

Psychosocial Impact of living with a family member with Alopecia Areata

Submitted by

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Abstract

The present study examined psychosocial impact of a diagnosis Alopecia Areata (AA) on other family member. AA is a hair loss disorder that appears to be caused by problems associated with the autoimmune system, and can occur in any person at any stage of their life. The aim of this study was to examine the psychosocial consequences of AA on the family members of patients with AA in order to provide insight and develop better advice, assistance and support to those affected.

Five families were recruited via social functions run by Australia Alopecia Areata Foundation Incorporated (AAAF). Participants were adult relatives of AA sufferers who were aged between 6-53 years. Participants also provided advice to share with other families and Alopecia Areata (AA) sufferers considering there is limited information and assistance available.

The interviews were conducted individually and in a family group setting in their own homes. Participants were asked to respond to 10 semi-structured, open ended, questions related to their life experiences at home and in the public in relation to AA. Data from the interviews were transcribed verbatim and subjected to thematic analysis informed by grounded theory (Glaser & Strauss, 1967). Participants' responses were coded into five main domains: (1) Psychological and Psychosocial Stress issues, (2) Management of lifestyle of AA in the family issues, (3) Social Interactions, (4) Health Practitioners and Research, and (5) Participants Advice. Each of these domains was comprised of thematic categories and subcategories that further elucidated participants' experiences related to these domains.

The findings highlighted key areas of initial encounter, acceptance, coping, anxiety, stress, guilt, depression, bullies, staring, self-esteem, image, confidence, quality of life (QOL), frustration and uncertainty, management in family balance, treatments, financial expenses, social interactions, assistance from practitioners, and the need for further research and participants' advice. These findings provide information and recommend that future research and management of AA patients and their families include addressing the distress and faulty beliefs associated with diagnosis and the treatment of AA.

Declaration

“I declare that this thesis does not incorporate any materials that were previously written by another person except where due reference is made in the text”

“I further declare that this study was conducted with full approval of the Ethics Committee of Victoria University”.

Name: Jennifer Davis

Date: 14 October, 2014

Signature :

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CHAPTER 1: INTRODUCTION

Alopecia Areata (AA) is a chronic hair loss disorder that affects approximately 2% of people regardless of their sex or race (Hunt & McHale, 2005b). This disorder appears to be caused by problems associated with the autoimmune system and there are four prominent types of AA: Monocularis, Multicularis, Totalis and Universalis. Anyone of any age can develop AA, but most common in younger people around the pubescent stage of development. The chances of having AA are slightly greater if a relative has the disease as the condition has genetic bias, and approximately 60% of cases occur before the age of 20 (Price, 1999).

AA cannot be cured; however, it can be treated, and hair can grow back. In many cases, AA is treated with drugs that are used for other conditions. Rogaine is one of the steroidal drugs that can be administered topically for about 12 weeks before the hair begins to grow (Thiedke, 2003). Other drugs that are also used for AA with varying degrees of effectiveness include medications used to treat psoriasis and other autoimmune disorders. However, the results can be very disappointing.

Currently, no conclusive treatment to prevent the spread of the AA disorder (Hunt & McHale, 2005b; Shapiro & Madani, 1999). The success rate of all treatments is about 1%, which is statically equivalent to zero success. People with AA may have spontaneous remissions, but may also have repeated episodes of hair loss and remission. The hair that grows back is not always of the same type, colour, and texture as the hair that was lost. AA is seldom responsive to medical treatment(s), though the effectiveness of such treatment is very low. (Dubois et al, 2010).

Congenital and hereditary hypotrichosis and hair shaft abnormalities often have

no effective treatment (Harison et al, 2003). AA can be distinguished from other forms of hair loss by the pathophysiology involved during the shedding of hair (Thiedke, 2003). Three other forms of hair loss include androgenic alopecia, telogen effluvium, and cicatricial alopecia. Androgenic alopecia (generally known as male pattern baldness) is the most common form of hair loss in both men and women and is caused by higher levels of the androgen dihydrotestosterone. Teffluvium occurs when normal hair follicles deviate exclusively from the growth phase to the resting phase, thus making hair growth abnormal (Shapiro & Madani, 1999). Cicatricial alopecia is the result of damage to both the scalp and the hair follicles and differs from afore mentioned forms of hair loss in that the scalp is frequently scarred (Thiedke, 2003).

While the disease is not a medically serious condition, it can impact negatively on people psychologically and socially (Grimalt, 2005). The current literature is inconsistent concerning the role stress, anxiety, and other psychological factors may play in the aetiology of AA. Psychotherapy and cognitive behavioural therapy have resulted in the regrowth of hair in several recorded cases when three psychological stressors were identified as directly preceding the onset of AA (Elkin, Hilker, & Drabman, 2006; Reinhold, 1960), indicating at least a partial role of psychological factors in some cases of AA development. Support groups are available to help people with AA deal with the psychological and social effects of the condition. For example, in Australia information can be obtained from AAAF, which has a website and self-help groups.

However, a case-controlled study by Güleç, Tanriverdi, Dürü, Saray, and Akçali (2004) reported only limited support for psychological factors in the etiology of AA. A large-scale study on the relationship between AA and psychiatric comorbidities by Chu et al. (2012) found a high percentage of psychiatric disorders preceded diagnosis, suggesting

that AA and psychiatric disorders may share a common pathophysiology as a result of stressful life events. The link of stress in the aetiology of psychosis has been shown to stem from the involvement of metacognition in the face of a stressor in some cases (Palmier-Claus, Dunn, Morrison, & Lewis, 2011), and this may be reflected in reports that many AA sufferers view the control of their thoughts and emotions as being responsible for the onset and course of their condition (Firooz, Firoozabadi, Ghazisaidi, & Dowlati, 2005; Matzer, Egger, & Kopera, 2011).

The stress perception of the AA sufferer has also been reported as a possible riskfactor in the onset of the disorder (Gruber, 2003). Many people with AA have described the emotional distress experienced during bereavement or other specific stressful incidents as the primary cause of the condition (Hunt & McHale, 2005b; Matzer et al., 2011). In addition, significantly higher numbers of self-reported stressful life events preceding onset have been reported in people who attributed stress as the cause of their AA (Güleç et al, 2004).

Apart from drug treatments, there are various cosmetic and protective techniques that people with AA can use (Cash et al, 2004). These include using makeup to hide or minimize hair loss, and wearing coverings (wigs, hats, or scarves) to protect the head from the elements and reducing stress. Coping strategies evolve over time and if a person grows accustomed to the disorder in an adaptive style, then the anxiety associated with relapse in the early stages of AA that is commonly managed with appearance fixing is replaced with an optimistic outlook that embodies acceptance (Welsh & Guy, 2009).

It is apparent that the ability to employ positive acceptance as a coping strategy is often related to receiving strong social support in order to restore confidence

(Matzer et al., 2011; Welsh & Guy, 2009). The important role played by Alopecia Areata social support networks in helping people cope with the changes to their body image has been highlighted (Prickitt et al, 2004); however, the level of psychological support provided by doctors involved in diagnosis and treatment may not be adequately addressing the needs of many people (de Koning et al, 1990).

The association of alopecia with psychological comorbidities and the negative impact to quality of life (QOL) has led to the suggestion from both dermatologists (Shapiro & Madani, 1999) and psychologists (Hunt & McHale, 2005a) that potential psychological problems need to be addressed alongside diagnosis. In addition, recommendations have been made for diagnosis to include referral to mental health professionals in order to help people accommodate the coping management skills necessary to deal with hair loss (Ruiz-Doblado et al., 2003).

Successful regrowth and the reduction of psychological distress in instances that have included referral to a psychologist following diagnosis (Elkin et al., 2006) appear to advocate the recommendation to refer individuals to mental health professionals alongside diagnosis, and also suggest referral may help to combat the course of alopecia in some cases. In spite of this, psychotherapy as a potential treatment of AA appears to be largely unutilized (Matzer et al., 2011). Although several research studies concerning the impact AA can have on QOL have called for dermatologists to take psychological assessment into account when diagnosing AA (Dubois et al., 2010; Koo et al., 1994; Reid et al., 2012); to date there are limited findings in the literature to reveal whether this recommendation is also being largely unutilized.

Borg, L. (2012) in an exploratory study, identified the aspects of QOL associated with depression and anxiety. The study identified commonly used coping mechanisms

that were primarily positive, and were considered as effective in the literature such as emotional support and acceptance. The information can be used to support newly diagnosed individuals, those dealing with relapse or individuals who may have difficulty adjusting to the condition and may be using maladaptive coping mechanisms.

Many people with new-onset AA have had recent stresses in life, such as work, family concerns, deaths, surgeries, accidents, etc. (Gruber, 2003). However, none of these correlated events can be directly linked to the onset of AA. Very few studies have been done on how best to support and counsel AA sufferers and their families. Given that there is no cure or treatment available at this time for AA, further research is desperately needed on its cause and also on how to support those affected by this disorder.

Veal, R. (2013) findings suggested that developing positive rational acceptance (PRA) as a coping style is dependent on receiving strong social support, and satisfaction with the doctor at the time of diagnosis may be an important factor in this development. Referrals to mental health professionals by the diagnosing doctor alongside alopecia diagnosis may be a beneficial strategy for promoting PRA as a coping style in the absence of adequate treatments.

Martino, J. (2013), found that there are profound psychological and psychosocial implications of hair loss in women and that they are at a high risk of developing psychiatric disorders. The rationalisation for this decision was based on the evidences that AA is psychologically more distressing for females compared to males, and for adults who have established the foundations of their life, rather than adolescents who are still finding their identity and pathways. Studies had limited selection of subject suggested that her findings could represent an underestimation of participants' true self-esteem, depression, anxiety and stress scores. It is assumed that

participants prior knowledge received based on their relationship with the organisation (AAAF), and established support systems may have encouraged a ceiling effect when completing the questionnaire measures and interviews.

Therefore, future studies may consider advertising in clinics, schools, wig shops and newspapers, as an additional method of recruitment to strengthen research outcomes. Nevertheless, the unusually high response rate in this study would have been practically impossible without assistance from the AAAF Inc. The aim of this study was to investigate the psychosocial impact on families and the sufferers of AA. AA sufferers and their families are not receiving appropriate treatments or psychological support due to the limited assistance available. This study provide information of AA and recommends that future management of AA sufferers and their families include addressing the distress and beliefs associated with diagnosis and treatment of AA.

CHAPTER 2: METHOD

2.1 *Methodology*

The research involved investigating the psychosocial impact on the family members of people suffering from the condition AA. AA can have serious psychosocial consequences, causing intense emotional suffering, and personal, social and work-related problems. Surveys have shown that around 63 per cent of sufferers have claimed to have career-related problems (Hunt & McHale, 2004). Alopecia also leads to depression, anxiety and social phobia in a number of sufferers. This relationship between alopecia and psychosocial consequences can be complicated, in that alopecia can result from a stressful experience, and then, in turn, itself lead to further distress and hair loss. Limited research has been carried out in the area.

There is evidence that stressful life events have an important role in triggering some episodes of alopecia (Garcia- Hernandez et al., 1999). Therefore, the methods thematic analysis and phenomenological analysis were used in this research, to capture the themes and lived experiences of participants coping with supporting a family member with AA, usually a child or sibling.

2.2 *Methods – Study Design*

The current studies epistemological underpinning was constructionism. According to Crotty (1998) constructionists claim “that meaning comes into existence in and out of our engagements with the realities in our world”, that is, both the researcher and subject emerge as partners in the generation of meaning.

Constructionism allowed the researchers to gain an in-depth, ideographic understanding of participant's beliefs, perceptions and/or accounts regarding their coping strategies, through a means of interpretation.

