Alopecia and Acceptance: The Influence of Length in Time Since Diagnosis in Coping

with Hair Loss Disorders

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Abstract

Alopecia areata (AA) and other forms of chronic hair loss disorders are not life threatening; however, onset may result in an adverse psychological impact. Acceptance may be the only adaptive coping strategy, as there is no known cure for AA. The research is limited concerning whether a person with AA develops acceptance in conjunction with growing accustomed to the disorder. This study sought to determine if positive rational acceptance (PRA) is an inevitable progression following the onset of alopecia. The relationship between years since being diagnosed and the PRA coping style was investigated. Participants were also split into recently diagnosed and not recently diagnosed groups to establish differences in the utilization of coping styles. The Body Image Coping Strategies Inventory (BICSI), Depression, Anxiety and Stress Scale (DASS-42), Skindex-29 and Patient Satisfaction Questionnaire (PSQ-18) were completed. In contrast to other coping styles, levels of depression and anxiety, and also, negative impact to quality of life were not related to PRA as a coping strategy. Results indicated that PRA does not automatically progress with time, and that patient satisfaction with the doctor at the time of diagnosis could reliably predict higher levels of PRA. Participants who had been referred to mental health professionals alongside AA diagnosis were infrequent in this study. Such referrals could be beneficial in promoting PRA in people with AA who adopt less helpful coping strategies.

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: Ryan Veal

Date: 12th November 2013

Signature

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Table of contents

List of Tables

Alopecia and Acceptance: The Influence of Length in Time Since Diagnosis in Coping with

Hair Loss Disorders

Alopecia areata (AA) is a chronic hair loss disorder that affects approximately 2% of people regardless of their sex or race (Hunt & McHale, 2005b). Onset can occur at any age, although approximately 60% of cases occur before the age of 20 (Price, 1991). Manifesting as a single, or multiple oval-shaped non-scarring bald patches; severity can extend to the loss of all hair on the scalp, known as alopecia totalis; and also to alopecia universalis, the entire loss of all head and body hair (Hunt & McHale, 2005b). The etiology of AA is currently unknown, yet the physiological process has been determined as an inflammatory autoimmune response in which the hair follicle is attacked during the growth stage of development (Shapiro & Madani, 1999). Hair follicles then revert to a hibernation-like state that is capable of spontaneous regrowth at any time. Months or years may pass before this takes place, and remissions and recurrences in this manner make the course of the disorder extremely unpredictable (Price, 1991).

Alopecia areata 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 androgenetic alopecia, telogen effluvium, and cicatricial alopecia. Androgenetic 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. Telogen effluvium 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).

There is currently no conclusive cure to prevent the spread of the AA disorder (Hunt & McHale, 2005b; Shapiro & Madani, 1999). Current treatment options for AA may stimulate growth in some cases, however they do not prevent hair loss or alter the subsequent course of the disorder (Shapiro & Madani, 1999; Thiedke, 2003). Treatment plan selection is based on the extent of scalp involvement and the age of the patient. For those with less than 50% scalp hair loss, Shapiro and Madani (1999) recommend the first option should be to offer no treatment, as 50% of sufferers will regrow their hair within a year. For children under the age of 10, mild prescriptions of minoxidil solution and corticosteroid creams are recommended. Proactive treatment for those above the age of 10 can involve corticosteroid injections, minoxidil solutions anthalin cream, and other topical immunotherapeutic agents. The success rate for current treatments for AA is not high and relapse is common (Shapiro & Madani, 1999). Furthermore, side effects can include dermatitis, skin blistering, and pigmentary changes. Hair prostheses are commonly utilized when treatment is ineffective; yet are often said to be uncomfortable and a source of distress (Hunt & McHale, 2005b).

In line with the search for a cure, there is no known unequivocal cause of AA; however, a broad array of contributing factors have 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). The current literature is inconsistent concerning the role stress, anxiety, and other psychological factors may play in the etiology of AA. Psychotherapy and cognitive behavioural therapy have resulted in the regrowth of hair in several recorded cases when

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. Contrastingly, a case-control study by Güleç, Tanriverdi, Dürü, Saray, and Akçali (2004) reported 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 etiology 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 risk factor in the onset of the disorder (Brajac, Tkalcic, Dragojević, & 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, Tanriverdi, Dürü, Saray, & Akçali, 2004). However, whilst acknowledging that stress may be a legitimate contributor in some cases of AA onset; Firooz et al. (2005) reported that inadequate information and management provided to AA sufferers in some cases could be misleading many to falsely believe their disorder is the result of psychological stress. Firooz et al.

expressed concern that in these instances self-reports of stress as the causative factor of AA may be making it 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 onset often has a negative psychological impact (Tucker, 2009). 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). In addition, hair loss can lead to feelings of social stigmatization, particularly amongst women (Schmidt, Fischer, Chren, Strauss, & Elsner, 2001). This is to be expected given self-awareness of one's body-image is a salient factor of life for many people in Western societies (Cash, Santos, & Williams, 2005), and losing one's hair necessitates an identity change (Hunt & McHale, 2005b). Alopecia areata is not a life threatening disorder; but the factors subsequent to onset have been shown to give rise to a higher prevalence of comorbid psychological disorders than what is common in the general population (Koo, Shellow, Hallman, & Edwards, 1994), and can frequently induce a negative impact to quality of life (Fabbrocini et al., 2013).

Whether comorbid psychological problems directly result from AA onset, or are already coexistent due to stressful life events, is an issue that can make pinpointing causation difficult for researchers (Hunt & McHale, 2005a). Regardless of this dilemma, depression and generalized anxiety disorder are prominent comorbid psychological problems associated with AA onset that have been reported at higher rates than is to be expected in the nonsymptomatic population (Brajac et al., 2003; Koo et al., 1994; Ruiz-Doblado, Carrizosa, & García-Hernández, 2003). In order to investigate these prevalence rates Chu et al. (2012) reported comorbidity differences in regard to age at the time of AA onset. A higher risk of major

depressive disorder for those under 20 years of age highlighted the influence of appearance related peer pressure amongst adolescents. Differences were also observed amongst those aged 20-39 years at onset, with an increased rate of anxiety related disorders. Higher prevalence rates of anxiety disorders amongst immediate family members of people with AA have also been reported (Colón, Popkin, Callies, Dessert, & Hordinsky, 1991) indicating the scope of impact can be extended beyond the individual.

Positive or negative perspectives about the self comprise the concept of self-esteem (Zeigler-Hill, 2013) and stress has been listed as a significant factor in the development of negative self-esteem (Palmier-Claus et al., 2011). Correspondingly, Schmidt et al. (2012) reported that self-esteem is often significantly impaired in women with AA, regardless of the level of hair loss experienced. Self-esteem can be significantly more impaired in women with non-visible hair loss when compared to women with highly visible hair loss. In comparison to males with AA, females have been reported to experience higher levels of perceived stress as a result of living with the disorder (Matzer et al., 2011). A study on the self-reported experience of living with AA by Hunt and McHale (2005b) noted 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. However, some males reported being as affected by AA as females, and this supports the suggestion by Tucker (2009) that the psychological impact of AA on males may be underreported in the literature.

