people with AA.

Forty-two participants with AA were required to complete an online questionnaire comprising of demographic questions, the Brief COPE, Skindex-29 and the DASS42. The results showed that young people with AA did not have elevated anxiety or depression in comparison to normative data for a young Australian sample. However, the results did show that significantly higher depression scores in comparison to a community based adult sample. There were strong positive correlations between both anxiety and depression, and quality of life. In terms of quality of life and everyday concerns, public reactions and emotions were impacted the most. Coping strategies identified from qualitative data as the most frequently used included the following: (1) acceptance; (2) support and (3) use of wigs and head pieces. The brief COPE yielded responses as being the most frequently used such as active coping, support and acceptance, consistent with the short answer responses. The findings suggest that increasing community education and awareness about AA would be beneficial and that more detailed research exploring the issues facing young people with AA are needed for this vulnerable group. The information gathered from this research will be provided to the

Australian Alopecia Areata Foundation Inc. to assist in tailoring their counselling services to better serve people coping with AA.

Declaration

I, Louise Borg, declare that this Bachelor of Psychological Studies (Honours) thesis does not incorporate any materials 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.

Signature:

Name: Louise Borg

Date: October 2012

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List of Abbreviations

AA	Alopecia Areata
AAAF	Australian Alopecia Areata Foundation
AA Monocularis	Alopecia Areata Monocularis
AA Multilocularis	Alopecia Areata Multilocularis
AAT	Alopecia Areata Totalis
AAU	Alopecia Areata Universalis
DASS42	Depression Anxiety and Stress Scale

1.0 Introduction

The Symbolic Importance of Hair

Throughout history, great symbolic importance has been placed on hair (Grimalt, 2005). Stories have dated back to biblical times and one of the best known examples is of Samson losing his strength when Delilah cut off his hair. With the return of his hair, came his strength and ability to destroy his enemies (Thompson & Shapiro, 1996). Consistently, society's preoccupation with hair has been a focal point even as fashion changes with time. This still exists in the present day, with imposing trends and norms of physical attractiveness partially determined by hair (Grimalt, 2005). Given the symbolic importance placed on hair throughout time and its representation of strength and beauty, it is not surprising that hair loss may trigger adverse psychological effects within a person. This may reflect the fact that hair may provide a person with elements of individuality and identity. A new hairstyle may not only provide an "image-change", but definition of the face and perhaps, character (Grimalt, 2005).

Alopecia Areata (AA) is a hair loss condition. The word alopecia means 'baldness or loss of hair' and areata means 'occurring in patches' (Green & Sinclair, 2004). While it is not a life-threatening disorder, it has been associated with a variety of negative psychosocial impacts in sufferers (Hunt & McHale, 2007). This may be partly due to society being enamoured with physical appearance. For example, the media bombards us a daily basis with images of celebrities promoting hair products, which are in turn associated with beauty and personal success. Thus, this association between hair and psychosocial wellbeing and success can lead to those baldness issues suffering from various feelings of psychological inadequacy (Kalabokes & Besta, 2001). Furthermore, the nature of the disease is unpredictable and relapse is common, with psychological symptoms impacting upon daily functioning. This

uncertainty can impede the journey of acceptance creating a roller-coaster ride of emotions and experiences leading to a sense of lack of control over the body.

Types of Alopecia Areata and Clinical Manifestation

Alopecia Areata (AA) is a chronic, spontaneous disorder characterised by partial or total hair loss (Prickitt, McMichael, Gallagher, Kalabokes & Boeck, 2004). Although the scalp is the most commonly affected area, any hair bearing site on the body can be affected, such as the face, limbs or pubic regions (Hunt & McHale, 2007). AA has several clinical presentations, with severity of hair loss varying significantly between individuals (Harries, Sun, Paus & King, 2010). The most common forms of AA (excluding Androgenetic Alopecia Areata or male pattern baldness) are Alopecia Areata Monocularis, Alopecia Areata Multilocularis, Alopecia Areata Totalis (AAT) and Alopecia Areata Universalis (AAU). AA Monocularis causes hair loss on a singular or isolated area, which may occur on any part of the scalp (see Figure 1). AA Multilocularis describes multiple patches of hair loss that may merge together forming larger areas of hair loss (Hordinsky, 2001) (see Figure 2). AAT and AAU are the two most severe forms (Harries et al., 2010). AAT causes complete loss of hair from the scalp (see Figure 3). The complete loss of scalp and body hair including the eyebrows, eyelashes, pubic hair and limb hair is known as AAU (see Figure 4). In all four AA variants, hair loss occurs with no scarring or permanent damage to the affected area (Harrison & Sinclair, 2003; Hunt & McHale, 2007).



Figure 1: Alopecia Areata Monocularis showing patchy hair loss (Photo Courtesy of the AAAF Inc.)



Figure 2: Alopecia Areata Multilocularis showing multiple patches of hair loss (Photo Courtesy of the AAAF Inc.)



Figure 3: Alopecia Areata Totalis showing complete loss of scalp hair (Photo Courtesy of the AAAF Inc.).



Figure 4: Alopecia Areata Universalis showing complete loss of hair from all parts of the body, including eyebrows, eyelashes and body hair (Photo Courtesy of the AAAF Inc.).

Aetiology and Prevalence

The exact cause of AA remains unknown, although several potential causes have been identified that may trigger the immunologic onset of AA (Delamere, Sladden, Dobbins, Leonardi-Bee, 2008; Hunt & McHale, 2005; Kalish & Gilhar, 2003). These factors include genetic predisposition (Green & Sinclair, 2000), emotional and physical traumatic events, even dating back to childhood (Williamsen, Vanderlinden, Roseeuw & Haentjens, 2008), psychological stress (McKillop, 2010) and neurologic factors (Madani & Shapiro, 2000).

The prevalence of AA has not been extensively researched in Australia. However, according to the Australian Alopecia Areata Foundation (AAAF 2012), approximately 2% of the Australian population have some form of AA (which does not include male-pattern baldness). It has been reported that the prevalence of AA is the same in both males and females and that there is no racial preponderance (Price, 1991). AA may affect individuals at any age, from infancy to adulthood (Delamere et al., 2008; Prickett et al., 2004). However, according to Price (1991), approximately 60% of individuals develop AA before 20 years of age.

Treatment

Currently there is no cure, real or effective preventative treatments for AA. It is suggested that treatments that are available only suppress the underlying process (Hordinsky & Avancini Caramori, 2008). Treatment options differ for children less than ten years of age and for children older than ten years of age up to adulthood. However, the extent of hair loss (more or less than 50%), duration of AA and historical factors must be considered when choosing an appropriate treatment (Hordinsky & Avancini Caramori, 2008; Wasserman, Guzman-Sanchez, Scott & McMichael, 2007). In addition, the extent to which factors such as the general health and the psychological state of the individual also play a role in the disorder should also be considered (Thompson & Shapiro, 1996).

Most forms of treatment include either oral medications, topical creams or injections. Corticosteroids can be taken as pills orally, injected into the skin or applied as a cream. Photochemotherapy is a treatment using ultraviolet light, also known as PUVA (Wasserman et al., 2007). The type of treatment chosen usually depends on age and the amount of hair loss. Alternative therapies such as naturopathy, homeopathy, acupuncture, oils and aroma therapy have been trialled by AA sufferers, but there is limited evidence of the effectiveness and few clinical trials of treatments have been conducted.

Treatment is not a viable option for many individuals because the side-effects often outweigh minimal benefits derived from the majority of treatments available (Wasserman et al., 2007). Thus, it is usually better to promote effective coping strategies to newly diagnosed individuals or those dealing with relapse, due to the unpredictable nature of the condition (Shapiro & Madani, 1999). It is essential that effective coping skills are developed because there is no real treatment available and relapse is common in many cases of AA. It has been suggested that counselling or therapy is imperative upon diagnosis, to assist the individual with adjustment to the condition, and also for support and education about AA and the possibility of relapse (MacDonald Hull, Wood, Hutchinson, Sladden, & Messenger, 2003).

Definition of Coping

In circumstance where there are challenges to body image, strategies need to be developed by the individual to deal with feelings, thoughts and situations which may be distressing (Cash, Santos & Flemming-Williams, 2005). Occasionally, the strategies utilised are negative and only provide short-lived relief from discomfort and distress. The original work of Seyle (1978) regarding stages of the stress response has been the foundation for other research examining peoples' responses to various real or imaged threats to their wellbeing. In

particular dealing with negative diagnoses has been studied by a number of researchers (Garcia, 2009; Harries et al., 2010; Matzer, Egger & Kopera, 2001).

Lazarus and Folkman (as cited in Garcia, 2009, p. 168), describe coping as “the cognitive and behavioural efforts a person employs to manage stress”.

Coping Research

In general, coping during adolescence and adulthood has been extensively researched. However, despite the major psychosocial consequences associated with AA, it has become apparent that the literature regarding specific coping mechanisms is limited (Cartwright, Endean & Porter, 2009). Some research has focused on coping with AA practically, socially and emotionally (Thompson & Shapiro, 1996), yet evidence of specific, beneficial coping strategies for young individuals with AA is limited (Matzer, Egger & Kopera, 2001). The effects of AA may cause emotional changes, physical and/or social changes. The effects of AA may also affect family members, partners and loved ones, creating feelings of sorrow or sympathy. Parents may feel guilty or vulnerable, watching their child suffer with AA and the unpredictability of the condition, perhaps at times wondering if there may be an underlying illness or if something more can be done to improve the situation for their child (Thompson & Shapiro, 1996).

Coping capacity and effectiveness varies between individuals. Different methods may or may not work for particular individuals dealing with AA. It has been suggested that if an individual with AA surrounds themselves with positive, supportive people by building trustworthy and meaningful relationships with family and friends that this can assist with coping (Harries et al., 2010). Expressing thoughts and feelings enhances the coping process because it enables sharing of experiences and focuses on cultivating a supportive and understanding environment (Thompson & Shapiro, 1996). It is suggested that charity support groups may benefit individuals with AA providing an atmosphere of belonging and non-

judgment. This may also help an individual feel as though they are not isolated and can share experiences about AA (Prickett et al., 2004).

McKillop (2010) suggests that encouragement about discussing feelings is important. This may be achieved through talking to someone in a similar situation, family members, friends or a psychologist and/or counsellor. These methods have been considered effective for some individuals with AA (Prickett et al., 2004). This may encourage the individual with AA to learn about life perspectives and the challenges it presents. Friends, family or therapy may assist with support in terms of providing a positive view on the situation. In more recent times there has been an increased focus on research, support, public education and awareness about AA, which has tended to facilitate support for individuals via better knowledge about the condition (Kalabokes & Besta, 2001).