The theoretical framework was embedded in the current study and interviews were conducted with families from different backgrounds each with a member (usually a child), suffering from AA. The participants in the interviews were over 18 years of age, while the family members who were the sufferers varied from age 6 years to 53 years of age. The interview consisted of 10 leading semi-structured open-ended questions, designed to stimulate and bring issues of dealing with AA socially and psychologically. The open-ended questions are shown in Appendix A. Case studies are shown in Appendix B.

The responses to open ended questions reflect on the individual personal's reaction to the phenomenon under investigation rather than one elicited by way of a forced choice between predefined options often observed when questionnaires are used to elicit data.

The study design comprised of qualitative methods and endeavoured to elicit responses to key 10 questions. These answered questions were used in order to acquire understanding about the unique experiences regarding the psychosocial impact on the family of AA sufferers.

This framework enabled the families to speak out safely and tell their stories in their own way so that they could later be explored thematically and phenomenologically. The key considerations within this study were to acknowledge the individual and the family's psychosocial experiences with respect to living with another family member with AA. Utilizing a qualitative method enabled the researcher to immerse themselves in the life experiences of the participants via the interviews and focus group process.

Open-ended semi-structured questions allowed the researcher to enter the participant's world whilst creating a flexible atmosphere for the exploration of theoretical avenues, with researchers taking care to check and clarify the meanings of any unclear experiences (Smith et al, 1995). Qualitative enquiry also provided the participants of this study with an opportunity to raise the family issues, concerns and their advice through conversation and discussion and assist families with their need to reach out for assistance and further investigations into treatment for AA, via well regarded health practitioners.

The interviews were conducted in the families' homes. The participants chose their homes to be the place for the interview to be conducted, as it was more comfortable for their children. The conversations were recorded and later transcribed. The researcher also engaged in creative expression as a process of enquiry within the semi-structured opened ended questions to stimulate the conversation to detail fully all replies from individual family members. The opened ended questions allowed the researcher to explore further the themes and issues raised by each participant and to create a space in which to compare the similarities and differences in the family's stories and life experience of living with a family member with AA.

The complexity of the illustrated issues raised by the families/participants increased their interest in revealing their emotions and the truth of their insights. Each family member that was interviewed was over 18 years of age and was individually interviewed and also interviewed as part of a family group. All interviews were carried out at their selected location, which was usually at each family's home. Each family setting interview lasted approximately two hours and was audiotaped

with consent of the participants. The researcher then transcribed the audiotaped recordings. The data collected were then stored in the allocated location at Victoria University. The semi-structured 10 open ended questions can be seen in Appendix A.

2.3 Ethical Considerations

Following Victoria University Ethics Committee approval, the information to the participants and consent forms were sent to potential participants via AAAF Inc. and its connections. Five families with a family member suffering from AA condition were selected from a number of families that expressed an interest in participating. These families were representative of various backgrounds culturally and socio-economically that mirrored the general Australian community. Once these families agreed to participate a time and a place for the interviews to be conducted was agreed upon. Pseudonyms were used to protect the participants maintaining a confidentiality and anonymity.

2.4 Data Collection

The interviews were conducted in the family homes. The participants chose their homes to be the place for the interview to be conducted, as it was more comfortable for their children. The conversations were recorded and later transcribed. The researcher also engaged in a creative expression as a process of enquiry within the semi-structured opened ended questions to stimulate the conversation to detail fully all replies from individual family members. The opened ended questions allowed the researcher to explore further the themes and issues raised by each participant and to create a space in which to compare the similarities and differences in the families' stories and life experience of living with a family member with AA condition.

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2.5 Data Analysis

The data was analysed using thematic analysis. This involved reading and re-reading the transcripts and identifying the themes that appeared (Rennie, 2000). The transcripts from the recordings were analysed and themes were formulated and they were linked by any patterns in relation to thoughts, feelings and behaviour.

Finally, the data was analyzed to identify strong patterns of meaning and how these meanings were linked to the participants individual life experience. Through abstractions, the similar phrases of the participants were grouped and the predominant factors within the context were re-organised and subsequently identified as themes and sub-themes.

Using the specific opened ended question interview method and exploring the topic through the data collection and analysis, a greater depth and the strength of understanding on the psychosocial impact on the family was achieved. The interviews enabled the expansion of such themes as well as generating new

information.

Given that there has been limited research information, the present data will invite more interest in exploring the similarities and the insights of the families of AA sufferers. This research might bring forth assistance in aiding AA sufferers on a more focused basis such as education about AA, training counsellors and psychologist in specialising in this area, General Practitioners to be more accommodating to this condition and more informative specialists to assist in treating sufferers of AA.

2.5 Findings

The major themes to emerge from the research data were psychosocial effects of AA where; Management of AA lifestyle in the family, Social interactions and Health practitioners and research. Within these themes, there were common sub-themes in the families interviewed.

The following four categories of sub-themes reveal the way in which the families described their psychosocial stress and their role as parents and the family members including the AA sufferers. These four categorized sub-themes emerged from both the individual interviews and the family groups.

1. Psychological and Psychosocial Stress: the impact were the: initial encounter, acceptance and coping, anxiety, stress, guilt, depression, bullies, staring, self- esteem, image, confidence, quality of life (QOL), frustrations and uncertainties.
2. The Management of AA lifestyle in the family: management in family balance, treatments and financial expenses.

3. Social interactions: AAF Inc. and the social interactions.

4. Health practitioner and research: Health Practitioner and further research

5. Participants Advice:

The five families clearly articulated their concerns regarding their present situation and also how they have journeyed through the hard times in search for answers and treatments. They described a variety of issues involved and how these issues contributed directly to their levels of stress, frustrations and the uncertainties. Each family expressed their tortuous, exhaustive journey until they came to a level of acceptance and adjustment in their lifestyle to cope with the psychological and psychosocial impact of AA.

What is significant however, in the research findings, is that the parents of AA sufferers expressed a unique dedication and support to their children suffering from AA. Their role as parents was to take extreme care in monitoring any sudden change in the child's condition. Such as: to observe any sudden growth or loss of hair, blood test of low platelet counts, if the child was distressed, their interactions outside the house especially in school, interactions with the problems with people staring, bullying or people making judgmental comments.

These observations created sudden stress in life and a change of supervision towards the AA child for immediate attention. Having to find some specific head coverings or meetings with school authority(s) to reduce the problem(s), so that the child can face the outside world.

CHAPTER 3: PSYCHOLOGICAL AND PSYCHOSOCIAL STRESS

Alopecia can have serious psychosocial consequences, causing intense emotional suffering, and personal, social, and work-related problems. Surveys have shown that around 63 per cent of sufferers claimed to have career-related problems due to this condition (Hunt & McHale, 2004). Alopecia also leads to fear, depression, anxiety, and social phobia in a number of sufferers. This relationship between alopecia and psychosocial issues can be complex, in that the condition can be brought on by a stressful experience, and then itself lead to further distress. Despite these known consequences, limited research has been carried out thus far in the area.

There is evidence that stressful life events have an important role in triggering some episodes of alopecia (Garcia-Hernandez et al., 1999). According to York et al. (1998), women that experience high stress are 11 times more likely to suffer hair loss than are those who do not lead stressful lives. Compared with the general population, increased prevalence rates of psychiatric disorders are reported among individuals suffering from alopecia (Koo et al., 1994). This finding suggests that the condition may increase the risk for development of a major depressive episode, anxiety disorder, social phobia, or paranoid disorder.

In the few qualitative studies focusing on this issue, analysis of the survey responses proved particularly interesting, generating a number of themes. According to the findings reported by Hunt and McHale (2005b), many of the participants desperately wanted to find out why they had alopecia, and searched everywhere for a cure. Others had issues regarding their relationships, with some having very supportive spouses, while others reporting the opposite. In a few cases, the alopecia was the catalyst to end

a relationship.

3.1 *Initial Encounter*

In the present study, the participating families spoke about their initial traumatic encounter with the condition and their reactions. They also shared how they were psychologically affected by AA and where they initially went to seek help. Furthermore, they discussed their fears, worrying about health, family history of autoimmune problems, available treatments, their future long-term management plans, acceptance, coping, and recovery.

There is no known unequivocal cause of AA; however, a broad array of contributing factors has been reported, including the possibility that several factors are working in unison (Price, 1991). Genetic predisposition typically leads to poor prognosis (Shapiro & Madani, 1999), and a family history is present in approximately 20% of cases (Price, 1991). Physical trauma, diet, medication, and the presence of other autoimmune diseases have also been listed as influential factors (Hunt & McHale, 2005b; Shapiro & Madani, 1999; Thiedke, 2003). One of the participants in the second case study, Tom quoted, *“It was a shock, it was noticed when I went to the hairdresser, as a patch on the side of my head became patches all over my head.”*

While the exact cause of AA remains unknown, 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 et al, 2008), psychological stress (McKillop, 2010), and neurological factors (Madani & Shapiro,

2000). One of the participants in the second case study, Michelle, quoted,

“We were at the swimming pool when Lily was 9 years old, and a chunk of hair just fell out when I brushed her hair, I was shocked...”

There is currently no conclusive cure for AA or a treatment that can help prevent its spread (Hunt & McHale, 2005b; Shapiro & Madani, 1999). Some AA sufferers report spontaneous remission, while many may have repeated episodes of hair loss. Moreover, the hair that grows back is not always of the same type, colour, and texture as it was before hair loss. In some cases, AA is responsive to medical treatment, but the effectiveness of such treatment is limited (Thiedke, 2003). Belinda (case study 3, the mother) quoted:

“My son lost his hair at the age of two, by just running my hands through his scalp and all the hairs will just drop out on my hand. I was shocked. I knew nothing about AA when the doctor diagnosed my baby with AA and there was no treatment for it as he was only a baby. Everyone said that it was stress-related, and I left it then. But, within a year, his hair grew back and the texture of the regrowth hair was different...”

In most cases of AA, once the hair falls out, the remaining hair follicles revert to a hibernation-like state and are capable of spontaneous regrowth at any time. AA typically manifests as a single or multiple oval-shaped non-scarring bald patches. However, its severity can extend to the loss of all hair on the scalp, known as Alopecia Totalis, or to the complete loss of all head and body hair—referred to as Alopecia Universalis (Hunt & McHale, 2005b). As Belinda noted, *“And at the age of nine, within a month, he lost all his hair and an eyebrow.”*

3.2 *Acceptance and Coping*

Coping strategies evolve over time and if a person grows accustomed to the disorder in an adaptive manner, this may help with reducing the anxiety associated with relapse. This is particularly the case in the early stages of AA, when the condition is commonly managed with appearance fixing. In individuals that exhibit adaptive coping style, this is replaced by an optimistic outlook that embodies acceptance (Welsh & Guy, 2009). As seen in case one for Tom, who stated, *"It was kind of a relief when I was diagnosed with hair loss and not other systemic health issues, as my parents have autoimmune problems."* Tom also uses beanies and scarves to cover his head to avoid people staring at him, which also helps to keep him warm.

Michelle (case study 2, the mother) has always covered her daughter's baldness and no one even realises that the 16-year-old teenager had AA. It is apparent that the ability to employ positive acceptance as a coping strategy is often related to receiving strong social support in order to restore confidence (Matzer et al., 2011; Welsh & Guy, 2009).

According to Michelle, her daughter is quite pleased with her looks and, at times when she gets hot and irritable, she uses humour to cope with her condition.