In addition to comorbid mental health issues, several other problems stemming from the onset and course of AA have been reported that can impact on an individual's quality of life (QOL). In comparison to people with other dermatological conditions, people with AA have been reported to experience a broader range of issues that can impact QOL (Dubois et al.,

2010). Decreased energy levels and feelings of fatigue (Dubois et al., 2010; Güleç et al., 2004); difficulties maintaining and forming relationships (Fabbrocini et al., 2013); and the physical issues associated with hair loss (such as having dry and sore eyes as result of losing one's eyelashes) (Hunt & McHale, 2005b) are common problems. The level of impact on QOL as a result of AA onset 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). The level of negative impact on an individual's QOL is 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).

Disproportionate ratings between doctor and patient on the clinical severity of AA and resultant impact to QOL have led to the suggestion that some doctors may be underestimating the overall severity of AA (Dubois et al., 2010). In a research study by Reid et al. (2012) on the perceptual differences of hair loss severity between patient and dermatologist, it was reported that women rated their hair loss as more severe than their respective dermatologist's rating. The women's personal rating of hair loss were also found to be a better predictor of QOL impairment than their concurrent dermatologist's rating of hair loss. A discordance between physician and patient 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).

In addition to perceptual differences between a doctor and a patient concerning the severity of AA, dismissive attitudes have been reported in some doctors dealing with hair loss conditions (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, Kralik, & Koch, 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. This led to the suggestion that negative experiences associated with healthcare professionals' attitudes might be compounding the problem of hair loss for many people 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) define coping as a complex process involving a response to a stressor that is considered difficult or impossible to manage. In regard 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). Schmidt et al. (2001) observed unhelpful coping patterns in women with alopecia ranged from social withdrawal and resignation, to brooding and self-accusation. In contrast to maladaptive coping strategies, women with positive and helpful coping styles involving acceptance showed significantly better QOL.

Acceptance as a construct in research on coping warrants definition. 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 to be pathological (Telford et al., 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". Notwithstanding, the concept of acceptance as a stage of coping that is purely an alternative to pathological denial can be distinguished from the positive coping strategy employed in response to alopecia diagnosis, as exemplified in the findings of Schmidt et al. (2001).

In research on the characteristic coping strategies people adopt when faced with challenges and threats to one's body image; Cash, Santos and Williams (2005) discerned 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). Positive rational acceptance was found to be associated with a better quality of life, whilst avoidance and appearance fixing were both predictive of low levels of self-esteem and poorer psychosocial functioning. 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.

Acceptance utilized in a similar manner to that outlined by Cash, Santos and Williams (2005) has been suggested to be 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). 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 social support networks in helping people cope with the changes to their body image has been highlighted (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 association of alopecia with psychological comorbidities and the negative impact to QOL has led to the suggestion from both dermatologist (Shapiro & Madani, 1999) and psychologist (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 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.

The lack of treatment options; the unpredictable nature of relapse; and the changes to appearance associated with hair loss are some of the issues that make learning to live with alopecia a challenging prospect. The research indicates that underlying AA diagnosis is a complex 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 there are higher prevalence rates of depression and anxiety associated with the disorder. Furthermore, the negative impact to self-esteem and QOL that alopecia diagnosis can produce is comprehensive.

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. The aim of the present study was to ascertain whether positive rational acceptance is the inevitable state that people eventually evolve to following the onset and progression of alopecia. In order to achieve this aim, an investigation between the relationship of length of time since diagnosis and positive rational acceptance was planned. Levels of depression, anxiety and QOL were also measured to investigate the relationship between coping styles and psychological comorbidities.

The differences in adopted coping styles in people with AA who have been recently diagnosed in comparison to people who have been living with the disorder for a considerably longer period of time were analysed. There are currently no data in the coping with body-image

changes research to designate a predicted duration of time for positive rational acceptance to manifest. In order to denominate the time duration since diagnosis for the recently diagnosed group in the present study, a 24 month period will be adopted from research on the grieving process (Maciejewski, Zhang, Block, & Prigerson, 2007). Grieving in response to bereavement or terminal illness has been described as a process rather than an event (Goldie, 2011; Widera & Block, 2012), and a two year period since the triggering event has been shown to be an ample time frame for acceptance to become manifest (Maciejewski et al., 2007), or conversely, for comorbid issues to arise (Bryant, 2013).

The findings in the literature highlight the significant role empathy can play in a doctor-patient relationship, and many people may need a supportive environment to help promote acceptance based adaptive coping strategies following alopecia onset. Perceptual differences between patient and doctor concerning the overall severity of alopecia diagnosis, or a dismissive attitude in doctors, may compound the problem for many people. This may be particularly apparent if the person is prone to employing unhelpful coping strategies to deal with the changes in their appearance associated with hair loss. However, to date no studies have specifically focused on the role of the dermatologist-patient relationship in direct relation to alopecia coping styles. A concurrent aim of the present study was to investigate patient satisfaction with the attitude of one's physician at the time of AA diagnosis and treatment in relation to adopted coping styles.

In addition, it is recommended for assessment of the psychological impact of AA onset to be addressed in conjunction with diagnosis. Currently, there is no research investigating the occurrence of referrals to mental health professionals. An additional aim of this study was to

gauge the prevalence of referrals to mental health services following alopecia diagnosis in order to investigate if recommendations are being made in the clinical setting.

It was hypothesised that positive rational acceptance would be correlated with time since diagnosis. It was predicted that there would be significant differences in the type of coping style employed between people who have been recently diagnosed with alopecia (diagnosed within two years of participating) in comparison to people who have been living with the disorder for a considerable period of time. Based on the research of Cash, Santos and Williams (2005), it was also hypothesised that coping styles that do not employ positive rational acceptance would be associated with higher levels of depression and anxiety, and also negative impact on QOL.

In addition, it was hypothesised that there would be a negative, or inverse relationship between satisfaction with doctor at the time of alopecia diagnosis, and levels of depression, anxiety, and negative impact on QOL. It was predicted that higher levels of satisfaction with doctor at the time of AA diagnosis would lead to an increase in the use of positive rational acceptance as a coping style.

Finally, parallel to the use of psychotherapy as a potential treatment for alopecia, it was predicted that recommendations for referral to mental health professionals alongside alopecia diagnosis in the clinical setting would be largely unutilized.

Method

Participants

Forty-two volunteer participants were recruited in the present study, ranging in age from 23 to 71 years old ($M = 42.4$; $SD = 12.2$). Participants were required to be 18 years or older, and to have a clinical diagnosis of alopecia. Included were 34 females with a mean age of 44.26 ($SD = 11.97$), and 8 males with a mean age of 34.5 ($SD = 10.42$). Two participants reported depressive

symptoms had occurred prior to alopecia diagnosis, and were therefore excluded from any analysis involving depression and anxiety. All participants resided in Australia and were recruited with help from the Australia Alopecia Areata Foundation (AAAF).

Materials

An *Information to Participants* document was provided to potential participants in order to explain the nature of the research, and to outline the aims, research methodology, and potential benefits and risks of participating. It was made clear that: participation was voluntary, volunteers could be withdrawn at any time, all data would remain completely confidential, and that anonymity would be maintained (Appendix 1).

A *Demographics Questionnaire* was developed to attain participants' age, gender, date of alopecia diagnosis, and clinical type of alopecia. Two additional questions inquired as to whether referral to a mental health professional had taken place alongside diagnosis, and if the participant had sought mental health care since diagnosis as a result of alopecia onset (Appendix 2).