Humour may be another way to lighten up a situation, but it is not recommended practice because it may lead to the concealment of real emotions. Humour may be useful when and if an individual has accepted their condition and is feeling very positive about their situation (Thompson & Shapiro, 1996).

It is suggested that confidence is a key aspect to coping well with any situation (Thompson & Shapiro, 1996). Being practical about hair loss may mean gaining knowledge and acquiring correct facts about AA. Being confident may help an individual better cope with the condition and provide a basis for understanding, which may help them feel as though they have control over some aspects of AA (Harries et al., 2010). This may include expectations about the condition and treatment options. Excellent sources of knowledge can be gained through volunteer community support groups such as the Australian Alopecia Areata Foundation Inc. (AAAF). The AAAF is one organisation that provides support to those with AA as well as their families. Public awareness is promoted through awareness week, the World Wide Web, newsletters, research and education. In addition to this, the

AAAF Inc. aims to raise funds for assisting the development of a cure and/or viable treatments (AAAF, 2012).

The research has shown that planning or actively coping with a diagnosis (or relapse) of AA may mean that individuals may choose to wear hair pieces and head covers such as wigs, scarves, beanies and hats (Harries et al., 2010; McKillop, 2010). For some, this may help boost self-esteem and confidence, while for others it may feel as though they are concealing the real problem and thus impede the journey of acceptance or they may simply not be able to afford the added financial expense of cosmetics such as wigs (McKillop, 2010).

Accessories have been identified as beneficial in terms of coping with AA (Thompson & Shapiro, 1996). For women, accessories such as (petite) fake eyelashes may provide protection for the eyes and provide a sense of femininity. Using eyebrow pencils to lightly draw on eyebrows may also help. Wearing glasses with plain lenses (if no need to wear them for ophthalmological reasons) may work well to cover missing eyebrows for individuals that may not be comfortable using eyebrow pencils and especially for men (Hunt & McHale, 2005; Thompson & Shapiro, 1996). Glasses also serve as eye protection from dust, wind and rain, which is the purpose of eyelashes. Other accessories such as caps, beanies and scarves may also provide protection to the scalp from extreme weather conditions and may help conceal hair loss for an individual with AA (Hunt & McHale, 2005).

Maintaining low stress levels by means of religion, spirituality or meditation such as yoga may assist with coping. Relaxation may be able to provide an individual with inner balance, peace and the mental strength to face challenges. Pampering the body through massage can provide another means of maintaining low stress levels (Thompson & Shapiro, 1996). Maintaining a healthy lifestyle can strengthen an individual's ability to cope with AA. This may be achieved through exercise and a well balanced diet (Thompson & Shapiro, 1996).

Coping styles can vary from person to person and while some people may adopt a more positive approach to coping, for instance positive reframing or planning, others may take on a more maladaptive style of coping (Garcia, 2010). Maladaptive coping styles may include smoking or substance use, denial, behavioural disengagement, self-blame, self-distraction, suicide or high-risk sexual behaviours (Garcia, 2010). Denial may be used as a strategy to ignore the problem and hope the issue may go away and solve itself. Substance use, which includes smoking, is generally identified as a self-destructive behaviour and it is likely to cause harmful consequences (Frydenberg, 1997).

Withdrawal, isolation and self-distraction, may be negative psychosocial aspects of coping associated with AA (McKillop, 2010). Withdrawal can be achieved via withdrawal from society or immersing one's self in work, school or other activities such as video-games and/or reading. While these coping mechanisms may be beneficial and assist with detracting the person from the negative thoughts on a short-term basis, using them on a long-term basis may impair acceptance of the condition and/or impair their ability to cope with stressors because the problem has not been effectively dealt with (McKillop, 2010). Venting consistently used in a maladaptive manner may include constant negative thoughts and language, which may create anxiety, worry and self-blame (Thompson & Shapiro, 1996). While discussion of issues and concerns should be encouraged, it has been suggested that feelings and thoughts should be shared in a safe and non-judgemental environment (Kalabokes & Besta, 2001).

Factors such as gender and age, can influence the type of coping style adopted in the various threatening or stressful situations (Wilson, Pritchard & Revalee, 2005). While some adolescents demonstrate resilience to stress, many do not cope well and may experience depressive episodes or diminished quality of life due to ineffective coping (Garcia, 2010).

Education about effective coping styles may assist avoiding the dangers of destructive and potentially long-lasting, harmful consequences of negative coping styles (Garcia, 2010).

Increasing awareness of positive coping strategies is imperative to enhance the well-being of individuals with the condition AA. This may improve dealing with the condition or relapse and may lead to positive health outcomes. Further research is essential to investigate in more depth the negative and positive coping styles utilised by individuals with AA.

Quality of Life

Adolescents who are affected by AA may find it very difficult to “fit in” and are also generally concerned about physical appearance, with most trying to conform to current fashion trends. Adolescents are just beginning to shape their lives so maintaining relationships with the opposite sex can be difficult and awkward. Suffering from AA may create negative feelings such as humiliation, anxiety and low self-esteem, which in turn impact on their quality of life (Williamson, Gonzalez & Finlay, 2001). This may be caused by people staring or saying hurtful things, being bullied or facing ridicule at school (Kalabokes & Besta, 2001). Avoidance may be an aspect of how an individual copes with AA for example avoiding school or social events and interaction. They may feel uncomfortable disclosing their condition to peers and in turn, feelings of isolation may arise in those with AA (McKillop, 2010). Isolation and withdrawal may lead to increased feelings of depression which may negatively impact on the quality of life of the individual with AA.

The condition has been linked to negative psychosocial consequences such as emotional pain and suffering, negative effects on daily functioning and lifestyle and physical aspects or symptoms brought on by the condition or caused by treatments which may be painful or result in distressing side-effects (Hunt & McHale, 2005; Fox, 2003). Hunt and McHale (2005) conducted a study in relation to the psychological concerns associated with

AA, with three major themes emerging. A total of 196 participants were involved in this study, 162 wrote about their experience of AA and 34 participants were interviewed through an interactive email process.

Hunt and McHale (2005) found daily social functioning was low and some individuals with AA found it difficult to cope at school due to negative experiences. One response "*I was teased a lot and so had a lot of time off school*" (Hunt & McHale, 2005, p. 43), demonstrated the profound effect that this condition can have on a child or adolescent. Teasing from peers may adversely impact education especially if there are prolonged absences. Avoiding school may cause a child to be held back or a sense of isolation and difference. One participant expressed "*it is not much fun being a bald teenager*" (Hunt & McHale, 2005, p. 42), highlighting an unpleasant social implication of living with AA.

Functioning may also affect an individual with AA in the workplace. Insensitivity from co-workers; thoughts of others making comments – whether perceived or real and avoidance of work due to high anxiety, low self-esteem and/or confidence could impair everyday functioning (Hunt & McHale, 2005). A response indicated the negative impact AA had on work "*I have had more time off sick in the last 2.5 years with minor things than I have ever had off in my working life*" (Hunt & McHale, 2005 p. 38). There was an indication that AA created complexity and this was faced in everyday circumstances. Responses identified concerns about wearing wigs and the impact it has on their daily functioning "*My hair loss has had quite a profound effect on my life and I am just hoping that, one day, I can have a head of hair and not worry about my wig blowing off every time it is windy or I dive into the swimming pool*" (Hunt & McHale, 2005, p. 39). Another response communicated the inconvenience of wearing a wig, "*I have had to suffer wearing a wig ever since [1967]...it is harder to cope with now than when I was younger*" (Hunt & McHale, 2005, p. 40)

Symptoms of AA and the physical effects of losing hair, may bring with it additional concerns. Varied responses demonstrated the consequence of AA, in particular AAU when scalp and body hair is lost. Examples of this were “*My nose runs more than it used to due to lack of nasal hair*” and “*Eyes become dry and sore*” (Hunt & McHale, 2005, p. 37). Loss of eyebrows and eyelashes may affect the individual physically and emotionally. Physically, eyebrows and eyelashes protect the eye from rain and dust particles. Eyelashes help the eyelids turn outwards, without lashes, the eyelids are not protected and the cornea may become irritated more often than it would if eyelashes were present (Hunt & McHale, 2007). Eyebrows frame the face and help form expressions. Without eyebrows, expressing emotions through facial expressions may be difficult to achieve, therefore individuals with AA may feel as though they have lost the ability to express themselves.

Temperature may also profoundly affect those with AA. Hair protects the scalp from the sun in the hotter seasons and on the other end of the spectrum it serves as an insulator from heat escaping during the colder seasons. One respondent expressed “*Extreme temperatures have a surprising effect*” (Hunt & McHale, 2005, p. 37). Many responses indicated that wearing a wig during hotter temperatures caused overheating. Thompson and Shapiro (1996) record details about a day in the life of a person with AA. One aspect they pointed out was when the person wakes up feeling cold because their night cap kept falling off. The authors discussed how the individual can feel tired and restless during the night due to feeling cold and uncomfortable.

Emotions can be heavily impacted with a diagnosis of AA. Accepting changes may create a feeling of vulnerability and negative self-image. One respondent stated “*When it first happened I felt like a freak, lost all confidence in myself and was ashamed to go out*” (Hunt & McHale, 2005, p. 39). A diagnosis of AA provoked a traumatic response from one individual “*When I first discovered my alopecia I decided that I would not want to live if I*

lost all my hair. I seriously considered suicide that night" (Hunt & McHale, 2005, p. 39). This clearly demonstrated a massive impact on the quality of life and the associated distress, the feelings of loss, hopelessness, helplessness, and depression.

One response focused on the treatments that the person had tried, *"Travelled the country to find a cure"* (Hunt & McHale, 2005, p. 44), It demonstrated the lengths they had gone to in order to find a cure. Others wishing for a *"Miracle cure"* (Hunt & McHale, 2005, p. 44).

Finally, another aspect of importance was that of doctors' attitudes towards AA. Some respondents indicated that they felt helpless and there was a lack of support. One interviewee stated that after a visit to the doctor, they were advised to wear a wig and were told: *"after all it's only your pride that's hurt"* (Hunt & McHale, 2005, p. 46). Understanding and support are essential to an individuals' quality of life, possibly facilitating coping with the condition in a positive manner.

Web-based research conducted by Fox (2003), found some common themes among those with AA. The discourse was monitored for 18 months within a net-based support group with the majority of members based in the USA. The themes which emerged from the discussion explored concepts and the impact AA has on life. Almost 26% of the communications raised were about the unpredictability of hair loss, looking and feeling different and loss of self-confidence and self-esteem and also the emergence of a sense of fear (Fox, 2003). The impact of dealing with the uncertainty of hair loss and dealing with implications such as anxiety were raised with some individuals choosing to focus on self-growth and confidence (Fox, 2003).