Gender and age are among many factors that can influence the type of coping style adopted in 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). Given the importance of coping styles in management of many life events, including medical conditions, education about effective coping

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

While many AA sufferers resort to covering their head in order to hide their condition, this may be a challenge in the summer when it is hot. Temperature may also profoundly affect those with AA. Hair protects the scalp from the sun in the hotter seasons, while serving as an insulator, preventing the heat from escaping during the colder seasons. One of the respondents in the survey conducted by Hunt and McHale (2005) expressed *“Extreme temperatures have a surprising effect.”*

In the present study, many participants indicated that wearing a wig during hotter seasons would cause overheating. On the other hand, some joked about it, saying that being able to just strip the wig off and be bald was an advantage other people do not have. Clearly, humour was used by many AA sufferers to lighten up a difficult or embarrassing situation. However, overreliance on humour is not recommended because it may lead to the concealment of real emotions. Humour may be useful when and if an individual has accepted his or her condition, and is feeling very positive about their situation (Thompson & Shapiro, 1996).

Humour is another strategy that can help patients cope with AA. Tom’s (*case study 1*) coping mechanism at work was humour. As an educator, he placed priority on the relevance of the joke, rather than his appearance, *“as such, he still has his head rather than his hair.”*

Despite ongoing treatment, Anna (*case study 4*) continued to lose her hair. Egele and Tauschke (1987), identified a group of alopecia patients with an ongoing feeling of loss, suggesting that for some individuals the process of coping with alopecia may be equated with the grieving process following bereavement. Positive or negative perspectives about the self can affect one's self-esteem (Zeigler-Hill, 2013), with stress identified as a significant factor in the development of negative self-esteem (Palmier-Claus et al., 2011). Anna handles grief by isolating herself from the outside world periodically. Grieving can be a slow process and adopting positive coping strategies can assist in dealing with the outside world (Veal, 2013). Her PRA was looking forward to having hair transplant when she saved enough money.

Labelling people with a chronic illness in the absolutist "acceptance" or "denial" terms can be detrimental if the person internalizes the negative information associated with denial that is considered pathological (Telford et al., 2006). Joshua (*case study 5, the father*), reached the acceptance stage much quicker than the rest of the family. His attitude was, now that the son has AA and he has to learn to live with the condition, and the family had to deal with it. He noticed that, whenever the family was out in public, other kids would stare at his son and other parents would look at them in a strange way.

According to Joshua, when people saw his son, they would assume that he had some form of cancer and was undergoing chemotherapy. Joshua said "*it was not nice to think like that.*" He would hold his son's hand, knowing that he felt uncomfortable due to the staring and comments. People would even come up and say things like "*I got a good doctor that can help you.*" These and similar experiences were very hard on the family,

as they are just a normal family and wanted to be able to go out like others. They don't like people staring at them and commenting as if they are some kind of freaks. Hair loss can be especially devastating for adolescents and teenagers due to the impact on the person's identity and self-esteem. As a result, many report loss of desire to interact with friends and peers, and some avoid everyone they know. In most severe cases, AA can put a teenager at high risk of developing psychological issues, such as depressive or anxiety disorders.

Following their study on the characteristic coping strategies people adopt when faced with challenges and threats to one's body image, Cash, Santos, and Williams (2005) reported three consistent factors: positive rational acceptance, avoidance (attempting to escape from thoughts about the threat), and appearance fixing efforts to change or camouflage the threat). Anna (*case study 4*) and Lily (*case study 2*) continued wearing beanies, wigs, and scarves to camouflage themselves and avoid the threat of people staring and making stupid comments, assuming that they have some kind of disease.

Positive rational acceptance has been found to be associated with a better quality of life, whilst avoidance and appearance fixing have been shown to be predictive of low levels of self-esteem and poorer psychosocial functioning. Tom (*case study 1*) accepted that his condition, rather than being a systemic health issue, was limited to the hair loss, and he was happy to know that he is alive and enjoying life with his young children. Positive rational acceptance can be defined as positive or rational self-awareness about one's appearance, with an emphasis on accepting the challenge of a threat to body image.

During the interviews, most families indicated that, in their experience, when hair loss increased in volume, the blood test results of the sufferers usually showed low platelet count. They also shared that, when the AA diagnosis was made and the treatment protocol proposed, medical practitioners did not explain the connection between the low platelet count and the condition. At that point, steroidal treatment was suggested in most cases. It has been shown that, irrespective of the condition, a doctor that is dismissive of a person's disorder or illness may cause harm to their client's wellbeing (Telford, Kralik, & Koch, 2006). It is argued that healthcare professionals who do so are focused on matching behaviours and emotions to suit these categories, rather than listening to the person.

Although AA is not a chronic life threatening illness, parallels can be drawn to the implicit danger of labelling a person with alopecia as being "in denial" (Schmidt et al., 2001). Thus, it is essential that AA sufferers are approached as a whole person, rather than patients presenting a specific set of symptoms. They should be encouraged to adopt coping strategies, but not to the extent that, their suffering would be ignored.

3.3 *Psychological Stress*

3.3.1 *Anxiety*

The impact of dealing with the uncertainty of hair loss and its implications to one's quality of life may cause anxiety. However, some individuals choose to focus on self-growth and confidence instead (Fox, 2003). Still, as each individual deals with life stresses differently, the impact of AA on daily functioning may be strenuous for some more so than others. For example, a female participant in the study conducted by

Thompson and Shapiro (1996) expressed that she did not let her husband see her wigless. The authors noted that this was counterproductive, as the upkeep of maintaining the outer-work of AA can be mentally exhausting and physically draining. The same attitude was reported in the present study, as Anna (case study 4), said, *“My daughter had to use beanies, scarf or spray colour to cover her baldness as she gets very anxious at work, when people look at her in certain ways... Sometimes, she wouldn’t go to work or anywhere as she is exhausted concealing her baldness....”*

3.3.2 Guilt

When asked about the feelings of guilt, Belinda (case study 3) said:

“I was advised by the GP that my child was under stress and that was the reason for the hair loss. I felt so guilty and started looking into our life with great confusion, searching for faults as to where I went wrong. All his hair then grew back within the year and, 6 to 7 years later; it all fell out within a month. I am so shocked and confused, as I don’t know what happened. Could it be this or could it be that? Not sure, very frustrated until today. Is the hair going to grow back again or not? Not sure.”

Firooz et al. (2005) expressed concern that, when patients or family members feel guilt associated with AA, when stress is suggested as the causative factor of AA, this can only aggravate the situation. Moreover, in such cases, it may be difficult for researchers to pinpoint the actual root of onset, and subsequent course of the disorder. Regardless of what the underlying cause of AA may be for any specific individual, it is apparent that the onset of hair loss often has a negative psychological impact (Tucker, 2009).

3.3.3 Stress

Limited research on the relationship between AA and stress has been carried out thus far. However, some authors suggest that stressful life events have an important role in triggering some episodes of alopecia (Garcia-Hernandez et al., 1999). Tom (*case study 1*) mentioned that his hair loss coincided with starting a new job. Similarly, Belinda (*case study 3*) mentioned, “*people think that it is stress, that’s why my baby lost his hair.*”

According to Belinda, this attitude created more stress and guilt, as she was not only unsure of the course her son’s condition would take, but also started looking into her life and searching for the factors that would contribute to her son’s stress.

AA is not a life threatening disorder. Nonetheless, the factors subsequent to its onset have been shown to give rise to a higher prevalence of comorbid psychological disorders compared to that in general population (Koo, Shellow, Hallman, & Edwards, 1994). Hair loss can frequently diminish sufferer’s QOL (Fabbrocini et al., 2013). Whether comorbid psychological problems directly result from the AA onset (Ghanizabed et al., 2008), or are already coexistent due to stressful life events, is an issue that can make pinpointing causation difficult for researchers (Hunt & McHale, 2005a).

Living with AA may create negative feelings, such as humiliation, anxiety, and low self-esteem, which in turn impact in the sufferer’s QOL (Williamson et al., 2001). Stress may be caused by people staring or saying hurtful things, being bullied or facing ridicule at school (Kalabokes & Besta, 2001). Hunt and McHale (2005) found that, in AA sufferers, daily social functioning was low and some individuals found it difficult to cope

at school due to negative experiences. Joshua said, *“my son was teased a lot and so had a lot of time off school”* (Hunt & McHale, 2005).

3.4 Psychosocial Stress

3.4.1 Bullies

Families of those affected by AA never entirely accept the condition, as they will have psychosocial problems. The sufferers will always be facing public staring and unwanted comments, as they look different. This makes it difficult to carry on with their lives without constantly being reminded of AA and its outward effects. Children in particular suffer greatly, as they often have to endure bullying and being called names. Their peers may simply be curious about their condition, and may be making fun of them because they are different.

Children and adolescents deal with AA differently from adults. If one's physical appearance changes abruptly at a very young age, this can have catastrophic consequences. The issues surrounding relationships in particular highlight the importance of identity and selfhood. Empirical evidence indicates that one's identity is not just personal, but bound up in the physical and social worlds. Children with AA might be bullied at school, and the issue is further compounded by the fact that they are going through the stages of establishing identity. Joshua (case study 5), shared:

“Today is my son's birthday and he had a few good friends attended the party. He had a great time and that was good for him because he had big issues at school last week. He was picked on because of his baldness and he didn't want to go to school. His sister was also being picked on because of her brother's

baldness. We had to go to the school to sort out some issues with the bullying. My son has been picked on for a while about his baldness and we went to see the teachers and Principal to sort the problem out....”

According to Joshua, bullies would pick on his son at school, which would cause him to isolate himself in order to avoid the situation. Avoidance may be an aspect of how an individual copes with AA (for example, by avoiding school or social events and interaction). Many AA sufferers, particularly younger ones, may feel uncomfortable disclosing their condition to peers, which results in feelings of isolation (McKillop, 2010). As previously noted, isolation and withdrawal may lead to increased feelings of depression, which may negatively impact on the AA sufferer’s QOL.

The bullying was addressed by the parents, who went to school to speak to the teachers and Principal. The bullies’ comments caused unpleasant experience not only to the sufferer but his sisters as well. Following the intervention by the parents, this problem reduced tremendously, but the sufferer’s sisters continued getting some comments from school children about her brother’s baldness.

3.4.2 Staring

AA sufferers may experience stress because people are staring at them or saying hurtful things. Many children with AA report being bullied or facing ridicule at school (Kalabokes & Besta, 2001). In such cases, avoidance is often the strategy adopted, helping the individual cope with AA (for example, avoiding school or social events and interaction). As AA sufferers may feel uncomfortable disclosing their condition to peers, feelings of isolation may arise (McKillop, 2010). Isolation and withdrawal may

lead to increased feelings of depression, which may diminish the quality of life of the individual with AA. On this, Michelle (*case study 2*) noted,

“We never entirely accepted, but just enough to get by, so we could cope with the condition. I was very concerned about her interaction with the public and school. Lily fears of bullying and being picked on and this could affect her psychologically. Luckily, I have always covered her baldness, so no one knew that she had AA, and I sometimes spray the bald patches...”

Joshua (*case study 5*) also said:

“I experienced this when I take my family out in the public. Other kids stare at my son and parents would look at him in a strange way. People assume that he had chemotherapy and that he has some type of cancer. It’s not nice to think like that. I hold my son’s hand, knowing the staring and comments in public make him uncomfortable. People would even come up and said things like ‘I got a good doctor that can help you’ and these are things the family doesn’t like to face, as we are just a normal family going out like others so looking at us like freaks, staring and commenting, these things make me angry....”

3.4.3 Confidence & Self-esteem

Adolescents who are affected by AA may find it very difficult to “fit in.” Teenagers and young adults are generally concerned about their physical appearance, with most trying to conform to current fashion trends. As adolescents are just beginning to shape their lives, 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 affects their quality of life (Williamson, Gonzalez, & Finlay, 2001).