The *Skindex-29* was used in order to measure participants' QOL (Appendix 3). The scale is a 30-item self-report questionnaire developed in order to assess QOL in patients with dermatological disorders, and has been shown to be valid and internally reliable (Cronbach's alpha = .87 to .96) (Chren, Lasek, Flocke, & Zyzanski, 1997). This instrument has been used to assess QOL in studies on alopecia areata in both the regular (Dubois et al., 2010) and shortened form (Reid et al., 2012). In the present study, the term 'skin condition' was replaced with the word 'alopecia' in order to make the scale more appropriate to hair loss disorders. The participant is asked to rate the degree each question has applied in the four weeks prior to administration of the test on a Likert-type scale ranging from 1 (never) to 5 (all the time).

Responses for 29 items (item 18 is not included in scoring) are transformed to a linear scale ranging from 0 (never bothered) to 100 (bothered all the time). Higher scores reveal a lower QOL.

The *Depression, Anxiety and Stress Scale (DASS-42)* was used to measure each participant's level of depression and anxiety (Appendix 4). The instrument is a 42-item self-report questionnaire designed to assess current levels of depression, anxiety and stress; however, it is not a diagnostic tool (Lovibond & Lovibond, 1995). Due to the complicating nature of stress as a potential causative factor in alopecia (Firooz et al., 2005; Matzer et al., 2011), levels of stress were not assessed in the present study. Concurrent validity for the DASS-42 has been demonstrated (Ownsworth, Little, Turner, Hawkes, & Shum, 2008), and internal consistency has been reported for the depression, anxiety and stress subscales (Cronbach's alpha = .91, .84 and .90 respectively) (Lovibond & Lovibond, 1995).

Each of the subscales contains 14 items that are answered on a Likert-type scale ranging from 0 (Did not apply to me at all) to 3 (Applied to me very much, or most of the time). Participants are asked to consider how often the statement in each item has applied in the previous week when answering. The 14 items for each subscale are summed to give the overall relative subscale score. Specifically, the depression scale assesses: dysphoria, hopelessness, devaluation of life, self-deprecation, lack of interest/involvement, anhedonia, and inertia. The anxiety scale assesses: autonomic arousal, skeletal muscle effects, situational anxiety, and subjective experience of anxious affect.

The *Body Image Coping Strategies Inventory (BICSI)* was used to assess participants' coping techniques (Appendix 5). The instrument is a 29-item self-report questionnaire designed by Cash, Santos and Williams (2005) to measure how individuals characteristically manage

threats and changes to body-image. On a Likert-type scale participants are asked to rate how characteristic each statement is of how they cope with the threat to their body-image, ranging from 0 (Definitely Not Like me) to 3 (Definitely Like Me). Adapted versions of the BICSI have been used in research on coping with hair loss (Kranz, 2011).

Three subscales are discerned from the BICSI: 8 items measure avoidance (attempting to escape from thoughts about the threat); 10 items measure appearance fixing (efforts to change or camouflage the threat); and 11 items measure positive rational acceptance (rational self-awareness about one's appearance, with an emphasis on accepting the challenge of the threat). Relative items are totaled for each subscale, and the mean-average is then taken as a representative score. High mean-averages of certain subscales indicate high levels of employing the relative strategy. Cash, Santos and Williams (2005) reported convergent validity and internal consistency for the avoidance, appearance fixing, and positive rational acceptance subscales (Cronbach's alpha = .74, .90 and .80 respectively).

The *Short-Form Patient Satisfaction Questionnaire (PSQ-18)* was used to measure participant satisfaction with physician involved in diagnosing alopecia (Appendix 6). Validity and reliability (Cronbach's alpha = .88) have been demonstrated for this instrument (Vrijhoef et al., 2009). The PSQ-18 is a self-report 18-item questionnaire designed to assess overall patient satisfaction with healthcare (Marshall & Hays, 1994). On a Likert-type scale participants are asked to rate personal level of agreement with the statement for each item, ranging from 1 (Strongly Agree) to 5 (Strongly Disagree). Half the items are worded to reflect satisfaction with medical care and are reverse scored; high overall scores reflect satisfaction and low overall scores reflect dissatisfaction. In the current study, participants were explicitly asked to consider

their dermatologist or doctor at the time of alopecia diagnosis when completing this questionnaire.

Procedure

The Victoria University Human Research Ethics Committee deemed the requirements of the National Health and Medical Research Council of Australia were met for the present study, and granted ethical clearance. The majority of participants were recruited with help from the President of the AAAF via website and newsletter advertisement with brief details of the research design. People interested in participating contacted the researchers, and questionnaire packs containing: the information to participant document, demographics questionnaire, Skindex-29, DASS-42, BICSI, and PSQ-18 were then either emailed or sent by post. Time to complete questionnaires was left to the prerogative of the participant. Participants returned completed questionnaire packs via email or post to the researchers. Recruitment took place over a 5-month period.

Data analysis

The data were analysed using Version 18.0 of the PASW Statistics program. All analyses were between-subjects in design. Alpha levels were set at .05. Internal consistency was investigated using Cronbach's alpha for all scales. Independent variables were gathered from the demographics questionnaire. Dependent variables were scored from the relevant questionnaires. For data that were normally distributed: Independent sample *t*-tests were performed to determine differences between samples, and Pearson's correlation coefficient was used to examine relationships between variables. Simple regression was used to determine if patient satisfaction could predict higher levels of positive rational acceptance as a coping strategy. For data that were not normally distributed: Mann-Whitney U tests were utilized to

determine differences between samples, and Spearman's correlation coefficient was used to examine relationships between variables.

<div align="center">Results</div>

Demographic sampling

In order to examine differences in adopted coping strategies, participants were separated into recently diagnosed (≤2 years) and not recently diagnosed (>2 years) samples. Only 9 participants were separated into the recently diagnosed sample in comparison to 33 in the not recently diagnosed sample. Similar average ages were found for both samples. Table 1 presents demographic information for each sample.

Table 1

Demographic characteristics for recently diagnosed and not recently diagnosed samples

	Recently diagnosed (≤2yrs) ($n = 9$), M (SD)	Not recently diagnosed (>2yrs) ($n = 33$). M (SD)
Age (years)	41.22 (12.83)	42.73 (12.21)
Years since diagnosis	1.44 (.53)	17.76 (13.05)
Gender, n (%):		
Male	3 (33.3)	5 (15.2)
Female	6 (66.7)	28 (84.8)

Considering there were only nine participants in the recently diagnosed sample, a median split was also performed on the overall data to separate participants into sample groups of equal size; this was completed in order to confirm any comparison differences from the initial data split. The median split-samples were analysed in the same manner as the recently diagnosed and not recently diagnosed samples. The median split revealed a cut off at 10 years since alopecia diagnosis for the recent half of participants, and beyond 10 years since alopecia diagnosis for

the latter half of participants. As presented in Table 2, the median split resulted in similar characteristics for age and gender in each sample.