The emotional impact of AA was examined and issues such as trust, isolation, despair, uncertainty, anger and insight were discussed among 29% of the communications (Fox, 2003). It impacted individuals in relation to loss of self-identity and esteem and searching for

a new self. Symptoms emerged as a concern in this research, with 22% of individuals experiencing difficulty in terms of loss of eyebrows (and the pain experienced by cosmetic stencilling), pitting of the nails, as well as concerns in relation to the warmer weather and having a difficult time coping with the overall concern. The impact on daily functioning may be strenuous for some more so than others. A woman expressed that she did not let her husband see her wigless - the upkeep of maintaining the outer-work of AA can be mentally exhausting and physically draining (Thompson & Shapiro, 1996). One individual requested advice in relation to coping at work while wearing a wig. The forum addressed various aspects for individuals with AA. It provided an opportunity for practical ideas and advice, an outlet for understanding and support by others in a similar situation (Fox, 2003), education and extended knowledge and coping with a condition that has minimal social understanding.

Firooz, Firoozabadi, Ghazisaidi and Dowlati (2005) conducted a study in Iran which included 80 patients aged between 13 and 56 years. The Illness Perception Questionnaire (IPQ) was used in this study assessing cause, timeline, consequences and cure/control. The subscale which consisted of beliefs about consequences of having AA revealed significant findings especially among the younger participants. Approximately 58% believed that AA had major consequences for their life; almost 54% felt that AA negatively affected their self-esteem and nearly 51% considered AA as a serious condition. This indicated that AA had seriously impacted upon their quality of life (Firooz et al., 2005).

Dubois et al. (2010), used an approach combining three measures, the SF36 (Short Form 36), VQ-Dermato and Skindex-29, to assess the impact that AA has on quality of life. The participants were aged 16 years and over, recruited from a hospital based French sample. Although the sample was not representative of a community-based sample the results demonstrated impairment in quality of life in individuals with AA; especially impacting self-

perception, mental health and social life. This indicated a relationship between lowered quality of life and impact on their psychological well-being.

Psychological States - Depression and Anxiety

Depression is one of the most prevalent and debilitating disorders worldwide and it has become increasingly recognised that it begins in adolescence (Hankin, 2006). According to the DSM-IV-TR (2000), depression is characterised by symptoms including changes in appetite or weight, sleep, and psychomotor activity; decreased energy; feelings of worthlessness or guilt; difficulty thinking, concentrating, or making decisions; or recurrent thoughts of death or suicidal ideation, plans, or attempts. The aetiology of depression stems from various factors which include genetics, the environment, negative life events, cognitive vulnerabilities, and other psychological aspects (Hankin, 2006). A diagnosis of AA has been shown to trigger depression in some individuals (Koo, Shellow, Hallman & Edwards, 1994).

Generalized Anxiety Disorder often co-occurs with Mood Disorders such as Major Depressive Disorder or with other Anxiety Disorders such as Panic Disorder, Social Phobia, and Specific Phobias. This has been shown to be common among individuals with AA (Koo et al., 1994; Kokcam, Akyar, Saral & Oguzhanoglu 1999). According to the DSM-IV-TR (2000), Anxiety is characterised by symptoms such as restlessness, easily fatigued, concentration difficulties, irritability, muscle tension and sleep disturbances. Impairments in social and/or occupational functioning may occur when the person finds it difficult to control the anxiety.

Depression and Anxiety: The Research

Several studies have indicated an increased prevalence of psychological distress among people with AA (Ataseven, Saral & Godekmerdan, 2011; Koo, et al, 1994). Koo et al.

(1994) suggested that people with AA may be at a higher risk of developing depression, anxiety or other disorders such as social phobia or paranoid disorder. In their study, a questionnaire was distributed throughout the United States and abroad. A total of 294 responses were analysed. It was revealed that almost 9% of individuals with AA had a major depressive episode, compared to the general population range with a prevalence rate of approximately 1% to 4%. Generalised anxiety was diagnosed in approximately 18% of individuals with AA, compared to approximately 2% prevalence among the population sample. This anxiety rate was approximately eight times that of the population (Koo et al., 1994). This identified higher risk of clinical co-morbidity developing in AA patients.

Common psychological themes emerged from the Hunt and McHale (2007) research article. AA was stated to be the foundation for some individuals becoming reclusive, impacting upon their quality of life and feeling humiliated or anxious due to concerns about people commenting on their physical appearance. The psychological distress associated with AA identified may coincide with the risk of developing depression, anxiety or other disorders such as social phobia or paranoid disorder if excessive worrying and stress is consistent.

Kokcam, et al., (1999) conducted a study of psychosomatic symptoms in patients with Vitiligo and AA. The focus of the study was based on the effect that impaired appearance has on the lives of people with either condition. A total of 17 patients with the condition AA and twenty controls aged between 10 and 60 were assessed using the Zung Depression Scale and SCL-90-R (Symptom Check List 90-R). The results revealed a total of 36% of AA cases presented with raised depression scores in comparison with 15% of the control group. This indicated that depression was almost two and a half times higher in the group with AA. The SCL-90 R Scale results also indicated significant differences between the AA group and the control group. AA sufferers presented with higher levels of symptoms including interpersonal relationship difficulties, depression, anxiety, phobic reaction and paranoia (Kokcam et al.,

1999). The researchers concluded that there is an immense importance tied up in people's physical appearance and that it negatively affects the lives of people with AA. Relationship difficulties were identified in the Kokcam et al's (1999) study. Socially, AA can have a dramatic negative effect on the individual.

A study conducted by Ruiz-Doblado, Carrizosa and Garcia-Hernandez (2003), included 32 participants aged between 16 and 67 years. The researchers reported that approximately 22% of individuals' with AA experienced generalised anxiety and approximately 7% presented with a depressive episode. In total, 66% of the participants presented with a diagnosis of a psychiatric illness. Findings also revealed that adjustment to the illness was poor. This research indicated that high clinical co-morbidity and adjustment to the illness may be affected, thus an essential approach which can be beneficial to the adaptation of AA may be psychotherapy and support through counselling or psychological therapy (Ruiz-Doblado et al., 2003).

The prevalence of lifetime co-morbidity was investigated by Ghanizadeh (2008), in children and adolescents with AA. This clinical study included 14 patients with AA who were representative of all the AA referrals (between August 2004 and November 2006), to the Child and Adolescent Psychiatry Clinic in Iran. In relation to co-morbidity and AA, mood and anxiety disorders were the most common psychiatric disorders. Major depressive disorder was the highest reported amongst the sample (50%). General anxiety was only reported among approximately 7%; the rate of obsessive-compulsive disorder was approximately 36% (which is under the cluster of anxiety disorders). Overall, the results indicated approximately 78% of the patients as having one or more lifetime psychiatric co-morbidity (Ghanizadeh, 2008). Unfortunately, the study had a small sample size (N = 14); therefore, caution is needed in the interpretation of the data.

Much of the research is compelling, suggesting AA is associated to an increased risk of developing a psychological co-morbidity such as anxiety and/or depression (Ghanizadeh, 2008; Koo et al., 1994). In contrast, studies have reported no significant or elevated prevalence of psychological co-morbidity in individuals diagnosed with AA (Cordan Yazici et al., 2006; Gulec, Tanriverdi, Duru, Saray, & Akali, 2004).

A study conducted by Gulec et al., (2004) found that there was no significant difference between 52 adult individuals with AA and a control group (age and sex-matched), with regard to anxiety and depression levels. The Beck Depression Inventory, the Beck Anxiety Inventory and the Short Form-36 (SF-36) scales were used in participants aged between 18 and 65 years. The researchers concluded that the anxiety and depression scores were not statistically significant in their study of an AA group and a control group. In relation to the SF-36, 3 sub-scales revealed significant results. Vitality and general mental health was poorer in the AA group, indicating some psychological distress even though the results from the Beck anxiety and depression scores were not statistically significant. Another significant finding in their study revealed the AA group demonstrated better social functioning compared to the control group. However, the control group was a homogenous group, made up of busy hospital staff which may have influenced the significance of the results.

A study conducted by Cordan-Yazici et al. (2006) did not find any statistically significant results in for anxiety and depression differences between an AA group ($n = 43$) and 53 age-matched controls. The Hospital Anxiety and Depression Scale (HADS), Stress Scale, and Toronto Alexithymia Scale (TAS) were used to determine levels of anxiety, depression, stress and alexithymia, respectively. There were no significant differences relating to the anxiety, depression, and stressful major life events ($p > 0.05$).

A significant finding in this study were the TAS scores in the AA group were higher compared to the control group ($p = 0.01$). Alexithymia has been defined as the inability to

express one's feelings or emotions. This may be linked to individuals with AAT or AAU and the loss of eyebrows which may create a sense of an inability to form expressions. The high TAS scores may indicate that individuals with AA may have more coping difficulties due to the impaired ability of defining and interpreting emotions of oneself and others (Cordan-Yazici et al., 2006).

Rationale

The condition AA has been associated with a number of psychosocial concerns. Lowered quality of life and increased anxiety and depression are examples of the impact of the condition. While coping in general has been extensively researched in adults and adolescents, research on coping with a diagnosis of AA is still limited. Two common themes in the literature did suggest that particular techniques such as maintaining close relationships from supportive persons such as friends, family, support groups or therapy, may assist with coping and actively coping through the utilisation of hats, wigs and other accessories may also be beneficial to an individual just diagnosed with AA or in relapse. AA is an unpredictable condition which can create feelings of uncertainty. Therefore, coping with AA is imperative because relapse is a common occurrence in diagnosed individuals and although treatments are available, the effectiveness of the treatment largely depends upon circumstances surrounding the condition such as duration, genetics, history and severity.

Previous research has failed to identify particular coping strategies beneficial for diagnosed AA sufferers. Furthermore, research investigating the psychosocial effects of AA in young Australians is minimal. Therefore, the literature is relatively limited with regards to how coping, quality of life and the psychological state are impacted by AA in young diagnosed Australians.

It is envisioned that the findings of this study will assist the Australian Alopecia Areata Foundation to understand how coping, quality of life and mood are impacted among adolescents and young adults diagnosed with AA. This understanding may help AAAF Inc. to develop education and support programs for AA sufferers, their family and schools. In addition, the findings could be used to promote awareness about the condition and the everyday challenges that young AA sufferers' may face.

Aims

The aims of the present study was three-fold.

The first aim was to compare scores on the Depression Anxiety and Stress Scale for anxiety and depression in a young Australian sample of people with the condition AA to a young Australian community sample and an adult community sample from the UK. This was investigated using the normative data for the DASS42.