Hair loss can lead to feelings of social stigmatization, particularly amongst women (Schmidt, Fischer, Chren, Strauss, & Elsner, 2001). The mother of Anna (*case study 4*) commented:

“My daughter works in the public place, as a consultant, so she is required to deal with the public and people were staring at her making her very self-aware of her appearance. She feels very depressed at times and I used to encourage her and tell her to be positive, as there are hair transplants and plenty of places to go to improve her appearance. I am worried about her and not so much about my son. Her hair did maintain at one time and then started dropping again. She has sought treatment and the hair growth just comes and goes. It is very sad to watch her getting so frustrated with her looks. She is very reclusive and has put on weight.”

Furthermore, parents of boys suffering from AA often report that they are concerned with their son reaching puberty. They worry that, as an adolescent, their son would start noticing the effects of the condition more, as other boys will have facial and bodily hair and he will not. 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. At the time when an individual is beginning to shape his/her life, confidence and self-esteem is critical.

Thus, for AA sufferers, maintaining relationships with the opposite sex can be difficult and awkward. As Belinda (*case study 3*) said,

“I can see hard times coming ahead, as he is going to face no facial and bodily hairs...”

In case study five, the father of an AA sufferer commented, *“Having a good wig is kind of comforting, especially for girls, but not for boys...”* He also noted that his son does not really want to shave the remaining hairs off, even though his peers have suggested it. His refusal to shave and wear a wig seems to be his coping strategy. Still, he would occasionally wear a beany or a scarf.

Extant 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 towards acceptance. Unfortunately, some individuals 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, in particular, accessories such as fake eyelashes may provide protection for the eyes and increase their sense of femininity.

3.4.4 *Image*

Feelings of sadness and desire for isolation are to be expected, given that self-awareness of one’s body-image is a salient factor of life for many people living in Western societies (Cash et al., 2005). Thus, losing one’s hair necessitates an identity change (Hunt & McHale, 2005b). Anna’s daughter had also gained weight due to

depression, while her anxiety seemed to contribute to her complete hair loss. Being able to accept one's condition is essential for the overall wellbeing and may even help in managing hair loss. When this is not the case, depression and generalized anxiety disorder often emerge. These are prominent comorbid psychological problems associated with AA onset that have been reported at higher rates than is to be expected in the non-symptomatic population (Brajac et al., 2003; Koo et al., 1994; Ruiz-Doblado, Carrizosa, & García-Hernández, 2003). In the study aiming to investigate these prevalence rates, Chu et al. (2012) reported comorbidity differences with respect to age at the time of AA onset.

Male and female AA sufferers also accept the terms of their hair loss differently. Schmidt et al. (2001) observed unhelpful coping patterns in women with alopecia, ranging from social withdrawal and resignation, to brooding and self-accusation. In contrast to those employing maladaptive coping strategies, women with positive and helpful coping styles involving acceptance showed significantly better quality of life (QOL).

3.4.5 Depression

Alopecia can lead to depression, anxiety, and social phobia in sufferers. This relationship between alopecia and psychosocial consequences can be complicated, in that alopecia can result from a stressful experience, and then itself lead to further distress (Lovibond et al,1995). The effects of the hair loss problem Anna's experienced (case study 4), combined with those of the ongoing treatments (which is steroidal), have resulted in significant weight gain, which has compounded her depression.

Avoidance may be helpful for an individual trying to cope with AA. Many children start avoiding school or social events and interaction. This is also a common coping strategy for adult AA sufferers, including Anna (*case study 4*), who reported avoiding social interactions. They may feel uncomfortable disclosing their condition to peers and, in turn, feelings of isolation may arise in those with AA (McKillop, 2010). As isolation and withdrawal often lead to increased feelings of depression, the AA sufferers' QOL is compromised as a result (Auquier, 2010).

A higher risk of major depressive disorder for those under 20 years of age highlights the influence of appearance-related peer pressure amongst adolescents. This include Joshua's son (*case study 5*) isolated himself from others due to the peer pressure.

3.4.6 *Self-esteem & Quality of Life (QOL)*

Surprisingly, women with non-visible hair loss may have lower self-esteem than those with highly visible hair loss. Madeleine (*case study 4*) commented, "*my daughter's self-esteem is significantly affected since her boyfriend left her for another person, as she blames it on her looks.*" Schmidt et al. (2012) reported that self-esteem is often significantly impaired in women with AA, regardless of the level of hair loss experienced.

Following their study on the self-reported experience of living with AA, Hunt and McHale (2005b) reported that women with AA attribute higher rates of distress and lower levels of self-esteem to the fact that, unlike for men, baldness is not socially acceptable for a woman. This is in line with the view shared by Michael (*case study 2*, the father), "*I felt very sorry to see that special relationship of mother and daughter is not there like other girls that have hair. It would be somewhat different, if my daughter had normal appearance...*"

Apart from the difficulty associated with managing appearance and the uncertainty, parents' quality of life is significantly affected by the child's condition. In addition to comorbid mental health issues, several other problems stemming from the onset and course of AA have been reported that can affect an individual's QOL. Belinda (case study 3) said, *"I can see hard times are coming ahead when my son goes through his puberty, because other boys would have facial hair and body hair and he would have this experience of not feeling like a man, and this uncertainty worries me...."*

The extent of the AA's impact on QOL can range from a minor negative effect on mental health (Güleç et al., 2004) to extreme cases in which the burden can lead to suicidal thoughts (Hunt & McHale, 2005b). However, studies have shown that the level of negative impact in an individual's QOL is comprehensive and often unrelated to the dermatologist-rated clinical severity of hair loss caused by AA (Dubois et al., 2010; Hunt & McHale, 2005b; Matzer et al., 2011).

Positive rational acceptance appears to be the only current adaptive method for adjusting to the onset of AA. To date, there has been limited research into whether acceptance as a coping strategy employed in AA is commonly attained across time as a person becomes accustomed to having the disorder, or whether it is indicative of several contributing factors in the individual.

3.6 *Frustrations and Uncertainty*

The AA sufferers' parents believed that their stress management was directly related to the condition. Most also shared the view that there is no psychological

support during these hard times, as the families try to push through the traumatic journey and go on with their lives. These families had similar experiences during the early stages of coping with AA. Most reported eventually feeling worn down by the aimless pursuit of treatment and answers, which resulted in having to accept the condition. According to some, there was no other choice but to accept the condition. Michelle (*case study 2*), however, continued to relentlessly search for treatments for her daughter. She noted, *"I wanted to keep trying to help her, hoping there was something I can do for her condition. I was desperately wanted to help her, and went everywhere after work and during weekends."*

The impact of this effort was very draining and exhausting, given that her other children or members of the family required her parental guidance at the same time. Michael, Michelle's husband, commented on this:

"In the end, we went to places for help because Michelle desperately wanted to help Lily. There were many talks and cries in the car after seeing someone about the problem, as they all ended up saying the same thing. In the end, we gave up hope of finding a cure for Lily. Eventually, the trying stopped and we came to a level of acceptance. There was feeling of relief and things just settled."

To that, Michelle replied, *"we never really came to full acceptance, but because there was nothing out there, we had to accept to a level, so we could go on with life."*

The relentless exhaustion and continuous seeking of treatment can be very devastating when there is no definite answer. Even after a prolonged treatment, some study participants reported that the condition remained the same or got worse. This

made coping with AA very hard, and for some finding a way to accept the condition almost impossible. Acceptance was reported by Cash et al. (2005) as the only helpful coping mechanism a person can employ in response to hair loss (Hunt & McHale, 2005b; Matzer et al., 2011).

Other strategies that make use of avoidance or appearance fixing techniques have been shown to be largely unhelpful at reducing hair loss distress (Kranz, 2011). For many people, implementing these unsuccessful strategies, coupled with the unpredictability of relapse, leads to the conclusion that accepting hair loss is the only way to move on with life (Hunt & McHale, 2005b).

CHAPTER 4: MANAGEMENT OF AA LIFESTYLE

4.1 AA Management

The families that took part in this research discussed their lifestyle and financial difficulties regarding the outcomes and positive health promotion. The participants chose to continue seeking effective treatments despite the challenging circumstances. However, many reported that searching for treatment, combined with visiting practitioners, reduced the family QOL, as this limited the time they could spend together.

The study participants also spoke of heightened emotions and stress involved in searching for and failing to find the answers. This has made the families very confused and restless. Still, many continued in their search, trying to remain positive and retain hope for a cure. Michelle (*case study 3*) stated,

"I took my son for DCP treatments in the city for three months at the Cancer and Skin Hospital. It was expensive, costing \$50 for each treatment. I had to juggle the time, having to take my son out of the school earlier, go for the treatment and rush back to pick my other children up from school. This went on for a few months, every Wednesday, until the treatment did not work anymore. The hair would easily fall out just by running my fingers through his scalp. My husband and I would talk about it and often cried during these times. There was nothing available to treat the condition at this point in time. We were hoping the treatments might work. The on and off hope was very traumatising for both of us and my son."

4.2 *Financial Implications*

Financial difficulties and time management were also taxing for a young establishing family when suddenly faced with AA. The ability of the parent/parents to cope sometimes declined when there was no assistance from outside the family.

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

4.3 *Treatment Options*

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, when advising newly diagnosed individuals or those dealing with relapse, it is usually better to promote effective coping strategies, due to the unpredictable nature of the condition (Shapiro & Madani, 1999).

For Belinda(*case study 3*), as her baby was two years old when she first noticed hair loss, it was not advisable to have treatment. While the hair grew back within a year, it fell out again at the age of nine. Although Belinda continued searching for right treatment for a little while, she eventually stopped, because she could not see any promising results. She dealt with the problem by trying to cope with it. It is thus essential that effective coping skills are developed by patients and their families,

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, as this can assist the individual with adjustment to the condition. Families should also be offered support and education about AA and be explained that the likelihood of relapse is high (MacDonald Hull, Wood, Hutchinson, Sladden, & Messenger, 2003).

Unfortunately, most families cannot afford an ongoing counselling or therapy.

In case study two, some participants reported receiving assistance from a few organisations, especially charity groups, such as Variety Australia, Princess Charlotte's Foundation, AAAF, and AASA. While some charities offered financial assistance, others offered practical help. Charity support groups may benefit individuals with AA by providing an atmosphere of belonging and non-judgment. This may also help the members feel as though they are not alone in their suffering, motivating them to share their experiences about AA (Prickitt et al., 2004).

Due to the limited facilities designed to help with this condition, there are few trained practitioners out there who are able to assist AA sufferers. Presently, the only available help is through AAAF and other societies, aiming to assist the family in coping with the condition. As there is no cure for AA at this point in time, the focus should be on assisting the families living with this condition in learning to cope as they are going through life with uncertainty. The lack of a conclusive cure and inadequate treatment options, coupled with the unpredictability of relapse, can undermine a person's ability to come to terms with the disorder (Hunt & McHale, 2005b).

CHAPTER 5: SOCIAL INTERACTIONS

5.1 *AAAF Organisation*

AAAF organisation provides support, social links and organised functions to AA sufferers and their families. A web-based survey conducted by Fox (2003) revealed some common themes among the accounts shared by those living with AA. In the study, the discourse was monitored for 18 months within a net-based support group, with the majority of members based in the USA. The themes that emerged from the discussion explored concepts and the impact AA has on life. According to the study findings, almost 26% of the communications raised were about the unpredictability of hair loss, looking and feeling different, loss of self-confidence and self-esteem, and the emergence of a sense of fear (Fox, 2003).

The other common theme that these participants shared was AAAF membership, which has brought the community together to share experiences. This sense of conviction and strength keeps them emotionally buoyant and they all acknowledge that belonging and participating in AAAF gives them a sense of connection.

According to the participants, being a family member of an AA sufferer also involved assisting others through what could be potentially their most critical life moments. All of their life experience and knowledge was extremely important to others that faced the same challenges. AAAF meetings and functions helped in bringing the society together, assisting new sufferers and allowing members to meet other sufferers that have had a lot more life experience. The study participants spoke about the benefits of AAAF, and many commented on their role as advocates for the AA sufferers.