Table 2

Demographic characteristics for median split diagnosed samples

	Recent half diagnosed (≤10yrs) ($n = 21$), *M* (SD)	Latter half diagnosed (>10yrs) ($n = 21$), *M* (SD)
Age (years)	42.38 (12.49)	42.43 (12.22)
Years since diagnosis	4.00 (2.95)	24.52 (11.70)
Gender, *n* (%):		
Male	5 (23.8)	3 (14.3)
Female	16 (76.2)	18 (85.7)

Internal consistency

For the Skindex-29, internal consistency was acceptable for the overall QOL score (.95). Internal consistency was acceptable for depression (.96) and anxiety (.95) on the DASS-42. For the BISCI, internal consistency was attained for avoidance (.72), appearance fixing, (.89), and positive rational acceptance (.84). As presented in Table 3 and Table 4, after separating according to length of time since diagnosis, reliability for each of the three coping strategies was satisfactory (>.7) for all subsamples except the recently diagnosed (≤2yrs) sample and the recent half diagnosed (≤10yrs) sample, which both showed poor reliability for the avoidance coping strategy. Internal consistency was satisfactory for the PSQ-18 overall patient satisfaction score (.82).

Table 3

BICSI reliability for recently diagnosed and not recently diagnosed samples

	Avoidance	Appearance Fixing	Positive rational acceptance
Recently diagnosed (≤2yrs) ($n = 7$)	.69	.80	.94
Not recently diagnosed (>2yrs) ($n = 32$)	.75	.88	.80

Table 4

BICSI reliability for median split samples

	Avoidance	Appearance Fixing	Positive rational acceptance
Recent half diagnosed (≤10yrs) ($n = 18$)	.49	.93	.94
Latter half diagnosed (>10yrs) ($n = 21$)	.85	.75	.80

Positive rational acceptance across time

Pearson's correlation coefficient was used to examine the relationship between length of time since diagnosis and positive rational acceptance, and revealed no significant relationship, $r_s = .18$, $n = 37$, $p = .30$.

Coping style differences

Independent sample *t*-tests between the recently diagnosed sample and the not recently diagnosed sample compared means for each of the appearance fixing, avoidance, and positive rational acceptance coping strategies. Table 5 presents the findings. Levels of appearance fixing were significantly higher in the not recently diagnosed group. No significant differences

between the two groups were found for avoidance or positive rational acceptance as a coping

strategy; positive rational acceptance was marginally higher for the not recently diagnosed

sample.

Table 5

Independent sample t-tests of recently diagnosed group in comparison to not-recently

diagnosed group for coping strategies

	Recently diagnosed (≤2-yrs) (*n* = 7) *M (SD)*	Not-recently diagnosed (>2-yrs) (*n* = 32) *M (SD)*	*T*	*df*	*p*
Appearance fixing	.77 (.47)	1.55 (.61)	-3.18	37	.003*
Avoidance	1.02 (.61)	1.05 (.57)	-.15	37	.88
Positive rational acceptance	1.10 (.80)	1.37 (.60)	-1.02	37	.31

*p < .05

Independent sample *t*-tests between the recent-half diagnosis sample and the latter half

diagnosis sample from the median split compared means for each of the appearance fixing,

avoidance, and positive rational acceptance coping strategies. Table 6 presents the findings.

Parallel to findings from the initial *t*-test, levels of appearance fixing were significantly higher

in the latter diagnosed group. No significant differences between the two groups were found for

avoidance or positive rational acceptance as a coping strategy.

Table 6

Independent sample t-tests of median split groups for coping strategies

	Recent half diagnosis (≤10-yrs) (*n* = 18) *M (SD)*	Latter half diagnosis (>10-yrs) (*n* = 21) *M (SD)*	*t*	*df*	*p*
BICSI Appearance fixing	1.13 (.76)	1.65 (.44)	-2.60	26.3	.02*
BICSI Avoidance	.92 (.48)	1.16 (.64)	-1.33	37	.19
BICSI Positive rational acceptance	1.21 (.65)	1.43 (.62)	-1.08	37	.28

*p < .05

Coping style characteristics

Spearman's correlational analyses were performed to investigate the relationship of each of

the three coping styles to both depression and anxiety because both these variables were not

normally distributed. There were positive correlations between appearance fixing and both

depression and anxiety (moderate in strength). Avoidance was not significantly correlated with

either depression or anxiety. Positive rational acceptance was not correlated to either depression

or anxiety. Table 7 presents the findings.

Table 7

Spearman's correlations between coping styles and both depression and anxiety

	DASS Depression		DASS Anxiety	
	r_s	*P*	r_s	*p*
BICSI Appearance fixing	.39*	.02	.47**	.004
BICSI Avoidance	.33	.05	.26	.14
BISCI Positive rational acceptance	.22	.19	.26	.14

**p < .01
*p < .05
n = 35

Pearson's correlation coefficient analyses were used to examine QOL in relation to each of the three coping styles. Both appearance fixing and avoidance were positively correlated to overall impact on quality of life; each relationship was moderate in strength and significant. Positive rational acceptance was not correlated with overall impact on quality of life. Table 8 presents the findings.

Table 8

Pearson's correlations between coping styles and quality of life

	Skindex-29 Overall QOL	
	R	*P*
BICSI Appearance fixing (*n* = 38)	.40*	.01
BICSI Avoidance (*n* = 38)	.45**	.004
BISCI Positive rational acceptance (*n* = 37)	-.07	.68

**p < .01
*p < .05

Satisfaction with doctor at the time of alopecia diagnosis

Spearman's correlation coefficient analyses were performed to observe participant satisfaction with doctor at the time of diagnosis in relation to depression and anxiety. No significant correlations were found for participant satisfaction with doctor and depression. No significant correlations were found for participant satisfaction with doctor and anxiety. Pearson's correlation coefficient revealed participant satisfaction at the time of diagnosis was significantly correlated to overall impact on quality of life; the relationship being negative and moderate in strength. Table 9 presents the findings.

Table 9

Correlational analyses between participant satisfaction and depression, anxiety and QOL

	DASS Depression (n = 37)		DASS Anxiety (n = 35)		Skindex QOL (n = 36)	
	r_s	P	r_s	P	r	p
PSQ Overall satisfaction	-.007	.96	.03	.87	-.42*	.01

*p < .05

Pearson's correlation analyses revealed patient satisfaction with doctor at the time of diagnosis was not significantly correlated with either of the appearance fixing and avoidance coping strategies, $r = .10$, $n = 37$, $p = .27$ and $r = -.20$, $n = 37$, $p = .12$ respectively. A simple linear regression analysis showed patient satisfaction at the time of diagnosis could significantly predict levels of positive rational acceptance as a coping strategy, $b = .56$, $t_{(35)} = 3.19$, $p = .003$; the model accounting for 23% of the variance.

Recommendations for referral to mental health professionals

Participants who had been referred for mental health assessment at the time of diagnosis were in the minority when compared to participants who had not been referred. Over a third of participants had sought mental health care as a direct result of their alopecia onset. Table 10 presents the findings.