The second aim was to investigate the psychosocial aspects of individuals with AA. The relationship(s) between quality of life and the psychological state was examined using the domains from the Skindex-29 and the DASS42.

The third aim was to examine the most commonly utilised coping style(s) among this young AA sample. This was achieved through the analysis of the Brief COPE.

The short answer responses were explored through identification of themes. The responses were in reference to coping and concerns about AA. This allowed for further exploration regarding the most commonly utilised coping mechanism and the aspects of quality of life which may be impacted by the condition AA.

Hypotheses

The present research study sought to test the following three hypotheses in young Australians with AA and explore two research questions based on short answer responses.

With reference to the psychological state of individuals with AA, it was predicted that both the anxiety and depression scores on the DASS42 would be significantly elevated in the AA sample in comparison to normative data for a young adult Australian sample and an adult community sample from the UK.

It was predicted there would be a strong, positive relationship between the domains from the DASS42, measuring the psychological state of individuals with AA and the domains from the Skindex-29 measuring quality of life. It would indicate that due to the condition AA, elevated anxiety and/or depression or anxiety would be associated with a higher impact on quality of life.

It was hypothesised that examination of the Brief COPE would yield high usage of positive coping styles. The recruitment base (AAAF Inc.) and the age group of the participants would impact upon the utilisation of particular coping styles and this would include use of emotional support (i.e., family, friends and support groups) and active coping.

Two research questions were included to explore themes regarding concerns resulting from AA and the coping strategies utilised to address the condition AA. These would be examined further through identification of the emerging themes.

2.0 Method

Participants

A total of 42 participants were recruited in the current study. Seven participants were excluded as they did not answer the questionnaires in their entirety. The inclusion criteria were that individuals were between the ages of 12 to 25 years ($M = 18.77$ years, $SD = 4.23$). Of the 35 individuals, 23 (66%) were female with a mean age of 18.83 years ($SD = 4.52$). Twelve (34 %) were male with a mean age of 18.67 years ($SD = 3.99$).

Participants were required to reside in Australia, be proficient in English and have a formal diagnosis of AA. The participants all had a diagnosis of one or more of the following types of AA; including three (8%) with AA Monocularis, eight (23%) with AA Multilocularis, 12 (34%) with AAT and seven (20%) with AAU. The remaining five (14%) of individuals had other forms of AA or may have had more than one form of AA. The participants were recruited via the Australian Alopecia Areata Foundation Inc. (AAAF Inc.).

Materials

Information to Participants

The Information to Participants was used to invite potential participants to take part in the study. The letter provided an outline explaining the aims and nature of the research. This was used to explain the research methodology as well as potential benefits and risks (Appendix 1).

Consent Forms

A standard Victoria University Consent Form (Appendix 2) was used to obtain informed consent from participants wanting to take part in the study. A parental consent form was used to obtain informed consent from the parent/guardian of participants under the age of 18 years old (Appendix 3).

Demographic questionnaire

The demographics questionnaire was developed to gain information regarding the participants age, gender, and type of AA. In addition, two short answer questions were included to elicit qualitative information about participants concerns about AA and how they coped with the disorder (Appendix 4). These questions were: "*Did you have any or have you encountered particular concerns about living with alopecia areata? If so, can you please discuss some of these issues?*" and "*What particular type/s of coping strategies have you developed that you find beneficial in terms of coping with alopecia areata?*"

Brief COPE

Coping skills were assessed using the Brief COPE (Appendix 5), which was developed by Carver (1997). The Brief COPE is a shortened validated version of the COPE Inventory (Carver, Scheier & Weintraub, 1989). The questionnaire contains 28 items assessed on a 4-point Likert scale (0 = I haven't been doing this at all, 1 = I've been doing this a little bit, 2 = I've been doing this a medium amount and 3 = I've been doing this a lot). The Brief COPE assesses 14 sub-categories of coping.

The Brief COPE was developed so the subscales could be examined independently (Carver, 1997). Scores for each of the coping strategies can range from zero to six, with higher scores indicating higher use of that particular type of coping strategy. Hence, a total score less than or equal to two indicated low use and a score of three and above indicated medium to high use of particular coping strategies.

The 14 sub-categories were as follows; self-distraction (items 1 and 19), denial (items 3 and 8), religion (items 22 and 27), humour (items 18 and 28), acceptance (items 20 and 24), self-blame (items 13 and 26), venting (items 9 and 21), positive reframing (items 12 and 17), active coping (items 2 and 7), substance abuse (items 4 and 11), emotional support (items 5

and 15), instrumental support (items 10 and 23), behavioural disengagement (items 6 and 16) and planning (items 14 and 25) were created for the Brief COPE.

Reliability was assessed for the Brief COPE for the current sample (refer to Table 2). Behavioural Disengagement and Self-Distracton demonstrate moderate reliability for this sample therefore; results in relation to these two subscales should be interpreted with caution. Reliability was assessed for the Brief COPE subscales. Table 1 shows the Cronbachs' alpha for each coping style for the AA sample and the Carver (1997) sample. Table 1 shows that reliability coefficients derived in the present study are comparable to those reported in the original Carver study.

Table 1

Brief COPE Reliability:

Coping Style	AA Sample	Carver Sample
Self-Distracton	.56	.71
Active Coping	.75	.68
Denial	.93	.54
Substance Use	.97	.90
Use of Emotional Support	.79	.71
Use of Instrumental Support	.69	.64
Behavioural Disengagement	.48	.48
Venting	.66	.50
Positive Reframing	.88	.64
Planning	.67	.73
Humour	.95	.73
Acceptance	.87	.57
Religion	.79	.82
Self-Blame	.80	.69

Skindex-29

The Skindex-29 was designed by Chren, Lasek, Flock and Zyzanski (1997), (Appendix 6), for measuring quality of life for patients with dermatology issues. The survey refers to the skin condition which has bothered the individual the most in the previous four week period. A five-point Likert scale (1 = never, 2 = rarely, 3 = sometimes, 4 = often, and 5

= all the time) is used to assess of the 30 items asking about the skin condition. Higher scores indicate that the condition is having a higher impact. The raw scores are transformed to produce a scale from zero to a maximum of 100, (1 = 0, 2 = 25, 3 = 50, 4 = 75, and 5 = 100). The totals were divided by the number of items for each domain to obtain a score out of 100. The higher the score the higher the impact of the condition (0 = no effect to 100 = effect experienced all the time). The Skindex-29 comprises of 30 items. The 30 items, except item 18, which is a single item not included in scoring, are assigned to three subscales.

Three subscales were created for the Skindex-29; Emotions (10 items; 3, 6, 9, 12, 13, 15, 21, 23, 26 and 28), Symptoms (7 items; 1, 7, 10, 16, 19, 24 and 27) and Functioning (12 items; 2, 4, 5, 8, 11, 14, 17, 20, 22, 25, 29 and 30).. The first subscale is the emotions and assesses emotions related to the condition such as embarrassment, frustration and anger. The symptoms domain refers to symptoms such as skin irritation and skin sensitivities. The third domain assesses functioning and the impact the condition has on personal well-being such as intimate and social relationships and daily interactions (Chren et al., 1997). According to Both, Essink-Bot, Busschbach and Nijsten (2007), the Skindex-29 is the most appropriate scale to use for measuring quality of life in individuals diagnosed with AA. The Skindex-29 has been used in previous research in relation to AA (Sampogna et al., 2004), this study attempted to make the scale more applicable to individuals with AA by altering the questions with the inclusion of the word hair following the word skin. For example, question two "My skin/hair condition affects how well I sleep".

The Skindex-29 is an internally reliable (Cronbachs' alpha = .87 to .96) and valid, self-administered, instrument (Chren et al., 1997). Reliability was assessed for Skindex-29 and the Cronbach's alpha for the subscales for the current sample were acceptable; Emotions .93, Symptoms .92 and Functioning .93.

Depression, Anxiety and Stress Scale (DASS42)

The DASS42 (Appendix 7), is a 42-item, self-report inventory used to screen and assess the emotional states depression, anxiety and stress. It was designed by Lovibond and Lovibond (1995). The DASS42 consists of three subscales, each with 14 items. The Depression scale assesses dysphoria, hopelessness, devaluation of life, self-deprecation, lack of interest/involvement, anhedonia, and inertia. The Anxiety scale assesses autonomic arousal, skeletal muscle effects, situational anxiety, and subjective experience of anxious affect. The Stress scale assesses levels of chronic non-specific arousal. It assesses difficulty relaxing, nervous arousal, and being easily upset/agitated, irritable/over-reactive and impatient (Lovibond & Lovibond, 1995). The items on the DASS42 refer to current emotional state. It rates the extent to which individuals have experienced each state over the past week on a four-point Likert 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 and 3 = Applied to me very much, or most of the time). The Depression, Anxiety and Stress scale scores are determined by calculating the applicable 14 items. Depression (items; 3, 5, 10, 13, 16, 17, 21, 24, 26, 31, 34, 37, 38 and 42), Anxiety (items; 2, 4, 7, 9, 15, 19, 20, 23, 25, 28, 30, 36, 40 and 41) and Stress (items; 1, 6, 8, 11, 12, 14, 18, 22, 27, 29, 32, 33, 35 and 39). Lovibond and Lovibonds' interpretation of total scores uses the guidelines presented in Table 2.

Table 2

DASS42 Interpretation Scores

	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) assessed the psychometric properties to a large non-clinical sample. Assessing reliability using the Cronbach's alpha indicated acceptable values for the depression, anxiety and stress scales (.91, .84 and .90, respectively). Reliability was conducted for the DASS42 scale and Cronbach's alpha for the current AA sample was acceptable for Depression (.96), Anxiety (.91) and Stress (.92), which is comparable to the reliability by Lovibond and Lovibond.

Procedure

Subject Recruitment and Briefing

Ethics approval was obtained from the Victoria University Human Research Ethics Committee (approved on the 30th July, 2012; case number 12/83). Arrangements were made through communication with the President of the Australian Alopecia Areata Foundation Inc. (AAAF Inc.) and permission to advertise on the website and approach members affiliated with the foundation was granted. The majority of participants were recruited from the AAAF Inc. The survey period was July 31st 2012 to September 7th 2012.

Potential participants were informed about the research through the AAAF Inc. website via a link (www.aaaf.org.au). A summary was posted online which included the title of the research, brief aims and contact details of the researchers. Potential participants contacted the researchers via email or phone if they were interested in participating in the study. Once contact was made, the researcher either posted or emailed (preference was up to the participant) the information to participant form and consent form to potential participants.