They shared their frustrations with the health system, which has motivated them to help others in the same situation. Many families spoke of their empathy for children and other AA sufferers out there, affirming their commitment to helping others by taking an active role in participating in AA-related events.

Although sharing their stories was considered stressful or emotionally distressing to the participants, they also found the opportunity to interact with others valuable. The participants believed that they were privileged to have other members choose to share their feelings with them. Moreover, when the participants shared their patient stories collectively, there was an implicit sense of belonging, which helped in better understanding their life and the role of AA in it. Some people that took part in the discussions stated that they could not go outside or go to work for fear of being mocked. Women, in particular, described having problems, perhaps because of the importance of hair to a woman's notion of self and her identity (Kingsley , 2003).

5.2 *Benefits of Social Interactions*

The important role played by alopecia social support networks in helping people cope with the changes to their body image has been highlighted by many authors (Prickitt, McMichael, Gallagher, Kalabokes, & Boeck, 2004). However, the level of psychological support provided by doctors involved in diagnosis and treatment may not be adequately addressing the needs of many people (de Koning, Passchier, & Dekker, 1990).

The families interviewed have joined AAAF, which seemed to help in managing their lives better, as they know that are not the only ones having to live with AA.

Many other families in a similar situation have joined AAAF and they are supportive of each other, helping new members with their experiences. The newcomers particularly value meeting some more experienced AAAF members, who can assist them by sharing their knowledge of coping and acceptance. Most of the families interviewed reported that, during the initial visits, they felt overwhelmed and awkward.

Eventually, after more exposure and allowing themselves to enjoy the environment, they and their children started interacting with others. They felt normal and relaxed, surrounded by others who had the same condition. According to one participant,

“We could also help other new sufferers to understand and cope with the disorder, which also enables them to make new friends... My son was normalising his condition and situation with familiar surroundings.”

McKillop (2010) suggested that encouraging AA sufferers to discuss 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 (Prickitt et al., 2004). Talking about the condition and its effect on one’s life 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).

There are charitable organisations that could assist with AA, as

Michelle mentioned:

“There are organisations that can help with funding, such as AAAF, AASA, Princess Charlotte Foundation, and Variety Australia. Go out and join AAAF and especially for children, mixing with a society who have the same problem and condition. This makes the child feel better and makes it easier to accept their condition. A good wig also makes a difference. The appearance is very natural, and it is hard to tell the difference between the wig and real hair.”

CHAPTER 6: HEALTH PRACTITIONERS AND RESEARCH

Thus far, there has been little systematic research into alopecia's psychological consequences (Hunt & McHale, 2005a). There is also no definite cure or treatment available at this point. The affected families have done extensive research and many report going to great lengths in order to see different specialists, without any concrete results. Thus, while these parents are acutely proud of their skills and knowledge about AA, they feel that some practitioners in this field are still lacking the required level of expertise. Further studies and training is desperately required in these areas, especially support and counselling for the sufferers and the family, as the psychological effects of AA cannot be ignored.

Reid et al. (2012) recently conducted a research study on the perceptual differences of hair loss severity between patient and dermatologist, reporting that women rated their hair loss as more severe than their respective dermatologists did. The women's personal rating of hair loss was also found to be a better predictor of QOL impairment than their concurrent dermatologist's rating of hair loss. A discordance between physician's and patient's assessments of hair loss has been noted in other studies relating to QOL and the psychological distress associated with the disorder (Fabbrocini et al., 2013).

Recommendations have been made for diagnosis to include referral to mentalhealth professionals in order to help people develop the coping management skills necessary to deal with hair loss (Ruiz-Doblado et al., 2003). Successful regrowth and the reduction of psychological distress in instances that have included referral to a psychologist following diagnosis (Elkin et al., 2006) appear to advocate the

recommendation to refer to mental health professionals alongside diagnosis. Moreover, empirical evidence suggests that referral may help to combat the course of alopecia in some cases. In spite of the strong support for greater availability of counselling, psychotherapy as a potential treatment of AA appears to be largely unutilized (Matzer et al., 2011).

The perceptual differences between a doctor and a patient concerning the severity of AA, along with dismissive attitudes of some doctors, make dealing with hair loss conditions particularly challenging (Hunt & McHale, 2005b; Van Neste & Rushton, 1997). Regardless of the condition, a doctor that is dismissive of a person's disorder or illness may cause harm to their client's wellbeing (Telford et al., 2006).

In addition, patient satisfaction with healthcare has been shown to be an important factor in the experience of chronic illness (Vrijhoef, Berbee, Wagner, & Steuten, 2009). Hunt and McHale (2005b) documented that people with AA are invariably disgruntled with doctors that trivialize the disorder as a mild condition, equating this attitude to a lack of support and empathy.

Given the above, it is plausible to suggest that negative experiences associated with healthcare professionals' attitudes might be compounding the problem of hair loss for many AA sufferers. Thus, it is hoped that this study might prompt further research and investigation in this field, aiming to provide financial and practical assistance to AA sufferers and families.

CHAPTER7: PARTICIPANTS ADVICE

Participants provided information in order to assist with AA due to limited assistance available. One of the Case Studies quoted: *“To fight it doesn’t help; Be active and go out with it, participate, help other people and cope together with other sufferers and learn to live with it. There is only limited treatment at the moment, but you are able to talk to others and get support. We need questions, answers and factsheets. This would be helpful to those who are trying to understand who they are, why this has happened and where to get information, and how to cope with it. This would provide some information and understanding at the initial time of dealing with the situation until such time as there is proper treatment. Earlier on, the family avoided joining and participating, because it was overwhelming but now that they are having more interaction they appreciate being with others who understand their problem.”*

CHAPTER 8: CONCLUSION

All families interviewed commented that initial diagnosis of AA came as a shock and that there was very little assistance and information available. Prior to the diagnosis, the AA sufferers and their families had no knowledge of AA, its symptoms, and prognosis. Thus, they required education and assistance, as well as information on where to go for help and counselling. The lack of information and assistance from medical practitioners was very disconcerting, in particular since the condition is an autoimmune problem. For many patients, this uncertainty about the future causes frustration and fear, which can be very difficult for parents and family members to deal with. Discrepancies in the AA clinical severity ratings determined by the doctor and the patient, and the resultant impact on QOL, have led to the suggestion that some doctors may be underestimating the overall severity of AA (Dubois et al., 2010).

Upon receiving the diagnosis, many families face the shock and fear of the condition. Lacking the knowledge of AA, its treatment, and long term prognosis, the sufferer and family members start a long and exhaustive search for help and treatment. Their inability to accept the condition and the opinion of the medical practitioner is due to the perceptual differences between a doctor and a patient concerning the severity of AA. Some doctors reportedly have dismissive attitude towards patients having to deal with hair loss conditions (Hunt & McHale, 2005b; Van Neste & Rushton, 1997). Irrespective of the condition, a doctor that does not appreciate the effect a disorder or illness has on the patient may cause harm to their wellbeing (Telford et al., 2006). In addition, patient satisfaction with healthcare has been shown to be an important factor in the experience of

chronic illness (Vrijhoef et al., 2009). Hunt and McHale (2005b) reported that people with AA are invariably disgruntled with doctors that trivialize the disorder as a mild condition, equating this attitude to lack of support and empathy. This has led to the suggestion that negative experiences associated with healthcare professionals' attitudes might be compounding the problem of hair loss for many people living with AA.

The influence of a doctor's dismissive attitude has also been highlighted in research on coping with hair loss. In addition to the finding that self-esteem may be impaired in women with alopecia, regardless of the level of hair loss visibility, Schmidt et al. (2001) reported that maladaptive coping styles were also unrelated to hair loss visibility. Women with non-visible hair loss and maladaptive coping patterns "repeatedly mentioned not being taken seriously by their physician" (p. 1041). Lazarus and Folkman (1984) defined coping as a complex process involving a response to a stressor that is considered difficult or impossible to manage. With respect to threats to body image, coping requires both cognitive and behavioural efforts that typically utilize negative reinforcement in order to minimize the problem (Cash et al., 2005).

In case study 5, both husband and wife said, "We felt helpless and there was a lack of support from doctors." Understanding and support are essential to an individual's quality of life, and may facilitate coping with the condition in a positive manner (Hunt & McHale, 2005). Several research studies on the impact AA can have on QOL have called for dermatologists to take psychological assessment into account when diagnosing AA (Dubois et al., 2010; Koo et al., 1994; Reid et al., 2012). However, due to the limited literature on this issue, it is difficult to establish whether this recommendation has been heeded in practice.

The participants in this research cited lack of treatment options, the unpredictable nature of relapse, and the changes to appearance associated with hair loss as the key issues that make learning to live with alopecia a challenging prospect. The research indicated that underlying AA diagnosis is a complex phenomenon, affected by a multitude of factors that can result in comorbid problems. Regardless of whether psychological comorbidities are the result of AA onset, or are coexisting problems, it is apparent that the prevalence rates of depression and anxiety associated with the disorder is higher compared to the unaffected population.

Even though families have accepted that AA will remain in their lives, they experience ups and downs and still hope that the hair would come back one day. Most of them have accepted the condition because there is no other choice at this point in time. While some did so because of their naturally positive outlook, most were more or less forced to accept the condition and situation due to the lack of other alternatives. Thus, as they have come to the realisation that there is nothing out there that could offer the family the treatment that would restore hair loss, they felt that living with AA as best as they could was the only way. Most of them have tried steroid treatments and the results were not promising.

Utilising steroids can result in very severe side-effects. In addition, these treatments can only be used for a limited period, such as 12 weeks at a time. During this treatment time, limited improvements are often seen, and as soon as the treatment stops, the hair would fall out. Moreover, when the next treatment begins, the texture and volume of newly grown hair is not the same. Most sufferers cannot afford this treatment, as it is not funded. Thus, due to the financial constraints, families would try the treatment for few weeks to see whether the condition would improve.

Unfortunately, even in cases where hair loss did reduce for a little while, it would eventually resume, at the same rate as it was before the treatment. All study participants reported initially trying different treatment options, some persevering for months and some for several years. Eventually, having tried everything and having exhausted all their options, most families stopped looking for a way to fix the hair loss.

Once they stop the treatment and looking for a cure/solution, the families would shift the focus on trying to accept the condition. After reaching some level of acceptance, they would gradually find peace and start interacting with others that have the same problem. The interaction and association will gradually make them feel better and happier with themselves. Thus, all participants found joining associations such as AAAF beneficial.

The families initially suffered psychologically, physically, and socially. They felt exhausted due to constantly having to manage appointments, while bringing up their families and often working as well. Many would turn to their friends and family for support, as very little psychological support was offered by medical professionals. The answers given by the practitioners were not promising, further compounding this issue. Lack of understanding resulted in many families feeling shock, fears, frustrations, uncertainty, and depression. These issues are psychological and psychosocial and must be addressed at the time the AA diagnosis is made. These impacts on families are of great concern when there is no adequate information and assistance to help live with AA.

The families interviewed went through tedious journeys of searching for answers and cures. Eventually, after realising that there is nothing out there that could help to eliminate their problems, they came to terms with the fact that they would have to live with the AA. There is clearly a need for further investigation of the effects of the AA condition on the lives of those affected by it and their families. The lack of a conclusive cure and inadequate treatment options, coupled with the unpredictability of relapse, can undermine a person's ability to come to terms with the disorder (Hunt & McHale, 2005b). These families require psychological assistance, trained practitioners, and associations to provide a network of strategies to assist with living with an uncertainty.