Table 10

Descriptive information for mental health care after alopecia diagnosis

	Affirmative n (%)	Negative n (%)
Referrals to mental health following diagnosis	3 (7.1)	39 (92.9)
Sought mental care as a result of diagnosis	14 (33.3)	28 (66.7)

Discussion

The present study examined whether positive rational acceptance is the inevitable coping strategy that people with AA adopt following the onset and progression of hair loss. Specifically, the relationship between the length of time in years since a formal diagnosis of alopecia had taken place, and PRA as a coping mechanism was observed. In addition, participants were separated into recently diagnosed (≤2-yrs) and not-recently diagnosed (>2-yrs) groups in order to discern characteristic differences in coping strategies between these two groups. These groups revealed a large difference in sample size and therefore a median split was also performed on the data to create groups of equal sample size. The median split groups (diagnosis of ≤10-yrs and >10-yrs) confirmed all findings from the recently diagnosed and not-recently diagnosed samples.

The results did not support the hypothesis that PRA would be related to time since diagnosis. In addition, no significant differences between the recently diagnosed and not recently diagnosed groups were found for levels of the PRA coping strategy, or the avoidance coping strategy. In contrast, the results supported the hypothesis of significant differences between groups for the appearance fixing coping strategy in the present study; participants with a more recent diagnosis of alopecia utilized this coping strategy to a lesser degree in comparison to participants who had been living with alopecia for a longer amount of time. In agreement with research on coping with body image changes (Cash et al., 2005), the results supported the hypothesis that coping styles that do not employ PRA may be associated with an increased level of negative impact to QOL. For the hypotheses that coping styles that do not employ PRA would be associated with higher levels of both depression and anxiety, the results supported for

the appearance fixing coping strategy only; no significant relationships were found between the avoidance coping strategy and either depression or anxiety.

The present study also investigated the role of the doctor-patient relationship in relation to both PRA as a coping strategy, and also comorbid psychological problems following AA diagnosis. There were no significant relationships between participant satisfaction with doctor at the time of alopecia diagnosis and either depression or anxiety. In contrast, the results supported the hypothesis that there would be a negative, or inverse relationship between satisfaction with doctor at the time of alopecia diagnosis, and increased levels of negative impact on QOL. As hypothesized, it was found in the present study that higher levels of satisfaction with one's doctor at the time of AA diagnosis could predict an increase in the use of positive rational acceptance as a coping style. Finally, the results supported the hypothesis that recommendations for referral to mental health professionals alongside alopecia diagnosis in the clinical setting would be largely unutilized.

The findings of the present study concerning PRA as a coping strategy in relation to length of time since diagnosis of alopecia call for discussion. The absence of a relationship between the two variables suggests that acceptance is not an inevitable state of coping attained for people diagnosed with alopecia. There is currently a lack of literature concerning this area of research; however, these findings are in contrast to the report that PRA is gradually developed over time following alopecia diagnosis, as suggested in the qualitative research of Welsh and Guy (2009). Welsh and Guy observed that a strong network of social support was a necessary precursor to the development of PRA for all participants interviewed in their study, and it is possible in the sample of the present study that participants who did not report PRA as a coping strategy are not receiving adequate social support.

Recently diagnosed and not recently diagnosed groups did not employ significantly different levels of PRA as a coping strategy in the present study. This finding appears to further support the suggestion that acceptance is not an inevitable state of coping attained for people diagnosed with alopecia. This is consistent with prior research on coping with threats to body-image, which have shown that hair loss distress depends neither on age or stage of hair loss (Kranz, 2011). Alternatively, these findings could be resultant of the low proportion of recently diagnosed participants (≤2yrs, $n = 9$) in the present sample. If people diagnosed with alopecia who have not developed PRA as a coping style are more likely to be in the early stages of onset (Welsh & Guy, 2009), then the present sample may be underrepresented. Participants willing to contribute to the present study may have already largely developed PRA as a coping strategy, and potential participants for the recently diagnosed group may have been unwilling to participate due to the initial shock of hair loss.

The significant increase in appearance fixing as a coping strategy between the recently diagnosed and not recently diagnosed groups in the present study suggests that participants who do not develop PRA as a coping style resort to amplifying alternative maladaptive strategies. This finding is consistent with previous research on coping with body-image threats (Cash et al., 2005). High levels of appearance fixing as a coping style alternative to PRA may be attributed to the predominant number of female participants in the present sample; women have been reported to utilize the appearance fixing coping style particularly more so than men (Cash et al., 2005). This interpretation may conversely explain the low levels of avoidance as a coping style in the present study.

Although avoidance marginally increased in the present study between the recently diagnosed and not recently diagnosed groups, this difference was not significant. This finding

suggests that avoidance is a coping strategy adopted in the early stages of alopecia onset that is maintained or disregarded, as opposed to a strategy newly adopted or strengthened in the later stages following alopecia onset. Cash et al. (2005) reported that utilization of avoidant coping is relative to a person's belief that their physical appearance influences their personal worth, and this consideration supports the unlikeliness that this strategy would be adopted anew after growing accustomed to alopecia over several years.

The finding that PRA as a coping strategy is not associated with higher levels of depression and anxiety, or a negative impact to QOL is consistent with previous research demonstrating that PRA may be the only adaptive coping style available when faced with body image-threats (Cash et al., 2005; Kranz, 2011). The significant relationship between appearance fixing and negative impact to QOL is also consistent with previous research (Cash et al., 2005), and the significant relationships between usage of this coping style and higher levels of both depression and anxiety in the present study further implicates appearance fixing as a maladaptive method for dealing with body-image changes. Depression and generalized anxiety disorders have been reported at higher rates in the AA population in comparison to the nonsymptomatic population (Chu et al., 2012), and these findings suggest that an individual predisposed to depression and anxiety may resort to maladaptive coping styles such as appearance fixing when faced with alopecia onset.

In the present study, depression and anxiety were not normally distributed. Alternative interpretations could therefore explain these findings. Appearance fixing was the coping strategy primarily used by the not-recently diagnosed group and the latter half diagnosis median split group in the present study, and the significant relationship between this coping style and both depression and anxiety may be a reflection of this. Specifically, depression and anxiety

symptoms may only have been elevated in participants utilizing appearance fixing as a coping strategy. Appearance fixing may be associated with problems accepting the condition, and hence more related to negative emotions. This explanation may also apply to the findings on the avoidance coping style.

Avoidance as a coping strategy in the present study provided mixed results in relation to psychological comorbidities. The significant inverse relationship with QOL is consistent with previous research on avoidance as a maladaptive coping strategy (Cash et al., 2005; Kranz, 2011). The finding that avoidance as a coping style was not associated with higher levels of either depression or anxiety was unexpected given reports of maladaptive similarities between this strategy and appearance fixing (Cash et al., 2005). Two explanations are suggested here. Avoidance as a coping style may only be associated with a negative impact to QOL, and be less detrimental to mental health than appearance fixing considering the long term increases in usage of appearance fixing in the present study. However, this explanation contrasts to previous research that has suggested the avoidance coping strategy is just as, or more problematic than the appearance fixing strategy (Kranz, 2011). Alternatively, the low levels of avoidant coping reported in the present study in comparison to appearance fixing may have resulted in lower reports of depression and anxiety symptoms by participants associated with avoidant coping.