The researcher attended various AAAF Inc. charity events (charity events were open to the general community and was aware of these through liaison with the AAAF Inc. representative). Potential participants were also introduced by the AAAF representative to the researcher using this method. Those who expressed interest in participating, were given the

participant information sheet and consent form to take home. In both the recruiting situations if participants wanted to be involved in the study, details for the return of the consent forms were available on the participant information form. These details included the provision for the consent form(s) (parental or young adult) to be returned either by reply-paid envelope and/or scanning and emailing back to the researcher. Upon receipt of the signed consent forms, the potential participants were sent the questionnaire package and a reply-paid envelope or had the option to request an electronic form of the questionnaires that could be completed and returned via email. The questionnaire package included the demographics questions, Brief COPE, Skindex-29, and DASS42. Individuals had the opportunity to ask questions or raise concerns during meetings and via email correspondence. They were advised that participation in the study was completely confidential and voluntary, and that they could withdraw from the study at any time.

Statistical Analysis and Design

The study design comprised of quantitative methods and endeavoured to elicit responses from two short answer questions. These short answer questions were used in order to acquire understanding about the unique experiences regarding quality of life and coping in individuals diagnosed with the condition AA. Two questions were posed "*Did you have any or have you encountered particular concerns about living with alopecia areata? If so, can you please discuss some of these issues?*" and "*What particular type/s of coping strategies have you developed that you find beneficial in terms of coping with alopecia areata?*" These questions were posed so that participants could answer in relation to concerns about living with AA and coping with AA, that may not be entirely captured using the Skindex-29 and the Brief COPE. The open ended questions were reviewed to identify common themes in the data.

Participant information was gathered such as age, gender and AA-specific data (type of AA) through the demographic questionnaire.

Coping was measured using the Brief COPE. Subjects were asked to rate the extent to which they used a particular type of coping style from a total of 28 items, with in turn, yielded 14 coping subscales. The higher the number indicates the more that a particular type of strategy was used. There is no normative data for this scale and its various subscales.

Quality of life was measured with the Skindex-29. Subjects were asked to rate the extent to which they had experienced each of the 30 items on the scale, producing the three subscales. The scores were summed to provide a total score for each subject; higher scores indicate higher impact of AA. There is no normative data for this scale and the subscales.

Depression and anxiety was measured with the DASS42. Stress was not used as a variable in this research design, but was included in analysis of the DASS42 domains. Subjects were asked to rate the extent to which they had experienced each of the 42 items on the scale. The scores were summed to provide a total score for each subject. The norms presented by Crawford, Cayley, Lovibond, Wilson and Hartley (2011), are representative of a young Australian sample, 7.75 ($SD = 8.87$) for depression, 5.34 ($SD = 6.16$) for anxiety and 10.04 ($SD = 9.37$) for stress. The Australian sample normative data was based on 102 individuals, both males and females, with an age range between 18 and 24 years (Crawford et al., 2011). The norms presented by Crawford and Henry (2003), are representative of a community sample in the UK. The norms are 5.55 ($SD = 7.48$) for depression, 3.56 ($SD = 5.39$) for anxiety and 9.27 ($SD = 8.04$) for stress. The community sample comprised of data collected from 1,771 members, 965 female and 806 males, from an adult population from the United Kingdom, with an age range from 15 to 91 years ($M = 40.9$ years), (Crawford & Henry, 2003).

The aim of the data collection was to obtain data from an AA sample and provide comparisons, correlations, determine use of coping styles and examine short answer questions. The variables were obtained after scoring as per the methods section (refer to section 2.0). Statistical analysis was performed using the PASW Statistics program. Due to a small sample size, the data collected was not suitable for factor analysis ($n = 35$), however, reliability analyses were conducted on all the scales.

Single sample *t*-tests were used to determine if significant differences existed between the AA sample and normative data. Classification of the AA sample and the normative data were the independent variables for the *t*-test and depression, anxiety and stress were the dependent variables. For all the single sample *t*-tests, Alpha levels were set at .05. Pearson's correlations were conducted to determine whether there were associations between aspects of quality of life; emotions, daily functioning and symptoms and psychological states; depression and anxiety.

The Brief COPE was used to examine frequently used coping styles among this sample. In particular, it was anticipated to determine which coping styles were minimally utilised and which were in the medium to high usage category. The coping variables violating tests of normality were substance use and religion. For these variables, the non-parametric alternative Spearman's correlation was conducted to determine associations between quality of life and coping.

3.0 Results

Demographic

Participants' demographics regarding gender and type of AA are presented in the table below (refer to Table 3). This analysis was conducted to determine the breakdown of the sample on the basis of gender particular types of AA.

Table 3

Demographic descriptive data

	<i>Male</i> <i>n (%)</i>	<i>Female</i> <i>n (%)</i>	<i>Total</i> <i>n(%)</i>
<i>Total Participants:</i>	12 (34)	23 (66)	35
<i>Type of AA:</i>			
Alopecia Areata Monocularis	1 (8)	2 (9)	3 (9)
Alopecia Areata Multilocularis	3 (25)	5(22)	8 (23)
Alopecia Areata Totalis	6 (50)	6 (26)	12 (34)
Alopecia Areata Universalis	2 (17)	5 (22)	7 (20)
Other	0 (0)	5 (22)	5 (14)

n = 35

The results indicate a majority of the respondents were female (66%), and only 12 (34%) were male. AAT was the most common type of AA (34%), followed by AA Multilocularis (23%), AAU (20%), and lastly AA Monocularis (9%). The remainder of respondents (14%) reported other forms of AA, which may indicate more than one type of diagnosis or other extremely rare forms of AA not mentioned in this research.

Psychological States

Categorised Total and Percentage of Psychological States

The total and the percentage of the participants falling into each range (normal, mild, moderate, severe and extremely severe) for the anxiety, depression and stress domains for the AA sample were obtained. This was achieved using the interpretation guide developed by Lovibond and Lovibond (1995). The examination of the categories was for the purpose of

clarifying the exact number and percentage of individuals which fell under each of the ranges. The results are presented in Table 4.

Table 4

The ranges from the Depression and Anxiety Domains with Total and Percentage of the AA sample

	Normal	Mild	Moderate	Severe	Extremely Severe
	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>
Depression	22 (62.9)	3 (8.6)	5 (14.3)	2 (5.7)	3 (8.6)
Anxiety	24 (68.6)	2 (5.7)	3 (8.6)	4 (11.4)	2 (5.7)
Stress	26 (74.3)	2 (5.7)	5 (14.3)	2 (5.7)	0 (0)

n = 35

The results indicated that the majority of the sample fell into the normal range for scores on the anxiety and depression scales. That is; 69% and 63% of the participants had normal scores for anxiety and depression respectively. There were from two to five participants in each of the other categories for mild, moderate, severe and extremely severe anxiety and depression scores.

Single Sample t-Tests

The data were normally distributed for the DASS42, allowing parametric tests to be conducted. The Mean (*M*) and Standard Deviation (*SD*) were obtained for the depression and anxiety scores for the AA sample to allow a comparison with the normative data. The mean and standard deviation for the AA sample are shown in Tables 5 and 6. In addition, single sample *t*-tests were performed to examine levels of anxiety and depression in comparison to sets of normative data from a young adult Australian sample and an adult UK community sample. The results are displayed below in Table 5 and Table 6.

Table 5

Depression, Anxiety and Stress single sample t-test analysis of AA sample in comparison to normative data for a young adult Australian Sample

	AA Sample <i>M(SD)</i>	Young Adult Australian Sample <i>M(SD)</i>	<i>t(df)</i>	<i>p</i>
Depression	9.26 (10.45)	7.75 (8.87)	.85 (34)	.40
Anxiety	6.23 (6.92)	5.34 (6.16)	.76 (34)	.45
Stress	10.86 (8.61)	10.04 (9.37)	.56(34)	.58

*Significant at the 0.05 level.

Table 6

Depression, Anxiety and Stress single sample t-test analysis of AA sample in comparison to normative data for a community sample from the United Kingdom

	AA Sample <i>M(SD)</i>	Adult UK Normative Data <i>M(SD)</i>	<i>t(df)</i>	<i>P</i>
Depression	9.26 (10.45)	5.55(7.48)	2.10(34)	.04*
Anxiety	6.23 (6.92)	3.56(5.39)	2.28(34)	.03*
Stress	10.86 (8.61)	9.27 (8.04)	1.09(34)	.28

*Significant at the 0.05 level.

In comparison to a young Australian sample (age range 18 to 24 years, no mean age presented), the results indicated no significant difference in the depression or anxiety domains. In contrast, the community sample revealed a significantly lower mean in comparison to the AA sample for both the depression and anxiety scores. However, the community sample mean age was 40.9 years ($SD = 15.9$), almost twice that of the AA sample ($M = 18.77$ years).

The results for the AA sample were indicative of the normal range for depression, anxiety and stress, for this age group, according to the Lovibond and Lovibond (1995) interpretation rating scale (refer to Table 2).

Coping

Frequency of Coping Styles

To determine commonly utilised coping strategies, the sample of AA participants was divided into two groups based on level of usage of each coping strategy. A total score less than or equal to two indicated low use and a score of three and above indicated medium to high use of particular coping strategies on the Brief COPE questionnaire. Low usage and medium to high usage of the 14 coping styles are shown in Table 7 below.

Table 7

Low usage and Medium to High usage of the 14 Brief COPE subscales for the AA sample.

Coping Style	Low Use <i>n</i> (%)	Medium to High Use <i>n</i> (%)
Self-Distraction	16 (45.7%)	18 (51.4%)
Active Coping	10 (28.6%)	24 (68.6%)
Denial	31 (88.6%)	3 (8.6%)
Substance Use	31 (88.6%)	3 (8.6%)
Use of Emotional Support	9 (25.7%)	25 (71.4%)
Use of Instrumental Support	17 (48.6%)	17 (48.6%)
Behavioural Disengagement	25 (71.4%)	9 (25.7%)
Venting	22 (62.9%)	12 (34.3%)
Positive Reframing	10 (28.6%)	24 (68.6%)
Planning	15 (42.9%)	19 (54.3%)
Humour	16 (45.7%)	19 (54.3%)
Acceptance	3 (8.6%)	31 (88.6%)
Religion	30 (85.7%)	4 (11.4%)
Self-Blame	20 (57.1%)	14 (40%)
<i>n</i> = 34		

The most highly utilised coping style by the AA sample were positive coping styles, such as planning, humour, active coping, use of emotional support, positive reframing and acceptance. The least utilised type of coping primarily comprised of maladaptive coping such as denial, substance use, behavioural disengagement, venting and self-blame. Religion, which may be considered as a positive coping mechanism, fell in the low usage category for this

sample. Self-distraction and use of instrumental support fell in both the low usage category and the medium to high usage category. This indicated that the two coping styles were equally utilised by this sample.