REFERENCE

- Auquier, P., & Grob, J. J. (2010). Quality of Life in Alopecia Areata: A study of 60 *Australia Alopecia Areata Foundation*. (2012). Retrieved March 3, 2012, from <http://www.aaaf.org.au>.
- Borg, L. (2012). *Coping and the Psychosocial Impact of Alopecia Areata in Young Australians*, Victoria University of Victoria, AAAF Inc., p.10 – 61.
- Brajac, I., Tkalcic, M., Dragojević, D. M., & Gruber, F. (2003). Roles of stress, stress perception and trait-anxiety in the onset and course of alopecia areata. *The Journal Of Dermatology*, 30 (12), 871-878.
- Cash, T. F., Santos, M. T., & Fleming Williams, E. (2004). Coping with body-image threats and challenges: validation of the body Image Coping Strategies Inventory. *Journal of Psychosomatic Research*, 58, 191-199.
doi:10.1016/j.jpsychores.2004.07.008
- Chren, M. M, Lasek, R. J, Flock, S. A, Zyzanski, S J. (1997). Improved discriminative and evaluative capability of a refined version of skindex, a quality-of-life instrument for patients with skin diseases. *Archives of Dermatology*, 133, 1433-440
- Chren, M. M., Lasek, R. J., Flocke, S. A., & Zyzanski, S. J. (1997). Improved discriminative and evaluative capability of a refined version of Skindex, a quality-of-life instrument for patients with skin diseases. *Archives Of Dermatology*, 133 (11), 1433-1440.
- Cash, T. F., Santos, M. T., & Williams, E. F. (2005). Coping with body-image threats and

challenges: Validation of the Body Image Coping Strategies Inventory. *Journal of Psychosomatic Research*, 58 2), 191-199. doi: 10.1016/j.jpsychores.2004.07.008

Chu, S. Y., Chen, Y. J., Tseng, W. C., Lin, M. W., Chen, T. J., Hwang, C. Y., . . . Liu, H. N. (2012).

Psychiatric comorbidities in patients with alopecia areata in Taiwan: a case-control study. *The British Journal Of Dermatology*, 166 3), 525-531. doi:

10.1111/j.1365-

2133.2011.10714.x

Crotty, M. (1998). The foundations of social research. Crows Nest, Australia: Allen &

Unwin. de Koning, E. B., Passchier, J., & Dekker, F. W. (1990). Psychological problems

with hair loss in

general practice and the treatment policies of general practitioners. *Psychological Reports*, 67 3, Pt 1), 775-778. doi: 10.2466/pr0.67.7.775-778

Dubois, M., Baumstarck-Barrau, K., Gaudy-Marqueste, C., Richard, M.-A., Loundou, A.,

Auquier, P., & Grob, J.-J. (2010). Quality of life in alopecia areata: a study of 60 cases. *The Journal Of Investigative Dermatology*, 130 12), 2830-2833. doi: 10.

Dubois, M., Baumstarck-barrau, K., Gaudy-marqueste, C., Richard, M. A., Loundou, A., Cases.

Journal of Investiagtive Dermatology, 130, 2830-2833.

doi:10.1038/jid.2010.232. Case study of alopecia universalis and web-based

news groups. *British Journal of Nursing*,

12 9), 550-558.

Egele, U.T. & Tauschke, E. (1987). Die Alopezie: Ein psychosomatisches Krankheitsbild. *Psychoter*

Psychosomatic Medical Psychology, 37,31–35.

Elkin, T. D., Hilker, K. A., & Drabman, R. S. (2006). Anxiety and Psychosocial Concerns in Alopecia

Areata: A Case Study. [Article]. *Clinical Case Studies*, 5(2), 103-111.

Fabbrocini, G., Panariello, L., De Vita, V., Vincenzi, C., Lauro, C., Nappo, D., Tosti, A. (2013).

Quality of life in alopecia areata: a disease-specific questionnaire. [Article]. *Journal of the*

European Academy of Dermatology & Venereology, 27(3), e276-e281. doi:

10.1111/j.1468-3083.2012.04629.x

Firooz, A., Firoozabadi, M. R., Ghazisaidi, B., & Dowlati, Y. (2005). Concepts of

patients with alopecia areata about their disease. *BMC Dermatology*, 5, 1-1.

Garcia-Hernandez, M. J., Ruiz-Doblado, S., Rodriguez-Pichardo, A. & Camacho,

F.(1999). Alopecia areata: Stress and psychiatric disorders: A review. *The Journal of Dermatology*, 26, 625–

632. Garcia-Hernandez MJ, Ruiz-Doblado S, Rodriguez-Pichardo A, Camacho F.

Alopecia areata: stress and psychiatric disorders: a review. *J Dermatol* 1999;26: 625-32. [PubMed] Great Britain: Routledge.

Garcia, C. (2010). Conceptualization and Measurement of Coping During Adolescence: A review of the Literature. *Journal of Nursing Scholarship*, 42(2), 166-185.

doi:10.1111/j.1547-

5069.2009.01327.x

Ghanizadeh, A. (2008). Comorbidity of psychiatric disorders in children and adolescents with alopecia areata in a child and adolescent psychiatry clinical sample.

International Journal of Dermatology, 47, 1118-1120.

Glaser & Strauss, (1976). *The Discovery of Grounded Theory*.

Grimalt, R. (2005). Psychological aspects of hair disease. *Journal of Cosmetic Dermatology*, 4, 142-147.

Gruber, F. (2003). Roles of stress, stressperception and trait-anxiety in the onset and course of alopecia areata. *The Journal Of Dermatology*, 30 12), 871-878. Bryant, R. A. 2013). Is

pathological grief lasting more than 12 months grief or depression?

Gulec, A. T., Tanriverdi, N., Duru, C., Saray, Y., & Akcali, C. (2004). The role of psychological factors in alopecia areata and the impact of the disease on the quality of life. *International Journal of Dermatology*, 43, 352-356.

Harison, S., & Sinclair, R. (2003). Optimal Management of Hair Loss (Alopecia) in Children. *American Journal of Clinical Dermatology*, 4 11), 757-770.

Hordinsky, M. K. (2001). Clinical presentations of alopecia areata. *Dermatologic Therapy*, 14, 291-296. Doi: 10.1046/j.1529-8019.2001.01036

Hordinsky, M., & Avancini Caramori, A. P. (2008). Alopecia Areata. In A. J. McMichael & M. K.

Hordinsky Eds.), *Hair and scalp diseases: medical, surgical, and cosmetic treatments* pp.

91 - 105). Doi: 10.3109/9781420018660.007).

- Hunt, N., & McHale, S. (2005a). The psychological impact of alopecia. *BMJ: British Medical Journal*, 331 7522), 951-953. doi: 10.1136/bmj.331.7522.951
- Hunt, N., & McHale, S. (2005b). REPORTED EXPERIENCES OF PERSONS WITH ALOPECIA AREATA. [Article]. *Journal of Loss & Trauma*, 10 1), 33-50. doi: 10.1080/15325020490890633
- Hunt, N., & McHale, S. (2004). *Coping with alopecia*. London: Sheldon Press.
- Hunt, N., & McHale S. (2005b). Reported experiences of persons with alopecia areata. *Journal of Loss and Trauma*, 10, 33–50.
- Hunt, N, McHale S. The psychological impact of alopecia. *BMJ* 2005; 331: 951–953. Hunt N. *Coping with alopecia*. London: Sheldon, 2004.
- Hunt, N., & McHale, S. (2007). The psychological impact of alopecia. *The Psychologist*, 20 6), 362-364.
- Kalabokes, V., & Besta, R. M. (2001). The role of the National Alopecia Areata Foundation in the management of alopecia areata. *Dermatologic Therapy* 14 4), 340-344.
- Kalish, R. S., & Gilhar, A. (2003). Alopecia Areata: Autoimmunity - The Evidence Is Compelling. *Journal of Investigative Dermatology*, 8 2), 164-167.
- Kingsley, D. H. (2003). The psychological and quality of life effects of hair loss in women. Presented at the 11th Annual Meeting of the International Society of Hair Restoration Surgery, New York.
- Koo, J. Y., Shellow, W. V., Hallman, C. P., & Edwards, J. E. (1994). Alopecia areata and

increased prevalence of psychiatric disorders. *International Journal Of Dermatology*, 33 12), 849-850.

Lovibond, S. H., & Lovibond, P. F. (1995). *Manual for the Depression Anxiety Stress Scales*. 2nd ed.). Sydney: Psychology Foundation.

Madani, S., & Shapiro, J. (2000). Alopecia areata update. *Journal of the American Academy of Dermatology*, 42, 549-566. doi:10.1067/mjd.200.103.909

Matzer, F., Egger, J. W., & Kopera, D. (2011). Psychosocial Stress and Coping in Alopecia Areata: A Questionnaire Survey and Qualitative Study Among 45 Patients. *Acta Dermato- Venereologica*, 91, 318-327. doi:10.2340/00015555-1031

MacDonald Hull, S., Wood, M., Hutchinson, P., Sladden, M., & Messenger, A. (2003). Guidelines for the management of alopecia areata. *The British Journal of Dermatology*, 149 4), 692-699.

McKillop, J. (2010). Management of autoimmune associated alopecia areata. *Journal of Art and Science Dermatology*, 24 36), 42-46.

Martino, J. (2012). *Investigation the impact of Alopecia Areata on women's self-esteem, mood states and coping*, Victoria University of Victoria, AAAF Inc., p.10-35.

Messenger, A. G. & Rundegren, J. (2004). Minoxidil: Mechanisms of action on hair growth. *British Journal of Dermatology*, 150, 186–194.

Palmier-Claus, J. E., Dunn, G., Morrison, A. P., & Lewis, S. W. (2011). The role of

metacognitive beliefs in stress sensitisation, self-esteem variability, and the generation of paranoia. [Article]. *Cognitive Neuropsychiatry*, 16 6), 530-546. doi: 10.1080/13546805.2011.561583

Price, V. H. (1991). Alopecia areata: clinical aspects. *The Journal Of Investigative Dermatology*, 96 5), 68S-68S.

Prickitt, J., McMichael, A. J., Gallagher, L., Kalabokes, V., & Boeck, C. (2004). Helping patients cope with chronic alopecia areata. *Dermatology Nursing / Dermatology Nurses' Association*, 16 3), 237-241.

Reid, E. E., Haley, A. C., Borovicka, J. H., Rademaker, A., West, D. P., Colavincenzo, M., & Wickless, H. (2012). Clinical severity does not reliably predict quality of life in women with alopecia areata, telogen effluvium, or androgenic alopecia. *Journal Of The American Academy Of Dermatology*, 66 3), e97-e102. doi: 10.1016/j.jaad.2010.11.042

Reinhold, M. (1960). Relationship of stress to the development of symptoms in alopecia areata and chronic urticaria. *British Medical Journal*, 1 5176), 846-849.

Ruiz-Doblado, S., Carrizosa, A., & Garcia-Hernandez, M. J. (2003). Alopecia areata: psychiatric comorbidity and adjustment to illness. *International Journal of Dermatology*, 42, 434-437.

Shapiro, J., & Madani, S. (1999). Alopecia areata: diagnosis and management. [Article]. *International Journal Of Dermatology*, 38, 19-24. doi: 10.1046/j.1365- 43

Strategies of coping and quality of life in women with alopecia. *The British Journal Of Dermatology*, 144 5), 1038-1043. Schmidt, S., Fischer, T. W., Chren, M. M., Strauss, B. M.,

& Elsner, P. 2001). 62.1999.00004.x

Telford, K., Kralik, D., & Koch, T. (2006). Acceptance and denial: implications for people adapting to chronic illness: literature review. [Article]. *Journal of Advanced Nursing*, 55 4), 457-

464. doi: 10.1111/j.1365-2648.2006.03942.x

Thiedke, C. C. (2003). Alopecia in women. *American Family Physician*, 67 5), 1007-1014.