The significant inverse relationship between participant satisfaction with doctor at the time of diagnosis and QOL is consistent with previous research that suggests the attitude of a doctor can influence the well being of a patient following diagnosis (Telford et al., 2006). In particular, this finding appears to reflect reports that the negative experiences associated with a doctor's attitude may be complicating the problem of alopecia for some people (Hunt & McHale, 2005b). Contrastingly, the finding that participant satisfaction with one's diagnosing doctor was

not related to higher levels of either depression or anxiety in the present study implies that the influence of satisfaction with one's diagnosing doctor may not be extensive. These results need to be interpreted with caution. Participants who have had negative experiences with their doctor at the time of alopecia diagnosis may have been inclined to overestimate the dissatisfaction with their doctor whilst participating in the present study. In the present study, the impact of participant satisfaction with doctor at the time of diagnosis may be more thoroughly represented in the relationship between satisfaction and PRA as a coping strategy.

The finding that participant satisfaction with doctor at the time of diagnosis could predict usage of PRA as a coping style in the present sample further supports the suggestion that developing PRA as a coping style in relation to body-image threats can be dependent on receiving social support (Matzer et al., 2011; Welsh & Guy, 2009). Higher levels of participant satisfaction meant it was more likely the participant utilized PRA in the present study. Conversely, less satisfaction with doctor at the time of diagnosis predicted less utilization of PRA as a coping style. This finding is consistent with reports that some women with maladaptive coping styles complained that their doctor was not taking their alopecia diagnosis seriously (Schmidt et al., 2001). Nevertheless, the relationship between the utilization of PRA and levels of satisfaction with diagnosing doctor in the present study did not take into account additional sources of social support, such as family and friends. Welsh and Guy (2009) observed that the adequate amount of social support required for acceptance as a coping strategy often came from a variety of sources. It is therefore possible in the present study that participants who reported highly on satisfaction with their doctor were also receiving sufficient social support from alternative sources to enable the development of PRA as a coping mechanism.

Referrals to mental health professionals alongside alopecia diagnosis in the clinical setting were largely unutilized in the present study, indicating that recommendations (Hunt & McHale, 2005a; Shapiro & Madani, 1999) for potential psychological problems to be addressed alongside diagnosis are not commonly taking place. There is limited research literature in this area; however, reports that people with AA may be at higher risk to develop comorbid psychological issues have been made for over decade (Koo et al., 1994). The higher proportion of individuals who sought mental health intervention as a direct result of their alopecia onset in comparison to the proportion of individuals who were referred to mental health assessment in the present study add additional support for the recommendations made for either psychological assessment, or referral to mental health professionals alongside alopecia diagnosis (Dubois et al., 2010; Reid et al., 2012).

The present study contributed to the research on coping with body-image threats by investigating whether the development of PRA as a coping style is an inevitable state following alopecia onset. The findings not only support previous research that has suggested that PRA is the only helpful coping style to employ when faced with alopecia diagnosis (Cash et al., 2005; Schmidt et al., 2001), they also suggest that PRA is not commonly attained as a person learns to live with the condition. Contrastingly, it appears from the findings of the present study that maladaptive coping strategies, such as appearance fixing, are increased if PRA is not adopted. To encourage people with alopecia to adopt PRA as a coping style in the absence of effective treatments for this disorder, diagnosing clinicians could follow recommendations made in the literature concerning referral to mental health professionals (Hunt & McHale, 2005a), or psychological assessment alongside diagnosis (Koo et al., 1994; Shapiro & Madani, 1999). The

findings on referrals in the present study suggest that such recommendations are not taking place.

In addition, the present study highlighted the importance placed on understanding the potential for psychological comorbidities alongside alopecia onset. Social support, including empathy and understanding from one's diagnosing clinician, is suggested in the present findings to be an integral part of the development of PRA as a coping strategy. Clinicians might need to be mindful of providing adequate social support when diagnosing chronic hair loss disorders in order to avoid patient perceptions of a dismissive attitude of the overall scope of psychological impact.

The present study has a number of limitations that need to be addressed. Due to inadequate numbers in the recently diagnosed (≤2yrs) group, this research sample did not allow for an investigation for the stipulated recently diagnosed and not-recently groups without confirmation from the median split groups. Although the confirmation produced similar findings, the median split profile may not be an accurate representation to confirm results due to the large difference in the years since diagnosis for the recently diagnosed (≤2yrs) and recent half diagnosed (≤10yrs) groups.

In addition, males were underrepresented in the present sample. Shapiro and Madani (1999) reported that a differential diagnosis for alopecia areata is commonly androgenetic alopecia. Considering alopecia areata occurs in approximately equal proportions for males and females (Price, 1991), it is possible that the disproportionate number of males in the present study is due to some men being misdiagnosed, or not seeking diagnosis at all. Furthermore, the present sample was not randomized; all participants volunteered and this could have led to a selection bias of women who were relatively adjusted to the shock of hair loss. It is possible that potential

recently diagnosed participants were unwilling to contribute due to the shock of hair loss. Future research could focus on a within subjects design with proportionate differences between genders that would enable accurate generalizability, and investigation of coping style differences between genders.

Two scales utilized in the present study were not specific to the needs required for alopecia research. The Skindex-29 is a scale designed for measuring QOL in participants with dermatological disorders of the skin. Although questions were altered to meet the needs of an alopecia related QOL questionnaire as in prior research on AA and QOL using the Skindex-29 (Dubois et al., 2010), future research could develop a scale specific to QOL in alopecia patients to enable a more accurate portrayal. In addition, the PSQ-18 scale used to measure participant satisfaction with doctor at the time of alopecia diagnosis is a questionnaire that covers several elements of patient satisfaction, rather than specific dismissive attitudes in one's doctor. Future research could also include qualitative interviewing to fully gain the impact of participant satisfaction. In spite of these limitations, the results proved reliable for both the Skindex-29 and PSQ-18 in the present study.

As afore mentioned, the findings regarding participant satisfaction with diagnosing doctor need to be interpreted cautiously. For example, some participants may have been inclined to underestimate satisfaction levels if they felt their diagnosing doctor dismissive of their condition. In addition, participants were asked to recall their satisfaction with their doctor at the time of diagnosis and retrospective memory may have been affected by extended periods of time for some participants, particularly for the not-recently diagnosed group. Future research could control these issues by investigating participant opinions of diagnosing doctor immediately following diagnosis.

Notwithstanding these limitations, the present study compared two different types of groups within the present sample in addition to a correlational analysis, and the findings did not support PRA as an inevitable state of coping in alopecia. The results instead suggest that PRA might only develop as a result of several contributing factors both inherent and external to an individual, rather than as an inevitable coping strategy employed when faced with alopecia onset. Positive rational acceptance was the only coping style not associated with increases to depression, anxiety or a negative impact to QOL. It is apparent from the present study that a negative impact to QOL may be the initial concern for many people with alopecia; this factor was involved in the maladaptive coping styles and related to decreased participant satisfaction with doctor at the time of diagnosis. The findings suggest that developing PRA as a coping style is dependent on receiving strong social support, and satisfaction with doctor at the time of diagnosis may be an important factor in this development. Referrals to mental health professionals, or psychological assessment by a diagnosing doctor alongside alopecia diagnosis may be a beneficial strategy for promoting PRA as a coping style in the absence of adequate treatments.

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Appendix A

INFORMATION TO PARTICIPANTS INVOLVED IN RESEARCH

Thank you again for participating in this research. Please take the time to read the following before completing the 5 questionnaires included in this pack.

Background

This research project seeks to evaluate the quality of life, psychological impact, and resultant acceptance of Alopecia Areata (AA) diagnosis. The study is entitled "Alopecia Areata: Reducing the impact over time."