Quality of Life

Correlation between Quality of Life and Psychological States

The data was normally distributed for the Skindex-29 and Pearson's correlations were computed to investigate the relationships between quality of life (emotions, symptoms, functioning) and psychological state (depression and anxiety). The correlations were conducted to examine the direction and strength of these relationships. Table 8 displays the correlations between these variables.

Table 8

Correlations between Skindex-29 and DASS42 scores for the AA Sample

	Skindex Emotions		Skindex Symptoms		Skindex Functioning	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
Skindex Symptoms	.39*	.02				
Skindex Functioning	.73**	.001	.27	.13		
DASS Depression	.63**	.001	.10	.56	.59**	.001
DASS Anxiety	.54**	.001	.16	.36	.64**	.001

* Correlation is significant at the 0.05 level (2-tailed)

** Correlation is significant at the 0.01 level (2-tailed)

n = 35

With regards to quality of life, moderate, positive correlations were identified between the emotions domain with symptoms (15.2% variance explained). Strong, positive correlations were identified between the emotions domain with functioning, (53.3% variance explained), depression (40.7% variance explained), and anxiety (29.2% variance explained).

In addition, there were significant positive correlations between the functioning domain with depression (34.8% variance explained) and anxiety (41.6% variance explained).

No significant correlations were found between the symptoms of AA with the functioning domain, depression or anxiety. Depression and anxiety were found to be positively, strongly, correlated, $r (n = 35) = .75, p = .001$.

Correlation between Quality of Life and Coping

Pearson's correlations were calculated to investigate the relationships between quality of life variables (emotions, symptoms, functioning) and the 14 coping styles. Three coping styles were not normally distributed and within the ranges of +3 and -3. Non-parametric, Spearman's correlations were conducted to examine the relationships between the three coping styles; denial, substance use and religion and quality of life variables. Table 9 shows the findings for the correlation analyses.

Table 9

Correlations between Quality of life (Skindex-29) and Coping (Brief COPE)

	Skindex Emotions		Skindex Symptoms		Skindex Functioning	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
Self Distraction	.06	.75	-.08	.67	.28	.11
Active Coping	.09	.61	-.52	.78	.05	.79
Denial	.56**	.001	.04	.84	.44**	.01
Substance Use	-.01	.96	-.26	.14	.09	.63
Use of Emotional Support	.04	.82	.12	.50	-.13	.47
Use of Instrumental Support	.16	.36	.18	.30	.03	.84
Behavioural Disengagement	.28	.11	-.12	.51	.37*	.03
Venting	.38*	.03	.11	.54	.13	.47
Positive Reframing	-.33	.05	-.22	.21	-.16	.36
Planning	.41*	.02	.28	.11	.29	.10
Humour	-.15	.41	-.33	.06	-.20	.26
Acceptance	-.46**	.01	-.11	.55	-.54**	.001
Religion	.23	.20	.16	.36	.24	.18
Self-Blame	.60**	.001	.001	.997	.54**	.001

* Correlation is significant at the 0.05 level (2-tailed)

** Correlation is significant at the 0.01 level (2-tailed)

$n = 34$

Spearman correlations' were conducted to investigate the relationships between quality of life Skindex-29 domains; emotions, symptoms and functioning and the three coping styles from the Brief COPE, denial, substance use and religion. The results indicated there was a significant, positive relationship between denial and an increased emotional impact of AA and impact on daily functioning. Denial was not significantly associated to increased symptoms. There was no significant relationship between substance use or religion and emotional impact, increased symptoms or functioning of daily life.

Pearson's correlations were conducted to investigate the relationships between the quality of life Skindex-29 domains; emotions, symptoms and functioning, and the Brief COPE coping styles; self distraction, active coping, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance and self-blame.

Behavioural disengagement was weakly, positively correlated with impact on daily functioning. However, there was no correlation with emotions or symptoms domains of the Skindex-29. Venting and planning demonstrated a weak, positive relationship to emotions with no correlation to the symptoms or functioning domains.

There was no significant correlation between symptoms of AA and acceptance or self-blame. Acceptance indicated a moderate negative relationship to emotions and functioning, whereas self-blame demonstrated a moderate, positive relationship to emotions and functioning. There were no significant correlations between self-distraction, active coping, use of emotional support, use of instrumental support, positive reframing and humour with any of the quality of life variables on the Skindex-29.

Short Answer Responses

Concerns about Alopecia Areata

The open ended questions were reviewed to reveal common concerns in relation to AA. Thirty-nine responses were analysed and the emerging themes were consistent with the three domains from the Skindex-29, emotional aspects, impact on daily social functioning and symptoms such as permanent hair loss. However, additional themes emerged from this group, such as lack of community awareness and understanding about AA and coping with peoples' reactions. Several responses identified multiple concerns about living with the condition AA and the impact on their life. Refer to Table 10 for a full list of concerns.

Table 10

Concerns about Alopecia Areata

Concerns	<i>n</i> (%)
Public Reactions: (e.g. Stares, Laughter, etc.)	23 (59%)
Emotional Aspects (e.g. Worry, Anxiety, etc.)	21 (54%)
Impact on Daily Functioning (e.g. Sports, Activities, etc.)	12 (31%)
Symptoms and Relapse	11 (28%)
Wearing Headpieces (e.g. Wigs, Hats, etc.)	9 (23%)
Disclosure	5 (13%)
Bullying and Loss of Friendships	4 (10%)
Lack of Awareness and Understanding	3 (8%)
Maintenance and Time Consuming	3 (8%)
Concealment	2 (5%)

n = 39

Coping with Alopecia Areata

The open ended question was reviewed to reveal common coping strategies. Thirty responses were analysed and some emerging themes were in line with the Brief COPE domains, such as acceptance and support. Other themes identified included the use of wigs and hair pieces such as hair extensions, which were a common coping mechanism for a majority of individuals and several responses indicated that the awareness of AA and

education was a form of coping. A number of responses utilised multiple coping strategies, for example one individual utilised acceptance, headwear and positive reframing as coping mechanisms. Refer to Table 11 for a full list of coping themes.

Table 11
Coping Styles Identified in an AA Sample

<u>Coping Mechanism</u>	<u>n (%)</u>
Acceptance	12 (40%)
Headwear (e.g. Hats, Beanies, Bandannas, etc)	11 (37%)
Educating and Informing Others	9 (30%)
Support (e.g. AAAF, Family, Friends, etc.)	9 (30%)
Aesthetic (e.g. Wigs, Make-Up, etc.)	8 (27%)
Positive Reframing	3 (10%)
Denial	2 (6%)
Relaxation & Natural Remedies	2 (6%)
Withdrawal	2 (6%)
Self-Distracton	1 (3%)
Sport	1 (3%)

n = 30.

The majority of the group utilised positive coping mechanisms. However, two coping styles, sport and relaxation which may be considered as positive, were not highly used in this sample. The maladaptive coping styles identified in this sample are minimally utilised such as denial, withdrawal and self-distracton.

4.0 Discussion

The present study investigated coping, quality of life and psychological states in adolescent and young adult Australians diagnosed with AA and in addition, explored two research questions based on short answer responses.

Psychological States - Depression and Anxiety

The first hypothesis, predicted that the psychological state of individuals with AA (depression and anxiety on the DASS42), would be significantly elevated in the AA sample in comparison to normative data for a young Australian sample and an adult community sample. This was partially supported. The results indicated that there were no significantly elevated depression or anxiety levels in comparison to the normative data of a young Australian sample presented by Crawford et al., (2011). An explanation for this non-significant result could be due to the group of individuals which were recruited from a positive and constructive support group (AAAF Inc.). If symptoms of depression or anxiety were present, the support group may have already been aware and possibly assisted with appropriate referrals, support packs and information.

The results of this study support the theory presented by Cordan-Yazici et al., (2006) and Gulec et al., (2004), suggesting that AA is not associated with depression or anxiety. However, the results were indicative of elevated depression in comparison to the normative data presented by Crawford and Henry (2003), which is representative of a community, adult sample from the UK. Therefore, this partially supports the hypothesis and upholds the theory in relation to a majority of the literature, suggesting AA is linked with significant depression and anxiety (Ataseven et al., 2011; Koo et al., 1994).

While no control groups were used to compare the data, normative data was available and an interpretation guide for the DASS42 developed by Lovibond and Lovibond. Although the mean results were significantly elevated in comparison to the community normative data,

it should be interpreted with vigilance, as the mean score for the sample fell within the normal range for depression and anxiety on the interpretation guide for participants aged 14 years and above.

The sample did not demonstrate pathological levels of anxiety, depression or stress. While a minority of people presented with mild to severe levels, the majority of the individuals with AA cope well with the condition, with little impact on their psychological well-being. This could mean adequate support is offered to this group through family, friends and peers. In addition, most of the sample was associated to the AAAF organisation and this could be an explanation for the healthy psychological state of the sample. The AAAF encourages and supports people with a diagnosis of AA through the use of youth ambassadors, support and information packs and charity awareness days to raise awareness and funds.

Quality of Life

The second hypothesis predicted there would be a strong, positive relationship between the domains from the DASS42 measuring the psychological state of individuals with AA and the domains from the Skindex-29 measuring quality of life. It was predicted that elevated depression and anxiety would be associated with a bigger impact on quality of life.

This hypothesis was partially supported. The results indicated a strong, positive correlation between the emotions and the functioning domain (quality of life) with depression and anxiety (psychological state). The positive correlations reported in this study are consistent with the theory with regards to the impact that AA may have on quality of life in terms of higher impact on daily functioning and higher emotional impact and the association with elevated depression or anxiety.

In contrast, the symptoms domain was not significantly correlated with depression or anxiety and did not support the hypothesis or the theory. A rationalisation for the insignificant results with regards to the symptoms domain and psychological state could be a result of the items on the Skindex-29 which are classified as symptoms that may not be applicable to individuals diagnosed with AA. The Skindex-29 symptoms domain included items such as: item one, *my skin hurts*, item seven, *my skin condition burns or stings* and item ten, *my skin itches*. These have not been described as common symptoms of AA and the relevance of the items are questioned. Symptoms are more likely to include hair loss, pitting of the nails, dry eyes and a runny nose due to facial and body hair loss (Hunt & McHale, 2005).

Emotional impacts of AA have been examined in the literature (Fox, 2003; Hunt & McHale, 2005) and have found that emotions such as anger and despair have emerged. It is suggested that some individuals diagnosed with AA may experience a loss of identity which may be an aspect related to depression and anxiety (Fox, 2003). It is suggested that the more elevated the impairment of daily functioning, the higher the chance of depression or anxiety. This could be due to the strenuous up keep associated with AA (Thompson & Shapiro, 1996). Everyday activities, hobbies, work and school may also be impacted upon and this may be an explanation for significant associations.