Tucker, P. 2009). Bald is beautiful?: The psychosocial impact of alopecia areata. *Journal of Health Psychology*, 14 1), 142-151. doi: 10.1177/1359105308097954

Thompson, W., & Shapiro, J. (1996). *Alopecia Areata Understanding and Coping with Hair Loss*. pp. 1-142). Baltimore, Maryland, United States of America: Johns Hopkins.

Tucker, P. (2009). Bald is beautiful?: The psychosocial impact of alopecia areata. *Journal of Health Psychology*, 14 1), 142-151. doi: 10.1177/1359105308097954

Van Neste, D. J., & Rushton, D. H. (1997). Hair problems in women. *Clinics In Dermatology*, 15 1),

113-125. Vrijhoef, H. J. M., Berbee, R., Wagner, E. H., & Steuten, L. M. G. 2009). Quality of integrated chronic care measured by patient survey: identification, selection and application of most appropriate instruments. [Article]. *Health Expectations*, 12 4), 417-

429. doi: 10.1111/j.1369-7625.2009.00557.x

Veal, R. (2013). *Alopecia and Acceptance*. Victotrian University of Victoria., AAAF Inc.,

p.1-33. Vrijhoef, H. J. M., Berbee, R., Wagner, E. H., & Steuten, L. M. G. 2009). Quality

of integrated

chronic care measured by patient survey: identification, selection and application of most appropriate instruments. [Article]. *Health Expectations*, 12 (4), 417-429. doi: 10.1111/j.1369-7625.2009.00557.x

Wasserman, D., Guzman-Sanchez, D. A., Scott, K., & McMichael, A. (2007). Alopecia Areata. *International Journal of Dermatology*, 46, 121-131.

Welsh, N., & Guy, A. (2009). The lived experience of alopecia areata: a qualitative study. *Body Image*, 6 (3), 194-200. doi: 10.1016/j.bodyim.2009.03.004

Willemsen, R., Vanderlinden, J., Roseeuw, D., & Haentjens, P. (2008). Increased history of childhood and lifetime traumatic events among adults with alopecia areata. *Journal of the American Academy of Dermatology*, 60 (3), 388-393. doi:10.1016/j.jaad.2008.09.049

Williamson, D., Gonzalez, M., & Finlay, A. Y. (2001). The effect of hair loss on quality of life. *Journal of European Academy of Dermatology and Venerology*, 15, 137-139.

Wilson, G. S., Pritchard, M. E., & Revalee, B. (2005). Individual differences in adolescent health symptoms: the effects of gender and coping. *Journal of Adolescence*, 28, 369-379. doi:10.1016/j.adolescence.2004.08.00

York, J., Nicholson, T., & Minors, P. (1998). Stressful life events and loss of hair among adult women: A case-control study. *Psychological Reports*, 82, 1044-1046.

Zeigler-Hill, V. (2013). Self -Esteem Retrieved from

<http://VU.ebib.com.au/patron/FullRecord.aspx?p=1154311>

APPENDIX A

10 Questions to assist in stimulating a conversation about AA.

1. When you first noticed your “relative” (insert, child, brother, sister, mother, wife etc...) was losing a lot of hair what was your first reaction?
2. When the condition was verified to be Alopecia Areata and you found out that treatment was very limited, what did you think? How did you feel?
3. What is your understanding of AA in terms of its
 - causes?
 - cures?
 - Treatments/alternatives?
 - coping with it?
3. When you and your family go out in public how do you/your family react to public perception/comments/reactions? How do you feel about comments people make?
4. What are your main concerns about AA in terms of the future for your “relative”
5. Does your family worry about image for your “relative”?
 - do they use hats/wigs/colour painting/dress up
6. Are there any special ways that you and your family cope with AA? Practical ways, emotional ways? Intellectual ways?
7. Do you have any advice for other people with AA sufferers in the family about how best to cope with the disorder and how best to cope with societies reactions? Or other advice about understanding the condition?
8. Do you have any advice about how best to support the family member with

AA? How to assist them in moving forward and being more confident? Other suggestions?

9. How long did it take for you/your family to accept the condition of AA if you have? Is there anything you would do differently now that you have lived through the experience?

10. Do you have any advice or suggestions that might be useful to individuals and families facing a new diagnosis of AA?

Appendix B

Case Studies

Case Study 1:

Husband Tom, (32) and wife Garcia, (33) and two children a son 3 years old and a daughter (5 months). Husband age 32 had AA for four years. In 2011, he noticed a small bald patch on his side of the head and it was slightly itchy. The bald patch was more noticeable whenever he had a haircut. His wife thought the hair dresser had made a mistake and took a chunk of his hair on the side of his head giving him a bald patch.

Thereafter, he was shocked that the patch became patches so he sought medical advice from the General Practitioner. After all the tests were done he was diagnosed with AA. He felt relieved because he knew it was only a hair loss problem and not his systemic health problem as his parents had a history of autoimmune problems. He accepted the condition AA within 12 months of diagnosis.

He then told Garcia of the condition and she also felt relieved that there was nothing major to his health. At the same time, Garcia was expecting the second child. Garcia was very worried early in 2013, Tom had fainted and fell. He was then admitted in hospital, his condition was idiopathic, and Garcia said that he could fall anytime and if that happens again, he could die as his platelet count was very low.

Garcia is a nurse and she understands the medical terms and condition. That is the reason why there are not worried about the hair loss condition in comparison to health. Tom mentioned that his hair did grow back now and then and when stress

began, all the hair would drop out. So not only is his condition autoimmune it is also stress related. Tom had tried steroid treatments. He said it there would be regrowth and he would lose the hair again and again. Hence, it wasn't doing anything for him, so he eventually shaved his head bald in November 2011 as they were going to a wedding. He then built up the courage for the first time to face everyone in their family and friends and to deal with their questions as to what and why.

His 3 year old son now also noticed is hair loss and started questioning about his appearance. His family accepted his condition but his wife's family has frequently asked about his treatment or any treatment plan. Although, Garcia and Tom have accepted the condition and are happy with their family life, there is still a nagging concern and uncertain about the future, since it is an autoimmune condition.

Their advice would be as he mentioned, "it is only hair and health is more important and looking into life and enjoying your future, as these days there are many ways to improve your looks, with wigs, hair transplant, hats, beanies and scarf. And steroid don't help or fight and don't fight it. Just accept it and join AAAF with people who have the same problem. Go out there and enjoy the interactions, you will feel better."

Case Study 2:

Husband Michael, (44) and wife Michelle, (45) with a 11 year old son Siegel and 16 year daughter Lily who suffers from AA. Michelle first noticed her daughter lost a chunk of her hair in a swimming pool at 9 years of age. The first encounter of the hair loss was a shock to both Michelle and Michael as it was a chunk of hair that just fell out.

Without hesitation, they got a call out nurse to examine Lily to make sure there were no immediate health issues.

The family then went to see the GP, and Lily was diagnosed with the condition AA. Thereafter they went to Royal children hospital to see the skin cancer specialist. The specialist prescribed steroid type treatments and Lily was always hungry and couldn't stop eating. She gained a considerable amount of weight. The treatment was helping with her condition but her hair continued to fall out. She stopped the medication and her weight went back to normal.

The person most affected by the situation was her mother, as she wanted to continue trying to help her daughter and in hope that there was something for her condition. Michelle was desperately seeking places and assistance and went everywhere after work and during weekends to look for a cure for her daughter. In the end, the Michael, Siegel and Lily also only went to places for help because Michelle desperately wanted to help Lily.

During the search for treatments, the family got very frustrated with the results, They had many family talks and often cried in the car after seeing someone about the problem. Eventually, they gave up hope of finding a cure for AA and came to terms with it and decided to begin from there. They never entirely accepted but only enough to get by and cope with the condition, as at this point in time, there was nothing else they could do.

Michelle was very concerned and worried about the uncertainty; about Lily's interaction with the public and school. She fears her daughter could be bullied and picked on and could this could harm her psychologically. Fortunately, Lily has always covered her baldness and no one knew that she had AA. Her mother sometimes sprayed

colour on the scalp to cover the bald patches. The sufferer has her moments, and her ups and down. She does get irritated at times with her wigs as they can get very itchy and hot in the summer and that can get her down. At other times it was good.

Lily was quite happy to wear a wig in the winter and not so much in the summer when it is hot. Humour may be another way to lighten up a situation, as she would say that she was fortunate that she could just strip her hair off to cool down when others don't have that luxury.

Michael, being the father, felt very sympathetic towards the special relationship that mother and daughter have that could somewhat be different if his daughter had normal appearance and did not have to worrying about her condition and enjoy life like everyone else. Michael also has an autoimmune problem. He has vitiligo, and there were white patches around his arms and hands. He also mentioned that grandfather (father's side) also had hair loss patches. There was a family history of autoimmune problems. Michelle has accepted Lily's condition just enough to cope for now, but he still has hope that there might be something out there to help Lily's condition. The family still have that feeling of uncertainty about what is going to happen?

Their Advice:

"Through the journey of hunting and seeking for a cure, at this point time there is no cure available. They have to manage the condition the best they can and hope for a cure in the future. They have a good quality wig which is adjustable to head size. There are organisations that can help with funding: such as AAAF, AASA, Princess Charlotte

Foundation and Variety Australia. Go out and join AAAF and especially for children, mixing with a society who have the same problem and condition. This makes the child feel better and makes it easier to accept their condition. A good wig also makes a difference. The appearance is very natural, and it is hard to tell the difference between the wig and real hair”.

Case Study 3:

Family of six, husband Zieg, (40) and wife Belinda, (36) four children 2 daughters and two sons and the eldest son 11 years old Max has the condition AA. Max had AA at 2 years of age and Belinda had no knowledge of the condition AA. Max totally lost his hair within a short period of time and Belinda was totally shocked and she was told by her friends it was due to stress. She did not thought much of it as the hair grew back within that year and she wasn't so concerned about it, but did have a nagging thought whether the bald spots might return.

When Max turned nine (seven years later), he totally lost his hair within a month and half his eyebrow and he decided to shave the other one. Belinda had three other children to look after from age 6 to 7 apart from Max. When Max lost his hair for the second time, Belinda was totally confused, frustrated and stressed, as it was hard to manage when this situation came about suddenly. Thoughts were going through her mind that during her pregnancy with the Max, she had a kidney infection and whether this could be a linked to his autoimmune system now.

There was no genetic history of autoimmune in this family except her husband's sister had cancer and had chemotherapy after when she lost her hair. They noticed that

she also had AA earlier on, as the patches were showing then she went completely bald. Belinda and her husband felt alone in this situation. The doctors had given no advice about where to seek help or support. Belinda felt very angry and frustrated.

She was quite traumatised by the whole situation as there was so much uncertainty and no proper treatment available. She said there was no treatment for this condition except corticosteroid which she had learned through research. She knew the treatments available at the time were only temporary. They only lasted a few weeks at a time and had major side effects. Max was only a child. Max did try the treatment, and during this time his hair grew back, but in matter of weeks it would fall out again.

The period when the son was going through this was very emotional and traumatic for both the son and the mother. There were a lot of tears and sadness during these times. His mother was very upset and angry and asked why this was happening to her son. At times Belinda felt guilty about Max's condition. She did not know how to discipline him as she knew he was already going through the suffering of AA and extra stress would not help. Belinda knew than there was nothing she could do for Max's condition.

There was still a small amount of hair remaining on his head. Belinda would take Max to the hairdresser some times, and the hairdresser would ask how should the hair be cut. Max would say cut normally. He liked to savour the amount of hair he that he still had. He did not want it shaved. People they knew would always comment that he should shave it. Some people would also say his condition was due to stress. That made the parents feel guilty and they examined their lives to try and see where they might have put such stress on the child to cause this condition.