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

Project explanation

Previous research has demonstrated the possible risk of individuals with AA developing other health issues such as depression and anxiety, and has also shown AA can negatively impact quality of life. Research has also shown that the bedside manner of many AA diagnosing health professionals can be lacking in support and compassion.

Aim

To investigate the psychological impact of AA diagnosis between people who have grown accustomed to having AA over several years (diagnosis of 5 years or more) in comparison to people with a more recent diagnosis. Differences in levels of depression, anxiety, stress and overall quality of life will be observed. An additional focus of the study will be on the different reactions to news of the diagnosis, including the bedside manner of the health professional and the current level of acceptance of the diagnosis.

What do I do?

I ask you to please complete the following questionnaires, which I have included in this pack:

1. The demographics page containing basic information about you and your diagnosis.

2. Skindex-29 scale, which is a measure of your current quality of life.
3. Patient Satisfaction Questionnaire (PSQ-18), which is a measure of whether or not you are/were satisfied with your doctor/dermatologist. Please consider your doctor/dermatologist at the time of your alopecia diagnosis when completing this questionnaire.
4. Depression, Anxiety and Stress Scale (DASS42), designed to measure your current depression, anxiety and stress levels.
5. Body Image Coping Strategies Inventory (BICSI), designed to measure how you cope with your alopecia.

Once you have completed the questionnaire packs:

- **If you have received the pack in the mail:** All you need to do is complete the 5 questionnaires, then you can then return the completed questionnaires to the researchers via regular post using the enclosed reply-paid envelope.

- **If you received the pack via email:** All you need to do is print the questionnaire pack, complete them, then scan them and reply to this email with the attached completed files. If this is not convenient, please contact me and I will send you a reply paid envelope in the mail (with a hard copy of the questionnaires if necessary). Note: Any identifying information in an email to us will be deleted and we will only retain your completed questionnaire, so as to maintain anonymity of your responses.

What will I gain from participating?

You will be assisting research that may identify the psychological risks associated with AA at different stages of a person's life. It is anticipated that by participating in this study, the information collected will assist to enhance quality of life, acceptance of diagnosis and possibly reduce the risk of developing issues such as depression and/or anxiety by promoting support in diagnosing clinicians.

How will the information I give be used?

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

What are the potential risks of participating in this project?

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

How will this project be conducted?

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

Who is conducting the study?

Victoria University

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

Mr Ryan Veal. His contact details are 0429 931 043 or ryan.veal@live.vu.edu.au

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

Appendix B

Demographic Information

- Age:

    ....

- Gender (Please tick)

    ☐   Male

    ☐   Female

- Date of Alopecia diagnosis (approximately):

    ………/………/…………….

- Type of Alopecia (Please tick)

    ☐   Alopecia Areata

    ☐   Alopecia Totalis

    ☐   Alopecia Universalis

    ☐   Androgenetic Alopecia

    ☐   Other (Please state):

        ………………………………………………………………………………

- Diagnosing physician (Please tick)

    ☐   General Practitioner

    ☐   Dermatologist

    ☐   Other (Please state):

        ………………………………………………………………………………

- Were you referred to a mental health professional after diagnosis? (Please tick)

  ☐   Yes

  ☐   No

- Have you sought mental health care since your diagnosis, as a result of your alopecia? (Please tick)

  ☐   Yes

  ☐   No

Appendix C

These questions concern your feelings over the past **4 weeks** about your **alopecia**. Check the answer that comes closest to the way you have been feeling.

HOW OFTEN DURING THE PAST FOUR WEEKS
DO THESE STATEMENTS DESCRIBE YOU?

	NEVER	RARELY	SOMETIMES	OFTEN	ALL THE TIME
1. My skin hurts as a result of my alopecia	$\square_1$	$\square_2$	$\square_3$	$\square_4$	$\square_5$
2. My alopecia affects how well I sleep	$\square_1$	$\square_2$	$\square_3$	$\square_4$	$\square_5$
3. I worry that my condition may be serious	$\square_1$	$\square_2$	$\square_3$	$\square_4$	$\square_5$
4. My alopecia makes it hard to work or do hobbies .	$\square_1$	$\square_2$	$\square_3$	$\square_4$	$\square_5$
5. My alopecia affects my social life	$\square_1$	$\square_2$	$\square_3$	$\square_4$	$\square_5$
6. My alopecia makes me feel depressed	$\square_1$	$\square_2$	$\square_3$	$\square_4$	$\square_5$
7. My skin burns or stings because of my alopecia	$\square_1$	$\square_2$	$\square_3$	$\square_4$	$\square_5$
8. I tend to stay at home because of my alopecia. .	$\square_1$	$\square_2$	$\square_3$	$\square_4$	$\square_5$
9. I worry about getting scars from my alopecia . . .	$\square_1$	$\square_2$	$\square_3$	$\square_4$	$\square_5$
10. My skin itches as a result of my alopecia.	$\square_1$	$\square_2$	$\square_3$	$\square_4$	$\square_5$

11. My alopecia affects how close I can be with those I love	$\square_1$ $\square_5$	$\square_2$	$\square_3$	$\square_4$
12. I am ashamed of my alopecia.	$\square_1$ $\square_5$	$\square_2$	$\square_3$	$\square_4$
13. I worry that my alopecia may get worse	$\square_1$ $\square_5$	$\square_2$	$\square_3$	$\square_4$
14. I tend to do things by myself because of my alopecia.	$\square_1$ $\square_5$	$\square_2$	$\square_3$	$\square_4$
15. I am angry about my alopecia	$\square_1$ $\square_5$	$\square_2$	$\square_3$	$\square_4$
16. Water bothers my skin (in areas affected by my alopecia) .	$\square_1$ $\square_5$	$\square_2$	$\square_3$	$\square_4$
17. My alopecia makes showing affection difficult . . .	$\square_1$ $\square_5$	$\square_2$	$\square_3$	$\square_4$
18. I worry about side-effects from alopecia medication/treatment	$\square_1$ $\square_5$	$\square_2$	$\square_3$	$\square_4$
19. My skin is irritated in areas affected by my alopecia. . . .	$\square_1$ $\square_5$	$\square_2$	$\square_3$	$\square_4$
20. My alopecia affects my interactions with others . .	$\square_1$ $\square_5$	$\square_2$	$\square_3$	$\square_4$

Please turn to next page

These questions concern your feelings over the past **4 weeks** about your **alopecia**. Check the answer that comes closest to the way you have been feeling.

HOW OFTEN DURING THE PAST 4 WEEK
DO THESE STATEMENTS DESCRIBE YOU?