Concerns about Alopecia Areata

The research question was included to explore themes regarding concerns about the condition AA

The disturbances and the impact on quality of life were comparable to the concerns expressed by those in the literature review. Three themes identified from the responses of this group are in line with the Skindex-29 domains. Emotional impacts of AA, for instance worry

or anxiety was the biggest concern with this sample with 54% of responses indicating a form of distress. Some of the responses reported feeling afraid in terms of social interaction, embarrassed about hair loss and insecure about their appearance, which is also consistent with the literature (Firooz et al., 2005; Williamson et al., 2001).

The second most common concerns were in relation to daily social functioning (31%), impacting upon hobbies or social interactions. Although a diagnosis of AA is not life threatening, it may impair social life (Dubois et al., 2010). Symptoms were discussed, including instances such as relapse or exposure of patches of hair loss (28%). This could be a result of the importance placed on hair in terms of appearance and the attempt to disguise hair loss (Grimalt, 2005; Williamson et al., 2001). Additional themes emerged which were not only consistent with the literature, but insightful, demonstrating that quality of life is impacted with a diagnosis of AA (Dubois et al., 2010).

Over half of the responses, 59%, indicated that public reactions were a major concern in this group. Public reactions from people such as staring, laughter, judgements and assumptions (for instance thinking they have cancer or that it may be contagious), were a major concern for individuals with AA. This supports the research that identified children with AA as "cancer kids" (Kalabokes & Besta, 2001) or suffer ridicule from others. These reactions may be related to a lack of awareness about the condition. Although lack of awareness and understanding was recorded in only 8% of the responses, this is mentioned in the literature (Williamson et al., 2001), suggesting that some individuals diagnosed with AA feel as though they are not understood and this is due to a lack of public knowledge about the condition.

Wearing head pieces such as wigs and hats were a concern identified among 23% of this group. Respondents indicated that hobbies and activities such as swimming or going to the beach were (or still are) difficult. This is comparable to the research by Hunt and McHale

(2005), which identified that some individuals with AA felt that wearing a headpiece impacted upon their way of life, highlighting key aspects such as work and school.

Coping Styles

The third hypothesis was partially supported. It was predicted that examination of the Brief COPE would yield high usage of the positive coping styles, use of emotional support and active coping.

The positive coping styles most utilised by this group was acceptance (89%), followed by the use of emotional support (71%). Active coping (67%) and positive reframing (67%) were equally, the third highest utilised coping style.

Acceptance was highly utilised among this group of individuals. It was identified in the theory that an effective means of coping is accepting the condition and a diagnosis of AA as it ultimately allows for the individual to manage with the condition and accept themselves for the person they are (Thomson & Shapiro, 1996).

In addition, the theory suggested that cultivating a supportive and understanding environment is crucial for those with AA (Thompson & Shapiro, 1996). Evidently, emotional support such as affection, care, understanding and non-judgemental attitudes are important and this can be obtained from a therapeutic environment (MacDonald Hull et al., 2003; Prickett et al., 2004). Emotional support was relatively highly used, indicating the use of support from family, friends and support groups as vitally crucial when dealing with AA. Encouraging people to discuss feelings or having a voice and being heard and understood is highlighted in the literature as a positive means to cope and even when assisting others to manage with AA (McKillop, 2010). This partially supported the hypothesis as it was the second highest used coping mechanism.

Sixty-seven percent utilised an active coping approach and a positive reframing approach. This partially supported the hypothesis. Actively coping through attempts to make the situation better or concentrating on undertaking action about the condition was highly utilised. For example, the participants may concentrate their efforts on how they can better educate themselves about the condition, maintain healthy relationships, exercise to maintain health and wellbeing or use head pieces to assist with hair loss. These types of active coping are seen as beneficial to the individual, as it may facilitate self-acceptance (McKillop, 2010).

This group demonstrated low usage of maladaptive coping styles including denial, and substance use. As suggested, the dangers of some of the maladaptive coping styles may impose a larger, self-destructive consequence (Garcia, 2010). For the young individuals that do use these particular means to cope, it is important that positive styles are encouraged through education and continued support from family friends, peers, teachers, support groups and therapists (MacDonald Hull et al., 2003; McKillop, 2010).

Coping with Alopecia Areata

The coping strategies utilised to address the condition AA would be examined further through identification of the emerging themes from the short answer responses.

The coping themes which emerged from the responses were partially in line with the domains from the Brief COPE. Acceptance was the most widely used coping mechanism, with 40% of individuals, stating they had come to terms with their condition. This was comparable to the response from the Brief COPE, in terms of acceptance being a highly utilised coping mechanism.

Support was another theme identified from the responses, with 30% of individuals stating they used support as a means of coping. Support from family and friends were important, as was support from the AAAF Inc. foundation and websites such as

alopeciaworld.com. The literature presents that support is an important and effective means of coping, because people feel as though they are not alone and have some means to express their feelings to others in a similar situation (MacDonald Hull et al., 2003; Prickett et al., 2004). Education and informing others about the condition was identified as a way of coping among 30% of responses. This was important and mentioned as a concern about living with AA.

Aesthetic ways of coping such as wigs, hair extensions and make-up were identified in 27% of responses. This is consistent with the literature suggesting this particular type of coping is a common and an effective method (Harries et al., 2010; McKillop, 2010). However, there is the financial burden of maintaining this particular type of coping (Kalabokes & Besta, 2001), which was not mentioned in the responses. This could be a result of parents purchasing the required products for the adolescents and young adults and may be living at home.

Maladaptive coping such as denial (6%), withdrawal (6%) and self-distraction (3%) were identified among few of the individuals and it is identified in the research that this type of coping may be due to feeling different from others or uneasy disclosing their condition (McKillop, 2010).

Strengths and Limitations

The current study was one of the first to simultaneously examine coping, psychological states and quality of life, in a sample of Australian adolescents and young adults diagnosed with AA. Investigating psychosocial impacts and coping in persons diagnosed with AA allowed for the possibility of identifying coping strategies that are effective and positive for this group of individuals. The benefit of investigating the psychosocial impacts and coping styles within this young group was that support may be

provided to those diagnosed with AA. In addition, this study adds to the research and may encourage community awareness through means of education.

Rather than grouping the coping styles as problem focused coping, emotion focused coping and avoidant coping as some previous literature has done (Wilson, Pritchard & Revalee, 2005), the use of the 14 subscales allowed for investigation of common coping styles among this group of individuals diagnosed with AA. The information from the Brief COPE provided specifics regarding frequently used coping styles. This may be effective in terms of using the coping styles to determine means of support that is preferred or may be required by this group of individuals with AA.

Statistically, the sample size is considered small which may preclude the capacity to generalise to individuals with AA. Clinically, AA is a rare condition, occurring in only two percent of the Australian population. A sample size of 35 is promising (for this age group 12-25 years) and compares as a good average to previous studies. Research concerning AA, consisting of sample sizes as small as 14 (Ghanizadeh, 2008) and as large as 80 (Firooz et al., 2005), with a wider age range have been recorded. While the results would be difficult to generalise, it does provide insight to the psychosocial aspects and coping in a group of young Australians diagnosed with AA. A problem in recruiting large amounts of participants in AA studies is due to the rarity of the condition.

There was no control group used in this study. Therefore, this precluded the ability to compare the findings to individuals without AA. This did not enable the researcher to determine whether coping, mood and quality of life were impacted upon due to other life circumstances or if they were associated with AA. Due to the time constraints of the current study, the recruitment of a control group would have been laborious and may have impacted on the successful completion of the study in the time allocated. While no control group was recruited, the AA participants' results for the depression and anxiety domains were compared

to normative data. Additionally, an interpretation guide for the DASS42 was available. Therefore, this study did provide some indication about how AA differed from other groups in relation to their psychological state.

The Skindex-29 is an effective tool for investigating quality of life in persons' with dermatological concerns. It has been used and reviewed as the best measure for dermatological research in various populations (Chren, 1996). While the Skindex-29 is a valid, reliable and responsive instrument, the meaning of the scores is not well documented and no normative data was available. Essentially, this did not allow for the opportunity to effectively compare the data. At the time of the present study there were no tools specifically designed for individuals with AA, aside from the Hairdex. The Hairdex is a scale designed by German researchers and at this stage, is only available in German and little is known about the psychometric properties of this scale. The use of the Hairdex may improve the quality of the current study. A valid and reliable, English version of the Hairdex may be more applicable to individuals with AA.

The selection of the sample was not random, with most of the recruitment via volunteering individuals associated with the AAAF Inc. organisation. The results may be impacted as they could be an underestimation of true depression and anxiety scores. With most of the individuals associated with the AAAF Inc., it would be practically impossible to recruit and locate people without the assistance from the association. Additionally, the research was based in Melbourne with recruitment of individuals Australia wide. Sourcing the location of specific people diagnosed with AA may have otherwise been unattainable without the assistance from the AAAF Inc, due to the sensitive nature and the characteristics of the condition. Advertising in clinics, schools, wig shops and newspapers may be another method for recruitment. Again, the time frame allowed for the recruitment was restricted and

additional time to recruit may be beneficial. Furthermore, the study was endorsed by the AAAF Inc., which aimed for a particular focus concerning this group of individuals.

Future Directions and Research

Previous research has provided a considerable effort towards the investigation of AA both medically and psychologically. Literature has presented valuable insight regarding understanding about the condition, which has been identified as non life threatening, but can impact upon the psychosocial wellbeing of diagnosed individuals.

The current study presents insight to the psychological aspects which may be impaired by AA. This included depression and anxiety, however, were still within the normal ranges. There were significant correlations between psychological aspects and quality of life, demonstrating that increased emotional impact and impact on everyday social functioning was associated with increased depression and anxiety. Impairments on quality of life emerged, in line with the research. This was examined with the Skindex-29 and the short answer response indicated similar concerns regarding the condition, in particular public reactions, emotional impact, daily functioning and symptoms of AA.

Coping styles were also examined, enabling identification of highly used coping styles and positive coping mechanisms which were revealed through the brief COPE and a short answer response. Acceptance, emotional support, actively coping through wearing wigs and hats were identified as common coping behaviours. This research has identified that support is a crucial aspect of being and feeling accepted. Support maintained through family and friends and organisations like the AAAF inc., can support individuals while dealing with AA through forums or group activities. Group counselling may also provide an opportunity to promote and encourage discussion, fostering self-esteem and self-confidence.

Wigs, hair extensions, hats, beanies and scarves are all seen as effective coping styles. Public reactions towards individuals with AA were important. The feeling of uncertainty in terms of acceptance or rejection from peers was substantial. While negative reactions from some cannot be prevented, research contributing to awareness and understanding can facilitate the importance about being supportive and non-judgmental.