Initially when he started to lose his hair, no one noticed it until he bent down and kids would mention about the bald patches. He was healthy and quite happy and the hair just happened. It was a shock to the parents and Max. He would worry and cry about his condition as he could not understand why it was happening.

She mentioned her son has no sickness other than hay fever and that he was very healthy. And in the autumn season he lost all his hair within a month. That was the most traumatic time for both mother and son. This was when she needed psychological support. The mother mentioned a few times, that she was on her own with this problem as the Medical practitioners provided very little information about treatments or support groups where she could meet people with the same problems.

She researched the internet and put out a call on Facebook, where she made nine connections with people who had similar problems. The children in the school would pick on him and ask why he is bald and what are AA and that he look different. The parents had to go to the school and bring the subject up and then the kids would stop picking on him.

The mother took the son for DCP treatments in the city for three months at the, Cancer and Skin hospital. It was expensive, costing \$50 each treatment. She had to juggle the time taking her son out of the school earlier, go for the treatment and rush back to pick her other children up from school. This went on for few months on every Wednesday, until the treatment did not work anymore. The hair would quite easily fall out just by running the fingers through the scalp. Her husband and her would talk about it and often cried during these times.

There was nothing available to treat this condition at this point in time. The

parents were hoping the treatment might work. There so much uncertainty in this condition since it is autoimmune and there is nothing much you can do about it. The on and off hope was very traumatising for both parents and the AA sufferer.

The mother's strong advice was:

"If treatments were going to make things better, I would take him for treatments. But the fact is not knowing what is going to come out of this is very traumatic. The on and off hoping and seeing the hair growing back and falling out is very hard to deal with. We have cried often over this. We are still very sad when we really think about it, so I have to block these thoughts as I have other members of the family to take care of. To me, it is more important to give him a good philosophy in order to raise his self-esteem. It is not about how you look that matters but more about what kind of person you are.

This is helping him to cope and accept for his existence. We can see the hard stage is coming when he realises that he is not going to have facial hair, body hair like other boys his age as they get older. It is very hard for parent to see this through. I am just dealing with it on day to day basis. Having remaining patches of hair is also hard to watch. I wish it would all go away. It is also devastating to watch the hair growing and falling out again. It would be easier to deal with if you could understand why it is happening. Some people have said it could be diet, so we bought the Chinese medicine "Fusion". It showed very little obvious result, so you see we tried everything.

And another thing is people are very judgmental, they stare and it is terrible when they come over and think my son has cancer, I don't mind explaining, but to assume my son has cancer and make remarks is quite annoying. I later understood when it was explained to me that, that it is normal for people to have a reaction when they see

something different and it is not always bad they are curious and sometimes sympathetic. When I see someone from afar that is bald, my reaction is AA and it also could be cancer, but I don't approach them

My advice is be open about it and keep communicating with your partner and deal with the emotion when it is there as some days it could be good and some days bad. My son also have the same strategy in coping to be open about it and talk about the feelings and cry about it or joke about it. I find interacting with foundation and society that have the same problem and exposing the child to people with the same condition really helps the sufferer to cope and deal with it by figuring out when they talk to someone who has had it a lot longer than themselves. The other siblings see other AA sufferer also and learn that their family member with the condition is ok".

Case Study 4:

AA sufferer: Madeleine 53 year old lady, belated husband, 23 Anna year old daughter and 27 year old son. Initially, Madeleine was shocked when she saw Anna's bald patches became obvious and Anna was already been seeking for treatment and using all kinds of creams to thicken her hair and it wasn't working. Madeleine wasn't worried about her own look anymore, as she said she is old and not concerned about her condition but worries about her 23 year old daughter Anna. Anna is a consultant and deals with the public all the time.

She is still very conscious and aware of people looking at her strangely and she wears beanies and scarf to cover the bald patches. She never really fully accepts it.

Accessories such as caps, beanies and scarves may also provide protection to the scalp from extreme weather conditions and may help conceal hair loss.

She is still seeking treatment and hopes she can save enough money to go for hair transplant. Family and friends still comment about it and she is very uncomfortable to talk about it. Her mother feels very deeply saddened by the situation as it only started two years ago and still learning to deal with it. The 27 year son wasn't worried and he said that his dad was bald and he is going through the same thing and accepted his looks as it was genetic. The mother's advice was to stay positive and when she can afford, she could go for hair transplant.

Case Study 5:

A family: husband Joshua and wife Angelina in their 30's, three children, 2 daughters, Rowena and Rose, and son. The eight year old son Thomas has AA. It started when he was 3 and ½ years old. It started as a 10c patch on the left side of the head and the father thought he was playing with his clippers. Then a few weeks later other small patches appeared so the mother took him to the GP and he was diagnosed with AA. The mother knew what AA was and sought paediatrician advice. She was told the condition was due to stress. The parents felt so guilty and start analysing their lives to see where they cause so much stress to their child.

They further referred to Dermatologist and he confirmed it was not due to stress. AA condition is related to autoimmune related. This made them feel that it was not

caused by stress that they did not know about. The mother was very confused and very worried that it could be life threatening and whether it could be leukaemia or some type of cancer. They had blood tests done and these showed that the WBC was low, however a few months later the blood was checked again and it was back to normal. The father accepted a lot quicker than the rest of the family. His attitude was, now that the son has AA he had to accept deal with it in his everyday life.

He experienced this when he took his family out in the public. Other kids would stare at the son and parents and give them strange looks. As people would assume that he was having chemotherapy for cancer. The father said it was not nice to think like that. The father would hold the son's hand as he knew that the staring and comments in public made his son feel uncomfortable. People would even come up to them and say things like "I have a good doctor who can help you".

The family did not like to face this type of thing as they are just normal family going out like others but people made them feel like freaks the way they stared and made comments to their face. Both the parents went to the school and spoke with the Principal and teachers. They also discussed with them the bullying, and unpleasant comments their children were experiencing every day from other children in the school. This problem has reduced tremendously but they still get some comments from school children about the brother's baldness.

The parents also concerned that when he reaches adolescence and notices other boys the same age with facial and body hair he may feel isolated and feel like he does

not “fit in” with this growth stage. His son find it very difficult to “fit in” and are also generally concerned about physical appearance, such as watching other boys having facial hair and body hair or with most trying to conform to current fashion trends. It would be difficult to maintain relationships with the opposite sex and can be difficult and awkward. He might avoid school or social events and interaction. He might feel uncomfortable disclosing their condition to peers and in turn. All these uncertainties got very frustrating for the parents to go through in the near future

The mother said that he also had DCP treatments and it cost \$50 per bottle and it is expensive. She did some research and joined AAAF. The feedback she got from AAAF was that the treatment does not really work. The sufferer does not want the treatment any more.

Both parent strong comments: “I think we both accepted it but not completely only to a certain level. When we see people staring at us I don’t think we have accepted that. In AAAF, I see other people never really accepted.

Having a good wig is ok, especially for girls but our son never really likes to wear anything on his head. I hear comments from others that he should shave his hair but he doesn’t want it shaved. That is how he wants to deal with it. And we left it. For some, shaving or wigs 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.

We went to AAAF and it helps, not for the first few times because it was overwhelming and denying but now we are enjoying it. We can help other new sufferers and make new friends. My son is normalising his condition and situation within familiar surroundings”.

The Advice: “To fight it doesn’t help; be active and go out with it, participate, help other people and cope together with other sufferers and learn to live with it. There is only limited treatment at the moment, but you are able to talk to others and get support. We need questions, answers and factsheets. This would be helpful to those who trying to understand who they are, why this has happened and where to get information, and how to cope with it. This would provide some information and understanding at the initial time of dealing with the situation until such time as there is proper treatment. Earlier on, the family avoided joining and participating, because it was overwhelming but now that they are having more interaction they appreciate being with others who understand their problem.”

CONSENT FORM FOR PARTICIPANTS INVOLVED IN RESEARCH

Your consent is being sought to participate in this study. Please read the following information carefully before you decide whether or not you consent to participate.

INFORMATION TO PARTICIPANTS:

We would like to invite you to take part in a study which aims to examine "The psychosocial impact of living with a family member with Alopecia Areata".!

The purpose of this study is to examine the social and psychological impact on family members of living with a family member with Alopecia Areata. You will be asked to participate in an individual interview that will take about 30 minutes. The interview will be conducted at a place of convenience and privacy for you. During the interview the researcher will ask a series of questions to facilitate discussion of issues surrounding your experiences of living with a family member who suffers from Alopecia Areata. During the interviews you may become aware of issues that are distressing. If you require assistance with any issue raised by the research project Psychologist, Professor. Mark Andersen may be contacted free of charge Telephone: 9919 5413). The benefits of participation are that the discussions may assist you in better coping with issues surrounding your family members condition of Alopecia Areata and that information gathered may be of assistance to other families affect by Alopecia Areata.!

CERTIFICATION BY SUBJECT

I, _____ (Full name)

of _____ (Suburb / town)

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

“The psychosocial impact of living with a family member with Alopecia Areata” being conducted by Jennifer Davis under the supervision of A/Professor. 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: Jennifer , and that I freely consent to participation involving the below mentioned procedures:

- Taking part in an audio recorded individual interview of about 30 minutes duration discussing the social and psychological impact of living with a family member with 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.

!

INFORMATION TO PARTICIPANTS IN INVOLVED IN RESEARCH

You are invited to participate

You are invited to participate in a research project examining the effect on individuals of living with a family member who suffers from Alopecia Areata. The study is entitled "The psychosocial impact of living with a family member with Alopecia Areata". This project is being conducted by a student researcher, Jennifer Davis as part of an Honours Degree in a Psychology under the supervision of A/Prof. Gerard A. Kennedy at Victoria University.

Project explanation

Previous research has shown that there are risks that people with Alopecia Areata may develop other health issues such as anxiety and depression. Research also shown that other family members may also be negatively affected by living with family members who suffer from Alopecia Areata and that there are challenges at different developmental stages in the sufferers life in coping with stress, anxiety, depression and social interaction. The challenge is in making the adjustments to manage, accept and cope with Alopecia Areata at different life stages. Therefore, the aim of this study is to examine the impact living with a family member with Alopecia Areata has on individuals within the family unit. The information gathered will be used to assist other people with Alopecia and their families in improving their wellbeing.

What will I be asked to do?

You will be asked to take part in an individual interview which may take up to 30 minutes. The interview will be audio recorded. During the interview you will be asked questions about what it is like to live with a family member with Alopecia Areata.

What will I gain from participating?

You may gain a better understanding of your own and your family's experiences of living with a family member with Alopecia Areata..

How will the information I give be used?

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

What are the potential risks of participating in this project?

During the interview you may become aware of issues you or other family members have that may be distressing. If you require assistance concerning any issue relating to the study and interview, Psychologist, Professor Mark Andersen will be available for free assistance Telephone: 03) 9919 5413).

How will this project be conducted?

If you have volunteered to participate in the research project you will be contacted to organise a time at a place of convenience to you for the interview. During the interviews you will be asked questions to open up discussion about how having a family member with Alopecia Areata affects you and the family as a group. The individual interviews will take up

to 30 minutes. The interviews will be audio recorded and later transcribed verbatim for the analysis of themes and lived experiences reported.

Participation in the research is completely voluntary, and you are free not to answer any questions or to withdraw from the study at any stage during the study.

Who is conducting the study?

Associate Professor Gerard A. Kennedy. His contact details are 03) 9919 2481 or gerard.kennedy@vu.edu.au) and Jennifer Davis. Her contact details are 0412108155 or jen@uls-yoga.com) from Victoria University are conducting the study.

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.