	NEVER THE	RARELY	SOMETIMES	OFTEN	ALL TIME
21. I am embarrassed by my alopecia	$\square_1$	$\square_2$	$\square_3$	$\square_4$	$\square_5$
22. My alopecia is a problem for the people I love . .	$\square_1$	$\square_2$	$\square_3$	$\square_4$	$\square_5$
23. I am frustrated by my alopecia.	$\square_1$	$\square_2$	$\square_3$	$\square_4$	$\square_5$
24. My skin is sensitive in areas affected by alopecia. . . .	$\square_1$	$\square_2$	$\square_3$	$\square_4$	$\square_5$
25. My alopecia affects my desire to be with people .	$\square_1$	$\square_2$	$\square_3$	$\square_4$	$\square_5$
26. I am humiliated by my alopecia.	$\square_1$	$\square_2$	$\square_3$	$\square_4$	$\square_5$
27. My alopecia results in bleeding	$\square_1$	$\square_2$	$\square_3$	$\square_4$	$\square_5$
28. I am annoyed by my alopecia.	$\square_1$	$\square_2$	$\square_3$	$\square_4$	$\square_5$
29. My alopecia interferes with my sex life	$\square_1$	$\square_2$	$\square_3$	$\square_4$	$\square_5$
30. My alopecia makes me tired	$\square_1$	$\square_2$	$\square_3$	$\square_4$	$\square_5$

DASS *Date:*

Appendix D

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

The rating scale is as follows: 0 Did not apply to me at all 1 Applied to me to some degree, or some of the time 2 Applied to me to a considerable degree, or a good part of time 3 Applied to me very much, or most of the time

1	I found myself getting upset by quite trivial things	0	1	2	3
2	I was aware of dryness of my mouth	0	1	2	3
3	I couldn't seem to experience any positive feeling at all	0	1	2	3
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5	I just couldn't seem to get going	0	1	2	3
6	I tended to over-react to situations	0	1	2	3
7	I had a feeling of shakiness (eg, legs going to give way)	0	1	2	3
8	I found it difficult to relax	0	1	2	3
9	I found myself in situations that made me so anxious I was most relieved when they ended	0	1	2	3
10	I felt that I had nothing to look forward to	0	1	2	3
11	I found myself getting upset rather easily	0	1	2	3
12	I felt that I was using a lot of nervous energy	0	1	2	3
13	I felt sad and depressed	0	1	2	3
14	I found myself getting impatient when I was delayed in any way (eg, lifts, traffic lights, being kept waiting)	0	1	2	3
15	I had a feeling of faintness	0	1	2	3
16	I felt that I had lost interest in just about everything	0	1	2	3
17	I felt I wasn't worth much as a person	0	1	2	3
18	I felt that I was rather touchy	0	1	2	3
19	I perspired noticeably (eg, hands sweaty) in the absence of high temperatures or physical exertion	0	1	2	3
20	I felt scared without any good reason	0	1	2	3
21	I felt that life wasn't worthwhile	0	1	2	3

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

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

Appendix E

COPING WITH BODY IMAGE CHALLENGES (BICSI)
"Body image" refers to how we think and feel about our own physical
appearance. In the course of everyday life, there are situations and events that occur
which can negatively affect our body image. These situations and events are called
"body image threats or challenges," because they threaten or challenge our ability to
feel okay about our looks.
People do lots of different things to cope or deal with these challenges or threats.
Listed below are some of the ways that people may try to cope with body image threats
or challenges. For each item, think about how much it is characteristic of how you
usually cope or would probably cope with an event or situation that poses a threat or
challenge to your body image feelings.
Using the scale below, enter a number from 0 to 3 in the space to indicate how
well each way of coping describes what you actually do or would do. There are no right
or wrong answers. It doesn't matter how helpful or unhelpful your ways of coping are.
Don't answer based on how you wish you usually reacted. Just be completely truthful.

_____

Definitely Not	**Mostly Not**	**Mostly**	**Definitely**
Like Me 0	**Like Me 1**	**Like Me 2**	**Like Me 3**

_____ 1. I spend extra time trying to fix what I don't like about my looks.
_____ 2. I consciously do something that might make me feel good about myself
as a person.
_____ 3. I try to tune out my thoughts and feelings.
_____ 4. I seek reassurance about my looks from other people.
_____ 5. I do something to try to look more attractive.
_____ 6. I spend more time in front of the mirror.
_____ 7. I try to ignore the situation and my feelings.
_____ 8. I think about what I should do to change my looks.
_____ 9. I avoid looking at myself in the mirror.
_____ 10. I remind myself of my good qualities.

_____

Definitely Not	**Mostly Not**	**Mostly**	**Definitely**
Like Me 0	**Like Me 1**	**Like Me 2**	**Like Me 3**

_____ 11. I eat something to help me deal with the situation.
_____ 12. I tell myself that I'm just being irrational about things.
_____ 13. I fantasize about looking different.
_____ 14. I think about how I could "cover up" what's troublesome about my
looks.
_____ 15. I tell myself that the situation will pass.
_____ 16. I try to figure out why I am challenged or threatened by the situation.
_____ 17. I tell myself that I am helpless to do anything about the situation.
_____ 18. I tell myself that I am probably just overreacting to the situation.
_____ 19. I compare my appearance to that of physically attractive people.
_____ 20. I remind myself that I will feel better after awhile.
_____ 21. I react by overeating.

_____ 22. I tell myself that there are more important things than what I look like.
_____ 23. I tell myself that I probably look better than I feel I that do.
_____ 24. I make a special effort to look my best.
_____ 25. I withdraw and interact less with others.
_____ 26. I make a special effort to hide or "cover up" what's troublesome about my looks.
_____ 27. I react by being especially patient with myself.
_____ 28. I make no attempt to cope or deal with the situation.
_____ 29. I tell myself that the situation is not that important.

(BICSI⌐Thomas F. Cash, Ph.D., 2003)

53

Appendix F

Patient Satisfaction Questionnaire
20

SHORT-FORM PATIENT SATISFACTION QUESTIONNAIRE (PSQ-18)

These next questions are about how you feel about the medical care you receive.

On the following pages are some things people say about medical care. Please read each one carefully, keeping in mind the medical care you are receiving now. (If you have not received care recently, think about what you would expect if you needed care today.) We are interested in your feelings, good and bad, about the medical care you have received.

How strongly do you AGREE or DISAGREE with each of the following statements?

(Circle One Number on Each Line)

	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree
1. Doctors are good about explaining the reason for medical tests	1	2	3	4	5
2. I think my doctor's office has everything needed to provide complete medical care	1	2	3	4	5
3. The medical care I have been receiving is just about perfect	1	2	3	4	5
4. Sometimes doctors make me wonder if their diagnosis is correct	1	2	3	4	5
5. I feel confident that I can get the medical care I need without being set back financially	1	2	3	4	5
6. When I go for medical care, they are careful to check everything when treating and examining me	1	2	3	4	5
7. I have to pay for more of my medical care than I can afford	1	2	3	4	5
8. I have easy access to the medical specialists I need	1	2	3	4	5

How strongly do you AGREE or DISAGREE with each of the following statements?

(Circle One Number on Each Line)

	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree
9. Where I get medical care, people have to wait too long for emergency treatment	1	2	3	4	5
10. Doctors act too businesslike and impersonal toward me	1	2	3	4	5
11. My doctors treat me in a very friendly and courteous manner	1	2	3	4	5
12. Those who provide my medical care sometimes hurry too much when they treat me	1	2	3	4	5
13. Doctors sometimes ignore what I tell them	1	2	3	4	5
14. I have some doubts about the ability of the doctors who treat me	1	2	3	4	5
15. Doctors usually spend plenty of time with me	1	2	3	4	5
16. I find it hard to get an appointment for medical care right away	1	2	3	4	5
17. I am dissatisfied with some things about the medical care I receive	1	2	3	4	5
18. I am able to get medical care whenever I need it	1	2	3	4	5