Qualitative studies would ensure that the lived experience of the individual diagnosed with AA would be examined in depth, ensuring that the individual has had a chance to express their feelings about the condition and whether the condition has impacted upon quality of life. Ultimately, individuals with AA can express their feelings to gain understanding from health professionals and the general community. In turn, psychologists and / or counsellors, general practitioners, friends and family and support groups may provide individuals with extra support and understanding.

The inclusion of a control group as well as a clinical group (with another dermatological condition for instance eczema or acne) in future studies would assist with the comparison of groups and may provide a better indication of the impact of a diagnosis of AA in terms of coping, quality of life and mood. Additionally, a wider age range would assist with a comprehensive view of a diagnosis of AA and may assist with a larger sample to generalise. This may provide a better opportunity for comparisons between age groups and gender in terms of quality of life, mood, and coping. A bigger sample may allow for regression analysis to predict if quality of life is impacted by mood and coping, or if coping styles predict mood and quality of life in an individual diagnosed with AA.

There is minimal research regarding specific coping strategies regarding AA. Longitudinal studies may be another direction for research in terms of how the individual experiences the diagnosis of AA and how an individual experiences AA in the years' following the initial diagnosis. This would be of interest to understand the way an individual

experiences the condition when they are first diagnosed and whether the opinion changes drastically. The use of a scale which measures quality of life in individuals with AA would be effective.

Summary and Conclusion

The research was an exploratory study of coping, quality of life, depression and anxiety in adolescents and young adults diagnosed with AA. Psychological aspects were within normal range, but slightly elevated in comparison to a community sample norm. It has been identified that there were aspects of quality of life associated with depression and anxiety. The study identified commonly used coping mechanisms that were primarily positive and considered as effective in the literature such as emotional support and acceptance. This information can be used to support newly diagnosed individuals, those dealing with relapse or perhaps individuals who may have difficulty adjusting to the condition and may be using maladaptive coping mechanisms. The data gathered from the responses were beneficial to this study because it facilitated further understanding about the experience of AA in this group and has provided further knowledge about this rare condition AA.

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APPENDICES

Appendix 1



INFORMATION TO PARTICIPANTS INVOLVED IN RESEARCH

You are invited to participate

You are invited to participate in a research project to evaluate the quality of life, coping strategies, depression and anxiety. The study is entitled "Coping, Quality of Life, Depression and Anxiety in Young Australians with Alopecia Areata". This project is being conducted by a student researcher, Louise Borg 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. This study aims to determine the effect alopecia areata has on quality of life, depression and anxiety levels and whether particular coping strategies are used that may improve well-being among adolescents and young adults.

Project explanation

Previous research has demonstrated the possible risk of individuals with alopecia areata developing other health issues such as depression and anxiety and has also shown alopecia areata negatively impacts quality of life. Coping strategies have also been shown to differ across gender and among individuals of different ages.

The aim of this study will be to examine quality of life, coping, depression and anxiety levels, in adolescents and young adults with alopecia areata. In order to assess these issues, an online survey will be conducted. The other key aspects of this research are resilience and coping strategies that may assist young people with alopecia areata.

What will I be asked to do?

You will be requested to complete a series of questionnaires: (1) Depression, Anxiety and Stress Scale (DASS42) (2) Skindex-29 and (3) Brief COPE, which are designed to measure depression, anxiety, quality of life, and coping, respectively. You will also be requested to complete a demographic questionnaire. The completion of the questionnaires should take around 30 minutes. All you need to do is contact a member of the research team (see contact details at end of this form) and we will mail you out the questionnaire package so that you can complete the questionnaires in your own time. You can then return the completed questionnaires to the researchers via regular post using an enclosed reply-paid envelope. In addition, if you would prefer for us to send you the questionnaire package electronically (e.g., via email), all you need to do is supply us with your email address. You can return the completed questionnaires via regular mail or via email. Note, any identifying information in an email to us will be deleted and we will only retain your completed questionnaire, so as to maintain anonymity of your responses.

What will I gain from participating?

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 to enhance quality of life and may possibly reduce the risk of developing issues such as depression and/or anxiety. It may also help to promote community awareness of the condition.

How will the information I give be used?

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) 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?

By completing the questionnaires 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).

How will this project be conducted?

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.

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?

Victoria University

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

Miss Louise Borg. Her contact details are 0402 945 121 or louise.borg@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 2



CONSENT FORM FOR PARTICIPANTS INVOLVED IN RESEARCH

INFORMATION TO PARTICIPANTS:

We would like to invite you to take part in a study which aims to investigate the impact that alopecia areata has on adolescents and young adults' mental health and quality of life.

The aim of this study will be to examine quality of life, coping, depression and anxiety levels, in adolescents and young adults with alopecia areata. In order to assess these issues, a survey will be conducted.

The other key aspects of this research are resilience and coping strategies that may assist young people with alopecia areata.

In giving your consent to participate in this research, you may become aware of issues regarding alopecia 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.

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:

“Coping, Quality of Life, Depression and Anxiety in Young Australians with Alopecia Areata”

being conducted at Victoria University by: Louise Borg 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:

Louise Borg,

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

- Survey regarding coping strategies, quality of life, depression and anxiety and the impact of alopecia areata.

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 3



PARENTAL CONSENT FORM FOR PARTICIPANTS INVOLVED IN RESEARCH

INFORMATION TO PARTICIPANT PARENT/GUARDIAN:

We would like to invite your child to take part in a study which aims to investigate the impact alopecia areata has had on their mental health and quality of life.

The aim of this study will be to examine quality of life, coping, depression and anxiety levels, in adolescents and young adults with alopecia areata. In order to assess these issues, a survey will be conducted.

The other key aspects of this research are resilience and coping strategies that may assist young people with alopecia areata.

In giving your consent for your child to participate in this research, your child may become aware of issues regarding alopecia areata that were or are distressing. In the event that support is required, Psychologist Prof. Mark Andersen will be available for assistance, telephone: 9919 5413.

Links to counselling services will be provided to all participants.

CERTIFICATION BY SUBJECT

I, _____

(full name of parent)

of _____

(suburb / town)

certify that I am voluntarily giving consent for my child to participate in the study:

“Coping, Quality of Life, Depression and Anxiety in Young Australians with Alopecia Areata”

being conducted at Victoria University by: 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:

Louise Borg,

and that I freely consent to my child's participation involving the below mentioned procedures:

- Survey regarding coping strategies, quality of life, depression and anxiety and the impact of alopecia areata.

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 child's name is not used and the recording of data will not identify my child,

I certify that I have had the opportunity to have any questions answered and that I understand that I can withdraw my child from this study at any time and that this withdrawal will not jeopardise me or my child 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 4

Demographics Questions

1. Age in years

2. Gender

Male

Female

3. Form of Alopecia Areata

Alopecia Areata Monocularis

Alopecia Areata Multilocularis

Alopecia Areata Totalis

Alopecia Areata Universalis

Other (Please Specify)

4. Did you have any or have you encountered particular concerns about living with alopecia areata? If so, can you please discuss some of these issues? OPTIONAL

5. What particular type/s of coping strategies have you developed that you find beneficial in terms of coping with alopecia areata? OPTIONAL

Appendix 5

Brief COPE

These items deal with ways you've been coping with alopecia. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says, how much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

1 = I haven't been doing this at all

2 = I've been doing this a little bit

3 = I've been doing this a medium amount

4 = I've been doing this a lot

1. I've been turning to work or other activities to take my mind off things.
2. I've been concentrating my efforts on doing something about the situation I'm in.
3. I've been saying to myself "this isn't real".
4. I've been using alcohol or other drugs to make myself feel better.
5. I've been getting emotional support from others.
6. I've been giving up trying to deal with it.
7. I've been taking action to try to make the situation better.
8. I've been refusing to believe that it has happened.
9. I've been saying things to let my unpleasant feelings escape.
10. I've been getting help and advice from other people.
11. I've been using alcohol or other drugs to help me get through it.
12. I've been trying to see it in a different light, to make it seem more positive.
13. I've been criticizing myself.
14. I've been trying to come up with a strategy about what to do.
15. I've been getting comfort and understanding from someone.
16. I've been giving up the attempt to cope.
17. I've been looking for something good in what is happening.
18. I've been making jokes about it.
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
20. I've been accepting the reality of the fact that it has happened.
21. I've been expressing my negative feelings.
22. I've been trying to find comfort in my religion or spiritual beliefs.
23. I've been trying to get advice or help from other people about what to do.
24. I've been learning to live with it.
25. I've been thinking hard about what steps to take.
26. I've been blaming myself for things that happened.
27. I've been praying or meditating.
28. I've been making fun of the situation.

Appendix 6

Skindex29

Adapted from M.M.Chren (1996)

These questions concern your feelings over the past 4 weeks about the skin condition that has bothered you the most. Check the answer that comes closest to the way you have been feeling.

The Skindex29 is a dermatological survey. Some questions have included the word "hair" after the word "skin" as this may be more appropriate for you. This survey has been used in other research regarding alopecia areata and quality of life.

How often during the past four weeks do these statements describe you?

Never = 1

Rarely = 2

Sometimes = 3

Often = 4

All the time = 5

1. My skin hurts
2. My skin/hair condition affects how well I sleep
3. I worry that my skin/hair condition may be serious
4. My skin/hair condition makes it hard to work or do hobbies
5. My skin/hair condition affects my social life
6. My skin/hair condition makes me feel depressed
7. My skin/hair condition burns or stings
8. I tend to stay at home because of my skin/hair condition
9. I worry about getting scars from my skin/hair condition
10. My skin itches
11. My skin/hair condition affects how close I can be with those I love
12. I am ashamed of my skin/hair condition
13. I worry that my skin/hair condition may get worse
14. I tend to do things by myself because of my skin/hair condition
15. I am angry about my skin/hair condition
16. Water bothers my skin/hair condition (bathing, washing hands)
17. My skin/hair condition makes showing affection difficult
18. I worry about side-effects from skin medications / treatments
19. My skin is irritated
20. My skin/hair condition affects my interactions with others
21. I am embarrassed by my skin/hair condition
22. My skin/hair condition is a problem for the people I love
23. I am frustrated by my skin/hair condition
24. My skin is sensitive
25. My skin/hair condition affects my desire to be with people
26. I am humiliated by my skin/hair condition
27. My skin condition bleeds
28. I am annoyed by my skin/hair condition
29. My skin/hair condition interferes with my sex life
30. My skin/hair condition makes me tired

Appendix 7

DASS

Name:

Date:

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you *over the past week*. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

- 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

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 was 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